Experiences of Continuity of Care and Health and Social Outcomes: The ECHO Study

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Community psychiatric nurse	CPN
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Occupational Therapist	OT
Severe Mental Illness	SMI
Social Worker	SW

Executive Summary

Background

Continuity of care has rarely been defined or studied systematically. This study takes as its starting-point a multi-axial definition of continuity of care produced by the NCCSDO's Scoping Exercise, comprising.experienced, flexible, cross-boundary, information, longitundinal, relational, long-term and contextual continuity.

Developmental Phase

Methods

User- and carer-generated measures of continuity were developed through focus groups, expert panels, a consultation exercise and a pilot (acceptability) study. The psychometric properties of the measures, CONTINU-UM (user measure) and CONTINUES (carer measure) were tested, using a framework developed by Fitzpatrick and colleagues, with added criteria concerning acceptability to users/carers and their involvement in the measure development. The experiences and satisfaction of users were assessed by these measures, along with the importance of each domain to respondents.

Results

Two psychometrically sound and consumer-generated measures of continuity were produced: CONTINU-UM and CONTINUES, measuring continuity of care from the user and carer perspectives respectively. They represent the first examples of user- and carer-generated outcome measures that, particularly in the case of CONTINU-UM, have undergone rigorous psychometric assessment. The reliability, face validity, content validity, acceptability, responsiveness, precision and interpretability of CONTINU-UM were established, along with evidence of its construct validity. Factor analysis revealed that CONTINU-UM measures one overarching construct and two underlying constructs, 'preconditions for continuity' and 'transitional points'. CONTINUES was less thoroughly tested owing to the size of the available sample of carers, but there was some evidence of good psychometric properties. Both measures reflect consumers' priorities. Test-retest reliability was sufficient to suggest the validity of using aggregate scores of each measure as outcome measures.

Main Phase

Methods

180 service users with psychotic disorders and 98 with non-psychotic disorders were recruited from seven community mental health teams in two London mental health NHS trusts and interviewed at three and two annual time-points respectively to assess their experiences of continuity of care and health and social outcomes; data from medical records were also collected. 107 carers were recruited and data collected on their experiences of continuity, care-giving and their psychological wellbeing.

The analysis comprised three stages. For the group with psychotic disorders, the first stage explored the concept of continuity of care, operationalising the multi-axial definition for empirical use and performing a factor analysis on the resultant continuity components to assess the validity of the concept for this group. The second examined variables associated with varying levels of continuity. The third explored associations between the continuity of care factors and subsequent changes in clinical and social outcomes. Confirmatory factor analyses then explored the validity of the factor model for the group with non-psychotic disorders and repeated the remaining analyses for this group. Demographic and service use variables for the two groups were compared.

Results

The group with psychotic disorders differed from the group with non-psychotic disorders in several respects, with the latter group containing more women, more White people and having having had fewer lifetime hospital admissions. The group with non-psychotic disorders had also experienced more transitions in care.

Operationalisation of the multi-axial definition produced 32 continuity components, 22 of which were appropriate for entry into the exploratory factor analysis. Factor analysis on continuity data from the group with psychotic disorders produced seven independent continuity factors: *Experience & Relationship, Regularity, Meeting Needs, Consolidation, Care coordination* and *Supported Living*. Confirmatory factor analyses suggested that the seven factor model was not robustly replicated at other time-points and in the other sample, probably due to sample size limitations. The factors were independent of each other and behaved in similar ways in the two cohorts.

In the psychotic group, change in quality of life was associated positively with *Experience & Relationship* and negatively with *Meeting Needs*. Change in level of symptomatology was positively associated with *Meeting Needs*. In the non-psychotic group, change in level of symptomatology was associated negatively with *Experience & Relationship*, but positively with *Regularity* and *Meeting Needs*. Change in empowerment was positively associated with *Experience & Relationship* and change in quality of life was negatively associated with *Meeting Needs*.

For the psychotic group, higher *Experience & Relationship* and *Supported Living* scores were associated with an increase in symptoms in the subsequent year. A higher *Meeting Needs* score was associated with a decrease in symptoms. For the non-psychotic group, however, there were no significant associations between continuity factors levels and subsequent outcomes.

Levels of continuity for carers were low, but better continuity was experienced by carers who lived with the user and had had a carer's assessment. No relationship was shown between carers' experienced continuity and their experiences of care-giving. There were few differences between carers in the two groups.

Qualitative Strand

Methods

Qualitative interviews were conducted with sub-groups of service users from each cohort, purposively sampled to reflect high and low scores on the factors emerging from the Main Phase. They aimed to capture the experiences and view of users and carers focusing on the meaning associated with particular (dis)continuities and transitional episodes. The interview explored general experiences of relationship with services, continuity and transition from both the user and the carer perspectives. Thematic analysis was conducted.

Results

Interviews were conducted with 31 service users, 20 with psychotic disorders and 11 with non-psychotic disorders, and with 14 carers, 10 who were caring for users with psychotic disorders interviewed in this strand and four who were caring for users with non-psychotic disorders interviewed in this strand.

Five key themes emerged from the analysis: relational (dis)continuity; depersonalised transitions; invisibility and crisis; communicative gaps and social vulnerability. Many frustrations with the system were expressed. The relationship with the key worker emerged as crucial to the experience of services. The fragility of continuity of care was also clear. Transitions that were accomplished without due regard to the service user's social context were more likely to disrupt even long-term and supportive relationships. Sudden changes of key worker would negate positive experiences of the relationship with the worker and with services. Gaps in communication also occurred at several levels.

Organisational Strand

Methods

A comparative organisational diagnostic analysis was conducted in the two NHS Trusts, six GP practices and two voluntary sector organisations, comprising a questionnaire-based survey and in-depth interviews with professionals from a range of disciplines.

Results

The response rate to the survey was 70% (n=192) and 113 in-depth interviews were also conducted. The multi-axial definition of continuity of care was largely supported by professionals. Flexible continuity was found to be dependent on flexible care-planning, as well as effective team skill-mix and communication. Cross-boundary continuity was affected by team structures, cultures, processes and roles. Information continuity was affected by communication and provision of IT equipment to facilitate information-transfer and information-sharing. Longitudinal continuity needed to be supported by adequate resources and was affected by professional workloads, workforce stability, turnover and use of temporary staff. Relational continuity was affected by workforce stability and time allowed for user contact. Long-term continuity was adversely affected by gaps in service provision at points of transition from hospital to community.The two Trusts differed with respect to several barriers and facilitators to continuity of care; for instance, the adequacy of direct funding, wards and beds was significantly lower in Trust 2, where resource provision was seen as inadequate by most staff and loss of day care provision had also been problematic.

Conclusions

- Continuity of care in mental health is a multi-faceted concept comprising at least seven distinct factors
- Continuity of care is affected by care structures, which may have a differential impact on different diagnostic groups
- Continuity of care is adversely affected by organisational change, the impact of which was judged by users as equivalent to hospital admission
- Continuity is likely to be a dynamic process in the inter-relationship between services, professionals, service users and carers
- Continuity of care is fragile, with even robust relationships between users and professionals being easily jeopardised by transitions or disruptions in care that do not pay adequate heed to users' wider circumstances.

Recommendations

- Service re-organisation should only be undertaken in the face of compelling evidence for its likely increased effectiveness
- Attention should be paid by clinicians to a comprehensive range of needs, not simply the most pressing ones
- Higher priority should be given to the therapeutic relationship, including increased time for contact with users.

1. Background

1. 1. Continuity of care and mental health

The importance of continuity of care for people with severe mental illness (SMI) has long been recognised (Crawford *et al*, 2004). Continuity of care is particularly important in the wake of the deinstitutionalisation of psychiatric service users in order to coordinate needs in the community as opposed to inpatient settings (Lamb, 2001): particularly so with the development of multi-disciplinary community mental health teams (CMHTs) (Ramon, 1994). According to Bachrach and colleagues (1981), continuity for mentally ill service users is essential for planning treatment programmes and for enhancing the link between psychiatry and other medical disciplines. Tessler and colleagues (1987) argue that continuity of care has replaced dependency and deinstitutionalisation as the central issue in service provision while, more recently, it has been argued that its provision is a useful criterion for mental health service evaluation (Johnson *et al*, 1997).

The particular importance of continuity of care for people with SMI lies in the fact that people in this group have complex and pressing needs, often spanning both medical and social services (Johnson *et al*, 1997). Case Management has been proposed as a means of meeting and coordinating these needs (Holloway *et al*, 1995) and has been formalised in the UK as the Care Programme Approach (CPA) (Department of Health, 1999). CPA is designed to ensure continuity of care as stipulated by standards four and five of the National Service Framework for Mental Health (DoH, 1999).

There is, however, a discrepancy between the acceptance of continuity of care as an important goal and its actual implementation. A significant proportion of those with mental illnesses are cared for exclusively by their GPs (Kendrick *et al*, 2000), communication between primary and secondary sectors has been found to be insufficient (Bindman *et al*, 1997) and attempts to provide highly integrated shared-care and differing liaison strategies between primary and secondary care have been limited in their success (Burns & Bale, 1997; Essex *et al*, 1990; Warner *et al*, 2000). Continuity of care has been supported and used by medical professionals as an important factor for service users' health (Bachrach *et al*, 1981). Durgahee (1996), however, found that there was a lack of comprehension amongst mental health care professionals about the meaning of CPA. This lack of comprehension also filters to the users: Rose (2001) found that the majority of 220 users knew nothing about CPA as a process and were unaware of key elements such as having a care coordinator or care plan and review.

1. 2. Conceptualising and operationalising continuity

In a ‘Scoping Exercise’ investigating continuity of care in health care for the National Coordinating Centre for Service Delivery and Organisation, Freeman and colleagues (2000) found that ‘continuity of care is often lauded but seldom defined’. Although various simple and complex attempts have been made to conceptualise the idea of continuity of care, it is more frequently the case that no definition is given (Ware *et al*, 2003). Many studies thus do little to improve our understanding of the meaning of continuity of care (Crawford *et al*, 2004). This is equally true of studies specifically of severe mental illness, which usually fail to define continuity (Crawford *et al*, 2004). Although many studies pertain to continuity of care, definitions are frequently inadequate: either no specific definition is used or only one or two elements of continuity of care are included (Freeman *et al*, 2000).

Crawford and colleagues (2004) reviewed 435 relevant papers, most of which did not define continuity of care. The overview provided by Freeman and colleagues (2000) identified 32 continuity of care studies in mental health and 14 in primary care but found more than ten definitions and few attempts to explicate and analyse the idea substantively (Freeman *et al*, 2000). Many studies investigate service users’ and carers’ opinions of the *quality* of care but not continuity of care. Haggerty and colleagues (2003) argue that this process is further hindered by the use of terminology which is presented as though synonymous. Bachrach (1981), for example, argues that ‘continuous care’ (always under a healthcare professional), and 'continuity of care' (the orderly and uninterrupted movement of users among diverse elements of the health delivery system) should be viewed as different concepts.

Continuity of care has been conceptualised as ‘a sustained partnership between users and clinicians’ (Stange, 2003) and as maintenance of contact, consistency in the member of staff seen and transition (Johnson *et al*, 1997b); while discontinuity has been defined as gaps in care (Cook *et al*, 2000). Reid and colleagues (2002) provide a comprehensive definition of continuity of care as 'the result of a combination of adequate access to care for users, good interpersonal skills, good information flow and uptake between providers and organizations, and good care coordination between providers to maintain consistency'.

Crawford and colleagues (2004) define continuity of care using five factors based on sustained contact with services, breaks in service delivery, same member of staff seen, coordination of health and social professionals and the experience of care. The conceptualisation proposed by Johnson and colleagues (1997a) includes: maintenance of contact, consistency in the member of staff seen, transition and integration between services, adherence to service plans, and management of service users' needs. CONNECT (Ware *et al.*, 2003) is a tool that has been developed to measure continuity of care based on five domains: knowledge, flexibility, availability, coordination and transitions. Hautala-Jylha and colleagues (2005) investigated staff and user conceptualisations of continuity of care which emerged as: 'adherence to good cooperative relationships, adherence to care environments, flexibility in tailoring care, active maintenance of contacts in care, constant possibility to contact ward, up-to-date service user data and active cooperation between outpatient services and other collaborators'. Joyce and colleagues' (2004) systematic literature review found that continuity of care has been defined in terms of service delivery, accessibility, relationship base and individualized care. Haggerty and colleagues (2003) emphasise that without clear definitions of continuity of care it is possible neither to investigate nor to solve discontinuities.

According to Schaedle and colleagues (2000), although there are a plethora of conceptualisations, the majority are underpinned by common features. These common features, however, are not matched by methods or attempts to operationalise continuity of care (Johnson *et al*, 1997). Many studies of continuity focus on a few different aspects rather than providing comprehensive evidence to reflect the theoretical scope behind the concept. These studies also investigate continuity of care in one or a few service settings rather than a range, and usually span a short time-frame. Haggerty and colleagues (2003) accept the difficulties of investigating continuity of care in different healthcare contexts but emphasise that there are also shared definitions such as care of an individual user and care given over time.

Attempts at operationalisation have tended to focus on particular issues within continuity of care such as cross-boundary continuity between primary and secondary care (Bindman *et al*, 1997), psychiatric and emergency services (Heslop *et al*, 2000), or inpatient and community settings (Kopelowick *et al*, 1998), rather than encompassing a range of factors. Adair and colleagues (2003) chart the changing definitions of continuity of care starting from 1967 onwards and emphasise the necessity for further operationalisation of the concept in order to measure its effects. Freeman and colleagues (2000) rated continuity of care studies from the users' viewpoint according to relevance, method and concept and highlighted the necessity for clarity in the conceptualisation of continuity of care in order to be able to gauge its impact.

Freeman and colleagues (2000) summarise the principal characteristics of continuity of care in a 'multi-axial definition' comprising: *experienced*, *cross-boundary*, *flexible*, *information*, *relational* and *longitudinal*. In a subsequent study of continuity in mental health settings (Freeman *et al*, 2002), they added two further definitions, *contextual* and *long-term*. (See Box 1.)

Box 1: Multi-axial definition of continuity of care

Generic (Freeman et al, 2000)

Experienced (experience of a coordinated and smooth progression of care from the user's point of view)

Flexible (to be flexible and adjust to the needs of the individual over time)

Cross-boundary (effective communication between professionals and services and with service users)

Information (excellent information transfer following the service user)

Longitudinal (care from as few professionals as possible, consistent with other needs)

Relational (to provide one or more named individual professionals with whom the user can establish and maintain a therapeutic relationship)

Mental health-specific (Freeman et al, 2002)

Long-term (uninterrupted care for as long as the service user requires it)

Contextual (care which should sustain a person's preferred social and personal relationship in the community and enhance quality of life)

1.3. Outcomes and implications

The mental health studies reviewed by Freeman and colleagues (2000) divided broadly into those examining outcomes with implications for continuity (loss of contact, referral process) and those of interventions assumed to promote continuity (where other outcomes, such as clinical outcomes and satisfaction, were analysed, but the impact on continuity was not). Primary care studies, by contrast, focused on longitudinal or relational continuity. Crawford and colleagues (2004) found only two studies that investigate continuity of care from the user's perspective.

Freeman and colleagues (2002) used a Delphi study to investigate promoting continuity of care for people with severe mental illness and identified the following areas as requiring attention: the role of primary care, the integration of secondary health care and social care, staff retention and user involvement. A study carried out by Wasylenki and colleagues (1985) assessed the effectiveness of case management versus a control group and found no difference in social functioning or levels of symptomatology, although instrumental functioning was superior in the case management group. It has also been shown that case management is an effective means by which to improve continuity of care following hospitalisation (Rothbard *et al*, 2004).

Sytema and colleagues (1997) found higher continuity of care (conceptualised as time between discharge and outpatient contact and flexibility of care) in a community based mental health system compared to an institution-based mental health system. Olfson and colleagues (1998) focused on transition and found that those users who had some communication with their prospective outpatient clinician before discharge had better mental health outcomes and better outpatient compliance, but no significant difference in occurrences of hospital readmissions or emergency care. Killaspy and colleagues (2000) proposed that gaps such as those caused by psychiatric outpatients not attending follow-up appointments were more likely to lead to hospital admissions. Bassett and colleagues (2000) found that poor continuity of staff and services following hospital discharge leads to more rapid readmission.

Bindman and colleagues (1997) investigated communication between primary and secondary care and found discontinuity for those with mental health problems. Minore and colleagues (2005) examined continuity of care by looking at the effects of nursing turnover and found that high rates of turnover led to poorer communication and management of medication, a more limited range of services offered, illness outcomes, user disengagement and increased pressure on families. Cabana and Jee (2004) found that a sustained long-term relationship between user and healthcare provider was associated with greater user satisfaction, decreased hospitalisation and emergency department visits and improved receipt of preventive services.

Several other studies have found that high continuity of care leads to service user satisfaction (Saultz & Albedaiwi, 2004; Fan *et al*, 2004). Paykel and colleagues (1982) suggest that 'relational continuity' through the consistent provision of care from one professional is associated with higher satisfaction and earlier discharge, although not with symptoms or social adjustment. Saultz and Lochner (2005) concluded from a review of studies from 1966 to 2002 that it is probable that a relationship exists between 'interpersonal' continuity of care (defined as a persisting relationship between an individual doctor and service user) and improved preventive care and decreased hospitalisation. Other studies have focused on transition points in care and interventions designed to ensure continuity at those points (Olfson *et al*, 1998; Herman *et al*, 2000). Appleby (1999) and Desai and colleagues (2005) found that poorer continuity of care was associated with a higher rate of suicide. Greenberg and Rosenheck (2005) investigated the degree to which three aspects of continuity of care (regularity of care: measured by number of months out of six with at least one outpatient visit; continuity of treatment across organisational boundaries: measured by whether someone received outpatient treatment within 30 days of being discharged from inpatient care; and intensity of treatment: measured by number of visits in 180 days) were related to improved mental health status as measured by Global Assessment of Functioning (GAF) change scores. For those in transitional treatment circumstances, i.e. recently discharged from inpatient care or new outpatients, rather than continuing outpatients, the three aspects of continuity of care were associated with greater improvement in GAF change scores, suggesting that continuity of care may be particularly important for people in transitional states.

1.4. Organisational context

1.4.1. Organisational policy context

The need for reform of mental health services in the UK has been reflected in a number of key policies developed and implemented since 1997, designed to combat the substantive body of national and international evidence concerning inter-organisational fragmentation of services, poor interdisciplinary coordination and decision-making (Singh, 2000; Bosanquet & Kruger 2003; Onyett, 2003). A major initiative encapsulated within the National Service Framework for Mental Health (NSFMH, Department of Health, 1999), focused on the need to integrate mental health and social services to minimise the user and carer distress and confusion arising from service discontinuities. The NSFMH also sought to establish that a hallmark of quality service provision should be delivering continuity of care for as long as it was needed. The NHS Plan (Department of Health, 2000) gave a further impetus to integrate health and social care services for people with SMI through the formation of Care Trusts, the development of care programme and care management approaches within an integrated system.

The Mental Health Policy and Implementation Guide (Department of Health, 2002) emphasised the role of community mental health teams (CMHTs) as intrinsic to the delivery of a service designed to achieve continuity of care. This was to be achieved by the use of an integrated multi-disciplinary approach, in which team skill mix harnessed the professional skills of social work, nursing, medicine, psychology and occupational health to the benefit of service users and carers. It was envisaged that CMHTs should have clear leadership from both clinical and managerial perspectives, use one set of notes and achieve geographical co-location of team members. Subsequent approaches to modelling community care have resulted in the inception of the ‘generic’ non-specialised CMHT, accountable for the delivery of a wide range of interventions to adults with a serious mental illness in a local catchment area. Specialist teams have also been developed to provide services to people with SMI; assertive outreach teams designed to care for ‘difficult to engage service users’ and crisis resolution/home treatment teams intended to avert hospitalisation in adults with a mental health crisis. By contrast, early intervention teams aim to provide interventions to individuals within the age range 14-35 years, with first presentation of psychotic symptoms.

1.4.2. Policy implementation: organisational challenges

The implementation of policy encompassed in the Mental Health Policy and Implementation Guide (Department of Health, 2002) raises a number of challenges from an organisational perspective. These include the need to develop and establish positive organisational cultures for integrated working in CMHTs and acute support units through dynamic leadership and effective change management; to develop an understanding of local barriers and facilitators to effective teamwork; to recruit, develop and maintain a workforce with the skills intrinsic to sustain continuity of service and care over time; to deploy resources to support continuity and to enhance cross-boundary working between statutory and non-statutory agencies. The coordination of integrated working is vital, given the fact that people with the complex needs arising from SMI often require help from more than one agency and that these needs can fluctuate over time (Freeman *et al*, 2002).

Overall, the challenges for managers and leaders are to embed new ways of working and practices against the background comprised by organisational culture, resources, economic and political factors, all of which may create uncertainty (Iles & Sutherland, 2001). Managers or leaders can act as effective agents of change through the development of strategies to overcome local barriers to change, which foster ownership and enhance professional development in the workforce (Shaw *et al*, 2006; Thomson O'Brien, 2006). Delivering the government agenda for quality assurance, risk management and integrated working also requires commitment to the provision of multi-disciplinary, team-based continuing professional development in the workforce (Department of Health, 2004; Chambers & Scriver, 2001).

If the multi-axial definition of continuity of care (Freeman *et al*, 2000) is used as a framework, the challenges also encompass the implementation of systems for effective information transfer within and across organisational boundaries, together with the provision of consistent information to users and carers (informational continuity); the effective coordination of management services by teams, external agencies, users and carers (cross boundary/team continuity); the development of flexible care plans linked to effective monitoring (*flexible continuity*); the deployment of professional staff to remove disjointed episodes of service delivery (longitudinal continuity); the designation and accountability of one or more professional staff to foster therapeutic relationships and exert a positive impact on care outcomes (relational, personal and therapeutic continuity) and the development of systems and processes to provide care adequate to meet needs over time (*long-term continuity*).

1.4.3. Challenges for team working

Multi-disciplinary CMHTs were developed on the assumption that health and social care professionals should, in the context of team decision-making, be able to solve complex problems for and with service users and carers. Problem-solving is dependent on effective team-working and decision-making. Thus Onyett and Ford (1996) identified nine characteristics needing to be in place for a CMHT to work effectively: the need to target resources to people with SMI; to provide a range of skills, services and opportunities to people with SMI supported by an appropriate team skill mix; to provide effective, inter-agency, coordinated care; to enhance high-quality personal relationships between team workers and service users; to ensure opportunities for participation in decision-making by team, users and carers; to increase awareness of local facilities to support individuals with SMI; to provide 24 hour support and treatment; to have clear aims linked to strategic and operational management and to have access to adequate resources to sustain effective team-working.

Effective verbal and written communication underpins all these characteristics of effective team-working; Singh (2000) identified the lack of effective communication and care coordination as responsible for failures of care provision prior to the integration of health and social care services. Implicit in the characteristics identified by Onyett and Ford (1996) were specific definitions of continuity of care, notably cross-boundary and team continuity, longitudinal, relational, personal and therapeutic continuity aligned with effective operational management. Implementation of care programme approaches based on case management (Department of Health, 2000) stressed the need for care coordinators working in CMHTs to assess care needs, review care plans and coordinate services for people with SMI. This role was envisaged as key to developing long-term relationships with service users and, by implication, enhancing information, cross-boundary, longitudinal, flexible and relational continuity.

A final organisational challenge for the implementation of systems and processes to foster continuity of care relates to stressors experienced by the wider professional workforce in the UK. These stressors related to factors operating beyond workers' control, notably unreliable support services, old, poorly managed equipment, inadequate information technology (IT) and administrative support (Policy Studies Institute, 2001). A current priority in the NHS is the delivery of a national programme for IT to bring computer systems into the NHS with the intention of improving service user care and services; aligned with this is the NHS Care Records Service developed in recognition of the increasingly complex nature of organisational delivery of care, which requires personnel and organisations to work in partnership (Department of Health, 2006). The need to establish secure electronic systems, operated with user consent, has engendered recent intense debate (Cundy & Hassey, 2006; Orrell, 2006)

1.4.4. Fostering continuity: experiences of organisational working

In a qualitative investigation focused on interviews conducted with professional staff in three rural CMHTs, Brown and colleagues (2000) found that a blurring of roles had taken place resulting in team members undertaking tasks for which they were not trained, together with role confusion and erosion of professional identity. Furthermore, a lack of leadership and clearly developed team goals were found, which were not conducive to effective team working. By contrast, a later study by Gulliver and colleagues (2002) was conducted both before and after integration of health and social care services, utilising exploratory workshops with CMHT professionals. Key findings were that co-location of CMHT professionals facilitated the development of dependent relationships between team members in an environment conducive to continuity of information and cross-boundary continuity.

Later work by Lankshear (2003), utilising semi-structured interviews with Trust and Social Services managers and CMHT members, also found that co-location was beneficial in establishing dependent team relationships. Some sources of team conflict emerged, however, largely attributable to external sources. In response to new approaches to integrated working, a process of demarcation had taken place whereby clear professional boundaries were established to counter loss of professional identity. Concerns relating to loss of professional identity, status and power through shared professional team working have also been raised by clinical psychologists (Rogers & Pilgrim, 2001), while occupational therapists have been advised against assuming generic care coordinator roles in CMHTs by their professional body (Peck & Norman, 1999).

A survey employing mixed methods conducted by Carpenter and colleagues (2003), based on a sampling framework encompassing all NHS Mental Health Trusts in England, explored differences between health and social care professionals in relation to team identification. A key finding was that in comparison to other health professionals, social workers had poorer perceptions of team functioning and higher levels of role conflict. A later qualitative study by Blinkhorn (2004) investigating the adjustment of social workers post-integration also established that barriers to practice were [team] direction and imbalance, blurring of role function, bureaucracy, workloads, career and professional development. A later survey in this professional group conducted by Fakhoury and Wright (2004) also reported limited resources, lack of time and bureaucracy as barriers to effective CMHT coordination of services. By contrast, good communication was found to be a facilitator of CMHT work.

1.5. Rationale for the present study

Johnson and colleagues (1997) reviewed nine studies about continuity of care and found substantial limitations in many. Only two had follow-up periods of at least a year, many had low response rates, and most focused only on one or two dimensions of continuity of care. Studies looking at the outcomes of continuity of care had predominantly focused on hospital admissions and suicide and were retrospective. They identified a clear need for experimental continuity of care studies. Moreover, they found that evidence about the impact of continuity of care on the experiences and outcomes of those with severe mental illness has not been conclusive. Continuity of care is a ‘patient-orientated phenomenon’ (Bachrach, 1981), but work on ‘experienced continuity’ from both the service user’s and carer’s viewpoints is lacking in mental health research. Freeman and colleagues (2002) therefore reiterated the ongoing need for in-depth longitudinal research into continuity of care experienced by mental health service users and their carers to span long-term ever changing needs.

As well as the paucity of research from the user perspective, Crawford and colleagues (2004) found that there had been no studies investigating carers' perspectives. It is clearly important to examine carers' experiences: the National Service Framework has identified the carers of people with mental health problems as being in particular need of support from health and social services (DoH, 1999); carers are known to experience difficulties as a result of discontinuities in treatment approaches and record keeping (Griffin Francell *et al*, 1988); carers' perspectives will give a more holistic insight into the impact of continuities and discontinuities (Crawford *et al*, 2004).

Understanding the often complex organisational factors which contextualise users' experiences is essential. Continuity of care at the least may embrace cross-boundary continuity at any single time-point (Johnson *et al*, 1997) as well as longitudinal or temporal continuity and relational continuity between users and professionals. The context in which research on services takes place, in particular the organisational structure and culture, is increasingly recognised as impacting on, as well as illuminating, its findings (Pawson & Tilley, 1997).

There is thus a clear need for a longitudinal study that encompasses the wide range of theoretical continuity of care definitions and applies them to a number of service settings (Johnson *et al*, 1997). The inclusion of user and carer perspectives is paramount, given the dearth of such perspectives in the literature to date, while the paucity of evidence about what continuity of care is and of qualitative evidence necessitates an exploratory design incorporating qualitative and quantitative methodology.

As detailed above, a relatively small number of studies have attempted to evaluate different components of team working, both prior to and following policy implementation. Many of these studies do not include operationalised definitions of continuity or specific, related outcome measures, neither do they explore cultures, structures and processes from a wide range of professional perspectives. Furthermore, qualitative studies predominate, which while offering important insights are not generalisable. Consideration of these issues provided an impetus for the aims and design of the organisational strand of the present study.

The present study aims to capture longitudinally the experiences and health outcomes of people with severe mental illnesses through their own, their care coordinators' and their carers' perspectives. Data have also been drawn from each service user's medical records. This study has been conducted in seven community mental health teams (CMHTs) spread over two large mental health trusts with differing Jarman indices, the organisational cultures and practices of which are studied by means of diagnostic analyses. Freeman and colleagues' (2000) multi-axial definition of continuity (Box 1) was used as the conceptual starting-point for the study, but in view of the need to capture users' and carers' perspectives, a user-generated and a carer-generated measure of continuity were also developed, for use in the longitudinal study.

1.6. Developing outcome measures in mental health

The psychometric evaluation of outcome measures has traditionally focused on an almost entirely quantitative assessment of areas such as reliability and validity. More recently, there has been a shift towards a mixed methods approach to assessment. This enables a more comprehensive range of an instrument's properties to be considered in parallel with traditional psychometric properties such as reliability.

The trend to include qualitative methods of assessment in outcome measure development is in part a reflection of current approaches to health care research. There is also a trend for contemporary mental health services research to aim to be user-centred. It is perhaps unsurprising that recent authors have argued for a user-focussed approach to measure development (e.g. Blount *et al*, 2002). By including the perspectives of those for whom the measures are intended, researchers are more likely to produce measures that are understandable, relevant, significant and appropriate to respondents.

It has also been argued that standard outcome measures often fail to demonstrate the benefits of some elements of services, despite qualitative findings to the contrary. For example, Harvey and colleagues (2005) report that carers' support groups are often found to be of little benefit quantitatively, but much benefit qualitatively. They argue that this apparent discrepancy could be addressed through the inclusion of families' perspectives in measure development, making outcome measures more appropriate to the needs of those for whom the measure is intended.

A good model for assessing and reporting 'user-based outcome measures' has been produced by Fitzpatrick and colleagues (1998). This combines a variety of methods with a focus on users' perspectives. Fitzpatrick and colleagues note that this subjective element can leave many investigators feeling uncomfortable. This is because subjectivity is often seen as unscientific. The model of assessment they present draws heavily on established psychometric theory, however, as well as extending to a number of other dimensions. By utilising this model, researchers should produce measures that are of a high standard: rather than depending on just one method of assessment, a whole range of properties be considered.

The eight criteria laid out by Fitzpatrick and colleagues (reliability, validity, responsiveness, precision, interpretability, acceptability, feasibility and appropriateness) were operationalised by Harvey and colleagues (2005) in assessing outcome measures for carers of people with mental health problems. They proposed two additional criteria, 'importance to [users or] carers' and [user or] carer involvement in measure development'. These additional criteria are needed if measures are to be assessed on how well they incorporate and reflect the perspectives of users and their families, and all ten criteria are therefore used in the development of the new user- and carer-generated measures in the present study.

1.7. Summary

- The idea of continuity of care is often praised but few attempts have been made to define or explore it systematically
- A multi-axial definition of continuity of care has been proposed, comprising: *experienced*, *flexible*, *cross-boundary*, *information*, *longitudinal* and *relational* continuity, with *long-term* and *contextual continuity* added for service users with mental health problems
- Continuity studies have either examined outcomes with implications for continuity (loss of contact, referral process) or studied interventions assumed to promote continuity
- Understanding the complex organisational factors which contextualise service users' experiences is essential
- A user-focused approach to outcome measure development has been advocated
- There has been a clear need for a longitudinal study of continuity encompassing the wide range of definitions nd including user and carer perspectives.

2. Overall Aims, Objectives and Structure

The aims of the study were:

1. To examine how service users with severe mental illness and their carers conceive continuity of care through:

- an analysis of how they understand and evaluate continuity, which can be compared to extant definitions
- development of an instrument (on the basis of (a) above) to measure users' and carers' experiences of continuity;

2. To assess the relationships between service users' continuity of care and process variables (such as therapeutic alliance) and health and social outcomes (such as overall functioning, time in hospital, quality of life, degree of unmet need) and between carers' continuity of care and psychological distress.
3. To describe the organisational structures, cultures and processes which promote and inhibit continuity of care.
4. To assess the degree to which managerial and professional views of continuity of care are congruent with users' and carers' views.

To these ends, the study was divided into four strands:

- the *Developmental Phase* was responsible for developing user- and carer-generated measures of continuity of care (aim 1), for use in the Main Phase;
- the *Main Phase* comprised a follow-up study of 180 service users with psychotic disorders (Sample 1) over three years and 98 users with non-psychotic disorders (Sample 2) over two years, along with their informal carers and professional care coordinators (aim 2);
- the *Qualitative Strand* involved in-depth interviews with 20 users from each of the Main Phase cohorts (Samples 1 and 2) and their carers (enhancing aim 2);
- the *Organisational Strand* comprised diagnostic analyses over three years of the two Mental Health Trusts which provided the setting for the study, focusing on factors promoting and those hindering continuity of care (aim 3).

Aim 4 was addressed by bringing together complementary aspects of each strand, with the Developmental Phase and Qualitative Strand providing user and carer perspectives on continuity, to be compared to the professional perspectives provided by the Organisational Strand as well as the literature, and the Main Phase exploring how continuity works for users and carers in practice as well as exploring the congruence between user and professional views of relational continuity and needs.

Each strand is reported separately for the sake of clarity, but their findings are synthesised at the end of the report.

3. Developmental Phase

3.1. Aims

The aims of this phase were to ascertain how users and carers define continuity of care, what it means to them in concrete terms and the relative importance and value they give to its different elements (referred to as *experienced continuity*), and thus to develop user-centred and carer-centred instruments for use in the present study and other contexts.

3. 2. Methods

3.2.1. Users

The overall method consisted of three parts. In the first phase, item generation was completed through focus groups followed by Expert Panels, a consultation exercise and, finally, a pilot study to test acceptability. This phase depended on the ideas generated and validated by service users themselves. The second phase tested the psychometric properties of the instrument, CONTINU-UM (CONTINUity of care - User Measure). The third phase examined the reported experiences and satisfaction of users as assessed by the instrument, along with their ratings of the items' importance. The key researchers in direct contact with users in the first phase were themselves service users. CONTINU-UM is shown in Appendix 1. (Here, as in each strand of the study, missing data are treated as appropriate to that strand.)

Phase 1: Generating the measure

Focus groups

The sample was largely made up of people who used drop-in centres and members of user groups in South London. The first stage of item generation used a repeated focus group methodology (Morgan, 1993). A draft topic guide was prepared and used with a pilot focus group comprising six service users who met twice. As a result, the topic guide was refined and some practical problems ironed out.

For the initial stage of item generation, four focus groups each met twice making eight groups in all, with 26 people participating. All had a diagnosis of psychosis, were adults of working age (18-65) and had been in touch with services for at least two years, thus ensuring that they would meet the inclusion criteria for Sample 1 of the Main Phase of the study and have appropriate experience. The group discussions were audio-taped.

The first wave of focus groups began with users 'telling the story' of their contact with mental health services. After this, the idea of continuity of care was introduced. Although most users had not heard the term before, the groups were able to generate ideas around the term once it had been explained to them.

Between the first and second set of group meetings, the tape-recordings were transcribed and analysed using WinMAX software. Six elements of continuity of care were extracted from each focus group discussion. We then added the six definitions produced by the Scoping Exercise (Freeman *et al*, 2000), re-worded to make them accessible.

The second wave of focus groups began with a brief validation exercise. The results of the analysis were fed back to ensure that we had captured the group's intentions. There were some expansions and very few retractions. The groups then ranked the six elements of continuity extracted from their own discussion and the six from the Scoping Exercise in terms of importance, first individually and then collectively. Since some groups found this a difficult task, it was made possible for them to sort the statements into blocks of importance.

Each thematic analysis, along with the results of the individual and group ranking exercises, was used to identify elements of continuity of care important to users, thus generating items for CONTINU-UM.

Expert Panels

The second stage in generating the measure was conducted by Expert Panels of service users. We refer to these as 'expert panels' as we consider users to be experts in their own experiences. There were two panels, one drawn from members of the original focus groups and the other an independent group of service users. Their task was to comment on the items generated by the focus groups and the structure of the items. They were also asked to pay particular attention to the layout and language used in the draft questionnaire. Twelve service users participated at this stage, four of whom had no previous connection with the study. Both Expert Panels were fully minuted.

Table D1: Pilot, main focus group and Expert Panel participant demographics

		Users **n=37[1]**	**Carers** **n=20**
Mean age		47	58
Gender	Male	22 (59.5%)	6 (30.0%)
	Female	15 (40.5%)	14 (70.0%)
Ethnicity	White British, Irish or Other	26 (76.0%)	13 (65.0%)
	Asian/Asian British or Chinese Group	2 (6.0%)	4 (20.0%)
	Black/Black British	2 (6.0%)	1 (5.0%)
	Mixed Heritage	4 (12.0%)	2 (10.0%)
Mean years in contact with services		16	13

1. Two user Expert Panel users did not provide demographic information

Consultation exercise

The questionnaire was then sent to a small number of user and non-user experts in the field of continuity of care.

Pilot study

We were concerned to make our measure as acceptable as possible to potential respondents, to make sure that the language was clear and that it was easy to complete. We therefore visited one day centre and two user groups in South London and asked for volunteers to fill in the questionnaire. A number of users completed the questionnaire by post making a total of 37 respondents at this stage. These results were used to refine CONTINU-UM.

Comparison to multi-axial definition

The gradual construction of the measure over successive phases was examined using both the results pertaining directly to the questionnaire and the qualitative information from the focus group transcripts. The relationships between the domains in CONTINU-UM and the multi-axial definition (Freeman *et al*, 2000) were examined.

Phase 2: Psychometric testing

The psychometric properties of CONTINU-UM were investigated, as reporte din Appendix 2.

Phase 3: Users' importance, experiences and satisfaction

Main Phase data were used to assess users' views on the importance of continuity of care elements, their experiences of continuity and their satisfaction with those experiences. The proportion of users who did or did not have each element of continuity of care in place was calculated. In order to do this binary variables were created by combining points 1, 2 and 3 to represent not having continuity (sometimes satisfied to very dissatisfied) and points 4 and 5 to represent having continuity (satisfied and very satisfied). Satisfaction scores were then calculated for each of the two groups, with satisfaction defined as selecting points 4 and 5 on the scale.

3.2.2. Carers

CONTINUES (Carers CONTNUity of care Experiences Scale) was developed, like CONTINU-UM, in three phases. Firstly, the measure was generated through focus groups, Expert Panels and a pilot study. Secondly, 65 Main Phase participants self-completed CONTINUES. These data were used to establish the psychometric properties of the measure and to explore carers' experiences of continuity of care. An additional 18 carers participated in a test retest reliability exercise and provided information on acceptability. Finally, Main Phase CONTINUES data were used to assess carers' priorities for, experiences of and satisfaction with the continuity of care they received. The main researcher throughout this process was a carer and also had personal experience of mental distress and service use. CONTINUES is shown in Appendix 3.

Phase 1: Generating the measure

Focus Groups

The focus group sample was recruited from local carers' groups (n=9) and CMHTs (n=2). Two of the carers supported someone who had participated in focus groups to develop CONTINU-UM. Additional carers were recruited from carers' groups to participate in a pilot focus group (n=5). All matched the carers' inclusion criteria for the Main Phase of the study, namely, relatives or friends having at least a weekly contact with users who themselves met the inclusion criteria of the Main Phase (Sample 1). The demographic profile of participants appears in Table D1.

The main facilitator of all focus groups had personal experience of supporting a relative who met the inclusion criteria of the study. A pilot focus group aimed to test the facilitator roles, research design and topic guide. Two focus groups were then held, each meeting twice. Groups again began with each participant 'telling their story'. This typically focused on people's experiences and emotions when they came to realise that the person they cared for needed help from outside agencies, and whether and how that help was first obtained. The idea of continuity of care was then introduced and discussed. All groups were tape-recorded and transcribed.

Second groups were held one week later. An interim, thematic analysis of the first group was presented and discussed as a form of validation. The analysis focused on definitions and experiences of continuity of care and was undertaken using a qualitative software package (winMAX99). Six elements of continuity of care identified through the analysis, and six simplified elements identified in the Scoping Exercise (Freeman *et al*, 2000) were then presented. Carers ranked these elements individually and then as a group. The facilitator encouraged discussion around the ranking to gain an understanding of why elements were or were not prioritised. The second focus groups were also analysed thematically and in addition, comments made during the ranking exercise were coded and assessed.

The analysis of the first group, the second group, the individual ranking results and the group ranking results were used to identify elements of continuity that were important to carers, thus generating items for CONTINUES.

Expert Panels

Two Expert Panels were held with carers to explore the generated measure (CONTINUES). The first Expert Panel was attended by six carers who had taken part in a focus group. Carers in the second Expert Panel were recruited via a carers' group (n=1) and users already participating in the research (n=3). Once again, all met the inclusion criteria of the Main Phase. The Expert Panels were conducted as they had been for CONTINU-UM.

Pilot study

Pilot study participants were recruited through researcher attendance at carers' groups and adverts in carers' group newsletters (n=30). Again, all met the inclusion criteria of the Main Phase. Approximately half completed CONTINUES with the researcher present and half by post. Face-to-face participants reported difficulties to the researcher whilst postal questionnaires were scrutinised to ensure that the results were interpretable.

Phase 2: Psychometric testing

The psychometric properties of CONTINUES were investigated, as reported in Appendix 4.

Phase 3: Carers' importance, experiences and satisfaction

Main phase CONTINUES data was used to investigate carers' views on importance of, experiences and satisfaction with continuity. Simple descriptive statistics were calculated for each item (frequency, range, mean and standard deviation). Binary variables were then created by combining scale points 1, 2 and 3 to represent not important/does not have/unsatisfied and points 4 and 5 to represent important/does have/satisfied. Valid percentages for each group were then calculated.

The relationship between experience and satisfaction was explored by calculating the satisfaction of those with an element of continuity and the satisfaction of those without**.**

3.3. Results

3.3.1. Users

Phase 1: Generating the measure

Focus groups

When the groups met for the second time, only one participant did not return. This demonstrates that the service users in the focus groups were very engaged with the process.

The individual and group ranking exercises, users' definitions of continuity and the thematic analysis of two raters of the focus group transcripts were examined. Elements were classified as high, medium or low priority depending on their rank in the exercises, or frequency count in the thematic analysis. Items that appeared as a top priority on at least one of the sources were re-examined to see the issues they related to, the strength and range of feeling. This resulted in 16 items being taken to Expert Panels for consideration, two of which were on the same topic, *staff changes*.

Expert Panels

Both Expert Panels thought the structure of the items was good. They made numerous suggestions as to how the layout and language could be improved and made more acceptable to potential respondents. Between them, the panels added a domain, dropped two and changed one, making 15 domains in total.

Consultation exercise

Two additional domains were suggested as a result of the consultation exercise. The focus group transcripts were checked to see whether the suggestions had relevance and importance. Support was found and so the domains were adopted. This resulted in the final draft measure with 17 topics.

Pilot study

The object of preliminary testing was to find out how easy the measure was to complete. As a result of this, some refinements were made to the wording but the measure did not change substantially at this point as most people did find it acceptable.

Final structure of the measure

Our final measure had 17 domains (see Appendix 5 for the development of topics) and each domain was split into four questions: 'How important do you think this element is?'; 'How often have you received this element over the past 12 months?'; 'How satisfied are you with this?' and 'Any other comments' (free text). (See Appendix 1.) Questions '***a***' to '***c***' were scored on a five-point adjectival Likert scale. Three domains – *staff changes*, repeating your *life history* and *waiting* - were reverse-scored. There were two types of missing data: first, when there was no response at all and second, when a respondent ticked 'not applicable'.

Comparison to multi-axial definition

Table D2 compares the multi-axial definition of continuity of care to the user-generated measure to see how many of the former are represented in the latter. Two of the multi-axial definitions are not represented in CONTINU-UM. These are: experiencing care as smooth (part of the definition of *experienced continuity*); and having one or more named professionals with whom to develop a therapeutic relationship (*relational or personal continuity*). *Information* is present in both models but means different things. In the multi-axial definition it means that information follows the user. In CONTINU-UM it means that information is given to the service user.

When investigating the links between the CONTINU-UM domains and the multi-axial definition, we have allowed some latitude. More than half the CONTINU-UM domains link, though sometimes loosely, to '*flexible continuity*'. It is perhaps not surprising that *care plans* and *peer support* do not directly appear in the generic multi-axial definition, particularly given the specificity of the former to mental health.

Table D2: Presence of multi-axial definition in CONTINU-UM

SDO definitions	CONTINU-UM presence
Experienced Continuity: experiencing care as a coordinated and smooth progression	Not represented
Continuity of Information: excellent information transfers following the service user	(Have you been able to get appropriate information from staff?)
Cross-boundary and Team Continuity: effective communication between different professionals and services	Have the staff involved in your care seemed to communicate with each other?
Flexible Continuity: flexible care which adjusts to the needs of the individual over time	Have the levels of support you get from services changed to match your needs?
Longitudinal Continuity: care from as few professionals as possible consistent with other needs	Have the staff involved in your care changed frequently?
Relational or Personal Continuity: to provide one or more named individual professionals with whom the user can establish and maintain a therapeutic relationship	Not represented

Phase 2: Psychometric properties

The psychometric properties of CONTINU-UM were found to be good (see Appendix 2).

Phase 3: Users' importance, experiences and satisfaction

As was seen in Table D5, the majority of items were rated 'important' or 'very important' by participants.

Table D3 has been ordered in terms of the proportion of respondents who did not have the element of continuity in place. As the table shows, for the majority of questions, users reported that they did have the element of continuity in place. The ratio was, on average, two thirds to one third. However, on three domains – *avoiding contact*, *choice* and *out of hours support* – more respondents did not have the element. Half reported that they did not have appropriate *day care* but a significant minority reported that this question was not applicable to them. Slightly fewer respondents than average had significant *staff changes* or had to repeat their *life history* to several different people.

Table D3: Negative and positive experiences with continuity of care in 17 domains based on the 167 responders in the Main Phase[1]

Domain n (%)	Element not in place	Satisfaction when element is not in place	Element in place	Satisfaction when element in place
Avoiding services	59 (67.0%)	27 (46.0%)	27 (31.0%)	22 (82.0%)
Choice	87 (58.0%)	34 (39.0%)	64 (42.0%)	59 (94.0%)
Out of hours support	57 (56.0%)	15 (26.0%)	44 (44.0%)	39 (87.0%)
Day centres	50 (51.0%)	6 (12.0%)	49 (49.0%)	44 (92.0%)
Repeating life history	60 (47.0%)	18 (30.0%)	68 (55.0%)	57 (84.0%)
Staff changes	64 (45.0%)	20 (31.0%)	79 (52.0%)	68 (88.0%)
Support from other users	54 (39.0%)	19 (35.0%)	84 (61.0%)	77 (92.0%)
Individual progress	54 (37.0%)	10 (19.0%)	91 (63.0%)	90 (99.0%)
Crisis plans	36 (37.0%)	7 (19.0%)	61 (63.0%)	52 (88.0%)
Hospital discharge	20 (35.0%)	6 (30.0%)	37 (65.0%)	34 (92.0%)
Flexible levels of support	43 (34.0%)	11 (26.0%)	85 (66.0%)	79 (93.0%)
Care plans	43 (34.0%)	7 (16.0%)	84 (66.0%)	74 (88.0%)
Waiting	46 (33.0%)	21 (46.0%)	92 (67.0%)	72 (82.0%)
Communication between staff	45 (31.0%)	3 (7.0%)	102 (69.0%)	97 (95.0%)
Accessing services	46 (30.0%)	8 (17.0%)	105 (70.0%)	93 (89.0%)
Range of services	44 (30.0%)	6 (14.0%)	104 (70.0%)	97 (94.0%)
Information	41 (28.0%)	5 (12.0%)	102 (71.0%)	94 (92.0%)

1. Missing data or data scored as not applicable have been excluded.

The relationship between experience and satisfaction

Satisfaction was compared for those who did have an element of continuity and those who did not. The results in Table D3 show that those with elements of continuity in place had much higher satisfaction scores than those who did not. This suggests that people were more satisfied when they had these elements of continuity of care in place.

3.3.2. Carers

Phase 1: Generating the measure

Focus groups

The results of the thematic analyses, individual and group ranking exercises, and carers' stated definitions of continuity of care were examined. Each element of continuity of care was classified as high, medium or low priority to carers, dependent on assigned rank or frequency count in the thematic analysis. Items with higher priorities were re-examined for content, strength and range of feeling and relevance. This resulted in ten topics being taken forward to Expert Panels with a further eight for discussion.

Expert Panels

Carers in the first Expert Panel found the format of the questionnaire acceptable. Following discussion, the group dropped seven topics, changed four and added one.

The second Expert Panel considered seven topics, with a further six being discussed. Carers found the domains similar which caused confusion. Changes were subsequently made to the language, Likert response categories and explanations. At this stage two topics were dropped.

Pilot study

Throughout piloting minor changes were made to language, definitions and instructions. The feasibility (acceptability) of CONTINUES was also considered at this stage.

Final structure of the measure

The final measure follows the same format as CONTINU-UM but with eleven rather than seventeen domains (see Appendix 4 for the development of topics). This means that each of the 11 domains is comprised of four parts. Items ***a-c*** are five-point adjectival Likert scales and item ***d*** is free text:

a. How important do you think this element is?

b. How often have you received this element over the past 12 months?
c. How satisfied are you with this?
d. Any other comments.

Phase 2: Psychometric properties

The psychometric properties of CONTINUES were found to be good (see Appendix 4.

Phase 3: Carers' importance, experiences and satisfaction

High means and low standard deviations suggest that respondents considered the items important. This is supported by the finding that nine of 11 items were rated as important by at least 80% of respondents (excluding missing data). The exceptions to this were *carers' groups* and *carers support* from services.

These results reveal that whilst the majority of items are endorsed, *carers' group* was consistently seen as the least important item.

Experience items typically elicited lower means and higher standard deviations than importance items. The majority of carers who rated items did not have staff to talk to - *talking* (68%), *carers group* (92%) or *carers support* from services (67.5%) (Table D4). These items also had the lowest means (2.5 and below).

Around half the carers who selected a rating for items did have (and half did not have) *information*, a *relationship* with a member of staff, a *hospital discharge* date and *staff changes*. These items all had means of 3.1 or 3.2.

Finally, a slightly higher proportion of respondents who rated an item reported that staff was *taking action* when they were told the user was in *crisis* (61.5%), respected *confidentiality* (61.5%), dealt with hospital *admissions* sensitively (69%) and that *users received support* from services (58%). These items also had the highest means.

The most striking finding was that the highest proportion of carers who stated that they did have an element of continuity of care in place was just 69%. This indicates that carers' experiences of continuity of care, as defined by CONTINUES, were fairly poor.

Table D4: Experience of CONTINUES elements: summary statistics and ratings

	n	**Mean (sd)**	**Doesn't have the element %**[1]	**Does have the element %**[1]
Talking	56	2.5 (1.20)	68.0%	32.0%
Taking action	39	3.6 (1.30)	38.5%	61.5%
Information	49	3.1 (1.30)	51.0%	49.0%
Relationship	52	3.1 (1.60)	52.0%	48.0%
Confidentiality	39	3.9 (1.10)	38.5%	61.5%
Admission	16	3.7 (.900)	31.0%	69.0%
Discharge	19	3.2 (1.70)	47.0%	53.0%
Staff changes	57	3.1 (1.30)	49.0%	51.0%
Carers group	51	1.4 (.900)	92.0%	8.0%
Carers support	40	2.5 (1.40)	67.5%	32.5%
Users support	57	3.4 (1.30)	42.0%	58.0%

1. Percentages of valid cases. Missing data excluded. Point 3 on the Likert scale is included in 'doesn't have the element'.

Measures of central tendency and valid percentages revealed that approximately half the carers were satisfied and half dissatisfied with each item. The exceptions to this were *confidentiality* and *hospital admission* where two thirds were satisfied, and *carers' groups* where just one third was satisfied.

Table D5: Satisfaction with CONTINUES elements: summary statistics and ratings				
	n	**Mean (sd)**	**Unsatisfied %**[1]	**Satisfied %**[1]
Talking	58	3.3 (1.10)	50.0%	50.0%
Taking action	39	3.7 (1.20)	41.0%	59.0%
Information	51	3.4 (1.00)	51.0%	49.0%
Relationship	53	3.4 (.800)	49.0%	51.0%
Confidentiality	41	3.9 (1.00)	34.0%	66.0%
Admission	16	3.6 (1.20)	31.0%	69.0%
Discharge	18	3.3 (1.20)	50.0%	50.0%
Staff changes	57	3.3 (1.30)	46.0%	54.0%
Carers group	43	3.1 (1.20)	63.0%	37.0%
Carers support	42	3.2 (1.20)	50.0%	50.0%
Users support	52	3.3 (1.20)	52.0%	48.0%

1. Percentages of valid cases. Missing data excluded. Point 3 on the Likert scale is included in 'unsatisfied'.

The relationship between experience and satisfaction

Rather than looking at satisfaction in isolation it is perhaps more revealing to explore the satisfaction rates of those respondents who stated that they had an element in place and those who stated that they did not. Table D6 shows that there was a strong link between experience and satisfaction. Carers without an item of continuity of care typically failed to report satisfaction. The highest satisfaction rates reported when an element was not in place were for staff *talking* to the carer (21%), *support for carers* (26%) and *carers' support group* (28%). Conversely, when carers reported that they did have an element in place, they tended to be satisfied: satisfaction was greater than 73% for ten of the 11 items where the element was in place. The single anomaly was *carers' support groups*, where just one of the 13 people who reported having this element also reported satisfaction.

Table D6: Satisfaction with CONTINUES elements by experience of the domains

	No Information		Element NOT in place		Element in place	
	Not applicable n (%)	Missing n (%)	Frequencies n (%[1])	Satisfaction among this subset n (%[1])	Frequencies n (%[1])	Satisfaction among this subset n (%[1])
Talking	5 (8.0%)	4 (6.0%)	37 (67.0%)	8 (21.0%)	18 (33.0%)	18 (100.0%)
Taking action	16 (25.0%)	10 (15.0%)	14 (37.0%)	2 (13.0%)	24 (63.0%)	21 (87.5%)
Information	8 (12.0%)	8 (12.0%)	24 (50.0%)	4 (16.0%)	24 (50.0%)	21 (87.5%)
Relationship	10 (15.0%)	3 (5.0%)	26 (51.0%)	2 (7.0%)	25 (49.0%)	25 (100.0%)
Confidentiality	15 (23.0%)	11 (17.0%)	13 (35.0%)	2 (13.0%)	24 (65.0%)	23 (96.0%)
Admission	35 (54.0%)	14 (21.5%)	5 (31.0%)	0 (.0%)	11 (69.0%)	11 (100.0%)
Discharge	30 (46.0%)	16 (25.0%)	8 (44.0%)	1 (11.0%)	10 (56.0%)	8 (80.0%)
Staff changes	3 (5.0%)	5 (8.0%)	28 (49.0%)	5 (18.0%)	29 (51.0%)	26 (90.0%)
Carers group	9 (14.0%)	5 (8.0%)	39 (91.0%)	13 (28.0%)	4 (9.0%)	3 (75.0%)
Carers support	13 (20.0%)	12 (18.5%)	25 (66.0%)	7 (26.0%)	13 (34.0%)	1 (8.0%)
Users support	5 (8.0%)	3 (5.0%)	22 (42.0%)	1 (4.0%)	30 (58.0%)	24 (73.0%)

1. Percentages of valid cases

3.4. Discussion

The process used to generate our outcome measures was a novel one. It is a form of participatory research (Cornwall & Jewkes, 1995; Mason & Boutilier, 1996) which is uncommon in psychiatric research, although it is used extensively in other disciplines. Our particular contribution to this model was to include user researchers in the study.

Continuity of care in psychiatry is a policy priority partly because of concerns that users will ‘fall though the net’ to the detriment of themselves or others. CONTINU-UM shows how service users themselves believe this could be prevented. It is an example of a user-generated outcome measure that asks about the issues that matter to service users. It also incorporates an element of individual choice, as users are invited to rate items by importance. Moreover, it represents what users feel are high-quality continuous services, and what, therefore, would help prevent them falling through the gap.

Government policy has emphasised the need for carers to receive support from health and social services. CONTINUES can be seen as representing one way of achieving this support, as it explores elements of continuity of care that are significant for the satisfaction of carers.

Test retest reliability and use of aggregate scores as outcome measures

For CONTINU-UM, the test retest reliability of the overall scores aggregated over items, whether as total scores or mean scores, is high for satisfaction and acceptable for importance and experience. This is despite the relatively low reliability for individual items. This argues for the use of these aggregate scores as potential outcome measures. While the individual responses are of interest in themselves, they are influenced by ceiling effects and discriminatory power is likely to be seen only when several are considered together.

The aggregate scores do appear to be reliable for this purpose. The choice of whether to use a total or mean score depends on the type of question and the context. A total score which increases can be interpreted as the number of elements experienced increasing. Alternatively, satisfaction might be more appropriately measured by a mean score since the mean reflects the level of satisfaction whatever elements have actually been experienced. Both have acceptable test retest reliability. An aggregated importance score would be less interpretable as an outcome, although useful to put the individual experience and satisfaction items into context. Whether or not sub-scores based on aggregating specific domains are valid and interpretable will be the subject of further investigation.

The test retest of overall CONTINUES scores was high for all three scales (importance, experience and satisfaction) whilst the reliability of individual items was typically low. This similarly suggests that these aggregate scale scores can be used as potential outcome measures.

Psychometric properties of CONTINU-UM

CONTINU-UM can be considered psychometrically robust, despite areas of weakness. Its importance to users has been demonstrated and their involvement in measure development was very strong. CONTINU-UM consists of three reproducible, interpretable, internally consistent scales, although individual items are less reliable.

CONTINU-UM possesses good face, consensual, content and construct validity. Construct validity was explored through hypothesis-testing for convergence and factor analysis. Evidence of convergent validity was found for *staff changes*, *day centres* and aggregate scores, but not for *avoiding services*. Interestingly, it was the single test that did not use participant-reported data that failed to converge. This could indicate respondent bias or, alternatively, it could be that staff-generated records are not a good match with participant perceptions. Similarly, correlations tell us little more than that variables are related. Whether this is due to an individual's tendency to report things more or less favourably or because continuity of care is related to both needs being met and positive relationships with staff is unclear.

Construct validity assessed through factor analysis found that a three-factor orthogonal solution produces results that are interpretable, close to simple structure and have good internal consistency. The model was, however, based on data that had been prorated because many responses (for those items that were inapplicable for a particular individual) were missing. The assumption of prorating is that services that were not used would have been rated in the same way as those that were, had they been experienced. Thus, while the prorating was inevitable, it means that the factor analysis is only indicative of the relevant constructs and should be interpreted cautiously in understanding broad categories of continuity as it is experienced.

This model produced an initial general factor alongside two additional constructs. The *general factor* provides some evidence that CONTINU-UM items are measuring an overarching construct and represents a definition of continuity of care from the service user perspective. The third factor is fairly simple to interpret, with each loading item representing a point of *transition* in the system. The second factor, however, which we have named *preconditions for continuity* is harder to interpret. *Access*, *range*, *information* and *individual progress* all load on to it, with *hospital discharge* being assigned to Factor 3 where it has a better conceptual fit. These items can be seen as representing preconditions or building blocks for continuity: without easy access to a range of services continuity cannot be in place. The presence of *information* echoes comments of focus group users who helped develop the measure. Some of these users reported that, particularly during first contact with mental health services, access to services needed (*range*) should be quick and simple, and crucially, that this should be accompanied by good-quality information. This is because if users do not have information they will not know what range of services it is possible to access. Furthermore, these items are ones where little disagreement was found: approximately 95% of respondents selected either ‘important’ or ‘very important’ for *access*, *range* and *information*, more than for any other element. *Individual progress* does not have a good conceptual fit with this interpretation, and only just loads.

This factor solution was unable to account for choice, suggesting that this element may not fit well with the concept of continuity of care.

Evidence of responsiveness, precision and interpretability was found. CONTINU-UM is largely acceptable, with problems in understanding potentially resolvable through interviewer presence. This reduces feasibility, but CONTINU-UM can still be seen as feasible as it remains on the whole easy to administer, process and analyse. Finally, the development of CONTINU-UM can be seen as appropriate as it is a psychometrically robust user-generated measure of continuity of care, filling this gap in the literature.

Psychometric properties of CONTINUES

CONTINUES can be seen as possessing a number of psychometric properties. Its domains are typically important to carers and significant for their satisfaction. Carers were involved in the development of CONTINUES and it can be seen as a reflection of their priorities for continuity of care. The scales of CONTINUES possess good reliability, although the reproducibility of individual items is weaker.

In terms of validity, the lack of convergence between CONTINUES item 3***b*** ('over the past 12 months, have you been able to get advice and information from staff?') and ECI52 ('during the past month how often have you thought about the difficulty of getting information about his/her illness?') could be due to a number of factors. It may be caused by problems within the CONTINUES item. Conversely, it may be that the items are measuring different things, ECI being far more specifically focused on illness. Finally, it may be that the different time-frames of the two questions (one year versus one month) contributed to a lack of convergence.

Convergence was found between CONTINUES item 9***b*** on whether the respondent had been to a carers' group and additional data on whether the participant belonged to a carers' support group. As these items were highly similar, this convergence is to be expected and demonstrates that this CONTINUES item is able to generate results that can be validated.

Finally, CONTINUES was found to be acceptable to participants on a number of measures and feasible to administer and process.

Importance, experience and satisfaction as measures of validity

The consensus between the priorities identified in the generation of CONTINU-UM and the importance assigned to them by those in the Main Phase sample can be seen as a form of validation of CONTINU-UM. It was always the case that the vast majority of those who have an element of continuity in place were satisfied with this. Conversely, for most domains, few people were satisfied if they did not have the element. The high, but not absolute, correlations between experience and satisfaction demonstrate that the presence or absence of the 17 domains of continuity made a clear difference to how satisfied the field trial sample declared themselves to be. This is again an argument for the validity of the measure.

There were some exceptions to the general picture of high correlations between experience and satisfaction and these take us beyond its psychometric properties. In four cases – *choice*, *avoiding contact*, support from other users (*peer support*) and *waiting* – more than one third who did not have the element were satisfied with this situation. This finding tends to mirror what was said in the focus groups. For example, some focus group members said they would not mind waiting for a really good service and so having to wait did not necessarily disrupt continuity.

The issue of choice is interesting. More people reported that they did not have choice in their care than reported that they did. Nevertheless, 39% of those without *choice* were satisfied with this. This may be because users trust their care team to do what is best for them. The picture is far from clear, however, as a majority expressed dissatisfaction when they did not have *choice* and an overwhelming majority were satisfied when they *did* have *choice*. The links here may be complex in relation to continuity of care.

For CONTINUES, whilst caution must be applied to the interpretation of these results due to the small numbers, they suggest that the focus groups were successful in generating items of continuity of care that were significant for the satisfaction of the Main Phase sample. The majority of elements were endorsed as important, the least important being carers' support groups (which refers to the existence of mutual support groups) and the support for carers that they receive from services. Whilst much emphasis has been given to the support that carers receive, these results suggest that carers prioritise high quality support for the person who uses services over personal support (Bucknall & Homes, 2001). Interestingly, the vast majority of those who did receive support from services for themselves failed to report satisfaction, indicating that carers feel the support they receive is inadequate.

Despite the elements of continuity of care being important to carers, their experiences were typically poor. The majority of carers did not have a staff member to talk to, attend a carers' group or receive support from services. One half to one third of carers did not have the remaining elements. It is therefore unsurprising that satisfaction was found to be low.

User-generated domains

While there is a dearth of research literature on continuity of care for carers, there is sufficient literature on continuity for users themselves to be a point of comparison for the user perspective. Two user-generated domains in CONTINU-UM seem to lie outside the current literature. One of these asked whether the service user could avoid services if they wanted to. This item was intended to measure the extent to which service contact varied with needs and/or wishes of the service user and it links with Freeman and colleagues' (2000) *flexible continuity*. Two thirds of respondents in the Main Phase said they could not avoid services but nearly half of these were satisfied. In the focus groups, some members were puzzled by this issue. They stated that there was no reason why they should avoid services – what they wanted was better services and to access services when they were needed. This is consistent with the finding that 45% of respondents said that this domain was 'not applicable' to them. For those who said they could avoid services when they wanted to and were satisfied with this (13%), the focus group data and consultation exercise suggest that this is consensual between users and mental health professionals and that people use services less when they are well These findings suggest that most of the people involved in this study were at no risk of 'falling through the net' of care.

One further extra domain was *peer support*. Almost two thirds of respondents said they relied on support from other users thus emphasising elements of continuity of care quite outside the formal system. We would argue that a clinically produced measure would miss this aspect of continuity. While nearly all those who relied on peer support were satisfied with this, however, a sizeable minority were satisfied with *not* having *peer support*. In the focus groups, some people were keen not to spend time only with other service users.

Policy implications

The field trial data, collected in the Main Phase of the study, also gives rise to issues that bear directly on policy. For example, current government policy is to give healthcare users more choice over the services they receive and over their own lives

(DoH, 2006). It is clear from our findings that the issue of choice in mental health is extremely complex. Further work is needed on what exactly choice means in mental health services and how it can best be delivered in accordance with government policy.

Out of hours support was also lacking for many service users, a finding that corresponds with a recent report by the Health Care Commission (2006). It is important for continuity that services are not confined to office hours. Nevertheless, 63 users answered ‘not applicable’ to this domain and this confirms a finding in the Main Phase that the cohort with psychotic illnesses (Sample 1) comprised a fairly stable group.

Traditionally, day centres played an important role in continuity of care but recent policy is to modernise these centres and replace them with vocational facilities (Social Exclusion Unit, 2004). Half of those who responded in our field trial said they received appropriate day care and half said they did not. The focus group discussions clearly showed that many users valued the relaxed atmosphere in day centres and the opportunity to spend time with others like themselves. They said they would not attend the new facilities and so would become more socially isolated as day centres were an important feature of continuity in their lives. Of course, other users shied clear of day centres in the first place (63 people reported that this question was not applicable to them).

The Care Programme Approach (CPA) has been government policy for many years but 40 of our 167 respondents said that the question about care plans was not applicable to them. There is evidence that users are neither aware of, nor involved in, their care plans (Rose, 2003). This is often explained by saying that users are not interested or ‘forget’ about their care plans. Date collection from users in the Main Phase, however, revealed that a substantial proportion of people reported not having seen a care coordinator in the year prior to the first interview and some did not have a designated care coordinator noted in their records. As far as continuity of care goes, this is indeed worrying.

This government has made carers a high priority, promoting the recognition of the valuable contribution carers make and outlining ways of supporting and maintaining them in their roles (e.g. National Service Framework, DoH, 1999) and Caring for Carers (DoH, 1999). Despite these efforts our research has found that carers' experiences of continuity of care are often poor, and that this can lead to dissatisfaction. In particular, few carers received personal support either from services or carers groups. Focus group users echoed this, the majority also tending to report that they had not received a 'carer's assessment'. Although the main priority of carers may be that the person using services receives high-quality support, this does not mean that personal support is irrelevant or unimportant.

Information provision is one of three strategic elements of 'caring for carers'. It is particularly worrying then that half the sample did not have access to information. This finding is echoed by the Social Exclusion Unit (2004) who state that carers can lack information about how to help the person they are supporting and what external support is available. These results suggest that government policy is not yet fully achieving its aims.

Limitations

Despite the fact that this is the first study to have developed a continuity of care measure from the service user perspective that is psychometrically sound, CONTINUUM was developed and validated for a specific group: those who had been in high levels of contact with mental health services over at least two years, who had a diagnosis of psychosis and were aged 18 to 65 years. We know that the measure is appropriate to this group but it is not clear whether people with different diagnoses would have rated aspects of continuity of care differently to our focus groups. It is also likely that those living in more rural settings might have a different view, as might those from a different age group.

The factor analyses were based on prorated data. They are thus indicative and cannot be used to suggest scoring systems. {The method of scoring used by the Main Phase is detailed below in its Methods section.)

Users involved in the development of the measure were not randomly recruited but purposefully sampled. Users involved in psychometric testing were randomly recruited and so can be considered a representative sample.

A further limitation is that all those in the field trial sample were engaged with services. If CONTINU-UM had been administered to a group less likely to engage with services, the results might have been different. Whether CONTINU-UM was predictive of outcome is examined as part of the Main Phase analysis.

Similarly, CONTINUES was developed and tested with carers who had face-to-face contact at least once a week with a user diagnosed with psychosis of adult age (18-65) who had been in contact with services for at least two years. It has not been tested for use in any other context.

Again, carers involved in the development of CONTINU-UM were purposefully sampled. Those involved in psychometric testing were representative of carers involved with the key group of users.

Conclusion and Recommendations

Many of the features of continuity of care, identified and discussed by the users and carers in this study, are apparent because of the model of service user involvement in research and development that was followed. As well as producing measures which tap continuity of care from the service user’s and carer’s perspective, we have shown that these measures are psychometrically sound as well as reflect respondents’ concerns. The method used also enabled us to draw out some important policy implications in respect of user- and carer-centred continuity of care.

CONTINU-UM and CONTINUES represent the first examples of user- and carer-generated outcome measures that, particularly in the case of CONTINU-UM, have undergone rigorous psychometric assessment. Reliability, face validity, content validity and acceptability were established, along with evidence of construct validity. Factor analysis revealed that CONTINU-UM has one overarching construct and two underlying constructs, ‘preconditions for continuity’ and ‘transitional points’. Further work is required utilising the measure with different samples of mental health service users. This analysis demonstrates that users of mental health services are able to produce outcome measures that not only explore the outcomes that matter to them but are also valid. Indeed, this work demonstrates that service users *can* tell us about continuity of care.

This is the first time that users' definitions of continuity of care have been subjected to construct validity assessment through factor analysis and so it is essential that further factor analyses are undertaken before any firm conclusions can be drawn. This could include confirmatory factor analysis or exploratory factor analyses with different samples, for example those with diagnoses of depression. Further research on CONTINUES, using larger samples of carers, would be valuable in determining the factors underlying this measure and its validity for this and other groups.

3.5. Summary

- Participatory research involving user researchers successfully led to the development of two measures of continuity of care, generated by users and carers themselves
- CONTINU-UM is psychometrically robust, while there is evidence for CONTINUES having a number of psychometric properties
- Factor analysis suggests that CONTINU-UM has one overarching construct and two underlying constructs, ‘preconditions for continuity’ and ‘transitional points’
- Aggregate scores of each measure appear to be reliable for use as outcome measures
- Service users generated some items not found in the continuity of care literature, avoiding services and peer support.

4. Main Phase

4.1. Aims

The Main Phase of the study aimed to explore the meanings of continuity of care for users of mental health services by assessing how different types of continuity relate to each other in practice. It further aimed to determine the user and carer characteristics associated with each type of continuity and to assess the relationship of continuity of care with health outcomes (such as overall functioning, symptomatology, time in hospital, quality of life, degree of unmet need) and for carers with psychological distress and experiences of care-giving.

The extension of the Main Phase methodology from the original sample of people with psychotic disorders to a second sample of people with non-psychotic disorders under the care of the same CMHTs led to a broadening of the study aims. This extension of the study had the aim of comparing the experiences of service users with non-psychotic disorders to those with psychotic disorders with respect to continuity of care.

4.2. Methods

4.2.1. Recruitment of Sample 1 (People with psychotic disorders)

Service Users

People with long-term psychotic disorders were sampled from the caseloads of seven CMHTs covered by two mental health Trusts. Quantitative interviews were conducted at baseline (T1) and annually for two years (T2 and T3) and mapped the users' journeys through care in the year prior to interview (thus covering three years). The inclusion criteria were: diagnosis of any psychotic disorder received at least two years previously, on the caseload of the CMHT for at least six months and aged 18 to 65 (inclusive). Sampling was stratified to ensure that 25.0% were from minority ethnic groups.

Carers

Each user was asked to identify their primary ‘carer’, defined for the purposes of this study as a relative or friend with whom the user had at least weekly contact. If the user consented to the carer being contacted, the carer was invited to take part in the study. If the user identified more than one carer, the carer nominated by the user as more significant was approached. At subsequent time-points, the user was again asked to identify their primary ‘carer’ thus defined, whether or not this was the same person as at T1.

Professionals

Each user was asked to identify the professional (usually the care coordinator) who they felt had the primary role in their care. At baseline and at each time-point, whichever professional was identified by the user as currently having the primary role was contacted.

Sample size justification

The study was originally powered on the possibility of 31 variables being analysed as possible predictors of days in hospital. The variables were: CONTINU-UM; 'activity' variables from records (12 variables estimated); ten socio-demographic, illness (diagnosis, T1 days in hospital and *Brief Psychiatric Rating Scale*) and care variables (mental health trust, time with service, presence of an informal caregiver); and nine further variables (*Scale to Assess Therapeutic Relationships in Community Mental Health Care – service user version* total score, disengagement from care, professional rating of *Camberwell Assessment of Need* (CAN), user CAN and *Schedule for the Evaluation of Individual Quality of Life* scores). (For details of these measures, see below.) Using the estimate of 15 subjects required for each explanatory variable in the multi-level analysis, gave a sample size of 465. Because the variables were to be collected at repeated time-points, this sample size could be adjusted (Machin *et al*, 1997). Assuming a correlation between two observations made on the same subject of 0.6 (ibid.) and the study design allowing for data to be collected at T1, T2 and T3, this gave an adjustment factor of 0.373. A sample size of (465*0.373=) 174 would therefore be sufficient. To allow for drop-outs and the number of assumptions made, this sample size was increased to an ideal 200.

Data from a previous study suggested that approximately two fifths of users living independently in the community live with a relative (32.0%) or friend (9.0%) (Harvey, 2000). This suggested that from 200 service users, 80 would have a carer eligible for recruitment.

4.2.2. Recruitment of Sample 2 (People with non-psychotic disorders)

Service users

People with long-term non-psychotic mental health problems were recruited from the caseloads of the seven CMHTs already participating in the study, assessed at baseline and followed up one year later. The inclusion criteria were: primary diagnosis of any non-psychotic disorder received at least two years previously; on the caseload of the CMHT for at least six months; aged 18 to 65 (inclusive).

Carers

Each user was asked to identify their primary ‘carer’, defined as for Sample 1. If the user consented to the carer being contacted, the carer was invited to take part in the study. If the user identified more than one carer, the carer nominated by the user as more significant was approached. At T2, the user was again asked to identify their primary ‘carer’ thus defined, whether or not this was the same person as at T1.

Professionals

As with Sample 1, each user was asked to identify the professional (usually the care coordinator) who they felt had the primary role in their care. At baseline and at one-year follow-up, whichever professional was identified by the user as currently having the primary role was contacted.

Sample size justification

The aim was to recruit 100 service users, slightly more than half the sample size for Sample 1. This sample size was primarily determined by pragmatic considerations, but was adequate for the planned analyses. When comparing the levels of continuity of care between the two groups (non-psychotic and psychotic users), adjusting for the unequal size of the groups (180 psychotic and 98 non-psychotic users), the sample sizes would be sufficient to detect effect sizes of 0.4 and above with 90% power at a 5% significance level. (An effect size of 0.35 or above can be detected with 80% power at a 5% significance level.) These detectable effect sizes would be categorised as small to medium effect sizes according to the classification suggested by Cohen (1992).

4.2.3. Procedure, Data & Measures (Sample 1)

Service users

Interviews with users were conducted at baseline (T1) and at one- and two-year follow-up, to collect the following data:

Demographic and mental health data (including duration of contact with psychiatric services, number of contacts with psychiatric services in previous year, diagnosis, age, gender, ethnicity and having a carer);
Patterns of contact with organisations and individual professionals (year prior to interview);
Breaks in care (number and duration in the year prior to interview);
Information flow: between CMHT and GP; CMHT and inpatient dept (from records, below);
Days in hospital: (year prior to interview);
Brief Psychiatric Rating Scale (BPRS): a well-validated scale assessing psychiatric symptoms in five areas during the week prior to interview: anxiety and depression, anergia, thought disturbance, activation and hostility-suspiciousness (Overall & Goreham, 1976);
Global Assessment of Functioning (GAF): rates the severity of symptoms and disability in the week prior to interview (Endicott *et al*, 1976);
Camberwell Assessment of Need (CAN): measures perceived 'needs' in 22 domains, covering: basic needs (e.g. accommodation); health needs (e.g. physical); social needs (e.g. company); functioning (e.g. household skills); and service receipt (e.g. information). The CAN is designed to be completed concurrently by users and their care coordinators, to ascertain the degree of congruence between their views. The

acceptability of its psychometric properties has been satisfactorily established (Phelan *et al*, 1995);

Scale to Assess Therapeutic Relationships in Community Mental Health Care – service user version (STAR): measures the relationship between the service user and professional as rated by the user; psychometric properties have been found satisfactory (McGuire-Snieckus *et al*, 2007); users were asked to complete the scale regarding their relationships with their care coordinator, psychiatrist and a third professional if applicable;

Schedule for the Evaluation of Individual Quality of Life (SEIQoL): is a user-led assessment of quality of life. Interviewees select five areas of life regarded as important, weight them in order of importance, and rate their current satisfaction with each area (McGee *et al*, 1991);

Manchester Short Assessment of Quality of Life (MANSA): a 16-item measure consisting of four yes/no questions and 12 seven-point likert scaled questions measuring quality of life (Priebe *et al.* 1999);

User Empowerment Scale: a 28-item scale measuring the personal construct of empowerment as defined by service users. Psychometric testing has established its internal consistency and provided evidence of its validity (Rogers *et al*, 1997);

CONTINU-UM: user-generated and refined through a user-centred process in the Developmental Phase (see above). For each of the 17 domains identified, questions are asked around the degree to which continuity has been received, the value placed on continuity and satisfaction with it. For the purposes of our analysis, only the questions about the degree to which continuity has been experienced were utilised ('b' questions) and the overall mean (rather than total) score was utilised, as this reflects the degree of perceived continuity experienced by each user for the domains relevant to them.

The five-item *MacArthur Perceived Coercion Scale* (Gardner *et al*, 1993) was added to the T3 interviews, adapted for use in community-based psychiatric services. This measures perceived coercion through three sub-scales: 'negative pressure', 'perceived coercion' and 'voice' (users feeling that they are allowed to express their view of their care).

'Activity' data, such as breaks in care and number of professionals seen, were verified from records wherever possible, utilising both electronic and paper CMHT records.

Whether information regarding the user had passed from the CMHT to primary care, social care, or any other agencies or individuals identified, was ascertained wherever possible. The data collection tool is presented in Appendix 6.

Carers

Data on carers were collected through self-completed questionnaires, as follows:
12-item General Health Questionnaire (GHQ-12): a widely-used measure of psychological distress (Goldberg, 1978);
Experience of Caregiving Inventory (ECI): a well-validated measure of carers' experiences of caring for people with serious mental health problems (Szmukler, 1996);
CONTINUES: carer-generated measure of continuity: generated in the Developmental Phase (see above). Comprising 11 domains, it is structured in the same way as CONTINU-UM and the 'b' questions (about the degree to which continuity had been experienced) were again utilised.

Professionals

Each care coordinator identified by a user participating in this phase of the study was contacted and requested to complete the CAN and professional-rated STAR (McGuire-Snieckus *et al*, 2007) in a face-to-face or telephone interview.

4.2.4. Procedure, Data & Measures (Sample 2)

The procedure used for Sample 1 was repeated for Sample 2, with follow-up at one year only. To reflect the different nature of this group clinically, the BPRS was not used and the *Hospital Anxiety and Depression Scale (HADS)* (Zigmond & Snaith, 1983) was added. This is a self-report questionnaire developed to detect adverse anxiety and depressive states. Each question has four possible responses scored on a scale from zero to three, with maximum scores of 21 each for depression and anxiety. The two sub-scales, anxiety and depression, have been found to be independent measures. In its current form the scale is divided into four ranges: normal (0-7), mild (8-10), moderate (11-15) and severe (16-21). The *MacArthur Perceived Coercion Scale* was used at T2 only.

4.2.5. Analytical Strategy & Statistics: Users Sample 1

The analytic strategy was divided into three phases. The first explored the concept of continuity of care, the second looking at variables associated with varying levels of continuity and the third relating continuity to subsequent changes in clinical and social outcomes.

Phase 1: What is Continuity of Care and what are the levels of it in this sample?

Overview

The multi-axial definition of continuity of care developed by Freeman and colleagues (2000, 2002) was taken as the starting-point for the present study. Each definition was operationalised for use with people with mental health problems in the care of CMHTs, by identifying the data and measures used to approximate each type. More than one variable was used for any given type of continuity if appropriate; these are referred to as *components* of continuity.

A factor analysis was conducted including each continuity component. This was designed to show how the different components of continuity relate to each other and whether in practice they cluster as seven independent dimensions of continuity of care (factors) reflecting Freeman and colleagues' theoretical model or if instead the variation within components could be sufficiently explained by new factors. Factor loadings determined the interpretation of the resultant factors. The factor analysis was performed using the data for T1. Confirmatory factor analyses were performed using the T2 and T3 data to see whether the factor structure was valid for and confirmed by the subsequent years' data.

The actual levels of continuity experienced by the service users with psychotic disorders were calculated both as individual components and as total scores for each factor. How the factor scores were related to each other was also explored at T1 using correlation coefficients and one-way analysis of variance. To aid in the interpretation of the further analyses of the factors an illustration of the factor scores was carried out, showing how hypothetical service users would achieve high, medium and low scores. Actual data from two randomly selected users are then presented, indicating how their data transforms into factor scores.

Variable selection

The six definitions that formed the generic multi-axial definition of continuity of care (Freeman *et al*, 2000) were, in this phase of the study alone, supplemented by two others, *long-term continuity* and *contextual continuity*, produced by the same team's second study of continuity in mental health (Freeman *et al*, 2002). The operationalisation of *contextual continuity* was of a limited definition (social context reflected in living and daily circumstances). The eight types of continuity were operationalised by the Main Phase team, with the exception of *experienced continuity*, defined as an over-arching concept from the service user's perspective, for which the user-generated measure of continuity (CONTINU-UM) was used as a proxy. The strategy for operationalising the multi-axial definition was deliberately over-inclusive as this set of variables would be reduced prior to factor analysis based on data constraints.

Sources and construction of variables

The selected variables were collected through interviews with service users and from case-notes. Some data were collected from standard measurement scales completed in a research interview, the CONTINU-UM, STAR and CAN, while health service utilisation data during the previous year as reported by the service user were also included. The remaining variables were calculated using data from each user's CMHT case-notes. For each contact between the CMHT and the service user in the year prior to data collection, the date, setting and the discipline of the professional making the contact were recorded, as well as admissions and discharges to and from psychiatric hospital, transitions and referrals to other agencies and data on whether letters were copied to users and whether copies of the care plan (CPA) had been sent to other parties (the user, any carer and the GP).

Variables were then manipulated in order to give them comparable weight. Continuous variables which were sufficiently normally distributed were z-scored (data-point minus the mean divided by its standard deviation). Highly skewed continuous variables were categorised into trichotomised variables, cut-offs being derived to ensure sufficient numbers within categories and provide clear, interpretable divisions between categories. Dichotomous and trichotomous categorical variables were coded as ‘-1’, ‘+1’ and ‘-1’, ‘0’, ‘+1’, respectively. Variables were coded so that a positive score indicated an assumed positive scenario. The direction of relationships as determined by the factor analysis, however, would indicate the final direction of the variables.

Variable selection for entry into factor analysis

The variables chosen above were then assessed as to their appropriateness for inclusion in the factor analysis. Variables were omitted from further analysis if they met any of the following criteria: a) there was strong evidence that they were inconsistently recorded, b) there was insufficient spread of response (less than 5.0% in any category) or c) two variables had a Spearman Rank correlation coefficient of 0.8 or greater, in which case one would be omitted from further analysis; the one to be included would be chosen based on its robustness or clinical relevance.

Exploratory factor analysis

Bartlett's test of sphericity and the Kaiser-Meyer-Olkin (KMO) measure of sampling adequacy (Kaiser, 1974) were used to evaluate the strength of the linear association between the items in the inter-item correlation matrix. Further variables were omitted at this stage if their individual measure of sampling adequacy was unacceptably low. Variables were omitted until the overall KMO measure of sampling adequacy reached an acceptable level. Exploratory factor analysis was carried out on eligible variables. Firstly, a Principal Component Analysis was used to extract factors with an eigenvalue greater than one. A Varimax rotation was then used to produce interpretable independent factors. Factors were extracted and interpreted by identifying the items which loaded onto each with a rotated factor loading of over 0.5. The factor scores were then calculated by summing the items relevant to each and descriptive statistics were presented.

Validation of tool

Confirmatory factor analyses were performed to test the factor structure derived above in subsequent data-sets: the same group of service users with psychotic disorders at two subsequent time-points and the sample of users with non-psychotic disorders at two time-points.

Confirmatory factor analysis

Confirmatory factor analyses were performed to test and cross-validate the fit of the empirical seven-factor model obtained from the exploratory factor analysis, using the Sample 1 data at T2 and T3 and Sample 2 data at T1 and T2 (see Appendix 7).

Levels of continuity

The actual levels of continuity experienced by the service users with psychotic disorders were calculated both as individual components and as total scores for each factor at each time-point. Descriptive statistics are presented for these variables using mean, standard deviation, minimum and maximum values for all continuous variables and frequencies and percentages for categorical variables.

An analysis of how the factor scores were related to each other at T1 was carried out using Pearson correlation coefficients and a one-way analysis of variance (when analysing Factor 5 only as this was transformed into a categorical variable). Only Pearson correlation coefficients greater than or equal to |0.2| are commented upon.

Illustration of continuity factors

An illustration of the magnitude of the factor scores was carried out in order to aid in the interpretation of subsequent analyses (see Appendix 8).

Phase 2: What factors are associated with Continuity of Care?

This phase aimed to test what explanatory variables, including clinical and social functioning variables, might be associated with varying levels of continuity.

This research question was addressed by means of two analyses. Firstly (analysis 2a), associations between possible explanatory variables and continuity of care factors were explored using contemporaneous data-points. Secondly (analysis 2b), associations were explored between levels of continuity factors and *change* in clinical and social functioning variables in the year prior to the continuity factor rating (e.g. change in variable between T1 and T2 associated with T2 factor score).

Phase 2a

Variables tested included socio-demographic variables, dual diagnosis, duration of contact with psychiatric services, hospitalised in previous year, ethnicity, presence of informal carer, team (as proxy for organisational factors and socio-economic factors/deprivation), clinical and social functioning variables (psychiatric symptomatology, global functioning, empowerment, quality of life) and perceived coercion (T3 only). Whether the factors changed significantly over time was also tested.

A multi-level model provided the framework for this phase of analysis. This allowed the maximum use of all data, the methodology not requiring complete data on all variables at all time-points, while accounting for the dependent structure within the data (multiple time-points per subject). PROC MIXED from SAS version 9.1 statistical software (SAS Institute Inc, 1989) was used when the dependent variable was continuous, incorporating a random effect for service user.

For continuous dependent variables, the associations between each explanatory variable listed above and each level of continuity variable were initially tested individually. A final model for each level of continuity outcome was then fitted, entering all explanatory factors which were significantly related univariately ($p<0.1$). For each level of continuity outcome, those explanatory factors found to be significant at the 10% level are presented with both their unadjusted parameter estimates (when each explanatory factor is the sole variable in the model) and adjusted parameter estimates (when all explanatory factors are entered). Continuous explanatory variables provide parameter estimates which indicate the rate of change of the variable in relation to the level of continuity. For each categorical explanatory variable, the estimated mean level of the level of continuity for each category of the variable is presented. All parameter estimates are presented with 95% confidence intervals.

PROC GLIMMIX was used for any factor which proved to be categorical in nature (binary or trichotomous). Multinomial logistic regression was carried out incorporating a user random effect to allow for repeated measurements using methodology as described in Kuss & McLerran (2007) for trichotomous dependent variables. For these analyses, the same strategy was used as above but parameter estimates were presented as odds ratios with 95% confidence intervals.

Phase 2b

The continuity factors were tested for possible associations with change in clinical and social outcomes in the year prior to measurement of the factor. The dependent variables for this analysis were changes between T1 and T2 and T2 to T3 in global functioning (GAF), psychiatric symptoms (BPRS), quality of life (SEIQoL and MANSA)**,** empowerment and whether the user had been in hospital or not in the previous year. For the continuous dependent variables (one-year change in outcomes), the independent variables were each continuity factor corresponding to the contemporaneous year: T2 continuity factor against change in outcome from T1 to T2, T3 continuity factor against change in outcome from T2 to T3 simultaneously. As change variables were being used, the multiple measurements per user were not correlated, so a simple linear regression was used when testing the continuous continuity factors and a one-way analysis of variance when testing the categorical continuity factors. When ‘hospitalised in the previous year’ was the dependent variable PROC GLIMMIX was used to incorporate a random user effect. Data from all three time-points were used in this analysis, as the dependent variable related to information over the previous year.

Parameter estimates are presented for all independent variables significant at the 10% level and adjusted models were also fitted if more than one independent variable was significant.

Phase 3: Does Continuity of Care affect Clinical and Social Outcomes?

In this analysis, continuity of care at each time-point was tested for association with change in clinical and social variables between that time-point and the subsequent one. The analysis thus measured the impact of each continuity factor on clinical and social functioning in the subsequent year.

Details of the analysis were as for Phase 2b, except that the level of continuity at T1 was regressed against the change in each clinical and social variable from T1 to T2 and level of continuity at T2 was regressed against the change in each clinical and social variable from T2 to T3 simultaneously. When ‘hospitalised in the previous year’ was the dependent variable, the level of continuity at T1 was tested for association with whether the service user had been hospitalised between T1 and T2 and the level of continuity at T2 was tested for association with whether the user had been hospitalised or not between T2 and T3.

Comparison of users with psychotic disorders scoring in the upper and lower quartiles on each factor

Service users scoring in the upper and lower quartiles for each factor were compared in order to illustrate further the differences between the experiences and characteristics of those scoring high and low on each continuity factor (see Appendix 9).

4.2.6. Analytic Strategy and Statistics: Users Sample 2

The levels of each continuity factor were calculated and levels for the two samples were compared. Factor scores are again illustrated in Appendix 8 and a comparison of users scoring in the upper and lower quartiles presented in Appendix 9.

The study design allowed for the repetition of Phases 2 and 3 of the analytic strategy with one combined sample of Sample 1 and Sample 2 service users if the data made this appropriate (if levels of continuity or demographic data suggested the groups were comparable). Otherwise, Phases 2 and 3 analyses would be repeated using only the Sample 2 data.

4.2.7. Analytical Strategy & Statistics: Carers Sample 1

The analysis of carer data was designed to replicate that for users as far as possible.

Phase 1: What is Continuity of Care for Carers and what are the levels of it in this sample?

Continuity of care for carers was defined and operationalised as the carer-generated scale, CONTINUES. The level of continuity experienced by the carers was described through presentation of the CONTINUES total score

How carers’ experience of continuity relates to the user's experience of continuity was explored using a correlation matrix and factor analysis.

Phase 2: What factors are associated with Continuity of Care for Carers?

Phase 2a

Possible associations between psychological wellbeing (GHQ-12 total score), positive and negative appraisal of care-giving (ECI) and experienced continuity of care (CONTINUES) at contemporaneous time-points were assessed using a multi-level model incorporating a random user effect. Socio-demographic variables, users’ CONTINU-UM scores, functioning (GAF) and symptomatology (BPRS) were used as further potential independent variables.

Phase 2b

In order to assess the relationship between change in psychological wellbeing and experiences of caregiving in the previous year and *experienced continuity*, the level of CONTINUES score at T2 and T3 was regressed against the change in the GHQ-12 and the positive and negative appraisal sub-scales of the ECI from T1 to T2 and T2 to T3, respectively.

Phase 3 - Does Continuity of Care affect Carers' psychological wellbeing?

To explore the impact of CONTINUES on change in psychological wellbeing and positive and negative appraisal of caregiving, CONTINUES at T1 and T2 was regressed against change in psychological well-being and positive and negative appraisal of caregiving from T1 to T2 and T2 to T3, respectively.

4.2.8. Analytic Strategy and Statistics: Carers Sample 2

The carer analysis was conducted as for Sample 1.

4.2.9. Other analyses

Those dropping out of the study were compared to those remaining and those discharged from secondary care by the end of the study were compared to those remaining in secondary care (see Appendix 11).

Service user and professional concordance

The concordance between service user and professional views as measured by the CAN and the STAR were assessed (see Appendix 12).

Comparison of Samples 1 and 2

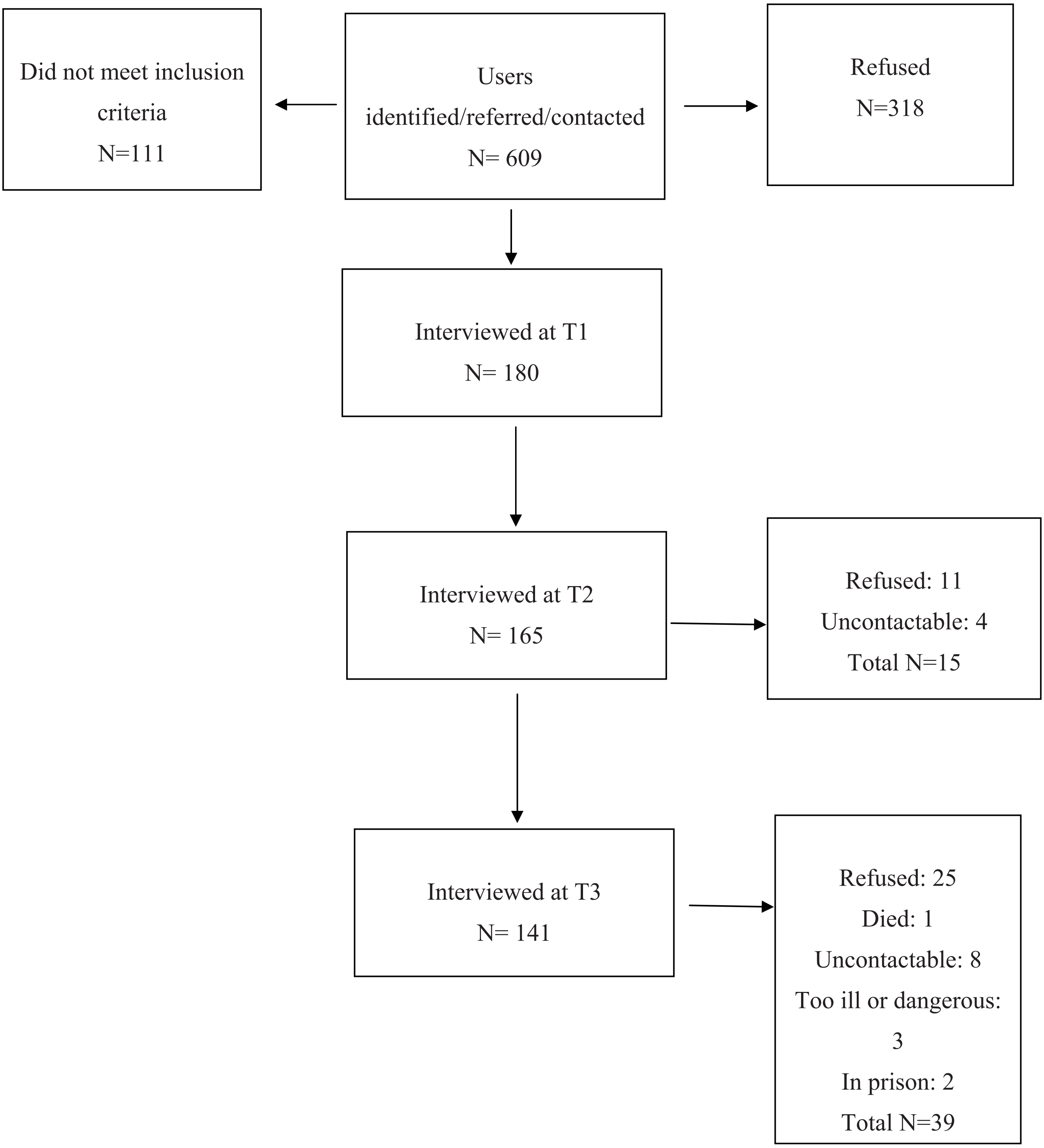
Service users with psychotic disorders and their carers were compared to service users with non-psychotic disorders and their carers (see Appendix 13).

4.3. Results

4.3.1. Sample recruitment and characteristics

Service users with psychotic disorders

Figure 1: Psychotic sample recruitment figures



Recruitment

Initially, 609 users were identified as being eligible for the study. Of these, 111 did not meet the inclusion criteria and 318 refused to participate, leaving 180 service users to be interviewed at Time 1. At Time 2, 15 users refused to be interviewed or were not contactable and 165 (91.7%) were interviewed. At Time 3, 141 users (78.3%) were interviewed as 39 were not contactable or refused.

Demographic characteristics

Sample 1 comprised 180 service users: 85 from Trust 1 and 95 from Trust 2.

A small majority of the total group was male (55.6%). The mean age was 43.1, ranging from 19 to 65. The ethnic distribution was 66.7% White, 19.4% Black, and 13.9% 'Other' (including users from Asian, Chinese, mixed and other ethnic backgrounds). More service users in Trust 2 were White than in Trust 1 (76.8% versus 55.3%), while almost three times as many in Trust 1 were Black (28.2% versus 11.6%).

More service users lived with other people than alone (59.4% versus 40.6%) and more Trust 1 users lived alone than Trust 2 users (45.9% versus 35.8%). More than three quarters of the users lived in unsupervised accommodation (77.2%) and the Trust 2 group had over twice as many users living in supervised accommodation (31.6% versus 12.9%). Regarding education, 61.7% of the users had attended school beyond the age of 16 and more of the Trust 2 group (45.3% versus 30.6%) had left school by 16. More Trust 1 service users had jobs (16.7% versus 10.8%), although 86.9% of all service users were not employed. (Table M1.)

Table M1: Sample 1 Demographic characteristics at T1 by Trust							
		n	**Trust 1**	**n**	**Trust 2**	**n**	**Total**
Age mean (sd)		85	42.5 (10.71)	95	43.7 (11.09)	180	43.1 (10.90)
Min – max			22-63		19-65		19-65
Gender n (%)	Female	85	36 (42.4%)	95	44 (46.3%)	180	80 (44.4%)
	Male		49 (57.6%)		51 (53.7%)		100 (55.6%)
Ethnic group n (%)	White	85	47 (55.3%)	95	73 (76.8%)	180	120 (66.7%)
	Black		24 (28.2%)		11 (11.6%)		35 (19.4%)
	Other		14 (16.5%)		11 (11.6%)		25 (13.9%)
Living situation n (%)	Living alone (+/- children under 18)	85	39 (45.9%)	95	34 (35.8%)	180	73 (40.6%)
	Living w/ others (+/- children under 18)		46 (54.1%)		61 (64.2%)		107 (59.4%)
Accommodation type n (%)	Unsupervised accommodation	85	74 (87.1%)	95	65 (68.4%)	180	139 (77.2%)
	Supervised accommodation		11 (12.9%)		30 (31.6%)		41 (22.8%)
Education n (%)	School up to 16	85	26 (30.6%)	95	43 (45.3%)	180	69 (38.3%)
	School above 16		59 (69.4%)		52 (54.7%)		111 (61.7%)
Employment Status n (%)	Paid employment[1]	54	9 (16.7%)	83	9 (10.8%)	137	18 (13.1%)
	Unemployed or unpaid work[2]		45 (83.3%)		74 (89.2%)		119 (86.9%)

1. Includes full-time work, part-time work, sheltered work and self-employment.
2. Includes users seeking work, unable to work, students, retired, and other.

Diagnoses

According to OPCRIT, 97.7% of the service users in Sample 1 had a diagnosis of some form of psychosis.

Table M2: Sample 1 OPCRIT diagnosis

Diagnosis n=173[1]	**n (%)**
Schizophrenia and Schizoaffective disorder	117 (67.6%)
Bipolar Disorder (including mania with psychosis)	19 (11.0%)
Delusional disorder and non-organic psychosis	33 (19.1%)
Depression (with and without psychotic features)	4 (2.3%)

1. OPCRIT could not be completed for seven service users due to missing records.

Care characteristics

The average duration of psychotic illness was 212.3 months (about 18 years), ranging from 18 to 588 months. Mean age at first contact with psychiatric services was about 25, and varied across service users from eight to 48 years of age. Over 65.0% of the sample had had between 1 and five lifetime admissions. Over half of the service users at T1 (54.5%) rated their mental health in the past year as stable or mostly stable.

The mean duration of users' relationship with the care coordinator was about 30 months, or two and a half years. The duration of the relationship with the psychiatrist was much shorter for users in Trust 2 (21.3 months) than in Trust 1 (34.9 months). Over the previous year, about 80.0% of the whole sample had seen one or two designated care coordinator(s) and seen one or two designated psychiatrist(s) (81.2% and 78.9%, respectively). More than a fifth of the service users from Trust 2, however, had not seen a care coordinator over the previous year (22.2% compared to 3.5% at Trust 1). Fewer Trust 1 service users, however, had seen a designated psychiatrist over the last year (15.3% versus 8.4%).

Regarding the pattern of care, 13 service users, ten from Trust 2 and three from Trust 1, reported having had breaks in their mental health care in the previous 12 months. Among the Trust 2 service users, seven had one break, one had two breaks and another participant four breaks (data was missing for one). The breaks had been at the service users' request in only three of these instances. Two out of the three Trust 1 service users with breaks in their mental health care (with only one break each) had requested the suspension in care. (Data about breaks in care were obtained from 177 users.) (Table M3.)

Table M3: Sample 1 Therapeutic care characteristics at T1 by Trust

		n	Trust 1	n	Trust 2	n	Total
Age at first contact with psychiatric services mean (sd)		81	24.3 (7.72)	91	25.5 (8.99)	172	24.9 (8.41)
Min – max			8-41		8-48		8-48
Duration of illness (months) mean (sd)		81	209.7 (134.08)	91	214.6 (141.5)	172	212.3 (137.69)
Min – max			18-564		24-588		18-588[1]
Number of lifetime hospital admissions n (%)	None	85	4 (4.7%)	95	8 (8.4%)	180	12 (6.7%)
	1-5		59 (69.4%)		62 (65.3%)		121 (67.2%)
	6 and over		22 (25.9%)		25 (26.3%)		47 (26.1%)
Duration of relationship with care coordinator (months) mean (sd)		73	28.1 (37.97)	63	31.4 (34.55)	136	29.6 (36.32)
Min – max			1-180		1-180		1-180
Duration of relationship with psychiatrist (months) mean (sd)		42	34.9 (27.53)	56	21.3 (15.66)	98	27.1 (22.49)
Min – max			2-96		1-72		1-96
Duration of relationship with other professional (months) mean (sd)		10	12.9 (9.57)	16	35.8 (62.17)	26	27.0 (49.81)
Min – max			1-30		2-240		1-240
Number of different designated care coordinators seen over past year n (%)	None	85	3 (3.5%)	90	20 (22.2%)	175	23 (13.1%)
	1-2		76 (89.4%)		66 (73.3%)		142 (81.2%)
	3-4		6 (7.1%)		4 (4.5%)		10 (5.7%)
Number of different designated psychiatrists seen over past year n (%)	None	85	13 (15.3%)	95	8 (8.4%)	180	21 (11.7%)
	1-2		67 (78.8%)		75 (78.9%)		142 (78.9%)
	3-4		4 (4.7%)		9 (9.5%)		13 (7.3%)
	5 and over		1 (1.2%)		3 (3.3%)		4 (2.3%)

1. Clearly at least one service user had been ill for less time that our inclusion criteria stipulated. Users were recruited on the basis of information from clinical teams and were not excluded subsequently if data collection revealed them not to meet an inclusion criterion.

Medication

All but two of the total group were taking medication and compliance was self-rated as good by over 90.0% of the study users. Overall, 65.1% were on atypical anti-psychotics, with a much larger proportion in Trust 2 than in Trust 1 (78.0% versus 51.2%). Twice as many service users from Trust 2 were on anti-depressants (38.0% versus 19.0%). Conversely, twice as many from Trust 1 were on depot medication (Table M4).

Table M4: Sample 1 Medication status at T1 by Trust

		n	**Trust 1**	**n**	**Trust 2**	**n**	**Total**
Currently on medication n(%)	Yes	85	85 (100.0%)	95	93 (97.9%)	180	178 (98.9%)
	No		0 (0%)		2 (2.1%)		2 (1.1%)
Type of medication n (%)[1]	Depot Injection	84	37 (44.6%)	93	20 (22.0%)	177	57 (32.8%)
	Atypical anti-psychotic		43 (51.2%)		71 (78.0%)		114 (65.1%)
	Typical anti-psychotic		4 (4.8%)		3 (3.2%)		7 (4.0%)
	Mood stabiliser		21 (25.0%)		25 (26.9%)		46 (26.0%)
	Anti-depressant		16 (19.0%)		36 (38.0%)		52 (29.4%)
	Side effect medication		10 (11.9%)		23 (24.7%)		33 (18.6%)
Compliance with medication n (%)	Poor compliance	84	2 (2.4%)	93	8 (8.6%)	177	10 (5.6%)
	Good compliance		82 (97.6%)		85 (91.4%)		167 (94.4%)

1. Total per trust may be greater than one as some service users may be on more than one type of medication.

Substance use

Overall, 53.3% of all study users reported using alcohol, and they had done so for an average of about nine days in the previous month. While fewer service users from Trust 1 reported alcohol use (49.4% versus 56.8% for Trust 2), they reported drinking more often (10.4 days versus 7.8 days). More than twice as many service users from Trust 1 reported illegal drug use (11.8% versus 5.3% from Trust 2), and reported drug use on average every other day in the last month, versus only once a month for the Trust 2 group (Table M5).

Table M5: Sample 1 Substance use at T1 by Trust

	n	Trust 1	n	Trust 2	n	Total
Use alcohol n (%)	85	42 (49.4%)	95	54 (56.8%)	180	96 (53.3%)
Alcohol consumption in the last month (days) mean (sd) Min – max	39	10.4 (10.37) 0-30	52	7.8 (8.63) 0-30	91	8.9 (9.45) 0-30
Use drugs^1 n (%)	85	10 (11.8%)	95	5 (5.3%)	180	15 (8.3%)
Drug consumption in the last month (days) mean(sd) Min – max	7	14.1 (12.56) 0-30	3	1.0 (1.00) 0-2	10	10.2 (12.07) 0-30

1. Includes cannabis, cocaine and crack cocaine.

Clinical and social functioning

The mean GAF (functioning) rating for the whole group was 51.6, a moderately low level of functioning, and the mean BPRS (symptomatology) rating was 33.1 out of 126, indicating mild to moderate symptoms. User empowerment (Empowerment Scale) was modest at 74.2 and individual quality of life, rated by the SEIQoL and MANSA, was 62.5 (out of 100) and 4.5 (out of 7), respectively.

The sample's mean *experienced continuity*, operationalised as the CONTINU-UM measure, was 44.1, a moderate level. Regarding needs for care (CAN), the average total number of needs was 6.2, of which about two thirds (4.3) were met. On average, over half of the needs for care were met informally (3.4) and the proportion of needs met for the sample was 73.7%. Therapeutic relationship rated by the service users about the care coordinator (STAR-c) and the psychiatrist (STAR-p) was moderate at 37.1 and 34.3, respectively. Coercion scores indicate moderate but identifiable coercion. (Table M6).

Table M6: Sample 1 Clinical and social functioning at T1 by Trust

		n	Trust 1	n	Trust 2	n	Total
GAF Total Score (0-100) mean(sd)		85	52.9 (13.88)	94	50.3 (14.23)	179	51.6 (14.08)
Min – max			22-90		21-84		21-90
BPRS Total Score (18-126) mean(sd)		85	32.8 (11.04)	94	33.4 (10.86)	179	33.1 (10.92)
Min – max			18-70		19-74		18-74
EMP Total score (28-112) mean(sd)		82	75.2 (10.36)	95	73.3 (10.97)	177	74.2 (10.70)
Min – max			32-97		23-92		23-97
SEIQoL Total score (0-100) mean(sd)		71	61.3 (16.20)	83	63.6 (16.85)	154	62.5 (16.54)
Min – max			24.1- 94.9		22.1-100.0		22.1-100.0
MANSA Total score (0-7) mean(sd)		85	4.6 (.817)	95	4.5 (.833)	180	4.5 (.825)
Min – max			2.5-6.2		2-6.5		2-6.5
CONTINU-UM Total Score (16-80) mean(sd)		78	46.1 (12.37)	89	42.3 (15.48)	167	44.1 (14.20)
Min – max			20-75		2-70		2-75
CAN (0-22) mean(sd)	Total number of needs	84	5.9 (2.86)	94	6.3 (3.19)	178	6.2 (3.04)
Min – max			0-13		0-17		0-17
	Number of met needs		4.2 (2.15)		4.4 (2.54)		4.3 (2.36)
			0-9		0-12		0-12
	Number of unmet needs		1.7 (1.87)		2.0 (2.55)		1.9 (2.25)
			0-6		0-9		0-9
	Number of needs met informally		3.6 (4.18)		3.2 (3.96)		3.4 (4.06)
			0-21		0-19		0-21
	Proportion of needs met (0-100)		75.4 (25.90)		72.2 (30.17)		73.7 (28.20)
			0-100		0-100		0-100
STAR Total score user version (0-48) mean(sd)		79	38.2 (8.33)	64	35.8 (8.48)	143	37.1 (8.46)
Min – max			14-48		9-48		9-48
STAR Total score Psychiatrist version (0-48) mean(sd)		47	33.2 (11.43)	55	35.2 (10.11)	102	34.3 (10.73)
Min – max			7-48		6-48		6-48
STAR Total score Other version (0-48) mean(sd)		11	40.8 (4.62)	16	37.1 (8.56)	27	38.6 (7.35)
Min – max			34-48		20-48		20-48

Table M6: Sample 1 Clinical and social functioning at T1 by Trust (continued)							
		n	**Trust 1**	**n**	**Trust 2**	**n**	**Total**
Coercion Scale (T3 only) mean(sd) Min – max	Perceived coercion sub-scale (0-5)	63	2.5 (1.60) 0-5	64	1.9 (1.72) 0-5	127	2.2 (1.69) 0-5
	Negative pressure sub-scale (0-6)	62	2.0 (2.10) 0-6	64	1.9 (1.74) 0-6	126	1.9 (1.91) 0-6
	Voice sub-scale (0-3)	62	1.2 (1.05) 0-3	64	0.9 (1.05) 0-3	126	1.0 (1.05) 0-3

Services used in the previous 12 months

Data on services used in the 12 months prior to T1 were obtained from about 83.0% of the sample. The majority of service users reported having seen a psychiatrist (80.1%) and a community psychiatric nurse (CPN) (72.2%) as part of their core team (Table M7).

For services used in the 12 months prior to the first (T1) interview, attendance for scheduled appointments at home was 95.0% for both Trust. Attendance at scheduled meetings in service settings, however, was better for Trust 1 than Trust 2 users (93.8% versus 77.9%) (Table M8).

Art therapy was the most frequently used specialist service (by 10.6% of the sample), particularly among Trust 2 service users (15.2% versus 5.6% for Trust 1). The most commonly used primary care services included seeing a GP (70.8% of Trust 1 and 41.8% of Trust 2 users) and a pharmacist (18.0%). In terms of statutory services used, 16.1% consulted a benefits advisor, 11.4% an employment advisor and 10.7% a housing worker (Table M9).

The most frequently used emergency care services were the Crisis Line (20.8%) and A&E (16.8%).The most frequently contacted voluntary organisation was MIND, but by only 17.4% of the total group (Table M10). Day centres were attended by 18.2% of the service users. About 13.0% lived in supported accommodation, 8.1% attended a day hospital. While in hospital, the majority had been seen by a psychiatrist (73.3%) or a care coordinator (55.2%) known to them (Table M11).

Table M7: Sample 1 Services used: discipline of team members

	n	Trust 1	n	Trust 2	n	Total
Community psychiatric nurse n (%)	72	49 (68.1%)	79	60 (75.9%)	151	109 (72.2%)
Social worker n (%)	72	23 (31.9%)	79	18 (22.8%)	151	41 (27.2%)
Psychiatrist n (%)	72	54 (75.0%)	79	67 (84.8%)	151	121 (80.1%)
Occupational therapist n (%)	72	12 (16.7%)	79	9 (11.4%)	151	21 (13.9%)
Psychologist n (%)	71	7 (9.9%)	78	8 (10.3%)	149	15 (10.1%)
Other team member[1] n (%)	72	3 (4.2%)	79	10 (12.6%)	151	5 (3.3%)

1. Includes vocational worker, care assistant, junior doctor and placement officer.

Table M8: Sample 1 Self-rated attendance at scheduled meetings

		n	Trust 1	n	Trust 2	n	Total
Attendance for scheduled meetings at home n (%)	None or poor	69	2 (2.8%)	51	4 (7.8%)	120	6 (5.0%)
	Good attendance		67 (97.1%)		47 (92.2%)		114 (95.0%)
Attendance for scheduled meeting at service settings n (%)	None or poor	65	4 (6.2%)	86	19 (22.1%)	151	23 (15.3%)
	Good attendance		61 (93.8%)		67 (77.9%)		128 (84.8%)

Table M9: Sample 1 Services used: statutory and specialist services

	n	Trust 1	n	Trust 2	n	Total
Psychotherapy and Specialist psychology n (%)	72	3 (4.2%)	79	4 (5.0%)	151	7 (4.6%)
Art therapy n (%)		4 (5.6%)		12 (15.2%)		16 (10.6%)
Other specialist services[1] n (%)		7 (9.7%)		8 (10.1%)		15 (9.9%)
General practitioner[2] n (%)	72	51 (70.8%)	79	33 (41.8%)	151	84 (55.6%)
Pharmacist n (%)		14 (19.7%)		13 (16.5%)		27 (18.0%)
Other primary care services[3] n (%)		23 (31.9%)		22 (27.8%)		45 (29.8%)
Private car[4] n (%)	72	4 (5.6%)	79	2 (2.6%)	151	6 (4.0%)
Non-CMHT social worker n (%)	72	4 (5.6%)	77	7 (9.1%)	149	11 (7.4%)
Housing worker n (%)		9 (12.5%)		7 (9.1%)		16 (10.7%)
Benefit advisor n (%)		17 (23.6%)		7 (9.1%)		24 (16.1%)
Employment advisor n (%)	72	12 (16.7%)	79	5 (6.5%)	151	17 (11.4%)
Other statutory service[5] n (%)		14 (19.5%)		12 (15.6%)		26 (17.4%)

1. Includes substance abuse services, dietician, drama therapist, Ex Users Group, family therapy, homeopathy, hypnotist, occupational therapist, psychosexual counselling.
2. Consultation about mental health only.
3. Includes practice nurse, NHS direct, locum.
4. Includes private counsellor, private alternative health practitioner, CBT, hypnotist, and spiritual healer.
5. Includes non-CMHT social worker, disability advisor, home help, independent living team officer, occupational therapist, support worker and welfare rights support worker.

Table M10: Sample 1 Services used: emergency care and voluntary organisations

	n	Trust 1	n	Trust 2	n	Total
A&E n (%)	72	12 (16.7%)	77	13 (16.9%)	149	25 (16.8%)
Crisis Line n (%)		13 (18.1%)		18 (23.4%)		31 (20.8%)
Crisis Team or Home Treatment n (%)		1 (1.4%)		9 (11.7%)		10 (6.7%)
MIND n (%)		9 (12.5%)		17 (22.1%)		26 (17.4%)
Help lines (Saneline or Samaritans) n (%)		2 (2.8%)		3 (3.9%)		5 (3.4%)
Other voluntary organisation[1] n (%)		7 (9.8%)		6 (7.8%)		13 (8.6%)

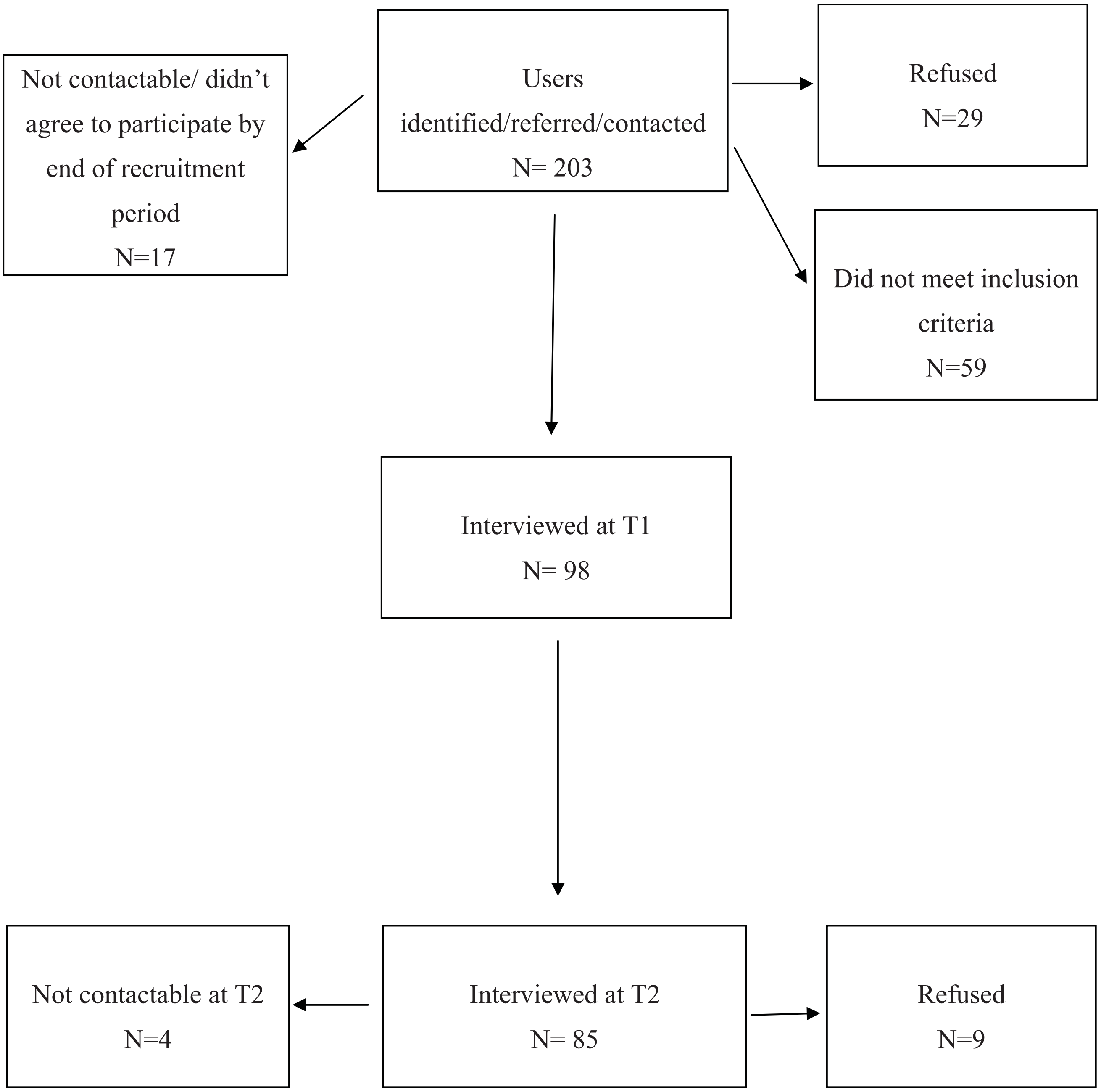
1. Includes RETHINK (NSF), Manic depression fellowship, carers, transport services, domestic violence charities, family welfare association, youth counselling service, voluntary bureau etc.

Table M11: Sample 1 Services used: day services and hospitalisations						
	n	**Trust 1**	**n**	**Trust 2**	**n**	**Total**
Attended a day hospital n (%)	72	8 (11.1%)	77	4 (5.2%)	149	12 (8.1%)
Day centre/ Drop-in n (%)		16 (22.5%)		11 (14.3%)		27 (18.2%)
Supported accommodation n (%)		4 (5.6%)		15 (19.5%)		19 (12.8%)
Other day services[1] n (%)		6 (8.4%)		2 (2.6%)		8 (5.3%)
Known psychiatrist during hospitalisation n (%)	16	13 (81.3%)	14	9 (64.3%)	30	22 (73.3%)
Known care coordinator during hospitalisation n (%)	15	9 (60.0%)	14	7 (50.0%)	29	16 (55.2%)

1. Includes employment project, a music group and a charity.

Service users with non-psychotic disorders

Figure 2: Non-psychotic sample recruitment figures



Recruitment

Initially, 203 service users were identified as eligible for the study. Of these, 59 did not meet the inclusion criteria, 29 refused and 17 were not contactable or had not agreed to participate by the end of the recruitment period, leaving 98 people to be interviewed at Time 1. At Time 2, 85 users (86.7%) were interviewed, with four being uncontactable and nine refusing.

Demographic characteristics

Sample 2 was comprised of 98 service users with non-psychotic disorders, 63 from Trust 1 and 35 from Trust 2.

The sample consisted predominantly of women (67.3% versus 32.7%) and was mainly of White ethnic background (83.7%). The mean age was 41.4, ranging from 19 to 67. Most service users lived alone (58.2% versus 41.8% living with others), predominantly in unsupervised accommodation (91.8%). In terms of education, 53.1% of the sample had attended school until 16 years of age. More of the Trust 2 group attended school beyond 16 (52.9% versus 43.5% for Trust 1). The majority (87.8%) were not employed, but almost twice as many users from the Trust 2 group were employed (17.1% versus 9.5%) (Table M12).

Table M12: Sample 2 Demographic characteristics at T1 by Trust

		n	Trust 1	n	Trust 2	n	Total
Age mean (sd)		63	41.0 (11.74)	35	42.1 (11.09)	98	41.4 (11.47)
Min - max			19-67		21-60		19-67
Gender n (%)	Female	63	41 (65.1%)	35	25 (71.4%)	98	66 (67.3%)
	Male		22 (34.9%)		10 (28.6%)		32 (32.7%)
Ethnic group n (%)	White	63	51 (81.0%)	35	31 (88.6%)	98	82 (83.7%)
	Black		4 (6.3%)		1 (2.9%)		5 (5.1%)
	Other		8 (12.7%)		3 (8.6%)		11 (11.2%)
Living situation n (%)	Living alone (+/- children under 18)	63	38 (60.3%)	35	19 (54.3%)	98	57 (58.2%)
	Living w/ others (+/- children under 18)		25 (39.7%)		16 (45.7%)		41 (41.8%)
Accommodation type n (%)	Unsupervised accommodation	63	58 (92.1%)	35	32 (91.4%)	98	90 (91.8%)
	Supervised accommodation		5 (7.9%)		3 (8.6%)		8 (8.2%)
Education n (%)	School up to 16	62	35 (56.5%)	34	16 (47.1%)	96	51 (53.1%)
	School above 16		27 (43.5%)		18 (52.9%)		45 (46.9%)
Employment Status n (%)	Paid employment[1]	63	6 (9.5%)	35	6 (17.1%)	98	12 (12.2%)
	Unemployed or unpaid work[2]		57 (90.5%)		29 (82.9%)		86 (87.8%)

1. Includes full-time work, part-time work, sheltered work and self-employment.
2. Includes users seeking work, unable to work, students, retired and other.

Diagnoses

Clinical diagnoses for the sample were taken from case-notes (Table M13). Many service users had multiple diagnoses. In these cases, diagnoses of anxiety, depression or both were treated as the primary diagnosis for the purposes of classification.

Table M13: Sample 2Clinical diagnoses

Diagnosis n=98	**n (%)**
Depression (with/without psychotic features)	52 (53.1%)
Anxiety disorder, OCD, PTSD	16 (16.3%)
Depression and Anxiety	8 (8.2%)
Personality Disorder	14 (14.3%)
Other[1]	8 (8.2%)

1. Includes bipolar affective disorder, Asperger's syndrome, body dysmorphic disorder, eating disorder and drug- and alcohol-related mental disorder.

Care characteristics

Almost 80.0% of the total group reported having been unstable or sometimes unstable during the past year. The average age of onset was 26.8 years, ranging from four to 61 years. The mean duration of illness was 171.1 months (about 14 years). The mean duration of illness for Trust 2 service users, however, was over four years longer than for Trust 1 users (203.8 versus 152.9 months). Half the study users had had up to five hospital admissions in their lifetime, although 41.3% of Trust 1 service users had never been admitted into hospital compared to 20.0% of Trust 2 users.

The vast majority (93.0%) of the group had seen one or two designated care coordinators in the previous year and 72.5% of the sample had seen one or two designated psychiatrists over the previous year, although 17.5% of Trust 1 service users had not seen a designated psychiatrist (versus 2.9% in Trust 2). Only one service user (from Trust 2) had seen no care coordinator over the previous year. Conversely, 31.3% of Trust 2 service users had seen three or four designated psychiatrists (compared to 3.2% among Trust 1 service users). The duration of the relationships with the care coordinator and psychiatrist were twice as long for Trust 1 as for Trust 2 service users (22.6 months versus 10.4 months and 22.5 months versus 11.5 months, respectively).

Data concerning breaks in care was obtained for 99.0% of the sample: five users (4.1%) reported having had breaks in their mental health care in the last 12 months, three from Trust 1, of whom two had one break each and one had two breaks. It had been requested in only one of these instances. The two users from Trust 2 reported having had one break in care but only one of them had requested it (Table M14).

Table M14: Sample 2 Therapeutic care characteristics at T1 by Trust

		n	Trust 1	n	Trust 2	n	Total
Age at first contact with psychiatric services mean (sd)		63	27.9 (13.87)	35	24.9 (11.47)	98	26.8 (13.09)
Min - max			4-61		5-51		4-61
Duration of illness mean (sd)		63	152.9 (116.94)	35	203.8 (156.39)	98	171.1 (133.85)
Min - max			18-516		24-660		18-660
Number of lifetime hospital admissions n (%)	None	63	26 (41.3%)	35	7 (20.0%)	98	33 (33.7%)
	1-5		30 (47.6%)		19 (54.3%)		49 (50.0%)
	6 and over		7(11.1%)		9 (25.7%)		16 (16.3%)
Number of different designated care coordinators over the past year n (%)	None	63	0 (.0%)	35	1 (2.9%)	98	1 (1.0%)
	1-2		58 (92.0%)		33 (94.3%)		91 (92.9%)
	3-4		4 (6.4%)		1 (2.9%)		5 (5.1%)
	5 and over		1 (1.6%)		0 (.0%)		1 (1.0%)
Number of different designated psychiatrists over the past year n (%)	None	63	11 (17.5%)	35	1 (2.9%)	98	12 (12.2%)
	1-2		50 (79.3%)		21 (60.0%)		71 (72.5%)
	3-4		2 (3.2%)		11 (31.3%)		13 (13.3%)
	5 and over		0 (.0%)		2 (5.8%)		2 (2.0%)
Duration of relationship with care coordinator (months) mean (sd)		61	22.6 (27.31)	32	10.4 (8.10)	93	18.4 (23.29)
Min – max			1-132		1-48		1-132
Duration of relationship with psychiatrist (months) mean (sd)		31	22.5 (19.36)	28	11.5 (10.61)	59	17.3 (16.63)
Min – max			2-84		1-47		1-84
Duration of relationship with other professional (months) mean (sd)		29	46.3 (81.13)	14	63.5 (76.97)	43	51.9 (79.30)
Min – max			2-408		4-288		2-408

Medication

Most (81.6%) of the group were on medication and 75.0% rated themselves as compliant with it. Over 76.0% were on anti-depressants and about 32.0% were on atypical anti-psychotic medication. Trust 1 service users were less likely to be taking medication, with 10% fewer being on anti-depressants (73.0% versus 83.0%) and 10% fewer on atypical anti-psychotics (28.6% versus 37.1%) (Table M15).

Table M15: Sample 2 Medication status at T1 by Trust

		n	**Trust 1**	**n**	**Trust 2**	**n**	**Total**
Currently on medication n (%)	Yes	63	50 (79.4%)	35	30 (85.7%)	98	80 (81.6%)
	No		13 (20.6%)		5 (14.3%)		18 (18.4%)
Type of medication n (%)[1]	Depot Injection	63	1 (1.6%)	35	1 (2.9%)	98	2 (2.0%)
	Atypical anti-psychotic		18 (28.6%)		13 (37.1%)		31 (31.6%)
	Typical anti-psychotic		3 (4.8%)		1 (2.9%)		4 (4.1%)
	Mood stabiliser		7 (11.1%)		5 (14.3%)		12 (12.2%)
	Anti-depressant		46 (73.0%)		29 (82.9%)		75 (76.5%)
	Side effect medication		3 (4.8%)		4 (11.8%)		7 (7.2%)
Compliance with medication n (%)	None or poor compliance	50	13 (26.0%)	30	7 (23.3%)	80	20 (25.0%)
	Good compliance		37 (74.0%)		23 (76.7%)		60 (75.0%)

1. Total per trust may be greater than 100 as some users may be on more than one type of medication.

Substance use

Over 46.0% of all study users reported using alcohol. Users from Trust 1 had in the last month consumed alcohol more frequently than their counterparts from Trust 2 (13.2 days versus 9.4 days). Furthermore, 12.2% of all users reported using drugs. More Trust 1 service users reported illegal drug use (14.3% versus 8.6%) and they reported drug use almost four times as frequent (17.1 days versus 4.3 days) (Table M16).

Table M16: Sample 2 Substance use status at T1 by Trust

	n	Trust 1	n	Trust 2	n	Total
Use alcohol n (%)	63	29 (46.0%)	35	17 (48.6%)	98	46 (46.9%)
Alcohol consumption in the last month (days) mean(sd) Min – max	29	13.2 (11.69) 0-31	17	9.4 (7.94) 1-30	46	11.8 (10.53) 0-31
Use drugs[1] n (%)	63	9 (14.3%)	35	3 (8.6%)	98	12 (12.2%)
Drug consumption in the last month (days) mean(sd) Min – max	9	17.1 (9.40) 3-30	3	4.3 (3.51) 1-8	12	13.9 (9.99) 1-30

1. Includes cannabis, cocaine, crack cocaine, ecstasy, marijuana, heroin, magic mushrooms and pain killers.

Clinical and social functioning

The sample's mean GAF rating was 53.9, a moderately low level of functioning. Depression and anxiety were moderate, rated at 12.8 and 10.8, respectively. The mean user empowerment score was 70.0 and the mean quality of life scores on the SEIQoL and MANSA were 54.1 (out of 100) and 3.8 (out of 7), respectively.

The mean *experienced continuity* total score (CONTINU-UM) was 50.1. The mean total number of needs was 8.0, with an average of 4.7 being met. On average, over half of the needs for care were met informally (4.3) and the mean proportion of needs met was 62.1%. The mean ratings of the user's relationships with the care coordinator and psychiatrist were 38.2 and 30.8 (out of 48), respectively. Reported coercion was low (Table M17).

Table M17: Sample 2 Clinical and social functioning at T1 by Trust

		n	Trust 1	n	Trust 2	n	Total
GAF Total Score (0-100) mean(sd)		63	53.7 (11.15)	35	54.4 (10.40)	98	53.9 (10.84)
Min - max			21-73		35-80		21-80
EMP Total score (28-112) mean(sd)		63	71.3 (10.77)	35	67.5 (7.31)	98	70.0 (9.81)
Min - max			32-102		56-80		32-102
HADS mean(sd)	Anxiety (0-21)	63	12.4 (4.72)	35	13.5 (4.51)	98	12.8 (4.65)
Min - max			4-21		5-21		4-21
	Depression (0-21)		10.0 (4.89)		12.3 (4.81)		10.8 (4.97)
			1-21		3-21		1-21
Internal State Scale	Activation	63	181.6	35	165.5 (124.73)	98	175.8 (109.77)
mean(sd)	(0-500)		(101.13)		0-454		0-454
Min – max	Well-Being		115.8 (65.68)		72.9 (52.18)		100.5 (64.34)
	(0-300)		3-264		10-194		3-264
	Perceived Conflict		166.3		171.4 (101.37)		168.1 (102.78)
	(0-500)		(104.32)		24-406		0-488
	Depression Index		93.1 (56.52)		112.0 (68.02)		99.9 (61.26)
	(0-200)		0-198		0-199		0-199
SEIQoL Total score (0-100) mean(sd)		61	55.2 (19.65)	32	52.2 (18.85)	93	54.1 (19.33)
Min – max			7.1-86.0		20.4-92.9		7.1-92.9
MANSA Total score (0-7) mean(sd)		63	3.8 (.843)	35	3.7 (.798)	98	3.8 (.827)
Min – max			1.9-5.6		2.2-5.5		1.9-5.6
CONTINU-UM Total Score (16-80) mean(sd)		63	51.1 (10.14)	33	48.1 (11.61)	96	50.1 (10.70)
Min – max			31-73		20-69		20-73

Table M17: Sample 2 Clinical and social functioning at T1 by Trust (continued)

		n	Trust 1	n	Trust 2	n	Total
CAN (0-22) mean(sd)	Total number of needs	63	7.5 (2.96)	35	8.9 (2.56)	98	8.0 (2.88)
Min – max			1-13		4-14		1-14
	Number of met needs		4.4 (2.19)		5.2 (2.54)		4.7 (2.34)
			0-10		1-11		0-11
	Number of unmet needs		3.1 (2.69)		3.6 (2.73)		3.3 (2.70)
			0-11		0-10		0-11
	Number of needs met informally		4.0 (2.67)		4.9 (2.67)		4.3 (2.68)
			0-10		1-12		0-12
	Proportion of needs met (0-100)		63.5 (27.02)		59.6 (25.60)		62.1 (26.45)
			0-100		14.3-100		0-100
TAQ Total score (0-4) mean(sd)		63	2.4 (.245)	35	2.3 (.341)	98	2.4 (.283)
Min - max			1.9-2.9		1.6-3.0		1.6-3.0
STAR Total score user version (0-48) mean(sd)		62	38.5 (7.81)	32	37.5 (9.44)	94	38.2 (8.37)
Min – max			18-48		12-48		12-48
STAR Total score Psychiatrist vers. (0-48) mean(sd)		32	32.1 (11.63)	28	29.2 (12.97)	60	30.8 (12.25)
Min – max			4-48		1-48		1-48
STAR Total score Other version (0-48) mean(sd)		29	37.7 (8.47)	14	40.7 (5.34)	43	38.7 (7.67)
Min – max			18-48		35-48		18-48
Coercion Scale (T2 only) mean(sd)	Perceived coercion sub-scale (0-5)	44	1.6 (1.69)	27	1.0 (1.37)	82	1.3 (1.54)
			0-5		0-5		0-5
Min – max	Negative pressure sub-scale (0-6)	44	1.2 (1.31)	27	0.9 (1.05	82	1.0 (1.18)
			0-5		0-4		0-5
	Voice sub-scale (0-3)	43	0.6 (0.82)	27	0.4 (0.57)	81	0.5 (0.76)
			0-3		0-2		0-3

Services used in the last 12 months

Most of the users reported having seen a psychiatrist (84.7%) while fewer had seen a CPN (40.8%) within their CMHTs. More Trust 2 users reported having seen a psychiatrist (97.1% versus 77.8%) and a community psychiatric nurse (57.1% versus 31.7%). (Table M18). Over the previous 12 months, four service users had been discharged (three from Trust 1, one from Trust 2), but they were all readmitted to the core team within that period.

Study users made use of a wide variety of services in the 12 months prior to interview and 75.6% self-rated their attendance for scheduled meetings at service settings as good (Table M19). Attendance for scheduled appointments at home was self-rated as good for 78.6% of the users.

The specialist services employed most often included psychotherapy and specialist psychology (for 16.3% of users), substance abuse services (8.2%) and other specialist services (23.5%). The most frequently used primary care services were those offered by GPs (67.3%) and pharmacists (57.1%) while the most used statutory services were benefit advisors (17.3%), housing workers (10.2%) and employment advisors (9.2%) (Table M20).

Emergency services more frequently used included A&E (32.7%) and the Crisis Line (25.5%), with Trust 2 service users making use of these services more frequently (42.9% versus 27.0% and 37.1% versus 19.0%, respectively). The most commonly used voluntary organisations were MIND (18.4%) and Help lines (18.4%). Again, Trust 2 service users reported contacting those services more often (34.3% versus 9.5% and 28.6% versus 12.7%, respectively) (Table M21).

Finally, day and drop-in centres were frequented by 22.4% of the study respondents, but other day activities such as day hospitals were seldom used (5.1%). More than half the users admitted into hospital were visited by a known psychiatrist and a known care coordinator (53.3% and 50.0%, respectively) (Table M22).

Table M18: Sample 2 Services used: discipline of team members

	n	Trust 1	n	Trust 2	n	Total
Community psychiatric nurse n (%)	63	20 (31.7%)	35	20 (57.1%)	98	40 (40.8%)
Social worker n (%)		29 (46.0%)		20 (57.1%)		49 (50.0%)
Vocational worker n (%)		12 (19.0%)		0 (.0%)		12 (12.2%)
Psychiatrist n (%)		49 (77.8%)		34 (97.1%)		83 (84.7%)
Occupational therapist n (%)		14 (22.2%)		9 (25.7%)		23 (23.5%)
Psychologist n (%)		26 (41.3%)		12 (34.3%)		38 (38.8%)
Other team member[1] n (%)		1 (1.6%)		3 (8.6%)		4 (4.1%)

1. Include independent living officers and support workers.

Table M19: Sample 2 Self-rated attendance at meetings

		n	Trust 1	n	Trust 2	n	Total
Attendance for scheduled meetings at home n (%)	None or poor attendance	35	8 (22.9%)	21	4 (19.0%)	56	12 (21.4%)
	Good attendance		27 (77.1%)		17 (81.0%)		44 (78.6%)
Attendance for scheduled meetings at service settings n (%)	None or poor attendance	56	15 (26.8%)	34	7 (20.6%)	90	22 (24.4%)
	Good attendance		41 (73.2%)		27 (79.4%)		68 (75.6%)

Table M20: Sample 2 Services used: statutory and specialist services						
	n	**Trust 1**	**n**	**Trust 2**	**n**	**Total**
Psychotherapy and Specialist psychology n (%)	63	8 (12.6%)	35	8 (22.9%)	98	16 (16.3%)
Substance abuse service n (%)		4 (6.3%)		4 (11.5%)		8 (8.2%)
Other specialist services[1] n (%)		10 (15.9%)		13 (37.2%)		23 (23.5%)
General practitioner n (%)	63	44 (69.8%)	35	22 (62.9%)	98	66 (67.3%)
Pharmacist n (%)		36 (57.1%)		20 (57.1%)		56 (57.1%)
Other[2] n (%)		11 (17.5%)		4 (11.5%)		15 (15.3%)
Private care[3] n (%)	63	4 (6.4%)	35	3 (8.7%)	98	7 (7.1%)
Housing worker n (%)	63	8 (12.7%)	35	2 (5.7%)	98	10 (10.2%)
Benefit advisor n (%)		13 (20.6%)		4 (11.4%)		17 (17.3%)
Employment advisor n (%)		7 (11.1%)		2 (5.7%)		9 (9.2%)
Other statutory service[4] n (%)		11 (17.5%)		3 (8.7%)		14 (14.3%)

1. Includes personality disorder, Art therapy and Trauma service, anxiety management group, counsellor services, dietician, family therapy, psychiatrist, psychosexual therapist, relaxation therapy, rheumatology, physiotherapy and support groups.
2. Includes NHS direct, practice nurse and NHS walk-in centre.
3. Includes private psychiatrist, private counsellor, private psychotherapist acupuncturist, healer, massage therapist, carers and meals on wheels.
4. Includes non-CMHT social worker, disability advisor, care workers, carers, cleaners, occupational health advisors, occupational therapists, outreach worker etc.

Table M21: Sample 2 Services used: emergency care and voluntary organisations						
	n	**Trust 1**	**n**	**Trust 2**	**n**	**Total**
A&E n (%)	63	17 (27.0%)	35	15 (42.9%)	98	32 (32.7%)
Crisis Line n (%)		12 (19.0%)		13 (37.1%)		25 (25.5%)
Crisis Team and Home treatment n (%)		14 (22.2%)		11 (31.4%)		25 (25.5%)
MIND n (%)		6 (9.5%)		12 (34.3%)		18 (18.4%)
Help Lines (Saneline and Samaritans) n (%)		8 (12.7%)		10 (28.6%)		18 (18.4%)
Other voluntary organisation[1] n (%)		6 (9.5%)		2 (5.7%)		8 (8.2%)

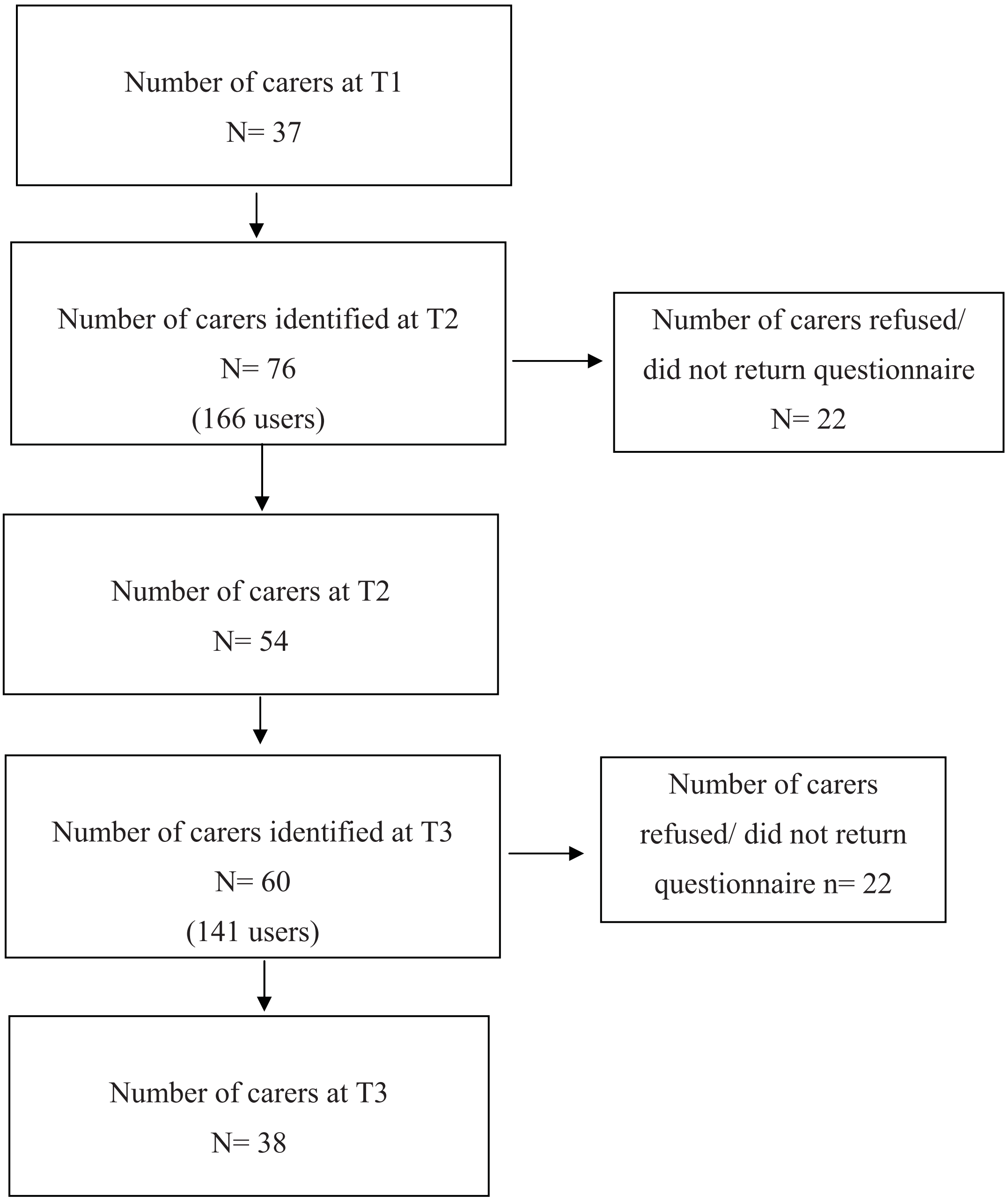
1. Includes Citizen's Advice Bureau, NA and OA self-help groups, Oasis and St. Marks, Psychiatric Pharmaceutical Society, RASASC voluntary organisation, SOBS and SUN project.

Table M22: Sample 2 Services used: day services and hospitalisations						
	n	**Trust 1**	**n**	**Trust 2**	**n**	**Total**
Attended a day hospital n (%)	63	5 (7.9%)	35	0 (.0%)	98	5 (5.1%)
Day centre/ Drop-in n (%)		16 (25.4%)		6 (17.1%)		22 (22.4%)
Other day services[1] n (%)		2 (3.2%)		3 (8.6%)		5 (5.1%)
Known psychiatrist during hospitalisation n (%)	14	10 (71.4%)	16	6 (37.5%)	30	16 (53.3%)
Known care coordinator during hospitalisation n (%)	14	9 (64.3%)	16	6 (37.5%)	30	15 (50.0%)

1. Includes employment project and voluntary work.

Carers of people with psychotic disorders

Figure 3: Psychotic Sample carer recruitment figures



Recruitment

At Time 1, 37 carers consented to being involved in the study and returned the questionnaire. At Time 2, 76 carers were identified and 54 of these (71.1%) returned the questionnaire. At Time 3, 60 carers were identified and 38 of these (63.3%) returned the questionnaire. In total, 68 carers took part, 20 completing the questionnaire at all three time-points.

Characteristics

As shown in Tables M23-M24, the profiles of carers were similar in the two Trusts. The mean age of the carers was 51.9 years, with 61.8% female and 76.5% White; 58.8% were married or in a long-term partnership and 70.1% were living with their spouse, partner and/or children. Almost one third of carers (30.9%) were working full-time whilst over half (57.4%) were not working or looking after children. There were more differences between the Trusts in the carer-user relationship. The largest group of carers were parents (29.4%) or spouses/partners (22.1%). Just over half (57.6%) lived with the user.

The majority of carers (23.9%) contacted the users four times a week or more. Although they had been identified by the user as their main carer, only 86.4% of the Trust 2 carers reported that they were the main carer (only 65.0% in Trust 1), while 60.9% overall regarded themselves as carers at all. Few carers reported attending a carer support group in either Trust (15.6%) and few reported having had a carer’s assessment (19.4%).

Table M23: Sample 1 Carer demographic characteristics at baseline by Trust

		n	Trust 1	n	Trust 2	n	Total
Age mean (sd) Min – max		31	51.2 (16.17) 25-83	37	52.5 (13.79) 25-82	68	51.9 (14.82) 25-83
Gender n (%)	Female	31	17 (54.8%)	37	25 (67.6%)	68	42 (61.8%)
	Male		14 (45.2%)		12 (32.4%)		26 (38.2%)
Ethnic group n (%)	White	31	19 (61.3%)	37	33 (89.2%)	68	52 (76.5%)
	Asian		6 (19.4%)		0 (0%)		6 (8.8%)
	Black		4 (12.9%)		4 (10.8%)		8 (11.8%)
	Other		2 (6.5%)		0 (0%)		2 (2.9%)
Marital status n (%)	Single	31	7 (22.6%)	37	10 (27.0%)	68	17 (25.0%)
	Married/ long-term partnership		19 (61.3%)		21 (56.8%)		40 (58.8%)
	Divorced/Separated/Widowed		5 (16.1%)		6 (16.2%)		11 (16.2%)
Work status n (%)	No/No, looking after children	31	16 (51.6%)	37	23 (62.2%)	68	39 (57.4%)
	Part-time work (< 30 hours)		4 (12.9%)		4 (10.8%)		8 (11.8%)
	Full-time work (>30 hours)		11 (35.5%)		10 (27.0%)		21 (30.9%)
Living situation n (%)	Alone	29	1 (3.3%)	36	9 (24.3%)	65	10 (14.9%)
	Spouse/ partner and/or children		21 (70.0%)		26 (70.3%)		47 (70.1%)
	Parents and/or brothers/sisters		5 (16.7%)		1 (2.7%)		6 (9.0%)
	Friends		2 (6.7%)		0 (0%)		2 (3.0%)
Number of cohabitants n (%)	0	30	1 (3.3%)	35	7 (19.4%)	65	8 (12.1%)
	1-2		16 (53.3%)		19 (52.8%)		35 (53.0%)
	3-4		13 (43.3%)		9 (25.0%)		22 (33.3%)

Table M24: Sample 1 Carer-user relationship at baseline by Trust

		n	Trust 1	n	Trust 2	n	Total
Relationship to user n (%)	Parent	31	8 (25.8%)	37	12 (32.4%)	68	20 (29.4%)
	Child		5 (16.1%)		4 (10.8%)		9 (13.2%)
	Sibling		5 (16.1%)		2 (5.4%)		7 (10.3%)
	Spouse/partner		5 (16.1%)		10 (27.0%)		15 (22.1%)
	Girlfriend/boyfriend		1 (3.2%)		1 (2.7%)		2 (2.9%)
	Friend		5 (16.1%)		7 (18.9%)		12 (17.6%)
	Other		2 (6.5%)		1 (2.7%)		3 (4.4%)
Carer-user contact during past month n (%)	2-3 times	30	1 (3.2%)	35	3 (8.3%)	35	4 (6.0%)
	4 times (once a week)		2 (6.5%)		1 (2.8%)		3 (4.5%)
	More than 4 times but not every day		7 (22.6%)		9 (25.0%)		16 (23.9%)
	Nearly every day		4 (12.9%)		6 (16.7%)		10 (14.9%)
	Every day		16 (51.6%)		16 (44.4%)		32 (47.8%)
Carer living with user n (%)	Yes	29	16 (55.2%)	37	22 (59.5%)	66	38 (57.6%)
	No		13 (44.8%)		15 (40.5%)		28 (42.4%)
Carer or not n (%)	Yes	27	19 (70.4%)	37	20 (54.1%)	64	39 (60.9%)
	No		8 (29.6%)		17 (45.9%)		25 (39.1%)
Main carer n (%)	Yes	20	13 (65.0%)	22	19 (86.4%)	42	32 (76.2%)
	No		7 (35.0%)		3 (13.6%)		10 (23.8%)
Carer support group n (%)	Yes	28	4 (14.3%)	36	6 (16.7%)	64	10 (15.6%)
	No		24 (85.7%)		30 (83.3%)		54 (84.4%)
Carer's assessment n (%)	Yes	28	7 (25.0%)	34	5 (14.7%)	62	12 (19.4%)
	No		21 (75.2%)		29 (85.3%)		50 (80.6%)

The mean positive total score for the ECI at T1 was comparable for both Trusts and averaged at 25.0 (range 0-53). The mean negative total score differed between the two groups (67.0 in Trust 1 and 60.3 in Trust 2). The CONTINUES mean scores averaged at 3.0 over the Trusts with a range of 1.6-5.0 and mean scores for the GHQ were similar for both Trusts (mean 25.4). (Table M25).

Table M25: Sample 1 Carer clinical and social functioning at T1 by Trust

	n	Trust 1	n	Trust 2	n	Total
ECI-Positive Total Score (0-56) mean (sd)	31	24.7 (11.71)	37	25.4 (13.21)	68	25.1 (12.46)
Min - max		0-52		1-53		0-53
ECI-Negative Total Score (0-208) mean (sd)	31	67.0 (41.00)	37	60.3 (39.58)	68	63.4 (40.07)
Min - max		0-161		8-154		0-161
CONTINUES Mean Score (1-5) mean (sd)	28	3.1 (.894)	35	2.9 (.815)	63	3.0 (.849)
Min - max		1.8-5.0		1.6-4.7		1.6-5.0
GHQ Total score (12-48) mean (sd)	26	25.6 (6.55)	34	25.2 (5.82)	60	25.4 (6.09)
Min - max		15-37		15-42		15-42

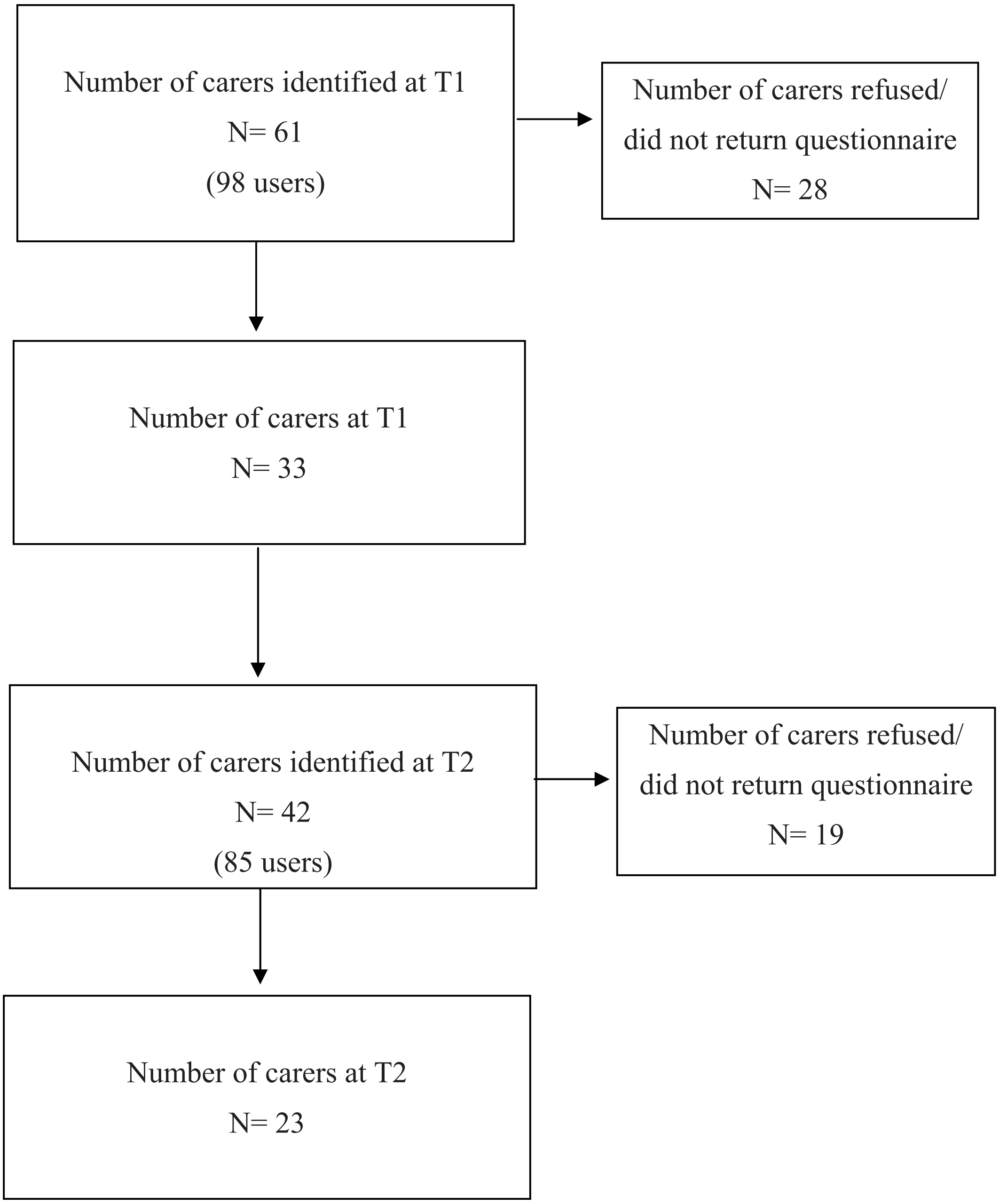
Almost one third (31.7%) of carers at T1 showed evidence of distress (with a GHQ total score of more than 27) and more severe problems were indicated in 15.0% of the sample (GHQ total score >32). (Table M26)

Table M26: Sample 1 Carer level of functioning by GHQ score

GHQ Total score		**n (%)**
GHQ total score indicating distress (>27)	Yes	19 (31.7%)
	No	41 (68.3%)
GHQ total score indicating severe problems & psychological distress (>32)	Yes	9 (15.0%)
	No	51 (85.0%)

Carers of people with non-psychotic disorders

Figure 4: Sample 2 carer recruitment figures



Recruitment

At T1, 61 out of 98 users identified carers, of whom 33 (54.1%) consented to be involved in the study and returned the questionnaire. At T2, almost a third fewer carers were identified (n=42) and 23 carers (54.8%) returned the questionnaire. In total, 39 carers took part, 17 of them completing the questionnaire at both time-points.

Characteristics

Across the two time-points of the study, 39 different carers were recruited, 28 from Trust 1, and 11 from Trust 2. Their mean age was 49.2 years and the majority were female and White (71.8% and 84.6% respectively). Most were married or in a long-term partnership (56.4%), living with a spouse, partner and/or children (69.2%) and lived with up to two other people (65.8%). Over half (57.2%) in Trust 1 were not working or looking after children, while almost two thirds of carers (63.7%) in Trust 2 were in employment. (Table M27)

There were some differences between Trusts in the user-carer relationship. Carers in Trust 1 had a wider range of relationships with users, ranging from parents (37.0%), to spouses/partners (22.2%), to friends (11.1%) among others. In Trust 2, however, parents constituted the largest carer group by far (72.7%). The majority of carers (51.3%) contacted the users daily. Overall only 67.6% of carers regarded themselves as a carer and 74.1% regarded themselves as the user's main carer. Few carers reported attending a carer support group in either Trust (10.5%) and only some had had a carer's assessment (27.8%). (Table M28)

Table M27: Sample 2 Carers demographic characteristics at baseline by trust							
		n	**Trust 1**	**n**	**Trust 2**	**n**	**Total**
Age mean (sd)		28	45.0 (16.48)	11	59.7 (12.78)	39	49.2 (16.75)
Min – max			19-71		19-73		19-73
Gender n (%)	Female	28	19 (67.9%)	11	9 (81.8%)	39	28 (71.8%)
	Male		9 (32.1%)		2 (18.2%)		11 (28.2%)
Ethnic group n (%)	White	28	24 (85.7%)	11	9 (81.8%)	39	33 (84.6%)
	Non-White		4 (14.4%)		2 (18.2%)		6 (15.4%)
Marital status n (%)	Single	28	10 (35.7%)	11	2 (18.2%)	39	12 (30.8%)
	Married/ long-term partnership		15 (53.6%)		7 (63.6%)		22 (56.4%)
	Divorced/Separated/Widowed		3 (10.7%)		2 (18.2%)		5 (12.8%)
Work status n (%)	No/No, looking after children	28	16 (57.2%)	11	4 (36.4%)	39	20 (51.3%)
	Part-time work (< 30 hours)		7 (25.0%)		3 (27.3%)		10 (25.6%)
	Full-time work (>30 hours)		5 (17.9%)		4 (36.4%)		9 (23.1%)
Living situation n (%)	Alone	28	3 (10.7%)	11	3 (27.3%)	39	6 (15.4%)
	Spouse/ partner and/or children		20 (71.4%)		7 (63.6%)		27 (69.2%)
	Parents and/or brothers/sisters		4 (14.3%)		1 (9.1%)		5 (12.8%)
	Friends		1 (3.6%)		0 (0.0%)		1 (2.6%)
Number of cohabitants n (%)	0	28	3 (10.7%)	10	2 (20.0%)	38	5 (13.2%)
	1-2		19 (67.9%)		6 (60.0%)		25 (65.8%)
	3-5		6 (21.4%)		2 (20.0%)		8 (20.9%)

Table M28: Sample 2 Carer–user relationship at baseline by trust							
		n	**Trust 1**	**n**	**Trust 2**	**n**	**Total**
Relationship to user n (%)	Parent	27	10 (37.0%)	11	8 (72.7%)	38	18 (47.4%)
	Child		3 (11.1%)		0 (0.0%)		3 (7.9%)
	Sibling		2 (7.4%)		0 (0.0%)		2 (5.3%)
	Spouse/partner		6 (22.2%)		1 (9.1%)		7 (18.4%)
	Girlfriend/boyfriend		2 (7.4%)		1 (9.1%)		3 (7.9%)
	Friend		3 (11.1%)		1 (9.1%)		4 (10.5%)
	Other		1 (3.7%)		0 (0.0%)		1 (2.6%)
Carer-user contact during past month n (%)	None	28	0 (0.0%)	11	1 (9.1%)	39	1 (2.6%)
	2-3 times		1 (3.6%)		1 (9.1%)		2 (5.1%)
	4 times (once a week)		2 (7.1%)		1 (9.1%)		3 (7.7%)
	More than 4 times but not every day		5 (17.9%)		1 (9.1%)		6 (15.4%)
	Nearly every day		5 (17.9%)		2 (18.2%)		7 (17.9%)
	Every day		15 (53.6%)		5 (45.5%)		20 (51.3%)
Carer living with user n (%)	Yes	28	12 (42.9%)	10	4 (36.4%)	38	16 (42.1%)
	No		16 (57.1%)		6 (54.5%)		22 (57.9%)
Regard self as carer or not n (%)	Yes	28	19 (67.9%)	9	6 (66.7%)	37	25 (67.6%)
	No		9 (32.1%)		3 (33.3%)		12 (32.4%)
Main carer n (%)	Yes	21	14 (50.0%)	6	6 (100.0%)	27	20 (74.1%)
	No		7 (25.0%)		0 (0.0%)		7 (25.9%)
Carer support group n (%)	Yes	28	1 (3.6%)	10	3 (27.3%)	38	4 (10.5%)
	No		27 (96.4%)		7 (63.6%)		34 (89.5%)
Carer's assessment n (%)	Yes	27	5 (17.9%)	9	5 (45.5%)	36	10 (27.8%)
	No		22 (78.6%)		4 (36.4%)		26 (72.2%)

At T1, the mean ECI positive sub-scale total score differed between the carers in the two Trusts (26.8 in Trust 1 and 33.1 in Trust 2). The mean ECI negative sub-scale total score also differed between the two groups (67.6 in Trust 1 and 97.8 in Trust 2). The CONTINUES mean scores were the same in both Trusts (3.4) and mean scores for the GHQ differed between Trusts (26.8 in Trust 1 and 33.1 in Trust 2). (Table M29)

GHQ scores for the Sample 2 carers showed evidence of distress (total score over 27) in 43.2% of the sample and suggested severe problems and psychological distress (GHQ total score >32) in 18.9% of the sample. (Table M30)

Table M29: Sample 2 Carer clinical and social functioning at T1 by Trust

	n	Trust 1	n	Trust 2	n	Total
ECI-Positive Total Score (0-56) mean (sd)	28	26.8 (8.29)	11	33.1 (9.06)	39	28.5 (8.88)
Min – max		8-44		19-45		8-45
ECI-Negative Total Score (0-208) mean (sd)	28	67.6 (43.21)	11	97.8 (38.61)	39	76.1 (43.68)
Min – max		8-161		52-160		8-161
CONTINUES Mean Score (1-5) mean (sd)	26	3.4 (1.06)	11	3.4 (0.83)	37	3.4 (0.98)
Min – max		1.6-5		1.7-4.7		1.6-5
GHQ Total score (12-48) mean (sd)	27	24.6 (6.10)	10	29.7 (8.08)	37	26.0 (6.96)
Min – max		16-39		15-43		15-43

Table M30: Sample 2 Carer level of functioning by GHQ score

GHQ Total score		**n (%)**
GHQ total score above the threshold to indicate distress (>27)	Yes	16 (43.2%)
	No	21 (56.8%)
GHQ total score above the threshold to indicate severe problems and psychological distress (>32)	Yes	7 (18.9%)
	No	30 (81.1%)

4.3.2. Analysis: Service users with psychotic disorders

Phase 1: Continuity of Care

Operationalised continuity

Each definition of continuity was operationalised as follows. Definitions in parentheses are those given by Freeman and colleagues (2000) unless otherwise stated. Where indicated, types of continuity were further defined or adjusted for clarity prior to being operationalised. Each component was collected for the year prior to interview, unless otherwise stated.

Experienced continuity ('experience of a coordinated and smooth progression of care from the user's point of view'): this was defined as an over-arching concept for the purposes of this phase of the study (and therefore not necessarily interpreted as either 'coordinated' or 'smooth'), designed to capture the service user perspective and therefore operationalised using the user-generated scale, CONTINU-UM. Only the questions for each domain asking about the degree to which the type of continuity had been experienced ('b' questions) were utilised.

Flexible continuity ('to be flexible and adjust to the needs of the individual over time'): operationalised as both needs and changes over time. This was re-conceptualised firstly as the *range of needs* at any single time-point being met, operationalised using CAN (total needs, total met needs, total unmet needs); and secondly as *response to change in clinical needs over time*, focusing only on clinical deterioration and operationalised as a) increased contacts in the three months prior to hospital admission and b) increased contacts in any three-month period in the year when the user assesses their mental health to have deteriorated.

Cross-boundary continuity ('effective communication between professionals and services and with users'): re-conceptualised as transitions and fragmentations and operationalised as: referrals to other services, admissions to hospital, discharges from hospital and number of agencies involved.

Continuity of information ('excellent information transfer following the service user'): determined by the number of transitions collected for *cross-boundary continuity*. This was operationalised as a) documents sent as proportion of situations where this is necessary (number of documents sent divided by number of relevant transitions); b) proportion of letters copied or sent directly to the user; c) number of people to whom CPA documentation was copied.

Longitudinal continuity ('care from as few professionals as possible, consistent with other needs'): operationalised as a) any change in who acts as the user's care coordinator and the number of staff in that role; b) any change in who acts as the user's psychiatrist and the number of psychiatrists in that role; c) 'spread of non-medical CMHT input' (number of different non-medical CMHT disciplines seen face-to-face divided by total number of face-to-face contacts with non-medical CMHT staff) and d) 'spread of medical CMHT input' (number of different medical disciplines seen face-to-face divided by total number of face-to-face contacts with medical members of core team).

Relational or personal continuity ('to provide one or more named individual professionals with whom the service user can establish and maintain a therapeutic relationship'): operationalised as user-rated and professional-rated STAR. STAR-c data were used wherever available (in 87.2%, 79.3% and 77.2% of cases at T1, T2 and T3 respectively), supplemented by STAR-p and STAR-o data.

Long-term continuity ('uninterrupted care for as long as the service user requires it': Freeman *et al*, 2002): interpreted as breaks in care and user-initiated discontinuity. This was operationalised as: user-reported level of attendance of appointments with CMHT; number of user-initiated exits from mental health care reported by user; user-reported medication adherence; total number of CMHT contacts in year; longest gap between contacts with secondary team; number of gaps of more than two months; number of more than average gaps (quantified as user's individual mean gap * 2 + 2 weeks); number of days between hospital discharge and face-to-face contact with a member of the CMHT.

Contextual continuity (which 'should sustain a person's preferred social and personal relationship in the community and enhance quality of life': Freeman *et al*, 2002): operationalised as social context reflected in living situation and daily activities. The components used were ‘supported accommodation’ and day care (day centre or day hospital) attendance.

Table M31 lists the 32 components of continuity to be considered for entry into the factor analysis and how they were defined and coded. Sub-headings indicate the definition of continuity which they were operationalising. The extent of missing data for each variable is also presented.

Table M31: Continuity of care components[1]

	Type of continuity **Variable retained** *Variable later omitted*	**Calculation**	**Missing data n (%)**
	Experienced Continuity		
C1	CONTINU-UM[2]	z-score of mean score	13 (7.2%)
	Flexible Continuity (Range of needs)		
C2	*CAN Total number of needs*[2, 3]	z-score	2 (1.1%)
C3	CAN Number of met needs[2]	z-score	2 (1.1%)
C4	*CAN Number of unmet needs*[2]	z-score	2 (1.1%)
C5	CAN Total level of needs[2, 3]	z-score	2 (1.1%)
C6	CAN Total level of needs met by informal carers[2, 3]	z-score	2 (1.1%)
C7	Proportion of needs met[2]	3 categories: -1=< 65% needs met, 0 = 66-90% needs met and 1 = > 91% needs met	2 (1.1%)
	Flexible Continuity (Meeting changes in clinical needs)		
C8	*Increased contacts in 3 months prior to user deterioration*[2]	categories: -1, 0, 1 as above	5 (2.8%)
C9	*Increased contacts in 3 months prior to hospital admission*	categories: -1, 0, 1 as above	2 (1.1 %)
	Cross-boundary continuity		
C10	Had a transition?	-1 = yes, 1 = no	6 (3.3%)
C11	*Referred to other agency*	-1 = yes, 1 = no	6 (3.3%)
C12	Contacts with primary care professionals[2]	-1 = yes, 1 = no	29 (16.1%)
C13	Number of agencies used in previous year[2]	z-score	29 (16.1%)

Table M31: Continuity of care components[1] (continued)

	Type of continuity **Variable retained** *Variable later omitted*	**Calculation**	**Missing data n (%)**
	Information continuity		
C14	Documented transition	3 categories: -1 = transition with no documentation, 0 = no transition, 1 = transition with documentation	6 (3.3%)
C15	Proportion of letters sent by CMHT which were copied to user	- 1 = 0%, 0 = 1 to 50%, 1 = 51 to 100%	21 (11.7%)
C16	CPA copied to GP and user	-1 = no, 0 = copied to1 of GP or user, +1 = copied to both	33 (18.3%)
	Longitudinal continuity		
C17	Designated care coordinators (CC)[2]	2 categories: -1 = no CC or more than 2 CCs, 1 = 1 or 2 CCs, as reported by user	0 (.0%)
C18	Designated psychiatrists (Psych)[2]	2 categories: -1 = no Psych or more than 2 Psych, 1 = 1 or 2 Psych, as reported by user	0 (.0%)
C19	Non-medical input spread (number of different non-medical team members seen out of the total number of contacts with non-medical team members)	3 categories: -1 = >50% of non-medical input spread, 0 = 21 to 49% non-medical team input and people who have no non-medical input, 1 = < 20% of non-medical input spread	58 (32.2%)
C20	*Medical input spread (number of different medical team members seen out of the total number of contacts with medical team members)*	3 categories: -1 = >50% of medical input spread, 0 = 21 to 49% medical team input and people who have no medical input, 1 = < 20% of medical input spread	28 (15.6%)

Table M31: Continuity of care components[1] (continued)			
	Type of continuity **Variable retained** *Variable later omitted*	**Calculation**	**Missing data n (%)**
	Relational continuity		
C21	STAR total score-any professional[2, 4]	z-score of total STAR score for key worker. If missing then substituted by the STAR psychiatrist score. When both are missing then the STAR-other professional score is used as a substitute when applicable.	16 (8.9%)
	Long-term continuity		
C22	Average gap between face-to-face contacts [3]	z-score	14 (7.8%)
C23	Gaps of 2 months or more	-1 = yes, 1 = no	4 (2.2%)
C24	*Longest gap between contacts* [3]	z-score	14 (7.8%)
C25	*Gaps of (average gap*2 +2 weeks)*	-1 = yes, 1 = no	14 (7.8%)
C26	*Number of user-rated breaks in care*[2, 3]	z-score	2 (1.1%)
C27	*Total number of face-to-face contacts*	z-score	2 (1.1%)
C28	*Total number of phonecalls*	z-score	2 (1.1%)
C29	*Saw known CMHT member when hospitalised*[2]	-1 = no; 1 = yes; 0= not hospitalised	31 (17.2%)
C30	Any user-rated breaks in care?[2]	-1 = no, 1 = yes	2 (1.1%)
C31	Attendance at day care[2, 5]	-1 = no, 1 = yes	31 (17.2%)
C32	Supported accommodation[2, 5]	-1 = no, 1 = yes	31 (17.2%)

1. Items in italics were subsequently dropped from the analysis, for reasons given below.
2. Information from the service user.
3. Variable reversed so that a high score indicates an assumed positive scenario: e.g. a high score for ‘average gap between face-to-face contacts’ would indicate short average gaps.
4. For users with no identified care coordinator (STAR-c rating), the STAR concerning the relationship with the psychiatrist (STAR-p) was used; where no psychiatrist was identified or rated, the STAR concerning the relationship with a third identified professional (STAR-o) was used, to maximise data.
5. Items added as reflecting important elements of this group’s experience.

Variable selection for entry into factor analysis

Feedback from the researchers who collected data from the CMHT case-notes indicated that ‘phonecall contacts’ (C28) had not been consistently recorded. ‘Total number of phonecalls’ was therefore omitted from further analysis. A further three components, 'saw known CMHT member when hospitalised' (C29), 'increased contacts in three months prior to admission' (C9), and 'increased contacts in three months prior to user deterioration' (C8), were omitted as they had at least one category containing fewer than 5% of the sample, thus exhibiting insufficient spread of response. For the first two of these components, although almost 14.0% of the sample had been hospitalised in the preceding year, only 2.8% had an increased response prior to admission and only five users (2.8%) had seen a known CMHT staff while inpatients. With the third component, only eight (4.4%) users did not receive increased contacts in the three months prior to deterioration. Only 12 users indicated that they had had a break in care. While this meets the 5% criteria, ten users had one break in care, one had two breaks and one had four breaks, producing a highly positively skewed variable. The dichotomised component, ‘any user-rated breaks in care?' (C30) is therefore much more robust and was retained, while the continuous variable (C26) was removed.

When the item-correlation matrix was constructed, ‘total number of face-to-face contacts’ (C27) was found to be correlated with ‘average gap between face-to-face contacts’ (C22) (r=0.88) and was therefore omitted from further analysis. ‘Longest gap between face-to-face contacts’ (C24) was highly correlated with ‘average gap between face-to-face contacts’ (C22) (r=0.86) and ‘gap of two months or more’ (C23) (r=0.86), so was omitted. ‘Referred to other agency?’ (C11) was highly correlated with ‘had a transition?’ (C10) (r=0.81) and so was omitted, as the variable ‘number of agencies used in previous year’ (C13) was also retained. ‘Number of unmet needs’ (C4) was highly correlated with ‘proportion of needs met’ (C7) (r=0.94) so it was omitted, while ‘CAN total number of needs’ (C2) was highly correlated with ‘CAN total level of need’ (C5) (r=0.93) and was thus omitted. See Appendix 10 for the full correlation matrix.

Following this process, 22 variables were appropriate for entry into the exploratory factor analysis.

Exploratory factor analysis

Case-notes were not available for four of the Sample 1 users so the factor analysis was based on 176 service users with psychotic disorders (Sample 1). Including the 22 components described above in the factor analysis produced a KMO statistic equal to 0.49, which is just below the 0.5 threshold of an acceptable measure of sampling adequacy (Kaiser, 1974). The individual measures of sampling adequacy (IMSA) were then examined and two were found to be very low. These were 'gaps of (average gap*2 +2 weeks)' (C28) (IMSA=0.28) and 'medical input spread' (C22) (IMSA=0.22). These two variables were therefore removed from the factor analysis. In the repeated factor analysis, Bartlett's test of sphericity indicated that the correlation matrix was not an identity matrix ($\chi^2 = 540.5$, $p<0.001$). The KMO measure of sampling adequacy was 0.54, which while still low was acceptable. While the KMO statistic was not desirable, it was not unexpected given the disparate nature of the concepts relating to continuity of care.

Seven factors were extracted with an eigenvalue of one or more, explaining 62.5% of the variance in the data.

Table M32 shows the Varimax rotated factor loadings for the 20 items, with absolute rotated factor loadings of less than 0.4 suppressed. The majority of items loaded significantly onto one factor only, with rotated loadings of 0.5 and above. There were four exceptions to this. 'Any user-rated breaks in care?', 'CPA copied to GP and user?', 'number of care coordinators in the past year' and 'attended a day centre' all had absolute loadings between 0.4 and 0.5 onto only one factor so were allocated to that respective factor.

In Table M33, the seven factors are described and interpreted and names are ascribed to each of them. The percentage of the variance explained by each factor is also presented. Where the factor was predominately characterised by a component or components used to operationalise the multi-axial definition of continuity, the name of that definition is added to the factor name in parentheses.

Factor 5, *Managed Transitions*, was recoded into a straightforward trichotomous variable, as the summation of the two dichotomous variables only created three possible categories. Throughout the remaining analyses, it is therefore analysed differently from the other factors in order to account for this trichotomous structure.

Table M32: Rotated factor loadings

Items	**Factor**						
	1	**2**	**3**	**4**	**5**	**6**	**7**
CONTINU-UM - Mean Score	.833						
Proportion of needs met	.720						
STAR - Any professional version total	.630						
Any user-rated breaks in care?	-.408						
Average gap between face to face contacts		.853					
Gaps of 2 months or more between face-to-face contacts		.787					
Spread of non-medical community team input		.724					
CAN - Met needs			.864				
CAN - Total level of need	.469		-.746				
CPA copied to GP and User?			.432				
Had contact with primary care services?				.822			
Number of agencies used in the last 12 months per user				.728			
Documented transition?					.772		
Had a transition?					.650		
Number of psychiatrists in the past year						-.688	

Table M32: Rotated factor loadings (continued)							
Items	**Factor**						
	1	**2**	**3**	**4**	**5**	**6**	**7**
CAN - Total level of need being met by informal carers			-.444			.559	
Number of care coordinators in the past year						.499	
Proportion of letters sent by CMHT which were copied to user							.733
Resided in supported accommodation?							.576
Attended a day centre?							.423

Table M33: Continuity of care factors (T1)			
Factor	**Items**	**Description**	**Variance**
1	CONTINU-UM STAR total score-any professional Proportion of needs met Any user-rated breaks in care? (negative[1])	***Experience & Relationship*** high score means: high experienced continuity, good therapeutic relationship, a greater proportion of needs met and not having a user-rated break in care	12.5%
2	Average gap between face-to-face contacts Gaps of 2 months or more Non-medical input spread	***Regularity*** high score means: being seen more frequently by staff from fewer different non-medical disciplines	12.2%
3	CAN Total level of needs CAN Number of met needs CPA copied to GP and user	***Meeting Needs)*** high score means: high level of need, high number of met needs and CPA copied to GP and user	9.5%
4	Number of agencies used in previous year Contacts with primary care professionals	***Consolidation*** high score means: having contact with fewer different agencies and not seeing primary care professionals	8.1%
5	Had a transition? Documented transition	***Managed Transitions*** Categorical variable, where 1=no transition, 0=documented transition, and -1=undocumented transition	7.3%
6	Designated care coordinators Designated psychiatrists (negative[1]) CAN Total level of needs met by informal carers (reversed[1])	***Care Coordination*** High score means: having a designated care coordinator, having no psychiatrist or more than two and fewer needs met by informal carers	6.5%
7	Supported accommodation Attendance at day centres or hospitals Proportion of letters sent by CMHT which were sent or copied to user	***Supported Living*** High score means: living in supported accommodation, attending day care and having more letters copied to the user	6.4%
		Total	**62.5%**

1.'Negative' indicates the component loads negatively on the factor, indicating an inverse relationship, while 'reversed' indicates that the variable was reverse-scored from the outset so that a high score would indicate a positive scenario.

Confirmatory factor analyses

The seven-factor model was not validated by confirmatory factor analysis procedures when applied to subsequent time-points of Sample 1 (see Appendix 7).

Relationship between different continuity factors at T1

As shown in Table M34, there were no statistically significant associations between any factors of a magnitude usually considered meaningful (>0.3), but two pairs of factors had correlations above |0.2| , while the categorical factor, *Managed Transitions*, differed significantly in relation to three other factors.

Factor 2, *Regularity*, was negatively correlated with Factor 4, *Consolidation* (r=-0.27), suggesting that being seen more frequently by fewer different non-medical staff is associated with using more different agencies and using primary care.

Factor 3, *Meeting Needs*, was negatively correlated with Factor 6, *Care Coordination* (r=-0.22), suggesting that having a lower level of need and fewer met needs is associated with having a designated care coordinator, having seen either no psychiatrists or more than two and having fewer needs met by informal carers.

Factor 5, *Managed Transitions*, was significantly associated with *Regularity*, *Meeting Needs* and *Consolidation*. (Table M35). Those with higher *Regularity* scores were more likely to have had a transition documented or no transition, as were those with more needs and met needs and those using fewer agencies and not using primary care.

Table M34: Relationships between the different types of continuity of care

Pearson correlation coefficients (95% C.I.s)	Experience & Relationship	Regularity	Meeting Needs	Consolidation	Care Coordination	Supported Living
Experience & Relationship	1	.04 (-.11, .19)	-.13 (-.27, .02)	.09 (-.07, .24)	.15 (.01, .29)	.07 (-.08, .21)
Regularity	.04 (-.11, .19)	1	.10 (-.05, .24)	-.27 (-.42, -.12)	-.06 (-.20, .09)	.14 (-.01, .29)
Meeting Needs	-.13 (-.27, .02)	.10 (-.05, .24)	1	-.11 (-.27, .05)	-.22 (-.35, -.07)	.06 (-.09, .21)
Consolidation	.09 (-.07, .24)	-.27 (-.42, -.12)	-.11 (-.27, .05)	1	.10 (-.06, .26)	-.19 (-.34, -.04)
Care Coordination	.15 (.01, .29)	-.06 (-.20, .09)	-.22 (-.35, -.07)	.10 (-.06, .26)	1	-.07 (-.21, .08)
Supported Living	.07 (-.08, .21)	.14 (-.01, .29)	.06 (-.09, .21)	-.19 (-.34, -.04)	-.07 (-.21, .08)	1

Table M35: Associations between Factor 5 and the other factors[1]				
	No transition	**Documented transition**	**Undocumented transition**	**Significance F statistic (p-value)**[2]
Experience & Relationship	1.08 (2.24)	.65 (2.63)	.76 (2.37)	.45 (.636)
Regularity	-.32 (2.27)	.73 (2.27)	1.36 (1.49)	9.42 (<.001)
Meeting Needs	-.28 (1.98)	.23 (1.85)	1.16 (1.83)	7.76 (.001)
Consolidation	.11 (1.55)	-.36 (2.11)	-.83 (1.81)	4.03 (.020)
Care Coordination	.14 (1.53)	-.14 (1.82)	-.20 (1.71)	.76 (.470)
Supported Living	-1.39 (1.52)	-1.82 (1.70)	-1.03 (1.52)	1.66 (.194)

1. Mean (sd) of continuous measures of continuity of care for each category of transitions.
2. One-way analysis of variance (ANOVA).

Levels of continuity in the cohort

Data on continuity components are here reported for each variable in turn (Table M36) and for each factor (Table M37). Factor scores have no intrinsic meaning, so change must be interpreted with reference to the changing values of each component.

Experience & Relationship

Users' mean *experienced continuity* (CONTINU-UM) was low at all three time-points (T1 & T2: 3.5, T3: 3.4). The total therapeutic relationship score (STAR-c, STAR-p or STAR-o as applicable) was moderate at T1 (36.5), T2 (35.0) and T3 (36.3) respectively. Just over a third (39.3%) of users reported that a high proportion (>91%) of their needs were being met at T1, with a decline to 29.0% of the users at T2 and an increase to 35.7% at T3. The vast majority of users reported no breaks in care in the year prior to T1 (93.3%), T2 (86.4%) and T3 (89.2%). The overall mean Factor 1 score rose considerably at T2 and fell to a similar level at T3, but the changes in components on which this was based were thus not very meaningful clinically.

Regularity

The average gap between face-to-face contacts decreased from T1 (44.9 days) through T2 (30.5) to T3 (29.4). The proportion of users reporting gaps of two months or more in their care decreased steadily from 59.1% (T1) to 46.0% (T2) ending at 40.5% (T3). There was a decrease in non-medical input spread (the proportion of non-medical CMHT care delivered by professionals from more than one discipline) from T1 to T3 with the proportion of users scored at 'greater than 50%' (such that someone having six non-medical contacts in a year would have seen professionals from three different disciplines) declining from 19.7% at T1 to 4.9% at T3. The factor score increased over time.

Meeting Needs

The total level of needs was rated as low at all three time-points (T1:8.5, T2:8.9, T3:9.3 out of 22 domains), as was the number of met needs (T1: 4.4, T2:4.6, T3:5.3). Care Plan Assessments (CPAs) were not copied to either the GP or the user in 23.8% of cases at T1 and this increased to 46.8% at T3. The factor score increased to T2 and then fell at T3.

Consolidation

Less than half the users (42.4%) had had no contact with primary care professionals in the year to T1, but this increased at T2 (66.3%) and T3 (58.2%). The number of agencies used in the previous year fell slightly from 5.1 to 4.0 and then rose to 4.2. The factor score fell at T2 and then resumed its original level at T3.

Managed Transitions

The majority of users (69.0%) had no transitions in each year. Of those who had had a transition, these were more likely not to have been documented, with the proportion not varying meaningfully over time.

Care Coordination

Most users had only seen one or two care coordinators in each year, although this dropped from 81.1% at T1 to 73.8% at T3. The majority of users (78.9% falling to 66.7%) had seen only one or two psychiatrists. The total level of needs met by informal carers increased over time from 3.4 to 5.8. The factor score decreased at T2, then increased at T3.

Supported Living

Only 12.8% of users were living in supported accommodation at T1, which increased to 29.1% by T3. The proportion using day care also increased from 20.1% to 33.3%. The proportion of letters sent or copied to users also increased, with over half of users having no letters sent or copied to them at T1, but only just over a quarter having none at T3. The factor score thus increased over time.

Table M36: Sample 1 Levels of continuity components

mean (sd)[1]		n	T1	n	T2	n	T3
Factor 1: Experience & Relationship							
CONTINUUM Mean score (possible range 1-5)		167	3.5 (.764) 1.5-4.8	155	3.5 (.790) 1.3-5.0	135	3.4 (.659) 1.5-4.8
STAR Total score - Any professional (possible range 0-48)		164	36.5 (9.01) 6-48	150	35.0 (8.72) 10-48	127	36.3 (7.78) 10-48
CAN-Proportion of needs met	< 65%	178	59 (33.1%)	162	59 (36.4%)	140	33 (23.6%)
	65-91%		49 (27.5%)		56 (34.6%)		57 (40.7%)
	> 91%		70 (39.3%)		47 (29.0%)		50 (35.7%)
Any user-rated breaks in care	Yes	178	12 (6.7%)	162	22 (13.6%)	139	15 (10.8%)
	No		166 (93.3%)		140 (86.4%)		124 (89.2%)
Factor 2: Regularity							
Average gap between face-to-face contacts (days)		166	44.9 (39.71) 4-206	154	30.5 (26.49) 3.7-187.0	145 0	29.4 (28.36) 4.7-247.
Gaps of 2 months or more	Yes	176	104 (59.1%)	161	74 (46.0%)	158	64 (40.5%)
	No		72 (40.9%)		87 (54.0%)		94 (59.5%)
Non-medical input spread	=> 50%	122	24 (19.7%)	148	16 (10.8%)	142	7 (4.9%)
	21-49%		14 (11.5%)		12 (8.1%)		21 (14.8%)
	=< 20%		84 (68.9%)		120 (81.1%)		114 (80.3%)

1. Or n (%) when applicable.

Table M36: Sample 1 Levels of continuity components (continued)

mean (sd)[1]		n	T1	n	T2	n	T3
Factor 3: Meeting Needs							
CAN- Total level of needs (possible range 0-66)		178	8.5 (4.87) 1-23	162	8.9 (4.78) 1-23	140	9.3 (4.93) 1-30
CAN- Number of met needs (possible range 0-22)		178	4.4 (2.33) 0-12	162	4.6 (2.68) 0-13	140	5.3 (2.54) 1-11
CPA copied to GP and user	No	147	35 (23.8%)	127	39 (30.7%)	139	65 (46.8%)
	To one		61 (41.5%)		32 (25.2%)		42 (30.2%)
	To both		51 (34.7%)		56 (44.1%)		32 (23.0%)
Factor 4: Consolidation							
Number of agencies used in the previous year		151	5.1 (2.89) 1-16	166	4.0 (2.07) 1-11	141	4.2 (1.98) 1-11
Contact with primary care professionals	Yes	151	87 (57.6)	166	56 (33.7%)	141	59 (41.8%)
	No		64 (42.4)		110 (66.3%)		82 (58.2%)

1. Or n (%) when applicable.

Table M36: Sample 1 Levels of continuity components (continued)

mean (sd) [1]		n	T1	n	T2	n	T3
Factor 5: Managed Transitions							
Had a transition?	Yes	174	54 (31.0%)	174	53 (30.5%)	180	55 (30.6%)
	No		120 (69.0%)		121 (69.5%)		125 (69.4%)
Documented transition?	Documented transition	174	17 (9.8%)	174	19 (10.9%)	180	19 (10.6%)
	No relevant transition		120 (69.0%)		121 (69.5%)		125 (69.4%)
	Undocumented transition		37 (21.3%)		34 (19.5%)		36 (20.0%)
Factor 6: Care Coordination							
Number of designated care coordinators	0 or 3+	175	33 (18.9%)	166	44 (26.5%)	141	37 (26.2%)
	1 or 2		142 (81.1%)		122 (73.5%)		104 (73.8%)
Number of designated psychiatrists	0 or 3+	180	38 (21.1%)	165	36 (21.8%)	141	47 (33.3%)
	1 or 2		142 (78.9%)		129 (78.2%)		94 (66.7%)
CAN- Total level of needs met by informal carers (possible range 0-22)		178	3.4 (4.06) 0-21	162	5.5 (5.15) 0-24	140	5.8 (5.78) 0-35

1. Or n (%) when applicable.

Table M36: Sample 1 Levels of continuity components (continued)							
mean (sd) [1]		**n**	**T1**	**n**	**T2**	**n**	**T3**
Factor 7: Supported Living							
Supported accommodation	Yes	149	19 (12.8%)	166	32 (19.3%)	141	41 (29.1%)
	No		130 (87.2%)		134 (80.7%)		100 (70.9%)
Attendance at day centres or hospitals	Yes	149	30 (20.1%)	166	45 (27.1%)	141	47 (33.3%)
	No		119 (79.9%)		121 (72.9%)		94 (66.7%)
Proportion of letters sent by CMHT sent or copied to user	None	159	88 (55.3%)	160	67 (41.9%)	159	42 (26.4%)
	<= 50%		25 (15.7%)		18 (11.3%)		54 (34.0%)
	> 50%		46 (28.9%)		75 (46.9%)		63 (39.6%)

1. Or n (%) when applicable.

Table M37: Sample 1 Levels of continuity factors							
mean (sd) (min-max)[1]		**n**	**T1**	**n**	**T2**	**n**	**T3**
Factor 1: Experience & Relationship		180	.93 (2.31) -5.3 – 4.8	166	2.6 (2.23) -2.8 – 6.9	141	.89 (2.30) -7.0 – 5.6
Factor 2: Regularity		176	.16 (2.22) -5.7 – 3.0	162	.72 (2.16) -7.9 – 3.0	158	.87 (1.99) -9.7 – 2.9
Factor 3: Meeting Needs		180	.09 (1.98) -4.4 – 6.6	178	.10 (1.82) -4.0 – 5.1	171	-.19 (1.83) -4.0 – 4.8
Factor 4: Consolidation		151	-.15 (1.70) -4.8 – 2.4	166	.33 (1.55) -3.9 – 2.5	141	.16 (1.61) -4.4 – 2.6
Factor 5:Managed Transitions	No transition	174	120 (69.0%)	174	121 (69.5%)	180	125 (69.4%)
	Documented transition		17 (9.8%)		19 (10.9%)		19 (10.6%)
	Undocumented transition		37 (21.3%)		34 (19.5%)		36 (20.0%)
Factor 6: Care Coordination		180	.03 (1.62) -5.9 – 2.8	166	-.09 (1.48) -3.7 – 3.1	141	.14 (1.47) -5.1 – 3.0
Factor 7: Supported Living		177	-1.4 (1.53) -3.0 – 3.0	179	-.95 (1.47) -3.0 – 3.0	177	-.48 (1.52) -3.0 – 3.0

1. Or n (%) when applicable.

Illustration of continuity factors

The continuity factor scores are illustrated in Appendix 8.

Phase 2: User, care and illness characteristics associated with continuity of care

Phase 2a

Tables M38-M44 present the results of the analyses of possible explanatory variables (service user demographics and clinical and social variables) tested for association with each continuity factor. The following variables were tested: time, Trust, team, gender, total number of lifetime admissions, type of accommodation, living situation, ethnic group, education, employment, informal carer, use of depot medication, alcohol or drugs, whether hospitalised in the previous year, age, duration of illness, functioning (GAF), symptomatology (BPRS), empowerment and quality of life (MANSA and SEIQoL).

Only those variables univariately associated with each factor at the 10% significance level are included in the table. These were entered into the adjusted analysis; in the column for the adjusted model, those significant at the 5% level are shown in bold. For categorical variables, the values given are the mean level of the factor for each category in the variable; for continuous variables, the values given represent slope estimates, that is, the amount of change in the factor given a one unit change in the variable. Values for the factor scores have no inherent meaning (such that a value of zero does not indicate having no continuity) and should only be interpreted relatively, as indicating higher or lower scores on each particular factor. As the *Managed Transitions* factor was categorical, the parameter estimates indicating the relationship between variables and transitions are odds ratios, presented with their accompanying 95% confidence intervals.

Factor 1, *Experience & Relationship* (comprising user-rated experienced continuity, therapeutic relationship, proportion of needs met and user-rated breaks in care), was higher at T2 than the other time-points. Service users in Trust 1 scored more highly on this factor, as did those living with others and those with an informal carer. A ten-point higher GAF score (better functioning) was associated with a 0.3 point higher Factor 1 score, a five-point lower BPRS score (less symptomatology) was associated with a 0.3 higher Factor 1 score, a ten-point higher empowerment score (feeling more empowered) was associated with a 0.4 point higher Factor 1 score, a one-point higher MANSA (quality of life) score was associated with a one-point higher Factor 1 score and a ten-point higher SEIQoL (quality of life) score was associated with a 0.4 point higher Factor 1 score.

When these variables were entered into the multifactorial analysis, only time-point and MANSA score remained in the model (a one-point higher score being associated with a 0.6 higher Factor 1 score). Thus users were more likely to report a good therapeutic relationship, high *experienced continuity*, a high proportion of their needs being met and having not had any breaks in care if they also reported better quality of life, and at T2. (Table M38)

Factor 2, *Regularity* (comprising non-medical input spread, average gap between face-to-face contacts and gaps of two months or more), increased over time. Service users scoring more highly were in Trust 1 (confirmed by the analysis of team), had an informal carer and received depot injections. When these variables were entered into the multifactorial analysis, time-point, Trust, team and having a depot injection remained in the model. Thus users were more likely to have been seen more frequently by fewer different non-medical staff if they were in Trust 1 and had depot injections, while this also became more likely over time. (Table M39)

Factor 3, *Meeting Needs* (comprising number of met needs, level of need and CPA copied to user and GP), was scored more highly on by service users who lived in supervised accommodation, those who lived with others, those who were White or of other ethnic background as opposed to Black, those who had left school by 16, and those who were having depot injections. Having been ill for ten more months was associated with a 0.3 point higher Factor 3 score, a ten-point lower GAF score (poorer functioning) was associated with a 0.5 point higher Factor 3 score, a ten-point higher BPRS score (more symptomatology) was associated with a 0.7 point higher score, a ten-point lower empowerment score was associated with a 0.3 point higher Factor 3 score, a one-point lower MANSA (quality of life) score was associated with a 0.8 point higher Factor 3 score and a ten-point lower SEIQoL (quality of life) score was associated with a 0.2 point higher Factor 3 score.

When these variables were entered into the multifactorial analysis, accommodation type, duration of illness, GAF, BPRS and MANSA remained in the model. A ten-month longer duration of illness was associated with a 0.2 point higher Factor 3 score, a ten-point lower GAF score was associated with a 0.2 point higher Factor 3 score, a ten-point higher BPRS score was associated with a 0.3 point higher Factor 3 score and a one-point lower MANSA score was associated with a 0.6 point lower Factor 3 score. Thus users were more likely to have a high level of need, a high number of their needs met and have their CPA copied to their GP and themselves if they were living in supervised accommodation, had been ill for longer, had a lower level of functioning, more symptomatology and if they reported poorer quality of life. (Table M40)

Factor 4, *Consolidation* (comprising contacts with primary care professionals and number of agencies used), was higher for users in Trust 2, Team 2a and Team 2c, for females, those who had left school at 16, those who were on depot injections and those who had not been hospitalised in the previous year. Being ten months older was associated with a 0.2 point higher *Consolidation* score, having been ill for ten more months was associated with a 0.2 point higher Factor 4 score, a ten-point higher GAF score (better functioning) was associated with a 0.1 point higher Factor 4 score, while a five-point lower BPRS score (less symptomatology) was associated with a 0.1 point higher Factor 4 score. One-point higher MANSA or SEIQoL scores (better quality of life) were associated with 0.3 point and 0.01 point higher Factor 4 scores respectively. When these variables were entered into the multifactorial analysis, being in Trust 2 or Team 2c and having depot injections remained in the model. Thus users were more likely to have been in contact with more different agencies and to have seen primary care professionals if they were in Trust 2 or having depot injections. (Table M41)

Factor 5, *Managed Transitions*, was related to GAF, MANSA, SEIQoL, age and duration of illness. Higher levels of functioning and quality of life were associated with having lower odds of experiencing transitions (whether documented or not). This is not unexpected as transitions included admissions and discharges from hospital. The odds ratios indicate that this relationship was slightly greater for undocumented transitions than documented ones. Being older and having a longer duration of illness were also associated with lower odds of experiencing a transition, whether documented or not. In the adjusted model only GAF (functioning) remained significant (p=0.028), the odds ratios being very similar to before: a five-point higher GAF rating was associated with 10% lower odds of experiencing transitions. (Table M42)

It was not possible to compare directly the levels of this factor for the documented and undocumented transitions groups as insufficient data meant that the regression models did not converge to provide parameter estimates.

Factor 6, *Care coordination* (comprising designated psychiatrists, level of needs met by informal carers and designated care coordinators), was higher for those who had no informal carer and for those who were having depot injections. A ten-point higher GAF score (better functioning) was associated with a 0.1 point higher Factor 6 score, a ten-point lower BPRS score (less symptomatology) was associated with a 0.2 point higher Factor 6 score, a ten-point higher empowerment score was associated with a 0.2 point higher Factor 6 score, a one-point higher MANSA (quality of life) score was associated with a 0.3 point higher Factor 6 score and a ten-point higher SEIQoL (quality of life) score was associated with a 0.1 point higher Factor 6 score.

When these variables were entered into the multifactorial analysis, informal carer was the only variable remaining in the model. Thus users were more likely to have seen a designated care coordinator, no psychiatrist or more than two and have fewer needs met by informal carers (who might include any relative or friend) if they had no identified informal carer. (Table M43)

Factor 7, *Supported Living* (comprising proportion of CMHT letters sent or copied to the user, supported accommodation and attendance at day centres or day hospitals), increased over time. Service users in Trust 1 scored more highly on this factor, as did those who lived with others and those who left school by 16. Being ten months older was associated with a 0.1 point higher Factor 7 score, a ten-month longer duration of illness was associated with a 0.2 point higher Factor 7 score, a ten-point lower GAF score (poorer functioning) was associated with a 0.2 point higher Factor 7 score and a ten-point lower empowerment score was associated with a 0.1 point higher Factor 7 score. When these variables were entered into the multifactorial analysis, time-point, Trust, education, living situation and GAF score remained in the model, with a ten-point higher GAF score being associated with a 0.1 point lower Factor 7 score. Thus users were more likely to be living in supported accommodation, attending day care and having more letters copied to them if they were in Trust 1, had left school by 16, lived with others and had poorer functioning. (Table M44)

Table M38: Sample 1 FACTOR 1 – Experience & Relationship					
		Univariate model		**Adjusted model**	
Variable	**Label**	**Mean (se)**	**95% CI**	**Mean (se)**	**95% CI**
Time	T1	.93 (.170)	(.59, 1.3)	**1.1 (.183)**	**(.71, 1.4)**
	T2	2.6 (.175)	(2.2, 2.9)	**2.7 (.176)**	**(2.3, 3.0)**
	T3	.84 (.186)	(.47, 1.2)	**.89 (.188)**	**(.52, 1.3)**
Trust	1	1.7 (.204)	(1.3, 2.1)	1.8 (.197)	(1.4, 2.2)
	2	1.2 (.193)	(.84, 1.6)	1.3 (.186)	(.95, 1.7)
Living situation	Living alone (+/- children under 18)	1.2 (.208)	(.80, 1.6)	1.3 (.198)	(.92, 1.7)
	Living with others (+/- children under 18)	1.7 (.179)	(1.3, 2.0)	1.8 (.177)	(1.4, 2.1)
Informal carer	Yes	2.0 (.238)	(1.5, 2.6)	1.7 (.218)	(1.2, 2.1)
	No	1.3 (.156)	(1.0, 1.6)	1.4 (.145)	(1.1, 1.7)
GAF		.03 (.009)	(.01, .05)	.01 (.011)	(-.01, .03)
BPRS		-.06 (.011)	(-.08, -.04)	-.01 (.014)	(-.04, .01)
Empowerment		.04 (.010)	(.02, .06)	.01 (.012)	(-.01, .04)
MANSA		1.0 (.130)	(.71, 1.2)	**.59 (.179)**	**(.24, .95)**
SEIQoL		.04 (.007)	(.02, .05)	.01 (.008)	(-.00[1], .03)

1. Lower 95%CI: -0.005

Table M39: Sample 1 FACTOR 2 – Regularity

		Univariate model		Adjusted model	
Variable	**Label**	**Mean (se)**	**95% CI**	**Mean (se)**	**95% CI**
Time	T1	.17 (.160)	(-.15, .49)	**.47 (.165)**	**(.15, .80)**
	T2	.66 (.166)	(.33, .98)	**.92 (.166)**	**(.59, 1.2)**
	T3	.79 (.168)	(.46, 1.1)	**1.1 (.177)**	**(.76, 1.5)**
Trust	1	1.3 (.156)	(1.0, 1.7)	**1.6 (.164)**	**(1.3, 1.9)**
	2	-.25 (.153)	(-.55, .05)	**.08 (.171)**	**(-.26, .41)**
Team [1]	Team 1a	1.5 (.274)	(.93, 2.0)	**1.8 (.286)** [1]	**(1.3, 2.4)** [1]
	Team 1b	1.7 (.394)	(.89, 2.4)	**1.7 (.382)** [1]	**(.99, 2.5)** [1]
	Team 1c	1.3 (.360)	(.56, 2.0)	**1.5 (.360)** [1]	**(.83, 2.2)** [1]
	Team 1d	1.1 (.272)	(.59, 1.7)	**1.3 (.275)** [1]	**(.77, 1.9)** [1]
	Team 2a	.05 (.220)	(-.39, .48)	.35 (.237) [1]	(-.11, .82) [1]
	Team 2b	-.49 (.337)	(-1.2, .17)	-.31 (.353) [1]	(-1.0, .38) [1]
	Team 2c	-.53 (.273)	(-1.1, .00)	-.10 (.280) [1]	(-.66, .45) [1]
Informal carer	Yes	.84 (.218)	(.41, 1.3)	1.0(.198)	(.62, 1.4)
	No	.42 (.137)	(.15, .69)	.66 (.128)	(.40, .91)
Depot injections	Yes	1.4 (.192)	(.99, 1.8)	**1.3 (.186)**	**(.90, 1.6)**
	No	.12 (.148)	(-.17, .41)	**.40 (.144)**	**(.11, .68)**

1. Estimates of all the variables in the adjusted model are reported for the model when variable team is omitted, (The perfect correlation between the variables ‘Team’ and ‘Trust’ makes a model with both spurious).

Table M40: Sample 1 FACTOR 3 – Meeting Needs

		Univariate model		Adjusted model	
Variable	**Label**	**Mean (se)**	**95% CI**	**Mean (se)**	**95% CI**
Accommodation type	Unsupervised Accommodation	-.17 (.130)	(-.43, .09)	-.04 (.172)	(-.38, .30)
	Supervised accommodation	.76 (.221)	(.32, 1.2)	**.81 (.270)**	**(.28, 1.3)**
	Other	-.21 (.607)	(-1.4, .99)	.18 (.648)	(-1.1, 1.5)
Living situation	Living alone (+/- children under 18)	-.25 (.174)	(-.59, .09)	.22 (.297)	(-.36, .81)
	Living with others (+/- children under 18)	.26 (.150)	(-.04, .55)	.41 (.274)	(-.13, .95)
Ethnic group	White	-.08 (.137)	(-.35, .18)	.11 (.260)	(-.41, .62)
	Black	-.13 (.255)	(-.63, .37)	.28 (.325)	(-.36, .92)
	Other	.64 (.300)	(.05, 1.2)	.57 (.366)	(-.15, 1.3)
Education	School up to 16	.34 (.181)	(-.02, .69)	.31 (.295)	(-.27, .90)
	School beyond 16	-.20 (.142)	(-.47, .08)	.32 (.275)	(-.22, .86)
Employment	Paid employment	-.93 (.267)	(-1.5, -.40)	.11 (.342)	(-.56, .79)
	Unemployed or unpaid work	.26 (.127)	(.01, .50)	.52 (.244)	(.04, 1.0)
Depot injections	Yes	.32 (.188)	(-.05, .69)	.46 (.293)	(-.12, 1.0)
	No	-.07 (.143)	(-.35, .21)	.18 (.275)	(-.36,.72)
Duration		.03 (.010)	(.01, .05)	**.02 (.009)**	**(.01, .04)**
GAF		-.05 (.007)	(-.07, -.04)	**-.02 (.010)**	**(-.04, -.00[1])**
BPRS		.07 (.008)	(.05, .08)	**.03 (.012)**	**(.01, .06)**
Empowerment		-.03 (.008)	(-.04, -.01)	-.02 (.010)	(-.04, .00)
MANSA		-.78 (.106)	(-.99, -.57)	**-.63 (.143)**	**(-.91, -.35)**
SEIQoL		-.02 (.005)	(-.03, -.01)	.01 (.006)	(-.01, .02)

1. Upper 95%CI: -.00179

Table M41: Sample 1 FACTOR 4 - Consolidation

		Univariate model		Adjusted model	
Variable	**Label**	**Mean (se)**	**95% CI**	**Mean (se)**	**95% CI**
Trust	1	-.16 (.134)	(-.43,.10)	-.25 (.164)	(-.57,.08)
	2	.36 (.127)	(.11,.61)	**.41 (.175)**	**(.06,.75)**
Team[1]	Team 1a	-.23 (.240)	(-.71,.24)	-.30 (.254)	(-.80,.20)
	Team 1b	-.38 (.335)	(-1.0,.28)	-.45 (.332)	(-1.1,.21)
	Team 1c	.13 (.318)	(-.49,.76)	.16 (.326)	(-.48,.80)
	Team 1d	-.15 (.228)	(-.60,.30)	-.19 (.241)	(-.67,.28)
	Team 2a	.52 (.188)	(.15,.89)	.40 (.215)	(-.02,.83)
	Team 2b	-.08 (.296)	(-.66,.50)	.14 (.315)	(-.48,.76)
	Team 2c	.38 (.213)	(-.04,.80)	**.59 (.245)**	**(.10,1.1)**
Age		.02 (.009)	(.01,.04)	.01 (.012)	(-.02,.03)
Sex	Male	-.05 (.125)	(-.30,.20)	-.01 (.159)	(-.32,.31)
	Female	.32 (.140)	(.04,.59)	.17 (.174)	(-.18,.51)
Education	School up to 16	.39 (.151)	(.10,.69)	.19 (.188)	(-.18,.56)
	School beyond 16	-.06 (.118)	(-.29,.17)	-.03 (.153)	(-.33,.27)
Duration		.02 (.008)	(.01,.04)	.00 (.001)	(-.00[3],.00)
Depot injections	Yes	.43 (.150)	(.13,.72)	**.38 (.189)**	**(.01,.76)**
	No	-.09 (.113)	(-.31,.13)	-.22 (.149)	(-.52,.07)
GAF		.01 (.007)	(-.00[2],.02)	.01 (.009)	(-.01,.03)
BPRS		-.02 (.008)	(-.04,-.01)	-.01 (.011)	(-.03,.02)
MANSA		.28 (.097)	(.09,.47)	.09 (.137)	(-.18,.36)
SEIQoL		.01 (.005)	(.00,.02)	.01 (.006)	(-.01,.02)
Hospitalised	Yes	-.28 (.223)	(-.72,.16)	-.01 (.239)	(-.48,.46)
	No	.17 (.098)	(-.02,.37)	.17 (.105)	(-.03,.38)

1. Estimates in adjusted model are reported for the model when variable Team is omitted. (The perfect correlation between the variables ‘Team’ and ‘Trust’ makes a model with both spurious).
2. Lower 95%CI: -.00177
3. Lower 95%CI: -.00098

Table M42: Sample 1 FACTOR 5 – Managed Transitions[1]

	Undocumented vs. no transition		Documented vs. no transition	
Variable	**OR**	**95% CI**	**OR**	**95% CI**
GAF	**.98**	**(.96, 1.00)**	**.98**	**(.96, 1.01)**
MANSA	.75	(.57, 1.00)	.69	(.47, 1.01)
SEIQoL	.98	(.97, 1.00)	1.00	(.98, 1.02)
Age	.97	(.95, .99)	.95	(.92, .98)
Duration of illness	.97	(.95, .99)	.96	(.93, .99)

1. For the sake of clarity, the unadjusted results are presented here, but those that remained significant in the adjusted models are presented in bold. Odds ratios were sufficiently close to show no change once rounded to two decimal places.

Table M43: Sample 1 FACTOR 6 - Care Coordination

		Univariate model		Adjusted model	
Variable	**Label**	**Mean (se)**	**95% CI**	**Mean (se)**	**95% CI**
Informal carer	Yes	-.47 (.149)	(-.76,-.18)	**-.55 (.148)**	**(-.85,-.26)**
	No	.17 (.097)	(-.02,.36)	**.21 (.098)**	**(.02,.40)**
Depot injections	Yes	.24 (.144)	(-.04,.52)	-.03 (.145)	(-.32,.25)
	No	-.12 (.108)	(-.33,.09)	-.31 (.107)	(-.52,-.10)
GAF		.01 (.006)	(.00,.03)	.01 (.008)	(-.00[1],.03)
BPRS		-.02 (.007)	(-.04,-.01)	-.02 (.010)	(-.03,.00)
Empowerment		.02 (.006)	(.01,.03)	-.00[2] (.008)	(-.02,.01)
MANSA		.32 (.090)	(.14,.49)	.17 (.118)	(-.06,.41)
SEIQoL		.01 (.004)	(.00,.02)	.01 (.005)	(-.00[3],.02)

1. Lower 95%CI: -.00470
2. Mean: -.00159
3. Upper 95%CI: -.00449

Table M44: Sample 1 FACTOR 7 - Supported Living

		Univariate model		**Adjusted model**	
Variable	**Label**	**Mean (se)**	**95% CI**	**Mean (se)**	**95% CI**
Time	T1	-1.4 (.113)	(-1.6, -1.1)	**-1.4 (.118)**	**(-1.6, -1.1)**
	T2	-.95 (.113)	(-1.2, -.73)	**-1.1 (.123)**	**(-1.3, -.81)**
	T3	-.49 (.113)	(-.71, -.26)	**-.67 (.130)**	**(-.93, -.42)**
Trust	1	-.77 (.118)	(-1.0, -.54)	**-.82 (.131)**	**(-1.1, -.56)**
	2	-1.1 (.112)	(-1.3, -.86)	**-1.2 (.120)**	**(-1.5, -1.0)**
Living situation	Living alone (+/- children under 18)	-1.3 (.132)	(-1.6, -1.1)	**-1.2 (.131)**	**(-1.5, -.98)**
	Living with others (+/- children under 18)	-.89 (.114)	(-1.1, -.67)	**-.81 (.114)**	**(-1.0, -.59)**
Education	School up to 16	-.64 (.129)	(-.90, -.39)	**-.82 (.147)**	**(-1.1, -.54)**
	School beyond 16	-1.1 (.102)	(-1.3, -.91)	**-1.2 (.111)**	**(-1.4, -1.0)**
Age		.01 (.007)	(-.00[1], .03)	.01 (.011)	(-.01, .03)
Duration		.02 (.007)	(.00, .03)	.00 (.011)	(-.02, .02)
GAF		-.02 (.006)	(-.03, -.01)	**-.01 (.007)**	**(-.03, -.00[2])**
Empowerment		-.01 (.007)	(-.03, .00)	-.01 (.008)	(-.02, .01)

1. Lower 95%CI: -.00025
2. Upper 95%CI: -.00095

Coercion

The Coercion Scale was not part of the study's original analytic strategy and could not be incorporated into it. Adjusted models testing the coercion sub-scales were not produced, as the sub-scales were all highly correlated with each other. They were univariately associated with several different factors, however (Table M45).

For Factor 1, *Experience & Relationship*, a one-point higher 'perceived coercion' sub-scale score (scored from zero to five with five being the most coerced) was associated with a 0.3 point lower Factor 1 score, a one-point increase on the 'negative pressure' sub-scale (scored from 0-6 with 6 being the most coerced) was associated with a 0.2 point lower Factor 1 score and a one-point increase on the reverse-scored 'voice' sub-scale (scored 0-3 with 3 being the most coerced) was associated with a 0.5 point lower Factor 1 score.

For Factor 2, *Regularity*, a one-point higher 'perceived coercion' score was associated with 0.2 point higher Factor 2 score and a one-point higher 'voice' score (greater coercion) was associated with a 0.2 point higher Factor 2 score.

For Factor 3, *Meeting Needs*, a one-point higher 'perceived coercion' score was associated with a 0.2 point higher Factor 3 score, a one-point higher 'negative pressure' score was associated with a 0.2 point higher Factor 3 score and a one-point higher 'voice' score (greater coercion) was associated with a 0.4 point higher Factor 3 score.

For Factor 5, *Managed Transitions*, a one-point higher 'negative pressure' score was associated with an 18.0% increase in odds of having an undocumented transition rather than no transition and a 15.0% increase in odds of having a documented transition rather than no transition.

For Factor 6, *Care Coordination*, a one-point higher 'voice' score (greater coercion) was associated with a 0.2 point lower Factor 6 score.

Table M45: Sample 1 Coercion Scale		
	Univariate model	
	Mean (se)	**95% CI**
Factor 1 - Experience & Relationship		
Perceived coercion sub-scale	-.34 (.092)	(-.52, -.16)
Negative pressure sub-scale	-.22 (.084)	(-.39, -.06)
Voice Sub-scale	-.52 (.150)	(-.82, -.23)
Factor 2 - Regularity		
Perceived coercion sub-scale	.18 (.088)	(.01, .35)
Voice Sub-scale	.24 (.144)	(-.04, .52)
Factor 3 - Meeting Needs		
Perceived coercion sub-scale	.15 (.082)	(-.01, .32)
Negative pressure sub-scale	.23 (.071)	(.09, .37)
Voice Sub-scale	.44 (.129)	(.19, .70)
Factor 5 - Managed Transitions		
Odds ratio (95% CI)	**Undocumented *vs.* no transition**	**Documented *vs.* no transition**
Negative pressure sub-scale	1.18 (1.02, 1.38)	1.15 (.94, 1.41)
Factor 6 - Care Coordination		
Voice Sub-scale	-.18 (.104)	(-.38, .03)

Phase 2b

The aim of this phase was to explore how the levels of the continuity factors at T2 and T3 were associated with the change in clinical and social functioning in the previous year. Table M46 summarises the amount of change found in the measures of clinical and social functioning, with positive values indicating an average increase in scores. There was a considerable range of change scores for each variable, but the mean changes were not of great magnitude.

Table M46: Sample 1 summary statistics of change in outcome measures

Mean (sd) Min, Max	**n**	**T2 – T1**	**n**	**T3 – T2**
GAF	157	-.27 (10.91) -33, 24	133	1.3 (9.59) -29, 31
BPRS	163	-1.5 (9.09) -31, 30	138	1.9 (8.05) -22, 22
Empowerment	158	-.13 (11.93) -74, 48	133	1.2 (10.63) -44, 68
MANSA	164	.05 (.601) -2.1, 1.6	138	.01 (.637) -1.4, 3.3
SEIQoL	134	4.6 (17.10) -38.6, 62.9	131	-2.6 (16.24) -49.5, 39.2

Phase 2b analyses were conducted to test whether one-year changes in clinical and social outcomes in Sample 1 between T1 and T3 were associated with levels of continuity factors.

A one-point higher Factor 1 score was associated with an increase of 1.5 points in mean SEIQoL score (β=1.4; 95%CI: 0.59; 2.3, r=0.202; p=0.001). A one-point higher Factor 3 score was associated with a 0.05 point decrease in mean MANSA score (β=-0.05; 95%CI: -0.09; -0.01, r=0.156; p=0.007) during the previous year. A one-point higher Factor 3 score was also associated with a 0.6 point increase in mean BPRS score (β=0.61; 95%CI: 0.10; 1.1, r=0.135; p=0.020) during the previous year.

No other significant associations were found. Mean change between T1 and T3 in functioning (GAF) and empowerment were not associated with any of the continuity factor levels.

In terms of hospital admissions, 24 users (13.9%) were hospitalised at T1, 22 (12.6%) at T2 and 27 (15.0%) at T3. When hospitalisation is the outcome, users scoring one-point higher on Factor 4 (*Consolidation*) were 18.7% less likely to have been hospitalised in the previous year (OR=0.813, 95%CI: 0.674, 0.981). This suggests that users seeing fewer different agencies and not using primary care were less likely to be hospitalised. Those scoring one-point higher on Factor 6 (*Care Coordination*) were 16.0% less likely to have been hospitalised in the previous year (OR=0.83, 95% CI: 0.68, 1.02), although this was only a weak association. This suggests that users whose care had been focused on by one or two care coordinators were less likely to have been hospitalised during that year. Both factors retain similar significance when entered into the model together, suggesting that they are independent of each other.

It was not possible to estimate how Factor 5 (*Managed Transitions*) was related to hospitalisation, as all users who were hospitalised had experienced some form of transition, producing a non-estimable model. No other factors were found to be associated with hospitalisation in the previous year.

Phase 3: Impact of continuity on health and social outcomes

The aim of the Phase 3 analysis was to investigate whether levels of continuity factors were related to change in social and clinical outcomes in the subsequent year. The magnitude of change in these variables is presented in Table M46. Only change in BPRS (symptomatology) showed any relationship with the continuity factors.

A one-point higher Factor 1 (*Experience & Relationship*) score was associated with a 0.7 point increase in mean BPRS score (increased symptoms) (β=0.69; 95%CI: 0.28; 1.1, r=0.192; p=0.001), a one-point higher Factor 3 (*Meeting Needs*) score was associated with a 0.5 point decrease in mean BPRS score (decreased symptoms) (β=-0.52; 95%CI: -1.0; -0.1, r=0.116; p=0.044) and a one-point higher Factor 7 (*Supported Living*) score was associated with a 0.9 point increase in mean BPRS score (increased symptoms) (β=0.89; 95%CI: 0.23; 1.6, r=.152; p=0.009).

In terms of hospitalisation as the outcome, users scoring one-point higher in Factor 2 (*Regularity*), were 17.0% more likely to be hospitalised in the subsequent year (OR: 1.166, 95%CI: 0.977, 1.393). This suggests that those being seen more regularly were more likely to be hospitalised subsequently. There were no other significant associations between levels of continuity factors and hospitalisation in the subsequent year.

Comparison of users with psychotic disorders scoring in the upper and lower quartiles on each factor

The comparison of users scoring in the upper quartile on each factor to those scoring in the lower quartile is presented in Appendix 9.

Other analyses

Comparisons between those dropping out of the study and those remaining, and between those discharged from secondary care and those remaining, are presented in Appendix 11. There were few differences.

4.3.3. Analysis: Service users with non-psychotic disorders

Phase 1

Confirmatory factor analyses

The seven-factor model was not validated by confirmatory factor analyses applied to the two Sample 2 data-sets (see Appendix 7).

Levels of continuity in the cohort

Experience & Relationship

Users' mean experienced continuity (CONTINUUM) was low at both time-points (T1=3.3, T2=3.2). *Relational continuity* (STAR-c, STAR-p and STAR-o as applicable) was moderate at both time-points (37.9 and 36.9) (Table M47). At T1, 17.3% of users reported that a high proportion (>91%) of their needs were met, with a slight increase to 20.0% at T2. The number of users reporting breaks in care increased six-fold from 5.1% at T1 to 31.8% at T2. The factor score decreased over time (Table M48).

Regularity

The average gap between face-to-face contacts increased slightly from 27 to 30 days between the time-points, while the proportion percentage of users having had a gap of two months or more increased from 44.9% to 56.8%. The proportion of service users experiencing a low non-medical input spread (<20%) decreased from 71.9% at T1 to 58.4% at T2. The factor score decreased over time.

Meeting Needs

The total level of needs was low at both time-points (T1=11.7, T2=10.6), as was the number of met needs (T1=4.7, T2=4.4). The proportion of CPAs not copied to either GP or user increased very slightly (T1=45.9%, T2=48.0%). The factor score decreased over time but the changes in components on which this was based were clearly not meaningful clinically.

Consolidation

The number of agencies used decreased slightly from 6.6 at T1 to 5.5 at T2. The majority (67.3% and 64.7%) had contact with primary care professionals. The factor score increased over time but the changes in components on which this was based were clearly not meaningful clinically.

Managed Transitions

The majority of users (59.2%) had a transition in the year preceding T1, but this fell to 42.9% at T2. Of those who had a transition, it had been documented in most cases.

Care Coordination

The proportion of users who had one or two care coordinators decreased from 92.9% to 88.2%. The number of service users who had seen no or more than three psychiatrists increased from 27.6% at T1 to 35.7% at T2. The total level of needs met through informal carers remained fairly stable at just over seven. The factor score increased very slightly over time.

Supported Living

The number of users living in supported accommodation fell slightly from 11.2% to 9.4%. Only about a fifth of the study sample visited day centres or day hospitals at either time-point. The proportion who did not receive letters or copies increased sharply from 10.2% to 44.9%. Similarly, the proportion of users who were copied in on more than half of the letters sent by their teams decreased from 42.9% at the first time-point to 18.4% at T2. The factor score decreased over time.

Table M47: Sample 2 Levels of continuity components					
Mean (sd)[1]		**n**	**T1**	**n**	**T2**
Factor 1: Experience & Relationship					
CONTINUUM Mean score		96	3.3 (.691) 1.3-4.6	85	3.2 (.717) 1-4
STAR Total score-Any professional		98	37.9 (8.56) 12-48	75	36.9 (9.39) 7-48
CAN-Proportion of needs met	< 65%	98	53 (54.1%)	85	44 (51.8%)
	65-91%		28 (28.6%)		24 (28.2%)
	> 91%		17 (17.3%)		17 (20.0%)
Any user-rated breaks in care	Yes	98	5 (5.1%)	85	27 (31.8%)
	No		93 (94.9%)		58 (68.2%)
Factor 2: Regularity					
Average gap between face-to-face contacts (days)		98	26.9 (25.45) 5.4-175.0	90	30.1 (22.80) 5.1-112. 0
Gaps of 2 months or more	Yes	98	44 (44.9%)	95	54 (56.8%)
	No		54 (55.1%)		41 (43.2%)
Non-medical input spread	=> 50%	96	10 (10.4%)	89	20 (22.5%)
	21-49%		17 (17.7%)		17 (19.1%)
	=< 20%		69 (71.9%)		52 (58.4%)
Factor 3: Meeting Needs					
CAN- Total level of needs		98	11.7 (4.84) 1-23	84	10.6 (5.74) 1-24
CAN- Number of met needs		98	4.7 (2.34) 0-11	84	4.4 (2.42) 0-11
CPA copied to GP and user	No	98	45 (45.9%)	98	47 (48.0%)
	To one		27 (27.6%)		34 (34.7%)
	To both		26 (26.5%)		17 (17.3%)

Table M47: Sample 2 Levels of continuity components (continued)					
Mean (sd) [1]		**n**	**T1**	**n**	**T2**
Factor 4: Consolidation					
Number of agencies used in the previous year		98	6.6 (3.00) 1-18	85	5.5 (2.48) 1-12
Contact with primary care professionals	Yes	98	66 (67.3%)	85	55 (64.7%)
	No		32 (32.7%)		30 (35.3%)
Factor 5: Managed Transitions					
Had a transition?	Yes	98	58 (59.2%)	98	42 (42.9%)
	No		40 (40.8%)		56 (57.1%)
Documented transition?	Yes	98	24 (24.5%)	98	13 (13.3%)
	No relevant transition		68 (69.4%)		81 (82.7%)
	No		6 (6.1%)		4 (4.1%)
Factor 6: Care Coordination					
Number of designated care coordinators	0 or 3+	98	7 (7.1%)	85	10 (11.8%)
	1 or 2		91 (92.9%)		75 (88.2%)
Number of designated psychiatrists	0 or 3+	98	27 (27.6%)	84	30 (35.7%)
	1 or 2		71 (72.4%)		54 (64.3%)
CAN- Total level of needs met by informal carers		98	7.7 (5.60) 0-31	84	7.6 (5.73) 0-27
Factor 7: Supported Living					
Supported accommodation	Yes	98	11 (11.2%)	85	8 (9.4%)
	No		87 (88.8%)		77 (90.6%)
Attendance at day centres or hospitals	Yes	98	22 (22.4%)	85	17 (20.0%)
	No		76 (77.6%)		68 (80.0%)
Proportion of letters sent by CMHT which were sent or copied to user	None	98	10 (10.2%)	98	44 (44.9%)
	<= 50%		46 (46.9%)		36 (36.7%)
	> 50%		42 (42.9%)		18 (18.4%)

1. or n (%) when applicable.

Table M48: Sample 2 Levels of continuity factors

		n	T1 mean (sd) min-max[1]	n	T2 mean (sd) min-max[1]
Factor 1: Experience & Relationship		98	.53 (2.20) -5.9 – 4.7	85	.05 (2.35) -5.5 – 4.2
Factor 2: Regularity		97	.71 (2.18) -7.8 – 2.8	95	.20 (2.24) -5.2 – 3.1
Factor 3: Meeting Needs		98	-.19 (1.81) -3.8 – 4.0	98	-.31 (1.72) -4.1 – 4.3
Factor 4: Consolidation		98	-.35 (1.55) -4.8 – 2.9	85	-.29 (1.64) -3.6 – 2.8
Factor 5: Managed Transitions	No transition	97	40 (41.2%)	98	56 (57.1%)
	Documented transition		23 (23.7%)		13 (13.3%)
	Undocumented transition		34 (35.1%)		29 (29.6%)
Factor 6: Care Coordination		98	.41 (1.45) -4.2 – 3.4	85	.48 (1.53) -3.4 – 3.3
Factor 7: Supported Living		98	1.0 (1.32) -3.0 – 3.0	98	-1.5 (1.38) -3.0 – 2.0

1. or n (%) when applicable.

Illustration of levels of continuity

The continuity factor scores are illustrated in Appendix 8.

Phase 2: User, care and illness characteristics associated with continuity of care

Analysis of the different levels of the continuity factors in Sample 2 compared to Sample 1, as well as their different characteristics, made combination of both data-sets inappropriate. Phase 2 and 3 analyses were therefore conducted using Sample 2 data alone. A comparison of the two samples is presented below ('Comparison of Samples 1 and 2').

Phase 2a

Factor 1, *Experience & Relationship* (comprising user-rated experienced continuity, therapeutic relationship, proportion of needs met and user-rated breaks in care), was higher for service users in Trust 2 than Trust 1, particularly for users with Team 1a. Being ten months older was associated with a 0.4 point higher Factor 1 score. A ten-point higher HADS-A score (more anxiety) was associated with a 0.7 point lower Factor 1 score and a ten-point higher HADS-D score (more depression) with a 0.9 point lower Factor 1 score. Furthermore, a one-point higher MANSA score (better quality of life) was associated with a 0.8 point higher Factor 1 score. When entered into the multifactorial analysis, Trust, being with Team 1a or Team 1c, having been discharged, age and MANSA score remained in the model. (Table M49).

Factor 2, *Regularity* (comprising average gap between face-to-face contacts, gaps of two months or more and non-medical input spread), decreased over time. A ten-point higher SEIQoL (quality of life) score was associated with a 0.2 point lower Factor 2 score, a one-point higher MANSA (quality of life) score was associated with a 0.4 point lower Factor 2 score, a ten-point higher empowerment score was associated with a 0.3 point lower Factor 2 score and a ten-point higher HADS-A and HADS-D score (more anxiety and depression) was associated with a 1.1 and a 0.8 point higher Factor 2 scores, respectively. A ten-point increase in GAF (better functioning) was associated with a 0.4 point lower Factor 2 score. When entered into the multivariate analysis, none of the variables remained in the model. (Table M50).

Factor 3, *Meeting Needs* (comprising level of need, number of met needs and CPA copied to user and GP), was scored more highly by service users who were in Trust 2, lived alone, had six or more admissions in their lifetime and did not use drugs. A ten-point higher GAF score (better functioning) was associated with a 0.7 point lower Factor 3 score, while ten-point higher HADS-A and HADS-D scores (more anxiety and depression) were associated with 1.2 and 1.1 point higher Factor 3 scores respectively. A ten-point higher Empowerment score was associated with a 0.6 point lower Factor 3 score. A ten-point higher MANSA (quality of life) score was associated with a 0.6 point lower Factor 3 score. In the multifactorial analysis, having had one to five lifetime admissions, drug use and GAF remained in the model. A ten-point lower GAF score was associated with a 0.4 point higher Factor 3 score. (Table M51).

Factor 4, *Consolidation* (comprising contacts with primary care professionals and number of agencies used) was scored more highly by service users who lived in unsupervised accommodation, did not use alcohol, did not have a carer, were not receiving medication by depot injection and had been moved to the care of teams other than the original one. Being ten months older was associated with a 0.3 point higher Factor 4 score, while a ten-point higher HADS-A score (more anxiety) was associated with a 0.5 point lower Factor 4 score. When these variables were entered into the multifactorial analysis, accommodation type and alcohol use remained in the model. Thus users were more likely to have had contact with different agencies and to have seen primary care professionals if they were living in supported accommodation and using alcohol. (Table M52).

Factor 5, *Managed Transitions*, was related to GAF, HADS (anxiety and depression), accommodation and time. Those scoring ten-points more on the GAF (better functioning) were 56.0% less likely to have had an undocumented transition as opposed to no transition, while those scoring one-point higher on HADS-A and HADS-D (more anxious and depressed) were 11.3% and 9.9% more likely respectively to have had an undocumented transition as opposed to no transition. Those scoring ten-points more on the GAF were also 44.0% less likely to have had a documented transition as opposed to none, while those in unsupported accommodation were 81.2% less likely to have had a documented transition as opposed to none. Users were also 2.7 times as likely to have had a documented transition as opposed to none at T2. (Table M53).

This analysis was carried out using two separate logistic regressions including a random effect with PROC GLIMMIX, ‘no transition’ being the reference category in each model. This was necessary because, given the smaller sample size in the non-psychotic sample and their having one fewer data collection time-point, the more appropriate way of analysing this data used for the psychotic sample did not produce models which could converge.

Factor 6, *Care Coordination* (comprising designated psychiatrists, level of needs met by informal carers and designated care coordinators was related to GAF, HADS and empowerment. A ten-point higher GAF score (better functioning) was associated with a 0.4 point higher Factor 6 score, a ten-point higher HADS-A score (more anxiety) was associated with a 0.7 point lower Factor 6 score, a ten-point higher HADS-D score (more depression) was associated with a 0.5 point lower Factor 6 score and a ten-point higher Empowerment score was associated with a 0.2 point higher Factor 6 score. When entered into the multifactorial analysis, GAF was the only variable remaining in the model, with a ten-point higher GAF score being associated with a 0.4 point higher Factor 6 score. Thus users who had a care coordinator, saw no or many psychiatrists and had fewer needs met by an informal carer had better functioning. (Table M54).

Factor 7, *Supported Living* (comprising supported accommodation, attendance at day centres or day hospitals and proportion of CMHT letters sent or copied to the user) was highest at T1, among those who were unemployed and those under the care of Team 2c. Having a ten-point higher GAF score (better functioning) was associated with a 0.2 point lower Factor 7 score. When entered into the multifactorial analysis, only time-point remained in the model. Thus users were more likely to have letters sent or copied to them, to live in supported accommodation and attend day centres or day hospitals at T1. (Table M55).

Table M49: Sample 2 FACTOR 1 – Experience & Relationship

		Univariate model		Adjusted model	
Variable	**Label**	**Mean (se)**	**95% CI**	**Mean (se)**	**95% CI**
Trust	1	-.43 (.185)	(-.80, -.06)	**.57 (.230)**	**(.11, 1.0)**
	2	.09 (.254)	(-.41, .60)	.21 (.307)	(-.40, .83)
Team	Team 1a	1.6 (.512)	(.56, 2.6)	**1.3 (.483)**	**(.30, 2.2)**
	Team 1b	-.34 (.583)	(-1.5, .82)	-.40 (.535)	(-1.5, .66)
	Team 1c	.84 (.546)	(-.25, 1.9)	**1.1 (.529)**	**(.01, 2.1)**
	Team 1d	.27 (.400)	(-.53, 1.1)	.38 (.376)	(-.37, 1.1)
	Team 2a	.00 (.450)	(-.89, .90)	.28 (.416)	(-.55, 1.1)
	Team 2b	.28 (.621)	(-.96, 1.5)	.03 (.581)	(-1.1, 1.2)
	Team 2c	.59 (.822)	(-1.1, 2.2)	.34 (.754)	(-1.2, 1.8)
	Other	-.94 (1.41)	(-3.7, 1.9)	-1.7 (1.37)	(-4.4, 1.1)
	Discharged	-1.7 (.607)	(-2.9, -.52)	**-2.1 (.612)**	**(-3.3, -.85)**
Age		.04 (.017)	(.01, .07)	**.04 (.016)**	**(.01, .07)**
HADS-A		-.07 (.037)	(-.15, .00)	.00 (.044)	(-.09, .09)
HADS-D		-.09 (.034)	(-.16, -.02)	-.03 (.045)	(-.12, .06)
MANSA		.84 (.196)	(.45, 1.22)	**.80 (.243)**	**(.32, 1.3)**

Table M50: Sample 2 FACTOR 2 - Regularity

		Univariate model		**Adjusted model**	
Variable	**Label**	**Mean (se)**	**95% CI**	**Mean (se)**	**95% CI**
Time	T1	.71 (.221)	(.27, 1.2)	.66 (.220)	(.22, 1.1)
	T2	.17 (.223)	(-.28, .61)	.34 (.237)	(-.13, .81)
SEIQoL		-.02 (.008)	(-.03, -.00[1])	-.01 (.010)	(-.03, .01)
MANSA		-.42 (.195)	(-.80, -.03)	.03 (.273)	(-.52, .57)
Empowerment		-.03 (.017)	(-.07, .00)	.00 (.021)	(-.04, .05)
HADS-A		.11 (.034)	(.04, .18)	.08 (.051)	(-.02, .18)
HADS-D		.08 (.033)	(.02, .15)	-.01 (.052)	(-.11, .09)
GAF		-.04 (.016)	(-.08, -.01)	-.02 (.019)	(-.06, .02)

1. Upper 95% CI: -0.00055

Table M51: Sample 2 FACTOR 3 – Meeting Needs

		Univariate model		**Adjusted model**	
Variable	**Label**	**Mean (se)**	**95% CI**	**Mean (se)**	**95% CI**
Trust	1	-.43 (.185)	(-.80, -.06)	.16 (.245)	(-.33, .65)
	2	.09 (.254)	(-.41, .60)	.31 (.276)	(-.24, .86)
Living situation	Living alone (+/- children under 18)	-.05 (.188)	(-.43, .32)	**.05 (.436)**	**(-.82, .92)**
	Living with others (+/- children under 18)	-.56 (.232)	(-1.0, -.10)	-.48 (.476)	(-1.4, .47)
Admission	None	-.57 (.259)	(-1.1, -.06)	-.66 (.482)	(-1.6, .30)
	1-5	-.25 (.213)	(-.68, .17)	**-.37 (.460)**	**(-1.3, .54)**
	6 or more	.43 (.372)	(-.31, 1.2)	.39 (.521)	(-.65, 1.4)
Do you use drugs?	Yes	-.35 (.168)	(-.69, -.02)	**-.68 (.416)**	**(-1.5, .14)**
	No	.53 (.396)	(-.26, 1.3)	.26 (.528)	(-.79, 1.3)
GAF		-.07 (.012)	(-.09, -.04)	**-.04 (.015)**	**(-.06, -.01)**
HADS-A		.12 (.028)	(.07, .18)	.04 (.035)	(-.03, .11)
HADS-D		.11 (.026)	(.06, .16)	.02 (.037)	(-.05, .10)
Empowerment		-.06 (.013)	(-.09, -.03)	-.02 (.016)	(-.06, .01)
MANSA		-.57 (.160)	(-.89,-.25)	-.11 (.189)	(-.48, .27)

Table M52: Sample 2 FACTOR 4 – Consolidation

		Univariate model		Adjusted model	
Variable	**Label**	**Mean (se)**	**95% CI**	**Mean (se)**	**95% CI**
Age		.03 (.012)	(.00, .05)	.02 (.013)	(-.01, .04)
HADS-A		-.05 (.026)	(-.10, .00)	-.05 (.026)	(-.10, .00)
Accommodation type	Unsupervised accommodation	-.23 (.141)	(-.51, .06)	-.88 (.525)	(-1.9, .16)
	Supervised accommodation	-1.3 (.395)	(-2.0, -.46)	**-1.8 (.564)**	**(-3.0, -.71)**
Uses Alcohol	Yes	-.65 (.192)	(-1.0, -.27)	**-1.7 (.532)**	**(-2.8, -.65)**
	No	-.04 (.178)	(-.39, .32)	**-1.0 (.502)**	**(-2.0, -.01)**
Has a carer	Yes	-.69 (.233)	(-1.2, -.23)	-1.59 (.540)	(-2.7, -.51)
	No	-.16 (.162)	(-.48, .17)	-1.13 (.499)	(-2.1., -.14)
Depot injections	Yes	-2.2 (.969)	(-4.1, -.25)	-2.07 (.954)	(-4.0, -.16)
	No	-.28 (.139)	(-.56, -.01)	-.65 (.238)	(-1.1, -.18)
Team	Team 1a	-.26 (.360)	(-.97, .46)	-1.76 (.602)	(-3.0, -.55)
	Team 1b	-.37 (.410)	(-1.2, .45)	-1.51 (.596)	(-2.7, -.33)
	Team 1c	-.60 (.383)	(-1.4, .17)	-1.30 (.603)	(-2.5, -.10)
	Team 1d	.10 (.282)	(-.47, .66)	-1.16 (.562)	(-2.3, -.04)
	Team 2a	-.98 (.317)	(-1.6, -.35)	-2.06 (.536)	(-3.1, -.99)
	Team 2b	.43 (.438)	(-.44, 1.3)	-.85 (.652)	(-2.2, .45)
	Team 2c	-.96 (.579)	(-2.1, .19)	-2.02 (.734)	(-3.5, -.56)
	Other	1.6 (.980)	(-.37, 3.5)	.14 (1.08)	(-2.0, 2.3)
	Discharged	-.31 (.423)	(-1.2, .53)	-1.71 (.640)	(-3.0, -.43)

Table M53: Sample 2 FACTOR 5 – Managed Transitions[1]					
		Undocumented *vs.* no transition		**Documented *vs.* no transition**	
Variable		**OR**	**95% CI**	**OR**	**95% CI**
GAF		.94	(.91, .96)	.96	(.91, 1.0)
HADS-A		1.1	(1.0, 1.2)	-	-
HADS-D		1.1	(1.0, 1.2)	-	-
Time	T1 vs. T2	-	-	**2.7**	**(1.2, 6.2)**
Accommodation type	unsupervised versus supervised	-	-	**.19**	**(.05, .77)**

[1] For the sake of clarity, the unadjusted results are presented here, but those that remained significant in the adjusted models are presented in bold. Odds ratios were sufficiently close to show no change once rounded to two decimal places.

Table M54: Sample 2 FACTOR 6 -- Care Coordination					
		Univariate model		**Adjusted model**	
Variable	**Label**	**Mean (se)**	**95% CI**	**Mean (se)**	**95% CI**
GAF		.04 (.011)	(.02, .07)	**.04 (.013)**	**(.01, .06)**
HADS-A		-.07 (.024)	(-.12, -.02)	-.03 (.031)	(-.09, .03)
HADS-D		-.05 (.022)	(-.10, -.01)	-.00[1] (.030)	(-.06, .06)
Empowerment		.02 (.012)	(.00, .05)	.00 (.014)	(-.03, .03)

1. Mean: -0.00222

Table M55: Sample 2 FACTOR 7 – Supported Living

		Univariate model		Adjusted model	
Variable	**Label**	**Mean (se)**	**95% CI**	**Mean (se)**	**95% CI**
Time	T1	-1.0 (.137)	(-1.3, -.73)	**-1.1 (.203)**	**(-1.5,-0.7)**
	T2	-1.5 (.137)	(-1.8, -1.2)	**-1.7 (.180)**	**(-2.1,-1.3)**
Employment Status	Paid employment	-1.7 (.239)	(-2.2, -1.2)	-1.4 (.270)	(-2.0, -.90)
	Unemployed or unpaid work	-1.2 (.119)	(-1.4, -.91)	-1.3 (.165)	(-1.7, -.99)
Team	Team 1a	-1.2 (.283)	(-1.8, -.65)	-1.3 (.314)	(-1.9, -.65)
	Team 1b	-.89 (.310)	(-1.5, -.27)	-1.2 (.357)	(-1.9, -.46)
	Team 1c	-.96 (.315)	(-1.6, -.34)	-1.3 (.320)	(-1.8, -.49)
	Team 1d	-1.1 (.221)	(-1.5, -.65)	-1.2 (.262)	(-1.8, .70)
	Team 2a	-1.8 (.247)	(-2.3, -1.3)	-1.9 (.263)	(-2.4, -1.3)
	Team 2b	-1.6 (.340)	(-2.3, -.95)	-1.8 (.375)	(-2.6, -1.1)
	Team 2c	-.33 (.431)	(-1.2, .52)	-.73 (.476)	(-1.7, .22)
	Other	-2.2 (.924)	(-4.1, -.38)	-1.8 (.896)	(-3.5, .03)
	Discharged	-1.7 (.395)	(-2.5, -.89)	-1.5 (.415)	(-2.3, -.63)
GAF		-.02 (.010)	(-.04, -.00[1])	-.02 (.011)	(-.04, .00)

1. Upper 95%CI: -.00229

Coercion

The Coercion Scale was not part of the study's original analytic strategy and could not be incorporated into it. Adjusted models testing the coercion sub-scales were not produced, as the sub-scales were all highly correlated with each other. They were univariately associated with several factors, however (Table M56).

For Factor 1, *Experience & Relationship*, a one-point higher 'perceived coercion' score was associated with 0.2 point lower Factor 1 score and a one-point higher 'voice' score was associated with a 0.8 point lower Factor 1 score.

On Factor 3, *Meeting Needs*, a one-point higher 'perceived coercion' score was associated with an increase of 0.3 in score on Factor 3.

For Factor 5, *Managed Transitions*, a one-point higher 'negative pressure' score was associated with a 67.0% increase in odds of having an undocumented transition rather than no transition and a 132.0% increase in odds of having a documented transition rather than no transition.

Table M56: Coercion Scale		
	Univariate model	
Variable	Mean (se)	95% CI
Factor 1- ***Experience & Relationship***		
Perceived coercion sub-scale	-.24 (.134)	(-.51, .03)
Voice Sub-scale	-.80 (.265)	(-1.3, -.23)
Factor 3- ***Meeting Needs***		
Perceived coercion sub-scale	.26 (.110)	(.04, .48)
Factor 5 - ***Managed Transitions***		
Odds ratio (95% CI)	**Undocumented *vs.* no transition**	**Documented *vs.* no transition**
Negative pressure sub-scale	1.7 (1.2, 2.4)	2.3 (1.3, 4.0)

Phase 2b

Table M57: Sample 2 Summary statistics of change in outcome measures

	n	**T2 – T1 Mean (sd), Min, Max**
GAF	84	1.9 (8.54) -23, 25
HADS-A	83	-.73 (3.41) -7, 9
HADS -D	83	-1.4 (4.25) -15, 7
Empowerment	82	2.3 (8.46) -14, 46
MANSA	85	.15 (.645) -1.8, 1.8
SEIQoL	81	-.13 (21.88) -43.3, 65.3

Phase 2b analysis for Sample 2 investigated the association of the one-year changes in clinical and social outcomes between T1 and T2 with the continuity factors. (Table M57).

For mean HADS-D (depression) score, a one-point higher Factor 1 score, *Experience & Relationship*, was associated with a 0.5 point decrease (β=-0.47; 95%CI: -0.85; -0.09, r=0.261; p=0.017), a one-point higher Factor 2, *Regularity*, score was associated with a 0.5 point increase in HADS-D (β=0.50; 95%CI: 0.07; 0.93, r=0.254; p=0.022) and a one-point higher Factor 3, *Meeting Needs*, score was associated with a 0.7 point increase in the depression sub-scale (β=0.69; 95%CI: 0.21; 1.2, r=0.302; p=0.005) during the previous year. Users with undocumented transitions tended to have higher mean HADS-D score (more depression) during the previous year compared to users with no transition, approaching statistical significance (mean difference=2.4, 95% CI: -0.03; 4.8, p=0.06).

A one-point higher Factor 1 (*Experience & Relationship*) score was significantly associated with a 0.8 point increase in mean empowerment score (β=0.78, 95%CI: 0.002, 1.6, r= 0.218, p=0.049) during the previous year.

A one-point higher Factor 3 (*Meeting Needs*) score was associated with a 0.08 point decrease in mean MANSA score (β=-0.08; 95%CI: -0.16; -0.01, r=0.229; p=0.035) during the previous year.

Users with no transition during the previous year had a statistically significant higher difference in mean SEIQoL score than users with undocumented transitions (mean difference=13.6; 95% CI: 0.83; 26.3; F=3.40; p= 0.038).

26 users (26.5%) were hospitalised at T1 and 10 (10.2%) at T2. When using hospitalisation as the outcome, users scoring one-point higher on Factor 2 (*Regularity*) were 21.0% more likely to have been hospitalised in the previous year (OR:1.21, 95%CI: 0.984, 1.488). This suggests that those experiencing more regular contacts were more likely to be hospitalised. Users scoring one-point higher on Factor 3 (*Meeting Needs*) were 28.0% more likely to have been hospitalised in the previous year (OR:1.281, 95%CI: 1.028, 1.596). This suggests that those with more met needs and a higher level of need were more likely to be hospitalised. When both factors were entered into the model together, *Regularity* ceased to be significant at the 10% level.

Phase 3: Impact of continuity on health and social outcomes

No significant associations between change in social and clinical outcomes and factor levels were found in Sample 2. Nor were there any significant associations between levels of the continuity factors and hospitalisation in the subsequent year.

Comparison of users with non-psychotic disorders scoring in the upper and lower quartiles on each factor

The comparison of users scoring in the upper quartile on each factor to those scoring in the lower quartile is presented in Appendix 9.

Other analyses

Comparisons between those dropping out of the study and those remaining, and between those discharged from secondary care and those remaining, are presented in Appendix 11. There were few differences.

4.3.4. *Analysis: Carers of people with psychotic disorders*

Phase 1

Carers' continuity was operationalised using CONTINUES. Table M58 shows the overall mean of responses on the CONTINUES to be 2.9 at T1, a moderate level, rising to 3.2 at T2 and 3.4 at T3. The overall mean score on the ECI 'positive experiences' sub-scale was 26.8 at T1, 23.8 at T2 and 26.0 at T3 (moderate scores). The overall mean on the ECI 'negative experiences' sub-scale was 66.5 at T1, 59.7 at T2 and 64.3 at T3 (relatively low scores). The GHQ mean was 26.1 at T1, 25.7 at T2 and 25.1 at T3 (moderate scores).

Table M58: Sample 1 Carers' overall scale scores

		T1		**T2**		**T3**
	n	**Mean (sd)** **Min, Max**	**n**	**Mean (sd)** **Min, Max**	**n**	**Mean (sd)** **Min, Max**
CONTINUES (1-5)	33	2.9 (.840) (1.8-5.0)	51	3.2 (1.00) (1.0-5.0)	35	3.4 (.890) (1.3-5.0)
ECI-Positive Total Score (0-56)	36	26.8 (13.15) (0-53)	54	23.8 (11.37) (1-48)	38	26.0 (13.31) (0-56)
ECI-Negative Total Score (0-208)	36	66.5 (36.52) (0-154)	54	59.7 (40.30)- (5-161)	38	64.3 (42.36) (0-166)
GHQ Total score (12-48)	28	26.1 (6.45) (17-42)	53	25.7 (6.60) (15-47)	34	25.1 (7.20) (12-46)

Phase 2a

Possible associations between carers' experienced continuity (CONTINUES) and psychological wellbeing (GHQ-12) and positive and negative appraisal of care-giving (ECI) were assessed using a multi-level model. Further potential explanatory factors included the carers' age, gender, ethnicity, marital status, employment status, type and number of cohabitants, the relationship to the user, the frequency of carer-user contact in the past month, whether the carer lived with the user, whether the carer regarded him- or herself as a carer, whether the carer had attended a carer support group, whether the carer had had a carer's assessment, the user's experience of continuity (CONTINU-UM), the user's functioning (GAF) and user's symptomatology (BPRS for the Sample 1 data-set and HADS-A and HADS-D for the Sample 2 data-set). Variables that were significant at the 0.1 significance level were then entered into an adjusted model.

The carers' experienced continuity (CONTINUES) scores were higher among male carers and carers who were employed. It was also higher for carers who lived with the users, for carers who regarded themselves as carers and those who had had a carer's assessment. A ten-point lower GHQ (lower psychological wellbeing) score was associated with a 0.3 point higher CONTINUES score while a ten-point increase in the user's mean CONTINUUM score was associated with a 3.2 point higher CONTINUES mean score.

Carers had a higher CONTINUES mean score if they were male, employed and regarded themselves as carers and these were significant at the 5% level when entered into the adjusted analysis. (Table M59).

Table M59: Sample 1 CONTINUES					
		Univariate model		**Adjusted model**	
Variable	**Label**	**Mean (se)**	**95% CI**	**Mean (se)**	**95% CI**
Gender	Male	3.1 (.155)	(2.8, 3.4)	**3.1 (.159)**	**(2.8, 3.4)**
	Female	2.6 (.129)	(2.4, 2.9)	**2.5 (.139)**	**(2.2, 2.8)**
Employment Status	Paid employment	3.0 (.127)	(2.8, 3.3)	**3.0 (.135)**	**(2.7, 3.3)**
	Unemployed or unpaid work	2.5 (.144)	(2.2, 2.8)	**2.6 (.153)**	**(2.3, 2.9)**
Carer living with User?	Yes	3.0 (.151)	(2.7, 3.3)	2.8 (.175)	(2.5, 3.2)
	No	2.6 (.135)	(2.3, 2.9)	2.8 (.140)	(2.5, 3.1)
Regards self as a carer for User?	Yes	3.0 (.122)	(2.8, 3.3)	**3.1 (.125)**	**(2.8, 3.3)**
	No	2.4 (.160)	(2.1, 2.7)	**2.5 (.186)**	**(2.1, 2.9)**
Had a carer's assessment?	Yes	3.1 (.185)	(2.7, 3.4)	2.8 (.174)	(2.5, 3.2)
	No	2.7 (.111)	(2.5, 2.9)	2.8 (.106)	(2.5, 3.0)
General Health Questionnaire		-.03 (.013)	(-.05, -.00[1])	-.02 (.013)	(-.05, .01)
CONTINU-UM		.32 (.112)	(.10, .55)	.22 (.115)	(-.02, .45)

1. Upper 95%CI: -0.00031

Phase 2b

The aim of the Phase 2b analysis was to investigate the association between one-year changes in carers' outcomes with their experience of continuity as measured by CONTINUES at the end of that year. Hence, for Sample 1'carers the change between T1 and T2 was tested against the continuity level at T2 and the change between T2 and T3 against the continuity level at T3. The magnitude of these changes was small.

Table M60: Carers Summary statistics of change in outcome measures

	Sample 1 T2 – T1		Sample 1 T3 – T2		Sample 2 T2–T1	
	n	Mean (sd) Min, Max	n	Mean (sd) Min, Max	n	Mean (sd) Min, Max
ECI-Positive Total Score	26	-.96 (9.15) -16 to 22	32	2.5 (12.66) -30 to 45	17	-.06 (8.42) -17 to 20
ECI-Negative Total Score	26	.04 (21.24) -58 to 37	32	1.0 (31.40) -94 to 71	17	2.5 (21.80) -35 to 34
GHQ Total score	22	.27 (6.49) -14 to 12	28	.50 (5.22) -9 to 15	14	-2.6 (6.74) -15 to 12

No significant associations were found between continuity levels and change in experience of care giving (measured by the ECI sub-scales) and general health (measured by GHQ) in a year up to that point.

Phase 3

Phase 3 analyses were conducted to investigate whether one-year changes in carers' outcomes (ECI and GHQ scores) were associated with level of experienced continuity at the beginning of the one-year period for Sample 1. No significant associations were found.

4.3.5. Analysis: Carers of people with non-psychotic disorders

Phase 1

Table M61 shows the overall mean responses on CONTINUES to be 2.67 at T1, rising to 3.35 at T2, a moderate level. The overall mean score on the ECI 'positive experiences' sub-scale was 28.1 at T1 and 27.6 at T2 (moderate scores). The overall mean score on the ECI 'negative experiences' sub-scale was 77.7 at T1 and 84.1 at T2 (relatively low scores, but higher than those observed amongst Sample 1 carers). The GHQ mean was 25.4 at T1 and 26.6 at T2 (moderate scores).

Table M61: Sample 2 Carers' overall scale scores

		T1		**T2**
	n	**Mean (sd)** **Min, Max**	**n**	**Mean (sd)** **Min, Max**
CONTINUES (range 1-5)	31	2.7 (1.05) 1.0-4.4	22	3.4 (1.00) 1.9-5.0
ECI-Positive Total Score (range 0-56)	33	28.1 (9.45) 8-45	23	27.6 (8.87) 7-45
ECI-Negative Total Score (range 0-208)	33	77.7 (45.98) 8-161	23	84.1 (39.33) 14-167
GHQ Total score (range 12-48)	31	25.4 (7.00) 15-43	20	26.6 (7.44) 17-46

Phase 2a

For carers of people with non-psychotic disorders, the CONTINUES mean score was higher if the carer was from the user's immediate family (mother, father, child or sibling), if the carer lived with the user and if they had had a carer's assessment. When these variables were entered into the adjusted analysis, whether the carer lived with the user was the only variable remaining in the model. Thus carers had a higher CONTINUES mean score if they lived with the user. (Table M62).

Table M62: Sample 2 CONTINUES					
		Univariate model		**Adjusted model**	
Variable	**Label**	**Mean (se)**	**95% CI**	**Mean (se)**	**95% CI**
Relationship to User	Spouse or partner	2.6 (.182)	(2.2, 3.0)	2.8 (.170)	(2.5, 3.2)
	Immediate Family	3.2 (.305)	(2.5, 3.8)	3.2 (.301)	(2.5, 3.8)
	Friends or other	1.8 (.404)	(.91, 2.6)	2.0 (.371)	(1.2, 2.8)
Carer living with User?	Yes	3.1 (.220)	(2.6, 3.5)	**3.0 (.226)**	**(2.5, 3.5)**
	No	2.3 (.196)	(1.9, 2.7)	**2.4 (.215)**	**(1.9, 2.8)**
Had a carer's assessment?	Yes	3.0 (.258)	(2.5, 3)	2.9 (.254)	(2.4, 3.5)
	No	2.5 (.173)	(2.1, 2.9)	2.4 (.185)	(2.0, 2.8)

Phase 2b

For Sample 2, the number of valid data-points was too small to proceed with the analyses, as pairs of data-points were required for this analysis and there were too few paired data-points (where questionnaires had been returned by the same carer at both T1 and T2).

Phase 3

Again, there was not enough power in this sample to proceed with the analyses.

4.3.6. Service user and professional concordance

The concordance between service user and professional views as measured by the CAN and the STAR is presented in Appendix 12.

4.3.7. Comparison of Samples 1 and 2

The comparison of service users and their carers in the two samples is presented in Appendix 13.

4.4. Discussion

4.4.1. Overview

The Main Phase of the study recruited 180 service users with psychotic disorders and 98 with non-psychotic disorders, along with their carers, and followed them over three-year and two-year periods respectively. There were clear differences between these groups. Despite meeting the same inclusion criteria for minimum duration of illness and service contact, the service users with non-psychotic disorders were more likely to be female, White, living alone and independently of services, to have been ill for less time, to have left school by 16 and to have an identified carer. They reported slightly lower quality of life but felt less coerced by services. They also had different levels of several of the continuity factors. In particular, they had experienced far more transitions – such as hospital admission and discharge, referral to another service or discharge to GP - than the users with psychotic disorders (41.0% had had no transition compared to 69.0% of those with psychotic disorders). These considerable differences, particularly in transitions in care and continuity factor levels, necessitated the separate analysis of each cohort. Findings relating to each group – as well as the disparate findings of the different analyses - are therefore drawn together in the discussion below.

Our analysis confirms Freeman and colleagues' (2000) argument that continuity of care conceptually constitutes more than one single entity. The overarching concept of continuity of care can be broken down into a number of independent concepts. The factors that emerged from our factor analysis are intuitively meaningful. They had different relationships with a range of clinical and social functioning variables, which suggests that deconstructing continuity of care is a worthwhile exercise.

Evidence of causal relationships is scant here and less meaningful than the network of associations that emerged from the data. This may be largely due to study design. This was an exploratory study and hence provides more evidence of associations than of causality. This exploratory approach was necessitated by the paucity of knowledge regarding the conceptualisation of continuity of care. Moreover, Freeman and colleagues' (2000) review found that the relationship between different kinds of continuity and different user characteristics or outcomes had rarely been explored: studies either measured outcomes assumed to have implications for continuity (such as loss of contact with services) or tested interventions assumed to promote continuity by measuring clinical outcomes; either way, the relationship between continuity and the other variables was usually assumed. By contrast, our study was deliberately designed to explore both the possible impacts of a range of variables on continuity factors and the impact of the continuity factors on clinical and social functioning variables. This will provide the essential foundation for future research with research designs better able to assess causality.

Our analyses also suggest, however, that relationships between continuity of care factors and user characteristics, including clinical ones, are not uni-directional. On the contrary, our study provides evidence that key elements of continuity of care may be provided by professionals in response to specific service user needs as these change, as well as impacting on them, and that continuity of care may thus be a dynamic process. Conversely, in-depth interviews showed the interplay between continuity of care, user characteristics, different care events and social context to be complex, with continuity of care being impacted on by care events or contextual factors that were either adverse or inadequately taken into consideration.

Mood may have been a predictor of users' own ratings of continuity of care, as those scoring highly on *Experience & Relationship* were those who were better functioning, less symptomatic (whether with psychotic or non-psychotic symptoms) and who also reported better quality of life and feeling less coerced. This factor, which explained the greatest proportion of the variance, was largely made up of user-rated measures

(CONTINU-UM, STAR and CAN), upon which the user's overall mood or general impression of their experiences might be expected to have an impact.

4.4.2. Methodological issues and limitations

This was an exploratory study, in view of the lack of clarity in the literature about what continuity of care means and how it works in practice. We therefore took an inclusive approach to operationalising and measuring the concepts provided by Freeman and colleagues. Consistently with this, we did not remove items from the Exploratory Factor Analysis which were weakly correlated with each other (<0.3 as is sometimes advised), as it was quite possible that different components of continuity would be unrelated to each other.

Many eligible service users refused to take part in the study and it was not possible to assess possible differences between these refusers and those who took part. It is possible that the refusers represented people with less continuous contact with the team, but this could not be systematically assessed.

All service users were recruited on the basis of the CMHTs' clinical diagnoses. For those with psychotic disorders, diagnosis was subsequently confirmed through the use of OPCRIT. This instrument is known to identify psychosis accurately but to be less reliable at distinguishing the different psychotic diagnoses, so its identification of some users as having 'depression with psychotic features' was not of undue concern. It is known to be of less utility for non-psychotic disorders and was therefore not used for Sample 2. We did not include diagnosis in our analyses, as the psychotic and non-psychotic groups needed to be analysed separately; differences between the two groups are thus made clear when the analyses are compared. We did not analyse sub-groups of diagnoses due to the known imprecision of OPCRIT-generated categories, the relatively small proportion of service users with psychotic disorders identified as having bipolar disorder and, for the group with non-psychotic disorders, the high degree of overlap between categories owing to this group receiving multiple co-occurring diagnoses.

We had not expected many of the Main Phase users, particularly those in Sample 1, to be discharged during the course of the follow-up period; the number discharged

(23.0% of Sample 1 over two years and 25.0% of Sample 2 over one year) is a striking finding of the study. It was clearly important to test for differences between those who were discharged and those who were not in terms of baseline (T1) characteristics and levels of the continuity factors. This analysis demonstrated that there were few differences between the two groups, other than those discharged having had better functioning and fewer symptoms at Time 1. There were no differences in factor levels.

The majority of those who were discharged (76.0% of those discharged in each cohort) remained in the study. The analysis comparing those who dropped out of the study (did not complete the interviews) to those who remained was a means of testing for response bias, and it suggested that users with psychotic disorders who dropped out were likely to be younger, to have more symptoms and to report lower quality of life and less likely to be living in supported accommodation, whereas those with non-psychotic disorders were more likely to report better quality of life and scored more highly on *Care Coordination* at T1. No other factor scores differed between completers and non-completers for either cohort at T1. It is difficult to assess the likelihood of response bias, but having more symptoms and lower quality of life were associated with having lower *Experience & Relationship* scores, which suggests that the overall *Experience & Relationship* scores, while not very high, may have been slightly inflated by the absence from analysis of those who had dropped out.

The study was designed around the cohort with psychotic disorders and subsequently extended to the cohort with non-psychotic disorders. Study design and the selection of measures were, however, based on the service users being people with chronic disorders served by CMHTs, rather than being designed for people with psychotic disorders specifically. The extension of the methodology to the new cohort was therefore assumed to be appropriate (with the substitution of one specific measure), but the applicability of the continuity factor structure to the non-psychotic cohort was separately assessed.

The aim of this phase of the study was not to develop a single measure of continuity of care, but rather to develop a means of collecting appropriate data and making sense of it. Given the nature of some of the components included, it was likely that some of them would not be related to each other, affecting the KMO-statistic (measuring sampling adequacy). Overall measures of good fit may therefore not be applicable to our aims. Although the seven-factor continuity model was not confirmed by the Confirmatory Factor Analyses (see below), this does not make it invalid conceptually. Sample size limitations constrained the ability of this study both to provide a robust model and to test its robustness at later time-points and for the second cohort of service users, each of which had smaller sample sizes. The sample size for users with psychotic disorders (180), though just 'fair' according to established guidelines (Pett *et al*, 2003, p. 48), was not ideal for developing the model initially, while the sizes of the data-sets at follow-up and the size of the sample of users with non-psychotic disorders (98) were not sufficient either to develop separate exploratory models or robustly to test the fit of the Sample 1 Time 1 model. In view of the limitations constraining the CFAs, we did not discard the seven-factor continuity model on the basis of their results, but used it to analyse data from the subsequent time-points and for Sample 2. (The CFAs are discussed in more detail below.)

While the factors are intuitively meaningful, their scoring is not and this complicates interpretation, which needs to be based on the components loading onto each factor. Care is also needed in interpreting the factors and their associations with clinical and social functioning variables in the years prior to and following their measurement. Continuity components taken from interviews give a picture of the service user at each time-point, which in all cases apart from CONTINU-UM (which covers the previous year) measures the user's position at that point (STAR) or over the previous week (BPRS) or month (CAN). Data from the records covers the year prior to interview. The levels of factors comprising STAR or aspects of CAN (*Experience & Relationship* and *Meeting Needs*) thus largely reflect the user's position at the time of the interview, while the other factors, comprising components from the activity data, largely reflect their experiences over the previous year. (The loading of CONTINU-UM, which rates the previous year, onto *Experience & Relationship* complicates this dichotomy, however.) Any associations between change in clinical or social variables and *Experience & Relationship* or *Meeting Needs* thus provide at least some evidence of cause and effect, while associations between change in these variables and the other factors are contemporaneous, with implications for causal direction much less clear.

Changes in clinical and social functioning variables over time were not of great magnitude for either cohort. This may have limited the ability of the study to detect causal links between continuity factors and outcomes.

‘Activity’ data, collected from the users’ records rather than through interview, were limited by the availability of the information on file. In assessing *information continuity* and its related components, whether the requisite information was on file was of the greatest relevance. We therefore worked on the assumption that information not on file (such as a letter to accompany admission to hospital) had not been sent, a conservative estimation of information flow. It is possible, however, that the accuracy of service contact or transitions data may have been compromised by the quality of case-notes in a way that could not be so easily quantified.

The battery of instruments used here, including the schedule used to collect data from users’ records, does not constitute a continuity measure, and therefore attempting to test a range of psychometric properties would be inappropriate. We did, however, test its feasibility by virtue of using it successfully with 278 service users, while the factor analysis provides some evidence of the nature of the constructs measured. Given the limited ability of the CFAs to test the fit of the continuity model, it is also useful to consider the evidence provided by our further analyses of how the factors operated in the two different samples. In four cases (*Experience & Relationship*, *Meeting Needs*, *Consolidation* and *Care Coordination*), the factors behaved very similarly in each cohort despite different levels of mean scores, while in the other three they were reasonably similar. These are discussed further below and thus provide some evidence of construct validity.

4.4.3. The factors

The seven factors emerging from this analysis between them accounted for 62.5% of the variation in all the data concerning continuity of care (the 20 variables we had identified) in Sample 1. Only two factors accounted for more than 10% of the variance each and they were close in weight. The seven factors are discussed here in order of relative weight. There were few correlations between them and these were of small magnitude, suggesting that the seven factors are largely distinct. This is not unexpected given the orthogonal rotation used to produce interpretable factors.

Experience & Relationship

This factor accounted for 12.5% of the variance. It is complex to interpret, because *experienced continuity* was defined as an over-arching concept as well as emphasising the service user's perspective. Our proxy for this concept, the user-generated measure CONTINU-UM, therefore covers a range of different aspects of care, although the factor analysis conducted of this measure in the Developmental Phase suggests the validity of the use of its aggregate score. The CONTINU-UM overall mean score loaded onto this factor along with the user-rated therapeutic relationship, having proportionately more needs met by services and having no breaks in care. This may suggest that if users perceive their care to be relatively seamless, with no breaks and most of their needs being met, they will regard their relationship with their care coordinator or psychiatrist positively. An alternative interpretation, however, that positive therapeutic relationships are effective mechanisms for better delivery of interventions as well as therapeutic change, would be well supported by the literature (Catty, 2004). Both groups of users reported low levels of *experienced continuity* (CONTINU-UM) and only moderate levels of therapeutic relationships (STAR).

Having a higher *Experience & Relationship* score for users with psychotic disorders was associated with being in Trust 1, living with others and having a carer, better functioning, fewer symptoms, higher reported empowerment, better quality of life as measured by both MANSA and SEIQoL and lower reported coercion. These findings were confirmed by the fact that users scoring in the upper quartile for this factor had fewer symptoms and better quality of life (MANSA). They experienced a slight worsening of symptoms over time, whereas those in the lower quartile experienced a striking improvement in symptoms. This factor was also associated with quality of life (SEIQoL only) having improved over the previous year and with an *increase* in symptoms over the subsequent year, although only of small magnitude (1.5 or 1.9 points from T1 to T2 and T2 to T3 respectively). It was not associated with hospitalisation.

Service users with non-psychotic disorders had lower mean *Experience & Relationship* scores than those with psychotic disorders. Those with higher scores were likely to be in Trust 2, be older, be less anxious and depressed and have better quality of life (MANSA). This was confirmed by the fact that those scoring in the upper quartile had better quality of life. Those with higher scores were more likely to have become less depressed in the previous year and to have increased their sense of empowerment. There was no evidence of a relationship between this factor and subsequent clinical and social functioning.

For both groups, this factor clearly relates to the user’s experience of their illness, whether psychotic symptoms or anxiety and depression, and to ratings of quality of life. The cohort with non-psychotic disorders were more likely to be depressed than the cohort with psychotic disorders (although this was not tested systematically) and they also reported slightly lower quality of life than the cohort with psychotic disorders. It may be that lower perceived quality of life and greater depression – perhaps proxies for mood - may thus at least partially account for the lower overall *Experience & Relationship* score of the non-psychotic sample. Evidence of the impact of this factor on clinical and social variables is unclear, as better *experienced continuity* and therapeutic relationship might be either a product of or give rise to better quality of life or fewer symptoms. Service users with psychotic disorders who scored high on this factor actually reported a slight worsening of symptoms over time, while those with non-psychotic disorders had reported an improvement in their depression over the year prior to the measurement of this factor. The fact that overall levels of this factor were low for both cohorts may have limited the ability of the analysis to explore causal relationships here. (Box M1.)

Box M1: High Factor 1, Experience & Relationship[1]

Sample 1	Sample 2
Trust 1	Trust 2
Living with others	Older
Have a carer	**Fewer symptoms**
Better Functioning	**Better QoL (MANSA)**
Fewer Symptoms	
Higher Empowerment	
Better QoL (SEIQoL & MANSA)	
Increase in symptoms over the subsequent year	

1. Items in bold apply to both samples.

Regularity

This factor accounted for 12.2% of the variance. Users scoring highly on this factor were being seen more often by the CMHT, had not experienced a gap of two months or more and more of their contacts with non-medical team members were with people from the same discipline. This is consistent with the original concept of *longitudinal continuity* as 'ensur[ing] that care is provided by as few professionals as possible, consistent with need'. *Regularity* was negatively associated with *Consolidation*, suggesting that service users being seen more regularly by fewer different CMHT staff were also seeing more different agencies and using primary care, although the correlation was of small magnitude.

Having a higher *Regularity* score for users with psychotic disorders was associated with being in Trust 1, having an informal carer, having depot injections and feeling more coerced. Not surprisingly, service users having depot injections were being seen more regularly, but also by fewer different non-medical staff. Those scoring in the upper quartile felt more coerced, suggesting a possible disbenefit of this type of continuity, while all of those in the lower quartile were in the care of Trust 2. *Regularity* was not associated with any change in clinical or social functioning variables during the preceding or subsequent years, except that those with higher scores were more likely to be hospitalised in the subsequent year, perhaps an indicator of *flexible continuity*, indicating services picking up on the needs of those whose mental health was deteriorating.

There was no statistically significant difference between the mean *Regularity* scores of service users in the two samples. Users with non-psychotic disorders scored higher on *Regularity* if they had lower quality of life (MANSA and SEIQoL), lower empowerment and lower functioning and were more anxious and depressed. Users from the non-psychotic sample with higher scores had become more depressed and were more likely to have been hospitalised during the previous year. This again suggests that services were responding to users' deterioration by seeing more often those who had been severely ill. There was no evidence of a relationship between this factor and subsequent clinical and social functioning.

While for users with psychotic disorders, *Regularity* related to organisational factors, the presence of a carer and depot injections, for those with non-psychotic disorders it related to clinical factors, quality of life and empowerment. For those with psychotic disorders, however, having a depot injection may also indicate greater clinical need. That this factor was negatively correlated with *Consolidation*, albeit weakly, might seem counter-intuitive. It may be that more frequent contact between the CMHT and the service users was enabling the team to make more referrals to other relevant agencies; equally, these may have been users with more clinical needs. There was some association with hospitalisation for each group: those with psychotic disorders seem to have been more likely to be hospitalised in the subsequent year if they had higher *Regularity* scores, while those with non-psychotic disorders with higher scores were more likely to have been hospitalised in the previous year. (Box M2.)

Box M2: High Factor 2, Regularity

Sample 1	**Sample 2**
Trust 1	Low QoL (SEIQoL and MANSA)
Have a carer	Lower empowerment
Have depot injections	Poorer functioning
Feel more coerced	More symptomatic
Younger	
Hospitalised in subsequent year	

Meeting Needs

This factor accounted for 9.5% of the variance. *Flexible continuity* was originally defined as '[being] flexible and adjust[ing] to the needs of the individual over time'. We operationalised this, firstly, as the range of needs of any individual at a single time-point (giving rise to the components that loaded onto this factor) and, secondly, as the team's response to clinical deterioration, expressed by increased contact frequency. There was clearly a strong association between the level of need and the number of needs being met by services. The loading of the variable 'CPA copied to user and GP' onto this factor suggests that staff were more likely to copy CPA documentation for users who both reported more needs and were having more of these needs met, perhaps suggesting a greater emphasis on care-planning, although this component was unstable (see below).

Meeting Needs was negatively correlated with *Care Coordination*, suggesting that having a lower level of need and fewer met needs is associated with having a designated care coordinator. The direction of this correlation might have been expected to be positive, with better *Met Needs* scores for those with care coordinators. It may be that the inclusion of the overall level of need in the *Meeting Needs* factor (indicating that a service user needed to have a high level of need in order to have a high number of met needs) accounts for this inverse relationship, whereby those with care coordinators were reporting low levels of need. Conversely, those with more met needs may have been deemed not to need care from a care coordinator. On the other hand, a high *Care Coordination* score yields no information about frequency of contact or the quality of the relationship with the care coordinator. It may be that the absence of a positive association between these factors may indicate that the provision of a single care coordinator may be a prerequisite for, but not in itself a guarantee of, a better relationship, greater contact frequency or the better meeting of needs.

Service users with psychotic disorders had higher *Meeting Needs* scores if they lived in supported accommodation, lived with others, were White (or of ‘Other’ ethnic background, including Asian and mixed backgrounds), had left school by 16, were having depot injections, had been ill for longer, had poorer functioning and more symptoms and reported poorer quality of life (MANSA and SEIQoL) and slightly greater coercion. This was confirmed by the fact that those scoring in the upper quartile had more symptoms and reported lower quality of life. *Meeting Needs* was also associated with a deterioration in quality of life and an increase in symptomatology during the previous year, as well as a decrease in symptomatology during the subsequent year. Proportionately more of those in the upper quartile were hospitalised in the subsequent year compared to those in the lower quartile.

There was no difference in the mean levels of this factor between service users in the two groups. Users with non-psychotic disorders had higher *Meeting Needs* scores if they were in Trust 2, lived alone, had six or more admissions in their lifetime, did not use drugs, had poorer functioning and more anxiety and depression, lower empowerment and quality of life (MANSA) and had been hospitalised in the previous year. Those in the upper quartile also had poorer functioning and felt less empowered. There was no evidence of a relationship between this factor and subsequent clinical and social functioning, except that those with higher scores were more likely to be hospitalised in the subsequent year.

Box M3: High Factor 3, Meeting Needs[1]

Sample 1	**Sample 2**
Living in supported accommodation	Trust 2
Living with others	Living alone
White or Other ethnicity (not Black)	Six or more lifetime admissions
Left school by 16	Not using drugs
Have depot injections	**Poorer functioning**
Been ill for longer	**More symptomatology**
Poorer functioning	Lower empowerment
More symptomatology	**Lower QoL (MANSA)**
Lower QoL (MANSA & SEIQoL)	Hospitalised in the previous year
Decrease in QoL during previous year	
Increase in symptomatology during previous year	
Decrease in symptomatolgy during subsequent year	

1. Items in bold apply to both samples.

Given the loading of the level of need onto this factor as well as the number of met needs, it is not surprising that users in both groups had higher *Meeting Needs* scores if they had poorer functioning and more symptoms, whether psychotic or non-psychotic. The relationship with increased symptomatology in the previous year for both groups also suggests an interplay between users' needs and services' response; but whereas for users with psychotic disorders, the CMHT response seems to have been followed by a decrease in symptomatology, for those with non-psychotic disorders, it was followed by increased hospitalisation. (Box M3.)

Consolidation

This factor accounted for 8.1% of the variance. Service users scoring highly on this factor had been in contact with fewer different agencies and not seen any primary care professionals. This factor's link with *cross-boundary continuity* is a more remote one than those of the other factors to parts of the multi-axial definition, as *Consolidation* indicates having care that involves *few* professional boundaries. *Consolidation* was negatively correlated with *Regularity* (as discussed above).

Users with psychotic disorders with high *Consolidation* scores were more likely to be in Trust 2, be female, be older, have longer duration of illness, have left school at 16, be having depot injections and not have been hospitalised in the previous year, have better functioning and less symptomatology and report better quality of life. This was confirmed by the fact that those in the upper quartile had better functioning. The direction of effect here is unclear, as users might use fewer agencies because they were less ill, or be less ill because of receiving more consolidated care. Those in the upper quartile also felt less coerced, suggesting that it might be the involvement of multiple agencies that made users feel more coerced. There was no evidence of an association between *Consolidation* and any change in clinical or social functioning variables during the previous or subsequent years, but those in the upper quartile at T1 were more likely to be discharged during the course of the study. This is consistent with our finding that those who were better functioning and less symptomatic at T1 were also more likely to be discharged subsequently.

There were no differences between the mean *Consolidation* scores of the two cohorts. Those in the non-psychotic group with higher *Consolidation* scores were older, less anxious, lived in non-supported accommodation, did not use alcohol, did not have a carer and had been transferred to other teams than the original seven CMHTs. Those in the upper quartile had better functioning. There were thus some similarities in how the factor behaved between the two groups, in relation to age, functioning, symptoms and quality of life. There was no evidence of a relationship between this factor and change in clinical and social functioning in the previous or subsequent years. (Box M4.)

Box M4: High Factor 4, Consolidation[1]

Sample 1	**Sample 2**
Trust 2	**Older**
Female	Less anxious
Older	Living in unsupervised accommodation
Been ill for longer	Not using alcohol
Left school by 16	No identified carer
Having depot injections	Referred to a new CMHT
Not hospitalised in previous year	**Better functioning**
Better functioning	
Less symptomatology	
Better QoL	

1. Items in bold apply to both samples.

Managed Transitions

This factor accounted for 7.3% of the variance. It was expressed as a categorical variable, with service users grouped into those who had not experienced a transition, those who had had an undocumented and those who had had a documented transition. It was significantly associated with *Regularity*, *Meeting Needs* and *Consolidation*. Those with higher *Regularity* scores were more likely to have had a transition 'documented' in a letter to an appropriate party or to have had no transition, as were those with more needs and met needs and those using fewer agencies and not using primary care.

Service users with psychotic disorders with better functioning or greater quality of life were not as likely to have transitions as those with lower functioning or quality of life. The direction is again unclear, as transitions in care might be a result or a cause of lower functioning and quality of life. Older users and those with longer duration of illness were also less likely to have had transitions, suggesting that their care was more settled, and were more likely to have had these documented. Those with documented transitions were more likely to have been hospitalised than those with undocumented transitions. There was no evidence of any association between *Managed Transitions* and change in clinical or social functioning variables during the previous or subsequent years.

Users with non-psychotic disorders had significantly different *Managed Transitions* scores, with proportionately fewer documented transitions, more undocumented ones and more of them experiencing transitions. Having documented and undocumented transitions were both associated with lower functioning compared to having no transitions, while having undocumented transitions was also associated with greater anxiety and depression. Having documented transitions as opposed to undocumented transitions was also associated with having more lifetime admissions. Users with documented transitions were more likely to have been hospitalised than those with undocumented transitions. There was no evidence of a relationship between this factor and subsequent clinical and social functioning except that those who had had a documented transition had experienced a decrease in symptomatology over the subsequent year whereas those with an undocumented transition had experienced an increase in symptomatology.

For both cohorts, having more transitions, whether or not documented, was associated with poorer functioning. Having documented transitions rather than undocumented ones was associated with being hospitalised for both groups. Users with non-psychotic disorders had proportionately more undocumented transitions, associated (in both groups) with greater symptomatology and (for this group alone) with being more depressed and anxious, having had fewer admissions in the past and feeling less empowered. (Box M5.) The design of the analysis meant that we were unable to assess whether there was any relationship between types of transitions and the likelihood of their having been documented.

Box M5: Factor 5, Managed Transitions

Sample 1	Sample 2
Transitions (compared to none)	
Lower functioning	**Lower functioning**
Lower quality of life	More anxiety
Younger	More depression
Shorter duration of illness	Less improvement in quality of life in previous year
Documented transitions (compared to undocumented)	
Hospitalised that year	Have had an admission in lifetime

Care Coordination

This factor accounted for 6.5% of the variance. Service users scoring highly on this factor were seeing fewer care coordinators and more psychiatrists or no psychiatrists at all, while reporting fewer needs being met by informal carers. This closely reflects the definition of *longitudinal continuity* as ‘care from as few professionals as possible’ in terms of the provision of a care coordinator. Those who had seen fewer care coordinators (one or two over the year as opposed to none or more than two) were either not seen by any psychiatrist or seen by more psychiatrists, suggesting that there was deemed to be no need to focus psychiatric care on a single psychiatrist. They also had fewer needs met by informal carers. Conversely, those who had either seen no care coordinator or more than two had seen fewer psychiatrists, perhaps because psychiatrists were formally or informally taking over a care coordination role; correspondingly, their informal carers were meeting more of their needs.

Service users with psychotic disorders were more likely to have a higher *Care Coordination* score if they had no informal carer, suggesting that services may have taken into account these service users’ greater isolation, and if they were having depot injections. They were also likely to have better functioning and less symptomatology and report higher empowerment and quality of life. This was confirmed by the fact that those in the upper quartile were more likely to have no informal carer than those in the lower quartile. They were less likely to have been hospitalised in the previous year, although this was only a weak association. This factor had no other relationship with clinical or social functioning variables in the previous or subsequent years.

Service users with non-psychotic disorders had higher mean *Care Coordination* scores. They scored higher if they had better functioning, less anxiety and less depression and reported higher empowerment. Similarly, those in the upper quartile also had better functioning. There was no evidence of a relationship between this factor and change in clinical and social functioning in the previous or subsequent years.

Box M6: High Factor 6, Care Coordination[1]

Sample 1	Sample 2
No identified carer	**Better functioning**
Have depot injections	**Less symptomatology**
Better functioning	**Higher empowerment**
Less symptomatology	
Higher empowerment	
Higher QoL	

1. Items in bold apply to both samples.

For both groups, higher scores on this factor were associated with better functioning and fewer symptoms, whether psychotic symptoms or anxiety and depression, as well as with empowerment. There was no evidence of causality for either group, but it may be that care focused on a single care coordinator was having a positive impact on functioning and symptoms. (Box M6.)

Supported Living

This factor accounted for 6.4% of the variance. Users scored highly if they were living in supported accommodation and attending day centres or day hospitals. The emergence of this factor partially substantiates Freeman and colleagues’ (2002) addition of ‘contextual continuity’ to the generic multi-axial definition, defined as continuity that 'should sustain a person's preferred social and personal relationship in the community and enhance quality of life'. The *Supported Living* factor clearly relates to the service user’s personal context in the form of daily support through both accommodation and daytime activities or social contact. The fact that the proportion of CMHT letters sent or copied to the user loaded onto this factor suggests that staff were more likely to keep users informed if they lived in supported accommodation or attended day care, suggesting that they thus become part of the ‘system’, while users living independently of services or not attending day care were less likely to be receiving such letters.

Users with psychotic disorders scored highly on *Supported Living* if they were in Trust 1, had left school by 16, lived with others (which was probable if they were in supported accommodation), were older, had been ill for longer, had poorer functioning and reported lower empowerment. It is not surprising that this older and more chronically ill group needed the additional support of supported accommodation and day care. This factor was not associated with any change in clinical and social functioning variables in the previous year, but was associated with increased symptomatology in the subsequent year.

There were no differences between the mean *Supported Living* scores of the two groups. Service users with non-psychotic disorders scored higher on this factor if they were unemployed, were under the care of Team 2c and had poorer functioning. There was no evidence of a relationship between this factor and change in clinical and social functioning in the previous or subsequent years, but those in the upper quartile became more depressed over the subsequent year while those in the lower quartile became less depressed.

Box M7: High Factor 7, Supported Living[1]

Sample 1	**Sample 2**
Trust 1	Unemployed
Left school by 16	Team 2c
Living with others	**Poorer functioning**
Older	
Been ill for longer	
Poorer functioning	
Lower empowerment	

1. Items in bold apply to both samples.

For both groups, poorer functioning was associated with higher factor scores. That this group had higher scores if they were less educated while the group with non-psychotic disorders had higher scores if they were unemployed provides some evidence of the relevance of social context, beyond living situation, to this factor. Users in both groups with high *Supported Living* scores were among the less well functioning and more symptomatic, and for both groups there was a worsening of symptoms over time. This was not accompanied by any increase in hospitalisation, however, suggesting that supported accommodation and day care may have been containing the needs of these service users and obviating the need for hospitalisation that their worsening symptoms might otherwise have necessitated. (Box M7.)

4.4.4. Confirmatory factor analyses

The seven-factor model was not validated by confirmatory factor analytic procedures when applied to subsequent time-points of Sample 1 or to the two Sample 2 data-sets. Modifications to the model suggested by the analyses, however, indicated that the relationships between the components were more complex than assumed by the model, and that the lack of fit was largely caused by the presence of components linked to multiple factors, as well as by other methodological limitations discussed above. The failure of the CFA to confirm the model at subsequent time-points and for Sample 2 is thus likely to be due predominately to methodological reasons and not to any unreliability of the concepts and constructs.

Overall, then, the analyses suggested that the model tested did not appropriately fit the data for subsequent time-points or for Sample 2, and although some fit indices were in the acceptable range, these were not confirmed by others. Some problems inherent to the model, however, such as the presence of two two-component factors (Factors 4 and 5), known to be generally highly unstable, may explain these findings. Furthermore, improvement suggestions yielded by the analyses seem to indicate that the model is more complex than initially assumed, with at least three multi-dimensional manifest variables. For instance, the analyses of all four data-sets indicated that the components ‘CAN total number of needs’ and ‘CAN total level of needs’ were also manifest variables of *Experience & Relationship*, while in three out of four data-sets, the latter was also a manifest variable of *Care Coordination*.

Modification recommendations also varied between the sample with psychotic and the sample with non-psychotic disorders: dropping the components ‘user-rated break in care’ and ‘supported accommodation’ was recommended by Sample 1 analyses but not Sample 2. The variable ‘CAN total level of need met by informal carer’ seemed to be a manifest variable of both *Meeting Needs* and *Experience & Relationship* for the Sample 1 T2 and T3 data-sets, while ‘attended a day centre’ was a manifest variable of *Consolidation* for Sample 1 only.

Finally, on the basis of the CFAs it was recommended across all four data-sets that the components ‘CPA copied to user and GP’ be dropped from the model. In the Exploratory Factor Analysis, the rotated loading of this component onto Factor 3 had been slightly lower than the loadings of the other variables, although not sufficiently low to exclude it at that point. Modification findings are presented in Table M63.

Table M63: Model modification suggestions for each time-point

	Sample 1 T2	Sample 1 T3	Sample 2 T1	Sample 2 T2
Factor 1: Experience & Relationship				
CONTINUUM Mean score				
STAR Total score-Any professional				
CAN-Proportion of needs met		Add to F3		Add to F3
Any user-rated breaks in care	Drop	Drop		
Factor 2: Regularity	**No modifications suggested**			
Factor 3: Meeting Needs				
CAN- Total level of needs	Add to F1 & F6	Add to F1	Add to F1 & F6	Add to F1 & F6
CAN- Number of met needs	Add to F1 & F6	Add to F1	Add to F1	Add to F1
CPA copied to GP and user	Drop	Drop	Drop	Drop
Factor 4: Consolidation	**No modifications suggested**			
Factor 5: Managed Transitions	**No modifications suggested**			
Factor 6: Care Coordination				
Number of designated care coordinators	Add to F1 & F3	Drop		Drop
Number of designated psychiatrists	Drop			Drop
CAN- Total level of needs met by informal carers	Add to F1 & F3	Drop Add to F1 & F3		Drop
Factor 7: Supported Living				
Supported accommodation	Drop	Drop Add to F3	Add to F5 & F6	
Attended a day centre or hospital?	Drop Add to F4 & F6	Drop Add to F4	Drop	
Proportion of letters copied to user		Add to F3		Drop

4.4.5. The multi-axial definition in practice

These seven continuity factors reflect fairly closely all but one of the eight factors in Freeman and colleagues' multi-axial definition (six from Freeman *et al*, 2000, two from Freeman *et al*, 2002). The components we had used to operationalise the multi-axial definition, however, did not all load onto the factors that might have been anticipated.

Two of the components used to operationalise *longitudinal continuity* loaded onto one factor, *Care Coordination*, while another, 'non-medical input spread' loaded onto *Regularity*. 'Contact with primary care professionals', however, loaded onto *Consolidation*.

One of the variables used to operationalise *long-term continuity* loaded onto *Regularity*, while the other, about user-rated breaks in care, loaded onto *Experience & Relationship*. As discussed, this may have been to do with this variable and the two scales (CONTINU-UM and STAR) all being user-rated.

Relational continuity and *experienced continuity*, which had each been operationalised in one single variable, loaded onto a single factor, *Experience & Relationship*, along with the proportion of needs met and breaks. Our operationalisation of *experienced continuity* as CONTINU-UM did not incorporate its original definition as 'smooth', but simply reflected the user perspective.

Flexible continuity had been operationalised firstly as 'range of needs' and secondly as 'change in clinical need'. The first definition was closely reflected by the factor *Meeting Needs*. The second could not be tested as there was an insufficient spread of response in the data.

Cross-boundary continuity had been operationalised as transitions and this was closely reflected in the factor *Managed Transitions*, although a component about information flow (whether the transition was documented or not) also loaded onto this factor. The variable about different agencies used, however, loaded onto *Consolidation*, a factor which could be seen as the converse of *cross-boundary* *continuity*, reflecting a state of not having many professional boundaries involved in the user's care.

Continuity of information was the only type of continuity from the multi-axial definition not to be reflected by one of our continuity factors. The variables used to operationalise this type of continuity loaded onto three different factors, *Managed Transitions*, *Meeting Needs* and *Supported Living*. Moreover, one of these variables, 'CPA copied to user and GP', was highly unstable and recommended to be dropped from the model.

4.4.6. Congruence of user and professional views

The lack of correlation between STAR scores for service users with psychotic disorders and their professionals may be due to a number of factors. Although both the user and professional STAR questionnaires ask about their relationship, they ask different questions. Nevertheless, low levels of congruence between service users and professionals in rating the therapeutic relationship are commonly reported in the psychotherapy literature (Horvath & Symonds, 1991), and this has also been borne out by studies of the relationship in community mental health care, with a significant but low correlation being found between user and professional ratings (Bale *et al*, 2006). For users with non-psychotic disorders and their care coordinators, however, the correlation in STAR scores was higher (moderate rather than low), suggesting that professional ratings of the relationship are likely to be a better guide to user ratings for this group, although the correlation fell at the second time-point.

For the group with psychotic disorders, the numbers of service users and professionals identifying needs was similar at T1, but subsequently users were more likely to identify needs. This could suggest either over-identification by users or under-identification by professionals, although not all the domains of CAN reflect areas within the usual remit of CMHTs. Agreement on the number of need domains tended to be higher than on specific domains, but agreement on domains also increased over time. For the group with non-psychotic disorders and their care coordinators, there was a much stronger correlation for the level of need at both time-points.

When rating needs, our results were consistent with Slade and colleagues (1996, 1998; also Lasalvia *et al*, 2000), with users identifying more needs than professionals and also rating more unmet needs than professionals (Slade *et al*, 1998; Lasalvia *et al*, 2000; Hansson *et al*, 2003; Macpherson *et al*, 2003). This suggests a possible lack of communication between the two groups. The level of agreement on the presence of a need, measured by kappa scores, ranges from zero (no agreement) to 0.8 (almost perfect agreement) in the literature. Our results were similarly spread with a range of zero to one at one time-point with one of the cohorts. Our mean levels of agreement as kappa scores ranged from 0.27 to 0.43, suggesting a mild to moderate agreement, similar to those reported by Slade and colleagues (0.34, 1996; 0.44, 1998).

One of the needs domains most agreed upon was ‘accommodation’, which was one of the top three most agreed upon needs at all three time-points for the cohort with psychotic disorders. This basic need also came within the top three in most studies (Slade *et al*, 1996, 1998; Issakidis & Teeson, 1999). This was not the case for the cohort with non-psychotic disorders, perhaps because users in the non-psychotic cohort were less likely to be living in supported accommodation. Consistent with Slade and colleagues (1998) and Issakidis and Teeson (1999), ‘childcare’ was one of the three most agreed upon needs at both time-points for the non-psychotic cohort, though not for the cohort with psychotic disorders. This is likely to be due to the greater proportion of the non-psychotic cohort who were female.

A low level of agreement between staff and users regarding ‘safety to others’ was common in the literature (Slade *et al*, 1996, 1998; Issakidis & Teeson, 1999; Macpherson *et al*, 2003) and similarly had one of the three lowest levels of agreement for the cohort with psychotic disorders at T3. Perhaps not surprisingly, professionals tended to rate ‘safety to others’ as a need where users did not. Level of agreement on the need ‘information about condition and treatment’ was one of the lowest in our study, as is typical (Slade *et al*, 1996, 1998), with users consistently identifying a need in this area and professionals not. This may suggest that professionals feel they have given the required amount of information but users feeling that they still have unanswered questions. The lack of agreement over this need is of concern.

The presence of the need for help with ‘sexual expression’ had a low level of agreement at both time-points for the cohort with non-psychotic disorders and was also found to be one of the three needs with the lowest levels of agreement by Slade and colleagues (1998) and Issakidis and Teeson (1999). Users tended to be more likely to rate this domain as a need and, anecdotally, professionals often said they had not yet explored this area with the service users in their care. It is disappointing that users and professionals had a low level of agreement on such a sensitive area of need. Agreement on benefits was also particularly low for both cohorts, with users more likely to be unsure whether they were receiving all possible benefits. This may be due to the complexity of benefit laws, but needs in this domain might have been reduced with greater communication between users and professionals.

4.4.7. Ethnicity

The study design for Sample 1 was designed with stratified sampling to ensure that 25% were from minority ethnic groups, in view of the known over-representation of, in particular, people of African-Caribbean background among users of psychiatric services and in view of Freeman and colleagues' (2000) finding that the particular issues of continuity of care for people from minority ethnic groups are rarely focused on in studies of continuity. In practice, over-sampling was found not to be necessary and consequently Sample 1 included 19.4% who were Black and 13.9% who were from other groups including Asian, Chinese and mixed race. The sample with non-psychotic disorders, however, were more likely to be White, with only 5.1% who were Black and 11.2% 'Other'.

The only continuity factor that had any association with ethnic group was *Meeting Needs* which, for the group with psychotic disorders only, was lower for Black service users. This suggests that Black users with psychotic disorders were more likely to have fewer of their needs met by services, as well as fewer needs overall. There was no other evidence of relationships between the continuity factors and ethnicity. Our findings are thus largely in line with those of Bindman and colleagues (2000), who failed to detect any difference between ethnic groups.

4.4.7. Carers

Over the three time-points of the study of users with psychotic disorders, 68 carers were recruited in total (not all of them at each time-point). Over the two time-points of the study of users with non-psychotic disorders, 39 were recruited in total, just over half (54.1%) of identified carers, but fewer could be followed up. The sample size of carers may have been limited by the design of the study, whereby data were collected from them by self-complete questionnaire, as carers have subsequently been found to prefer face-to-face interview (Harvey *et al*, 2005). Vigorous attempts were made, however, to engage them in the study and follow them up, including visiting them if possible. Nevertheless, our findings in relation to carers are necessarily limited by the small sample sizes and by the fact that, while the majority of available carers participated at each time-point, this was often not a large majority.

The impact of carers on the people for whom they care

The impact of carers on the service users for whom they cared is apparent in our analyses through: how the carer-related continuity component appears in the factor structure; how the factor behaved onto which this component loaded; and how having a carer relates to the continuity factors.

The level of need met by informal carers (as self-rated by the service user using CAN) loaded onto *Care Coordination*, suggesting that people with informal carers were less likely to have seen a designated coordinator. This suggests that services may have worked harder to provide care focused on a single care coordinator for those service users with no known carer, or conversely that carers were filling a gap in professional input.

People with psychotic disorders who had a carer scored higher on *Experience & Relationship*, *Regularity*. This suggests that those with carers were reporting higher *experienced continuity*, better therapeutic relationships, proportionately more of their needs being met by services and also that they were being seen more regularly, without breaks in their care. It may be that for users with an identified carer, the carer was able to play a mediating role with services, enabling the user to access their care (such as by encouraging attendance); conversely, it may be that those users who were less well functioning were both less able to maintain a relationship with a carer (and hence more likely not to have one to identify for the purposes of this study) and correspondingly less able to engage with the services offered by professionals. For

Care Coordination, however, people with carers scored lower, again suggesting that carers may have been filling a gap in professional input.

Those with non-psychotic disorders who had a carer scored lower on *Consolidation*, suggesting that it was those without carers who were getting more consolidated care (using fewer agencies and not using primary care). This too suggests that a user having a carer may make them less of a priority for services. This is of concern, as those users with lower *Consolidation* scores were more anxious, worse functioning and more likely to have been hospitalised.

Although these findings were only significant at the 10% level, they provide tentative albeit somewhat conflicting evidence about the carer's role. Users who had carers may have been less likely to receive care focused on a single care coordinator or on the primary team, but their self-reported *experienced continuity*, therapeutic relationships and meeting of needs (by services as well as by the carers themselves or other friends or relatives) were all better, while they also seem to have been seen more regularly.

Carers' experiences

There were few differences in characteristics between the two groups of carers, although those caring for users with psychotic disorders were more likely to be working full-time. There was some evidence that those caring for users with non-psychotic disorders appraised their experiences of caregiving significantly more positively (with no difference in negative appraisal) although this was no longer statistically significant when Bonferroni's correction was applied. This would suggest that while negative appraisal was at a similar level in each group, those caring for people with non-psychotic disorders had appraised their experiences more positively than those caring for people with psychotic disorders. It was striking that two thirds or fewer of the carers in each group regarded themselves as 'carers', confirming the problematic nature of this terminology for those caring for people with mental health problems and the necessity of using other language, as we had done, in recruiting them.

Carers of people with psychotic disorders reported higher experienced continuity if they were male, employed, lived with the user, regarded themselves as carers and had had a carer's assessment. The fact that less than half the carers lived with the user (45.6%), were employed (25.0%) or had had a carer's assessment (15.4%), while only small majorities were female (60.3%) or regarded themselves as carers (59.7%) may account for the low overall level of CONTINUES in this group. Carers also reported higher experienced continuity if the user for whom they cared reported higher experienced continuity on CONTINU-UM. High CONTINUES scores were also associated with the carer's lower psychological wellbeing, although this was not supported by the multifactorial analysis.

There was no difference between overall mean CONTINUES scores between the two groups of carers. Carers of people with non-psychotic disorders reported higher experienced continuity scores if they were from the user's immediate family, if they lived with the user and if they had had a carer's assessment. Again, only a minority lived with the user (43.2%) or had had a carer's assessment (25.7%), perhaps accounting for the low level of CONTINUES, although the majority (81.1%) were from the user's immediate family.

Box M8: High CONTINUES scores[1]

Sample 1	**Sample 2**
Male	User's immediate family
Live with user	**Live with user**
Regard self as a carer	**Had a carer's assessment**
Had a carer's assessment	
Higher user CONTINU-UM	

1. Items in bold apply to both samples.

Living with the user and having had a carer's assessment were thus positively correlated with higher *experienced continuity* for both groups. There was no evidence of associations between CONTINUES and change in psychological wellbeing in either the previous or the subsequent years, although for the carers of people with non-psychotic disorders this was because there were too few data to analyse. There was no evidence of any relationship between CONTINUES and carers' experiences of caregiving or users' clinical wellbeing or functioning. (Box M8.)

4.5. Summary

- There were clear differences between the two cohorts, with service users with non-psychotic disorders experiencing more transitions in care
- The concept of continuity of care was meaningful for both cohorts and conceptually constitutes more than one single entity
- There is evidence that continuity comprises at least seven distinct factors, which may ben named *Epxerience & Relationship*, *Regularity*, *Meeting Needs*, *Consolidation*, *Managed Transitions*, *Care Coordination* and *Supported Living*
- Continuity of care appears to be a dynamic process, with services responding to user need as it fluctuates as well as impacting on user need
- Mood may have an impact on user-rated continuity of care.

5. Qualitative Strand

5.1. Aims

The aim of the qualitative strand was to capture the experiences and views of users and carers focusing on the meanings associated with particular (dis)continuities and transitional episodes. The interviews explored general experiences of relationship with services, care, continuity and transition from both the user and (where available) carer perspectives.

5.2. Methods

Qualitative interviews were conducted in the final year of the study with a sub-group of service users and their carers sampled from Sample 1 of the Main Phase cohort and a second sub-group of users and their carers from Sample 2. Users were theoretically sampled on the basis of the quantitative findings, in order to capture the experiences and views of people for whom continuity of care had been particularly complex or problematic (for instance, because of multiple referrals, or changes of personnel or needs). For each user interviewed detailed quantitative data on their experiences of care and on transitional events and phases in their care history were available. The identification of these events and phases informed the qualitative interviews. The main carer, as identified by the service user (where such a person existed), was invited to be interviewed in depth, to ascertain their experiences and views about the care received by the user. The data was analysed using MAXQDA software and the qualitative findings were used to illuminate the quantitative data collected in the Main Phase.

5.2.1. Interview schedule

A semi-structured interview schedule was developed with the aim of guiding the interview towards discussing the user's career as a service user, looking at their history of contact with mental health services. The interview was not limited to discussing contact in the previous two years. This allowed a more complete picture of the user's experience, while also relating the interview to information that had been previously collected in the Main Phase.

In order to gather information on past experiences we piloted a life grid approach (Dex, 1991). This method has been successfully used to aid recall in a number of health studies (Berney & Blane, 1997). We found that this method proved unsuccessful in piloting, however. In particular, the users found the use of the life grid confusing and the process of completing the grid impaired the flow of the interview and tended to interfere with opportunities to discuss particular transitions in depth. Users found it easier to correlate their own major life events (marriage, childbirth, moving house, etc.) with different stages of their career history as a service user in conversation than through the construction of a life-grid. Whilst they were able to report that, for example, they had had their second hospitalisation at the time of the birth of their first child, they were often unable to remember the dates, offering a range such as 'my son is about 24-28 now.' This method to some degree echoes the aims of the life grid but is not as accurate in terms of dates. Where the carer was a parent or spouse it was often possible to gain further information on dates and events. We therefore adapted the life-grid approach, allowing users to talk more freely about their experiences starting with their first encounter with mental health services and making links to particular life events and episodes as they arose.

Following the interview, a service user career chart was drawn up based on the interviewer's notes and this was appended to the interview transcript. The chart used the information the user had been able to provide in the interview. These charts therefore varied in length and detail according to how much the users were able to recall. Self-ascribed diagnosis was collected during the interview.

5.2.2. Sampling

All the users for the qualitative study were purposefully selected from the quantitative Main Phase cohorts. Lists were drawn up of users scoring highest and lowest on each of the factors generated by an early iteration of the Main Phase factor analysis. For the cohort with psychotic disorders, there were nine factors at this point and for the cohort with non-psychotic disorders, eight factors.

Not all users had carers. Where possible, users with carers were selected, but the purposive sampling method also ensured an even distribution across gender, age and

NHS Trust. For the cohort with psychotic disorders, the number of available respondents on each factor ranged from four (low Factor 3) to 21 (high Factor 3), with a potential total sample size of 169. For the cohort with non-psychotic disorders, potential respondents varied in each of the sub-factors (high and low) from three (low Factor 4 and low Factor six) to 13 (high Factor 7), with a total sample size of 96.

The aim was to sample 20 users and their carers from each cohort giving a potential maximum of 80 interviews. Recruitment to this phase of the study proved difficult, however, and a number of users declined to participate. Recruitment was more difficult in the case of the cohort with non-psychotic disorders. Recruitment of carers was hampered by some users not identifying carers and a high rate of non-participation among carers in the Main Phase. We used a number of strategies to try to maximize recruitment: repeat calls, letters, e-mail, arranging interviews at times convenience for users and paying users a small amount in compensation (£10).

For the users with psychotic disorders, 25 were approached and 20 took part. For the five who did not take part, reasons given were being too unwell and contact details having changed. For the group with non-psychotic disorders, 38 users were contacted and were called repeatedly over different days and at various times to maximise the chances of getting hold of them. Letters inviting them to take part were sent out to users who were unavailable on the phone to try to increase participation. No responses were gained from postal invitations. Reasons for not participating varied from not wanting to take part and the researcher being unable to get hold of the user despite numerous letters and phone calls. Six users agreed to be interviewed but did not attend. Overall we recruited 20 users and ten carers from the cohort with psychotic disorders and 11 users and four carers from the cohort with non-psychotic disorders. Thus in total 45 interviews were available for transcription and analysis (31 with users and 14 with carers).

5.2.3. Demographics

For the group with psychotic disorders, of the 20 users interviewed there were 11 males and nine females. All of the carers interviewed were female; six were mothers, three were wives and one was the user's CPN (whilst it had not been part of the study design to interview a professional carer this was the carer identified by the user and the interview was interesting in that it highlighted the CPN's lack of knowledge about the user). The mean age of users was 42 with a range of 27-72. For the group with non-psychotic disorders, of the 11 users interviewed nine were female and two were male. Of the four carers interviewed, one was female (the user's mother) and three were male (long-term partner, husband and friend). The mean age of users was 49 with a range of 29-59.

5.2.4. Interviews

Interviews were undertaken between October 2005 and September 2006. For the most part, users were interviewed in the same location as they had been interviewed in for the quantitative study, at a site convenient for them. For the majority (85% of cases) this was the user's own home, with the remaining 15% being undertaken in a range of locations including assisted accommodation and designated rooms at CMHT bases. When carers were interviewed, wherever possible the user was interviewed alone first. In two instances, however, the user and carer interviews were conducted jointly at the request of the user. In both instances, the user was female and their carer was their mother whom with they lived. A further three of the carers (mothers) were interviewed before the user due to availability issues of either the user or the carer; all three of these carers did not live with the user. On average, interviews with users lasted approximately one hour and carer interviews approximately 40 minutes. All interviews were recorded and independently transcribed. The transcripts were then checked against the tape by the interviewer. All of the transcripts were formatted to include a synopsis of the interview content as well as the interviewer's field notes and demographic information on each respondent.

5.2.5. Analysis

All of the interviews were independently transcribed and entered into MAXQDA, a qualitative software package designed to aid with analysis (MAXQDA, 2001). Following initial familiarisation with the data, a thematic analysis was undertaken whereby an initial coding scheme was developed and indexing undertaken through constant comparison within and between cases. Transcripts were coded by the interviewer (NA) and categories developed, refined and validated in collaboration (NA and IRJ). Users and carers are identified here by numbers, indicating whether a user (U) or a carer (C) and in the sample with psychotic disorders (A) or the sample with non-psychotic disorders (B). The term ‘key worker’ is used in this section instead of ‘care coordinator’ as used elsewhere in this report, to reflect the language used by service users and carers in the interviews.

5.3. Results

Five key themes emerged from the analysis: relational (dis)continuity; depersonalised transitions; invisibility and crisis; communicative gaps and social vulnerability. We present here findings for the users with psychotic and non-psychotic disorders separately, and discuss carer responses. One of the most important findings was the fragility of continuity and its relationship to levels of satisfaction. Supportive, long-term relationships could be quickly undermined by a range of factors and general satisfaction levels were often closely related to moments of transition where these relationships were vulnerable.

5.3.1.Service users with psychotic disorders and their carers

Relational (dis)continuity

The mean length of contact with services for this group was 17.5 years with a range of three to 44 years. At the time of interview, two users were waiting for a new key worker to be assigned to them and one did not have a key worker but lived in supported accommodation. Users mostly provided accounts that emphasised repeated changes of staff and this appeared to be a major area of discontent with services for both users and carers.

> **Interviewer: How many key workers have you had?**
> I’ve had loads. I mean I got like a nurse at the hospital, [names nurse], I’ve had her about six months. Before that I was with another guy, before that another bloke, another woman, another… it always changes, that's what I don’t like, you know.
> [UA13, male, 27 years, schizophrenia]

The changing relationship with providers sometimes left users feeling helpless and isolated. Service user UA2’s occupational therapist stopped home visits and UA2 was unable to leave her house, expressing a need for the support that was offered by her OT.

I have got an OT, I'm under an OT, but the fact is I can't go out of the house and she won't come here. I have to go out if I want to see her, you know what I mean?

> **Interviewer: They can't arrange home visits?**
>
> Well, I can't cope, […] well she did do home visits and she just says she doesn't come here on her own, so I don't see her, you know. And if I don't go out, if I have a bad day and I can't go out, even though I've got people to take me, I still can't cope, you know what I mean? Say a couple of times, I've been out with [husband], like just seeing my GP, I'm bursting out crying getting on the bus, you know what I mean? And she won't come unless I go to the drop-in, you know, so I don't have no-one to talk to now. I just keep it by myself and I think that's what's happening, I'm bottling it all up and I could burst out crying, you know what I mean?
>
> [UA2, female, 59 years, schizophrenia]

Even when users were informed about staff changes and there was no wait for a new key worker, it still took time to build up a relationship. Carers also voiced their frustration at the emotional demands this put upon users.

> **Interviewer: Is there a member of staff that you have a relationship with, his key worker perhaps?**

No, because they've, er … they change all the time, every few months they seem to change. So as soon as I get to know one, then they've gone, so I don't know his current key worker […] the turn around of staff is a big problem I think.

> **How does [he] cope with that?**
>
> I think he's getting better now. It used to be very upsetting, very disruptive, because every time there was a new doctor or a new key worker or a new social worker, or whoever, you've got to start right from scratch; even though they've got a file which is kind of this thick, you know? They will still sit and ask him questions and he feels he's just got to repeat his whole lifestyle all over again, you know, every few months to whoever is new! So, that can be very frustrating.

> [CA13, carer of son with schizophrenia]

The frustration with having to re-tell the story was a common feature of relational discontinuity. This re-telling was sometimes referred to as becoming 'automatic' and the re-telling process could lead to a sense of de-valuing the user's experiences.

Depersonalised transitions

The transition between providers particularly for those changing teams was often a confusing time. Different types of transitional experience were identified: transition between teams as the teams underwent restructuring; transition between teams following the user’s change of residence and transition at discharge.

Four of the users were no longer under the care of a mental health team. Their experiences of discharge varied: UA1 had felt well enough for discharge ten years before she left services; UA2 felt his discharge to be appropriate in that services could not offer the talking therapies that he felt would benefit him and had resorted to private therapy. He continued to get his medication from his GP. UA4 felt that he needed some ongoing support; he was very isolated and displayed positive symptoms of schizophrenia. UA8 reported being discharged from services without being informed, only discovering this when he attempted to make an appointment with the psychiatrist. He was still attending the team base to get his regular medication but his key worker had left and not been replaced. He did not take this to be a sign that he had been discharged.

At the moment, I just recently found out that I was sort of discharged from the hospital, because I hadn’t seen the psychiatrist or anything for about two or three years, and I wanted to see one, because I was a bit worried, because recently I’ve been having these dreams whereby I sort of acted out my dreams. Erm. You know, and it’s been … I’ve been sort of doing things with [my wife], like swinging punches in her face and kicking her and things like that. I have sort of jumped out of bed as well, and sort of fell … you know, woke up on the floor.

> **Interviewer: Did you speak to your key worker?**
>
> No. That’s what I mean, I haven’t got one at the … well, I don’t know who my key worker is at the moment.

> **Interviewer: When was the last time you had one?**
>
> Erm. I think the last time I had one was [names key worker], which was about four years ago now, three or four years ago and she left, erm, and I haven't … I mean the only contact I have is with the nurses that do my injection. And like I say, I went to see the doctor, I thought I could just book an appointment, but they said I had to go through my GP, which I found a bit sort of … not upsetting, but, you know, I felt as though if I need to see a doctor, I should be able to see one, you know, fairly quickly.
>
> **Interviewer: The last key worker you had, when she stopped coming to see you, did you know that the relationship was finishing and that you were being discharged from services?**
>
> No. No, I didn't. I just sort of didn't see her for a while and then I asked, and they just said that she was … erm, she'd left. So … it was all of a sudden really.
>
> [UA8, male, 52 years, bipolar and schizophrenia]

Both UA11 and his carer had an excellent relationship with UA11's CPN. Following a house move, UA11 came under the care of a different team. All efforts were made to ensure the handover was a smooth as possible. Their previous CPN remained with UA11 for as long as he possibly could. The transition to the new team was, however, very difficult, with initial meetings not going well. Inevitably, comparisons were made with the previous team.

We were looked after by the X team and they were brilliant. And we had a very good CPN, you know, and we could always approach him, and he would come and visit. You always knew there was somebody at the end of the phone if you needed them. We are not quite finding the same level of care with the Y team, although they are trying to establish somebody now that we can contact. But it's extremely important to have a personal relationship with a CPN, absolutely vital. It's my number one priority. Although we're not going to get that, we're going to have a social worker from the Y team, but hopefully that will work out and to have some continuity of that, not to have somebody chopping and changing.

> **Interviewer: Has there been a lot of that?**
>
> Erm, not hugely, no, but we're *on unknown territory* with the Y team, we don't feel quite as well cared for, and really we haven't established any proper personal contact yet, you know. So I feel that really we're left dangling. It's an absolutely vital lifeline to have somebody that knows you, that listens to you, that responds to you, at the other end of the phone. It's absolutely vital.
>
> [CA11, carer of husband with schizophrenia]

Transitions were highlighted by carers as particularly stressful and problematic. There were, however, examples of transitions that were supportive and appeared to ensure good continuity. In these cases, there appeared to be a stronger emphasis on personalising the transition and situating it in the daily life of the user. For example UA9 discussed a successful transition between providers.

> **Interviewer: Have you always been with the same team, since you're in London?**
>
> No, er, because the teams changed; I think there was a sort of restructure at one point because I was with, er, X at one point. I'm now with, er, X Borough, so … Z I think that is.
>
> **Interviewer: So, how was that transition for you?**
>
> It was good, because they sort of dovetailed it really well, my old OT and my new OT dovetailed it; they met, they corresponded, er, before they met so they knew who I was and what my diagnosis was, and what I was like, what my life was like. So, er … and when asked if I would need a consultant on my new team, my old OT and new OT said, no, just an OT would be fine, so it worked really well. We had a meeting here that day, because I only moved in here a year and half ago. The day the carpets was laid was the day that the old OT and new OT and myself were meeting for the first time, so they were all thankfully laid and we then met in the kitchen! *(laughs)* So it worked out really well.
>
> [UA9, female, 42 years, bipolar disorder]

On the whole, however, most users who had undergone team change found the event stressful and long-winded, with communication from their present team not being appropriately followed up.

The number of hospital admissions over the course of each user's life varied from one admission to 11, as well as one user reporting having had too many to remember. For some the hospital offered a place of calm and respite during their most difficult times but the transition at discharge was a key point of vulnerability where, having kept to a strict routine during their period of stay, after discharge they were left to cope on their own and fill that time independently

> **Interviewer: What about your experiences in hospital?**
> Mm, like I say, I've been in there twice. Erm, it's just a haze to me, really. I don't think there's enough, sort of, like I said, I don't think there's enough explanation. I think they could really help more by explaining to people, things like that. Or discussing coping strategies with you, which I've not ever had either. Because you feel like, you go in there and you're very ill and all that, and you have your, your daily routine, which is really strict; and you sort of keep to that. And the time just goes, and they give you your medication, erm, and then they discharge you.
> [UA6, female, 35 years, schizophrenia]

For carers too, more advice and information was needed on the discharge process as often families were not kept informed, only to discover that the user had been discharged hours previously.

Invisibility and crisis

There was a sense from users, but more so from carers, that services were very much centred around responding to crises rather than preventative support. There was a strong feeling that being perceived as 'well' or 'functioning' resulted in an invisible status. UA11 recounted how he had been waiting for a new key worker for months after changing teams, despite his previous key worker highlighting his needs as urgent; it was only after a suicide attempt that services started to respond.

> **Interviewer: Did you have any support at all?**
> None whatsoever. We were lost. Literally lost. And then the overdose came along and all of a sudden I had the, they took notice. It was, after the overdose I was admitted at A [psychiatric hospital], erm, that day, I was discharged and they said I had to come back on the Monday. And when I went back on the Monday there was this, this guy [names person] which was the guy that had the letter sent to, along with the psychiatrist who'd had the letter sent to by [previous CPN] explaining everything, which was a real cry for help really. Saying you know, you got to get on with it and get something done. So they had all this and they'd not picked up on it. Not phoning, nothing.
> **Interviewer: Did they offer an explanation for it?**
> Nothing. I never got anything you know. And I'd gone in, I had to report back to A on the Monday because I was supposed to stay in over the weekend at least. And when I got there I was sat outside waiting to see this psychiatrist, Dr __ and the X team to be properly discharged and that. And when I went in there, erm, I'd had a letter from this __ and it more or less was fobbing me off, it was a waste of time, you know. He'd even written an appointment to see me, and when he never turned up and I phoned up to see where he was, he was on holiday! He'd gone on holiday! You know, the whole X team was a total waste of space!
> [UA11, male, 56 years, bipolar disorder]

UA6 also felt that her relative stability had meant that services were less geared to offering support. She emphasised that although she might not act out a suicide attempt she still required support.

> I don't have a drink problem or a drug problem, or I don't harm myself, and I wouldn't do any of those things. So as far as they're concerned, what's the problem? I'm not going to hurt myself or anybody else, so there's no urgency as far they're concerned. Whereas, I have said to them before, 'do you think I don't feel suicidal sometimes?' because I really do. But I know that I'd not do it, and so

> do they. So as far they're concerned, I'm coping with it.
>
> **Interviewer: And so do you feel that services are too crisis-oriented then?**
>
> Yeah. God, yeah. That's what I find quite, sometimes I find it quite frightening. If I'm having a bad day, I think, what if I keep going down as I have done before - it might happen again. And how far down do I have to go before they'd actually help. And that does bother me sometimes when I think about services.
>
> [UA6, female, 35 years, schizophrenia]

UA6's mother concurred, and further believed that because she was known to be caring for her daughter, services were given an extra motive for reducing support to UA6.

> But, we know what happens - until someone's in absolute crisis, it, you know, they don't get to the top of the list, because the resources aren't there. And she didn't always seem to be maybe as seriously ill as perhaps someone else just down the road. And quite honestly I have sometimes felt that because it was known that there was somebody there keeping an eye on her, she was maybe less of a priority than somebody who had nobody to keep an eye on them.
>
> [CA6, carer for daughter with schizophrenia]

Similarly, CA8 felt that her husband was viewed as less of a priority for services because he did not fit in to an expectation of a high-needs user.

> Sometimes I have felt that he's been pushed to one side - maybe because of his age, or that he's not violent enough, or that he's not nutty enough, because he has, he does have his moments! Between these four walls, he does have his moments! But I just, you know, I do what I do at work basically. You know, but erm, on the whole he's been alright and I think that that's told against him in a funny way because he's not quite normal and he's not absolutely nutty. He's like the middle-of-the-road and I don't think that's been redressed.
>
> [CA8, carer for husband with schizophrenia and bipolar]

Particularly where users presented well, carers felt that perhaps services were not providing as much support as they could. CA6 said that, whilst she was able to care for her daughter, it would be helpful for UA6 to have a continuous relationship with a key worker. Currently UA6's only contact with services was collecting her medication.

> **Interviewer: What services is she in touch with?**
> She has very little now, and whilst I can acknowledge that she is well, she still carries this erm, disease. She still has to live with it, and life isn't as easy as it is for other people without it, you know. […]I do worry a little bit that say, if I were very ill or something happened to me, I guess they would probably put a little bit more in - well I don't know - I hope so, but I don't feel that there's anybody at the moment who she can actually go and talk to on a regular basis. She's had some counselling, some cognitive therapy, and that's been very good, but what's she's lost, since coming, going in to the community, what she's lost is that erm, sort of case worker or key worker. Which again is something to do with resources and she doesn't need it that intensively, but I do sometimes think it would be quite nice, even if there was say once a month at her stage, to have somebody. They tell her she can phone up in a crisis or whatever, but because she doesn't see anybody regularly, you're not actually, it's going to have to be a pretty bad crisis. And why wait for a crisis when you can, if she knows now when things are not, she has quite a lot of anxiety, so she knows when she could perhaps do with some help, I think, she recognises the signs which she wouldn't have done before. So erm, I don't think there's actually quite enough, and I think for someone in her position, she is well, but she's had to work very hard at being well, its not easy, and I think she sometimes must feel, you know, 'this is not fair because if I didn't manage as well I'd get a bit more support' […] I think just someone constant, I mean, she no longer needs the sort of help with like managing things and doing things, she does such a lot now, she goes out a lot, she does voluntary work - she'll tell you all that. But she does, she's very active, and the place looks really nice. Erm, but it is

> more the emotional support, almost like, it's almost like she needs a befriender. Erm, she's quite intelligent and most of the other people she comes across who go even through the same experiences, I think because she did so well when she, prior to falling ill, she has got, she knows that she's lost quite a lot. And, you know, she is intelligent and to find people on the same sort of level as her, its just, it's quite difficult. It does happen, but it's difficult.
> [CA6, carer for daughter with schizophrenia]

Communicative gaps

The communication between different services was not always seamless and often it was left to the user or the carer to try to keep all agencies abreast of changes. This was further hampered by the high turnover of staff making it difficult to know who to contact and when.

> There are some times, you know, because there is so much of a staff turn around in both the mental health services and the [housing organisation], it makes it very difficult to communicate. So either one says something else and the other one … you know? Er. We found it quite difficult, you know. Mostly, both of us look after [him], his dad as well, but he works part-time so hence, you know, I see lots of doctors, on my own, because he's working.
> [CA16, carer of son with bipolar disorder]

There were also communicative gaps between users and their carers and communicative gaps between services and carers that centred around the ambiguous status of carers. Most of the disparity between user and carer reports were around the effectiveness of changes in the medication regime which became a site of conflict. CA14 discussed how since her husband's medication had been changed so had he:

> It's definitely been worse over the last few years since he's changed his medication, you know, when he was on the old style medication he seemed to cope quite well. He was a bit slow, but erm, you know, he was a bit more normal, you know, apart from the, just generally being

> a bit slower on the medication. You know, we didn't have some of the problems we've had more recently.
>
> **Interviewer: And does [he] feel the same way about the medication change?**
>
> No, he doesn't see it the same as us. But certainly the children and I, and the rest of his family see that he is a lot more aggressive now, and, and also he gets a lot more anxious and he just has a lot of changes to his personality that are really not, not like the person we used to know. And you know he has alienated a lot of his family and the neighbours and people. I wouldn't say, I wouldn't say he's, it's, he's been mega-aggressive to people, its just simply that he's just not the friendly person he used to be. Everybody, all the neighbours used to know and like him, and erm, he is a bit more isolated. I mean he lives in the, more or less lives in the shed now. And you know, I see all kinds of things about his behaviour, talking to himself a lot, he shouts a lot. […] I have spoken to [him] about erm you know how his behaviour's changed since he's been on these drugs. But he, you know, he's said that he would leave, he would leave erm, before he would go back on to [names medication]. He's made that quite clear on several occasions.
>
> **Leave?**
>
> Leave home. You know, if we found it so challenging to live with him not on [names medication] then he would pack up and leave; but he won't you know, he won't go back on it. So erm, you know, we, we plod along.
>
> [CA14, carer for husband with schizophrenia]

Similarly CA11 identified changes in her husband's wellbeing since his medication change. They were currently without support since changing teams. Like UA14 however, UA11 was happy with his new medication:

> If it was up to me I would never have changed his medication, but the psychiatrist won't change it back and [he] doesn't want it changed back. But I never would have changed it because I don't think they took it on board how ill he was before, and, and I still don't think

> they’ve taken it on board.
> [CA11, carer for husband with bipolar disorder]

Discharge from hospital was again a key point where gaps in continuity could appear and communication gaps appeared to be a significant part of this:

> **Interviewer: What about discharge, did you know when he would be coming out? Were you informed of these things?**
> The first time, it was a complete disaster. Erm, he was discharged on a Bank Holiday; he phoned me and said he was discharged, erm. I couldn’t get hold of a member of staff to have that confirmed so I went to pick him up, and there was no real member of staff; they just sort of said, ‘Oh, yes, if he says so, then he can go!’ And I asked about medication and they said, ‘Oh, the pharmacy’s shut because it’s a Bank Holiday!’ So eventually I kicked up and they did manage to find half a dozen tablets and put them in an envelope for me to take home for the weekend. And I brought him home and I said, well, what now? Should we contact anybody? And nobody really had any idea. So we got through the weekend, and I managed to contact his key worker on the Tuesday, I think it was, after the Bank Holiday. And she was horrified, because nobody had even been told, there’d been no discharge meeting, there’d been nothing. So again, I was quite appalled that, you know, I should be allowed to just go and pick him up, and nobody was even aware that he was out in the community, under no care again. I did actually write a big letter about that afterwards, because I thought it was quite appalling that, you know …
> **Interviewer: Did you get a response?**
> *(sighs)* I got a response … I wrote a two-page letter about a particular consultant, which, erm, I felt I didn’t like at all! His whole attitude and, er, so that was sort of among a lot of other complaints that I had at that time. Erm. And, yes, I got a response, but I wasn’t particularly satisfied with the response. All it basically said was, ‘We note you’ve said this!’ But it wasn’t, ‘We’re going to do this about it.’ That’s all it was; it was just acknowledging my letter, but there was no further outcome as far as I know.

> [CA13, carer for son with schizophrenia]

Social vulnerability

Many users gave accounts of their service user careers that highlighted their social vulnerability. The complexity of their needs and the uncertainty surrounding their illness and daily lives had consequences in terms of their reliance on carers and key workers. Support in negotiating the complex world of benefits, employment and housing needs appeared to be a key element of providing continuity. Furthermore, problems in these social areas could have negative effects on perceived levels of continuity.

Carers' experiences

There were differences in the intensity of care provided by carers across the sample, ranging from telephone support and meeting for weekly meals (most commonly for users who did not live with their carer) to managing finances and ensuring compliance with medication. For most carers the level of care provided fluctuated according to the health needs of the user. Care provision often had a wide-reaching impact on the rest of the family. For carer CA13, her son's illness got to the stage where his father refused to have him in the house any longer:

> It was quite hard, especially because I have a younger one that's quite a bit younger; well, she's fifteen now, but, erm, when he was ill, she was a lot younger and that was sort of quite hard; having her sort of watch it and go through it really and try explaining to her, you know, that this isn't quite right, and that sort of thing. So that was probably quite hard. Erm. And although, you know, he's the big brother, I couldn't sort of leave him in charge of her, it tended to be the other way round from sort of probably quite a young age. So, mmm, there were certain differences there. […] It just put such a strain on the family which then causes problems, you know, between the family.
> [CA13, carer for son with schizophrenia]

Carers also spoke about the need for them to have a relationship with the user's key worker personally.

> **Interviewer: Do you feel that you could be getting more support from services and what kind of support would be useful for you?**
> Just like a regular worker in the team, social worker or care worker, whoever, who has insight of [his] illness, who can understand what we are going through and explain to us, maybe have regular meetings with us, right? And have regular meetings to make sure, you know, [he] is doing well, otherwise, you know, we have to like, you know, keep thinking all today and tomorrow, how is he going to be! Somebody who is very regular in the team.
> [CA16 carer for son with bipolar disorder]

It was also important for carers that their comments and input be respected with regards to confidentiality:

> One time I was annoyed was when … I believe it was when he was in hospital, and he appealed to get out of hospital and during the appeal, his solicitor allowed him to look at his file - which I guess is fine - and on that file there was a lot of comments that I had made about his care in the past, which I had said confidentially to whoever, and he had read all that! So that did a lot of harm to our relationship, with regard to him trusting me, you know. 'You've said this! I had no idea you were telling them this, that and the other!' So, that did annoy me. And that makes me cross to think that he can say things in confidentiality, not to get back to me, but it can't happen the other way around; if I say something then he's got the right to that, which isn't, I don't feel, always in his best interests.
> [CA13, carer for son with schizophrenia]

5.3.2. Service users with non-psychotic disorders and their carers

Relational (dis)continuity

For the 11 service users with non-psychotic disorders, mean length of contact with services was exactly half that of the group with psychotic disorders at 8.7 years, with a range of 18 months to 42 years. As with the users with psychotic disorders, long spells of continuity were rare. Most users spoke of numerous key workers. All but two of the users had a key worker. One did not because she was living in a therapeutic community which did not accommodate outside support. One long-term service user stood out for having an usually long period of continuity. UB9 had been with the same key worker for the previous 12 years. Most, however, had experienced a variety of different workers.

For this group, discontinuity with psychiatrists was very common but perhaps felt less keenly because users usually had less contact with them. Nevertheless the frustration that accompanied having to repeat personal circumstances was commonly expressed, with some users anticipating a transient relationship on the basis of previous experiences:

> **Interviewer: The psychiatrist that you're seeing at the moment, how long has he been your psychiatrist?**
> Erm. Oh, only a couple of months, but I can't get too close to him, because he's bound to leave in another four months.
> **Interviewer: How does that make you feel?**
> It is frustrating, because I start to get to know them and then they move or they leave, and you've got another psychiatrist again.
> **Interviewer: And do you have to go through all the same thing all over again with each one?**
> Yeah, well, this is what I find difficult, having to start all over again.
> [UB8, female, 59 years, bipolar disorder]

One difficulty with high turnover of psychiatrists was that changes to care put in place by one might not be supported by another. This potential lack of consistency in treatment decisions and service providers could engender a feeling of a lack of commitment.

> I've been very lucky with my key worker but I've seen many other doctors and I know, for example, on my own team there were quite lengthy problems with keeping a permanent consultant on the team.

> Apparently the guy who's there now is permanent, but there have been a number of locums and, you know, locums … the use of locums is something that I find really distressing in that kind of service; there's no continuity of care, there are crazy people sometimes who turn up, who will completely throw over the care plan and come out with some version of events sometimes. And then they're not consistent, a consistent follower because they move on. Something I've found at consultant level and also the use of bank staff, etc. on the wards. *(sighs)* No, it takes away from that kind of team element, you know, and the patient really picks up on that and because you kind of feel that you need to be part of this team too and staff are changing all the time, or they're not committed because they're not permanent.
> [UB9, female, 40 years, personality disorder and depression]

Given the high turnover of staff, users found themselves having to repeat their history to new staff over and over again. For many users whose illnesses stemmed from difficult past experiences this was highly distressing. UB9 referred to this process as a 'second form of abuse':

> that is one of the most awful things about being a patient in this system, is that you find yourself having to repeat and repeat things that are so traumatic for you, and especially for somebody like me who's probably … I mean, I am a deeply private person, and because of my legal background I have major concerns around confidentiality and duty of care, etc. and evidence, basically! I'm paranoid about the evidence that's contained in my files that it's accurate and who has access to it, etc., and I've found it deeply distressing because you become desensitised, you become objectified yourself! You know, all of a sudden you no longer are the subjective person with your experiences; you've objectified yourself and you're having to sit there and trot out this stock story. The number of times I've had to sit there and say, 'Yes,' (like I have today), 'I have clinical depression, and I have personality disorder, my mother has manic depression, and my father … my brother has der-der-der … me, me, me, me, me, me, me!' And that is really, really, really quite … it's almost like a second form

> of abuse in a way, to you as a patient, you're totally divorced from your experience and you become an objectified set of symptoms and a diagnosis, you know! And people see the diagnosis and they don't see the person, and you don't feel validated, you don't feel that your experience is at all validated.
> [UB9, female, 40 years, personality disorder and depression]

UB3 made the observation that key workers often got their users mixed up when they arrived because they were taking on multiple caseloads. For already vulnerable users who felt alienated this could not be a good thing.

> **Interviewer: How has [staff changes] affected you, if at all?**
> It affects you every time, but sometimes it's more crucial than others. So, yeah, your key worker changing, it just takes ages to get to know them … well, not ages, but it just takes a while to get to know them and for them to catch up on notes and stuff. And very often when someone leaves or there's some kind of staff change, they're taking on not just one or two people, they're taking on a whole set of caseloads, so they're having to get to know everybody at the same time, which means they just get people mixed up and muddled up and *(little laugh)* forget who you are and stuff. Yeah, and sometimes you just don't have the energy to go through your life story. It's just like when you're not feeling well, you're just like, 'Read my notes, or ask someone else!' *(both laugh)* Or, you know, you're just like … *(sighs)* 'I really don't feel like going through this again.' And then other times, it's just OK.
> [UB3, female, 29 years, depression]

On the whole, users were very satisfied with their key workers and built trusting relationships with them. Their main point of dissatisfaction was the short-term nature of these relationships. Where there were problems with key workers, users were not always aware of their rights. Having experienced gaps between key workers, they were sometimes reluctant to complain in case this meant not having any support. One user who had experienced difficulties with her key worker complained and felt that this had biased the whole of the CMHT towards her.

> I was saying something to the psychiatrist, … and he said, ‘Oh, you’re not entitled to a key worker!’ and I was like … that’s not really about entitlement; who do I go to then if I don’t have a key worker? And it seemed like because I’d complained about one of the members of staff at the CMHT, all the CMHT was kind of like - OK, stay away from this girl!! You know, she’s like … be really firm with her. I didn’t know what they were saying, but that’s the impression I got. And then I was seeing someone for CBT before I got admitted to the … I can’t remember the name! X, that’s it! The X, so I was seeing someone as an intermediary within the Y [team] and I sort of discussed my sort of thoughts with her, and she said, ‘Well, nothing’s been sent to me and I’m fully part of the team. Maybe he just misunderstood, because he’s new here and doesn’t know how our system works. Because obviously everyone has to have a key worker, because that’s how we relate on the team.’ And she sort of apologised on his behalf really and apologised if anyone on the team had treated me badly as a result of my complaint, because she said that shouldn’t happen.
> [UB3, female, 29 years, depression]

She went on to talk about the lack of information available to someone who wished to change key worker.

> What is the …? You know, how often do people change? Do they just ask, is it OK to have a change, because I don’t really seem to connect with this person! And it’s not the same as if you have a GP and you don’t connect with them, because it’s a like a good GP, you can tell the difference between a good GP and a bad GP, even if you don’t like them. So I’ve had GPs that I’ve not liked at all, but they’re good GPs. And so at the end of the day, you just go to them because you know that they’re going to give you good advice and it’s not so personal to you. Some things can be, but in general you can then ask for support from your family and friends about the issue that you have with a particular illness or something, that’s happening to you at the time. But it’s just kind of it’s only five minutes that you get in there anyway, so you go in with a list of questions like this; making sure and writing

> down everything they're saying! Like, can I have a website to look this up on? And you know? So it's not really the same impact if your GP isn't very nice to you, but the impacts that your key worker has if you don't gel is huge, because I mean some people … I don't suffer from paranoia, but some people do and so you have to believe that they're 100% for you because otherwise you just can't engage and then you just don't get the support that you need! So, I mean, I'm really lucky, I have lots of good friends and some really close friends who've been there for me, even come to visit me in A [psychiatric hospital] and stuff, and seen me really ill. But I know another problem is that lots of people with mental health don't have many friendships and I don't know how people cope if they have a bad key worker, you know? And a lot of them might not have the sort of … I don't know what - I'll use the word courage, to complain as well.
> [UB3, female, 29 years, depression]

Most users in both the group with psychotic and the group with non-psychotic disorders, if dissatisfied with their key worker, tended simply to wait until the key worker had left. Their experience of discontinuity with key workers meant that they were all too aware that their current worker would not remain for too long.

Depersonalised transitions

Responses to transitions were varied with some users being able to cope with change while others finding even small disruptions difficult to respond to positively. Due to a restructuring of one CMHT, some users were going to be re-allocated to new key workers; this was less of an issue for some than others. Whilst it was a worry for service user UB7, he was confident that it would work out well and that there would be continuity in the meantime.

> I've only just recently learnt that there is this threat, with the reorganisation here, that I'll have to have a total change and be moved away from the X [team] over to Y, because my GP doesn't fall in the Z catchment area. But, [my key worker] has said that everybody is going to work to put that off for a year, which is the maximum time that they

> have to do it. But he's saying that they'll try and make it take that full length of time for me, so that I do get some continuity.
> [UB7, male, 53 years, depression]

UB4, however, spoke at great length of her distress at the prospect of having her key worker 'taken away' and in particular the impact this had on levels of trust:

> I'm just coming to what I call the crux of my treatment and they've taken away the one person that I trust. Now, erm, I'm keeping on with her at the moment, every two weeks until August, er, and then she's got to pass me over; she has no choice. Erm. And I'm not happy, because I mean, have I got to spend now another 18 months trying to build up a rapport with somebody else? What if I don't like that person? What if I don't trust that person? I'm back to where I started from, out on a limb again, and I think this is very, very unfair of the mental health service to do this to people. […]that's what really upsets me about the mental health service - the lack of continuity; everything else is fine! Everything else is fine. I can't say it's not. Erm. But the lack of continuity, when you get to this stage in your treatment is very wrong. I think they should look at each individual case, and in my case, you know, well she's at that crucial time; let's leave her with [my key worker]. […] I just don't see the necessity to take somebody off of me in this … at this crucial stage, when in another six months or a year, I could be back on my feet again and not have to have [my key worker] any more, erm, at all. … I just think this is very, very bad timing, and I think it's something that the mental health people should look into; talk to the care workers, they know what cases they can pass over and what they can't. …I think that should be her decision, not the mental health department, because she's the one that's dealing with us on a direct basis.
> [UB4, female, 58 years, cyclothymia and behavioural disorder]

Only one of the users in this group had been discharged from services, and she felt that the discharge had come too soon. From seeing her key worker once a fortnight for two years she had to cope without that regular support. She was interviewed about a month after discharge.

I thought it was just too early. I agree that I'm not as bad as I was at the beginning, but I still need help. So I wasn't ready. I didn't see … I mean, I was quite willing to see her once a month, but I just … just so that I had that back up. I mean the doctor at the surgery did say if it gets bad, they can refer me back, they can always do that. But I don't think I'd do that now, because I just feel let down by them.[…] I know she said to me her workload had like doubled, and I think that's what happened; their workload doubled, they looked at their cases and because I'm not mental-mental, they decided, oh, she can manage on her own!

> **And there was no indication of this [discharge]?**
>
> Well six months prior to that, they had said they were thinking about it, but nothing was definite. And now she said, 'Dr __ would come around and see you with her,' and she said, 'and that will be your last visit!' And I mean I was in tears - I just felt dumped. I mean I know my girls [daughters] are very good, but you can't constantly say to the girls, 'Oh god, I'm depressed.' They'll say, 'What's wrong?' 'I don't know what's wrong. God I feel suicidal!' You can't say those things. Whereas with a key worker, you could say what you liked. You could let out your true feelings and it would just make you feel better for a little while, knowing that someone was there.
>
> [UB10, female, 58 years, depression]

Luckily UB10 had support from her GP to fill the gap left by mental health services.

> I think when the psychiatric unit said that they weren't coming any more, I didn't need to see them any more, I wasn't ready. I knew I wasn't ready. I felt so badly let down by them. So I went to see my doctor. He was fantastic. He said, 'You're not on your own, you've got us.' And now I see a nurse at the surgery every fortnight. So even if I don't say anything to her, I know I've got that support. Yeah, I felt really badly let down by them.
>
> [UB10, female, 58 years, depression]

Invisibility and crisis

This group of users echoed the sentiments of the group with psychotic disorders with regards to services being focused on crisis cases and the sense of being invisible or abandoned until a crisis point was reached. UB9 had experience of being a carer as well as a service user, her mother and brother both having severe mental health problems as did an ex-partner. She described her frustration at this:

> It’s very hard. My partner has bipolar affective disorder, and I had this with my mother as well, erm, bipolar affective disorder, especially when it’s a manic episode, it accumulates and accumulates and accumulates. I was so frustrated, I was his chief carer, erm, and you know, when you live in close proximity, you become very good at spotting the signs that somebody’s mood is starting to elevate. And the number of times I called GPs, social workers, called the ward directly, and nobody wanted to know at a point when, if there’d been an intervention by mental health services, he may not have needed an admission. The only time that anybody jumped was the day I rang them up, I said, ‘Right. He’s now taking the house apart. He’s been out on the street challenging people with a knife!’ and then, boof … jump! Suddenly there’s an ambulance at the door, there’s a social worker and …! You couldn’t get anybody interested in the weeks running up to that crisis, you know, which to me is appalling, when preventative action could be taken and it’s not. And that then ends up with your partner spending at least six months in a secure unit for a manic episode that could have … <u>could</u> have been averted or possibly at least the volume turned down - you know, not such a serious relapse - had there been an earlier intervention. And even though I was well known, even though within the team, etc., people knew that I lived with my boyfriend, I knew the symptoms from my long experience of bi-polar affective disorder from my mother, nobody listened to me until the day it became a crisis - and then everybody jumped! You know? For weeks beforehand, you’d been telling people, ‘He’s getting worse, he’s getting worse, he’s getting worse! He’s not taking his medication. I know he’s not taking his medication. Der-der-der!’ No, didn’t want to

> know! And then it's a bit like a cosh, you know, it's a bit like all or nothing - then all of a sudden, its dramatic. Then all of a sudden everybody's there and everybody wants to know! And then, as the carer, you're frozen out because they turn up and they'll take that person away, and you'll be … hang on a minute! You know? I'm the one who's like … I'm his partner, I've been looking after him all this time, and now you're taking him off! And suddenly I've got no rights, you know? I can't know what you're doing, where you're taking him, der-der-der-der. It's insane, it's really insane. But again, that's my experience as a carer. My experience of me as a patient, erm, yeah, I mean I think it's still true. I think that you get … that the services seem to jump up and pay more attention when you are reaching crisis, but in the run up to it ….! *(sighs)* Hmm! Not so good!
> [UB9, female, 40 years, personality disorder and depression]

UB2 had been waiting for a new key worker for a couple of years and had recently been told she would not be getting a one.

> **Interviewer: When was the last time that you had a CPN or key worker?**
> A couple of years ago. It keeps getting mentioned that I will have one, but then I get turned down, I can't have one.
> **Interviewer: Do you know why?**
> Not serious enough, I suppose, or something like that. But I think when you're suicidal, you do need, because I still have that in my head, you know what I mean? It hasn't gone, but I'm just learning to sort of try and control it, the urge, you know? […]I kept waiting and hoping, and phoning and saying, 'When am I going to get my new …?' And I keep asking the different doctors I get, and they write down, 'See about a key worker.' And the last time I asked, they said that they don't think I need one; not the doctor, the nurses don't think I need one.
> [UB2, female, 58 years, personality disorder and depression]

A few weeks before the interview UB2 became so desperate she made a suicide attempt and received little help from the CMHT.

> I phoned them with a cry for help … well, I didn't, a friend of mine did because I tried to take an overdose and he stopped me. He phoned them up, he stayed with me all night and the hospital people - the ambulance people - they stayed with me as well, because they didn't trust me not to do anything. And they phoned here [the CMHT] early the next morning, and they told my friend, 'Yeah, we'll get onto it. Yeah, yeah.' Nothing! The next day, he phoned me in the evening and he said, 'Have they been in touch with you?' I said, 'No.' And he was so angry, so he phoned them again, here, and he phoned my GP. My GP came round straight away, and he told me that he's been in touch with here [CMHT], and then he left. Then I waited, nothing, didn't hear from anybody, and I thought, well, if that's how much they care, well I will take the overdose. So I went down the road, got myself a bottle of vodka and I got four packets of 16 paracetamol and started taking them. Then my doctor phoned and he said like, 'Have they been in touch?' and I said, 'No, because you're a liar, you didn't …' I even called my doctor a liar! 'You haven't been in touch with them!' He came straight round and I was sitting there with the vodka, taking the tablets, and he phoned here [CMHT] again, and he said, 'She's taking them now, in front of me!' And he got straight through to Dr __. Then all of a sudden, there was about three of them from here turned up at my house - bit late then, innit? Three days later! Not even a phone call, so …
> [UB2]

Communicative gaps

The users described varying levels of communication. In some cases GPs were copied into all communication, as with UB7:

> **Interviewer: All the staff that are involved in your care, is there communication between them? So your psychiatrist, your key worker or CPN?**
> Yes, it's generally being discussed and settled in a meeting where

> we've all been present.
>
> **Interviewer: And how involved is your GP involved in your care?**
>
> I see my GP once every eight weeks at present and that is really … I mean, I think it's very good of her to see me because really all I do is go along and she says, 'How are you?' And I said, 'Oh, all right!' But she has been very supportive and I do feel that it's, you know, somebody outside of the service that I can talk to if I've got any issues.
>
> **Interviewer: Is she [GP] kept informed of what's happening with regards to medication?**
>
> I know that letters go backwards and forwards and she always knows everything that's been happening.
>
> [UB7, male, 53 years, depression]

For others, communication was not always as good as it should have been:

> I think the communication … and I mean, this is a big thing! I think the communication between the two services needs to be tightened up because I've always gone down to the doctor, and she's never had any letters or anything, er, updating her of what my situation is. Erm. And so it's always a question of having to sort of say, 'Well, this is what's happening.' Which is great, I mean, in terms of, you know, communication and things like that, but you know in terms … you'd expect them to know what's happening, I think. So, yeah, primary and secondary care, there's a bit of a problem over that! *(laughs)* Hmm.
>
> [UB1, female, 40 years, depression and anxiety]

> **Interviewer: All the staff involved in your care - your GP, the hospital, everyone - is there good communication all the time?**
>
> No, often I've found that the left hand's not speaking to the right hand. You know, for example that my GPs don't know what's going on, erm. They don't know when I'm going through crisis periods; they don't know when, erm … they're not being informed. Erm. The left hand is just not speaking to the right hand, erm, and it's happened over and over again. Things have gotten better sort of recently; there's been more of an effort to copy my GP with correspondence, for example.

> Erm. And to copy me with correspondence, *(little laugh)* you know, because I like to know what's being written about me! But that's only been very recent in the last sort of like six months max. Before that, you know, it was deeply frustrating to have to keep going, you know … every time you had to use a different service that people weren't aware of what somebody else had said. Like the social workers on the team wouldn't be aware that I had a housing problem, you know? Or whatever - you do get a feeling that people are not communicating as well as they should be.
> [UB9, female, 40 years, personality disorder and depression]

Social vulnerability

Five of the 11 users had never been admitted to hospital for psychiatric care, three had been admitted more times than they could remember and two made use of women's crisis services as well as hospitals. As with the users with psychotic disorders, experiences of hospital admissions varied. Some were very positive but these experiences were juxtaposed against more negative occurrences. Users also reported problems with lack of security and staff attitudes. For some, hospitals served as a place to reinforce their self-harming tendencies. Again, users gave a sense of continuity, satisfaction and their own social vulnerabilities being inter-related. They gave positive and negative accounts of crisis services, day centres and social services. The complexity of their needs impacted on their experiences of services. For example, appropriate housing was a major priority for users who were currently or previously on transfer lists and getting safe and secure accommodation was seen as vital to dealing with mental health issues. This illustrated the extent to which social context might influence the experience of continuity or discontinuity. Similarly, as with the group with psychotic disorders, the users with non-psychotic disorders found navigating the benefits system very tricky. For the majority in this group, their key workers were still the first port of call for advice.

> I was reliant on [my key worker], erm, and she didn't know herself, so I mean it was … you know, she sort of suggested getting in touch with them, and it was … it was my mother, erm, who had to really sort of, you know, find out anything that was going to, you know, come to

> pass, really, because we had no support in that way, and no understanding of the system, erm, so … yeah.
> [UB1, female, 40 years, depression and anxiety disorder]

Her carer was also finding information on eligibility for financial support difficult to obtain. In order to give UB1 the time she needed, CB1 had had to reduce her hours of work and was finding it difficult to make ends meet financially.

> I've had no support at all, absolutely none at all. I sent a form in for help from a financial point of view, and I've heard nothing. So whether that means that I'm not eligible, or whether it means it's got lost, but with all the havoc that's been going on in my life, I just haven't followed it through and I suppose I should have done, but I haven't. No, I haven't had any.
> [CB1, carer for daughter with depression and anxiety disorder]

Carers' experiences

Only five of the 11 users interviewed had carers, of whom four were available for interview. Three lived with the user (two husbands and one mother) and one was a friend. For those who lived with the user, the care they delivered was more intense, but, as with the group with psychotic disorders, the level of care demands fluctuated according to the user's needs. Carers would have liked to have been kept more informed and more involved in the care that services were providing. As with some of the carers of people with psychotic disorders, they felt that they could have contributed more if they had had greater involvement with providers.

> I found it initially extremely difficult, because I've found this sort of code of confidentiality - where I couldn't really have a heart to heart with anybody - very, very difficult, because I could see the distress that was going through [her] and it was … you know, you could get to a certain point and then the doors closed so to speak, you know. I also found it extremely difficult getting access to information and access to the people involved too; that's now broken down a bit, and it's easier, but I mean, I … and I think from a carer's point of view, you've also

> got to be very aware of the fact that I don’t want to … I want [her] to have a certain amount of privacy, obviously, surrounding her situation, but on the other hand, you know, I know that I could have personally helped her over a lot of hurdles if I’d been privy to some of the earlier discussions. It’s very difficult, because I’m not quite sure how much [she] was sort of saying and you know, how much was actually sort of … you know, it’s difficult. It’s a sort of noman’s land to a certain extent, but certainly I felt that it would have been easier if there had been a more open approach to the early consultations. I think I could have indirectly helped by giving a background from my perspective of what [she] had been going through in the past. It might have helped to form a picture that could have sort of, you know, helped in some way or other. But, you know, that was very much against the grain […] I just felt it was rather a closed shop and you know there was, as I said earlier, this code of confidentiality - well, you know, you can go so far but over that mark, it’s no man’s land, so to speak. I feel very strongly about this actually, that in the early stages a lot of the things that happen within the scenario here, could have been averted I think, you know, if we’d had a better communication in line. But eventually when I did meet [her key worker], you know, she was absolutely fantastic and we had a long chat and I think it was quite useful what was discussed, but I mean, there’s only so much one could say at that time. But I think if it’d been sort of developed from the onslaught [*sic*], because it was pretty horrendous seeing [her] having these attacks that she did.
> [CB1, carer for daughter with depression and anxiety disorder]

5.4. Discussion

Five key themes emerged from the analysis: relational (dis)continuity; depersonalised transitions; invisibility and crisis; communicative gaps and social vulnerability. There were commonalities in the experiences of users in both groups with regards to issues of continuity and transition. In both groups, user experiences of continuity varied with some having been with their key worker since their first contact with services (as long as 12 years in one case), to more commonly having numerous key workers who stayed for limited periods of time. Discontinuity with psychiatrists was high, especially as many saw different psychiatrists every six months. But with the users with psychotic disorders having spent twice as much time in contact with services, they were more likely to experience a greater number of changes. Frequent changes and the limited contact users had with health care professionals, particularly psychiatrists, meant that they had become experts at condensing their life experiences in order to communicate their entire history of mental health problems in a short time. This led to frustrations with the system and a feeling that their experience was devalued and they were seen as collection of symptoms. This is a common occurrence in practice. As Barham (1997) has observed, ‘Traditionally psychiatric knowledge has provided thick descriptions of the service user and thin descriptions of the person in which the service user is represented as a notional person but never fully described as such’.

All users and carers spoke about how crucial the relationship with a key worker was and the energy that was invested in that relationship by all parties. Although most had experienced changes in key workers the process never became any easier and for some, the prospect of losing their key worker was devastating. This was linked to other social vulnerabilities. It seemed that where there were strong relationships between key workers and users, these were personalised to the extent that users referred to their key workers as close friends and gave examples of incidences such as sharing hedge trimmers, etc. Transitions were more successful where they were undertaken in the social context of the user’s life, understanding where the user was in relation to other services and needs including housing and support. Users in both groups complained about the reactive nature of services (which were often quick to respond to a crisis) but the corresponding invisibility of the user and carer in the period leading up to a relapse or episode. In some cases service providers retrospectively apologised to the users and/or families for not responding fast enough, but this was a repeated pattern and led to users and carers having particular expectations of services levels and contact with health professionals. The ‘crisis-led’ nature of services meant that those who were relatively stable, or did not display signs of potential risk to self or others felt isolated within services and as though on the periphery of service delivery. Users and carers desperately wanted services to listen to them more.

Gaps in communication occurred at a number of levels. Where users relied on more than one provider (supported housing, primary care) there was not always evidence of effective communication between providers and it was often left to the users to fill in each relevant party themselves. There were mixed reviews of hospital stays. Some had found the time beneficial and therapeutic whereas others found their admissions disturbing. Wards often held an array of users with a full spectrum of symptoms and some found this alarming. There were also accounts of violence on the wards including both staff and other users. Many users and their families were not kept informed of expected duration of stay and it was common for carers to report being unaware of the discharge of the user. This adds further support to the findings of Rapaport and colleagues (2006), who reported that carers found hospitalisation, both during admission and discharge, the one area that was the hardest to access information about.

Carers often felt excluded from the care that services provided. Many felt that they could complement the care that services were providing. These findings support previous work which found that carers felt marginalised by services (Rethink, 2003) Few had an established relationship with a member of the CMHT. For carers, their frustration at this was doubled by the knowledge that having been kept on the fringes of the care the user received if the user were to relapse or have a difficult episode, it would primarily be the responsibility of the carer to manage the situation. The issue of confidentiality was raised by many carers, whilst they fully respected the user's rights to privacy; they felt it would be useful if there were a similar opportunity for them to contribute to the care programme of the user. Cleary and colleagues (2006) discuss users’ rights to confidentiality and make the astute observation that ‘nowhere is staff confusion more apparent than in the area of confidentiality and privacy’. Often providers withhold information from carers in order to maintain the confidence of the user, but the carer is not always afforded the same discretion. Carers spoke passionately about their frustration at not being heard by services especially when they were trying to request an intervention before a crisis period. By dismissing carers’ accounts, much valuable information was being lost, particularly as the care provided in these circumstances is crucial to the success of government policies emphasising care in the community (Lloyd & Carson, 2005).

The main needs identified by users and carers were for greater continuity of key workers and for more information. An important finding of this strand is the fragility of continuity and its relationship to levels of satisfaction. Supportive, long-term relationships could be quickly undermined by a range of factors (including the social context in which users lived their lives). Satisfaction levels were often closely related to moments of transition where these relationships were vulnerable. Key workers whom users considered their closest confidantes could suddenly leave without sufficient warning, and the devastation that this caused would often negate any positive experiences of the relationship they had with their worker and by extension wider mental health services too.

5.5. Summary

- Five key themes emerged from the qualitative analysis: relational (dis)continuity; invisibility and crisis; communicative gaps and social vulnerability
- Frustration with the system was prevalent, particularly expressed as feeling that they were seen as a collection of symptoms
- The relationship with the key worker was seen as crucial
- Transitions were more successful where the user's social context was taken into account
- Gaps in communication occurred at several levels
- Carers often felt excluded from the care provided by services
- Barriers to continuity between primary and secondary care are most acute at points of transition
- Transitions appear to be most successful when taking account of the social context of the user's life.
- Continuity appears to be fragile, quickly undermined by a range of factors including transitions.

6. Organisational Strand

6.1. Objectives

Within the context of the reorganisation of health and social care as part of the NHS Plan (Department of Health, 2000) and the wider ECHO project aims, the organisational strand objectives were as follows:

- To evaluate organisational cultures, structures, processes and resources which could influence continuity of care for people with severe mental illness.
- To identify organisational factors which could either inhibit or facilitate the delivery of services or uptake of changing practices to promote continuity of care.

6.2. Methods

6.2.1 Setting

The study was conducted in two Mental Health NHS Trusts located in inner-city and outer, suburban areas of London. Trust 1 employed 3000 health and social care professionals and provided mental health and social care services to five London Boroughs; by contrast, Trust 2 employed 4,500 health and social care professionals and had four Borough Directorates. At the time of conducting the survey, Trust 1 had a slightly higher than average readmission rate to acute psychiatric care for people with severe mental illness. In contrast, Trust 2 had a slightly lower than average readmission rate to acute psychiatric care for seriously mentally ill service users. Both trusts had implemented the 'care programme approach' (CPA Systems) with the intention of providing seamless care to service users.

6.2.2. Design

A comparative organisational diagnostic analysis was conducted in the two NHS Trusts (incorporating their associated social service organisations), six GP practices and two voluntary sector organisations (MIND and the Family Welfare Association).
Diagnostic analysis is a design approach which utlises multi-methods to identify the complexities (barriers and facilitators) within an organisation that may frustrate or facilitate the uptake of change (Hamilton *et al*, 2007). Diagnostic analysis has been

used extensively in evaluation research to investigate structures, cultures and processes with the intent of identifying barriers and facilitators for organisational changes in services and practices (McLaren & Ross, 2000). The diagnostic analysis was conducted across years one to four of the study. A survey approach was utilised, encompassing quantitative and qualitative methods (questionnaires and interviews).

The sampling framework for the questionnaire comprised of the total population (n=276) of professional strategic and operational staff working in the Trusts who were accountable for the delivery of continuity of care through 19 community mental health teams (CMHTs) and their associated acute support units. Staff on long-term sick leave, long-term training and maternity leave were excluded. The response rate to the modified questionnaire was 70% (n=192).

Initially a postal self-report questionnaire was distributed based on that used by Whittock and colleagues (2002). After two re-mailings, this elicited a low response rate and was subsequently revised. This modified questionnaire, following further pilot work, comprised ten sections, exploring: definitions of continuity; communication; team working and decision-making; professional issues; workload; resources; staffing issues; education, training and role changes; workforce integration and pace of change; and organisational and demographic characteristics. Questions comprised a mix of structured five-point Likert scales, together with a small number of open-ended questions. Test-retest reliability of the modified questionnaire was established by administration to 24 respondents on two occasions, separated by an interval of two weeks. Data was entered and analysed on SPSS, Spearman-Brown coefficients were then determined, which ranged from 0.64-0.96 across all scaled items. Internal consistency was determined by measuring Cronbach's alpha coefficient, the overall value of which was 0.92, with values on subsets of items within each section of the questionnaire ranging from 0.68-0.84.

Quantitative data was entered into SPSS and analysed using descriptive and inferential non-parametric statistics, including χ^2 and Spearman's rho to test associations between variables.

An interview schedule was developed to explore all the areas covered in the questionnaire in greater depth. Semi-structured interviews were conducted with a proportionate sample of health and social care professionals (n=113) representative of strategic and operational staff working in eight CMHTs (four per Trust) and their associated acute wards, local general practitioners and representatives of voluntary organisations (MIND and the Family Welfare Association). Interviews were tape-recorded, transcribed, checked for reliability, entered and thematically analysed on NUDIST software.

Three other amendments to the original protocol were made. Firstly, it had originally been intended that the diagnostic analysis include a documentary analysis of material within the public domain. Only two documents could be identified which related to organisational aspects of continuity, both of which were independent Health Commission reports-insufficient to support a full documentary analysis. However, these reports noted that care programme approaches had been implemented in both NHS Trusts which could benefit information, cross boundary and team continuity and this important contextual information should be borne in mind when interpreting the findings of the organisational strand. More detailed information from these reports has not been included to maintain anonymity of the participating organisations.

Secondly, it had been intended to obtain data from Human Resources Departments in both NHS Trusts which would shed light on the workforce (and related continuity issues) of health and social care professionals working in the NHS Trusts. The assumption had been that this information existed at the level of detail required and would be accessible; this was not the case in either Trust. To compensate for this, the amended questionnaire described above was substantially modified to include more detailed sections on workloads, caseloads, time available to complete tasks, staff turnover and sickness, use of agency/locum staff, qualified and auxiliary staff support and investment in workforce skills development.

Finally, the original protocol had included direct non-participant observation of key meetings in the first 18 months of the project. Only four meetings could be accessed (two at senior management level) and observed during this period, none of which yielded any useful information on continuity of care and service reorganisation. It was hoped that direct observation would provide information relating to change management, major resource issues, and communication within and across organisations. Substantive modifications to the study questionnaire and interview schedules ensured sections addressing these topics were included.

6.3. Results

The results of the survey and in-depth interviews are here presented together, separated into the themes: ‘defining continuity of care’, ‘achieving continuity of care’ and ‘barriers and facilitators to continuity of care’. Sections on ‘context of service delivery’, ‘resources’ and ‘developing workforce skills to support continuity of care’ are presented in Appendices 14 and 15. Findings from these sections of the survey suggest that these organisational factors can exert an important impact on *information* and *cross-boundary continuity*. Findings for CMHTs alone in relation to each theme are presented in Appendix 16.

6.3.1. Characteristics of the Study Population

Survey

The overall response rate to the questionnaire was 70% (n=192 respondents, total population n=276) across the two NHS Trusts. Proportionately more respondents were female in Trust 2. Similar age profiles were evident within both Trusts. The majority of respondents were of white ethnic origin (n=111, 58%). The distribution of ethnic groupings was similar within both NHS Trusts. (Table 01.)

Table O1: Survey respondents demographic characteristics by Trust

		Trust 1 (n=111) n(%)	Trust 2 (n=81) n(%)	Total (n=192) n(%)
Gender	Male	52 (46.8%)	27 (33.3%)	79 (41.1%)
	Female	56 (50.5%)	54 (66.7%)	110 (57.3%)
	Unknown	3 (2.7%)	0 (.0%)	3 (1.6%)
Age (Years)	16-24	0 (.0%)	2 (2.5%)	2 (1.0%)
	25-34	27 (24.3%)	19 (23.5%)	46 (24.0%)
	35-44	41 (36.9%)	29 (35.8%)	70 (36.5%)
	44-54	28 (25.2%)	23 (28.4%)	51 (26.5%)
	>55	12 (10.8%)	7 (8.6%)	19 (9.9%)
	Unknown	3 (2.8%)	1 (1.2%)	4 (2.1%)
Ethnic Group	White	65 (58.6%)	46 (56.8%)	111 (57.8%)
	Black/ Black British	22 (19.8%)	15 (18.5%)	37 (19.3%)
	Asian/ Asian British	11 (9.9%)	8 (9.9%)	19 (9.9%)
	Mixed	9 (8.1%)	6 (7.4%)	15 (7.8%)

As shown in Table O2, the majority of respondents worked full-time (78%). The proportion of part-time workers was, however, greater in Trust 2 (25% versus 17%). The majority of respondents (45%) had been in post from one to five years.

Table O2: Survey respondents employment characteristics by Trust

		Trust 1 (n=111) n(%)	**Trust 2 (n=81) n(%)**	**Total (n=192) n(%)**
Employment status	Full-time	88 (79.3%)	61 (75.3%)	149 (77.6%)
	Part-time	19 (17.1%)	20 (24.7%)	39 (20.3%)
	Other	3 (2.7%)	0 (.0%)	3 (1.5%)
	Unknown	1 (0.9%)	0 (.0%)	1 (0.5%)
Time in current post (years)	< 1	18 (16.2%)	21 (25.9%)	39 (20.3%)
	1-5	54 (48.6%)	33 (40.8%)	87 (45.3%)
	6-10	25 (22.5%)	17 (21.0%)	42 (21.9%)
	11-15	4 (3.7%)	4 (4.9%)	8 (4.2%)
	>15	5 (4.5%)	1 (1.2%)	6 (3.1%)
	Unknown	5 (4.5%)	5 (6.2%)	10 (5.2%)

Nurses were found to be the dominant professional grouping, followed by social workers and psychiatrists (Table O3). Relatively few responses were obtained from psychologists and occupational therapists, who constituted a smaller proportion of the workforce in both Trusts, many working part-time. Proportionally fewer psychiatrists were represented from Trust 2, but profiles in professional groupings were otherwise similar within the Trusts. The majority of respondents were operational staff drawn from CMHTs.

Table O3: Professional and managerial status by Trust				
		Trust 1 (n=111) n(%)	**Trust 2 (n=81) n(%)**	**Total (n=192) n(%)**
Professional Groups	Psychiatrist	24 (21.6%)	9 (11.1%)	33 (17.2%)
	Psychologist	6 (5.4%)	7 (8.6%)	13 (6.8%)
	Social Worker	27 (24.3%)	18 (22.2%)	45 (23.4%)
	Nurse	42 (37.8%)	36 (44.4%)	78 (40.6%)
	Occupational Therapist	6 (5.4%)	4 (4.9%)	10 (5.2%)
	Team Support Worker	6 (5.4%)	7 (8.6%)	13 (6.8%)
Managerial/ Operational Status	Strategic Managers	1 (0.9%)	4 (4.9%)	5 (2.6%)
	Operational Managers[1]	12 (10.8%)	8 (9.9%)	20 (10.4%)
	CMHT Members	86 (77.5%)	56 (69.1%)	142 (74.0%)
	Ward Staff	12 (10.8%)	13 (16.1%)	25 (13.0%)

1. CMHT leaders and ward managers.

Semi-Structured Interviews

A total of 113 in-depth, semi-structured interviews were conducted with staff working in NHS Trusts, general practice and external voluntary sector organisations (MIND, Family Welfare Association). Of these, 62 (55%) were managers (Trust executives, either CMHT or ward managers, senior general practitioners, voluntary sector managers), while 51 (45%) were operational staff working in CMHTs, wards and external organisations. (Table O4).

Table O4: Profession of semi-structured interview participants by Trust

		Trust 1 **(n=52)** **n(%)**	**Trust 2** **(n=61)** **n(%)**	**Total** **(n=113)** **n(%)**
Profession	Psychiatrist	4 (3.5%)	2 (1.7%2)	6 (5.3%7)
	Psychologist	32 (2.6%)	3 (2.6%3)	6 (5.3%)
	Nurse	23 (20.3%)	29 (25.6%)	52 (46.0%)
	Occupational Therapist	2 (1.7%)	6 (5.2%)	8 (7.0%)
	Social Worker	13 (11.5%)	10 (8.8%)	23 (20.3%)
	General Practitioners	3 (2.6%)	3 (2.6%)	6 (5.3%)
	Voluntary Sector Workers	3 (2.6%)	5 (5.2%)	8 (7.0%)
	Support Workers	1 (0.8%)	1 (0.8%)	2 (1.7%)
	Non-Health and Social Care Professionals[1]	0 (.o%)	2 (1.7%)	2 (1.7%)

1. Managers without professional qualifications whose roles impacted on service delivery.

6.3.2. Defining Continuity of Care: Health and Social Care Professionals' Perspectives

Survey Findings

Respondents were asked to define continuity of care in their own words. During content analysis, coded categories of definitions were identified based on those used in the Scoping Exercise (Freeman *et al*., 2002). Of the definitions categorised across the total group (n=152), cross-boundary and team continuity were identified by 40 (26%); seamless continuity by 20 (13%); *long-term continuity* by 18 (12%); *relational continuity* by 16 (11%); combined informational and cross-boundary by five (3%) and *flexible continuity* by four (2%). Other compound definitions incorporating two to four elements were cited by 49 (32%). Table O5 summarises common categories of definitions used within different professional groups, cross-boundary and team continuity being the most common.

Table O5: Common definitions of continuity of care by professional group						
	Psychiatrists (n=33) n(%)	**Psychologists (n=12) n(%)**	**Occupational Therapists (n=10) n(%)**	**CPNs (n=53) n(%)**	**Social Workers (n=44) n(%)**	**Total (n=152) n(%)**
Cross-boundary and team continuity	5 (15.2%)	4 (33.3%)	3 (30.0%)	13 (24.5%)	15 (34.1%)	40 (26.3%)
Flexible Continuity	0 (.0%)	2 (16.7%)	2 (20.0%)	0 (.0%)	0 (.0%)	4 (2.6%)
Informational and Cross-boundary continuity	0 (.0%)	4 (33.3%)	1 (10.0%)	0 (.0%)	0 (.0%)	5 (3.3%)
Long-term continuity	5 (15.2%)	0 (.0%)	0 (.0%)	9 (17.0%)	4 (9.1%)	18 (11.8%)
Personal, Relational and therapeutic continuity	4 (12.1%)	0 (.0%)	0 (.0%)	7 (13.2%)	5 (11.4%)	16 (10.5%)
Seamless continuity	5 (15.2%)	2 (16.7%)	0 (.0%)	6 (11.3%)	7 (15.9%)	20 (13.2%)
Compound definitions[1]	14 (42.3%)	0 (.0%)	4 (40.0%)	18 (34.0%)	13 (29.5%)	49 (32.2%)

1. Drawing on more than one component of the above definitions.

Interview Findings

Exploration of definitions of continuity of care within interviews revealed the same profile as emerged from the survey data. Definitions of continuity of care emerging from the interviews were mapped against those identified by the Scoping Exercise (Freeman *et al.*, 2002). Selected exemplars of definitions are summarised in Box O1 and Box O2.

Box O1. Definitions of Continuity of Care: Cross-Boundary, Relational and Longitudinal

Cross boundary and team continuity

'Yes, having the same person is an important part of it. Ideally it would be the same person but when you can't I think it is important in those situations to keep it within the team.' (Consultant, Trust 1)

Relational, personal and therapeutic continuity

'I think it's about service users feeling that preferably they'll get to see the same worker whenever they need some support...' (Voluntary sector worker, Trust 2 catchment area)

Longitudinal, Long-term continuity

'That the patient is looked after in the community by the GP after discharging from the hospital or they follow it up by CPN...' (GP, Trust 2 catchment area)

'I think at its best continuity of care is the guarantee that one named individual will always be available to see that particular patient on a long-term basis. So underpinning continuity of care is a long-term relationship and a personal relationship.' (GP, Trust 1 catchment area)

Box O2. Definitions of Continuity of Care: Seamless and Compound

Seamless continuity

'I suppose the easiest way to describe it is as a seamless service, everything integrated and working efficiently to provide a good standard of care to the client. That's efficiency of resources, efficiency of what you're doing. I think continuity of care is about giving the care on the care plan...' (CPN, Trust 1)

Compound Definitions

'Continuity of care for me as a health professional and a team manager is to make sure the users, and carers, receive a service that meets their needs and that incorporates health and social aspects of care, to enable them to function and live in the community and have a reasonable quality of life.' (CPN, Team Leader, Trust 1)

'It's about having an overall package of care and treatment for each individual client, so different people may input into that package of care... obviously the relationship that the users have with whoever is providing their care is vital because if that doesn't work people will disengage from services... there needs to be user and carer involvement in setting up the package of care.' (Senior Manager, Trust 2)

6.3.3. Achieving Continuity of Care: Effectiveness of Teamwork and Team Communication

In this section survey findings relating to teamwork, team skill mix, team function and decision-making are explored in relation to continuity of care, with in-depth information provided from semi-structured interviews. In terms of team boundaries, it should be borne in mind that within both Trusts two sets of teams operated, namely CMHTs and ward teams responsible for inpatient care. Some professionals (psychiatrists, psychologists and occupational therapists) worked across both teams.

Survey Findings

Team Support, Team Working

As shown in Table O6, similar trends were evident within both Trusts. The majority of staff found that the current structure of their team was supportive of continuity of care and rated working in an integrated multi-disciplinary team as effective. Integrated team working was the only factor rated differently by the different professional groups ($\chi^2=15.537$, $p=0.004$), with 95% of the PPO group (n=55), 93% of social workers (n=41) and 82% of nurses (n=62) rating it as effective in relation to continuity of care.

Team Skill Mix and Development of Specialist Teams

In relation to team skill mix and specialist teams, similar trends were again evident within both Trusts, with the greater proportion of staff rating team skill mix and, to a lesser extent, the development of specialist teams as effective in relation to continuity (Table O6). There were no statistically significant differences between professional groups.

Team Decision-Making, Multi-disciplinary Recording

In both Trusts, team decision-making structures and personal involvement in decision-making were rated as effective in relation to continuity by the majority of respondents. While most respondents rated multi-disciplinary records as effective in relation to continuity, professionals in Trust 1 were more likely to do so than those in Trust 2 (Table O6). There were no statistically significant differences between professional groups, nor between managerial and operational staff views on these issues.

Table O6: Achieving continuity of care: effectiveness of teamwork by Trust

		n	Trust 1 n(%)	n	Trust 2 n(%)	χ^2 (p-value)
Team Support in Relation to Continuity of Care	Effective	108	93 (86.1%)	77	70 (90.9%)	1.99
	Ineffective		10 (9.3%)		3 (3.9%)	(.370)
	Neither		5 (4.6%)		4 (5.2%)	
Integrated Multi-disciplinary Team Working in Relation to Continuity of Care	Effective	109	98 (89.9%)	77	65 (84.4%)	1.31
	Ineffective		6 (5.5%)		6 (7.8%)	(.521)
	Neither		5 (4.6%)		6 (7.8%)	
Team Skill Mix in Relation to Continuity of Care	Effective	108	96 (88.9%)	77	65 (84.4%)	1.50
	Ineffective		4 (3.7%)		6 (7.8%)	(.472)
	Neither		8 (7.4%)		6 (7.8%)	
Development of Specialist Teams in Relation to Continuity of Care	Effective	103	62 (60.2%)	74	43 (58.1%)	0.09
	Ineffective		19 (18.4%)		14 (18.9%)	(.957)
	Neither		22 (21.4%)		17 (23.0%)	
Maintenance of Multi-disciplinary Records in Relation to Continuity of Care	Effective	106	86 (81.2%)	75	48 (64.0%)	7.50
	Ineffective		10 (9.4%)		17 (22.7%)	(.023)
	Neither		10 (9.4%)		10 (13.3%)	
Decision-Making Structures in Relation to Continuity of Care	Effective	109	78 (71.6%)	78	60 (76.9%)	2.15
	Ineffective		16 (14.7%)		6 (7.7%)	(.342)
	Neither		15 (13.7%)		12 (15.4%)	
Personal Involvement in Decision-Making in Relation to Continuity of Care	Effective	104	80 (76.9%)	71	51 (71.8%)	2.09
	Ineffective		14 (13.5%)		8 (11.3%)	(.352)
	Neither		10 (9.6%)		12 (16.9%)	

Team Communication in Relation to Continuity of Care

As shown in Table O7, across all categories of communication between the team and key groups within and external to both Trusts, the greater proportion of respondents rated communication as effective in relation to continuity of care. Those rating consultation between staff and senior management as effective, however, only just outweighed those rating it as ineffective, particularly in Trust 1. Whilst the greater proportion of respondents rated communication between team and senior management as effective in both Trusts, respondents in Trust 2 were more likely to do so than those in Trust 1. There were no significant differences between professional groupings or between managerial and operational staff.

Table O7: Achieving continuity of care: team communication in relation to continuity of care by Trust

		n	Trust 1 n(%)	n	Trust 2 n(%)	χ^2 (p-value)
Consultation Between Staff and Senior Management	Effective	105	39 (37.2%)	69	30 (43.5%)	0.92
	Ineffective		37 (35.2%)		20 (29.0%)	(.632)
	Neither		29 (27.6%)		19 (27.5%)	
Communication: Team Members and Leaders	Effective	109	92 (84.4%)	79	69 (87.3%)	3.03
	Ineffective		9 (8.3%)		2 (2.5%)	(.220)
	Neither		8 (7.3%)		8 (10.2%)	
Communication: Team and Senior Management	Effective	97	35 (36.1%)	72	43 (59.7%)	9.31
	Ineffective		29 (29.9%)		14 (19.4%)	(.010)
	Neither		33 (34.0%)		15 (20.8%)	
Communication: Team, Users and Carers	Effective	106	85 (80.2%)	76	60 (78.9%)	0.78
	Ineffective		4 (3.8%)		5 (6.6%)	(.676)
	Neither		17 (16.0%)		11 (14.5%)	
Communication: Team, Outside Agencies	Effective	104	78 (75.0%)	76	50 (65.8%)	4.65
	Ineffective		10 (9.6%)		16 (21.1%)	(.098)
	Neither		16 (15.4%)		10 (13.1%)	

Interview Findings

The two Trusts taking part in this study structured their community mental health services and particularly their CMHTs differently. Trust 1 had traditionally operated using a medical model, where the consultant psychiatrist leads the team and has responsibility for medical decision-making. In this model, everything hinges on the individual consultant and their willingness and capability to share decision-making power (Box O3). By contrast, in Trust 2, CMHTs had been restructured to be led by non-medical professionals, mainly social workers, CPNs and occupational therapists, although the style of the clinicians working within the teams had an impact on decision-making. Many teams in this Trust were still in the early stages of developing democratic processes and perceptions were that although traditional hierarchies were not present and team leaders were empowered, the psychiatrist still played a dominant role (Box O4).

Overall, the concept of integration was positively received in both Trusts, at all levels and in all professional groups, both within CMHTs and their organisational interfaces. There were more mixed reactions to the practice of integrated working, however, particularly generic working amongst health and social care professionals. There were indications that integration had worked well in Trust 2, at least initially, but then attrition began as people decided to leave (Box O5). Staff shortages and attempts to work together in an integrated way gave rise to issues about having set roles and ring-fencing professional boundaries, particularly for CPNs, social workers and occupational therapists. The majority of interviewees envisaged some degree of role change, with 70% of the CMHT staff in Trust 1 and 63% in Trust 2 expressing anxiety at the perceived erosion of their professional roles and identities (Box O6). For psychologists in Trust 2, the way the service was structured had supported the maintenance of professional boundaries in a way that had not materialised for other professional groups.

Box O3. Team Leadership and Decision-Making: Trust 1

'I have the final say. I have to because I have to take responsibility. It doesn't come down to that to a large extent very often. I very much encourage people to make their point...' (Consultant, Trust 1)

'Where you have a good relationship with a psychiatrist there isn't a real problem, but where there is friction there's a real mileage in them being able to say 'I'm the Clinical Team Leader, I make decisions and you have to do what I say.'' (Psychologist, Trust 1)

'I think it is almost as democratic as you can get although people understand that the consultants have clinical responsibility so sometimes someone will have to make a ruling but it is about as democratic a meeting as you can get.' (Team Leader, Social Worker, Trust 1)

Box O4. Team Leadership and Decision-Making: Trust 2

'I think there is a pull towards a more medical model. And I think it is harder for people to maintain their own sense of where they came from. The style of consultant psychiatrists has an effect on that. I've been able to observe different consultants at work and the less authoritarian the consultant is, the freer people are to express their own identity, if you like. The doctors having to be the main people, seems to be unnecessary, so people might be assessed a number of times, because they need the medical input first. The services are currently being reviewed, to try to change the way the system works, to become a more psychological model.' (Psychologist, Trust 2)

'I think the new team leader structure has empowered the team leaders. For the first time some of the other consultant psychiatrists are finding people saying what's this about, I disagree with this... it's uncomfortable but it needs to happen. We need to have increased democracy, increased empowerment and say in how our services are run and delivered and changed.' (Senior Manager, Trust 2)

Box O5. Responses to Integration

‘Personally I think it’s great. I mean I’ve heard other people – not from this team – saying how they think it’s a bad idea but I think it’s a really good idea and I’m surprised that other places have problems.’ (CPN, Trust 1)

‘Yes, very much integrated into the team and they know they can ask advice about users because we have formal supervision set up within the team. I don’t know if the team feels the same about me, but I certainly feel integrated. People know they can call in and just have a chat about a particular patient.’ (Psychologist, Trust 2)

‘...people started to leave, i.e. social workers. If you imagine you have two systems put in place and they’re working really well together, you start breaking down one of the systems and the other system starts to feel the pressure as well.’ (CPN, Trust 2)

Box O6. Professional Roles and Boundaries

'… I think in terms of actual CMHTs I expected that roles would blur. I think some people who have worked in mental health for years don't really like the idea and think that people should have very set roles.' (Social Worker, Trust 1)

'I think integration is a good thing but I have reservations whether we should all be doing the same thing. I think as a nurse myself I would be reluctant to give up that arm because…I have trained five years as a nurse and I want to retain my practice as a nurse … I would like to protect the nursing name I suppose.' (CPN, Trust 1)

'I'm an OT working as a team worker so I need to have a good part of my time doing work that only I can do, otherwise you might as well not have me as an OT, have somebody else.' (Occupational Therapist, Trust 2)

'I think having the separate psychology team helps keep professional boundaries in place, like having systems where we don't become care coordinators in the same way and we don't participate in assessments.' (Psychologist, Trust 2)

Many CMHT members were willing to take on tasks outside their remit, although CPNs particularly raised concerns over service quality and safety. The issue most frequently raised, however, related to reservations about taking on tasks for which individuals felt they had no training or experience. Specifically, CPNs expressed concerns about taking on social care aspects and the medicalisation of social workers and occupational therapists was also seen as problematic (Box O7).

Box O7. Generic and Professional Cross-Boundary Working

'People have huge caseloads and been expected to take on other roles that they haven't had the training for... don't know where to go for information, for advice... something has to give... I think what we're doing is becoming more and more diluted.' (CPN, Trust 2)

'I think the social workers are particularly concerned ... They're being invited to do things like check on side effects of medication and that's a problem.' (Team Manager, Social Worker, Trust 1)

'I heard of another borough where they were advertising for a job and it was primarily a CPN's role if you looked at it five years ago. And a social worker or an OT could apply for it and I thought that is not good... And it's dangerous because you don't have continuity, you have a blurring of roles and people feel disempowered and leave and I think that's what we're having.' (CPN, Trust 2)

A concern arising from the integration of staff from varying professional backgrounds was that of professional supervision, particularly in teams that might be managed by an individual from a different professional background. Difficulties in maintaining a professional identity might be exacerbated by inability to access a supervisor from a similar professional background. The format of some CMHTs meant that this was not always possible and was problematic for some. Conversely, some staff viewed supervision and management by an individual from another professional background in a more positive light (Box O8).

Box O8. Professional Supervision: Challenges and Opportunities

'I'm managed by a health manager who doesn't always see the social service's responsibilities, and some of those responsibilities have actually fallen by the by because of pressures ... and so we've been sort of trying to catch up and really do a bit of fire fighting.' (Social Worker, Trust 2)

'I personally quite like having a social worker for a manager, mainly because I can deal with all the medical things and I just go to a doctor for the medical things, but for the social things, for service requests, for home help, the things like that, it's nice to have a manager who is a social worker because he just signs it and says yes…' (CPN, Trust 1)

*'I know social workers have said that all over the country but actually I quite like being supervised by a nurse for a change. **** is a very good nurse ... she has to manage the social care and she is aware of the issues.' (Social Worker, Trust 1)*

Issues raised concerning how multi-disciplinary teams are structured, decisions made and professional working issues resolved highlighted the need for strong team leadership and the critical nature of the team leader role (Box O9).

Box O9. Team Leadership

'...it obviously raises issues about the quality of and the support to the team leaders because they become crucial. There are other parts of (the geographical area) where my consultant colleagues report that their life is made a misery by poor quality team leaders so they're having to sort of carry a service without the nominal responsibility, but still keep the show going. It is a terribly difficult role.' (Consultant, Trust 2)

6.3.4. Barriers and Facilitators to Continuity of Care

Team Working and Decision-Making: Survey Findings

Team Support and Integrated Working

As shown in Table O8, the majority of respondents rated team support and integrated working as facilitators of continuity of care, although there were no significant differences between the two Trusts. While the majority also rated integrated working as a facilitator of continuity, psychiatrists, psychologists and occupational therapists were significantly more likely to do so than social workers and nurses (Table O9).

Team Skill Mix and Development of Specialist Teams

Team skill mix and development of specialist teams were seen as facilitators to continuity of care by the majority of respondents within both Trusts (Table O8). Psychiatrists, psychologists and OTs were again more likely to rate these factors as facilitators (Table O9).

Team Decision-Making and Multi-disciplinary Recording

The majority of respondents rated multi-disciplinary recording, team and personal decision-making as facilitators of continuity. Those in Trust 1 were more likely to rate multi-disciplinary recording as a facilitator (Table O8). There were no significant differences between professional groups (Table O9). There were no significant differences between managerial and operational staff views.

Table O8: Team working and decision-making within Trusts: barrier or facilitator to continuity of care?

		n	Trust 1 n (%)	n	Trust 2 n (%)	χ^2 (p-value)
Team Support	Barrier	106	10 (9.5%)	78	5 (6.4%)	0.56
	Facilitator		91 (85.8%)		69 (88.5%)	(.758)
	Neither		5 (4.7%)		4 (5.1%)	
Working in an Integrated Multi-disciplinary Team	Barrier	107	5 (4.7%)	76	7 (9.2%)	1.82
	Facilitator		98 (91.6%)		65 (85.5%)	(.404)
	Neither		4 (3.7%)		4 (5.3%)	
Team Skill Mix	Barrier	108	5 (4.6%)	75	6 (8.0%)	1.51
	Facilitator		96 (88.9%)		62 (82.7%)	(.471)
	Neither		7 (6.5%)		7 (9.3%)	
Development of Specialist Teams (HTT, ACT)	Barrier	104	22 (21.1%)	73	17 (23.3%)	2.25
	Facilitator		66 (63.5%)		39 (53.4%)	(.324)
	Neither		16 (15.4%)		17 (23.3%)	
Maintenance of Multi-disciplinary Records	Barrier	106	10 (9.4%)	74	17 (23.0%)	8.18
	Facilitator		84 (79.3%)		45 (60.8%)	(0.17)
	Neither		12 (11.3%)		12 (16.2%)	
Team Decision-Making Structures	Barrier	109	20 (18.3%)	76	6 (7.9%)	4.08
	Facilitator		78 (71.6%)		62 (81.6%)	(.130)
	Neither		11 (10.1%)		8 (10.5%)	
Personal Involvement in Decision- Making	Barrier	103	12 (11.7%)	70	9 (12.9%)	4.90
	Facilitator		82 (79.6%)		47 (67.1%)	(.087)
	Neither		9 (8.7%)		14 (20.0%)	

Table O9: Team working and decision-making: barrier or facilitator to continuity of care? Professional views

		n	PPO n (%)	n	Social worker n (%)	n	Nurse n (%)	χ^2 (p-value)
Team Support	Barrier	54	4 (7.4%)	45	5 (11.1%)	74	5 (6.8%)	0.81
	Facilitator		47 (87.0%)		38 (84.4%)		65 (87.8%)	(.937)
	Neither		3 (5.6%)		2 (4.5%)		4 (5.4%)	
Integrated Team Working	Barrier	55	0 (.0%)	43	1 (2.3%)	74	9 (12.2%)	13.77
	Facilitator		55 (100.0%)		39 (90.7%)		61 (82.4%)	(.008)
	Neither		0 (.0%)		3 (7.0%)		4 (5.4%)	
Team Skill Mix	Barrier	55	1 (1.8%)	42	2 (4.8%)	75	7 (9.3%)	12.06
	Facilitator		53 (96.4%)		38 (90.4%)		57 (76.0%)	(.017)
	Neither		1 (1.8%)		2 (4.8%)		11 (14.7%)	
Development of Specialist Teams (HTT, ACT)	Barrier	52	14 (26.9%)	43	14 (32.6%)	74	8 (10.8%)	18.99
	Facilitator		36 (69.3%)		19 (44.2%)		46 (62.2%)	(.001)
	Neither		2 (3.8%)		10 (23.2%)		20 (27.0%)	
Maintenance of Multi-disciplinary Records	Barrier	55	8 (14.5%)	41	8 (19.5%)	75	10 (13.3%)	5.53
	Facilitator		44 (80.0%)		26 (63.4%)		52 (69.3%)	(.238)
	Neither		3 (5.5%)		7 (17.1%)		13 (17.4%)	
Team Decision-Making Structures	Barrier	54	7 (13.0%)	44	7 (15.9%)	77	10 (13.0%)	4.11
	Facilitator		45 (83.3%)		31 (70.5%)		57 (74.0%)	(.392)
	Neither		2 (3.7%)		6 (13.6%)		10 (13.0%)	
Personal Involvement in Decision-Making	Barrier	53	2 (3.8%)	42	7 (16.7%)	69	10 (14.5%)	7.75
	Facilitator		47 (88.7%)		29 (69.0%)		48 (69.6%)	(.101)
	Neither		4 (7.5%)		6 (14.3%)		11 (15.9%)	

Team Working and Decision-Making: Interview Findings

Interviewees exclusively in Trust 2 raised the issue of lack of management support and guidance; although certain individuals were supportive, the perceptions of some staff particularly in new roles and critical roles were that they did not always receive support tailored to their needs. Managers also reported the presence of gaps which had a detrimental effect on continuity of care. Lack of guidelines, business plans and accountability for these had also created problems for teamwork and continuity (Box

O10). Having a supportive, approachable team leader was described as a facilitator to continuity of care by staff in both Trusts. Team leaders were seen as ‘bridges’ between daily operational life and senior management, but also as ‘filters’ between teams and their respective Trusts.

Team working was the most frequently described facilitator to continuity of care, highlighted by 50% of all interviewees, in all professional groups and across all sectors in Trust 1 and in all professional groups within CMHTs and in-patient services in Trust 2. The support of individual team members was of particular importance as was effective supervision, communication and commitment. Some teamwork problems were experienced by interviewees in Trust 2, where a second phase of restructuring had only recently been conducted. Specific issues had two elements, the first relating to difficulties working in and with teams without clear boundaries or an overall philosophy (specialist teams) and the second to activities needed to kick-start working together in a more collaborative manner (Box O11).

Box O10. Managerial and Team Leader Support

'Now that we've merged, there are no clear guidelines, you know so it's quite ad hoc.' (CPN, Trust 2)

'I still think there's an enormous gap between management and the practitioner on the ground, which I think has a detrimental effect on continuity of care. Which is constantly bloody shifting at the moment, often for no reason than there's a financial pressure.' (Senior Manager, CPN, Trust 2)

'I think the team leader is a good idea, I think that's going to help pull all the strands together and look at gaps. And it means somebody is actually looking at a vision, because we don't have enough time to look at the vision every so, so it's good to have somebody doing that.' (Occupational Therapist, Trust 2)

'[ ] is a fantastic manager, I think he's very open and you can always approach him and I feel very lucky that I've got a decent manager. I think that makes life so much easier.' (Social Worker, Trust 1)

Box O11. Experiences of Teamwork Support

'I think there is a tremendous goodwill amongst team members to help out colleagues and generally not to dump work on other people so I think this sense of there being a good team atmosphere here and I think that counts for a lot when you're under pressure and team members being understanding of other team members and difficulties really.' (Social Worker, Trust 2)

'...the communication between the team is quite good, the level of supervision is there and the support is there and I'd say those are the important aspects.' (Ward Nurse, Trust 1)

'There are difficulties at times with who one of the specialist teams will and won't take on, that can lead to problems at times.' (Team Leader, Social Worker, Trust 2)

'One of the biggest problems is for us to be able to work as a team, to have one philosophy and to work towards that.' (CPN, Trust 2)

Team Communication: Survey Findings

As shown in Table O10, the majority of respondents rated consultation between team and senior management as a barrier to continuity of care, while most rated other categories of communication as facilitators. By contrast, consultation with senior management was rated as a barrier to continuity and communication with senior management was viewed as a barrier to continuity by social workers. Differences between professional groups were not significant, with the exception of communication between team members and leaders, where the PPO group (96%) was more likely than the social worker group (87%), who were more likely than the nursing group (80%), to rate this as a facilitator (χ^2=9.656, p=0.046).

Table O10: Communication: barrier or facilitator to continuity of care? Trust views

		n	Trust 1 n (%)	n	Trust 2 n (%)	χ^2 (p-value)
Consultation Between Team and Senior Management	Barrier	105	45 (42.9%)	71	30 (42.3%)	0.01
	Facilitator		39 (37.1%)		27 (38.0%)	(.993)
	Neither		21 (20.0%)		14 (19.7%)	
Communication Between Team Members and Leaders	Barrier	109	9 (8.3%)	79	3 (3.8%)	2.18
	Facilitator		94 (86.2%)		69 (87.3%)	(.336)
	Neither		6 (5.5%)		7 (8.9%)	
Communication Between Team and Senior Management	Barrier	98	37 (37.8%)	69	17 (24.6%)	3.65
	Facilitator		41 (41.8%)		38 (55.1%)	(.161)
	Neither		20 (20.4%)		14 (20.3%)	
Communication Between Team, Users, Carers	Barrier	105	9 (8.6%)	77	4 (5.2%)	4.26
	Facilitator		89 (84.7%)		61 (79.2%)	(.119)
	Neither		7 (6.7%)		12 (15.6%)	
Communication Between Team, Outside Agencies	Barrier	104	15 (14.4%)	76	18 (23.7%)	3.19
	Facilitator		78 (75.0%)		48 (63.2%)	(.203)
	Neither		11 (10.6%)		10 (13.1%)	

Team Communication: Interview Findings

Effective communication was described as a facilitator to continuity of care and many positive exemplars were given by interviewees of more transparency of communication in Trusts and in multi-disciplinary team communication, where professionals were located on one site. Both positive and negative experiences of communication with managers were reported, some of which appeared to be associated with management style (Box O12).

Box O12. Communication: Teams and Managers

'I think on the whole we communicate quite well, we have team meetings and we talk about the users, any particular problems...' *(Occupational Therapist, Trust 1)*

'Communication I think is one of the key areas where we have really improved over the last year. People do know much more about the Trust now I think and what's going on than they did. There seems to be less secrecy.' *(Senior Manager, Trust 2)*

'The facilitators are having true multi-disciplinary communication and having people together in one place to do that on a regular basis, and I don't just mean once a week, I mean the stuff that goes on when you share a space. I think that's a huge plus, because decisions don't get deferred, they get made.' *(Senior Manager, Occupational Therapist, Trust 2)*

'My immediate manager has quite a distant managerial style and that hasn't helped because I've felt very overwhelmed at times, you know, I think her style is more 'keep out the way, don't ask'...' *(Team Leader, CPN, Trust 2)*

Communication, both formal and informal, which enhanced interagency working and involvement of users and carers was mentioned as a facilitator to continuity of care by many interviewees. By contrast, some voluntary sector managers and workers had experienced a deterioration in working relationships with Trusts, marked by poor communication which constituted a barrier to continuity (Box O13). In a wider context, problems with systems communication and management, raised exclusively by CMHT staff in both Trusts, were felt to constitute a barrier for user access to services (Box O14).

Box O13. Communication: Voluntary Sector and General Practice

'We have good links with most of our GPs which facilitates discussions about referrals for people... We have other people in the team who have good other relationships so our OT has a relationship with MIND and the employment service and that is quite good.' (Consultant, Trust 1)

'...we have a three monthly meeting with our GPs and we invite relatives and all the professionals concerned as well. Everything is discussed and the care plans reviewed.' (Team Leader, CPN, Trust 1)

'The relationships aren't as good as they used to be because we don't have the time to spend with each other like we used to.' (Voluntary Services Manager, Trust 1 catchment area)

'*more input, more communication. Sometimes it feels like there has to be a crisis before we get to talk.' (Voluntary Services Worker, Trust 2 catchment area)*

Box O14. Systems Communication and User Access to Services

'...it's quite chaotic the way reviews are done, we have no intake system here, no duty system, so it leads to some problems, you know how do people access the service in some cases?' (Social Worker, Trust 1)

'Vulnerable people used to attend (day care) so you could monitor them and if you were seeing them every day you'd notice and I think a lot of people are probably ending up back in hospital because this isn't going on.' (Support Worker, Trust 2)

The Nature of Illness and Service Users' Complex Mental Health Needs: Interview findings

An emergent theme, not adequately served by the survey questionnaire's framework and raised by interviewees in both Trusts, in all sectors and in all professional groups, indicated that the often complex nature of service users' mental health needs could be a barrier to providing continuity of care. Reasons for this were that the nature of the illness could mean service users might not comply with treatment, service users' needs might change and services could fail to keep up with these changes. Interviewees in both Trusts indicated a difficulty in making and maintaining contact with vulnerable people and a scarcity of accommodation for this changing population, especially those with 'dual diagnosis' drug and alcohol related behavioural problems. Staff felt that they needed to be better equipped to cater for the growing behavioural challenges of violence and substance misuse, combined with other mental health difficulties (Box O15).

Box O15. Service Users' Complex Needs

'I've felt this through the years that our users have changed, we're working with a lot more damaged people these days, with quite a long history of difficult behaviour, forensic history, quite a few people will carry on like that. People with drug and alcohol problems as well as mental illness. Dual diagnosis. And you know, the hostels have procedures that make it very difficult for these people to be accepted sometimes.' (Social Worker, Trust 1)

'...certainly I've seen over the last couple of years, the client group has gotten iller. More disturbed, more day hospital type. ...it feels like there's been pressure to move people on from day hospitals. And we're usually the next port of call and that is something that we have seen to be quite a big problem.' (Voluntary Services Worker, Trust 2 catchment area)

'...the biggest challenge I've seen coming up is around violence and substance misuse. They're huge challenges that I think traditional mental health services are not equipped to deal with, and we need to be really focussing in on how we manage those things because they often help people, they're often the issues that make people drop out of services. And I think we have to get a lot more creative around how we manage that. We also need to protect staff within that, not just expect them to take anything that's going because it's part of the job. It's about making sure they're equipped to deal with them and they're not put at risk. That they feel confident and capable to deal with those unpredictabilities.' (Occupational Therapist, Trust 2)

6.4. Discussion

The multi-axial definition of continuity of care was largely supported by the findings of this strand. Here we focus on barriers to and facilitators of each type of continuity in turn, with the exception of *experienced continuity*, in this study operationalised to mean from the service user's point of view and therefore not a focus of this strand. Our findings highlight both general relationships across the two Trusts and also areas where their differing organisations had discernable effects on continuity of care (see Boxes O19 and O20). A limitation of the findings relates to the representation of the views of psychologists, psychiatrists and OTs, who make up a small proportion of mental health clinicians and consequently constituted a small proportion of the sample for the survey questionnaire. This should be borne in mind when interpreting the survey findings. Differences and similarities between the Trusts with regard to each type of continuity are summarised at the end of each section.

6.4.1. Flexible continuity

The need for services to be flexible, adjusting to the needs of the individual over time encapsulates this definition of continuity (Freeman *et al*, 2000). This is underpinned by *relational continuity* and can undermine *long-term continuity* where flexibility is not addressed. The concept of flexible service delivery in turn requires flexible care-planning linked to effective monitoring, given the nature of serious mental illness. In turn this requires effective decision-making structures, team skill mix and communication. Positive findings relating to team skill mix, decision-making and communication were facilitative of *flexible continuity*. Other findings suggested the dominance of medical models of decision-making in some areas, however, linked to authoritarian management styles which could be inhibitory in excluding other professional inputs required for flexible care-planning. Alternative models have been proposed which emphasise shared knowledge and shared territory with a range of disciplines and service users, which could enhance this form of continuity (Duggan *et al*, 2002).

Findings also revealed professional concerns that the increasingly complex nature of service users' mental health needs could be a barrier to *flexible continuity*. Difficulties were encountered in making and maintaining contact with users, and in those with dual diagnosis, encompassing alcohol and drug-related behavioural problems. Professionals felt that they needed support on how to manage violence and drug-related problems in ways which minimised risk and ensured that people did not 'drop out' of service contact. Monitoring is vital to ensure *flexible continuity*; concerns were also expressed that lack of day care facilities limited monitoring opportunities which could prevent readmission to hospital.

Flexible continuity is thus dependent on flexible care-planning, underpinned by effective team skill-mix, decision-making and communication; models of decision-making are also relevant to *flexible continuity*. No significant differences were found between Trusts in relation to team skill-mix, decision-making and communication, which were all found to be effective and facilitative of continuity. In Trust 1, use of medical models of decision-making was more commonly reported, potentially a constraint on *flexible continuity*.

6.4.2. Cross-boundary and team continuity

Cross-boundary and team continuity requires effective coordination of services by teams and external agencies underpinned by effective communication (Freeman *et al*, 2002). Both Trusts in this study had embedded care programme approaches, noted in the independent assessments of the Committee for Health Improvement. Thus, care coordinators were assigned to manage the integrated provision of services across inter- and intra-organisational boundaries; effective information management is intrinsic to this role which is pivotal to continuity of care.

Effective, integrated team work and cross-boundary work with other agencies is intrinsic to achieving this form of continuity and other aspects of service quality (Wells, 2004). Our study found that for the majority of professionals in both Trusts, experiences of working in integrated, multi-disciplinary teams were very positive. Current team structures, skill mix and the deployment of specialist teams were viewed as effective and supportive of continuity of care. Similarly, team decision-making structures, personal involvement in decision-making, multi-disciplinary recording practices and communication within teams and with users, carers and external agencies were also experienced as effective and facilitative of continuity. Strategies used to enhance communication and information transfer included the involvement of users, carers, health and social care professionals working in different settings in integrated care planning meetings.

Experiences within CMHTs reflected these findings, which are consistent with some of the key characteristics identified by Onyett and Ford (1996) exemplifying effective teamwork. In-depth interviews revealed that team members' support, particularly when under pressure, was valued and that this support was enhanced by effective leadership, supervision, communication and commitment. Overall, views of the greater proportion of professionals about the move to integrated working were that it had improved continuity of care. These findings endorse the qualitative findings of Gulliver and colleagues (2002) and Lankshear (2003) relating to co-location (health and social care professionals being located in the same office or area within their organisations) in integrated working and its positive impact on team-working relationships and *cross-boundary continuity*.

The move to integration had resulted in the majority of professionals in both Trusts experiencing role changes, most markedly in Trust 2. Although many professionals and CMHT members were satisfied with role changes, almost one third of professionals in Trust 1 were dissatisfied; many nurses and managers were also dissatisfied. Receiving appropriate training and support is vital to equip professionals with the knowledge and skills to develop their roles, support integrated working and thereby continuity of care. In a wider context, it is intrinsic to delivering the quality of service agenda (Department of Health, 2004). Although the majority of professionals in this study were confident in their current level of skills to deliver continuity of care and, more generally, were satisfied with opportunities to gain new skills and identify relevant training, some problems had been experienced with selected aspects of skills acquisition (see below).

Barriers to team continuity can arise where role conflicts occur. Despite the generally positive experiences of integrated working, specific aspects of role change were described by nurses, social workers, psychologists and occupational therapists, which revealed tensions and conflicts for professional identities, role blurring and working across professional boundaries. These findings were consistent with those of Brown and colleagues (2000) and Blinkhorn (2004). In Trust 2, psychologists had retained a separate team to maintain professional boundaries and job demarcation. Concerns were also expressed about having to take on new roles without adequate training, which could have negative effects on quality and safety, for example, medication management by social workers, findings consistent with concerns expressed by Brown and colleagues (2000) and Rogers and Pilgrim (2001).

In both Trusts, the majority of professionals and, more specifically, managers, were dissatisfied with training provision for the management of integrated working, locum and agency staff. In Trust 2 alone, almost one third were not satisfied with opportunities to gain IT skills and the majority were not satisfied with the training provided to work in an integrated team. Within CMHTs, preparatory training for integrated working was viewed as unsatisfactory by most nurses and social workers and training preparation for role change was identified as a specific need. Difficulties accessing CPD were identified by managers and operational staff, ascribed to workload pressures, sickness rates and staff shortages, findings consistent with those reported more widely in primary care settings by Boudioni and colleagues (in press).

In addition to lack of specific training opportunities and role conflicts, leadership was also identified as an issue by professionals working in CMHTs reflecting earlier findings by Brown and colleagues (2000). In Trust 1 a traditional 'medical model' was common, where the psychiatrist led the team and for some professionals, issues arose about power-sharing and decision-making where authoritarian styles (negatively perceived) predominated. In Trust 2, the use of the medical model was reported less commonly and teams had been restructured to allow leadership by other professionals, with a move toward a more democratic process of decision-making. In the latter, however, poor quality of leadership was identified by some medical consultants. Again this could reflect a lack of training for leadership and management, or resistance to the move away from medically-dominated hierarchies. In a wider management context, professionals cited lack of management support and guidance for integrated working; in contrast some managers reported lack of guidelines (policy implementation), financial pressures impacting on business plans, gaps between themselves, and professional staff and accountability problems as barriers to effective working.

Factors which can impact on *cross-boundary continuity* are thus team structures, cultures, processes and roles supported by appropriate training. No significant differences were found between Trusts relating to integrated team working, team support, skill-mix, use of specialist teams and decision-making, which were all found to be effective and facilitators for continuity of care. Multi-disciplinary recording practices were found to be significantly more effective in Trust 1 than Trust 2, however, probably a reflection of problems with IT support in Trust 2. In both Trusts, the greater proportion of staff had experienced role changes since integration and although the majority were satisfied, 30% and 23% were dissatisfied with these changes in Trusts 1 and 2 respectively. Confidence in current level of skills to deliver continuity was similarly high in both Trusts, whilst training for the management of integrated working/team working was found to be unsatisfactory by the majority of staff in both organisations.

6.4.3. Information continuity

Information continuity has been defined as 'effective communication based on excellent information transfer following the service user' (Freeman *et al*, 2000) reflecting the emphasis recently placed on user-centred care in the NHS, which requires information to follow the user so it is 'available wherever and whenever needed' (Department of Health, 2006). The importance of consistency of information provided by health and social care professionals to users, underpinned by the need for professionals to share information related to monitoring observations, assessments, care plans and discharge/transfer to other care settings has been emphasised by Bosanquet and Kruger (2003). A challenge for *information continuity* is the high degree of mobility documented for users with SMI, which can result in loss of contact with service providers. The interfaces within and between organisations across which information is transferred can encompass acute care wards, CMHTs, General Practitioners, day centres, housing departments and a number of voluntary agencies including MIND and the Family Welfare Association. In a wider context, this has generated debate about use of electronic records, confidentiality of information and consent from service users to its dissemination (Orrell, 2006; Cundy & Hassey, 2006).

Key findings of this study were that the majority of health and social care professionals working in both Trusts reported that communication between team members and leaders was effective and a positive facilitator of continuity of care, as was communication with users and carers. Communication between team and senior management was also rated as effective and a facilitator of continuity by most professional staff. In terms of communication interfaces, it should be borne in mind that in both Trusts the teams operating were CMHTs and ward teams responsible for acute care. Approaches which were facilitative of information transfer were in operation, for example, some professionals working within and across both teams and the practice of involving CMHT members in ward rounds and holding integrated care-planning meetings with CMHT staff, users, carers, GPs and external agencies. Maintenance of multi-disciplinary records and communication with outside agencies were also viewed as effective and facilitators of continuity of care, notwithstanding problems with IT support. Positive aspects of multi-disciplinary verbal communication, enhanced through co-location and regular team meetings, were emphasised, consistent with Gulliver and colleagues' (2002) findings. Within an ethical framework, less secrecy in team communication was also noted to be facilitative. No issues were raised by professionals working in CMHTs in relation to problems with confidentiality of information.

Effective information-sharing through electronic systems is vital to support *information continuity*, underpinned by the development of computer skills in the workforce. A barrier to *information continuity* was the provision of IT equipment, rated as inadequate by the majority of professionals in Trust 2 and one third of professionals in Trust 1. Reasons for this were incompatibility of software systems between health and social service professionals working in CMHTs and the provision of ageing, outdated machines which were in some cases shared with other professionals and lack of finance to update provision. These findings are consistent with earlier concerns raised by the Policy Studies Institute (2001) and serve to emphasise current concerns about the time delays which have affected IT developments in the NHS. It has now been recognised that delivery of the national IT programme will take time to implement over the next ten years and that a phased process will address priorities (Department of Health, 2006). From the perspective of *information continuity*, these findings support the need for services supporting the SMI to be prioritised in terms of IT systems implementation.

It was a matter of concern that competition for available machines had resulted in extended hours working for some staff. Furthermore, although the majority of health professionals were satisfied with opportunities for IT skills training, up to one third were dissatisfied with current training provision. Another barrier to *information continuity* was poor communication, identified by voluntary service managers as exerting a negative impact on working relationships with service organisations.

Communication between team members and leaders, users, carers and external agencies in both Trusts was thus found to be effective and a facilitator of information continuity by the majority of staff. Significantly fewer staff in Trust 1 experienced communication with senior management as effective, although it was a facilitator of continuity in both organisations. Significantly more staff in Trust 2 had inadequate provision of IT equipment to support information transfer. Fewer staff in Trust 2 were satisfied with provision for IT training, although the majority rated this as satisfactory in both Trusts.

6.4.4. Longitudinal continuity

Longitudinal continuity was defined by Freeman and colleagues (2000) as continuity provided by 'as few professionals as possible, consistent with need'. This form of continuity is closely linked to *relational continuity*, which hinges closely on the long-term therapeutic relationships between professionals, users and also on care coordination. Potential benefits are that the limited numbers of professionals consistently involved become more knowledgeable about the user, preventing fragmentation and enhancing care. Organisational factors impacting on this are professional workloads, workforce stability, turnover and use of temporary staff.

Resources available to support *longitudinal continuity* showed significant variation across Trusts. Adequacy of direct funding, wards and beds available for user referrals was significantly lower in Trust 2, where, in marked contrast to Trust 1, the extent of resource provision was viewed as inadequate by the majority of staff. In both Trusts the accommodation available for users in the community was found to be inadequate by similar majorities.

6.4.5. Relational, personal and therapeutic continuity

Freeman and colleagues (2000) defined this form of continuity as the need 'to provide one or more individual professionals with whom the service user can establish and maintain a consistent therapeutic relationship.' In this context, the relationship between the user and case manager/coordinator is crucial. Seeing the same professional over time can potentially result in trust, mutual understanding and a sustained sense of responsibility towards the user by the professional (Reid *et al*, 2002) which can potentially bring therapeutic benefits. Organisational factors which can impact on this type of continuity include time available for user contact, which is in turn affected by professional workloads, caseloads and resources. Although the majority of professionals in both Trusts rated overall workloads and size of caseload as manageable, a key finding was that a narrow majority of professionals in both Trusts rated the time available for direct user contact as inadequate.

More specifically, in contrast to the experiences of psychiatrists, psychologists and occupational therapists, most nurses and social workers rated time for direct user contact as inadequate. Reasons for this were the high caseloads carried by some staff, unmanageable administrative and clerical loads (notable in Trust 2), increased paperwork (underpinned by lack of IT support) and for ward nurses time taken up with managing bed shortages. These findings reflected those of Blinkhorn (2004), who also cited similar problems created by increased bureaucracy and workloads. Although clerical support was available, it was used in the main to support psychiatrists with their paperwork, which accounted for the predominantly positive ratings on user contact by this professional group. Despite the administrative problems, the majority of professionals rated the quality of care as satisfactory.

Relational continuity can also be affected by the stability of the workforce, particularly the use of agency and locum staff to cover for staff shortages and sickness. In both organisations, the majority of professional staff rated use of agency/bank staff as high, albeit by a narrow margin. Opinion was divided about staff turnover, but staff sickness levels and turnover were rated as higher in Trust 2 than Trust 1. Strategies to enhance recruitment and retention had been helpful in offsetting staff shortages in one organisation, but were not clearly identified in the other; further management training could be helpful in this area.

Time for user contact was found to be inadequate for the majority of professionals working in both Trusts. Similarly, the majority of professionals found overall workloads and caseloads were manageable, administrative loads unmanageable and quality of care satisfactory. No significant differences were apparent in any of these parameters between Trusts. Staff sickness levels were significantly higher in Trust 2, but no significant differences were found between Trusts regarding the extent to which temporary staff were employed.

6.4.6. Long-term continuity

This was defined by Freeman and colleagues (2002) as the provision of 'uninterrupted care for as long as the service user requires it'. Given the nature of SMI, there is the potential for gaps in service provision to occur during periods of transition from hospital to community, which can create barriers to *long-term continuity*. Key findings from our study not conducive to smooth transitions and *long-term continuity*, were the inadequate numbers of wards/beds available to cope with acute admissions in Trust 2 and in both Trusts the consensus was that availability of accommodation in the community was inadequate. Long waiting-lists for flats and protracted time in hostel accommodation, resulting in delayed discharge from acute wards, were problematic. Nurses also described pressures on bed availability, resulting in movement of users around acute wards on-site disrupting continuity. Loss of day care facilities in Trust 2 had also proved problematic. The level of direct funding available to resource *long-term continuity* was viewed as inadequate by all professional groups. The need for clarity in user access to services was also identified as a potential barrier to achieving *long-term continuity*.

6.4.7. Service delivery: changing organisational cultures

Across both Trusts, the consensus view was that cultural change in terms of the integration of health and social care had been successfully achieved; that the process of integration had been satisfactory; and that overall, new patterns of working had impacted positively on continuity of care. Dissatisfaction with cultural integration was expressed by many nurses, however, the professional group who had experienced the greatest degree of role change since integration. Although pace of change was described as rapid and positive, for some professionals, experiences of change management and managerial consultation had not been positive. Securing local ownership and tailoring implementation strategies to the local context are vital for effective change management (Iles & Sutherland, 2001; Shaw *et al,* 2006).

Furthermore, the provision of training for integrated team working, management of integrated working and deployment of temporary workers had also been lacking for many professionals, whilst more than one third were dissatisfied with the time available for continuing professional development. These findings are consistent with other reports on access to CPD more widely in the primary care workforce, where staff shortages and organisational support can be barriers to uptake (Boudioni *et al*, in press). Implications are that both managerial and operational professional staff could benefit from training in the deployment of flexible working systems, leadership and preparation for specific aspects of integrated team working. Overall, however, the emerging culture of service delivery to support continuity of care was positive, marked by effective team working but with continuing challenges present in the form of resource deficits, bureaucracy, lack of administrative support and reduced time available for contact with users.

Box O16: Organisational Facilitators of Continuity of Care

Facilitator	Trust Performance
Co-location of health and social care professionals	No differences found between Trusts. Co-location for many CMHT staff viewed positively in both Trusts.
Integrated teamwork (CMHTs, acute support units); team skill-mix, communication between teams, users, carers, managers; decision-making structures; recording practices.	Effective, facilitators for continuity of care in both Trusts. Multi-disciplinary recording rated as effective by significantly more staff in Trust 1. Team and senior management communication rated as effective by significantly more staff in Trust 2.
Shared decision-making through collaborative meetings with key professional workers, service and external agencies, users and carers.	Shared decision-making reported in both Trusts but extent of this not established.
Democratic decision-making linked to models of care which maximise professional, user and carer inputs.	Shift to more democratic models of decision-making reported in both Trusts, but more common in Trust 2.
Effective leadership, participative management styles, professional supervision.	Empowerment of team leaders viewed positively in Trust 2. Exemplars of supportive supervision arrangements in both Trusts.

Box O19: Organisational Facilitators of Continuity of Care (continued)

Facilitator	Trust Performance
Access to CPD to enhance knowledge and skills intrinsic to continuity of care.	Confidence in current knowledge and skills high in both Trusts. Majority of staff in both Trusts satisfied with selected training opportunities.
Manageable workloads, caseloads and administrative support.	Manageable overall workloads and caseloads for majority of staff in both Trusts
Workforce stability; low sickness, staff turnover and use of temporary staff.	Use of temporary staff marginally lower in Trust 1, but opinion varied in both Trusts. Staff sickness levels significantly lower in Trust 1.
Adequate accommodation for users in a range of settings.	Wards and beds available for service user referral rated as adequate by significantly more staff in Trust 1. Direct funding available to meet resource requirements rated as adequate by more staff in Trust 1.

Box O17: Organisational Barriers to Continuity of Care

Barrier	Trust Performance
Poor change management, inadequate training preparation for integrated working, management of integrated working.	Some staff in both Trusts critical of lack of consultation in management of change regarding move to integration. Preparative training for integrated working rated as unsatisfactory by a greater proportion of staff in Trust 2 (ns). Preparative training for management of integrated working rated as unsatisfactory by greater proportion of staff in both Trusts (ns).
Inadequate provision of up-to-date computing systems which impedes information transfer.	Availability of IT equipment rated as inadequate by significantly more staff in Trust 2.
Inadequate education and training to support role development.	Majority of staff in both Trusts had experienced much role change since integration.
Inadequate administrative support limiting user contact.	Time for direct user contact rated as inadequate by majority of staff in both Trusts (ns). Administrative loads rated as unmanageable by more staff in Trust 2; divided opinion in Trust 1.
Conflicts for professional identity, role blurring and cross-boundary work.	Some conflicts reported by staff in both Trusts, concerns expressed about lack of training for generic working (particularly nurses and social workers). Separate team boundary for psychologists in Trust 2.

Box O17: Organisational Barriers to Continuity of Care (continued)

Barrier	Trust Performance
Ineffective leadership, authoritarian styles of management, decision-making models which do not maximise professional inputs.	Concerns expressed in both Trusts about some leadership approaches and persistence of medical models of decision-making; latter more common in Trust 1.
High use of temporary professional workers due to staff shortages.	Use of temporary workers rated as high by more than one third of staff in both Trusts (ns). Deployment of temporary workers rated as unsatisfactory by majority of staff in both Trusts (ns).
Inadequate user accommodation in a range of settings.	Significantly more staff in Trust 2 reported availability of wards and beds for user referrals as inadequate. Accommodation in the community rated as inadequate by most staff in both Trusts (ns).
Enhanced training and support needed to meet increasingly complex nature of users' mental health needs (dual diagnosis).	Reported by some staff in both Trusts.

6.5. Summary

- The original multi-axial model of continuity of care was reflected in professionals' views of continuity
- Flexible continuity was found to be dependent on flexible care-planning, as well as effective team skill-mix and communication
- Cross-boundary continuity may be affected by team structures, cultures, processes and roles
- Information continuity is affected by communication and provision of IT equipment to facilitate information-transfer and information sharing
- Longitudinal continuity must be supported by adequate resources and is affected by professional workloads, workforce stability, turnover and use of temporary staff
- Relational continuity may be affected by workforce stability and time allowed for user contact
- Long-term continuity may be adversely affected by gaps in service provision at points of transition from hospital to community.

7. Synthesis & Discussion

7.1. Continuity of care in mental health

This study started from the premise that continuity of care is 'often lauded but seldom defined' (Freeman *et al*, 2000). As anecdotal evidence would suggest and our Organisational Strand confirmed, professionals tend to recognise the idea of continuity of care and intuitively accept it as a worthy goal, despite the paucity of evidence about what it means in practice as well as its possible effects. By contrast, our Developmental Phase demonstrated that service users and carers rarely recognise the term, although they are well able to think about and discuss the concept.

The four strands of this study all took as their starting-point Freeman and colleagues' (2000) generic conceptualisation of continuity of care as a multi-axial concept comprising: *experienced*, *flexible*, *cross-boundary*, *information*, *longitudinal* and *relational continuity*, while the Main Phase also utilised the further types specific to mental health added by Freeman and colleagues (2002), *long-term continuity* and *contextual continuity*. Each strand took a different methodological approach to the measurement or exploration of continuity, however, consistent with that strand's aims.

Thus the ***Developmental Phase***, with the aim of capturing user and carer perspectives by developing measures generated by users and carers themselves, elicited items through focus group discussions. Because users and carers were unfamiliar with the term, definitions from the literature, including the multi-axial definition, were used to prompt them and enable them to develop their discussion of these concepts. A wide range of domains emerged for users (Box S1), including two new to the literature: whether the service user could avoid services if they wanted to and peer support. While avoiding services was the more contentious item, with many users in the focus groups not perceiving its relevance and nearly half the users in the Main Phase cohort with psychotic disorders rating it as inapplicable, peer support was clearly highly valued by the majority, although less so than was the case for other domains.

The ***Organisational Strand*** sought professionals' definitions of continuity of care and explored these qualitatively. It used the multi-axial definition as a framework for interpretation of these findings, finding this framework relevant for the professionals surveyed.

The ***Main Phase*** of the study operationalised the multi-axial definition to enable the collection of quantitative longitudinal data. We used the global scores of the new measures, CONTINU-UM and CONTINUES, as proxies for *experienced continuity* (as an overarching concept) for users and carers respectively, but necessarily operationalised the remainder utilising multiple components. By exploring the relationships between these components through a factor analysis, we found them to be grouped differently in practice, providing a new seven-factor model comprising: *Experience & Relationship*, *Regularity*, *Meeting Needs*, *Consolidation*, *Managed Transitions*, *Care Coordination* and *Supported Living*. These have clear relationships with the different elements of the multi-axial definition.

The ***Qualitative Strand*** conducted in-depth interviews focusing on users' and carers' experiences, analysed using grounded theory. The emerging themes were therefore named without reference to either the multi-axial definition or the Main Phase's seven-factor model as: 'relational (dis)continuity', 'depersonalised transitions', 'invisibility and crisis', 'communicative gaps' and 'social vulnerability'. While they emerged from the perspectives of users and carers in the two Main Phase cohorts, they again bear some relationship to the Main Phase continuity factors and the multi-axial definition.

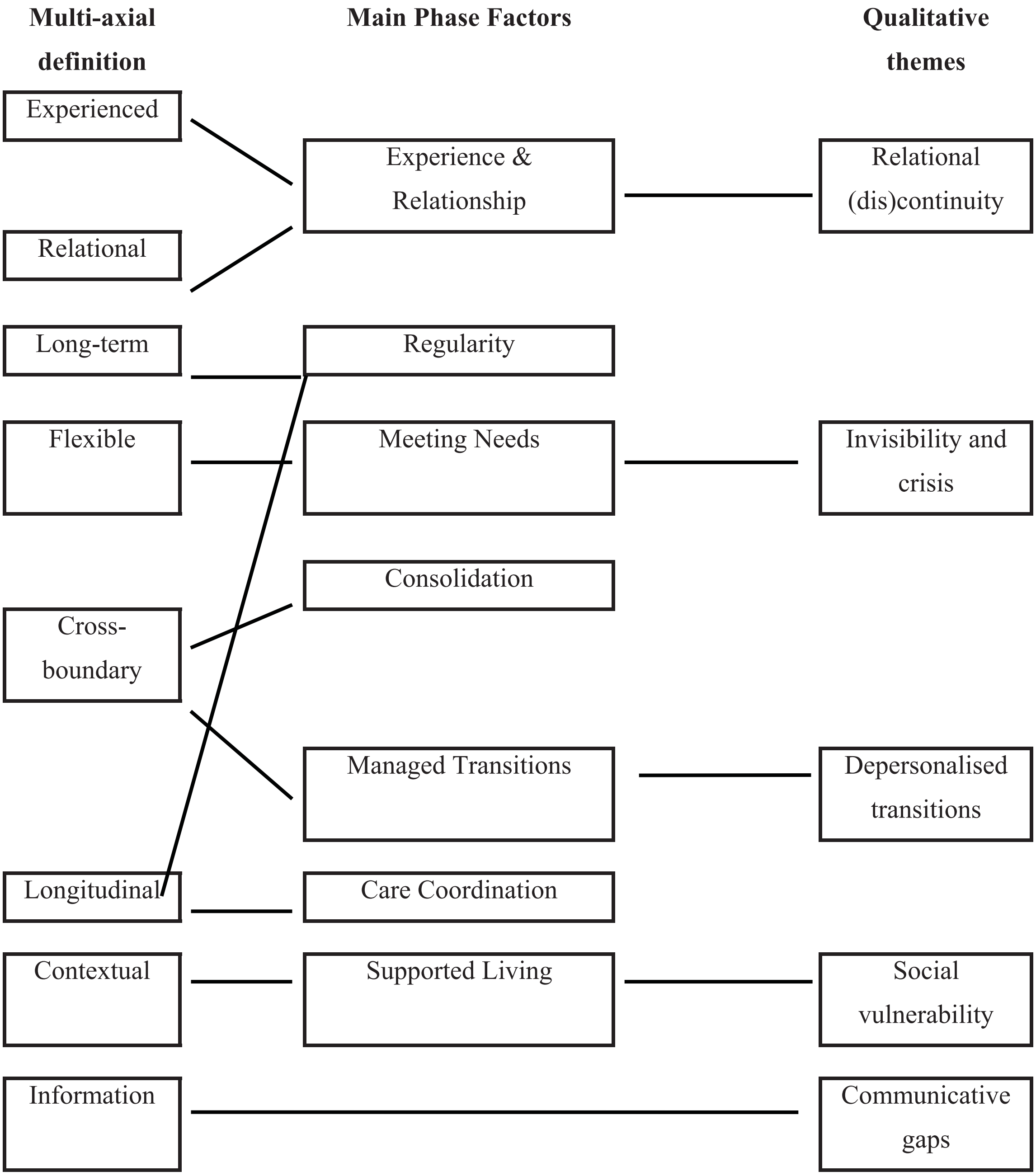
Figure 5 lists these different definitions, factors and themes, with Main Phase factor names followed by the multi-axial definitions they best match. 'Relational (dis)continuity' relates to both *relational continuity* and the *Experience & Relationship* factor. 'Depersonalised transitions' relates to *cross-boundary continuity* and the *Managed Transitions* factor. 'Invisibility and crisis' seems to be the counterpart to *flexible continuity* and *Meeting Needs*: where these were conceptualised as services responding to those with changing clinical needs, especially those in crisis, users interviewed in-depth emphasised that they felt ignored if they were *not* in crisis, as well as voicing their concerns about the response to early phases of crisis not always being adequate. The findings of the factor analysis of CONTINU-UM further suggested that it measures one general continuity factor, plus two further factors, measuring 'transitions' and 'preconditions for continuity'. While the latter is harder to interpret, the emergence of ‘transitions’ as a factor is comparable to the emergence of *Managed Transitions* as a factor in the Main Phase analysis and is further supported by qualitative evidence about the importance of transitions, in particular hospital admission and discharge.

While the differences between the continuity factors and the qualitative themes are of interest, however, and offer different perspectives on continuity of care, it is clear that the similarities between the multi-axial definition, continuity factors and qualitative themes are greater than their differences, although the user perspective also provided two important new domains. This study thus provides clear evidence of the robustness of this conceptualisation of continuity of care for service users with mental health problems.

Box S1: CONTINU-UM and CONTINUES domains

CONTINU-UM	CONTINUES
Accessing services	Staff involve carers
Range of services	Staff act on what carers tell them
Choice	Staff inform carers
Waiting	Establishing relationships with staff
Out of hours support	Confidentiality
Hospital discharge	Hospital admission
Staff changes	Hospital discharge
Information	Staff changes
Flexible levels of support	Carer support groups
Individual progress	Carer’s access to support from services
Day centres	User’s access to support from services
Care plans	
Crisis	
Communication between staff	
Support from other users	
Repeating your life history	
Avoiding contact with services	

Figure 5: Continuity definitions, factors and themes



7.2. Professional, user and carer views

The congruence of professional or managerial and user and carer views of continuity was assessed in multiple ways. As noted, the Developmental Phase used the multi-axial definition of continuity as a prompt but generated the components of continuity from focus groups of users and carers. This produced two domains unfamiliar from the literature, being able to avoid services and peer support, while the users' and carers' perspectives on some of the existing domains contrasted with the professional literature. Most notably, while professionals saw *information continuity* as involving information transfer *about* the service user, users themselves saw it as involving information coming to them, including copies of correspondence between professionals. The data collection methods of the Main Phase reflected this emphasis, although components related to *information continuity* did not form a separate continuity factor in our analysis.

The inclusion of professional views in the Main Phase had the more modest aim of assessing the concordance between care coordinator and user views of two aspects of continuity: needs for care (CAN) as a proxy for *flexible continuity* and therapeutic relationship (STAR) as a proxy for *relational continuity*. In neither case was concordance very strong, although this is not unusual. The Main Phase factor analysis, in demonstrating how continuity of care works in practice for our cohorts, sheds further light on contrasts between professional and user views, as does the analysis of the Qualitative Strand (as discussed above). Finally, the Organisational Strand sought the views of mental health professionals on continuity of care and found the multi-axial definition to have utility in a wide range of professional groups.

7.3. Continuity for the Main Phase service users

The study set out to focus on a group of service users with psychotic disorders who, by virtue of the nature of their illness and its chronicity, were expected to be receiving consistent and stable care. In fact, although the cohort was recruited according to the inclusion criteria, they experienced far more transitions in their care than anticipated, including being discharged. The cohort with non-psychotic disorders, although recruited using the same criteria regarding duration of illness and contact with the CMHTs, were an even more mobile group, experiencing more transitions and discharges during the follow-up year. It may be that continuity of care, in the senses utilised by this study, is far less regularly achieved for these groups than many professionals believe, with far more needing to be done to achieve it than is often assumed.

In-depth interviews with sub-groups of these service users for the Qualitative Strand revealed many commonalities with the perspectives of users accessed through the Developmental Phase, as expressed in the items of CONTINU-UM, as well as reflecting and enhancing the quantitative findings of the Main Phase. The in-depth interviews attested to frequent changes of staff: also a finding of the Organisational Strand, which uncovered professional concerns about staff turnover and its detrimental impact on continuity. Staff turnover frequently led to the repetition of the user's life story (an item of CONTINU-UM). Users also spoke of the need for help with social needs such as housing and benefits, reinforcing the importance of *flexible continuity* in the sense of meeting a range of needs, which emerged as a continuity factor (*Meeting Needs*) in the Main Phase analysis.

While *information continuity* did not come out as a free-standing factor in the Main Phase analysis, the importance of information flow and communication was highlighted by the Qualitative Strand, which identified that communication needed to be between different services and between services and the user (as well as the carer, discussed below). This echoes the reinterpretation of *information continuity* by the user focus groups in the Developmental Phase to emphasise information being passed to users as well as about them. Moreover, where the user-generated measure emphasised the importance of being able to disengage from services when the user wished it, the users interviewed in-depth emphasised the need to request a change of care coordinator where the relationship was not working, mentioning the lack of information about how this could be achieved. Both findings emphasise the importance of *dis*continuity when it is in the service user's interest.

7.4. Continuity and service structures

In view of the need to enhance continuity of care for these chronically ill populations, it is helpful to realise that, even with such established disorders as schizophrenia, healthcare organisation may have discernible effects at the service user level. We found several aspects of continuity of care to be significantly different in practice between the two adjacent mental health Trusts, despite there being no differences in clinical and social functioning between service users in the two Trusts at T1 in either cohort. Apparently superficial differences in how services deliver the same model of care (here, generic CMHT care) may have clear impacts. The experiences of continuity of care reported here both quantitatively and qualitatively are clearly not intrinsic to the illness, and attention to organisational aspects has real potential to improve users' experiences. For instance, the continuity factor *Regularity* (being seen more frequently by fewer different non-medical staff) was very much lower for service users with psychotic disorders if they were in Trust 2 (with those in the lowest quartile for this factor all being in Trust 2). This is not surprising given that Trust 2 was going through a great deal of reorganisation during the course of the study with clear impacts at the team level. (*Consolidation* was higher for users with psychotic disorders if they were in Trust 2, however.) The impact of this major reorganisation was attested to in the in-depth interviews, where users reported that transitions caused by restructuring were as significant and problematic as those caused by hospital admission and discharge, having an adverse effect on relationships between users and professionals.

The findings of the Organisational Strand suggested that the paucity of day care in Trust 2 might be expected to be problematic. Consistent with this, *Supported Living* was higher for users with psychotic disorders in Trust 1 than those in Trust 2. They also suggested that *flexible continuity* might be less good in Trust 1 owing to greater use of a more medical model of decision-making. This may relate to the finding that *Meeting Needs* scores for the group with non-psychotic disorders were lower for those in Trust 1; for the group with psychotic disorders, however, they were *higher* for those in Trust 1.

Staff turnover was greater in Trust 2. This would be likely to have an adverse effect on *relational continuity* and therefore on the factor *Experience & Relationship*. Again, Main Phase findings only partially supported this, with *Experience & Relationship* being higher for users with psychotic disorders in Trust 1 than in Trust 2, but the contrary relationship being found between the Trusts for users with non-psychotic disorders. There were no differences of a meaningful magnitude in *relational continuity* (therapeutic relationship) mean scores at T1 between the two Trusts in either cohort. It is of concern, however, that at T1 20 service users with psychotic disorders in Trust 2 (22.2%, all of whom were on the ‘enhanced’ level of CPA) reported that they had not seen a care coordinator in the previous year. Among Trust 1 service users, this was very rare (three users, 3.5%) and from the cohort with non-psychotic disorders only one user (also from Trust 2) reported such a situation.

Staff turnover is also likely to affect *Regularity* and this was confirmed by the Main Phase, with *Regularity* scores being higher for users with psychotic disorders in Trust 1. Professionals in both Trusts also rated time for user contact inadequate. This may partially account for the only moderate levels of *relational continuity* (therapeutic relationship) reported and this had an impact on the overall levels of *Experience & Relationship*. This is of particular concern not only because this was the factor accounting for most of the variance in the Main Phase continuity data, but because in-depth interviews confirmed the importance of therapeutic relationships to users. Previous research has also noted the adverse effects of high nursing turnover on communication, engagement and medication management (Minore *et al*, 2005).

The relationship between Trust and some factors thus differed between the two cohorts. In other cases, Organisational Strand findings were not confirmed by Main Phase analyses. The finding that Trust 2 had inadequate resources to support *longitudinal continuity* was not reflected in the Main Phase findings for *Care Coordination*. The inadequacy of bed provision in Trust 2 might also have been expected to make *Managed Transitions* worse for service users in Trust 2, but there was no evidence of this in the Main Phase analyses.

The Main Phase was not able to measure any differential relationships between continuity of care and narrower diagnostic groups, such as bipolar disorder or personality disorder. The need to recognise the disparate needs of different groups has been attested to for in the case of, for example, bipolar disorder (Morriss *et al*, 2002). It is equally important not to assume that care structures will be equally effective regardless of diagnosis, as optimal methods may be different for different care groups.

7.5. Continuity and outcomes

This study was designed to be exploratory and inevitably, therefore, the conclusions that can be drawn about causality are limited. Nevertheless, the study did demonstrate that those users with higher *Consolidation* scores (seeing fewer different agencies and not using primary care) at T1 were more likely to be discharged during the course of the follow-up period.

The findings of the Main Phase also provide some evidence of an interplay between professionals and service users, suggesting that continuity of care may be a dynamic process. This was particularly the case with the factor *Meeting Needs* and the components involving different ratings of need (total level, proportion of needs met, number of met needs), which the Confirmatory Factor Analyses suggested loaded onto several different factors. This seems to give evidence of an interaction between professional inputs and service user experiences, suggesting that treatment may be continually calibrated against service user need. Users with higher *Meeting Needs* scores had more met needs but also more care needs overall. It seems as though an increase in the level of need was met by increased professional attention to meeting those needs. Responsiveness of professionals to their users' clinical needs was something that service users and carers valued – perhaps emphasised by the loading of the 'proportion of needs met' onto *Experience & Relationship* as well as by the in-depth interviews - but service users also emphasised the importance of receiving preventative or supportive care when not in crisis.

This phenomenon may be comparable to what Weaver and colleagues (2003) have called 'sensitive anticipatory casework', whereby professionals keep attuned to changes in service users' needs and respond to them so as to avert deterioration or crisis. The extent to which this was successful for the service users in our study is unclear, however. While the Main Phase quantitative analysis provides evidence of such dynamism, the users interviewed in-depth in the Qualitative Strand felt that crises were not being sufficiently anticipated and that, on the contrary, they were invisible to services unless in crisis. These in-depth interviews also demonstrated clearly that continuity of care, particularly where it concerns relationships between users and professionals, may be fragile and subject to the various impacts of changing social context and care transitions. This also provides further evidence of a limitation of the natural science model for mental health service research, as the context – both the social context in which users live their lives and services are offered and the personal context of users' experiences, feelings and symptoms – are always in a state of flux.

What is as yet unclear, however, is to what extent the effects of different facets of continuity may be additive. While we have been able to delineate seven distinct factors that reflect different aspects of continuity of care, further evidence is needed about which are more important to user experiences and outcomes. For instance, *Experience & Relationship* (onto which loaded the measure of *relational continuity* and the user-generated CONTINU-UM) was the factor that accounted for most of the variance in continuity data. There was no clear evidence of its association with outcome, although sustained relationships between users and professionals have previously been found to be associated with greater satisfaction and decreased hospitalisation and emergency department visits (Cabana & Jee, 2004) while good therapeutic relationships have been found to be associated with a range of outcomes (Catty, 2004). Moreover, in our study, in-depth interviews revealed that *relational continuity* (or discontinuity) was regarded as key by users themselves. In view of this qualitative finding, the fact that overall levels of *relational continuity* (therapeutic relationship) were modest, while those of *experienced continuity* (CONTINU-UM) were low, is of real concern.

It is also noteworthy that focusing care on a single care coordinator was no guarantee in itself of better *relational* or *experienced continuity* (as *Care Coordination* was not associated with *Experience & Relationship*). Moreover, service users in the Main Phase reported both anecdotally and in the in-depth interviews not liking having to see multiple psychiatrists, even if they had a single care coordinator (which the loading of 'designated psychiatrist' onto *Care Coordination* suggested was common, with users more likely to see no psychiatrist or more than two if they saw only one or two care coordinators).

7.6. Continuity for Carers

The conclusions that can be drawn about continuity of care for carers are more limited. Nevertheless, the development of CONTINUES, along with the findings of the Qualitative Strand, stand in marked contrast to the dearth of literature on what continuity of care means for the carers of people with mental health problems. Carers generated a range of items about continuity of care as it affects both them and the people for whom they care. In contrast to many studies in other areas of healthcare, where carers' views may be sought on the experiences of the service user, the carers participating in focus groups generated a wide range of items concerning the continuity of care as experienced by carers themselves; indeed, most of the items of CONTINUES have this focus (see Box S1). These items make clear the value placed by carers on professionals involving carers in planning and information-sharing and they emphasised that information flow might be from the carer to the professional (with services taking carers' views into account) as well as vice versa. Alongside the users' emphasis on their relationships with professionals, then, is a clear message from carers too about their being able to establish relationships with staff: and this was also borne out by the findings of the Qualitative Strand. The focus groups carers thus also highlighted the importance of carers themselves receiving support from services.

While having a carer's assessment was not an item of CONTINUES, attending a carer's support group was and both might be seen as part of the process of receiving support from services, while having had a carer's assessment was associated with a higher CONTINUES score in the Main Phase cohort. Only 19% of the carers in the Main Phase cohorts had had a carer's assessment and 15.4% had attended a support group at T1, which may partially account for the low overall levels of CONTINUES in these groups.

That the two continuity measures, CONTINU-UM and CONTINUES, were positively correlated suggests that a service user's self-rated experience of continuity of care may have an impact on their carer's experience of continuity, as well as providing evidence of the measures' construct validity. There was no evidence of any relationship between experienced continuity (CONTINUES) and carers' experiences of caregiving, however, and there was some, counter-intuitive evidence of an inverse relationship with psychological wellbeing.

7.7. Evaluation of user input into ECHO

The support organisation 'INVOLVE - promoting public involvement in NHS, public health and social care research' (<www.invo.org.uk>) has established a set of criteria commonly used in the assessment of user involvement in research (Hanley *et al*, 2003). These are consultation, collaboration and control with the amount of user involvement increasing through each stage. We feel that all three types of user involvement have been key features of this research.

Consultation: SURE (Service User Research Enterprise, which led the Developmental Phase) was consulted at various stages of the Main Phase research, most typically at quarterly meetings and at a study day.

Collaboration: The Steering Group for the Developmental Phase was multi-disciplinary and included user, clinical and social science academics. This enabled a variety of perspectives to be gained on the data and its interpretation. SURE was involved in the design of ECHO and contributed to the interpretation of Main Phase data.

Control: The data collection, analysis and write-up for the Developmental Phase involved Diana Rose and Angela Sweeney, both of whom have experience of using mental health services. Angela Sweeney also supports a relative with a diagnosis of mental health problems.

8. Conclusions and Recommendations

8.1. Conclusions

- Continuity of care in mental health is a multi-faceted concept comprising at least seven distinct factors
- We have produced two psychometrically sound consumer-generated measures of continuity for use with service users and carers
- Continuity of care is affected by care structures, which may have a differential impact on different diagnostic groups
- Continuity of care is adversely affected by organisational change, the impact of which was judged by users as equivalent to hospital admission
- Continuity is likely to be a dynamic process in the inter-relationship between services, professionals, service users and carers
- Continuity of care is fragile, with even robust relationships between users and professionals being easily jeopardised by transitions or disruptions in care that do not pay adequate heed to users' circumstances.

8.2. Recommendations

8.2.1. Clinical Recommendations

- Service re-organisation should only be undertaken in view of compelling evidence for likely increased effectiveness, given the overwhelming evidence of its adverse impact on continuity of care
- Attention should be paid to a comprehensive range of needs rather than to addressing only the most obvious and pressing clinical needs
- Higher priority should be given to the therapeutic relationship (relational continuity) in service provision, including increased time for user contact.
- Users should be made aware of their care plans and regular contact with a care coordinator should be provided.
- Clinicians should attend to their relationships with carers in order to maximise communication.
- Staff training should aim to:

  - Incorporate understanding and the importance of social context at the point of transition
  - Incorporate methods of avoiding the perception of 'repetitiveness' of taking user histories
  - Emphasise the importance of confidentiality when working with users and carers.

8.2.2. Social Recommendations

- Adequate day care should be provided.
- Accommodation resources to support continuity of care in service settings should be reviewed.

8.2.3. Policy Recommendations

- Services supporting the care of people with mental health problems should be prioritized in terms of IT provision linked to a review of current models of administrative support.
- Further education and training as part of CPD (multi-disciplinary, team focus where appropriate) should be prioritised in the following areas to enhance continuity of care:
  - Integrated team working and team leadership.
  - Role development and competencies within CMHTs.
  - Management styles, change management strategies, management of temporary workers.
  - Strategies to maximize recruitment and retention of staff and minimize workforce turnover.
  - Models of care for the SMI; meeting users complex care needs for dual diagnosis, for example where alcohol and substance abuse co-exist with SMI.

8.2.4. Future Research

- Consideration should be given to including continuity of care routinely in service evaluations comparable to the way in which health economic outcomes or quality of life are currently included

- CONTINU-UM and CONTINUES should be promoted and tested in further studies, with a view to inclusion in such service evaluations
- Further work should be done to validate these measures for service users with non-psychotic disorders and for other chronic conditions
- This should be part of developing a battery of measures for evaluating continuity of care routinely
- Further work is needed to identify the optimal continuity of care factors as the minimum necessary components of care for service users with chronic mental health problems
- Given the increased emphasis on services focused on target populations, further work is needed to explore the differential impacts of continuity factors on different diagnostic groups (e.g. bipolar disorder, personality disorder)
- Studies of key organisational features are recommended (e.g. leadership styles, staff turnover)
- Research is needed to examine the impact of the increasing emphasis on user involvement in government initiatives on continuity of care
- Research is needed to gather longitudinal qualitative data on user ‘careers’ within the health care system
- Research is needed on improving methods of communication between primary and secondary care and health and social care workers and their clients.
- Exploration is needed of multi-professional models of decision-making within teams in CMHTs.

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Experiences of Continuity of Care and Health and Social Outcomes: The ECHO Study

Appendices

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Appendix 1: CONTINU-UM

Users' Experiences of Continuity of Care

- This questionnaire is to find out about users' views, experiences and satisfaction with different aspects of continuity of care over the past 12 months.
- It should take no more than 30 minutes to complete.
- There are 17 topics. Please read the introduction to each topic carefully.
- There are 3 short questions in each topic. Please circle your answer to these questions.
- Your answers to questions should be about your experiences of services in general.
- If you feel that a topic is not applicable, please write 'n/a' clearly next to the question number. You can explain why the question is not applicable in part d if you wish.
- If you are not sure about anything please ask the researcher.
- At the end of each topic there is an opportunity to add anything else you would like to say. Please write clearly in the spaces provided if you would like to do so.

Notes on the wording

- **Staff**

Staff here refers to anybody that you see for your mental health.

- **User**

The term 'user' has sometimes been used and means somebody who is, or has been, in contact with mental health services.

Topic One: Accessing Services

The first topic is accessing or getting services. This is about how easy it is to get the services you feel you need at the time that you need them.

1.a. How important is it that you can easily access services when you need to?

very important	important	sometimes important / sometimes not	not important	very unimportant

1.b. Over the past 12 months, have you been able to easily access services when you've needed to?

definitely	mostly	sometimes / sometimes not	partly	definitely not

1.c. How satisfied are you with this?

very satisfied	satisfied	sometimes satisfied / sometimes not	dissatisfied	very dissatisfied

1.d. Would you like to say any more about accessing services?

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Topic Two: Range of Services

This section looks at the range of services you are able to get. This is about getting the whole range of services you feel would help you, regardless of whether anyone else agrees or those services aren't available to you.

2.a. How important is it that you can get all the services you feel you need?

very important	important	sometimes important / sometimes not	not important	very unimportant

2.b. Over the past 12 months, have you been able to get all the services you feel you need?

definitely	mostly	sometimes / sometimes not	partly	definitely not

2.c. How satisfied are you with this?

very satisfied	satisfied	sometimes satisfied / sometimes not	dissatisfied	very dissatisfied

2.d. Would you like to say any more about the range of services you can get?

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Topic Three: Choice

This topic is about the amount of choice you have over the kinds of treatments you receive. This means the power you have to decide which treatments you get, again, regardless of what staff think or whether it's available.

3.a. How important is it that you have choice over the types of treatments you receive?

very important	important	sometimes important / sometimes not	not important	very unimportant

3.b. Over the past 12 months, have you had choice over the types of treatments you've received?

definitely	mostly	sometimes / sometimes not	partly	definitely not

3.c. How satisfied are you with this?

very satisfied	satisfied	sometimes satisfied / sometimes not	dissatisfied	very dissatisfied

3.d. Would you like to say any more about choice?

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Topic Four: Waiting

The next topic is waiting. This is about how long you have to wait to receive the services you need.

4.a. How important is it that you <u>don't</u> have to wait for services?

very important	important	sometimes important / sometimes not	not important	very unimportant

4.b. Over the past 12 months, have you had to wait a long time to receive services?

definitely	mostly	sometimes / sometimes not	partly	definitely not

4.c. How satisfied are you with this?

very satisfied	satisfied	sometimes satisfied / sometimes not	dissatisfied	very dissatisfied

4.d. Would you like to say any more about waiting for services?

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Topic Five: Out of hours support

This topic is about getting support from services outside of normal office hours. This means getting the support you need at any time of the day or night, at the weekends or during holiday periods.

5.a. How important is it that you have access to support from services outside of office hours?

very important	important	sometimes important / sometimes not	not important	very unimportant

5.b. In the past 12 months, have you had access to support from services outside of office hours?

definitely	mostly	sometimes / sometimes not	partly	definitely not

5.c. How satisfied are you with this?

very satisfied	satisfied	sometimes satisfied / sometimes not	dissatisfied	very dissatisfied

5.d. Would you like to say any more about support outside of office hours?

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Topic Six: Hospital discharge

The next topic is about what happens when people come out of psychiatric hospitals. Specifically, it is about you getting whatever support you feel you need.

Have you been discharged from a psychiatric hospital in the past 12 months? Please circle your answer:

Yes – go to 6.a.
No – go to 7.a.

6.a. How important is it that you receive the support you need from services when you leave hospital?

very important	important	sometimes important / sometimes not	not important	very unimportant

6.b. Over the past 12 months, have you received the support you've needed from services when you have left hospital?

definitely	mostly	sometimes / sometimes not	partly	definitely not

6.c. How satisfied were you with this?

very satisfied	satisfied	sometimes satisfied / sometimes not	dissatisfied	very dissatisfied

6.d. Would you like to say any more about hospital discharge?

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Topic Seven: Staff Changes

This topic is about members of staff changing. This means that the staff you see are the same each time you go. Please think about all of the professionals involved in your care when you answer.

7.a. How important is it that staff involved in your care don't change frequently?

very important	important	sometimes important / sometimes not	not important	very unimportant

7.b. Over the past 12 months, have the staff involved in your care changed frequently?

very often	often	sometimes	not often	never

7.c. How satisfied were you with this?

very satisfied	satisfied	sometimes satisfied / sometimes not	dissatisfied	very dissatisfied

7.d. Would you like to say any more about staff changing?

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Topic Eight: Information

The next topic is information. Information means anything that you would like to know or would help you to know and can be written or spoken. Specifically, it's about whether you are getting the information that you want or need from staff.

8.a. How important is it that you can get appropriate information from staff?

very important	important	sometimes important / sometimes not	not important	very unimportant

8.b. Over the past 12 months, have you been able to get appropriate information from staff?

definitely	mostly	sometimes / sometimes not	partly	definitely not

8.c. How satisfied are you with this?

very satisfied	satisfied	sometimes satisfied / sometimes not	dissatisfied	very dissatisfied

8.d. Would you like to say any more about information?

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Topic Nine: Flexible Levels of Support

This topic is about the levels of support you receive and whether these match your changing needs. This means that if you change or your mental health changes, what you get from services changes as well.

9.a. How important is it that the level of support you get from services changes to match your needs?

very important	important	sometimes important / sometimes not	not important	very unimportant

9.b. Over the past 12 months, have the levels of support you get from services changed to match your needs?

definitely	mostly	sometimes / sometimes not	partly	definitely not

9.c. How satisfied are you with this?

very satisfied	satisfied	sometimes satisfied / sometimes not	dissatisfied	very dissatisfied

9.d. Would you like to say any more about levels of support?

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Topic Ten: Individual Progress

This section looks at staff and services helping people to move forward. This means that services seek to help you progress, rather than keeping you where you are.

10.a. How important is it that services aim to help you move forward?

very important	important	sometimes important / sometimes not	not important	very unimportant

10.b. Over the past 12 months, have the services you've received helped you to move forward?

definitely	mostly	sometimes / sometimes not	partly	definitely not

10.c. How satisfied are you with this?

very satisfied	satisfied	sometimes satisfied / sometimes not	dissatisfied	very dissatisfied

10.d. Would you like to say any more about moving forward?

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Topic Eleven: Day Centres

The next topic looks at day centres. This means that you have the option to go to a day centre that would help you, if you wanted to.

11.a. How important is it that you have access to day centres that suit your needs?

very important	important	sometimes important / sometimes not	not important	very unimportant

11.b. Over the past 12 months, have you had access to day centres that suit your needs?

definitely	mostly	sometimes / sometimes not	partly	definitely not

11.c. How satisfied are you with this?

very satisfied	satisfied	sometimes satisfied / sometimes not	dissatisfied	very dissatisfied

11.d. Would you like to say any more about day centres?

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Topic Twelve: Care plans

The next topic is about care plans. A care plan is a plan of treatment. It is a written agreement between yourself and staff/services about what is going to happen in your care.

Do you have a care plan? Please circle your answer.
Yes – go to 12.a.
No – go to 13.a.

12.a. How important is it that you have a care plan you agree with?

very important	important	sometimes important / sometimes not	not important	very unimportant

12.b. Over the past 12 months, have you agreed with your care plan?

definitely	mostly	sometimes / sometimes not	partly	definitely not

12.c. How satisfied are you with this?

very satisfied	satisfied	sometimes satisfied / sometimes not	dissatisfied	very dissatisfied

12.d. Would you like to say any more about care plans?

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Topic Thirteen: Crisis

This section is about systems to deal with a crisis. This means that there is something in place to help you when you are most in need and that you have agreed with people what will happen if you go into crisis and are happy with this.

13.a. How important is it that you have systems in place for dealing with a crisis?

very important	important	sometimes important / sometimes not	not important	very unimportant

13.b. Over the past 12 months, have you had systems in place for dealing with a crisis?

definitely	mostly	sometimes / sometimes not	partly	definitely not

13.c. How satisfied are you with this?

very satisfied	satisfied	sometimes satisfied / sometimes not	dissatisfied	very dissatisfied

13.d. Would you like to say any more about crisis?

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Topic Fourteen: Communication between staff

This section looks at the communication between staff. This means that the people involved in your care tell each other what is happening and that all staff are informed of any changes in your health, circumstances, care or treatment.

14.a. How important is it that staff involved in your care communicate with each other?

very important	important	sometimes important / sometimes not	not important	very unimportant

14.b. Over the past 12 months, have the staff involved in your care seemed to communicate with each other?

definitely	mostly	sometimes / sometimes not	partly	definitely not

14.c. How satisfied are you with this?

very satisfied	satisfied	sometimes satisfied / sometimes not	dissatisfied	very dissatisfied

14.d. Would you like to say any more about communication between staff?

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Topic Fifteen: Support from other users

This topic is about the support you receive from other people who use mental health services. This means the levels of help you get from others who have experienced similar things to you.

15.a. How important is the support of other people who have experienced mental distress?

very important	important	sometimes important / sometimes not	not important	very unimportant

15.b. Over the past 12 months, have you had support from other people who have experienced mental distress?

definitely	mostly	sometimes / sometimes not	partly	definitely not

15.c. How satisfied are you with this?

very satisfied	satisfied	sometimes satisfied / sometimes not	dissatisfied	very dissatisfied

15.d. Would you like to say any more about the support of other users?

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Topic Sixteen: Repeating Your Life History

This topic is repeating your life history. This means explaining your mental health to members of staff that you are seeing for the first time.

16.a. How important is it that you <u>don't</u> have to tell your life history to new staff?

very important	important	sometimes important / sometimes not	not important	very unimportant

16.b. Over the past 12 months, have you had to tell your life history to new staff?

very often	often	sometimes	not often	never

16.c. How satisfied are you with this?

very satisfied	satisfied	sometimes satisfied / sometimes not	dissatisfied	very dissatisfied

16.d. Would you like to say any more about repeating your life history?

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Topic 17 – Contact with services

The final topic is about the amount of contact you have with services. This means that you are able to choose when you see services, including being able to choose not to have contact with services if you don’t want to.

17.a. How important is it that you can avoid contact with services when you want to?

very important	important	sometimes important / sometimes not	not important	very unimportant

17.b. Over the past 12 months, have you been able to avoid contact with services if you have wanted to?

definitely	mostly	sometimes / sometimes not	partly	definitely not

17.c. How satisfied are you with this?

very satisfied	satisfied	sometimes satisfied / sometimes not	dissatisfied	very dissatisfied

17.d. Would you like to say any more about avoiding contact with services?

....

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Please continue to next page

Some final questions

1.) Which of the topics covered in this questionnaire (from 1 to 17) is the **most** important to you? (find a list below)

☐

2.) Which of topics covered in this questionnaire (from 1 to 17) is the **least** important to you?

☐

Checklist of topics:

1. Accessing services
2. Range of services
3. Choice
4. Waiting
5. Out of hours support
6. Hospital discharge
7. Staff changes
8. Information
9. Flexible levels of support
10. Individual progress
11. Day centres
12. Care plans
13. Crisis
14. Communication between staff
15. Support from other users
16. Repeating your life history
17. Contact with services

3.) Did you find any of the questions:

- Distressing? Yes ☐ No ☐
- Confusing? Yes ☐ No ☐
- Difficult to understand? Yes ☐ No ☐

4.) Questionnaire length: Did it seem….

Too long? ☐ Just right? ☐ Too short? ☐

5.) Questionnaire enjoyment: When you filled in the questionnaire, did you….

Enjoy it? ☐ Have neutral feelings? ☐ Dislike it? ☐

6.) How easy was it to fill in?

Easy ☐ Mixed ☐ Difficult ☐

Please use this space to add any final comments

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Appendix 2: Psychometric testing of CONTINU-UM

Methods

Framework

The framework for assessing the properties of the measure was based on the work of Fitzpatrick and colleagues (1998) and its development by Harvey and colleagues (2005). Ten criteria for evaluating outcome measures were selected due to their breadth, the inclusion of qualitative elements and a user/family focus. Table 1 gives an overview of the ten criteria and their evaluation.

Table 1: Framework for evaluating the psychometric properties of CONTINU-UM		
Criterion	**Definition**	**Evaluation**
Importance[1]	The construct being measured is important to respondents.	Consideration of method of development.
Involvement[1]	Involvement of users/carers in the development of the outcome measure	Consideration of method of development.
Reliability[2]	The measure produces results that are internally consistent & reproducible.	Assessment of internal consistency, test retest reliability & comparison of conditions (user or non-user researcher & mode of administration).
Validity[2]	The measure assesses what it claims to, including a consideration of criterion, predictive, face & content & construct validity	Consideration of face & content validity. Assessment of construct validity via convergent validity testing & factor analysis.
Responsiveness[2]	The measure detects changes over time that matter to respondents (within & between respondents).	Consideration of variability in distribution of responses.
Precision[2]	The precision of measurement scores.	Consideration of response categories, discrimination between experiences, bias & dimensionality & precision of scales.
Interpretability[2]	The interpretability of measurement scores	Consideration of interpretability of sub-scales.
Acceptability[2]	The measure is acceptable to respondents.	Consideration of acceptability to respondents, response rate, time to complete & readability.
Feasibility[2]	The measure is easy to administer &process.	Consideration of administration & processing.
Appropriateness[2]	The measure is appropriate to the needs of the study.	Consideration of appropriateness to needs of Main Phase, of developing a new measure, & whether users' views are captured appropriately.

1. From Harvey *et al*, 2005.
2. From Fitzpatrick et al, 1998.

Data collection and analysis

Main Phase data were used for psychometric testing (with the exception of test retest reliability and acceptability) and the exploration of views on importance, experiences and satisfaction.

To assess test retest reliability, an independent sample of people completed the schedule twice. These users met the same inclusion criteria as for the Main Phase and were mainly contacted through day centres. Data were collected from 55 service users with an interval of approximately two weeks between time one (T1) and time two (T2). Eight people had a change in service between T1 and T2 and so were excluded from the analysis.

All quantitative data were analysed using SPSS version 12.01 with the exception of test retest reliability analyses for which we used Stata. Three items, 4b, 7b and 16b, were reverse-scored in order that all low scores represented poor continuity and all high scores good continuity. Qualitative responses (part ***d***) were entered into Microsoft Word for analysis.

Importance to users

The importance of items to users was assessed through a consideration of the method of item generation.

Involvement in outcome measure development

User involvement was assessed by considering CONTINU-UM's method of development.

Reliability

The total scores were computed by adding scores for all items responded to; as there were 17 items to be rated from one to five, the possible range was 17 to 85 assuming all items were applicable to the respondent. The mean score is the average of items responded to and had a possible range of one to five, as for the individual items. Total and means have different interpretations: the total depends on both the quality and extent of experiences; the mean depends only on the quality (someone rating one experience highly, if that was their only experience, would have the same score as someone rating several experiences equally highly).

Test retest reliability was measured by Lin's concordance coefficient (Lin, 1989). This has similar values and interpretation as an intra-class correlation (values lie between 0 and 1 with values over 0.6 generally being considered acceptable). The 95% limits of agreement were also calculated (Bland & Altman, 1986) to indicate the range of variation to be expected for a single person from T1 to T2. Overall means were compared at T1 and T2 to test for systematic changes.

The internal consistency of the items in relation to their overall mean (for each person) was measured by Cronbach's alpha.

Validity

Definitions of validity follow those provided by Fitzpatrick and colleagues (1998). Streiner and Norman's (1995) approach to validity testing was employed.

Face validity

Face validity is an assessment of what an item appears to be measuring, often considered the minimal requirement of a measure. This was assessed through a consideration of the method of developing CONTINU-UM.

Consensual validity

In order to explore consensus we considered how well the findings from the Main Phase sample corresponded with the focus groups' assessment of the importance of each domain.

Content validity

Content validity can be defined as an assessment of breadth of coverage. Good content validity enables a broader or more accurate range of inferences (Streiner & Norman, 1995) as a wider variety of conditions or variables are being used as the basis for inferences. A consideration of content validity was made when designing CONTINU-UM.

Criterion validity

Criterion validity refers to the correlation of CONTINU-UM with another measure which is accepted as a 'gold standard'. No gold standards were identified.

Discriminant validity

Discriminant validity refers to the ability of the measure to differentiate between different groups based on a set or sets of variables. Although this may be possible in the longer term it was not possible in this set of data because of the homogeneity of the data-set at baseline collected in the ECHO project. Analyses are planned in the longer term to investigate outcome groups with the measure.

Construct validity

Construct validity was explored in two ways, through convergent validity hypothesis testing and factor analysis.

Convergent validity

Convergent validity refers to the relationship of the construct being measured to sets of variables with which it is hypothesised that there may be a relationship. Additional data collected about study participants during the Main Phase were used to test these hypotheses.

It was hypothesised that:

- High scores on item 7 (*staff changes*) would be related to higher numbers of care coordinators, psychiatrists and total (care coordinator and psychiatrists) staff seen.
- High scores on item 11 (*day centres*) would be related to daytime activities as a met need on the Camberwell Assessment of Need (CAN: Phelan *et al*, 1995).
- High scores on item 17 (*avoiding services*) would be related to breaks and gaps in care.
- High CONTINU-UM aggregate ***b*** scores (assessing experiences) would correlate with higher numbers and proportions of met needs and lower numbers of unmet needs as defined by the CAN and good relationships with staff as measured by the Scale to Assess Therapeutic Relationships in Community Mental Health Care (STAR: McGuire-Snieckus *et al*, 2007).

Relevant CONTINU-UM ***b*** items (assessing experience) were converted into binary variables through combining points 1 and 2 on the Likert scale (negative experience) and points 4 and 5 (positive experience). A response of 3 (neither positive or negative i.e. was neutral) did not enter into this analysis. Users were asked how many care coordinators and psychiatrists had been seen over the previous year. These two variables were combined to create a third variable, total numbers of known staff seen. Number of psychiatrists seen and total numbers of staff seen were reduced to four categories (0, 1, 2 and 3+) due to strongly skewed data. Breaks in care were assessed by asking users whether or not they had a break in their care over the past year. Gaps in care were calculated from the pattern of face-to-face contacts collected from the users' records. In view of usual CMHT practice, a gap in care was defined as one of two months (operationalised as 56 days) or more. The proportion of needs met was created by calculating the percentage of total needs described as met in the CAN. The STAR total variable used the participant's rating of their relationship with the care coordinator; where that was missing, the participant's rating of their relationship with their psychiatrist was used and where that was missing, their rating of their relationship with another significant professional, if applicable, was used.

To test the convergent validity of items, contingency tables were generated and χ^2 test for trends (linear by linear association) conducted for ordinal data and Pearson χ^2 for categorical data. For CONTINU-UM total scores, scatter plots were examined and both parametric and non-parametric correlations calculated.

Factor analysis

Exploratory factor analysis was used to explore the construct validity of CONTINU-UM through an assessment of its internal structure. Principle Axis Factoring (PAF) was employed based on responses to ***b*** items, the key variables on continuity of care experiences. A high level of missing and not applicable data (range of missing/not applicable responses per item: 16-110) meant that the sample for the factor analysis did not achieve the recommended ten subjects per item (Nunnally, 1978). Hence, in order to be able to proceed, missing data were prorated, that is, imputed under the assumption that services that were not used would have been rated in the same way as those that were. Clearly this is an untestable assumption and therefore any results from these exploratory analyses must be treated with caution. A sample of 167 was thus created. This data was then assessed to see whether factor analysis was an appropriate method. Eigenvalues, scree plots and amount of common variance explained were used to help decide the number of factors in the model. Factor rotations were conducted based on three, four and five factor models. Both orthogonal (varimax method) and oblique (direct oblimin method) rotations were conducted with the results of each compared.

Responsiveness

A full assessment of responsiveness was not possible due to a lack of suitable data. Instead, each of the three broad areas that comprise responsiveness was briefly considered.

Precision

In assessing precision we investigated the variability, bias and halo effects inherent in the scale as well as the dimensionality of the scale using the factor analysis described above.

Interpretability

The interpretability of sub-scales was considered. Other methods for assessing interpretability – relating change scores to easily interpretable external changes and identifying ranges within which clinically important differences will occur – were not appropriate for this measure.

Acceptability

Whether the measure was acceptable to respondents was assessed through the research design (focus groups, expert panels and piloting), a series of short, closed questions (derived from Fitzpatrick *et al*, 1998) added to the end of the second CONTINU-UM for 55 retest users, and consideration of the response rate and length of time for completion. Cultural applicability could not be assessed. The Flesch formula for Plain English (Flesch, 1948) was used to assess readability. This formula is based on calculating word and sentence length in Microsoft Word to arrive at a readability score, interpreted according to predetermined levels of meaning. The minimum score for Plain English to have been achieved is 60.

Feasibility

Feasibility considers whether any burden was caused by administering and processing the measure.

Appropriateness

The concept of appropriateness was operationalised as: whether the measure was appropriate to the needs of the Main Phase; whether it was appropriate to develop a new measure; and whether the measure captured users' perspectives appropriately.

Results

CONTINU-UM was one of the assessment measures used in the Main Phase of this study and was completed by 167 users of the 180 participants interviewed at baseline.

Importance to users

The domains were initially generated through focus groups with users and were subsequently largely endorsed in Expert Panels. Participants in the Main Phase typically rated items as ‘important’ or ‘very important’ (see Table 2 below). The exceptions to this are *day centres*, *peer support*, *life history* and *avoiding services* where greater polarisation was found. However, we would expect greater polarisation of *waiting* and *staff changes* due to mixed feelings in the focus groups.

Additional information on the importance of items to respondents was provided by retest respondents who were asked which questions were most and least important. Respondents often selected more than one item, and each instance was counted. The item most frequently selected as important was *access* followed by *day centres*. *Day centres* was also the least important item, followed by *life history*.

Table 2: Main Phase participants rating items important / very important

CONTINU-UM Domains	Proportion rating item important/very important
Access	95.0%
Range	95.0%
Choice	84.0%
Waiting	91.0%
Out of hours support	86.0%
Hospital discharge	94.5%
Staff changes	88.0%
Information	95.0%
Flexibility	88.0%
Individual progress	86.0%
Day centres	65.0%
Care plans	86.0%
Crisis	91.0%
Staff communication	93.0%
Peer support	71.0%
Life history	65.0%

Avoiding services	47.0%

Involvement in outcome measure development

This is one of the strongest of CONTINU-UM's psychometric properties; users were involved at all stages of outcome measure development and producing a measure that reflected their concerns was a fundamental goal of this work.

Reliability

Test-Retest Reliability was assessed for the summary statistics for all three domains. Table 3 shows the observed ranges and T1 means, the limits of agreement and the Lin reliability measure (concordance statistic). The test retest values shown here indicate substantial agreement for all three dimensions of the measure. The limits of agreement show that mean values change by less than one point in either direction for all three domains. There was no evidence of any systematic difference (i.e. a trend to deterioration or improvement in overall opinion over time). The kappas for items showed lower levels of agreement, as expected. For importance they ranged from 0.25 to 0.6, for experience they ranged from 0.24 to 0.67 and for satisfaction they ranged from 0.29 to 0.65. The best items were *staff changes*, *day centres* and *communication* between staff and the worst *access* and *flexibility*.

Table 3: Concordance coefficients for range & means on the three dimensions of CONTINU-UM[1]

	Observed Range	**Time 1 Mean (sd)**	**Mean Difference T2-T1 (95% limits of agreement)**	**Lin's concordance coefficient (95% CI)**
Importance				
Total	14 - 44	27.00 (7.72)	2.45 (-8.15 to 13.04)	0.70 (0.55 to 0.84)
Mean	1.00 -2.75	1.70 (0.49)	0.13 (-0.53 to 0.80)	0.72 (0.59 to 0.86)

Experience				
Total	27 - 62	41.28 (9.18)	1.54 (-11.06 to 4.15)	0.76 (0.64 to 0.88)
Mean	1.80 - 3.88	2.64(0.62)	0.08 (-0.72 to 0.88)	0.79 (0.683 to 0.900)
Satisfaction				
Total	15 - 57	34.96 (9.19)	2.55 (-6.47 to 11.58)	0.85 (0.78 to 0.93)
Mean	1.00 - 3.67	2.23 (0.62)	0.12 (-0.65 to -0.89)	0.81 (0.71 to 0.91)

1. Zero, missing and not applicable responses are treated as zero when computing total scores; mean scores are computed over items for which a response was made (omitting 'missing' and 'not applicable' responses).

Internal consistency indicates whether items are coming from the same possible 'universe' of items, and therefore, whether they are assessing the same underlying construct. Internal consistency should not be so high as to suggest that exactly the same thing is being measured with each item. The internal consistency of CONTINUUM was measured through calculation of Cronbach's alpha, which estimates how much of the variance in a measure has come from a common source. Cronbach's alpha was calculated for ***a*** items, ***b*** items and ***c*** items in three separate analyses.

Internal consistency was 0.75 for ***a*** items, 0.743 for ***b*** items rising to 0.885 for ***c*** items (see Table 4). All results are within the suggested range cited by Fitzpatrick and colleagues (1998) of 0.7 to 0.9, indicating that items are measuring the same construct but are not overly homogenous. The number of valid cases was small, however, particularly for ***b*** items.

Table 4: Cronbach's alpha for *a*, *b* and *c* items

	Cronbach's Alpha	**Valid cases (n = 167)**
a items	.75	141
b items	.743	17
c items	.885	43

Validity

Face validity

The process of generating this measure ensured that it had good face validity for the group of respondents towards whom it was directed, that is, long-term users of mental health services. The Expert Panels and feasibility study in particular involved a rigorous scrutiny of the measure by the peers of the respondents in the Main Phase.

Consensual validity

As has been discussed, the Main Phase participants rated the majority of items as ‘important’ or ‘very important’, suggesting a consensus between participants at each stage of the study (see ‘Importance to users’).

The Expert Panels can be seen as a form of consensus conference. All groups involved in drawing up the measure – focus groups, Expert Panels and members of the pilot study - saw a real need for a measure of continuity of care that was generated by users and took the user’s perspective. Members of the research team who were clinical academic collaborators also saw this need.

Content validity

Users generated a number of elements from their perspectives and experiences during the qualitative phase of item generation. A general indicator was then selected for each domain based on frequency and endorsement during that qualitative phase. Each indicator was explored in four ways: through an assessment of its importance, experience, satisfaction and free comments. This means that there was a broad range of elements although each element was only explored using one general indicator.

Construct validity

The convergent validity of CONTINU-UM fell into two parts, items and aggregate scores. The convergent validity of items was mixed (see Table 5). Chi square tests for trends provided evidence that those with greater numbers of staff changes as defined by CONTINU-UM tend to be those who see greater numbers of either psychiatrists or psychiatrists and care coordinators combined. There was no similar trend with care coordinators, most likely because of the low range (0-3 for care coordinators compared to 0-7 for psychiatrists). This suggests that CONTINU-UM is sensitive to greater numbers of staff changes.

Evidence of convergence was found between access to appropriate *day centres* (item 11) and having this need met as assessed by CAN. *Avoiding services* (item 17) failed to converge with breaks or gaps in care. This could be due to item 17 being problematic, a lack of fit between the two measures (CONTINU-UM asks about perceptions whereas gaps in care was generated from records) or a lack of variance in breaks and gaps in care (just two people felt that they had had a break in care).

Each of the aggregate scores was significantly correlated with other study variables (CAN and STAR, see Table 6) although with correlation coefficients not so high as to suggest that the same constructs are being assessed by each measure. Our results therefore provide support for the scale’s convergent validity for these aggregate scores.

Table 5: Convergent validity of three CONTINU-UM items against Main Phase data

Variables	**n**	**χ^2 (p-value)**
CONTINU-UM item 7b (*staff changes*) and number of care coordinators seen over the past year	130	1.784 (.182)
CONTINU-UM item 7b (*staff changes*) and number of psychiatrists seen over the past year	134	12.127 (<.001)
CONTINU-UM item 7b (*staff changes*) and number of care coordinators and psychiatrists seen over the past year	130	8.092 (.004)
CONTINU-UM item 11b (*day centres*) and CAN item on daytime activities	86	11.363 (.003)
CONTINU-UM item 17b (*avoiding services*) and whether or not there have been breaks in care over the past year	68	.091 (.763)
CONTINU-UM item 17b (*avoiding services*) and whether or not there have been gaps in care over the past year	63	.653 (.419)

Table 6: Convergent validity of CONTINU-UM total score against CAN (Camberwell Assessment of Needs) and STAR (Scale to Assess Therapeutic Relationships in Community Mental Health Care)

Variables	n	Correlation	
		Pearson's r	Spearman's rho
CONTINU-UM total score and CAN number of met needs	167	.188	.2
CONTINU-UM total score and CAN number of unmet needs	167	-.316	-.345
CONTINU-UM total score and CAN proportion of needs that have been met	167	.384	.374
CONTINU-UM total score and STAR total score	153	.320	.321

Factor analysis

Assessments prior to factor analysis

An examination of the correlation matrix revealed that no correlations exceeded 0.7 (range -0.074 to 0.668) and there was therefore no evidence of multi-colinearity. A single negative correlation near zero (-0.074) suggested that there was no relationship rather than an inverse relationship. All items had correlations between 0.3 and 0.7 with at least two other items and a maximum of 12 other items.

Bartlett's test of sphericity, which tests the null hypothesis that there are no relationships among the items, was significant at the $p<0.001$ level (χ^2=1015.1). Individual measures of sampling adequacy test the null hypothesis that there is no relationship between each item and all other items. All exceeded 0.83. These tests provided evidence that the data were suitable for factor analysis.

Item communalities ranged from 0.166 to 0.742 (Table 7) demonstrating that there is variability in the amount of common variance in each item that the generated factors are able to explain. The factor solution is able to account for more of the common variance in *access*, *range*, *hospital discharge* and *individual progress* than it is in *choice*, *waiting*, *peer support*, *life history* and *avoiding services*.

Assessments prior to factor analysis therefore indicated relationships among items and that factor analysis could be expected to produce common factors.

Table 7: Extracted communalities

Item	Extracted communalities
Access	.660 (66%)
Range	.662 (66%)
Choice	.166 (17%)
Waiting	.261 (26%)
Out of hours support	.302 (30%)
Hospital discharge	.742 (74%)
Staff changes	.349 (35%)
Information	.550 (55%)
Flexibility	.462 (46%)
Individual progress	.602 (60%)
Day centres	.324 (32%)
Care plans	.391 (39%)
Crisis	.520 (52%)
Staff communication	.474 (47%)
Peer support	.239 (24%)
Life history	.293 (29%)
Avoiding services	.209 (21%)

Identifying the number of factors in the model

An examination of the scree plot suggested a three-factor model, although a four- or five-factor model would also be acceptable. Three-, four- and five-factor solutions were therefore examined and compared. The five factor solution accounted for 63% of the variance.

Rotated factor models

Factor rotation aimed to achieve simple structure, the most parsimonious and theoretically meaningful explanation making the solutions more likely to be both replicable and interpretable (Kline, 1994). Simple structure was operationalised as:

1. Items load on only one factor at 0.4 or above.
2. Items load on at least one factor at 0.3 or above.
3. Items load on at least one factor near zero (+/- 0.1).
4. At least two items load on any factor.

Factor loadings of 0.4 and above were considered substantial (Pett *et al*, 2003).

Factor interpretation

Based on closeness to simple structure and the internal consistency and interpretability of generated factors, the three-factor orthogonal rotation was selected. The five-factor model was rejected because it failed to achieve simple structure or produce interpretable results. The four-factor orthogonal rotation failed to produce a fourth factor, with only one item loading. Whilst the four-factor oblique model was able to produce four interpretable factors, it was further from simple structure than either the three- or four-factor orthogonal rotations. This model is able to account for all items except choice, which failed to load at the 0.4 level on any factor. (Table 8.)

Factor one

Ten of seventeen items loaded on to the first factor, indicating a *general* factor.

Factor two

Loading items were *access*, *range*, *information*, *individual progress* and *hospital discharge*. These items were internally consistent. This factor was named *preconditions for continuity.*

Factor three

The third factor consisted of *waiting*, *staff changes*, *life history* and *hospital discharge*. This factor was named *transitions*.

Table 8: Items loading above .4 on the 3 factor solution with orthogonal rotation

Item	Factor 1	Factor 2	Factor 3
Access		.796	
Range		.708	
Choice[1]			
Waiting			.41
Out of hours	.54		
Hospital discharge		.596	.478
Staff changes			.553
Information	.491	.447	
Flexibility	.602		
Individual progress	.642	.404	
Day centres	.454		
Care plans	.521		
Crisis	.573		
Staff communication	.611		
Peer support	.487		
Life history			.515
Avoiding services	.426		
Cronbach's Alpha	.85	.854	.622

1. Did not load above 0.4 cut-off

Responsiveness

Whilst importance and satisfaction questions tend to have less variability, the experience questions show great variability. This reflects the nature of the questions: ***a*** items are likely to be endorsed as they ask how important the topic is, and each topic was generated by other service users with similar characteristics. ***b*** items ask about experiences and therefore should detect variability in response. ***c*** items ask about satisfaction, and this is typically a form of question that invites endorsement. Therefore, presence or absence of variability would appear to reflect question type as much as instrument responsiveness. The spaces for open comments appear to have increased the likelihood of the measure detecting changes.

Precision

Likert scales were selected as the most appropriate response category format, following the recommendations of Streiner and Norman (1995). In terms of discriminating between various levels of experience, we found that the 'experience' (***b***) questions showed the greatest variability: larger differences between the means, medians and modes, higher standard deviations, less pronounced skews and points one and two being used far more than with the other questions. This suggests that CONTINU-UM is able to discriminate between levels of experience.

The dimensionality of the scale was explored through internal consistency and factor analysis, with uni-dimensionality anticipated. Cronbach's alpha revealed that the ***a***, ***b*** and ***c*** scales have good internal consistency suggesting that items in each scale are measuring similar, but not identical, constructs. Although the Cronbach's alpha for all items is high at 0.891, this is based on a small valid sample. Factor analysis did not aim to form sub-scales as the ***a***, ***b*** and ***c*** items each form internally consistent scales. Instead, the aim was to explore the concept of continuity of care to users. Two constructs underlying the concept were revealed with all but one item contributing. CONTINU-UM can therefore be seen as having three sub-scales comprising importance, experience and satisfaction. Evidence of uni-dimensionality was found through both Cronbach's alpha (although this was limited by a very small sample size) and a general factor. Two further constructs were found to underpin continuity of care: preconditions or essentials and transitions.

In the piloting exercise, some difficulties were encountered in respondents' interpretation of five topics: staff changes, flexibility, day centres, care plans and life histories. Changes were made to wording until these problems were resolved. Main Phase researchers subsequently reported that flexibility, individual progress and avoiding services often needed to be explained before a response could be given. It also appeared that *crisis* was sometimes not interpreted in the way intended: rather than reporting on whether a system was in place, users sometimes appeared to report whether or not they had experienced a crisis.

Main Phase researchers also reported that some respondents had difficulty completing CONTINU-UM. These respondents were also likely to have problems with other questions or measures, often due to literacy barriers, educational difficulties, English being a second language or temporary cognitive or concentration difficulties. These factors may lead to bias in the assessment of outcome where they interfere with understanding and interpretation of items. Offering the measure as an interview as well as a self-complete questionnaire goes someway towards addressing this, as researchers are able to answer questions and assist in understanding.

Regarding inference and estimation techniques, it is likely that respondents are considering a number of complex situations and issues, and then averaging a response. Whilst reliability of individual items was sometimes poor, the reliability of scales was good indicating that this form of bias was not adversely affecting overall reproducibility.

The combination of open and closed questions of CONTINU-UM enabled respondents to explain their thought processes, thus decreasing the bias associated with fixed response categories.

Streiner and Norman describe three forms of bias that are specific to scales scored on a continuum: end-aversion bias, positive skew and the halo effect. End-aversion bias refers to a reluctance to use the extreme ends of a scale. An examination of the CONTINU-UM distribution of scores does not provide any evidence for end-aversion bias and likewise there is no over-reliance on the central value. There was a strong trend for negative skew, particularly with importance questions and less so for satisfaction questions. This had been anticipated: the extreme skew of importance questions can be seen as a validation of the method of item-generation rather than a form of bias; the experience items produced the greatest variability in responses; and satisfaction questions notoriously lead to findings of satisfaction and thus skewed data. To assess for halo effects, interviewer effects were explored through a comparison of user and non-user researchers, with few differences being found. Respondent checking and validation was a strong part of the qualitative design and this will have reduced bias in the interpretation of focus group data.

Interpretability

As has been demonstrated, ***a***, ***b*** and ***c*** scales were found reliable in terms of internal consistency and reproducibility. They also have good face validity, as it makes intuitive sense to separate a person’s rating of importance, experience and satisfaction. High and low scores on each of the three scales are interpretable, revealing how important the continuity of care elements are, whether good or poor continuity has been experienced, and how satisfied the respondent is with these experiences. Individual items can be used to understand particular areas of strength and weakness in continuity of care provision.

Acceptability

The majority of respondents did not find the questionnaire distressing (84%), difficult to understand (76%) or confusing (84%). Most respondents felt that the length was about right (87%). Only one person reported that they did not enjoy filling in the questionnaire. This suggests that the questionnaire can be seen as acceptable to respondents. (Table 9)

Of the 180 Main Phase users, 167 completed CONTINU-UM at T1, a response rate of 93%, and it was reported to take between ten and 30 minutes as a self-complete instrument. The CONTINU-UM Flesch Readability score was 81.9, which is classified as ‘easy’ and suitable for students aged 11.

Table 9: Acceptability properties of CONTINU-UM		
Acceptability Property		**n (%)**[1]
Distressing	Yes	9 (16.0%)
	No	46 (84.0%)
Difficult to understand	Yes	13 (24.0%)
	No	42 (76.0%)
Confusing	Yes	9 (16.0%)
	No	46 (84.0%)
Length	Too long	7 (13.0%)
	Too short	0 (.0%)
	About right	48 (87.0%)
Enjoyment completing CONTINU-UM	Enjoyed filling it in	26 (48.0%)
	Did not enjoy	1 (2.0%)
	Neither	27 (50.0%)

1. Valid percentages

Feasibility

In assessing acceptability, it was concluded that interviewer presence was preferable during self-completion. It was further noted that, whilst Likert scales are easier to administer and process than either visual analogue scales or open questions, respondents may require assistance in selecting scale points. The presence of open questions also places a responsibility when interviewing to record the respondent's comments accurately. Finally, three ***b*** questions need to be reversed for analysis as they are negatively worded. Total scores are then calculated by prorating. The burden these issues place on researchers was not considered unacceptable or challenging, so CONTINU-UM can be seen as feasible.

Appropriateness

CONTINU-UM was developed specifically as a measure of user-defined continuity for the study and so is appropriate to the study's needs. This research is the first in the UK to ask users about their experiences and priorities for continuity of care. It therefore fills the gap in the literature identified by Freeman and colleagues (2000). It aimed to capture users' views in the most accurate and appropriate way through asking for views at numerous stages of the research. The main researchers had experience of using services.

Appendix 3 - CONTINUES

Carers' Experiences of Continuity of Care

- This questionnaire is to find out about carers' views, experiences and satisfaction with different aspects of continuity of care over the past 12 months.
- It should take no more than 30 minutes to complete.
- There are 11 topics. Please read the introduction to each topic carefully.
- There are 3 short questions in each topic. Please circle your answer to these questions.
- Your answers to questions should be about your experiences of services *in general*.
- If you feel that a topic is not applicable, please write 'n/a' clearly next to the question number. You can explain why the question is not applicable in part d if you wish.
- At the end of each topic there is an opportunity to add anything else you would like to say. Please write clearly in the spaces provided if you would like to do so.

Notes on the wording

- **Staff**

Staff here refers to anybody that the person you support sees for their mental health.

- **The person you support**

We have sometimes called the person you support 'the user'. The term user means somebody who is, or has been, in contact with mental health services

Topic 1: Staff involve carers

The first topic is about whether staff involve you in the care of the person you support. Specifically, that staff take the time to talk to you as a carer.

1.a. How important is it that staff spend time talking to you?

very important	important	sometimes important / sometimes not	not important	very unimportant

1.b. Over the past 12 months, have staff spent time talking to you?

very often	often	sometimes	not often	never

1.c. How satisfied are you with this?

very satisfied	satisfied	sometimes satisfied / sometimes not	dissatisfied	very dissatisfied

1.d. Would you like to say any more about staff involving carers?

……………………………………………………………………………………
……………………………………………………………………………………

Topic 2: Staff act on what carers tell them

This topic is about staff acting on carers concerns. Specifically, that when the person you support is most in need and you ask staff for help, they make changes or take action based on what you've told them.

*** In the past 12 months, has there been a situation where the person you support has been in crisis <u>and</u> you needed to ask staff for help?**

Yes – please go to 2.a.
No – please go to 3.a.

2.a. How important is it that staff take action when you say the person you support is in crisis?

very important	important	sometimes important / sometimes not	not important	very unimportant

2.b. Over the past 12 months, have staff taken action when you've said that the person you support is in crisis?

definitely	sometimes / mostly	sometimes not	partly	definitely not

2.c. How satisfied are you with this?

very satisfied	satisfied	sometimes satisfied / sometimes not	dissatisfied	very dissatisfied

2.d. Would you like to say any more about staff acting on what carers tell them?

……………………………………………………………………………………
……………………………………………………………………………………
………………………

Topic 3: Staff inform carers

This topic is about having access to information and advice. Specifically, that there is a member of staff that you can contact with any questions or concerns you might have.

3.a. How important is it that you can get advice and information from staff?

very important	important	sometimes important / sometimes not	not important	very unimportant

3.b. Over the past 12 months, have you been able to get advice and information from staff?

definitely	mostly	sometimes / sometimes not	partly	definitely not

3.c. How satisfied are you with this?

very satisfied	satisfied	sometimes satisfied / sometimes not	dissatisfied	very dissatisfied

3.d. Would you like to say any more about staff informing carers?

……………………………………………………………………………………
……………………………………………………………………………………
……………………………………………………………………………………
…………………………
……………………………………………………………………………………
……….

Topic 4: Establishing relationships with staff

This topic is about carers forming relationships with staff. Specifically, that there is a member of staff that carers are able to build a relationship with.

4.a. How important is it that there is a member of staff you can establish a relationship with?

very important	important	sometimes important / sometimes not	not important	very unimportant

4.b. Over the past 12 months, have you been able to establish a relationship with a member of staff?

definitely	mostly	sometimes / sometimes not	partly	definitely not

4.c. How satisfied are you with this?

very satisfied	satisfied	sometimes satisfied / sometimes not	dissatisfied	very dissatisfied

4.d. Would you like to say any more about establishing relationships with staff?

……………………………………………………………………………………
……………………………………………………………………………………
……………………………………………………………………………………

Topic 5: Confidentiality

This topic is about carers' rights to confidentiality. Specifically, that what you tell staff should not be shared with the person you support, if you don't want it to be.

5.a. How important is it that carers have a right to confidentiality?

very important	important	sometimes important / sometimes not	not important	very unimportant

5.b. Over the past 12 months, have things you've told staff stayed confidential?

definitely	mostly	sometimes / sometimes not	partly	definitely not

5.c. How satisfied are you with this?

very satisfied	satisfied	sometimes satisfied / sometimes not	dissatisfied	very dissatisfied

5.d. Would you like to say any more about confidentiality?

....

....

Topic 6: Hospital admission

This topic is about admission to a psychiatric hospital. This is NOT about the entire hospital stay; it is about the day the person is admitted. Specifically, it means that the day the person you support goes into hospital, they are treated with sensitivity and the experience is kept as untraumatic as possible.

*** In the past 12 months, has the person you support been admitted to a psychiatric hospital?**

Yes – please go to 6.a.
No – please go to 7.a.

6.a. How important is it that hospital admission is dealt with sensitively?

very important	important	sometimes important / sometimes not	not important	very unimportant

6.b. Over the past 12 months, have hospital admission(s) been dealt with sensitively?

definitely	mostly	sometimes / sometimes not	partly	definitely not

6.c. How satisfied are you with this?

very satisfied	satisfied	sometimes satisfied / sometimes not	dissatisfied	very dissatisfied

6.d. Would you like to say any more about hospital admission?

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....

Topic 7: Hospital discharge

This topic is about the person you support coming out of a psychiatric hospital. Specifically, that you are told when the person you support is likely to come out of hospital.

*** In the past 12 months, has the person you support been discharged from a psychiatric hospital?**

Yes – please go to 7.a.
No – please go to 8.a.

7.a. How important is it that you are told in advance the date the person you support is likely to be discharged from hospital?

very important	important	sometimes important / sometimes not	not important	very unimportant

7.b. Over the past 12 months, have you been told in advance the date the person you support is likely to be discharged from hospital?

sometimes /				
definitely	mostly	sometimes not	partly	definitely not

7.c. How satisfied are you with this?

very satisfied	satisfied	sometimes satisfied / sometimes not	dissatisfied	very dissatisfied

7.d. Would you like to say any more about hospital discharge?

……………………………………………………………………………………
……………………………………………………………………………………
……………………………………………………………………………………

Topic 8: Staff changes

This topic is about the staff who are involved in the care of the person you support changing. This means that the staff users see are the same each time they go.

8.a. How important is it that staff involved in the care of the person you support don't change frequently?

very important	important	sometimes important / sometimes not	not important	very unimportant

8.b. Over the past 12 months, have the staff involved in the care of the person you support changed frequently?

very often	often	sometimes	not often	never

8.c. How satisfied are you with this?

very satisfied	satisfied	sometimes satisfied / sometimes not	dissatisfied	very dissatisfied

8.d. Would you like to say any more about staff changing?

……………………………………………………………………………………
……………………………………………………………………………………
……………………………………………………………………………………

Topic 9: Carers' support groups

This topic is about carers' support groups. These are meetings held for carers to talk about what is going on in their lives and to share experiences and advice.

9.a. How important are carers' support groups?

very important	important	sometimes important / sometimes not	not important	very unimportant

9.b. Over the past 12 months, have you been to a carers' support group?

very often	often	sometimes	not often	never

9.c. How satisfied are you with this?

very satisfied	satisfied	sometimes satisfied / sometimes not	dissatisfied	very dissatisfied

9.d. Would you like to say any more about carers support groups?

....
....
....

Topic 10: Carers' access to support from services

This topic is about carers accessing help and support from services for themselves as carers. Specifically, that carers are able to get the help and support that they feel they need from services such as assessing your needs, asking how you are and so on.

10.a. How important is it that you can get support from services?

very important	important	sometimes important / sometimes not	not important	very unimportant

10.b. Over the past 12 months, have you been able to get support from services?

definitely	mostly	sometimes / sometimes not	partly	definitely not

10.c. How satisfied are you with this?

very satisfied	satisfied	sometimes satisfied / sometimes not	dissatisfied	very dissatisfied

10.d. Would you like to say any more about carers access to support?

....
....
....
....
....

Topic 11: Users' access to support

This topic is about users' access to help and support. Specifically, that users are getting the help and support from services <u>that you, as their carer, feel they need</u>.

11.a. How important is it that users are able to get the support from services that you feel they need?

very important	important	sometimes important / sometimes not	not important	very unimportant

11.b. Over the past 12 months, has the person you support been able to get the support from services that you feel they need?

definitely	sometimes / mostly	sometimes not	partly	definitely not

11.c. How satisfied are you with this?

very satisfied	satisfied	sometimes satisfied / sometimes not	dissatisfied	very dissatisfied

11.d. Would you like to say any more about users access to support from services?

…………………………………………………………………………………

…………………………………………………………………………………

…………………………………………………………………………………

………………………

Please continue to next page

Some final questions

Checklist of topics:

1. Staff involve carers
2. Staff act on what carers tell them
3. Staff inform carers
4. Establishing relationships with staff
5. Confidentiality
6. Hospital admission
7. Hospital discharge
8. Staff changes
9. Carers' support groups
10. Carers' access to support from services
11. Users' access to support

1.) Which of the topics covered in this questionnaire (from 1 to 11) is the **most** important to you?

☐

2.) Which of topics covered in this questionnaire (from 1 to 11) is the **least** important to you?

☐

3.) Did you find any of the questions:

- Distressing? Yes ☐ No ☐
- Confusing? Yes ☐ No ☐
- Difficult to understand? Yes ☐ No ☐

4.) Questionnaire length: Did it seem….

Too long? ☐ Just right? ☐ Too short? ☐

5.) Questionnaire enjoyment: When you filled in the questionnaire, did you….

Enjoy it? ☐ Have neutral feelings? ☐ Dislike it? ☐

6.) How easy was it to fill in?

Easy ☐ Mixed ☐ Difficult ☐

- **Please use this space to add any final comments**

Appendix 4 – Psychometric testing of CONTINUES

Methods

Framework for psychometric testing

The framework for assessing the psychometric properties of CONTINUES was the same as for CONTINU-UM (Table D2). The criteria selected for evaluation were importance to carers, involvement of carers, feasibility, validity, reliability and acceptability.

Data collection and analysis

Data used for psychometric testing (with the exception of retest reliability and acceptability) were taken from the Main Phase. This sample was also used to explore carers' priorities for, experiences of and satisfaction with continuity of care.

An additional 18 carers completed the measure twice in order to establish test retest reliability and acceptability. Seventeen carers (94%) provided demographics data (Table 1). This sample was recruited through a national mental health charity, which sent an information sheet to 250 active members across England. A small number of the charity's local groups in London were visited. Interested carers made contact with the Developmental Phase team for further information. The research was explained and a questionnaire pack containing CONTINUES, a consent form and a demographic information sheet was sent to interested parties. Participants then self-completed CONTINUES, inserting the date of completion and returning in a freepost envelope. On receipt a second questionnaire was posted with a letter giving the date it should be completed (this was seven days after the first questionnaire was completed). At retest, a number of additional closed questions were added to CONTINUES to explore acceptability along with a transition question, 'Have there been any changes to your services since the last time you filled in this questionnaire?'. Two carers were excluded due to changes, making a total sample size of 16. Gaps between administrations ranged from 7 to 14 days.

Table 1: CONTINUES retest participant demographics		
		n=17[1]
Mean age	Carer	61
	User that the carer supports	34
Gender	Male	4 (25.0%)
	Female	12 (75.0%)
Ethnicity	White British, Irish or Other	15 (94.0%)
	Asian/Asian British or Chinese Group	1 (6.0%)
	Black/Black British	0 (.0%)
	Mixed Heritage	0 (.0%)
Mean years user had been in contact with services		16

1. One carer did not provide demographic information

Likert data (questions ***a-c***) and acceptability question responses were entered into SPSS version 12.01. SPSS was then used to conduct the majority of quantitative analyses. The exception was test retest reliability analyses which used Stata. Item 8***b*** was reverse-scored so that a low score would represent poor continuity and a high score good continuity. Open responses (part ***d***) were entered into Microsoft Word for qualitative analysis.

Importance to carers

The importance of CONTINUES items to carers was assessed by considering the method of item generation. The responses of Main Phase participants were also considered.

Involvement in outcome measure development

The level of carer involvement was assessed by considering the method used to develop CONTINUES.

Reliability

Test retest reliability analysis was conducted in two ways: with individual items and with scale scores. In order to assess the reliability of individual items, non-weighted Kappas were computed.

To assess scale scores, total scores were calculated by adding scores for all items responded to. As CONTINUES contains 11 five-point Likert scale items, the possible range was 11 to 55 assuming all items were applicable to the respondent. The mean score was also calculated. This is the average score of all items responded to and has a range of one to five. Test retest reliability of scales was again measured by Lin's concordance coefficient (Lin, 1989), with values at 0.6 or above generally considered acceptable. The 95% limits of agreement were also calculated (Bland & Altman, 1986). Finally, overall means were compared at T1 and T2.

Validity

Face Validity

The face validity of CONTINUES was considered in terms of the method of its development.

Content validity

A consideration of content validity was made when designing CONTINU-UM.

Criterion validity

This is defined as correlation with another measure which is accepted as an accurate or criterion variable. No criterion measures were identified.

Discriminant Validity

Discriminant validity refers to the hypothesis of a lack of relationship of the construct to sets of variables. No items for discriminant validity testing were identified.

Construct/Convergent Validity

In order to investigate convergent validity, relationships between CONTINUES and additional data collected with carers during the Main Phase were explored. This identified two item pairings as suitable for construct validity assessment:

- CONTINUES item 3***b*** (advice and *information*) and ECI item 52 (difficulty getting information about the illness).
- CONTINUES item 9***b*** (attended *carers group*) and carers' assessment data (belong to carers support group).

The relationship between the first pair of items was explored through parametric and non-parametric correlations. For the second item pairing, a contingency table was created and χ^2 analyses conducted.

Factor analysis was not possible as the recommended sample size was not reached (Nunnally, 1978).

Acceptability

Acceptability was assessed through a series of short, closed questions at the end of the second administration of CONTINUES and consideration of the response rate and the Flesch formula for Plain English.

Feasibility

The feasibility of CONTINUES was assessed through a consideration of the ease of administration and processing.

Results

CONTINUES was completed by 65 carers in the Main Phase of the study, 34 recruited at Time 1 and 26 and five recruited for the first time at Time 2 and Time 3 of the Main Phase respectively.

Importance to carers

The entire method of item generation relied on the qualitative exploration of carers' experiences, priorities and views of importance. As Table 2 demonstrates, the majority of items were endorsed as important by Main Phase carers. Additional information was provided by retest respondents who stated which item was most important and which least important. Each instance of an item being selected was counted. The most important items were quite clearly staff *taking action in a crisis*, *support for users* from services and staff spending time *talking* to carers. These results shown in Table 2 demonstrate that *carers' group* was consistently the least important item.

Table 2: Importance of CONTINUES elements: summary statistics and rating

	n	Mean (sd)	Not important %[1]	Important %[1]	Most important n	Least important n
Talking	60	4.2 (.900)	20.0%	80.0%	9	1
Taking action	45	4.6 (.800)	7.0%	93.0%	14	1
Information	60	4.3 (.900)	15.0%	85.0%	5	1
Relationship	60	4.2 (.900)	15.0%	85.0%	7	3
Confidentiality	51	4.0 (1.20)	20.0%	80.0%	2	6
Admission	50	4.6 (.600)	5.0%	95.0%	2	5
Discharge	20	4.5 (.500)	.0%	100%	2	2
Staff changes	60	4.6 (.800)	8.0%	92.0%	4	3
Carers group	53	3.5 (1.20)	49.0%	51.0%	3	15
Carer support	54	3.9 (1.10)	24.0%	76.0%	4	3
Users support	61	4.5 (1.00)	8.0%	92.0%	12	1

1. Percentages of valid cases. Missing data excluded. Point 3 on the Likert scale is included in ‘not important’.

Involvement of carers in outcome measure development

The motivation for developing CONTINUES was to address a gap in outcome measures on continuity of care from the carers’ perspective identified in the Scoping Exercise (Freeman *et al*, 2000). Carers were fully involved in, first, generating the items through focus group discussions, second, selecting items and developing the measure in Expert Panels and third, refining the measure further through piloting. Furthermore, the main researcher was a carer. This can therefore be considered one of the strongest of CONTINUES’ psychometric properties.

Reliability

Test retest reliability values of individual items were typically low, with the unweighted kappas for importance items ranging from –0.1 to 0.65, for experience from 0.28 to 1 and for satisfaction from 0.13 to 0.65.

Conversely, the test retest reliability values of scales showed substantial agreement between test and retest, although limits of agreement were wide for **c** items total score (Table 3). This means that satisfaction as measured by total score produces higher levels of variability than experience, suggesting a degree of inconsistency in the reporting of satisfaction.

Table 3: Concordance correlation coefficients for mean and total a, b and c scores

		Range	T1 Mean (sd)	T2-T1 Mean difference	95% limits of agreement	Concordance coefficient (95% CI)
***a* items**	Total score	4 – 12	13.3 (1.89)	.75	-1.13, 2.63	.833 (.486, 1.18)
	Mean score	1 – 2.25	1.3 (.300)	.04	-.391, .461	.763 (.557, .969)
***b* items**	Total score	23 – 41	34.3 (8.62)	2.0	.040, 3.96	.969 (.874, 1.06)
	Mean score	2 – 3.75	2.9 (.610)	.16	-.360, .680	.873 (.757, .988)
***c* items**	Total score	26 – 47	37.0 (10.54)	2.0	-6.54, 10.54	.923 (.753, 1.09)
	Mean score	2 – 4.38	3.01 (.790)	.17	-.564, .897	.879 (.768, .989)

Face Validity

CONTINUES domains arose from an exploration of carers' experiences and priorities for continuity of care in focus groups. Expert Panels then discussed whether domains reflected their own experiences and views. CONTINUES can therefore be seen as reflecting the approach to continuity of care of carers who met the inclusion criteria, and therefore has very good face validity with this population.

Content Validity

Carers generated a number of elements of continuity of care from their perspectives and experiences. A general indicator was then selected for each domain based on frequency and endorsement. Each indicator is explored in four ways: through an assessment of its importance, experience, satisfaction and free comments. This means that there is a broad range of elements although each element is only explored using one general indicator.

Construct/ Convergent Validity

Convergent validity testing between CONTINUES item 3*b* (*advice and information*) and ECI item 52 (difficulty getting information about the illness) found no evidence of a significant correlation (Table 4).

Table 4: Correlation between CONTINUES 3b and ECI 52

Test	**n**	**Correlation Coefficient (Significance)**
Parametric correlation (Pearson's Product Moment Correlation Coefficient)	46	.265 (.076)
Non-parametric correlation (Spearman's Rho)	46	.242 (.105)

The analysis of CONTINUES item 9*b* with carer's assessment data (Table 5) revealed that six cells (75%) had an expected count of less than five and the minimum expected count was 0.17. For this reason an exact significance test, Fisher's exact, was selected. Strong evidence of convergence was found between CONTINUES 9*b* (been to a carers' group) and the carer's assessment data (belong to a carers' group) (Fisher's exact 19.007, p=0.001).

Table 5: Crosstabulation of CONTINUES 9b and carers' assessment data (carers' groups)

		CONTINUES 9b *carers group*			
		Doesn't have the element	**Does have the element**	**Total**	**Fisher's Exact Test (p-value)**
Belong to a carers group	No	38	1	39	19.007 (.013)
	Yes	5	3	8	
	Total	43	4	47	

Acceptability

All but one of the test retest carers responded to the acceptability questions (95%). Table 6 shows that CONTINUES items were not found distressing or difficult to understand and that they were rarely found confusing. The majority of carers felt that the length was 'about right' (90%). Whilst half the respondents enjoyed completing CONTINUES, 39% had no feelings either way and one person disliked it.

Table 6 : Acceptability properties of CONTINUES

Acceptability Property		**n (%)[1]**
Distressing	Yes	0 (.0%)
	No	18 (100.0%)
Difficult to understand	Yes	0 (.0%)
	No	18 (100.0%)
Confusing	Yes	1 (6.0%)
	No	17 (94.0%)
Length	Too long	1 (5.0%)
	Too short	0 (.0%)
	About right	17 (90.0%)
Enjoyment completing CONTINUES	Enjoyed filling it in	9 (50.0%)
	Did not enjoy	1 (6.0%)
	Neither	7 (39.0%)

1. Valid percentages

An additional way of assessing the acceptability of a measure is to assess the response rate. During the Main Phase, 65 of 68 carers completed CONTINUES, a response rate of 96%. Finally, CONTINUES attained a Flesch Readability score of 77.7. This is classified as fairly easy and suitable for students aged 12.

Feasibility

CONTINUES has 11 domains, each with three Likert scale items and a fourth space for comments. At the end of CONTINUES there is a final space for carers to write free comments. The main feasibility issue this raises is that of data entry and analysis. Open items must be transcribed and analysed. One closed item must be reversed as it is negatively worded (8***b***). This is not seen as placing an excessive burden on those administering and processing CONTINUES.

Appendix 5: Development of CONTINU-UM and CONTINUES

Table 1: Summary of the development of CONTINU-UM topics

Topics taken to the first Expert Panel (14 + 2 for discussion)	Topics taken to second Expert Panel (13 + 4 for discussion)	Topics taken to pilot (16)	Final topics (17)
Access Gaps Control Waiting Out of hours support Hospital Discharge Staff changes A & B Information Levels of support Individual progress Day services Care plans Telephone support	Access Gaps Choice Waiting Out of hours support Hospital Discharge Staff changes A Information Levels of support Individual progress Day services Care plans Crisis	Access Range Choice Waiting Out of hours support Hospital discharge Staff changes Information Levels of support Individual progress Day centres Care plans Crisis Communication between staff and services Peer support	Access Range Choice Waiting Out of hours support Hospital discharge Staff changes Information Levels of support Individual progress Day centres Care plans Crisis Communication between staff Peer support Repeating your life history Avoiding services
For discussion: Crisis (3 options given) Communication between staff	For discussion: Staff changes B Telephone support Communication between staff Peer support		

Table 2: Summary of the development of CONTINUES topics

Topics taken to the first Expert Panel (10 + 8 for discussion)	**Topics taken to second Expert Panel (7 + 6)**	**Topics taken to pilot (11)**	**Final topics (11)**
Staff involve carers Staff listen to carers Staff inform carers Staff support carers Hospital discharge Staff changes Professionals communicate Named professional to establish relationship with Telephone support Getting help from services	Staff involve carers Staff inform carers Establishing relationships with staff Hospital discharge Staff changes Carers support groups Users access to support	Staff involve carers Staff act on what carers tell them Staff inform carers Establishing relationships with staff Confidentiality Hospital admission Hospital discharge Staff changes Carers support groups Carers access to support from services Users access to support	Staff involve carers Staff act on what carers tell them Staff inform carers Establishing relationships with staff Confidentiality Hospital admission Hospital discharge Staff changes Carers support groups Carers access to support from services Users access to support
For discussion: Gaps in care Moving areas/between services Consistency Waiting Confidentiality Hospital admission Carers access to support from services Users access to talking therapies	Hospital admission Carers access to support from services Quality of services between areas Confidentiality x 2 Staff act on what carers say		

Appendix 6: Data Collection Schedule from Records

Researcher

EXPERIENCES OF CONTINUITY AND HEALTH AND SOCIAL OUTCOMES STUDY

ECHO

Service User Record Data Extraction Sheet

ID No. __________
Period Covered: ___/___/___ to ___/___/___
Team: ____________________

Discharged **NO** **YES** **Date of discharge ……………………**

Moved teams **NO** **YES from …………………to …………………date………**

1. Individual Contacts

DATE	TYPE OF CONTACT	DISCIPLINE *(Tick box if non-CMHT)*	
			☐
			☐
			☐
			☐
			☐
			☐
			☐
			☐
			☐
			☐

TYPE OF CONTACT
Code as follows:
1 = face-to-face with care coordinator
2 = face-to-face with consultant
3 = face-to-face with other CMHT staff
4 = face-to-face with other staff
5 = phone calls to service user
6 = carer review
7 = carer contact
8 = User and carer joint contact
9 = other type of contact (please state)

DISCIPLINE
Code as follows:
1 = Social worker
2 = CPN
3 = Occupational therapist
4 = Clinical psychologist
5 = Consultant psychiatrist

1. Individual Contacts

DATE	**TYPE OF CONTACT**	**DISCIPLINE** *(Tick box if non-CMHT)*	

TYPE OF CONTACT

Code as follows:

1 = face-to-face with care coordinator
2 = face-to-face with consultant
3 = face-to-face with other CMHT staff
4 = face-to-face with other staff
5 = phone calls to service user
6 = carer review
7 = carer contact
8 = Patient and carer joint contact
9 = other type of contact (please state)

DISCIPLINE

Code as follows:

1 = Social worker
2 = CPN
3 = Occupational therapist
4 = Clinical psychologist
5 = Consultant psychiatrist
6 = Mental health worker
7 = SHO
8 = Staff grade psychiatrist

2. Hospital Admissions

DATES		VOLUNTARY or COMPULSORY	DATE OF DISCHARGE LETTER TO GP
From	To		
___/___/____	___/___/____	____________________	____/____/____
___/___/____	___/___/____	____________________	____/____/____
___/___/____	___/___/____	____________________	____/____/____
___/___/____		____________________	____/____/____
___/___/____		____________________	____/____/____
___/___/____		____________________	____/____/____
___/___/____		____________________	____/____/____
___/___/____			____/____/____
___/___/____			____/____/____

If the service user is still in hospital please indicate by entering 8/8/8 in the 'Dates to' column.

b) For each discharge letter, please indicate the presence of the following items:

	Hospitalisation 1	2	3	4
Diagnosis	☐	☐	☐	☐
Treatment recommended to GP *	☐	☐	☐	☐
Follow-up arrangements by CMHT	☐	☐	☐	☐
Prognosis *	☐	☐	☐	☐
Concise explanation of the condition	☐	☐	☐	☐

* only record if these are explicit

3.)CPA Information

a) Does the service user currently have a named professional designated as their care coordinator?

YES ☐ Please indicate discipline of cc: ☐

NO ☐

DISCIPLINE

Code as follows:
1 = Social worker
2 = CPN
3 = Occupational therapist
4 = Clinical psychologist
5 = Consultant psychiatrist
6 = Mental health worker
7 = SHO
8 = Staff grade

b) *How many care coordinators has the service user had during the past year?* ☐

c) Have the following documents been sent?

	User	Carer	GP
CPA	☐	☐	☐
Crisis/contingency form	☐	☐	☐
Risk assessment	☐	☐	☐

4. Miscellaneous Communication With GPs

a) Name and address of GP ____
____
____
____
____

b) How many additional documents have been sent from the CMHT to the GP? ☐

5(i). Referral to Services Outside CMHT

Please complete a Q5 for *each* service to which the service user has been referred

a) Name of service to which referred:

Day care ☐
Rehabilitation ☐
Forensic ☐
ACT ☐
Other ____________________

b) Date of referral: _____/_____/______

c) Is this a transfer of clinical responsibility? YES ☐ NO ☐
d) If so, have past records been forwarded to the services? YES ☐ NO ☐
e) Was this a transfer to a different trust? YES ☐ NO ☐
If so,
f) Was a letter sent to the new trust? YES ☐ NO ☐

5(ii). Referral to Services Outside CMHT

a) Name of service to which referred:

Day care ☐

Rehabilitation ☐

Forensic ☐

ACT ☐

Other __________________

b) Date of referral: _____/_____/______

c) Is this a transfer of clinical responsibility? YES ☐ NO ☐

d) If so, have past records been forwarded to the services? YES ☐ NO ☐

e) Was this a transfer to a different trust? YES ☐ NO ☐

If so,

f) Was a letter sent to the new trust? YES ☐ NO ☐

Please use an additional sheet to continue Q6 if the service user has been referred to more than two services

6. Miscellaneous

a) Indicate the number of sets of notes for this service user held within the CMHT ☐

(n.b. this does not mean number of volumes)

b) Indicate the total number of letters that have been sent by the CMHT ☐

c) Number of letters that were copied to the service user ☐

Please collect the following from the information on page 1

7. Communication With Carers

This *does not* have to be the main carer.

a) Do the notes record the existence of any carer? YES ☐ NO ☐

b) Has any carer received a needs assessment? YES ☐ NO ☐

c) Indicate the number of recorded contacts with any carer ☐

Appendix 7 – Confirmatory Factor Analyses

Methods – Sample 1

The aim of the confirmatory factor analyses (CFAs) was to test and cross-validate the fit of the empirical seven-factor model obtained from the exploratory factor analysis (EFA), using the Sample 1 data at T2 and T3 and Sample 2 data at T1 and T2. The CFAs were conducted using the CALIS procedure of the SAS version 9.1 statistical software (SAS Institute Inc, 1989), and were based on the sample's covariance matrix using the maximum likelihood (ML) estimation method. This method was selected as it was shown to be robust and yield reliable goodness-of-fit indices and relatively unbiased parameters when used with smaller samples ($N \leq 250$), even under multivariate non-normality (Olson *et al*, 2000; Hu & Bentler 1998; Curran *et al*, 1997). Factors of the measurement model were allowed to correlate with one another.

The model's goodness-of-fit was assessed by the following criteria: 1) the χ^2 statistic and its corresponding p-value, which if non-significant indicates a good fit to the data; 2) the χ^2 to degrees of freedom ratio, which has been shown to provide a more adequate assessment of fit when model competence, sample size and multivariate normality assumptions are not respected, the rule of thumb being that a ratio of less than two suggests an acceptable fit (Hatcher, 1994); 3) the Bentler's Comparative Fit Index (CFI) and 4) the Bentler and Bonnet's Non-Normed Fit Index (NNFI), which should both exceed 0.95 for an acceptable fit (Hu & Bentler 1998); and 5) the root mean squared error of approximation (RMSEA), which should be between 0.05 and 0.08 for an acceptable fit to the data (Martin *et al*, 2004). The CFI and RMSEA range from zero to one while the NNFI may have values below zero and above one.

Multivariate kurtosis was also computed to assess multivariate normality using Mardia's Multivariate Kurtosis coefficient (Mardia, 1970), the t-statistics for the factor loadings were checked for significance (that is, $|t| >= 1.96$) and the standardised factor loadings checked for non-trivial values (>0.05). Actual and predicted covariances were compared and a standardized residual matrix was computed to identify potential specification errors (when residuals exceed 2 in magnitude), according to the criteria highlighted by Hatcher (1994) and Anderson and Gerbing (1988).

Finally, modification indices were generated for the Sample 1 data-sets. These indices include: a) the Lagrange multiplier test, which estimates the change in the overall χ^2 if a new path or covariance is to be added to the model and b) the Wald test which in turn estimated the change in the overall χ^2 if a path or covariance is deleted from the model.

Due to the large amount of missing data at some time-points (>10%), imputation methods for missing values were employed on the Sample 1 T2 and T3 data-sets and Sample 2 T1 and T2 data-sets, using the random number functions of SPSS version 14.0 for WINDOWS (SPSS Inc.):

- For the continuous variables in the model, missing values were replaced by random numbers generated from the standard normal distribution.
- For missing values from the dichotomous variables in the model, random binomial replacement was performed using the positive outcome's initial proportion (for each time-point) as the probability of success.
- Missing values from the trichotomous variables in the model were replaced using the random uniform function which generated random numbers between -1 and 1. Values were then rounded up to the nearest whole number.

This was a conservative approach to missing data was based on the assumption that such data were missing at random. More stringent assumptions about the likely values of missing data would have been inappropriate.

Methods – Sample 2

Confirmatory factor analysis was used at both time-points, as above, to assess whether the factors emerging for Sample 1 were valid in Sample 2. No modification indices were generated for the Sample 2 data-sets as such procedures have been shown to yield poor results on samples of 100 or fewer observations (Hatcher, 1994). Due to the amount of missing data at T2 (>10%), imputation methods for missing values were employed on the T1 and T2 data-sets, using the random number functions of SPSS version 13.0 for WINDOWS (SPSS Inc.):

- For the continuous variables in the model, missing values were replaced by random numbers generated from the normal distribution.
- For missing values from the dichotomous variables in the model, random binomial replacement was performed using the positive outcome's initial proportion (for each time-point) as the probability of success.
- Missing values from the trichotomous variables in the model were replaced using the random uniform function which generated random numbers between -1 and 1. Values were then rounded up to the nearest whole number.

Results – Sample 1

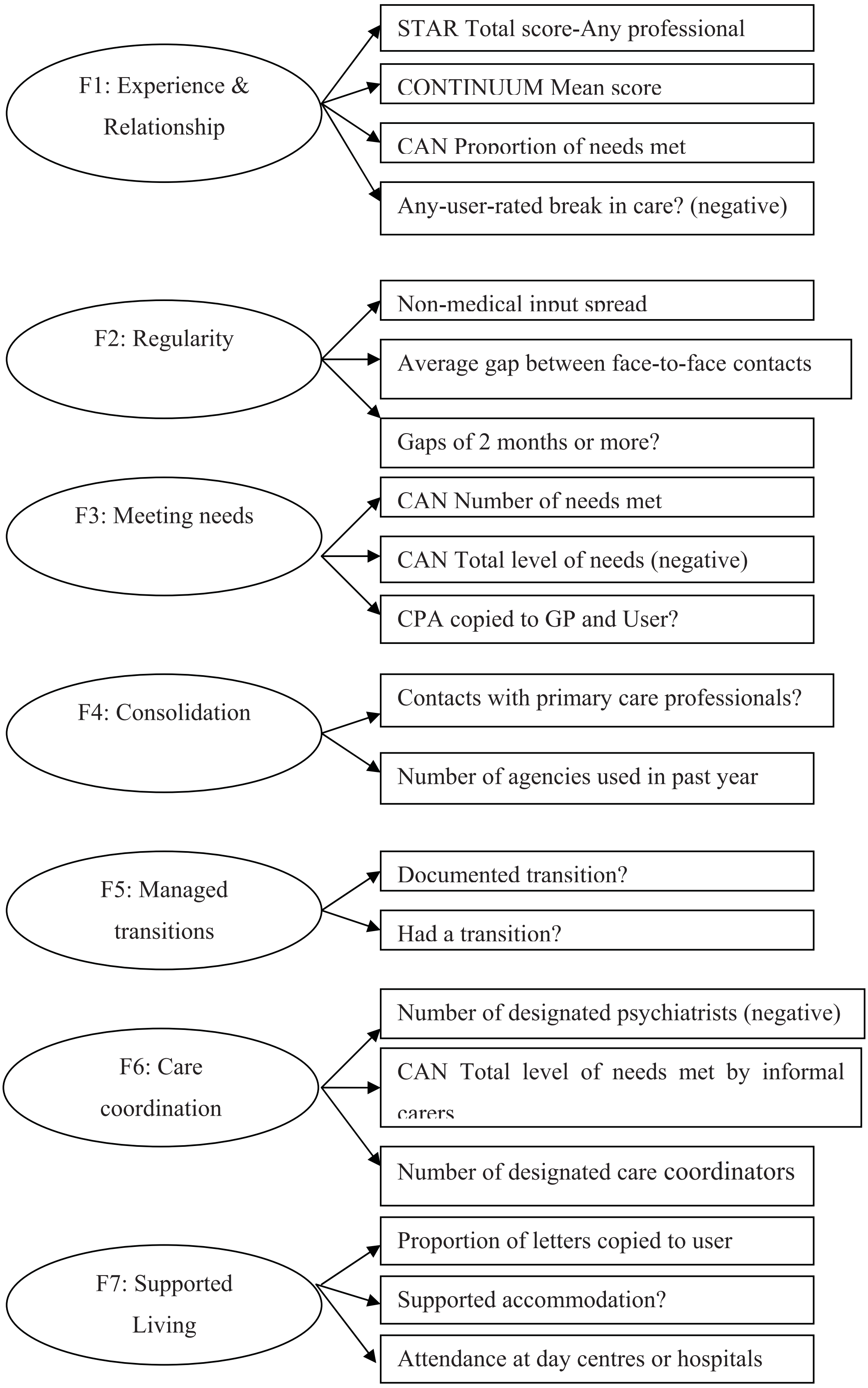
The procedure for all four CFAs (Sample 1 T2 and T3 and Sample 2 T1 and T2) is given here. Findings for Sample 2 are given under 'Users with non-psychotic disorders'. In the figures, rectangles represent manifest variables (continuity components) while ovals represent latent variables (the underlying factors). The double-headed curved arrows between the ovals to the left of the figure indicate covariances between the factors, while the single-headed straight arrows between ovals and rectangles represent the causal effects which the factors have on the manifest variables (factor loadings). The factor loadings in black are the ones set by the structural model tested. The lines remain solid black when the relationships hold after running the CFAs and interrupted black if it is recommended that they be dropped. Straight single-headed arrows in red indicate factor loadings recommended by residual patterns and modifications indices to improve fit.

Initial testing of the model (see Figure 1) with all four data-sets generated covariance matrices which were not 'positive definite' and yielded negative variances and correlations greater than one. According to Chen and colleagues (2001), these improper solutions, also known as Heywood cases, may be the result of 1) sampling fluctuation; 2) model mis-specification; 3) model under-identification, occurring when the number of parameters to be estimated exceeds the number of data-points; 4) empirical under-identification; or 5) outliers. Empirical under-identification can occur when some factor loadings are close to zero and in turn may affect the error variance estimates of the other variables in the model. This happens in the present study as at least two or more factor loadings of less than 0.05 were obtained at each time-point.

In general, occurrence of improper solutions is more frequent with smaller samples (less than 100) and having two or fewer variables loading onto a factor, rendering it highly unstable (Anderson & Gerbing, 1984). Although improper solutions have been shown to have no impact on a CFA's model fit statistics, they tend to bias the parameter estimates (Anderson & Gerbing, 1984; Chen *et al*, 2001), so further analyses were necessary.

To address the possible causes of Heywood cases in the present study, the following adjustments were made: a) model over-identification and the absence of extreme data values (outliers) were ascertained for all four samples; b) Dillon and colleagues' (1987) suggestion of setting low starting values for the error variance estimates in the model was adopted, setting starting values at 0.01; and c) in order to address problems of sampling variation the offending variances estimates were set to zero in the model as prescribed by Dillon and colleagues (1987) and Chen and colleagues (2001). Although this approach implies that the variables have been measured without error, it has been shown to be a simple and practical way to deal with Heywood cases and was comparatively as effective as other methods, such as boot-strapping. Finally, analyses of residual patterns, covariance matrices and modification parameters allowed the detection of potential model mis-specifications.

Figure 1: Factor Analysis: Empirical model obtained from Sample 1 T1 Factor Analysis



Sample 1 T2

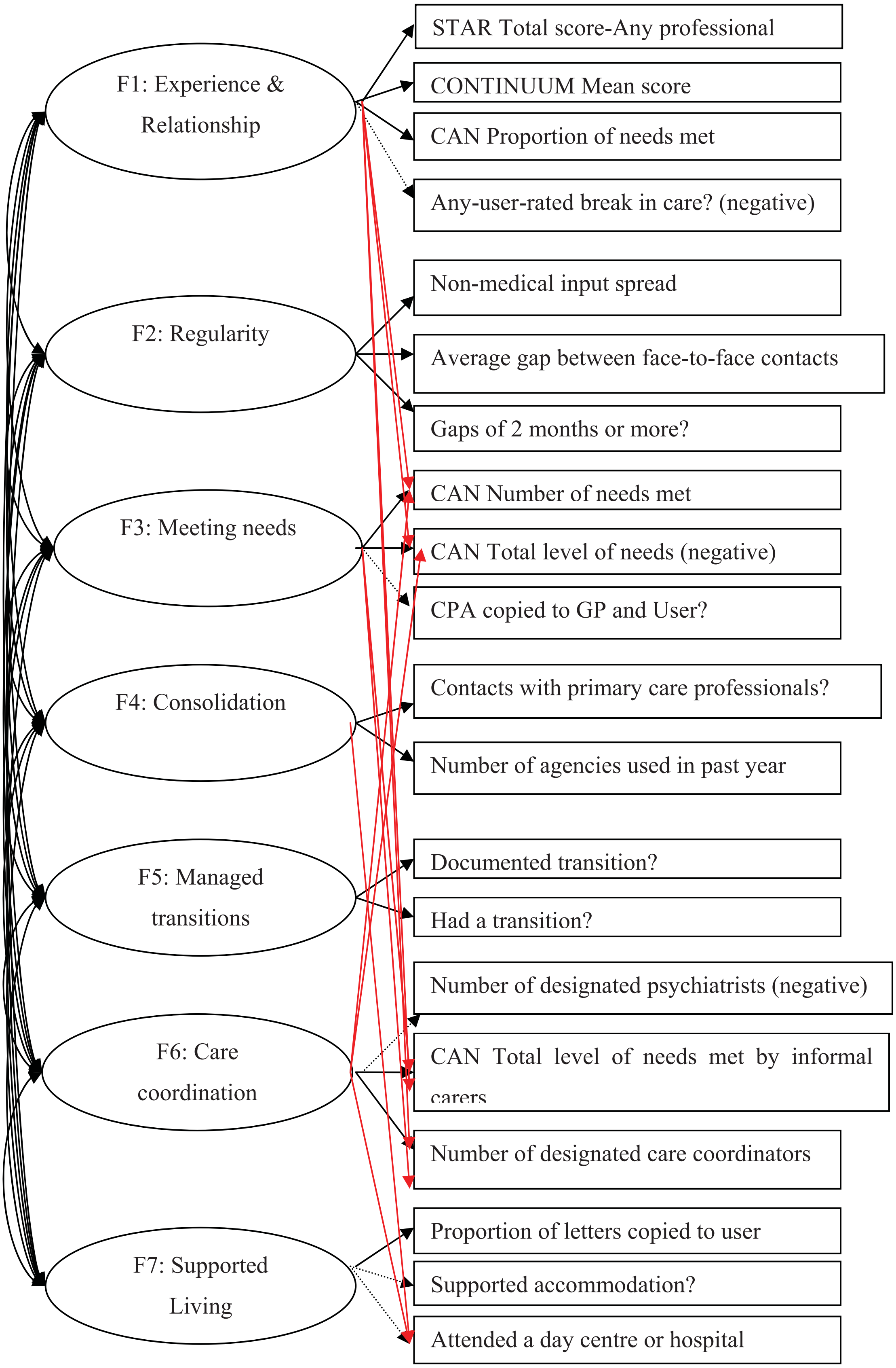
The CFA was run on 180 observations. The error variances for ‘CAN total level of needs’, ‘number of agencies used’, ‘had a transition’ and ‘proportion of letters copied to user’ were set to zero and as such the model did not yield any improper solutions. Mardia’s multivariate kurtosis coefficient was 19.24, indicating moderate multivariate non-normality for the data. Hence the use of ML as an estimation method was substantiated.

The seven-factor model was shown to be a poor fit to the data: the χ^2 goodness-of-fit statistic was significant (χ^2=313.49, df=153; p<0.001), the χ^2/df ratio was slightly greater than two (2.05), and only one index, RMSEA=0.077 (95%CI: 0.064; 0.089), reached the level indicative of an acceptable fit (CFI=0.662 and NNFI=0.580).

There were several very large standardised residuals (>3), indicating that some relationships between components were under-predicted while others were over-predicted. These potential model mis-specifications were also confirmed by results from the Lagrange multiplier test and the Wald test. They suggested the following modifications, as illustrated in Figure 2:

- The variables ‘CAN total level of needs’, ‘CAN number of needs met’, ‘CAN total level of needs met by informal carers’ and ‘number of designated care coordinators’ are all multi-dimensional, all loading on Factor 1, Factor 3 and Factor 6;
- Dropping ‘user-rated breaks in care’ from Factor 1, ‘CPA copied to user and GP’ from Factor 3 and ‘number of designated psychiatrists’ from Factor 6 would significantly improve the χ^2 statistics;
- ‘Supported accommodation’ and ‘attended a day centre’ should both be dropped from Factor 7 (factor loading < 0.01) and ‘attended a day centre’ reassigned to Factor 4 and Factor 6.

Figure 2: Confirmatory Factor Analysis model Sample 1 T2



Sample 1 T3

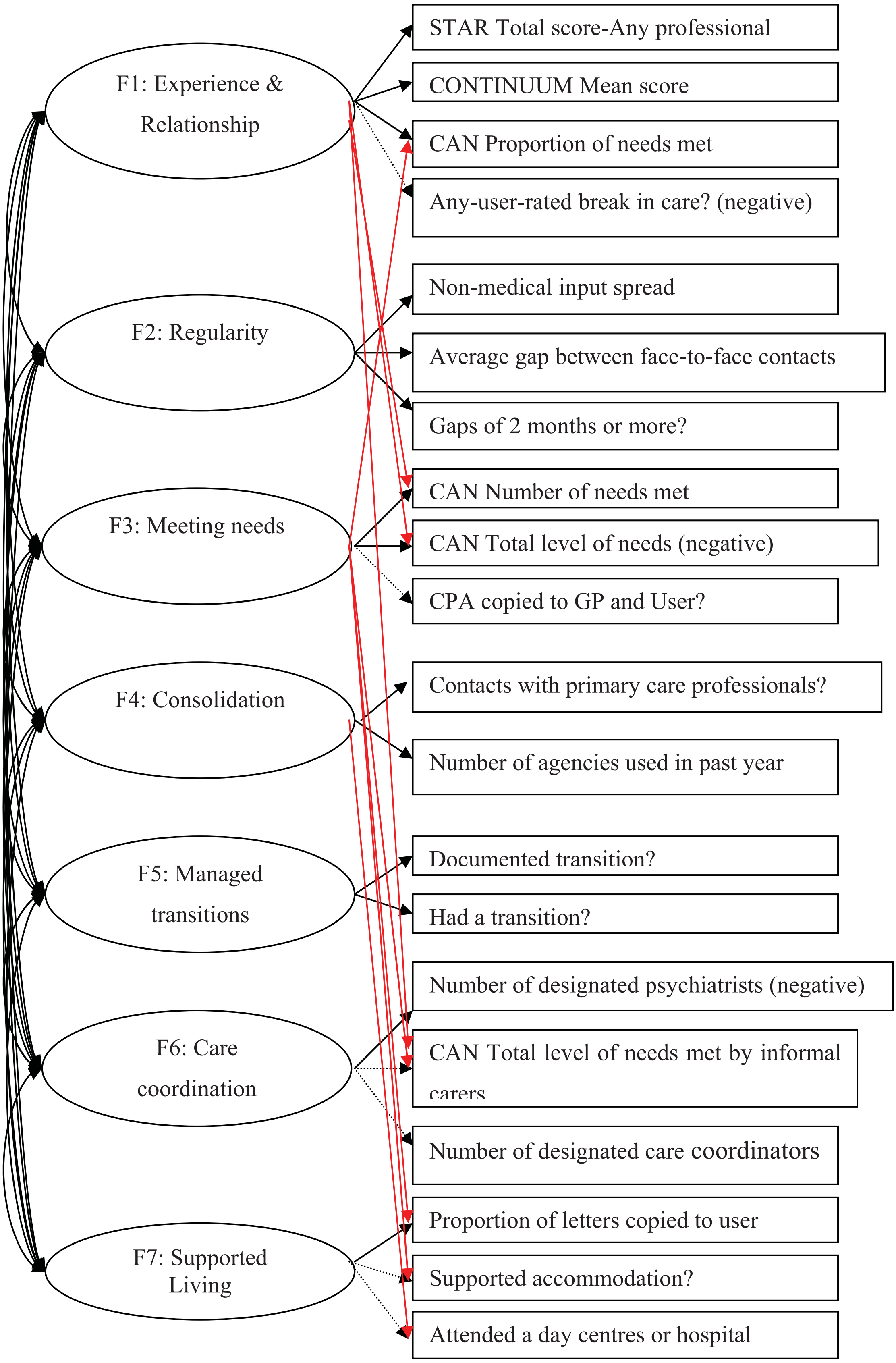
The T3 CFA was run using all 180 observations. The error variances for 'CAN total level of needs', 'number of agencies used', 'had a transition', 'number of designated psychiatrists' and 'proportion of letters copied to user' were set to zero. Multivariate kurtosis was evaluated to be 38.57, which was much larger that at T2; however the use of ML as an estimation method remained justified.

The seven-factor model was a worse fit to the data than at T2: the χ^2 goodness-of-fit statistic was significant (χ^2=403.58, df=154; $p<0.001$), the χ^2/df ratio was 2.62 and none of the other indices were indicative of an acceptable fit (RMSEA=0.095 (95%CI: 0.084; 0.11), CFI=0.479 and NNFI=0.357).

Further analysis of the residual patterns, actual and predicted covariances between manifest variables (variables we measured) as well as the results from the Lagrange Multiplier test and the Wald tests suggested the following modifications to improve the fit of the model, as shown in Figure 3:

- The components 'CAN total level of needs', 'CAN number of needs met', 'CAN total level of needs met by informal carers' and 'CAN proportion of needs met' are all multidimensional, loading onto Factor 1 and Factor 3. However, 'CAN total level of needs met by informal carers' and 'number of designated care coordinators should be dropped from Factor 6;
- The components 'proportion of letters copied to user' and 'supported accommodation' should be assigned to Factor 3;
- Dropping 'user-rated breaks in care' from Factor 1 and 'CPA copied to user and GP' from Factor 3 would significantly improve the χ^2 statistics;
- 'Supported accommodation' and 'attended a day centre' should both be dropped from Factor 7 and 'attended a day centre' reassigned to Factor 4.

Figure 3: Confirmatory Factor Analysis model Sample 1 T3



Results – Sample 2

Time 1

The CFA for the Sample 2 T1 data-set was run using 98 observations. The error variances for 'average gap between face to face contacts', 'number of agencies used' and 'supported accommodation' were set to zero. Multivariate kurtosis was evaluated to be 38.44, so the use of ML as an estimation method was justified.

The model yielded the following: the χ^2 goodness-of-fit statistic was significant (χ^2=242.80, df=152; p<0.001), but both the χ^2/df ratio (1.6) and the RMSEA (0.079 (95%CI: 0.060; 0.097)) were within an acceptable range. However the other indices were not indicative of a good fit (CFI=0.667, NNFI=0.584).

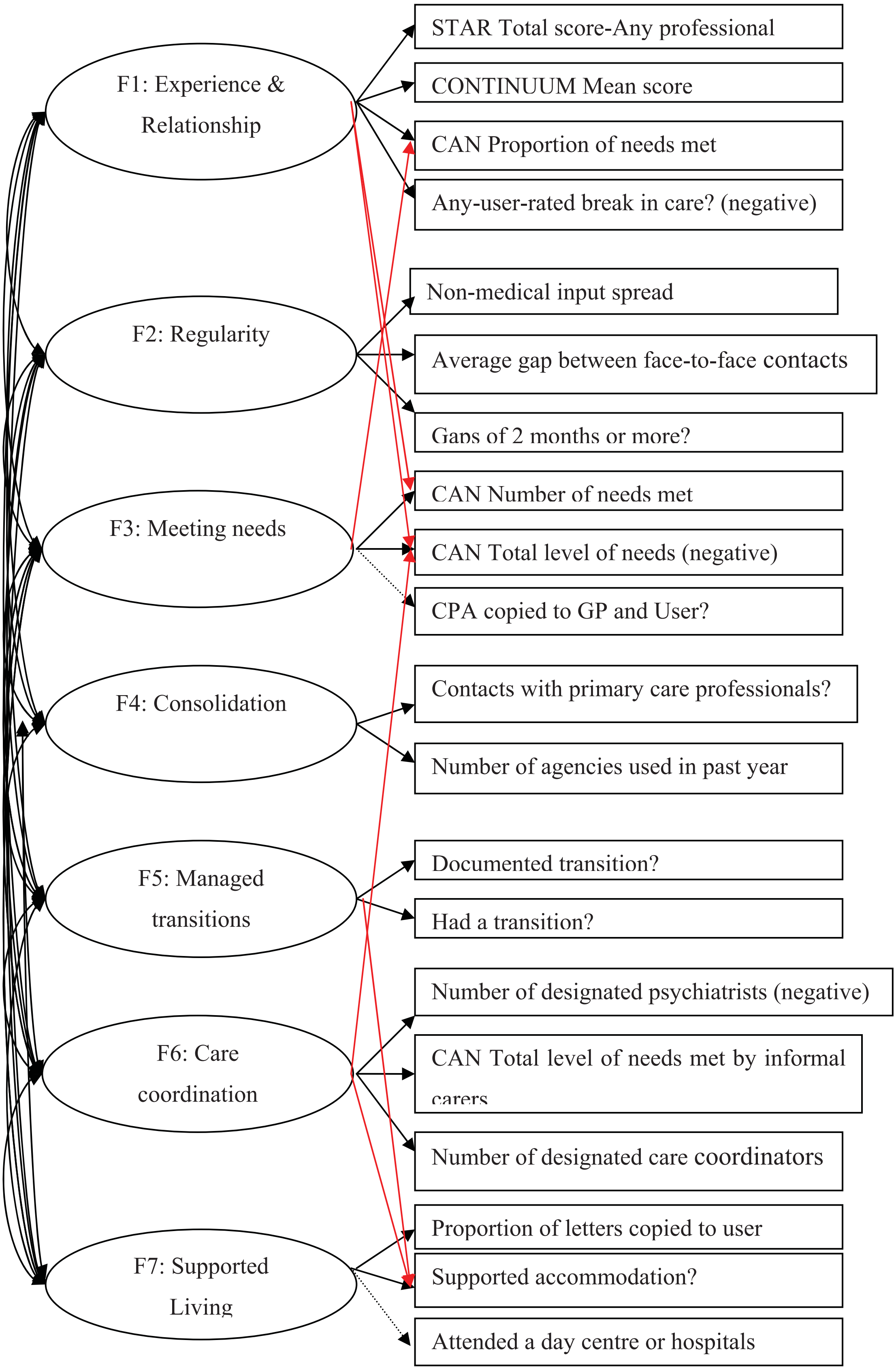
There were several large residuals which suggested potential model mis-specifications. Comparisons of predicted and actual residuals seemed to indicate the following (see Figure 4):

- The model appears to under-predict the relationship between the components 'CAN number of needs met' with three variables loading on Factor 1: 'STAR total Score - any professional', 'CONTINUUM mean score' and 'CAN proportion needs met'. Hence 'CAN number of needs met' is to be multi-dimensional, loading onto both Factor 1 and Factor 3;
- Similarly, the model under-predicts the relationship between 'CAN total level of needs' and the same three Factor 1 components as above, as well as all three Factor 6 components, 'number of designated psychiatrists', 'CAN total level of needs met by informal carers' and 'number of designated care coordinators', suggesting that 'CAN total level of needs' is multi-dimensional, loading onto Factor 1, Factor 3 and Factor 6;
- The component 'supported accommodation' also shares large residuals with the components 'documented transition' and 'had a transition' as well as the variables 'CAN total level of needs met by informal carers' and 'number of

designated care coordinators', indicating that 'supported accommodation' must be multi-dimensional, loading onto Factor 5, Factor 6 and Factor 7;

- The component 'CPA copied to GP and user' should be dropped from Factor 3 and the component 'attended a day centre' should be dropped from Factor 7.

Figure 4: Confirmatory Factor Analysis model Sample 2 T1



Time 2

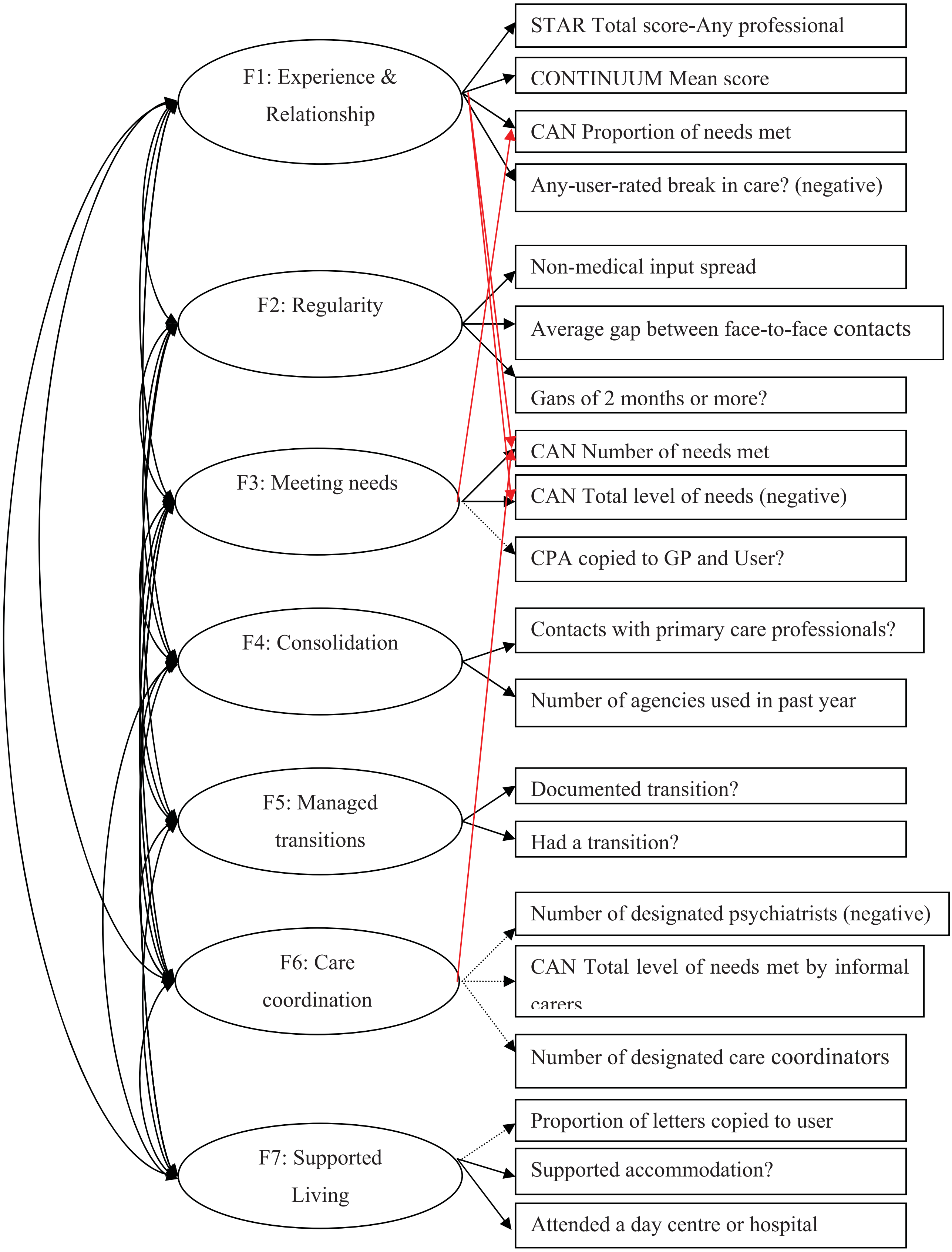
The CFA was run on all 98 observations of the Sample 2 T2 data-set. The error variances for 'number of agencies used' and 'had a transition' were set to zero. Multivariate kurtosis was evaluated to be 5.67, which is within the range of multivariate normality (<7).

The seven-factor model yielded a significant χ^2 goodness-of-fit statistic (χ^2=291.23, df=151; p<0.001). The χ^2/df ratio was acceptable (1.93), yet none of the other indices were indicative of an acceptable fit (RMSEA=0.098 (95%CI: 0.081; 0.12 CFI=0.599 and NNFI=0.495).

Further analyses of residual patterns, covariance matrices and factor loadings suggested the following, as illustrated in Figure 5:

- The relationships between the component 'CAN number of needs met' and the components 'CAN proportion of needs met' and 'CONTINUUM mean score', both loading on Factor 1, are under-predicted by the model. Moreover, 'CAN number of needs met' also shares a large residual with the component 'CAN total level of needs met by informal carers' and moderate residuals with the components 'number of designated psychiatrists' and 'number of designated care coordinators', loading onto Factor 6. Therefore 'CAN number of needs met' must be multi-dimensional, loading onto Factor 1, Factor 3 and Factor 6;
- The component 'CAN total level of needs' also shares a large residual with the variable 'CAN proportion of needs met'; hence they both must be multi-dimensional loading on Factor 1 and Factor 3;
- All the components loading onto Factor 6 as well as the components 'CPA copied to user' and 'proportion of letters copied to user' should be dropped from the model.

Figure 5: Confirmatory Factor Analysis model Sample 2 T2



Appendix 8 - Illustration of continuity factors

Methods – Both samples

An illustration of the magnitude of the factor scores was carried out in order to aid in the interpretation of subsequent analyses. Hypothetical service users' scores were calculated by assigning z-scores of zero (mean score) to those with medium scores on each variable, '2' (mean + two standard deviations) for high scores and '-2' (mean – two standard deviations) for low scores. The sum of each factor was calculated for low, medium and high scorers. The data from two randomly selected users is also presented and compared to the hypothetic low, medium and high scorers, indicating how their data transforms into factor scores.

Results – Sample 1

Data were not always normally distributed, so that illogical values occur when calculating values from z-scores, such as negative values for the average gap between face-to-face contacts and number of met needs. In the text below, these have been bounded at zero, but the true hypothetical values appear in the tables below.

Factor 1: Experience & Relationship

Someone scoring highly on Factor 1 (*Experience & Relationship* score of 6) would have a maximum STAR Total score (48) and a maximum CONTINUUM mean score (5). This person would also report more than 91% of their needs met and not report a significant break in their care. Conversely, someone scoring low on Factor 1 (*Experience & Relationship* score of -6) would have a STAR Total score of 18.5, a mean CONTINUUM score of 2.0, have fewer than 65.0% of their needs met and have reported a break in care. (Table 1)

Participant P1, a 46 year-old Black female from Trust 2, had an *Experience & Relationship* score of 3.3 at T1, suggesting a medium-high scoring on Factor 1. She had a medium-high score on the STAR (44.0), a slightly above medium mean score on CONTINUUM (3.9), a high proportion of her needs met (100.0%), and did not report having had a break in care.

Participant P2, a 29 year-old White male from Trust 1, had an *Experience & Relationship* score of 1.3, indicating a medium score. He had a score just above medium on the STAR (40.0), a medium-high CONTINUUM mean score (4.2), reported a low proportion of his needs being met (62.5%) and reported no break in care.

Factor 2: Regularity

Someone scoring highly on Factor 2 (*Regularity* score of 4) would have a non-medical input spread of less than or equal to 20.0% (such that someone with ten contacts during a year would have seen two different disciplines), have no gap (i.e. see a professional daily) between face-to-face contacts and no gaps of two months or more. Someone with a low score on Factor 2 (*Regularity* score of -4) would have a non-medical input spread of greater than or equal to 50.0% (such that someone with ten contacts during a year would have seen five different disciplines), have an average gap between face-to-face contacts of 124 days and have gaps between contacts of two months or more.

Participant P1 had a relatively low *Regularity* score at T1 (-2.6). She had 100% non-medical input spread (indicating that all her contacts were with someone from a different discipline), an average gap between contacts of 70.5 days and has gaps of two months or more.

Participant P2 had a relatively high *Regularity* score (2.7). He had a low non-medical input spread of 5.3% (indicating that about he saw someone from one discipline for every 20 contacts), a low average gap between face to face contacts of 16.4 days and reported no gaps of two months or more.

Factor 3: Meeting Needs

Someone with a high score on Factor 3 (*Meeting Needs* score of 5) would have 9.1 met needs, a total level of need of 18.2 and have their CPA is copied to the user and GP. Someone with a low score on Factor 3 (*Meeting Needs* score of -5) has no met needs, no total level of need and does not have their CPA copied to themselves or their GP.

Participant P1 had a low-medium score on Factor 3 (*Meeting Needs* score of -2.7). She had a slightly below medium number of met needs (3), a medium-low total level of needs (3) and did not have a copy of her CPA sent to her or her GP.

Participant P2 had a medium-high score on Factor 3 (*Meeting Needs* score of 2.6). He had a slightly greater than medium number of met needs (5), has a relatively high total level of need (15) and had his CPA copied to both him and his GP.

Factor 4: Consolidation

Someone scoring highly on Factor 4 (*Consolidation* score of 3) would not have had contact with primary care professionals nor used any agencies in the previous year. Someone with a low score on this factor (*Consolidation* score of -3) would have had contact with primary care professionals and used 10.9 agencies in the previous year.

Participant P1 had a high *Consolidation* score. She had not had contact with primary care professionals and had only used one agency in the past year.

Participant P2 had a low *Consolidation* score. He had had contact with primary care professionals and had used nine agencies in the previous year.

Factor 6: Care Coordination

Someone with a high score on Factor 6 (*Care Coordination* score of 4) would have seen one or two psychiatrists in the past year, have none of their needs met by informal carers and have seen one or two care coordinators in the past year. Someone with a low score on this factor (*Care Coordination* score of -4) would have seen no or more than three psychiatrists in the past year, have 11.5 of their needs met by informal carers and have had no or more than three care coordinators in the past year.

Participant P1 had a medium to low *Care Coordination* score (0.8). She had not seen a psychiatrist in the previous year but had had one care coordinator. She had not had any needs met by informal carers.

Participant P2 had a medium-low *Care Coordination* score (-0.4). He had had one psychiatrist and one care coordinator in the previous year and had had 13 needs met by informal carers.

Factor 7: Supported Living

Someone with a high *Supported Living* score (score of 3) would live in supported accommodation, attend a day centre or day hospital and have more than 50.0% of the letters sent by the CMHT directly to or copied to them. Someone with a low score on this factor (*Supported Living* score of -3) would not live in supported accommodation, would not attend a day hospital or day centre and would have had no letters sent or copied to them from the CMHT.

Participant P1 had a medium-low *Supported Living* score (0). She lived in supported accommodation, did not attend day centres or day hospitals and had had less than 50.0% of letters from the CMHT copied to or sent directly to her.

Participant P2 had a low-medium *Supported Living* score (-1). He did not live in supported accommodation but did attend day centres and he had not been sent or copied into any letters from the CMHT.

Table 1: Sample 1 Levels of continuity illustrated

	Hypothetical service user			Actual Participant chosen at random	
Component	**Low**	**Medium**	**High**	**P1 Actual value (z-score/ category value)**	**P2 Actual value (z-score/ category value)**
Factor 1					
CONTINUUM Mean score: (1-5)	-2 2.0	0 3.5	2 5.0	3.9 (0.5)	4.2 (0.9)
STAR Total score-Any professional: (0-48)	-2 18.5	0 36.5	2 54.5	44.0 (0.8)	40.0 (0.4)
CAN-Proportion of needs met: (0-22)	-1 <65%	0 65-91%	1 >91%	100 (1)	62.5 (-1)
Any user-rated breaks in care	-1 Yes	1 No	1 No	No (1)	No (1)
Experience & Relationship score	-6	1	6	3.3	1.3
Factor 2					
Average gap between face-to-face contacts (days)[1]	-2 124.3	0 44.9	2 -34.5	70.5 (-0.6)	16.4 (0.7)
Gaps of 2 months of more	-1 Yes	1 No	1 No	Yes (-1)	No (1)
Non-medical input spread	-1 =>50%	0 21-49%	1 =<20%	100 (-1)	5.3 (1)
Regularity score	-4	1	4	-2.6	2.7

Table 1: Sample 1 Levels of continuity illustrated (continued)					
	Hypothetical service user			Actual Participant chosen at random	
Component	**Low**	**Medium**	**High**	**P1 Actual value (z-score/ category value)**	**P2 Actual value (z-score/ category value)**
Factor 3					
CAN- Total level of needs: (0-66) [1]	-2 -2.2	0 8.5	2 18.2	3 (-1.1)	15 (1.3)
CAN- Number of met needs: (0-22)	-2 -0.3	0 4.4	2 9.1	3 (-0.6)	5 (0.3)
CPA copied to GP and user	-1 No	0 To one	1 To both	No (-1)	To both (1)
Meeting Needs score	-5	0	5	-2.7	2.6
Factor 4					
Number of agencies used in the previous year	-2 10.9	0 5.1	2 -0.7	1 (1.4)	9 (-1.4)
Contact with primary care professionals	-1 Yes	1 No	1 No	No (1)	Yes (-1)
Consolidation Score	-3	1	3	2.4	-2.4
Factor 6					
Number of designated care coordinators	-1 0 or 3+	1 1 or 2	1 1 or 2	1 (1)	1 (1)
Number of designated psychiatrists	-1 0 or 3+	1 1 or 2	1 1 or 2	0 (-1)	1 (1)
CAN- Total level of needs met by informal carers: (0-22) [1]	-2 11.5	0 3.4	2 -4.7	0 (0.8)	13 (-2.4)
Care Coordination score	-4	2	4	0.8	-0.4

Table 1: Sample 1 Levels of continuity illustrated (continued)					
	Hypothetical service user			**Actual Participant chosen at random**	
Component	**Low**	**Medium**	**High**	**P1 Actual value (z-score/ category value)**	**P2 Actual value (z-score/ category value)**
Factor 7					
Supported accommodation	-1 No	1 Yes	1 Yes	Yes (1)	No (-1)
Attendance at day centres or hospitals	-1 No	1 Yes	1 Yes	No (-1)	Yes (1)
Proportion of letters from CMHT sent directly/copied to user	-1 0	0 <=50%	1 >50%	14.3% (0)	0 (-1) No letters sent by CMHT
Supported Living Score	-3	2	3	0	-1

Results – Sample 2

(For hypothetical examples of each factor, see under Sample 1.)

Factor 1: Experience & Relationship

Participant P3, a 39 year-old White female from Trust 2 diagnosed with depression, had an *Experience & Relationship* score at T1 of 2.1, suggesting a medium-high score. She had a medium-high score on STAR (46.0), a medium mean score on CONTINUUM (3.4), a medium proportion of her needs met (75.0%), and did not report having had a break in care.

Participant P4, a 28 year-old mixed race female from Trust 1 diagnosed with OCD and depression, had an *Experience & Relationship* score at T1 of -3.3, indicating a low-medium score. She had a low score on STAR (20.0), a slightly above medium CONTINUUM mean score (3.9), reported a break in care and reported that none of her needs was being met. (Table 2)

Factor 2: Regularity

Participant P3 had a medium-high *Regularity* score (2.4). She had a low non-medical input spread of 7.7% (indicating a different discipline seen for every 14 contacts), an average gap between contacts of 17.3 days and had experienced no gaps of two months or more.

Participant P4 had a low-medium *Regularity* score (-0.1). She had a non-medical input spread of 20% (indicating one new discipline seen for every five contacts), an average gap between face-to-face contacts of 30.2 days and had experienced gaps of two months or more.

Factor 3: Meeting Needs

Participant P3 had a medium score on Factor 3 (*Meeting Needs* score of 0). She had a medium-high number of met needs (6), a medium-low total level of needs (9) and had had a copy of her CPA sent to either herself or her GP.

Participant P4 had a medium-low score on Factor 3 (*Meeting Needs* score of -2). She had no met needs, a medium-low total level of needs (7) and had had her CPA copied to both herself and her GP.

Factor 4: Consolidation

Participant P3 had a medium-low *Consolidation* score (-0.8). She had had contact with primary care professionals and had used six agencies in the previous year.

Participant P4 also had a medium-low *Consolidation* score (-0.5). She had had contact with primary care professionals and used five agencies in the previous year.

Factor 6: Care Coordination

Participant P3 had a medium to low *Care Coordination* score (-0.8). She had seen five psychiatrists in the past year, but had one care coordinator. She had had 12 needs met by informal carers.

Participant P4 had a high *Care Coordination* score (3). She had seen two psychiatrists and one care coordinator in the previous year and had had two needs met by informal carers.

Factor 7: Supported Living

Participant P3 had a low *Supported Living* score (-2). She did not live in supported accommodation, did not attend day centres or day hospitals and had had fewer than half of the letters from the CMHT copied to or sent directly to her.

Participant P4 had a low-medium *Supported Living* score (1). She lived in supported accommodation, did not attend day care and had had all the letters from the CMHT sent or copied to her.

Table 2: Sample 2 Levels of continuity illustrated

	Hypothetical service user			**Actual Participant chosen at random**	
Component	**Low**	**Medium**	**High**	**P3** **Actual value** **(z-score/ category value)**	**P4** **Actual value** **(z-score/ category value)**
Factor 1					
CONTINUUM Mean score: (1-5)	-2 1.9	0 3.3	2 4.7	3.4 (0.1)	3.9 (0.8)
STAR Total score-Any professional: (0-48)	-2 20.8	0 37.9	2 55.0	46.0 (1)	20 (-2.1)
CAN-Proportion of needs met: (0-22)	-1 <65%	0 65-91%	1 >91%	75 (0)	0 (-1)
Any user-rated breaks in care	-1 Yes	1 No	1 No	No (1)	Yes (-1)
Experience & Relationship score	-6	1	6	2.1	-3.3
Factor 2					
Average gap between face-to-face contacts (days)	-2 78.2	0 27.0	2 -24.2	17.3 (0.4)	30.2 (-0.1)
Gaps of 2 months of more	-1 Yes	1 No	1 No	No (1)	Yes (-1)
Non-medical input spread	-1 =>50%	0 21-49%	1 =<20%	7.7 (1)	20.0 (1)
Regularity score	-4	1	4	2.4	-0.1

Table 2: Sample 2 Levels of continuity illustrated (continued)

	Hypothetical service user			Actual Participant chosen at random	
Component	**Low**	**Medium**	**High**	**P3** **Actual value** **(z-score/ category value)**	**P4** **Actual value** **(z-score/ category value)**
Factor 3					
CAN- Total level of needs: (0-66)	-2 2.0	0 11.7	2 21.4	9 (-0.6)	7 (-1)
CAN- Number of met needs: (0-22)	-2 0.0	0 4.7	2 9.4	6 (0.6)	0 (-2.0)
CPA copied to GP and user	-1 No	0 To one	1 To both	To one (0)	To both (1)
Meeting Needs score	-5	0	5	0	-2
Factor 4					
Number of agencies used in the previous year	-2 12.6	0 6.6	2 0.6	6 (0.2)	5 (0.5)
Contact with primary care professionals	-1 Yes	1 No	1 No	Yes (-1)	Yes (-1)
Consolidation Score	-3	1	3	-0.8	-0.5
Factor 6					
Number of designated care coordinators	-1 0 or 3+	1 1 or 2	1 1 or 2	1 (1)	1 (1)
Number of designated psychiatrists	-1 0 or 3+	1 1 or 2	1 1 or 2	5 (-1)	2 (1)
CAN- Total level of needs met by informal carers: (0-22)	-2 18.9	0 7.7	2 -3.5	12 (-0.8)	2 (1.0)
Care Coordination score	-4	2	4	-0.8	3

Table 2: Sample 2 Levels of continuity illustrated (continued)					
	Hypothetical service user			**Actual Participant chosen at random**	
Component	**Low**	**Medium**	**High**	**P3 Actual value (z-score/ category value)**	**P4 Actual value (z-score/ category value)**
Factor 7					
Supported accommodation	-1 No	1 Yes	1 Yes	No (-1)	Yes (1)
Attendance at day centres or hospitals	-1 No	1 Yes	1 Yes	No (-1)	No (-1)
Proportion of letters from CMHT sent directly/copied to user	-1 0	0 <=50%	1 >50%	13.3% (0)	100% (1)
Supported Living Score	-3	2	3	-2	1

Appendix 9 – Comparison of service users in the upper and lower quartiles

Methods – Both samples

In order to illustrate further differences between the experiences and characteristics of those scoring high and low on each continuity factor, those scoring in the upper and lower quartiles for each factor were compared. Upper and lower quartile scores for each factor were calculated and used to assign each user to a quartile group. Users scoring in the lower and upper quartiles on each factor were then compared on a number of demographic, social and clinical variables. Scores on continuous variables were compared using t-tests, and scores on categorical variables were compared using χ^2 tests.

Results – Sample 1

Factor 1, *Experience & Relationship* *(25% percentile=-0.66, 75% percentile=2.74)*
Users in the upper quartile had significantly lower symptomatology (BPRS: 28.73 versus 35.78, t=3.413, p=0.008). The change in BPRS between T1 and T2 was smaller among those in the upper quartile group (0.79 versus -5.53, t=-3.451, p=0.006). Those in the upper quartile had a higher reported quality of life on the MANSA (MANSA: 4.94 versus 4.11, t= -5.100, p<0.001).

Factor 2, *Regularity* *(25% percentile=-1.47, 75% percentile=2.60)*
The most significant difference between people whose scores were in the lower and upper quartiles was for team (χ^2=67.018, p<0.001) with all of those in the lower quartile being in the care of Trust 2 teams (Team 2a=38.6%, Team 2c=38.6%, Team 2b= 22.7%,). The majority of those scoring in the upper quartile were under the care of Team 1a (29.5%), Team 1c (18.2%) and Team 1b (13.6%). Those scoring in the upper quartile for this factor felt more coerced on the perceived coercion sub-scale than those in the lower quartile (2.87 versus 1.65, t=-2.846, p=0.048).

Factor 3, *Meeting Needs* *(25% percentile=-1.26, 75% percentile=1.23)*

Participants in the upper quartile had lower GAF scores (poorer functioning) than those in the lower quartile (44.73 versus 59.76, t=5.80, $p<0.008$). People in the upper quartile also reported a lower quality of life (SEIQoL=55.57 versus 69.94, t=4.546, $p<0.008$; MANSA=3.96 versus 4.92, t=5.803, $p<0.008$), and had a higher BPRS total score (more symptoms, 39.07 versus 28.16, t=-4.533, $p<0.008$). A greater proportion of people in the upper quartile were hospitalised during the subsequent year (25.0% versus 4.4%, t=7.536, p=0.036).

Factor 4, *Consolidation* *(25% percentile=-1.32, 75% percentile=1.37)*

The majority of those scoring in the upper quartile for Factor 4 were under the care of Team 2c and Team 2a and this result approached significance (both Trust 2 teams, 29.7% and 27.0% respectively, $\chi^2=18.551$, p=0.07). The majority of those whose scores were in the lower quartile were seen by Team 1a, Team 1d and Team 2b (22.2% each). Those scoring in the upper quartile had higher GAF scores (better functioning, 56.92 versus 48.03, t=-2.805, p=0.056) which approached significance.

Factor 5, *Managed Transitions* *(documented versus undocumented transitions)*

Comparing those people who had documented and undocumented transitions, only whether or not someone was hospitalised during the follow-up period was statistically significant at the p=0.05 level. A larger proportion of people who had documented transitions were hospitalised (76.5% versus 30.6%, $\chi^2=9.825$, p=0.012). This may have been because hospitalisation was coded as a transition in the analysis.

Factor 6, *Care Coordination* *(25% percentile=-0.89, 75% percentile=0.83)*

More people whose *Care Coordination* scores were in the lower quartile had carers (28.6% versus 9.1%, $\chi^2=7.428$, p=0.084) which approached significance and is to be expected as having a high number of needs met by informal carers contributes towards gaining a low score on this factor.

Factor 7, *Supported Living* *(25% percentile=-3, 75% percentile=-0.5)*

More people scoring in the upper quartile on this factor were living in supervised accommodation (50.0% versus 10.0%, $\chi^2=22.740$, $p<0.014$), which is to be expected as this is one of the variables loading on this factor.

Results – Sample 2

Factor 1, *Experience & Relationship* *(25% percentile= -2.70, 75% percentile= 0.26)*
Users differed most significantly in quality of life (MANSA, t=-3.204, p=0.016) with those whose scores were in the upper quartile rating a higher quality of life (4.16 versus 3.39).

Factor 2, *Regularity* *(25% percentile= -0.19, 75% percentile= 1.47)*
When accounting for the Bonferroni correction, the two groups did not differ significantly on any of the variables tested.

Factor 3, *Meeting Needs* *(25% percentile= -1.67, 75% percentile= 1.24)*
People scoring in the upper quartile for this factor had poorer functioning (GAF, 52.21 versus 60.54, t=3.155, p=0.024) and felt less empowered (67.83 versus 75.46, t=2.840, p=0.056, approaching significance.

Factor 4, *Consolidation* *(25% percentile= -1.47, 75%= 0.87)*
The two groups only differed significantly in terms of their functioning with those scoring in the upper quartile having better functioning (59.39 versus 49.10, t=-3.104, p=0.024).

Factor 5, *Managed Transitions* *(undocumented versus documented transitions)*
Only total number of lifetime admissions differed significantly between the two groups (χ^2=12.306, p=0.028) with people who had had documented transitions having had an admission in their lifetime (95.8% versus 58.8%); this is to be expected as hospitalisation was classified as a transition in the analysis.

Factor 6, *Care Coordination* *(25% percentile= -0.28, 75% percentile= 1.20)*
The two groups only differed significantly at the p=0.05 level in terms of GAF score with those in the upper quartile having better functioning (56.78 versus 46.96, t=-3.376, p=0.016).

Factor 7, *Supported Living* *(25% percentile= -1, 75% percentile= 1)*

The most significant difference between the two groups was for accommodation type (upper quartile 62.5% supervised accommodation versus lower quartile 0%, χ^2=20.323, p<0.014) which is to be expected as living in supervised accommodation is a component loading onto this factor. Those scoring in the upper quartile were younger (32.75 versus 46.14, t=3.200, p=0.042).

Appendix 10: Correlation Matrix of continuity of care components

Correlation Matrix: Sample 1 T1 User measures^{a,b,c}

Spearman's rho		**C1**	**C2**	**C3**	**C4**	**C5**	**C6**	**C7**	**C10**	**C11**	**C12**	**C13**	**C14**	**C15**	**C16**	**C17**	**C18**	**C19**	**C20**	**C21**	**C22**	**C23**	**C24**	**C25**	**C27**	**C30**	**C31**	**C32**
C1	Corr. Coeff.	1.000	-.321	.044	-.498	-.326	-.043	.469	.033	.026	.112	-.033	-.082	-.020	.080	.278	.146	.033	-.090	.515	.009	.046	-.028	.112	.073	-.221	.223	.122
C2	Corr. Coeff.	-.321	1.000	.668	.578	**.934**	.338	-.406	-.222	-.218	.050	.135	-.149	.043	.044	.014	.034	-.008	-.019	-.241	-.090	.066	-.045	-.017	.016	.130	.003	.087
C3	Corr. Coeff.	.044	.668	1.000	-.140	.621	.323	.262	-.187	-.147	.083	.127	-.173	.113	.164	.163	.080	-.086	-.031	-.100	-.084	.005	.019	-.097	.055	-.023	.156	.190
C4	Corr. Coeff.	-.498	.578	-.140	1.000	.557	.115	**-.940**	-.087	-.128	.002	.053	-.048	-.022	-.073	-.120	-.111	.081	.017	-.256	-.054	.102	-.081	.087	-.004	.225	-.143	-.098
C5	Corr. Coeff.	-.326	**.934**	.621	.557	1.000	.366	-.400	-.234	-.224	-.013	.181	-.163	.065	.092	.018	.065	-.022	.045	-.237	-.108	.110	-.054	-.028	.053	.104	-.001	.042
C6	Corr. Coeff.	-.043	.338	.323	.115	.366	1.000	-.074	-.161	-.147	-.020	.328	-.121	.089	.124	-.009	.170	.044	-.094	-.082	-.154	.129	-.086	-.132	.153	.086	.064	-.085
C7	Corr. Coeff.	.469	-.406	.262	**-.940**	-.400	-.074	1.000	.047	.083	-.022	-.006	.036	.003	.109	.142	.151	-.061	-.042	.215	.015	-.073	.061	-.105	.042	-.207	.152	.064
C10	Corr. Coeff.	.033	-.222	-.187	-.087	-.234	-.161	.047	1.000	**.812**	.078	-.231	.365	-.074	-.140	-.156	-.106	-.200	-.152	.096	.369	-.276	.272	.123	-.277	-.028	-.067	-.025
C11	Corr. Coeff.	.026	-.218	-.147	-.128	-.224	-.147	.083	**.812**	1.000	.064	-.168	.437	-.086	-.117	-.101	-.031	-.193	-.111	.164	.321	-.266	.243	.076	-.253	-.017	-.160	.046
C12	Corr. Coeff.	.112	.050	.083	.002	-.013	-.020	-.022	.078	.064	1.000	-.513	.080	-.128	-.077	-.008	.018	-.234	-.012	.080	.214	-.183	.197	.067	-.239	.068	-.186	.085
C13	Corr. Coeff.	-.033	.135	.127	.053	.181	.328	-.006	-.231	-.168	-.513	1.000	-.173	.103	.213	.211	.150	.216	.098	-.076	-.241	.179	-.192	-.098	.293	-.047	.296	.105
C14	Corr. Coeff.	-.082	-.149	-.173	-.048	-.163	-.121	.036	.365	.437	.080	-.173	1.000	-.071	-.145	-.128	-.012	-.102	-.049	.133	.245	-.093	.124	.175	-.307	.053	-.135	-.099
C15	Corr. Coeff.	-.020	.043	.113	-.022	.065	.089	.003	-.074	-.086	-.128	.103	-.071	1.000	.016	.029	.044	.061	-.112	-.140	-.226	.233	-.202	.009	.188	.009	.160	.106
C16	Corr. Coeff.	.080	.044	.164	-.073	.092	.124	.109	-.140	-.117	-.077	.213	-.145	.016	1.000	.231	.057	.321	.034	.205	-.217	.228	-.221	.040	.321	-.112	.095	-.035
C17	Corr. Coeff.	.278	.014	.163	-.120	.018	-.009	.142	-.156	-.101	-.008	.211	-.128	.029	.231	1.000	.030	.169	-.120	.044	-.096	.086	-.040	-.012	.164	-.046	.028	.106
C18	Corr. Coeff.	.146	-.034	.080	-.111	.065	.170	.151	-.106	-.031	.018	.150	-.012	.044	.057	.030	1.000	.071	.155	.008	-.006	.032	.053	.018	.131	-.028	.181	.004
C19	Corr.	.033	-.008	-.086	.081	-.022	.044	-.061	-.200	-.193	-.234	.216	-.102	.061	.321	.169	.071	1.000	-.159	-.034	-.555	.423	-.489	.006	.685	-.004	.120	-.079

	Coeff.																										
C20	Corr. Coeff.	-.090	-.019	-.031	.017	.045	-.094	-.042	-.152	-.111	-.012	.098	-.049	-.112	.034	-.120	.155	-.159	1.000	-.120	.078	-.129	.139	-.022	.118	.075	-.032	-.031
C21	Corr. Coeff.	.515	-.241	-.100	-.256	-.237	-.082	.215	.096	.164	.080	-.076	.133	-.140	.205	.044	.008	-.034	-.120	1.000	-.046	.046	-.094	.126	.024	-.054	.055	.014
C22	Corr. Coeff.	.009	-.090	-.084	-.054	-.108	-.154	.015	.369	.321	.214	-.241	.245	-.226	-.217	-.096	-.006	-.555	.078	-.046	1.000	-.738	**.858**	.173	**-.875**	-.078	-.183	.094
C23	Corr. Coeff.	.046	.066	.005	.102	.110	.129	-.073	-.276	-.266	-.183	.179	-.093	.233	.228	.086	.032	.423	-.129	.046	-.738	1.000	**-.859**	.244	.597	-.026	.077	-.099
C24	Corr. Coeff.	-.028	-.045	.019	-.081	-.054	-.086	.061	.272	.243	.197	-.192	.124	-.202	-.221	-.040	.053	-.489	.139	.094	**.858**	**-.859**	1.000	-.224	-.663	-.020	-.070	.037
C25	Corr. Coeff.	.112	-.017	-.097	.087	-.028	-.132	-.105	.123	.076	.067	-.098	.175	.009	.040	-.012	.018	.006	-.022	.126	.173	.244	-.224	1.000	-.286	-.021	-.158	.120
C27	Corr. Coeff.	.073	.016	.055	-.004	.053	.153	.042	-.277	-.253	-.239	.293	-.307	.188	.321	.164	.131	.685	.118	.024	**-.875**	.597	-.663	-.286	1.000	-.098	.211	-.250
C30	Corr. Coeff.	-.221	.130	-.023	.225	.104	.086	-.207	-.028	-.017	.068	-.047	.053	.009	-.112	-.046	-.028	-.004	.075	-.054	-.078	-.026	-.020	-.021	-.098	1.000	-.143	-.032
C31	Corr. Coeff.	.223	.003	-156	-.143	-.001	.064	.152	-.067	-.160	-.186	.296	-.135	.160	.095	.028	.181	.120	-.032	.055	-.183	.077	-.070	-.158	.211	-.143	1.000	.209
C32	Corr. Coeff.	.122	.087	.190	-.098	.042	-.085	.064	-.025	.046	.085	.105	-.099	.106	-.035	.106	.004	-.079	-.031	.014	.094	-.099	.037	.120	-.250	-.032	.209	1.000

a. See Table M31: ‘Continuity of care components’ for names of ‘C’ variables.

b. The variables C8, C9, C26, C28 and C29 are not included in the correlation matrix as they were omitted from the analysis beforehand.

c. Correlations greater than 0.80 are in **bold** in the table.

Appendix 11 – Discharge and Drop-out

Methods – Both samples

Discharge and drop-out analyses

Service users who were discharged from secondary care by the final time-point of the study (T3 for Sample 1, T2 for Sample 2) were compared to those who stayed in secondary care in terms of T1 demographic characteristics, clinical and social functioning measures and levels of continuity (factor scores).

Service users who remained in the study (completed all interviews) were compared to those who dropped out in terms of the same variables. For continuous variables, the groups were compared using independent samples t-tests. For categorical variables, groups were compared using χ^2 tests.

Results – Sample 1

Discharged service users

A total of 41 service users (22.8%) were discharged from secondary care by the end of the study, while 139 remained in secondary care. There were few significant differences in demographic characteristics between service users who had not been discharged during the study period and those who had, but those who remained in secondary care were more than twice as likely to have been on depot injections at T1 (p=0.012) than those who were subsequently discharged. (Table 1)

There were some significant differences in clinical and social functioning at T1 between the two groups. Users who were subsequently discharged had higher GAF ratings (p=0.021) (better functioning) and lower total BPRS scores (p=0.025) (fewer symptoms) than those who were not discharged. Those who were subsequently discharged also scored significantly lower than those who were not on the negative pressures sub-scale of the Coercion Scale (p=0.039) indicating that users who were not subsequently discharged may have felt more coerced into treatment than those who were discharged during the study period. (Table 2)

Discharged users had a significantly lower *Regularity* score than users who remained in care (p=0.019) (Table 3). There were no other differences in factor scores between the two groups.

Table 1: Sample 1 Demographic characteristics by discharge status

		n	Not Discharged	n	Discharged	Test statistic (p-value)
Age mean (sd)		139	43 (10.27)	41	45 (12.84)	-.842 (.350)
Gender n (%)	Female	139	61 (43.9%)	41	19 (46.3%)	.077 (.781)
	Male		78 (56.1%)		22 (53.7%)	
Ethnic group n (%)	White	139	92 (66.2%)	41	28 (20.1%)	.196 (.907)
	Non-White		47 (33.8%)		13 (31.7%)	
Living situation n (%)	Living alone (+/- children under 18)	139	57 (41.0%)	41	16 (39.0%)	.052 (.820)
	Living w/ others (+/- children under 18)		82 (59.0%)		25 (61.0%)	
Accommodation type n (%)	Unsupervised accommodation	139	104 (74.8%)	41	33 (80.5%)	1.735 (.420)
	Supervised accommodation		34 (24.5%)		7 (17.1%)	
	Other		1 (2.4%)		1 (2.4%)	
Education n (%)	School up to 16	139	56 (40.3%)	41	13 (31.7%)	.986 (.321)
	School above 16		83 (59.7%)		28 (68.3%)	
Employment Status n (%)	Paid employment	100	10 (10.0%)	37	8 (21.6%)	3.196 (.074)
	Unemployed or unpaid work		90 (90.0%)		29 (78.4%)	
Has a carer n (%)	No	139	108 (77.7%)	41	35 (85.4%)	1.140 (.286)
	Yes		31 (85.4%)		6 (14.6%)	
Number of lifetime hospital admissions n (%)	None	139	8 (5.8%)	41	4 (9.8%)	1.121 (.571)
	1-5		93 (66.9%)		28 (68.3%)	
	6 and over		38 (27.3%)		9 (22.0%)	
Duration of illness mean months (sd)		139	212.1 (135.46)	41	213.0 (146.88)	1.120 (.264)
Depot injection? n (%)	No	136	85 (62.5%)	38	32 (84.2%)	6.356 (.012)
	Yes		51 (37.5%)		6 (15.8%)	
Uses Alcohol? n (%)	No	139	67 (48.2%)	41	17 (48.2%)	.578 (.447)
	Yes		72 (51.8%)		24 (51.5%)	
Uses Drugs?	No	139	126 (90.6%)	41	39 (95.1%)	.830 (.362)

n (%)	Yes		13 (9.4%)		2 (4.9%)	

Table 2: Sample 1 Clinical and social functioning by discharge status					
	n	**Not Discharged**	**n**	**Discharged**	**Test statistic (p-value)**
GAF Total Score (0-100) mean(sd)	139	51.1 (13.6)	40	55.5 (17.3)	-2.369 (.021)
BPRS Total Score (18-126) mean(sd)	138	33.3 (10.9)	41	31.3 (11.5)	2.281 (.025)
EMP Total score (28-112) mean(sd)	136	74.2 (11.1)	41	74.2 (6.6)	-1.577 (.117)
SEIQoL Total score (0-100) mean(sd)	139	61.7 (16.1)	40	70.0 (19.2)	-.585 (.559)
MANSA Total score (0-7) mean(sd)	139	4.5 (.8)	41	4.6 (.9)	-.327 (.744)
Perceived coercion sub-scale mean(sd)	105	2.3 (1.7)	26	1.1 (1.4)	-1.684 (.092)
Negative pressure sub-scale mean(sd)	104	2.0 (1.9)	26	1.2 (1.53)	-2.069 (.039)
Voice sub-scale mean(sd)	104	1.1 (1.0)	26	0.9 (1.1)	-.416 (.677)

Table 3: Sample 1 Levels of continuity by discharge status						
		n	**Not Discharged**	**n**	**Discharged**	**Test statistic (p-value)**
Experience mean(sd)		139	.98 (2.34)	41	.76 (2.23)	.544 (.587)
Regularity mean(sd)		136	.37 (2.21)	40	-.56 (2.12)	2.365 (.019)
Needs mean(sd)		139	.21 (2.00)	41	-.33 (1.89)	1.541 (.125)
Consolidation mean(sd)		120	-.24 (1.75)	31	.19 (1.52)	-1.256 (.211)
Transitions	Undocumented transition	136	31 (22.3%)	38	6 (15.8%)	.871 (.647)
n (%)	Documented transition		13 (9.6%)		4 (10.5%)	
	No transition		92 (67.6%)		28 (73.7%)	
Care Coordination mean(sd)		139	.02 (1.64)	41	.06 (1.58)	-.149 (.882)
Supported Living mean(sd)		137	-1.35 (1.52)	40	-1.43 (1.58)	.271 (.787)

Drop-out

By T3, 39 users with psychotic disorders had dropped out of the study, being either unavailable for interview or uncontactable, thus giving a follow-up rate of 78.3%. Those who dropped out were significantly younger than those who were interviewed at T3 (mean age=39.46 years versus 44.13, t=2.397, p=0.018). They also had lower MANSA scores (quality of life, 4.21 versus 4.60, t=2.661, p=0.008), higher BPRS scores (more symptoms, 36.79 versus 32.09, t=-2.384, p=0.018) and had a lower score on S*upported Living* (Factor 7, -1.95 versus -1.20, t= 2.740, p=0.007). Drop-out from the study also differed significantly by team (χ^2=14.18, p=0.028) with 38.5% of those who dropped out being under the care of the Team 2a and 20.5% from Team 1a. Accommodation type approached significance (χ^2=5.17, p=0.075) with 87.2% of users who dropped out living in non-supported accommodation. Whether or not users had a carer also approached significance (χ^2=3.23, p=0.072) with 89.7% of users who dropped out not having a carer. There were no other significant differences between the two groups.

Results – Sample 2

Discharged service users

By the end of the study, 25 service users (25.5%) had been discharged from secondary care, leaving 73 remaining. There were few significant differences between the groups in terms of T1 characteristics. The discharged group were, however, more likely not to have been educated beyond 16 (p=0.001) and there was a greater proportion of White people in the discharged group than in the group remaining on the caseload (p=0.053). There were no differences in factor levels. (Tables 4-6).

Table 4: Sample 2 Demographic characteristics at T1 by discharge status				
		Not Discharged (n=73)	**Discharged (n=25)**	**Test statistic (p-value)**
Age mean (sd)		42.3 (11.8)	39.0 (10.2)	1.25 (.214)
Gender n (%)	Female	49 (67.1%)	17 (68.0%)	.007 (.936)
	Male	24 (32.9%)	8 (32.0%)	
Ethnic group n (%)	White	58 (79.5%)	24 (96.0%)	3.73 (.053)
	Non-white	15 (20.5%)	1 (4.0%)	
Living situation n (%)	Living alone (+/- children under 18)	43 (58.9%)	14 (56.0%)	.065 (.799)
	Living w/ others (+/- children under 18)	30 (41.1%)	11 (44.0%)	
Accommodation type n (%)	Unsupervised accommodation	67 (91.8%)	23 (92.0%)	.001 (.972)
	Supervised accommodation	6 (8.2%)	2 (8.0%)	
Education n (%)	School up to 16	31 (43.1%)	20 (83.3%)	11.73 (.001)
	School above 16	41 (56.9%)	4 (16.7%)	
Employment Status n (%)	Paid employment	9 (12.3%)	3 (12.0%)	.002 (.965)
	Unemployed or unpaid work	64 (87.7%)	22 (88.0%)	
Has a carer n (%)	No	49 (67.1%)	16 (64.0%)	.081 (.775)
	Yes	24 (32.9%)	9 (36.0%)	
Number of lifetime hospital admissions n (%)	None	23 (31.5%)	10 (40.0%)	1.85 (.396)
	1-5	36 (49.3%)	13 (52.0%)	
	6 and over	14 (19.2%)	2 (8.0%)	
Duration of illness mean months (sd)		173.9 (136.2)	162.8 (129.1)	-.375 (.707)
Depot injection? n (%)	No	71 (97.3%)	25 (100.0%)	.699 (.403)
	Yes	2 (2.7%)	0 (.0%)	

Table 4: Sample 2 Demographic characteristics at T1 by discharge status				
		Not Discharged (n=73)	**Discharged (n=25)**	**Test statistic (p-value)**
Uses Alcohol?	No	39 (53.4%)	13 (52.0%)	.015 (.902)
n (%)	Yes	34 (46.6%)	12 (48.0%)	
Uses Drugs?	No	65 (89.0%)	21 (84.0%)	.440 (.507)
n (%)	Yes	8 (11.0%)	4 (16.0%)	

Table 5: Sample 2 Clinical and social functioning at T1 by discharge status			
	Not Discharged (n=73)	**Discharged (n=25)**	**Test statistic (p-value)**
GAF Total Score (0-100) mean(sd)	53.6 (10.6)	55.0 (11.8)	-.571 (.570)
HADS – Anxiety mean(sd)	12.6 (4.8)	13.4 (4.3)	-.675 (.501)
HADS – Depression mean(sd)	10.7 (5.0)	11.0 (5.1)	-.190 (.849)
EMP Total score (28-112) mean(sd)	69.9 (10.0)	70.2 (9.4)	-.159 (.874)
SEIQoL Total score (0-100) mean(sd)	60.0 (20.5)	64.1 (18.8)	-.871 (.386)
MANSA Total score (0-7) mean(sd)	3.8 (.9)	3.7 (.7)	.696 (.488)
Perceived coercion sub-scale mean(sd)	1.3 (1.6)	1.1 (1.4)	-.476 (.634)
Negative pressure sub-scale mean(sd)	0.9 (1.2)	0.9 (1.0)	-.419 (.675)
Voice sub-scale (negative score: high score=low voice) mean(sd)	0.4 (.7)	0.7 (.9)	-.975 (.330)
Internal State Activation sub-scale mean(sd)	177.3 (113.5)	171.5 (100.0)	-.061 (.951)
Internal State Well-Being sub-scale mean(sd)	94.8 (63.9)	116.9 (64.1)	-1.58 (.114)
Internal State Perceived Conflict sub-scale mean(sd)	165.7 (100.7)	175.0 (110.6)	-.126 (.899)
Internal State Depression Index sub-scale mean(sd)	103.7 (61.0)	89.1 (62.0)	-1.09 (.278)

Table 6: Sample 2 Levels of continuity at T1 by discharge status				
		Not Discharged (n=73)	**Discharged (n=25)**	**Test statistic (p-value)**
Experience mean(sd)		-1.20 (2.07)	-1.46 (1.84)	.555 (.580)
Regularity mean(sd)		.74 (.97)	.61 (.88)	.591 (.556)
Needs mean(sd)		-.03 (1.76)	-.69 (1.89)	1.59 (.115)
Consolidation mean(sd)		-.48 (1.49)	.04 (1.68)	-1.46 (.147)
Transitions n (%)	Undocumented transition	23 (31.5%)	11 (44.0%)	1.31 (.521)
	Documented transition	31 (42.5%)	9 (36.0%)	
	No transition	19 (26.0%)	5 (20.0%)	
Care Coordination mean(sd)		.46 (1.48)	.24 (1.38)	.654 (.515)
Supported Living mean(sd)		.03 (1.22)	.32 (1.25)	-1.03 (.307)

Drop-out

By T2, 13 service users with non-psychotic disorders had dropped out of the study (giving a follow-up rate of 86.7%). Those who dropped out reported significantly better quality of life on SEIQoL at T1 than those who were interviewed at T2 (73.6 versus 59.2, t=-2.376, p=0.020). They also had significantly higher *Care Coordination* scores (Factor 6) (1.25 versus 0.28, t=-2.295, p=0.024). There were no other significant differences between the two groups.

Appendix 12 – User-professional concordance

Methods - Both samples

Pearson correlation coefficients were used to test for associations between user-rated and professional-rated STAR total scores, calculated for each sample at each time-point. Data from multiple time-points were not analysed together due to the substantial proportion of users who were being seen by different professionals at the different time-points. Correlations between user-rated and professional-rated total scores on the CAN were calculated using Pearson correlation coefficients for normally distributed data and Spearman correlation coefficients for non-normally distributed data. The number of professionals and users rating a need for each individual domain of the CAN and the number of pairs identifying a need for each domain was presented and kappa coefficients calculated. Kappa coefficients are displayed to ascertain level of agreement between user and professional ratings. Kappa coefficients can take values between -1 and 1. A value of zero indicates a complete chance occurrence, -1 indicates complete disagreement, and 1 complete agreement (Cohen, 1960). According to Landis and Koch (1977), a kappa coefficient of 0.4 to 0.6 indicates moderate agreement, 0.6 to 0.8 indicates substantial agreement and 0.8 to 1.0 indicates almost perfect agreement. For all correlation and kappa coefficients, 95% confidence intervals are presented in order to provide a measure of the precision of the respective coefficient.

Results

Sample 1, Time 1

At T1, the correlation between the STAR total score for users and professionals was low (r=0.02) (Table 1).

The strongest correlation for CAN total scores was for the total level of need (r=0.45) while the weakest correlation was for the total number of unmet needs (r=-0.03). Professionals seemed to record a greater number of met needs than users and conversely, users rated more needs as unmet. Users also rated more needs as being met informally, presumably as they had more knowledge of the informal help they were receiving. (Table 2.)

Table 3 shows the number of professionals and users rating a need for each individual domain of the CAN at T1 and the number of pairs identifying a need on each of these topics in order of agreement. The mean number of professionals and users identifying any need was similar (22.9 users noted needs and 21.0 professionals identified needs on average). The mean number of users and professionals identifying the same need was lower, however, at 13.7 professional-user pairs.

The level of agreement between professional and user ratings was not high on any of the domains, but was moderate in a number of areas. The highest agreement was for the domain accommodation (kappa=0.55) and the weakest for the domains information and benefits (kappa=0.03). For both of these domains a relatively large number of users noted a need, whereas few professionals did. It could be that in the case of information, professionals felt that they had given sufficient information to service users as they might not have been directly asked for more, while users were expecting to be better informed.

The T1 mean kappa score was 0.28, a weak agreement, suggesting that users' and professionals' impression of needs tended not to agree.

Table 1: Sample 1 Correlation between professional and user STAR total scores			
	Correlation Pearson (95% CI)	**User Mean (sd)**	**Professional Mean (sd)**
STAR Total score n=84	.02 (-.20, .23)	37.5 (7.96)	48.4 (5.70)

Table 2: Sample 1 Correlations between professional and user CAN totals								
	n	**Correlation**	**Professionals**			**Users**		
		(95% CI)	**Mean (sd)**	**Min**	**Max**	**Mean (sd)**	**Min**	**Max**
Total number of needs	79	.29 Pearson (.08, .48)	5.6 (2.81)	1	21	6.0 (2.59)	1	13
Total level of need	81	.45 Pearson (.26, .61)	7.2 (3.83)	1	16	8.4 (4.39)	1	20
Number of met needs	81	.21 Pearson (.01, .41)	5.3 (2.78)	1	21	4.7 (2.17)	1	12
Number of unmet needs	84	-.03 Spearman (-.24, .19)	0.3 (0.81)	0	3	1.3 (1.65)	0	6
Total level of need being met by informal carers	84	.36 Spearman (.16, .54)	2.9 (3.47)	0	17	3.5 (4.13)	0	21

Table 3: Sample 1 Individual areas of need identified by professionals and users

CAN Item n=84	Professional noted need n (%)	User noted need n (%)	Professional-User pairs identifying need n (%)	Kappa coefficient (se)	95% Confidence Interval
Accommodation	20 (23.8%)	27 (32.1%)	16 (19.0%)	.55 (.09)	(.37, .73)
Drugs[2]	6 (7.1%)	3 (3.6%)	2 (2.4%)	.48 (.22)	(.05, .90)
Alcohol[2]	9 (10.7%)	3 (3.6%)	3 (3.6%)	.47 (.18)	(.12, .82)
Looking after the home[2]	30 (35.7%)	23 (27.4%)	16 (19.0%)	.44 (.10)	(.24, .64)
Transport[2]	65 (77.4%)	71 (84.5%)	60 (71.4%)	.41 (.13)	(.16, .66)
Safety to others[2]	4 (4.8%)	1 (1.2%)	1 (1.2%)	.39 (.27)	(-.14, .92)
Psychological distress	32 (38.1%)	28 (33.3%)	21 (25.0%)	.39 (.08)	(.23, .55)
Childcare	7 (8.3%)	7 (8.3%)	4 (4.8%)	.32 (.12)	(.08, .56)
Physical health	31 (36.9%)	35 (41.7%)	23 (27.4%)	.32 (.08)	(.16, .48)
Daytime activities	26 (31.0%)	26 (31.0%)	12 (14.3%)	.29 (.10)	(.09, .49)
Basic education	5 (6.0%)	5 (6.0%)	2 (2.4%)	.27 (.17)	(-.06, .60)
Safety to self	10 (11.9%)	6 (7.1%)	3 (3.6%)	.26 (.14)	(-.01, .54)
Food	24 (28.6%)	27 (32.1%)	13 (15.5%)	.24 (.10)	(.04, .43)
Company	30 (35.7%)	33 (39.3%)	16 (19.0%)	.23 (.09)	(.06, .41)
Sexual expression	13 (15.5%)	16 (19.0%)	4 (4.8%)	.19 (.14)	(-.08, .47)
Intimate relationships	29 (34.5%)	25 (29.8%)	13 (15.5%)	.17 (.10)	(-.03, .36)
Self care[2]	14 (16.7%)	3 (3.6%)	1 (1.2%)	.06 (.10)	(-.14, .26)
Money	16 (19.0%)	30 (35.7%)	7 (8.3%)	.05 (.08)	(-.11, .21)
Benefits	4 (4.8%)	20 (23.8%)	1 (1.2%)	.03 (.08)	(-.13, .18)
Information[2]	4 (4.8%)	31 (36.9%)	2 (2.4%)	.03 (.06)	(-.09, .15)
Psychotic symptoms	82 (97.6%)	84 (100.0%)	82 (97.6%)		[1]
Telephone	2 (2.4%)	0 (.0%)	0 (.0%)		[1]
Mean	**21.0 (25.1%)**	**22.9 (27.3%)**	**13.7 (16.3%)**	**.28 (.12)**	

1. Kappa coefficient could not be calculated.
2. Need levels 0, 1 and 2 have been grouped as need, no need (0, 1) in order to calculate kappa coefficient.

Sample 1, Time 2

At T2, the correlation between the STAR total score for users and professionals was low (r=0.06), but slightly higher than that observed at T1 (r=0.02) (Table 4).

Looking at overall correlations on the CAN total scores at T2, the correlations were relatively similar (r ranged from 0.30 to 0.43). The strongest correlation was for level of need being met informally (r=0.43) and, as at T1, the weakest correlation was for the number of unmet needs (r=0.30). The correlations at T2 were generally higher than those at T1. Users identified more needs than professionals (7.0 versus 5.8), as at T1, but with a greater difference at this time-point. The number of needs users rated as unmet was greater than at T1 and was again higher than the number of needs rated as unmet by professionals. (Table 5).

Table 6 shows the number of professionals and users rating a need for each individual domain of the CAN at T2 and the number of pairs identifying a need on each of these topics in order of agreement. The mean number of professionals identifying a need was 29 and the number of users was 34.2. This was a greater difference than at T1 (21.0 versus 22.9 respectively) and suggests that a mean of 5.2 more users identified needs than professionals. The mean number of professional-user pairs identifying needs was 19.4, which was higher than at T1, but to be expected as the total number of professionals and users identifying needs was also higher than at T1.

The level of agreement on each of the domains was generally lower than at T1, with the highest kappa score being 0.49 (indicating a moderate agreement) and the lowest being -0.03 (verging on a complete chance occurrence). The mean kappa score was 0.27, which is very similar to T1 and indicates that users and professionals agreed to a mild extent when rating needs.

The domains receiving the highest, though still moderate, agreement were ‘transport’ and ‘food’ (kappa=0.49) and that with the lowest agreement was ‘drugs’ (kappa=-0.03).

Table 4: Sample 1 T2 Correlation Between Professional and User STAR Total Scores				
	n	**Correlation Pearson (95% C.I)**	**User Mean (s.d.)**	**Professional Mean (s.d.)**
STAR Total score	106	.06 (-.13, .25)	36.05 (7.89)	49.24 (5.6)

Table 5: Sample 1 T2 Correlations Between User and Professional CAN Totals								
		Correlation	**Professional**			**Users**		
	n	**(95%C.I)**	**Mean (s.d.)**	**Min**	**Max**	**Mean (s.d.)**	**Min**	**Max**
Total number of needs	108	.40 Pearson (.23, .55)	5.8 (2.91)	0	13	7.0 (3.15)	2	13
Total level of need	108	.41 Pearson (.24, .56)	7.2 (3.98)	0	18	9.0 (4.71)	2	21
Number of met needs	108	.37 Pearson (.20, .52)	5.0 (2.66)	0	13	4.9 (2.59)	0	11
Number of unmet needs	108	.30 Spearman (.12, .46)	0.8 (1.28)	0	7	2.1 (2.15)	0	10
Total level of need being met informally	107	.43 Spearman (.26, .57)	4.8 (4.39)	0	19	6.1 (5.54)	0	24

Table 6: Sample 1 T2 Individual Areas of Need Identified by Professionals and Users					
CAN Item n=111	**Professional noted need n (%)**	**User noted need n (%)**	**Professional-User pairs identifying need n (%)**	**Kappa coefficient (SE)**	**95% Confidence Interval**
Food	41 (36.9%)	45 (40.5%)	30 (27.0%)	.49 (.08)	(.33, .65)
Transport	81 (73.0%)	90 (81.1%)	74 (66.7%)	.47 (.10)	(.27, .67)
Accommodation	21 (18.9%)	28 (25.2%)	14 (12.6%)	.45 (.1)	(.25, .65)
Alcohol[1]	10 (9.0%)	7 (6.3%)	4 (3.6%)	.43 (.16)	(.12, .74)
Looking after the home	40 (36.0%)	56 (50.5%)	30 (27.0%)	.36 (.09)	(.18, .54)
Daytime activities	56 (50.5%)	50 (45.0%)	35 (31.5%)	.36 (.07)	(.22, .50)
Physical health	38 (34.2%)	51 (45.9%)	28 (25.2%)	.35 (.08)	(.19, .51)
Psychotic symptoms	106 (95.5%)	100 (90.1%)	97 (87.4%)	.31 (.09)	(.13, .49)
Psychological distress	35 (31.5%)	56 (50.5%)	29 (26.1%)	.31 (.07)	(.17, .45)
Safety to self[1]	5 (4.5%)	7 (6.3%)	2 (1.8%)	.30 (.18)	(-.05, .65)
Telephone	5 (4.5%)	5 (4.5%)	2 (1.8%)	.28 (.17)	(-.05, .61)
Benefits[1]	8 (7.2%)	19 (17.1%)	4 (3.6%)	.27 (.13)	(.02, .52)
Self care	22 (19.8%)	23 (20.7%)	9 (8.1%)	.27 (.11)	(.05, .49)
Basic education	15 (13.5%)	25 (22.5%)	8 (7.2%)	.27 (.1)	(.07, .47)
Childcare	10 (9.0%)	11 (9.9%)	4 (3.6%)	.23 (.12)	(-.01, .47)
Intimate relationships	33 (29.7%)	25 (22.5%)	13 (11.7%)	.22 (.09)	(.04, .40)
Company	33 (29.7%)	51 (45.9%)	20 (18.0%)	.20 (.08)	(.04, .36)
Sexual expression	15 (13.5%)	22 (19.8%)	5 (4.5%)	.13 (.09)	(-.05, .31)
Money	35 (31.5%)	38 (34.2%)	12 (10.8%)	.1 (.09)	(-.08, .28)
Information	19 (17.1%)	41 (36.9%)	6 (5.4%)	-.01(.07)	(-.15, .13)
Drugs	4 (3.6%)	2 (1.8%)	0 (0%)	-.03(.01)	(-.05, -.01)
Safety to others	6 (5.4%)	0 (0%)	0 (0%)		[2]
Mean	**29 (26.1%)**	**34.2 (30.8%)**	**19.4 (17.4%)**	**.27 (.10)**	

1. Need levels 0, 1 and 2 have been grouped as need, no need (0, 1) in order to calculate kappa coefficient.
2. Kappa coefficient could not be calculated

Sample 1, Time 3

At T3, the correlation between the STAR total score for users and professionals (r=0.22) was higher than that found at T1 and T2 (r=0.03 and r=0.06 respectively). (Table 7).

The strongest correlation in CAN scores was between the level of need being met informally (r=0.60) which was also the case at T2. As with T1 and T2, the weakest correlation was for the number of unmet needs (r=0.23). The correlations at T3 were generally higher than those at T2 (which had also been generally higher than those at T1). The mean number of met needs was similar between users and professionals, however, unlike at T1 and T2, users rated slightly more needs as met than professionals. (Table 8).

Users tended to be more likely to note needs than professionals. The mean number of professionals noting a need was 23.6 and the mean number of users noting a need was 28.6. The mean number of professional-user pairs identifying needs was 21.4, which is higher than at T1 and T2 despite there being fewer user and professional pairs. This again suggests a greater concordance between user and professional rating of needs. (Table 9.)

The level of agreement on each of the domains was generally higher than at T1 and T2. The highest kappa score was 0.80 for the domain drugs (indicating a strong agreement). The weakest kappa score was -0.06 for the domain benefits. The mean kappa score was 0.35 which was higher than at T1 and T2 and indicates a mild agreement. It seems that users and professionals had the greatest concordance when assessing needs at T3 than at previous time-points.

Table 7: Sample 1 T3 Correlation Between Professional and User STAR Total Scores

	N	Correlation (95% C.I.)	User Mean (s.d)	Professional Mean (s.d)
STAR Total Score	82	0.22 (.01, .41)	37.1(7.58)	49.8(5.33)

Table 8: Sample 1 T3 Correlations Between User and Professional CAN Totals

			Professional			**User**		
	n	**Correlation (95% C.I.)**	**Mean (s.d.)**	**Min**	**Max**	**Mean (s.d.)**	**Min**	**Max**
Total number of needs	84	.51 Pearson (.33, 0.65)	6.2 (2.77)	0	13	7.5 (3.09)	1	14
Total level of need	82	.53 Pearson (.35, .67)	8.0 (3.73)	2	17	9.8 (4.56)	1	22
Number of met needs	84	.53 Pearson (.36, .67)	5.4 (2.51)	0	12	5.5 (2.48)	1	11
Number of unmet needs	84	.23 Spearman (.02, .42)	0.7 (1.18)	0	6	2.0 (2.02)	0	7
Total level of need being met informally	82	.60 Spearman (.44, .72)	5.6 (5.82)	0	27	6.3 (5.78)	0	28

Table 9: Sample 1 T3 Individual Areas of Need Identified by Professionals and Users

CAN Item N=84	Professional noted need n (%)	User noted need n (%)	Professional-User pairs identifying need n (%)	Kappa coefficient (SE)	95% Confidence Interval
Drugs	3 (3.6)	2 (2.4)	2 (2.4)	.80 (.20)	(.41, 1.19)
Food[1]	31 (36.9)	42 (50.0)	29 (34.5)	.66 (.08)	(.50, .82)
Accommodation	28 (33.3)	32 (38.1)	26 (31.0)	.64 (.07)	(.50, .78)
Childcare	5 (6.0)	5 (6.0)	3 (3.6)	.58 (.19)	(.21, .95)
Looking after the home	33 (39.3)	42 (50.0)	29 (34.5)	.57 (.09)	(.39, .75)
Transport	69 (82.1)	73 (86.9)	64 (76.2)	.49 (.12)	(.25, .73)
Physical health	28 (33.3)	42 (50.0)	24 (28.6)	.48 (.09)	(.30, .66)
Alcohol[1]	7 (8.3)	5 (6.0)	3 (3.6)	.46 (.19)	(.09, .83)
Daytime activities	55 (65.5)	42 (50.0)	35 (41.7)	.40 (.08)	(.24, .56)
Psychotic symptoms	81 (96.4)	82 (97.6)	79 (94.0)	.39 (.10)	(.19, .59)
Money	21 (25.0)	32 (38.1)	16 (19.0)	.39 (.10)	(.19, .59)
Intimate relationships[1]	20 (23.8)	22 (26.2)	11 (13.1)	.38 (.12)	(.14, .62)
Psychological distress	38 (45.2)	47 (56.0)	30 (35.7)	.33 (.08)	(.17, .49)
Company	43 (51.2)	41 (48.8)	28 (33.3)	.33 (.08)	(.17, .49)
Basic education	12 (14.3)	23 (27.4)	8 (9.5)	.29 (.11)	(.07, .51)
Information[1]	13 (15.5)	35 (41.7)	9 (10.7)	.20 (.09)	(.02, .38)
Self care	18 (21.4)	25 (29.8)	8 (9.5)	.16 (.11)	(-.06, .38)
Safety to self	2 (2.4)	12 (14.3)	1 (1.2)	.11 (.12)	(-.13, .35)
Sexual expression	7 (8.3)	13 (15.5)	2 (2.4)	.11 (.11)	(-.11, .33)
Safety to others[1]	1 (1.2)	1 (1.2)	0 (0)	-.01 (.01)	(-.03, .01)
Telephone[1]	1 (1.2)	1 (1.2)	64 (76.2)	-.01 (.01)	(-.03, .01)
Benefits	4 (4.8)	10 (11.9)	0 (0)	-.06 (.02)	(-.10, -.02)
Mean	**23.6 (28.1)**	**28.6 (34.1)**	**21.4 (25.5)**	**.35 (.10)**	

1. Need levels 0, 1 and 2 have been grouped as need, no need (0, 1) in order to calculate kappa coefficient.

Sample 2, Time 1

As Table 10 shows, there was a moderate correlation between professional and service user ratings of their relationship in the STAR (r = 0.36) at T1.

There were significant correlations between total number of needs, total level of needs, total number of unmet needs and total level of needs met by informal carer. The strongest correlation was for the total level of need (r=0.56). The only correlation that was not significant was for the total number of met needs. (Table 11.) The number of professionals and service users rating a need as being present for each individual domain of the CAN is shown in Table 12 together with the agreement between professionals and users about the presence of a need.

Total CAN scores for users and professionals were all strongly correlated at T1 apart from total number of met needs. Mean scores show that professionals rated this as higher than users.

There was a very poor agreement between professional and user ratings regarding looking after the home, self-care, daytime activities, psychotic symptoms, information about condition and treatment, safety to others, company, and sexual expression at T1. There was low agreement on whether the user had needs relating to the information that they receive about their condition and treatment.

There was a moderate agreement between professional and user ratings regarding accommodation, food, physical health, safety to self, alcohol, drugs, intimate relationships, basic education, transport, money and benefits. There was a substantial agreement for childcare, however, and perfect agreement for telephone needs, with only one user and one professional noting a need.

Table 10: Sample 2 Correlation between professional and user STAR total scores

	Correlation Pearson (95% CI)	User Mean (sd)	Professional Mean (sd)
STAR Total score (n=94)	.36 (.19, .54)	37.74 (8.68)	46.82 (6.78)

Table 11: Sample 2 Correlations between CAN totals for users and professionals								
	n	**Correlation (95% C.I)**	**Professionals**			**Users**		
			Mean (sd)	**Min**	**Max**	**Mean (sd)**	**Min**	**Max**
Total number of need)	94	.27 Pearson (.07, .45)	6.5 (3.09)	1	15	6.6 (5.44)	0	22
Total level of need	94	.56 Pearson (.40, .68)	9.0 (4.71)	1	25	11.8 (4.85)	1	23
Number of met needs	94	-.06 Pearson (-.26, .14)	4.6 (2.53)	0	11	3.3 (2.72)	0	11
Number of unmet needs	94	.42 Spearman (.24, .57)	2.0 (2.00)	0	10	3.3 (2.72)	0	11
Total level of need being met by informal carers	93	.54 Spearman (.38, .67)	6.4 (5.29)	0	26	7.9 (5.61)	0	31

Table 12: Sample 2 Individual areas of need identified by professionals and users

CAN Item **n=95**	**Professional noted need** n (%)	**User noted need** n (%)	**Prof and User pairs identifying need** n (%)	**Kappa coefficient (se)**	**95% Confidence Interval**
Telephone	1 (1.1%)	1 (1.1%)	1 (1.0%)	1.0 (.00)	(1.0, 1.0)
Childcare	13 (13.7%)	13 (13.7%)	10 (11.0%)	.70 (.10)	(.50, .90)
Transport	46 (48.4%)	65 (68.4%)	45 (47.0%)	.59 (.07)	(.45, .72)
Accommodation	18 (18.9%)	24 (25.3%)	15 (1.0%)	.57 (.09)	(.39, .75)
Basic education	18 (18.9%)	22 (23.2%)	13 (14.0%)	.55 (.10)	(.35, .75)
Money	23 (24.2%)	27 (28.4%)	17 (18.0%)	.51 (.08)	(.35, .67)
Intimate relationships	35 (36.8%)	31 (32.6%)	24 (25.0%)	.51 (.08)	(.35, .67)
Alcohol	24 (25.3%)	16 (16.8%)	14 (15.0%)	.50 (.09)	(.32, .68)
Drugs	5 (5.3%)	3 (3.2%)	2 (2.0%)	.48 (.22)	(.05, .91)
Food[1]	32 (33.7%)	45 (47.4%)	26 (27.0%)	.48 (.09)	(.30, .66)
Physical health[1]	58 (61.1%)	65 (68.4%)	49 (52.0%)	.47 (.10)	(.27, .67)
Safety to self	41 (43.2%)	48 (50.5%)	33 (35.0%)	.42 (.08)	(.26, .58)
Benefits	13 (13.7%)	25 (26.3%)	10 (11.0%)	.41 (.10)	(.21, .61)
Daytime activities	54 (56.8%)	66 (69.5%)	48 (51.0%)	.39 (.08)	(.23, .55)
Safety to others	10 (10.5%)	12 (12.6%)	5 (5.0%)	.32 (.13)	(.07, .57)
Self care	17 (17.9%)	30 (31.6%)	12 (13.0%)	.32 (.10)	(.12, .51)
Psychotic symptoms	13 (13.7%)	32 (33.7%)	11 (12.0%)	.32 (.09)	(.14, .5)
Looking after the home	24 (25.3%)	34 (35.8%)	15 (16.0%)	.31 (.09)	(.13, .49)
Psychological distress[1]	79 (83.2%)	86 (90.5%)	74 (78.0%)	.27 (.14)	(.00, .54)
Company[1]	54 (56.8%)	59 (62.1%)	40 (42.0%)	.27 (.10)	(.07, .47)
Sexual expression	21 (22.1%)	22 (23.2%)	9 (9.0%)	.17 (.09)	(-.01, .35)
Information about condition & treatment	15 (15.8%)	24 (25.3%)	3 (3.0%)	-.003 (.09)	(-.18, .18)
Mean	**27.9 (29.4)**	**34.1 (34.6%)**	**22.3 (22.2%)**	**.43 (.10)**	

1. Need levels 0, 1 and 2 have been grouped as need, no need (0, 1) in order to calculate kappa coefficient.

Sample 2, Time 2

The correlation between the STAR total score for users and professionals at T2 (r=0.13) was lower than that found at Time 1 (r=0.36). This is converse to what was observed in Sample 1 in which the STAR correlation improved over the three time-points. (Table 13).

At T2, the strongest correlation on CAN scores was between the level of need being met informally (r=0.68) which was also the case with Sample 1 at T2 and T3. The weakest correlation was for the number of unmet needs (r=0.32) which is consistent with all three time-points for Sample 1. The range in correlations at T2 was less than observed at T1. Users identified more needs than professionals (mean: 7.9 versus 6.8) and also rated slightly more needs as met (5.0 versus 4.9), but also unmet (2.9 versus 1.9). (Table 14).

As at T1, users tended to be more likely to note needs than professionals. The mean number of professionals noting a need was 13.9 and the mean number of users noting a need was 16.1. The mean number of professional-user pairs identifying needs was 10.4. (Table 15).

The range of agreement on each of the domains at T2 was smaller than at T1. The highest kappa score was 0.64 for the domain ‘childcare’ (indicating a substantial agreement). The weakest kappa score was 0.03 for the domain ‘benefits’. The mean kappa score was 0.37 which was lower than at T1 and indicates a mild agreement. It seems that users and professionals had greater concordance when assessing needs at T1 than at T2. (Table 15).

Table 13: Sample 2 T2 Correlation Between Professional and User STAR Total Scores

	n	Correlation Pearson (95%C.I)	User Mean (s.d)	Professional Mean (s.d)
STAR Total score	45	.13 (-.17, .41)	38.8 (7.68)	47.6 (5.75)

Table 14: Sample 2 T2 Correlations Between User and Professional CAN Totals

	N	Correlation (95%C.I)	Professional			User		
			Mean (s.d.)	Min	Max	Mean (s.d.)	Min	Max
Total number of needs	45	.52 Pearson (.27, .71)	6.8 (2.75)	1	13	7.9 (3.60)	1	15
Total level of need	45	.54 Pearson (.29, .72)	9.8 (4.42)	1	18	11.4 (5.99)	1	24
Number of met needs	45	.44 Pearson (.17, .65)	4.9 (2.54)	0	10	5.0 (2.59)	0	11
Number of unmet needs	45	.32 Spearman (.03, .56)	1.9 (1.58)	0	7	2.9 (2.95)	0	11
Total level of need being met informally	45	.68 Spearman (.48, .81)	4.8 (4.15)	0	19	7.6 (5.73)	0	27

Table 15: Sample 2 T2 Individual Areas of Need Identified by Professionals and Users					
CAN Item **n=45**	**Professional noted need N (%)**	**User noted need n (%)**	**Professional-User pairs identifying need n (%)**	**Kappa coefficient (SE)**	**95% Confidence Interval**
Childcare	8 (17.8)	8 (17.8)	7 (15.6)	.64 (.12)	(.40, .88)
Food[1]	19 (42.2)	23 (51.1)	16 (35.6)	.59 (.12)	(.35, .83)
Daytime activities	28 (62.2)	27 (60.0)	22 (48.9)	.59 (.10)	(.39, .79)
Basic education	6 (13.3)	8 (17.8)	4 (8.9)	.56 (.17)	(.23, .89)
Transport	27 (60.0)	31 (68.9)	25 (55.6)	.55 (.11)	(.33, .77)
Accommodation	14 (31.1)	10 (22.2)	8 (17.8)	.54 (.13)	(.29, .79)
Looking after the home	17 (37.8)	18 (40.0)	13 (28.9)	.53 (.12)	(.29, .77)
Intimate relationships	17 (37.8)	19 (42.2)	13 (28.9)	.49 (.11)	(.27, .71)
Safety to others	3 (6.7)	3 (6.7)	1 (2.2)	.37 (.29)	(-.20, .94)
Alcohol	13 (28.9)	7 (15.6)	6 (13.3)	.35 (.13)	(.10, .60)
Money	10 (22.2)	12 (26.7)	6 (13.3)	.34 (.14)	(.07, .61)
Psychological distress	40 (88.9)	41 (91.1)	38 (84.4)	.29 (.13)	(.04, .54)
Physical health	27 (60.0)	30 (66.7)	21 (46.7)	.29 (.12)	(.05, .53)
Company	28 (62.2)	29 (64.4)	21 (46.7)	.28 (.12)	(.04, .52)
Psychotic symptoms	8 (17.8)	18 (40.0)	6 (13.3)	.25 (.11)	(.03, .47)
Drugs[1]	5 (11.1)	2 (4.4)	1 (2.2)	.24 (.23)	(-.21, .69)
Safety to self	18 (40)	25 (55.6)	13 (28.9)	.23 (.11)	(.01, .45)
Self care	6 (13.3)	17 (37.8)	4 (8.9)	.16 (.11)	(-.06, .38)
Sexual expression	8 (17.8)	8 (17.8)	2 (4.4)	.05 (.13)	(-.20, .30)
Benefits	3 (6.7)	8 (17.8)	1 (2.2)	.03 (.08)	(-.13, .19)
Information	0 (0)	11 (24.4)	0 (0)	[2]	
Telephone	0 (0)	0 (0)	0 (0)	[2]	
Mean	**13.9 (30.8)**	**16.1 (35.9)**	**10.4 (23.0)**	**.37 (.13)**	

1. Need levels 0, 1 and 2 have been grouped as need, no need (0, 1) in order to calculate kappa coefficient.
2. Kappa coefficient could not be calculated.

Appendix 13 - Main Phase – Comparison of Samples 1 and 2

Methods

Service users in Samples 1 and 2 were compared in terms of socio-demographic variables, measures of clinical and social functioning at T1 and level of continuity factors, while carers in the two samples were compared in terms of socio-demographic variables, user-carer relationship, psychological wellbeing, experiences of caregiving and level of CONTINUES. When comparing continuous continuity factors, the mean level of the factors over time was calculated for each subject, while for categorical continuity factors only T1 data was utilised for comparison. For continuous variables, the samples were compared using independent samples t-tests. For categorical variables, samples were compared using χ^2 tests.

Results

Service users

Table 1 shows that users with psychotic and those with non-psychotic mental health problems differed significantly on a number of demographic characteristics. There were almost twice as many women as men in the non-psychotic group, with the two groups more even (with a slightly higher proportion of males) in the psychotic group. The two groups also differed significantly in terms of ethnic origin (p=0.002), with a higher proportion of White people in the non-psychotic group. After Bonferroni's corrections were applied, living situation and accommodation type did not differ significantly between the two groups.

The number of lifetime admissions also differed significantly (p<0.001): proportionately more of the psychotic group had been admitted to hospital and more times. Unsurprisingly, a greater proportion of those in the psychotic group were receiving their medication by depot injection (32.8% in the psychotic group and 2.0% in the non-psychotic group, p<0.001). (Table 1). After Bonferroni's corrections had been applied there were no significant differences between the two groups in terms of education, presence of a carer or duration of illness.

Table 2 shows that several aspects of clinical and social functioning difference significantly between the two groups. People in the psychotic group reported feeling more empowered than those in the non-psychotic group although the difference was not of great magnitude. Users in the psychotic group also reported a significantly higher quality of life on the MANSA with a mean score of 4.5 compared to 3.8 among the non-psychotic group (p<0.001). The two groups also differed on all sub-scales of the Coercion Scale. People in the psychotic group reported feeling more coerced on each of the sub-scales (p<0.001), reporting identifiable coercion whereas those in the non-psychotic group reported low coercion.

Table 3 reports the levels of continuity in each group. The non-psychotic group had lower mean *Experience & Relationship (*Factor 1, p<0.001) scores, but higher mean *Care Coordination* scores (Factor 6, p=0.002). The psychotic group had a higher proportion of documented transitions (69.0% versus 40.8%) and a lower number of undocumented transitions (21.3% versus 34.7%) (Factor 5, p<0.001). The non-psychotic group had slightly higher *Supported Living* scores (Factor 7, p=0.046) but this was non-significant when Bonferroni's correction was applied.

Table 1: Comparison of Samples 1 and 2 users: demographic characteristics at T1

		Sample 1 (n=180)	**Sample 2 (n=98)**	**Significance t-test statistic (p-value)**
Age mean (sd)		43.1 (10.9)	41.4 (11.5)	1.211 (.227)
Gender n (%)	Female	80 (44.4%)	66 (67.3%)	13.347[1] (.000)
	Male	100 (55.6%)	32 (32.7%)	
Ethnic group n (%)	White	120 (66.7%)	82 (83.7%)	9.239[1] (.002)
	Non-white	60 (33.3%)	16 (16.3%)	
Living situation n (%)	Living alone (+/- children under 18)	73 (40.6%)	57 (58.2%)	7.902[1] (.005)[2]
	Living w/ others (+/- children under 18)	107 (59.4%)	41 (41.8%)	
Accommodation type n (%)	Unsupervised accommodation	137 (76.5%)	90 (91.8%)	10.700[1] (.005)[2]
	Supervised accommodation	42 (23.5%)[3]	8 (8.2%)[4]	
Education n (%)	School up to 16	69 (38.3%)	51 (53.1%)	5.574[1] (.018)[2]
	School above 16	111 (61.7%)	45 (46.9%)	
Employment Status n (%)	Paid employment[2]	18 (13.1%)	12 (12.2%)	0.041[1] (.840)
	Unemployed or unpaid work[3]	119 (86.9%)	86 (87.8%)	
Has a carer n (%)	No	143 (79.4%)	65 (66.3%)	5.796[1] (.016)[2]
	Yes	37 (20.6%)	33 (33.7%)	
Number of lifetime hospital admissions n (%)	None	12 (6.7%)	33 (33.7%)	34.350[1] (.000)
	1-5	121 (67.2%)	49 (50.0%)	
	6 and over	47 (26.1%)	16 (16.3%)	
Duration of illness mean months (sd)		212.3 (137.7)	171.1 (133.8)	2.389 (.018)[2]
Depot injection? n (%)	No	117 (67.2%)	96 (98.0%)	34.825[1] (.000)
	Yes	57 (32.8%)	2 (2.0%)	

Table 1: Comparison of Samples 1 and 2 users: demographic characteristics at T1 (continued)				
		Sample 1 (n=180)	**Sample 2 (n=98)**	**Significance t-test statistic (p-value)**
Uses Alcohol? n (%)	No	84 (46.7%)	52 (53.1%)	1.038^{1} (0.308)
	Yes	96 (53.3%)	46 (46.9%)	
Uses Drugs? n (%)	No	165 (91.7%)	86 (87.8%)	1.107^{1} (0.293)
	Yes	15 (8.3%)	12 (12.2%)	

1. χ^2 test statistic

2. Not significant when Bonferroni corrections were applied (significance level of 0.004)

3. 41 of those in the psychotic group living in supervised accommodation were living with others.

4. 7 people in the non-psychotic group living in supervised accommodation were living with others.

Table 2: Comparison of Samples 1 and 2 users: clinical and social functioning at T1			
	Sample 1 (n=180)	**Sample 2 (n=98)**	**Significance t-test statistic (p-value)[1]**
GAF Total Score (0-100) mean(sd)	51.6 (14.1)	53.9 (10.8)	-1.564 (0.119)
EMP Total score (28-112) mean(sd)	74.2 (10.7)	70.0 (9.8)	3.221 (0.001)
SEIQoL Total score (0-100) mean(sd)	62.5 (16.5)	61.1 (20.0)	0.596 (0.552)
MANSA Total score (0-7) mean(sd)	4.5 (0.8)	3.8 (0.8)	6.970 (0.000)
Perceived coercion sub-scale (0-5) mean(sd)	2.2 (1.7)	1.2 (1.5)	4.069 (0.000)
Negative pressure sub-scale (0-6) mean(sd)	1.9 (1.9)	0.9 (1.1)	4.971 (0.000)
Voice sub-scale (negative score: high score=low voice) (0-3) mean(sd)	1.0 (1.0)	0.5 (0.8)	4.438 (0.000)

1. Bonferroni corrections yielded a significance level of 0.007.

Table 3: Comparison of Samples 1 and 2 users: mean levels of continuity over all time-points

		Sample 1 (n=180)	Sample 2 (n=98)	Significance t-test statistic (p-value)
Experience & Relationship mean(sd)		1.44 (1.91)	-0.75 (1.95)	9.067 (0.000)
Regularity mean (sd)		0.46 (1.71)	0.45 (1.24)	0.041 (0.967)
Meeting Needs mean (sd)		0.01 (1.52)	-0.25 (1.51)	1.379 (0.169)
Consolidation mean (sd)		-0.15 (1.70)	-0.35 (1.55)	0.932 (0.352)
Managed Transitions At T1 n (%)	Undocumented transition	37 (21.3%)	34 (34.7%)	21.788[1] (0.000)
	Documented transition	17 (9.8%)	24 (24.5%)	
	No transition	120 (69.0%)	40 (40.8%)	
Care Coordination mean(sd)		0.02 (1.19)	0.50 (1.26)	-3.158 (0.002)
Supported Living mean(sd)		-0.93 (1.10)	-0.69 (0.83)	-2.005 (0.046)[2]

1. χ^2 statistic
2. Not significant when Bonferroni corrections were applied (significance level of 0.007)

Carers

As indicated in Tables 4-6, there were very few differences between the two groups of carers in terms of demographic characteristics. Carers in Sample 1 were more likely to be employed full-time than those in Sample 2. They also tended to have more cohabitants than those in Sample 2, but both differences were not significant when Bonferroni's corrections were applied. Carers in Sample 1 tended to be slightly older than those in Sample 2 but this difference was not significant at the 5% level. The samples were not significantly different in terms of the user-carer relationship. Although carers from Sample 2 had higher positive experiences of caregiving scores (ECI - positive sub-scale), this too was not significant after Bonferroni's correction was applied. There was no difference in overall levels of CONTINUES nor in 'caseness' for psychological distress.

Table 4: Comparison of Samples 1 and 2 carers: demographic characteristics

		n	**Sample 1**	**n**	**Sample 2**	**Significance t-test statistic (p-value)**
Age mean (sd)		68	53.7 (14.85)	37	47.6 (16.59)	1.924
Min – max			25-83		17-71	(.057)
Gender n (%)	Female	68	41 (60.3%)	38	27 (71.1 %)	1.227[1]
	Male		27 (39.7%)		11 (28.9%)	(.268)
Ethnic group	White	68	52 (76.5%)	38	32 (84.2%)	4.257[1]
n (%)	Asian		6 (8.8%)		2 (5.3%)	(.235)
	Black		8 (11.8%)		1 (2.6%)	
	Other		2 (2.9%)		3 (7.9%)	
Marital status	Single	68	16 (23.5%)	38	11 (28.9%)	0.452 [1]
n (%)	Married/ long-term partnership		41 (60.3%)		22 (57.9%)	(.798)
	Divorced/Separated/Widowed		11 (16.2%)		5 (13.2%)	
Work status	No/No, looking after children	68	43 (63.3%)	38	20 (52.6%)	10.153 [1]
n (%)	Part-time work (< 30 hours)		7 (10.3%)		10 (26.3%)	(.017) [2]
	Full-time work (>30 hours)		18 (26.5%)		8 (21.1%)	
Living situation	Alone	68	10 (14.7%)	38	6 (15.8%)	1.437 [1]
n (%)	Spouse/ partner and/or children		49 (72.1%)		27 (71.1%)	(.920)
	Parents and/or brothers/sisters		5 (7.4%)		4 (10.5%)	
	Friends or other		4 (5.9%)		1 (2.6%)	
Number of cohabitants n (%)	0	67	9 (13.4%)	37	5 (13.5%)	8.446 [1]
	1-2		35 (52.2%)		24 (64.8%)	(.038)[2]
	3-4		22 (32.8%)		7 (18.9%)	
	5 or more		1 (1.5%)		1 (2.7%)	

1. Statistic based on Pearson's χ^2 test
2. Not significant when Bonferroni corrections were applied (significance level 0.007)

Table 5: Comparison of Samples 1 and 2 carers: carer-user relationship

		n	Sample 1	n	Sample 2	Significance t-test statistic (p-value)
Relationship to user n (%)	Parent	68	21 (30.9%)	37	18 (48.6%)	9.196[1]
	Child		7 (10.3%)		3 (8.1%)	(.239)
	Sibling		7 (10.3%)		2 (5.4%)	
	Spouse/partner		17 (25.0%)		7 (18.9%)	
	Girlfriend/boyfriend		2 (2.9%)		3 (8.1%)	
	Friend		11 (16.2%)		3 (8.1%)	
	Other		3 (4.4%)		1 (2.7%)	
Carer-user contact during past month n (%)	None	67	2 (3.0%)	38	1 (2.6%)	2.369[1]
	Once		1 (1.5%)		0 (.0%)	(.883)
	2-3 times		5 (7.5%)		2 (5.3%)	
	4 times (once a week)		3 (4.5 %)		3 (7.9%)	
	More than 4 times but not every day		14 (20.9%)		5 (13.2%)	
	Nearly every day		12 (17.9%)		7 (18.4%)	
	Every day		30 (44.8%)		20 (52.6%)	
Carer living with user n (%)	Yes	68	31 (45.6%)	37	16 (43.2%)	0.053[1]
	No		37 (54.4%)		21 (56.8%)	(.817)
Regard self as carer or not n (%)	Yes	67	40 (59.7%)	36	25 (69.4%)	0.955[1]
						(.329)
	No		27 (40.3%)		11 (30.6%)	
Main carer n (%)	Yes	43	33 (76.7%)	27	20 (74.1%)	0.064[1]
	No		10 (23.3%)		7 (25.9%)	(.800)
Carer support group n (%)	Yes	67	12 (17.9%)	37	4 (10.8%)	0.923[1]
	No		55 (82.1%)		33 (89.2%)	(.337)
Carer's assessment n (%)	Yes	65	10 (15.4%)	35	9 (25.7%)	1.577[1]
	No		55 (84.6%)		26 (74.3%)	(.209)

1. Statistic based on Pearson's χ^2 test

Table 6: Comparison of Samples 1 and 2 carers : clinical and social functioning					
		Sample 1		**Sample 2**	**Test statistic**[1]
	n		**n**		**(p-value)**
ECI-Positive Total Score (0-56) mean (sd)	68	24.3 (11.73)	38	28.4 (8.93)	-2.014
Min – max		1-50		8-45	(.047)[2]
ECI-Negative Total Score (0-208) mean (sd)	68	63.3 (41.76)	38	76.3 (44.26)	-1.507
Min – max		3-161		8-161	(.135)
CONTINUES Mean Score (1-5) mean (sd)	64	2.9 (.932)	36	2.6 (.999)	1.240
Min – max		1-5		1-4.4	(.218)
GHQ Total score (12-48) mean (sd)	61	25.6 (6.54)	36	25.8 (6.98)	-0.138
Min – max		15-46		15-43	(.891)

1. Statistic based on independent sample t-test.
2. Not significant when Bonferroni corrections were applied (significance level 0.013)

Appendix 14 – The Context of Service Delivery: Workforce Integration and Pace of Change

The development of integrated teams with a mandate to improve continuity of care has been a central driver for the reorganisation of mental health services in the UK (Department of Health, 2001). This preliminary section of findings sets the context of service delivery as seen by professional staff working in the participating NHS Trusts (through survey and interviews) and voluntary organisations (interviews). Experiences relating to integration, pace of organisational change and their impact on continuity of care were investigated.

Survey Findings

Integration of health and social care

Survey findings relating to integration are summarised in Table 1. None of the associations tested were statistically significant, but across both Trusts similar trends were evident. Although the majority of respondents stated that integration of health and social care had been successfully achieved within their organisation, more than a third disagreed. By contrast, a greater proportion of respondents in both Trusts were satisfied with the process of integration and the impact of integrated working on continuity of care.

Significant differences were found between different professional groups in their ratings of the achievement of cultural integration, with social workers and the combined group of psychiatrists, psychologists and occupational therapists (PPO) responding positively, while the majority of nurses responded that cultural integration had not been successfully achieved. Most respondents rated the impact of integrated working on continuity of care positively. (Table 2).

Pace of Change

As shown in Table 1, the greater proportion of respondents in both Trusts rated the pace of change since integration as rapid and also stated that this had impacted positively on continuity of care. The majority of respondents rated change as positive, although less so in Trust 1. Most professionals reported the pace of change as rapid, positive in direction and impacting on continuity of care (Table 2).

Role Change

Across both Trusts, the greater proportion of respondents reported that much role change had taken place since integration, more markedly in Trust 2; although many were satisfied with role changes, almost one third of respondents in Trust 1 were dissatisfied (Table 1). More respondents reported that a lot of role change had taken place since integration. Although most social workers and the combined group of psychiatrists, psychologists and occupational therapists were predominantly satisfied with role changes, many nurses were dissatisfied (Table 2). Managers (n=15, 39%) were less likely than operational staff (n=70, 46%) to rate the direction of organisational change as positive ($\chi^2=8.142$, $p<0.05$).

Table 1: Workforce integration and pace of change by Trust

		n	Trust 1 n(%)	n	Trust 2 n(%)	χ^2 (p-value)
Cultural Integration Successfully Achieved?	Yes	111	57 (51.4%)	81	37 (45.7%)	.67
	No		38 (34.2%)		32 (39.5%)	(.715)
	Don't know		16 (14.4%)		12 (14.8%)	
Satisfaction with Integration Process	Satisfied	67	51 (76.0%)	42	26 (62.0%)	2.52
	Dissatisfied		8 (12.0%)		8 (19.0%)	(.284)
	Neither		8 (12.0%)		8 (19.0%)	
Integrated Working: Improvement in Continuity of Care?	Yes	111	78 (70.3%)	81	54 (66.7%)	.42
	No		15 (13.5%)		11 (13.5%)	(.811)
	Don't know		18 (16.2%)		16 (19.8%)	
Pace of Organisational Change Since Integration	Rapid	99	75 (75.8%)	73	54 (74.0%)	3.32
	Slow		4 (4.0%)		11 (15.0%)	(.190)
	Neither		20 (20.2%)		8 (11.0%)	
Direction of Change	Positive	94	39 (41.5%)	67	47 (70.1%)	13.61
	Negative		23 (24.5%)		6 (9.0%)	(.001)
	Neither		32 (34.0%)		14 (20.9%)	
Pace of Change: Impact on Continuity of Care?	Yes	111	61 (55.0%)	81	50 (61.7%)	3.81
	No		26 (23.4%)		10 (12.3%)	(.149)
	Don't know		24 (21.6%)		21 (26.0%)	
Extent of Role Change Since Integration	A lot	102	63 (61.8%)	69	51 (73.9%)	3.64
	Little		27 (26.5%)		10 (14.5%)	(.162)
	Neither		12 (11.7%)		8 (11.6%)	
Satisfaction With Role Changes	Satisfied	96	45 (46.9%)	69	33 (47.8%)	1.31
	Dissatisfied		29 (30.2%)		16 (23.2%)	(.518)
	Neither		22 (22.9%)		20 (29.0%)	

Table 2: Workforce integration and pace of change: professional views

		n	PPO n(%)	n	Social worker n(%)	n	Nurse n(%)	χ^2 (p-value)
Cultural Integration Successfully Achieved?	Yes	56	34 (60.7%)	45	26 (57.8%)	78	31 (39.7%)	11.60
	No		14 (25.0%)		18 (40.0%)		35 (44.9%)	(.021)
	Don't know		8 (14.3%)		1 (2.2%)		12 (15.4%)	
Satisfaction with Integration Process	Satisfied	37	31 (83.8%)	31	23 (74.2%)	36	20 (55.6%)	9.29
	Dissatisfied		2 (5.4%)		6 (19.3%)		8 (22.2%)	(.054)
	Neither		4 (10.8%)		2 (6.5%)		8 (22.2%)	
Integrated Working: Improvement in Continuity of Care?	Yes	56	39 (69.6%)	45	41 (91.2%)	78	47 (60.3%)	16.56
	No		5 (8.9%)		2 (4.4%)		17 (21.8%)	(.002)
	Don't know		12 (21.5%)		2 (4.4%)		14 (17.9%)	
Pace of Organisational Change for the Last 2Years	Rapid	45	34 (75.6%)	42	31 (73.8%)	72	61 (84.7%)	4.78
	Slow		1 (2.2%)		3 (7.1%)		4 (5.6%)	(.331)
	Neither		10 (22.2%)		8 (19.1%)		7 (9.7%)	
Direction of Change	Positive	47	22 (46.8%)	41	26 (63.4%)	66	34 (51.5%)	2.71
	Negative		9 (19.1%)		6 (14.6%)		13 (19.7%)	(.607)
	Neither		16 (34.1%)		9 (22.0%)		19 (28.8%)	
Pace of Change: Impact on Continuity of Care?	Yes	56	29 (51.8%)	45	29 (64.4%)	78	50 (64.2%)	3.61
	No		11 (19.6%)		9 (20.0%)		14 (17.9%)	(.461)
	Don't know		16 (28.6%)		7 (15.6%)		14 (17.9%)	
Extent of Role Change Since Integration	A lot	46	21 (45.7%)	42	28 (66.7%)	74	61 (82.4%)	19.26
	Little		17 (37.0%)		7 (16.7%)		9 (12.2%)	(.001)
	Neither		8 (17.3%)		7 (16.7%)		4 (5.4%)	
Satisfaction With Role Changes	Satisfied	44	26 (59.1%)	42	21 (50.0%)	70	26 (37.1%)	8.98
	Dissatisfied		7 (15.9%)		10 (23.8%)		28 (40.0%)	(.062)
	Neither		11 (25.0%)		11 (26.2%)		16 (22.9%)	

Interview Findings

Interviewees’ descriptions of the experienced pace of change and its consequences over the preceding two years are summarised in Box 1. The pace of change was described as extremely rapid, characterised by moving goalposts, in some instances to meet government deadlines. Specific problems reported included increased bureaucracy and paperwork reducing time spent with users, increased workloads with instances of increased occupational stress in staff. Staff at all levels and in both Trusts were critical of how the process of integration had been managed, citing lack of consultation and in some instances, poor change management, which had evoked resistance by some staff. A need to have time to take stock and evaluate the effectiveness of changes made was thought essential by many.

The impact of changes on user involvement at all levels within both Trusts was perceived negatively, but particularly emphasised by voluntary sector representatives. Lack of consultation, less time for therapeutic working and increasing unsettled behaviour by users, many of whom coped less well with change due to their poor mental health, were identified (Box 2).

Box 1. Pace of Change, Change Management

'I always say to people that working in the NHS is like surfing, your job is to stay above the waves. The pace of change has been phenomenal and thus this job is to be fixed about the direction of travel. The government changes goalposts all the time.' (Consultant, Trust 1)

'… *we actually don't have a lot of say in it so consultation is a bit of a redundant term. These are changes that are coming down because the government says this is how we want it to be so consultation in that way is a bit pointless ... we don't always feel listened to or heard.' (Psychiatrist, Trust 1)*

'This change is just being forced on us ... and I just am resisting it to some extent because I think it's bureaucracy rather than what we are here for. It's more a case of I don't really see that we can effectively manage that change even if I agreed with it.' (Team Manager, CPN, Trust 2)

'You need to take stock. Sometimes you can't even take stock of your users ... that's having time to sit down and think about what am I going to do'. (CPN, Trust 2)

Box 2. Impact of Change: Users and Carers

'We've had significant changes. All of those changes have effects on staff and that has a knock on effect on service users… I can understand the reasons why those changes would be made but I think service users just haven't a place to go where they can feel safe and comfortable.' (Voluntary Sector Manager, Trust 1)

'I suppose here the marked change has been less focus on the more therapeutic type of working with users. I think funders wanted us to spend less time doing one to one work, so it's quite restricting, especially with some users that you know would really benefit.' (Voluntary Sector Worker, Trust 2 catchment area)

'Certainly the unsettling nature of all this change for service users and carers makes them a lot more volatile, a lot less receptive to new ideas and things when they come on line and we're getting a lot more violence on inpatient units. It's escalating, it never used to be as bad as it is now…' (Senior Manager, Trust 2)

Interview findings also suggested that for both Trusts, the emerging culture of integrated service delivery was positive, despite some setbacks encountered (Box 3). Positive markers of cultural change included the use of multi-disciplinary notes, shifts to generic working and changing attitudes to working across professional boundaries. Ineffective management of the rapid pace of change and loss of professional autonomy notably by social workers were perceived as problematic by some respondents, as was the negative impact of time-consuming paperwork on continuity of care.

Box 3. Emerging Culture of Integrated Service Delivery

'Well, I think it's the way forward, I really do. I suppose I'm quite shocked when I have to communicate with other trusts elsewhere and they haven't got it or they haven't got multi-disciplinary notes ...' (CPN, Trust 1)

'It certainly feels very autocratic or authoritarian. I think as a team we've got less autonomy now. I fear for the future of social work which isn't about integration but I think as a profession it's on its last legs to me.' (Social Worker, Trust 1)

'I feel it's very appropriate for us to be working as closely as we are and that we should be providing one service ... but in terms of the pace of change, I think, it hasn't been managed terribly well.' (Team Leader, Social Worker, Trust 2)

Appendix 15: Resources to Support Continuity of Care: Current Challenges

This section summarises findings related to the resources necessary to promote continuity of care in professionals' views, encompassing current staff workloads, availability of user accommodation and IT equipment, adequacy of staff support and turnover, workforce skills and training provision to promote continuity of care.

Workload Issues: Survey findings

As shown in Table 1, most respondents rated overall workloads and size of caseload as manageable, although the proportions were lower in social work than the other groups; similarly, quality of care was also rated as satisfactory. Opinion was divided about the time available to see a task through to completion and the amount of time for direct user contact was viewed as inadequate by the greater proportion of respondents. With regard to the administrative/clerical load, opinion was divided on manageability in Trust 1, while the majority in Trust 2 viewed it as unmanageable. There were no statistically significant differences between the two Trusts.

In relation to manageability of overall workload, the PPO (Psychiatrists, Psychologists and Occupational Therapists combined) group were more likely to rate this as manageable (n=39, 70%) than the nurses (n=48, 62%) or the social workers (n=20, 44%) (χ^2=15.946, p=0.003). They were also more likely to rate direct user contact time as adequate, with 32 of the PPO group (58%) giving this rating compared to 28 of the nurses (38%) and 12 of the social workers (28%). Operational staff (n=130, 85%) were more likely to rate quality of care as satisfactory than were managers (n=23, 66%) (χ^2=20.253, p<0.001).

Table 1: Workforce and workload issues by Trust						
			Trust 1		**Trust 2**	**χ^2**
		n	**n (%)**	**n**	**n (%)**	**(p-value)**
Overall Workload	Manageable	109	71 (65.1%)	79	46 (58.2%)	3.05
	Unmanageable		27 (24.8%)		18 (22.8%)	(.218)
	Neither		11 (10.1%)		15 (19.0%)	
Size of Caseload	Manageable	101	71 (70.3%)	71	46 (64.8%)	0.63
	Unmanageable		20 (19.8%)		16 (22.5%)	(.731)
	Neither		10 (9.9%)		9 (12.7%)	
Administrative/Clerical Load	Manageable	104	46 (44.2%)	75	28 (37.3%)	1.16
	Unmanageable		47 (45.2%)		40 (53.3%)	(.559)
	Neither		11 (10.6%)		7 (9.3%)	
Time for Direct user Contact	Adequate	106	46 (43.4%)	75	31 (41.3%)	0.27
	Inadequate		51 (48.1%)		36 (48.0%)	(.876)
	Neither		9 (8.5%)		8 (10.7%)	
Quality of Care Given to users	Satisfactory	109	95 (87.1%)	72	60 (83.3%)	4.37
	Unsatisfactory		3 (2.8%)		7 (9.7%)	(.112)
	Neither		11(10.1%)		5 (7.0%)	
Task Completion: Time Available	Manageable	107	43 (40.2%)	76	32 (42.1%)	.352
	Unmanageable		45 (42.0%)		33 (43.4%)	(.839)
	Neither		19 (17.8%)		11 (14.5%)	

Caseloads by Professional Group and Managerial Status

As shown in Tables 2 and 3, the greatest volume in caseload was carried by psychiatrists, more so in Trust 2. Caseload size was similar for nurses, social workers and occupational therapists within each Trust, but the ranges and medians were greater in Trust 2. By contrast, psychologists carried lower caseloads in Trust 2. Across both Trusts, caseloads of CMHT members markedly exceeded those of operational managers and ward staff.

Table 2: Professionals' caseloads by Trust

Professional Group	Case Numbers Median (Range) Trust 1	 Trust 2	 n
Psychiatrist	50 (10-300)	120 (40-350)	28
Psychologist	20 (12-30)	12.5 (0-75)	12
Social Worker	16.5 (5-34)	20 (4-30)	40
Nurse	17.5 (0-35)	24 (0-42)	71
Occupational Therapist	17 (10-29)	23.5 (15-28)	8
Team Support Worker	12 (0-23)	3 (0-8)	10

Table 3: Caseloads by managerial Status and Trust

Managerial Status	Case Numbers Range (median) Trust 1	 Trust 2	 n
Operational Managers	5-30 (10)	0-25 (2)	20
CMHT Members	0-300 (25)	2-350 (27)	142
Ward Staff	0-26 (5)	0-4 (3)	25

CMHT Team Leaders and Ward Manager

As shown in Table 4, working additional hours weekly was common for both full- and part-time staff. The median value for additional hours worked by social workers exceeded that of all other professional groups, although the greatest range of additional hours worked was by both full- and part-time nurses. Part-time psychologists' and Occupational Therapists' additional median weekly working hours exceeded those of full-time colleagues.

Table 4: Additional hours worked weekly by professional group (both Trusts)

Professional Group	Full-Time Range (median)	Part-Time Range (median)	n
Psychologist	0-10 (0)	0-16 (5)	12
Psychiatrist	0-10 (0)	0-16 (3)	26
Social Worker	0-15 (6)	2-6 (3)	39
Nurse	0-30 (4)	0-30 (3)	70
Occupational Therapist	2-15 (2.5)	0-6 (4)	9

Workload issues: Interview Findings

Interview findings also revealed that size of caseloads and caseload management were perceived as barriers to continuity of care by all professional groups, notably in Trust 1 (Box 1). Some team leaders struggled to subsume caseloads similar to team members alongside their management responsibilities. The caseloads seemed particularly problematic when viewed together with increased administration responsibilities and the paperwork this engendered. Negative impacts were described on staff attrition, user discharge and personal continuity.

Box 1: Caseloads, Caseload Management and their Impact

'...each team normally has three CPNs. Because I'm the team leader, I have other responsibilities, that's supposed to be half – the reality is, I've got a caseload very similar to everybody else's, but struggling to do the other part as well.' (Team Leader, CPN, Trust 2)

'...a female CPN is leaving because of the workload...' (Social Worker, Trust 1)

'...we have to maintain a certain caseload as a team and as individuals so therefore we are encouraged to have a throughput. Now obviously that can have an impact on people because you may have to move somebody from your caseload into another caseload or discharge them when perhaps they don't feel they should be.' (Psychologist, Trust 1)

Increases in administration and paperwork were described by CMHT staff in both Trusts and were felt to impact negatively on user contact, care time and continuity (Box 2). In some cases the underlying problems were lack of computing resources and diversion of scarce secretarial support.

Box 2: Administrative Loads

'...over the last 15 years, since I've worked in psychiatry, once upon a time you had, you spent say 25 to 30% on paperwork and 70% on the coalface with your client. It's now almost the reverse of that.' (Social Worker, Trust 1)

'The paperwork, you do less and less real hands on nursing and more paperwork.' (Ward CPN, Trust 1)

'...patients and carers want to see in writing what they're supposed to be getting. There are now Risk Assessment forms, Untoward Incidence forms, all these sorts of forms, so I don't have data but I'm pretty sure that probably a proportion of CPN's time is spent in paperwork now much more than it was five years ago, and no doubt they don't welcome that.' (Consultant, Trust 2)

We've got a very good secretary at the moment, but no matter how good they are, it's impossible to do all that work, so what happens is that the secretary mostly just does doctors, outpatient matters. It's not that doctors are more important than anyone else, it's simply been which work needs to get out. So, nurses, social workers, OTs, have always written their own letters. We're not experts at that and for me to do it will take an hour for what might take our secretary five, ten minutes to do.' (Occupational Therapist, Trust 2)

'The paperwork shouldn't interfere with (continuity) but it lengthens the initial phase spent in 'now I've just got to get you to fill out this form'. Some of it is useful... but the amount that we are being required to do is increasing so you have to collect more and more information before you even get down to 'well, lets' see what the issues are.' (Psychologist, Trust 2)

Availability of IT Equipment and Accommodation Resources: Survey findings

As shown in Table 5, the greater proportion of respondents in Trust 1 rated adequacy of IT equipment (computers) as adequate whereas the greater proportion in Trust 2 rated it as inadequate. Similar statistically significant differences in profiles between the Trusts were evident in responses on availability of direct funding, wards available for user referrals and numbers of beds available for user referrals. Availability of accommodation for users in the community was rated inadequate by the majority of respondents in both Trusts.

Table 5: Promoting continuity of care: equipment & accommodation resources by Trust

			Trust 1		**Trust 2**	**χ^2**
		n	**n (%)**	**n**	**n (%)**	**(p-value)**
Availability of Information Technology Equipment	Adequate	108	58 (53.7%)	79	19 (24.0%)	20.53 (<.001)
	Inadequate		38 (35.2%)		54 (68.4%)	
	Neither		12 (11.1%)		6 (7.6%)	
Direct Funding Available	Adequate	89	37 (41.6%)	52	8 (15.4%)	13.54 (.001)
	Inadequate		33 (37.1%)		35 (67.3%)	
	Neither		19 (21.3%)		9 (17.3%)	
Wards Available for user Referrals	Adequate	94	58 (61.7%)	57	23 (40.4%)	6.55 (.038)
	Inadequate		29 (30.9%)		28 (49.1%)	
	Neither		7 (7.4%)		6 (10.5%)	
Number of Beds Available for user Referrals	Adequate	88	54 (61.3%)	55	21 (38.2%)	9.99 (.007)
	Inadequate		21 (23.9%)		27 (49.1%)	
	Neither		13 (14.8%)		7 (12.7%)	
Accommodation Available in the Community	Adequate	102	13 (12.7%)	69	6 (8.7%)	0.73 (.694)
	Inadequate		76 (74.6%)		53 (76.8%)	
	Neither		13 (12.7%)		10 (14.5%)	

The combined PPO group rated wards available for user referrals as adequate, whereas opinion on its adequacy was divided in the social work and nursing groups. Availability of beds for user referrals was rated adequate by the combined PPO and social work groups (less so in the social work group) and inadequate by a narrow majority in nursing. A consensus was evident that availability of accommodation in the community for users was inadequate (Table 6). Managers were more likely to rate the availability of beds as inadequate (n=19, 49%) than operational staff (n=57, 37%) ($\chi^2=8.058$, $p<0.05$) and more likely to rate accommodation in the community as inadequate (managers n=29, 75%) than operational staff (n=99, 65%) ($\chi^2=9.585$, $p<0.05$).

Table 6: Promoting continuity of care: equipment and resources available: professional views

		n	PPO n (%)	n	Social worker n (%)	n	Nurse n (%)	χ^2 (p-value)
Information Technology Equipment Available	Adequate	55	21 (38.2%)	45	17 (37.8%)	75	32 (42.7%)	0.45
	Inadequate		29 (52.7%)		24 (53.3%)		36 (48.0%)	(.978)
	Neither		5 (9.1%)		4 (8.9%)		7 (9.3%)	
Direct Funding Available	Adequate	43	14 (32.6%)	37	10 (27.0%)	53	15 (28.3%)	6.81
	Inadequate		20 (46.5%)		24 (64.9%)		23 (43.4%)	(.146)
	Neither		9 (20.9%)		3 (8.1%)		15 (28.3%)	
Wards Available for user Referrals	Adequate	39	29 (74.4%)	39	19 (48.7%)	66	29 (43.9%)	13.07
	Inadequate		7 (17.9%)		19 (48.7%)		29 (43.9%)	(.011)
	Neither		3 (7.7%)		1 (2.6%)		8 (12.2%)	
Beds Available for user Referrals	Adequate	40	30 (75.0%)	37	18 (48.7%)	61	24 (39.3%)	15.41
	Inadequate		5 (12.5%)		16 (43.2%)		26 (42.6%)	(.004)
	Neither		5 (12.5%)		3 (8.1%)		11 (18.1%)	
Accommodation Available in the Community	Adequate	49	4 (8.2%)	43	6 (14.0%)	71	8 (11.3%)	10.34
	Inadequate		33 (67.3%)		35 (81.4%)		57 (80.3%)	(.035)
	Neither		12 (24.5%)		2 (4.6%)		6 (8.4%)	

Availability of I.T. Equipment and Accommodation Resources: Interview Findings

Information technology is an area currently earmarked for major development in the NHS. In describing current IT provision, interviewees presented two particular difficulties. The first related to the need to combine two entirely separate methods of record-keeping by health and social services for use by multi-disciplinary CMHTs. This highlighted an incompatibility in the software packages currently used by health workers and social workers to maintain joint records and difficulties encountered in using new software packages (Box 3).

Box 3: IT Provision: Systems Incompatibility

‘We’ve actually got quite an old social services IT system which I think came out in the late 80s sometime ... And it holds information which could be quite useful ... if everybody could make use of it. But unfortunately the health service has got another system which doesn’t even have any remote likeness to our system. We’re running on two systems basically that don’t understand each other.’ (Team Leader, Social Worker, Trust 2)

‘There are two computer systems and you cannot have software for both on one machine and that means that if you want to check whether someone is known to social services you’ve got to jump out of your seat and sit in that one and vice-versa. It’s a nuisance but it’s not insurmountable.’ (Team Leader, Social Worker, Trust 1)

‘...sometimes it’s extremely difficult with the amount of paperwork you’ve got to do for each patient and you can have patients that come and go every two days and you’re re-writing care plans and risk assessments. It can take a few days to get old notes of patients, so until they’re with us we don’t have a clue what their risk history is.’ (Ward Nurse, Trust 1)

Quality of equipment provision was also problematic, with some staff reporting ageing, out-of-date machines which were slow and hindered communication. The availability of machines could also be problematic, with sharing the norm in most places. Competition for available computers had led to shifts in working patterns, lengthening the working day for some staff (Box 4).

Box 4: IT: Quality and Lack of Equipment Provision

'I find it very difficult (not having a computer) because all of my training has been done via computer ... I think the thing I've found most difficult is trying to manage paperwork without doing it directly onto a PC.' (Social Worker, Trust 1)

'I have been trying to get a computer. There are three computers for a team of about fifteen people. It makes it difficult when you are asked to put on data electronically and you don't have easy access to it, so it is difficult.' (Psychologist, Trust 2)

'...we've got four machines between about 25 people and tempers really do fray.' (Occupational Therapist, Trust 2)

'We've got one computer that's working reasonably well ... all the rest are hay balers. They're ancient and they're slow and they do nothing for us. To get that computer there (indicates) to open an email would take twenty minutes!' (Occupational Therapist, Trust 1)

Interviewees in both Trusts described shortages of user accommodation in acute and community settings as problematic, though the specific requirements of each Trust differed. In the acute setting (Box 5) scanty bed provision for the local catchment area for Trust 1 had created acute daily pressures on beds, diverting nursing time away from users. The need to admit or move users to a ward where a vacant bed existed disrupted continuity of care in both organisations. In the community (Box 6) lack of accommodation in flats had led to long waiting-lists, protracted time spent by users in hostels or bed and breakfast accommodation and delayed discharge from acute wards. Day care was cited as a problematic issue in both Trusts, but was felt particularly acutely in Trust 2, where the closure of a major day care facility had created difficulties.

Box 5: Accommodation Provision for users in Acute Settings

'Well, the ridiculous thing is there's twenty-three beds ... they've got two very big CMHTs, it's a 90,000 catchment area for both of the CMHTs put together, and you've got twenty-three beds. How are you supposed to serve 90,000 people in twenty-three beds?' (CPN, Trust 1)

'Clearly there's times when we're absolutely choc-a-bloc ... You're sending people on leave at short notice, unplanned leave and moving people around the site. Some people have moved loads of times and for that sense of continuity of care it's absolutely dreadful.' (Ward Manager, Trust 1)

'And even if the person is on leave for one night they will use that bed. And they'll say, well, we'll have to worry about them in the morning. Once the beds are all used they will go to any other ward within the hospital to use a bed. So, and then once the whole hospital is full they would probably be pushed into private. (That happens) all the time ... It's not very nice for when they go on leave, to come back, to be given a different bedroom, or to be told, sorry, someone else is in your bed, you can go to a different ward. That is not continuity of care.' (Ward Nurse, Trust 2)

Box 6: Accommodation Provision for users in Community Settings

'Well, people end up going in to bed and breakfast accommodation which isn't ideal and that's very difficult to keep in contact with people in places like that.' (Consultant, Trust 1)

'There was a time, six or seven years ago, when you could get people into flats very quickly, within four or five months. And all that's changed, so we do have a lot of people waiting in hostels much longer than they should. Waiting two or three years, so that's a bit of a problem I think.' (Team Leader, Social Worker, Trust 1)

'I think we lost a lot from losing day care.' (Occupational Therapist, Trust 2)

Staffing Support, Turnover and Sickness: Survey Findings

As shown in Table 7, the majority of staff in both Trusts rated auxiliary staff support as inadequate and use of agency bank staff as high, albeit with a narrow margin for the latter. By contrast, qualified staff support was rated adequate by the majority in Trust 1 and inadequate by a narrow margin in Trust 2. None of these associations was significant. Divided opinion was evident in both Trusts in responses relating to use of locum staff and staff turnover. A significant association was found relating to staff sickness levels which were rated higher in Trust 2 than Trust 1.

Table 7: Workforce issues: staffing support, turnover and sickness by Trust

			Trust 1		**Trust 2**	**χ^2**
		n	**n (%)**	**n**	**n (%)**	**(p-value)**
Auxiliary Staff Support	Adequate	92	36 (39.1%)	64	16 (25.0%)	3.41
	Inadequate		39 (42.4%)		34 (53.1%)	(.182)
	Neither		17 (18.5%)		14 (21.9%)	
Qualified Staff Support	Adequate	102	52 (51.0%)	73	30 (41.1%)	3.49
	Inadequate		32 (31.4%)		33 (45.2%)	(.174)
	Neither		18 (17.6%)		10 (13.7%)	
Use of Agency/Bank Staff	High	88	31 (35.2%)	69	28 (40.6%)	2.22
	Low		27 (30.7%)		25 (36.2%)	(.329)
	Neither		30 (34.1%)		16 (23.2%)	
Use of Locum Staff	High	89	29 (32.5%)	64	28 (43.8%)	3.80
	Low		28 (31.5%)		22 (34.3%)	(.150)
	Neither		32 (36.0%)		14 (21.9%)	
Staff Turnover	High	99	30 (30.3%)	69	25 (36.2%)	1.35
	Low		32 (32.3%)		24 (34.8%)	(.508)
	Neither		37 (37.4%)		20 (29.0%)	
Staff Sickness Levels	High	96	26 (27.1%)	70	33 (47.2%)	7.22
	Low		44 (45.8%)		22 (31.4%)	(.027)
	Neither		26 (27.1%)		15 (21.4%)	

Qualified staff support was rated adequate by the majority within PPO and nursing but inadequate in social work. Use of agency/bank staff was rated high within the majority in social work, low in nursing and neither in PPO; a similar profile was evident in responses to use of locum staff, which reached statistical significance. Most staff in both the PPO and social work groups rated staff turnover as neither high nor low, whilst nursing rated it as low. Staff sickness was rated as low in the majority of responses in both social work and nursing, but neither in the PPO group. The latter two associations reached statistical significance (Table 8). There were no statistically significant differences between managerial and operational staff views regarding levels of staff turnover, sickness and support.

Table 8: Workforce issues: staffing support, turnover and sickness within Trusts: professional views

		n	PPO n (%)	n	Social worker n (%)	n	Nurse n (%)	χ^2 (p-value)
Auxiliary Staff Support	Adequate	48	16 (33.4%)	40	7 (17.5%)	61	24 (39.3%)	5.60
	Inadequate		22 (45.8%)		23 (57.5%)		27 (44.3%)	(.231)
	Neither		10 (20.8%)		10 (25.0%)		10 (16.4%)	
Qualified Staff Support	Adequate	52	22 (42.3%)	42	16 (38.1%)	72	39 (54.2%)	4.73
	Inadequate		19 (36.5%)		20 (47.6%)		24 (33.3%)	(.371)
	Neither		11 (21.2%)		6 (14.3%)		9 (12.5%)	
Use of Agency/Bank Staff	High	43	13 (30.2%)	40	19 (47.5%)	64	24 (37.5%)	8.90
	Low		13 (30.2%)		8 (20.0%)		27 (42.2%)	(.064)
	Neither		17 (39.6%)		13 (32.5%)		13 (20.3%)	
Use of Locum Staff	High	42	10 (23.8%)	42	23 (54.8%)	61	20 (32.8%)	17.71
	Low		12 (28.6%)		8 (19.0%)		28 (45.9%)	(.001)
	Neither		20 (47.6%)		11 (26.2%)		13 (21.3%)	
Staff Turnover	High	48	14 (29.2%)	42	16 (38.1%)	68	23 (33.8%)	10.54
	Low		14 (29.2%)		9 (21.4%)		31 (45.6%)	(.032)
	Neither		20 (41.6%)		17 (40.5%)		14 (20.6%)	
Staff Sickness Levels	High	47	13 (27.7%)	40	14 (35.0%)	70	28 (40.0%)	10.31
	Low		16 (34.0%)		15 (37.5%)		33 (47.1%)	(.036)
	Neither		18 (38.3%)		11 (27.5%)		9 (12.9%)	

Staffing Support, Turnover and Sickness: Interview Findings

Operational managers and staff from all professional groups described problems with staffing levels, from the adequacy of intended resources to maintaining adequate staffing levels through recruitment and retention processes, staff absences and a resulting reliance on temporary replacement workers. Many remarked on financial pressures which had resulted in cutbacks in staffing and the negative impact on caseloads and therapeutic environments was emphasised (Box 7.)

Box 7: Pressures on Staffing Levels

'Here they've cut back to save money. There are only twelve (in the team) whereas before there were a lot more of us. At least fifteen of us. So it is a small number for what we are supposed to do.' (Social Worker, Trust 1)

'I think one of the biggest problems we have that we are under-resourced. All my staff have very high caseloads and it's a struggle with the numbers of cases we have ... I think I need two more social workers ... and at least two more CPNs'. (Team Leader, CPN, Trust 2)

'The biggest barrier to me is the staffing level. It's too small, it's not creating a therapeutic environment.' (Ward Nurse, Trust 1)

Some evidence emerged that government recruitment policies were beginning to take effect, but this was proving a slow process due to national shortages of mental health professionals, an ageing workforce (particularly within nursing), the length of training required and retention problems associated with working in urban areas where living costs were high. Staff shortages impacted heavily on day-to-day working and continuity of care. In Trust 1, positive strategies to recruit newly qualified nurses who had trained within the Trust and offer trained staff a development scheme to enhance professional development had reduced vacancy rates (Box 8).

Box 8: Recruitment, Retention, Staff Sickness

'The biggest barrier I've encountered is staff retention because you need permanent staff to stay here in order to provide continuity of care and at one point I was finding it extremely difficult ... What I ended up doing was recruiting staff just out of university and they needed an enormous amount of support and supervising and training them and immediately after getting that training and experience they immediately took off, and off they go to a higher grade somewhere. That in itself impacted quite a lot on continuity of care.' (Ward manager, Trust 2)

'The major issue is ... getting and retaining staff. Especially in an environment where it's stressful, it's fast moving, it can be chaotic and it can be nerve wrecking. So getting and keeping staff in acute admissions, full stop, should be a priority. But it doesn't seem to be seen as a priority.' (Ward Nurse, Trust 2)

'I think we're fully staffed for the first time in memory.' (Social Worker, Trust 1)

'We had a very terrible time because one of our colleagues had a stroke, who is still recovering. The only CPN lady that we've got also became very unwell and was off for six months. So it means we're relying on agency staff and I was the only permanent CPN ... We haven't had a consultant for over a year now. We had a locum consultant for, I think, four months and he left ... I know they have been trying to recruit but they are finding it difficult to find the appropriate person to take up the position.' (CPN, Trust 1)

Staff absences and turnover resulted in dependency on agency, bank and locum staff, who could be difficult to acquire at short notice and expensive, creating additional pressures on Trust budgets which only covered the costs of permanent staff. In cases of long-term absence, this had a knock-on effect, delaying finance for other much needed resources. Interviewees also commented on the fact that agency staff were not always suitable for the required role and that subsequent time spent by permanent staff in the supervision of agency workers was at the expense of the user (Box 9).

Box 9: Use of Agency Staff

'Because of staffing levels we've had to use agency. Now the Trust here believes that you go through Trust temps. My belief is you cannot put somebody in, just because they're on a bank of nursing, into a working area without checking out background, experiences … It's unfair on us because not only have we been a nurse down, we're almost looking after another nurse.' (Ward Nurse, Trust 2).

'We get the agency staff who will come at seven and he or she will be told 'please take over so and so patient' and she doesn't know the patient, doesn't know their history … she doesn't know how to nurse the patient, she hasn't seen the care plan.' (Ward Nurse, Trust 2)

Developing Workforce Skills to Deliver Continuity of Care

Survey findings

As shown in Table 9, the majority of respondents within both Trusts rated their confidence in current level of skills as high and opportunities to gain new skills/qualifications satisfactory. With regard to specific training opportunities in the area of information technology, although the majority of respondents were satisfied with opportunities, in Trust 2 almost one third were not satisfied. Training for integrated team working was rated unsatisfactory in Trust 2 and one third of the respondents were unsatisfied in Trust 1. Training on the management of integrated working and deployment of part-time locum/agency staff were rated unsatisfactory by the greater proportion of respondents in both Trusts. None of these differences were statistically significant, although clear trends were evident. Trust 1 professionals were, however, significantly less likely to be satisfied with the identification of training opportunities. In contrast, although the majority of respondents were satisfied with time available to attend relevant training, more than one third of respondents in both Trusts were dissatisfied, although there was no statistically significant difference between the two Trusts.

Within all professional groups confidence in current level of skills was high and opportunities to gain new skills and qualifications were satisfactory, although one third of social workers were dissatisfied with the latter. Identification of relevant training opportunities and specifically those in information technology were also rated as satisfactory within professional groups. By contrast, divergent opinion was evident across professional groups in responses to training in deployment of part-time/locum staff and training for integrated team working. The majority of respondents were dissatisfied with provision on the management of integrated working and more than one third were dissatisfied with time available to attend relevant training in social work and nursing. There were no statistically significant differences between professional groups, except for satisfaction with deployment of part-time, locum and agency staff, which was rated as satisfactory by 44% of nurses (n=23) and 30% of social workers (n=9) but only 12% (n=4) of the PPO group (χ^2=12.240, p=0.016).

More managers (n=17, 44%) rated training for integrated working as unsatisfactory than did operational staff (n=37, 24%) (χ^2=9.075, p=0.028). Training in the deployment of part-time/flexible/bank/agency/locum staff was also more likely to be rated unsatisfactory by managers (n=16, 41%), than by operational staff (n=31, 20%), (χ^2=8.132, p=0.043). With regard to time available for training, managers were again more likely to rate this as unsatisfactory (n=21, 54%) compared to operational staff (n=43, 28%) (χ^2=9.781, p=0.021).

Table 9: Developing workforce skills to deliver continuity of care by Trust

			Trust 1		Trust 2	χ^2
		n	n (%)	n	n (%)	(p-value)
Staff Confidence in Current Level of Skills	High	108	90 (83.3%)	81	61 (%)	1.58
	Low		3 (2.8%)		5 (%)	(.454)
	Neither		15 (13.9%)		15 (%)	
Opportunities to Gain New Skills	Satisfactory	110	74 (67.3%)	86	56 (%)	3.04
	Unsatisfactory		18 (16.4%)		15 (%)	(.219)
	Neither		18 (16.4%)		15 (%)	
Opportunities to Gain New Qualifications	Satisfactory	106	60 (56.6%)	73	47 (64.4%)	2.69
	Unsatisfactory		21 (19.8%)		16 (21.9%)	(.260)
	Neither		25 (23.6%)		10 (13.7%)	
Training Opportunities: Information Technology	Satisfactory	105	70 (66.7%)	75	40 (53.3%)	3.83
	Unsatisfactory		20 (19.0%)		23 (30.7%)	(.147)
	Neither		15 (14.3%)		12 (16.0%)	
Integrated Team Working: Training	Satisfactory	96	35 (36.5%)	68	22 (32.4%)	0.88
	Unsatisfactory		34 (35.4%)		29 (42.6%)	(.644)
	Neither		27 (28.1%)		17 (25.0%)	
Management of Integrated Working: Training	Satisfactory	79	23 (29.1%)	59	21 (35.6%)	0.76
	Unsatisfactory		32 (40.5%)		23 (39.0%)	(.685)
	Neither		24 (30.4%)		15 (25.4%)	
Deployment of Part-time/ Locum/ Agency Staff: Training	Satisfactory	72	21 (29.2%)	49	17 (34.7%)	1.45
	Unsatisfactory		26 (36.1%)		20 (40.8%)	(.484)
	Neither		25 (34.7%)		12 (24.5%)	
Satisfaction : Identification of Relevant Training/ Education	Satisfied	103	62 (60.2%)	77	58 (75.3%)	6.70
	Dissatisfied		17 (16.5%)		12 (15.6%)	(.035)
	Neither		24 (23.3%)		7 (9.1%)	
Satisfaction: Time Available to Attend Relevant Training/ Education	Satisfied	105	45 (42.9%)	77	39 (50.6%)	3.78
	Dissatisfied		36 (34.3%)		29 (37.7%)	(.151)
	Neither		24 (22.8%)		9 (11.7%)	

When CMHTs alone were considered, confidence in current level of skills to deliver continuity was rated very highly across all professional groups and opportunities to gain new skills were rated highly across all professional groups. Opportunities to gain new qualifications were rated as satisfactory by more than half the respondents within all professional groups, as were levels of satisfaction with opportunities for IT training but training for integrated team working elicited variable opinion. With regard to training for the management of integrated working, within social work and nursing more respondents rated this as unsatisfactory, although this was not statistically significant. Training for deployment of part-time, flexible, bank, agency and locum staff was rated as unsatisfactory by more than half the respondents (n=18, 52%). More than half of the respondents in all professional groups were satisfied with their abilities to identify relevant training and education. Satisfaction with time available to attend relevant training elicited divided opinion.

Interview Findings

Although both Trusts provided mandatory and discretionary training, education and continuing professional development opportunities for mental health professionals, 40% of CMHT staff interviewed in Trust 1 and 46% in Trust 2 said that training was poor or inadequate for integrated working. Training was perceived by some not to have kept pace with changing roles and the available training was not perceived as easily accessible by staff. Reasons for the latter were provided by senior managers in one of the Trusts, who were acutely aware of the impact of staff shortages and time constraints on professionals taking up training and development opportunities. Changes to the way training and education is delivered, to more easily accommodate professionals' working patterns were suggested (Box 10).

Box 10: Workforce Training and Development

'I can't identify any training that any of us has been offered that's accessible ... We need stuff that's not time consuming. We could definitely benefit from a lot more training from the social side. To recognize that our roles are changing.' (Team Leader, CPN, Trust 2)

'We always have a problem that team members want to do training in other areas, social skills training, therapy training but then there is the issue of who is going to do the work while they are off.' (Consultant, Trust 1)

'I think what gets neglected is the more general things. If there were workshops on general mental health or specifically on continuity of care, or user perspectives, these things I wouldn't prioritise. But if there are training or courses that are part of my professional development, I have a requirement of attend a certain number of things to be able to practise, so I make a priority of that. Some of the stuff is available though the Trust, but it tends to be based at the Institute, out of the borough, which makes it even more difficult because it takes longer to travel.' (Psychologist, Trust 2)

'Well my way around it is that I've always thought that training should be in-house in some way, that people should be training each other so if you have got a psychologist on the team who obviously has CBT skills then they should be training team members. Then people say to me, well what about the theory, do we have to do that at home on our own, we shouldn't be using our time off and I suppose there is a point in that, but courses are going to have to be geared towards full-time working people, the method of delivery has to change in some way.' (Consultant, Trust 1)

Appendix 16 – Organisational Strand Findings from CMHTs alone

Context of Service Delivery

Analysis of data from CMHTs demonstrated similar findings. The greater proportion of respondents were satisfied with the process of integration and rated the pace of change as rapid, positive and impacting on continuity of care. The majority of respondents (n=80, 53%) felt that cultural integration had been successful, but this differed significantly between professional groups ($\chi^2=12.513$, $p<0.05$), with nurses more likely to feel that organisational change had been negative (positive n=21, 40% versus negative n=27, 52%). Significant associations were found between responses on the impact of integrated working on continuity of care and professional group. Most respondents (n=111, 74%) felt that integrated working had improved continuity of care, although again this differed significantly between professional groups ($\chi^2=14.949$, $p<0.01$).

Resources to support continuity of care

Workload issues

For CMHTs alone, the majority rated overall workload as manageable and quality of care as satisfactory. Most of the combined group of psychiatrists, psychologists and occupational therapists (n=28, 53%) rated administrative loads as manageable in contrast to the majority of nurses who rated it as unmanageable (n=32, 64%) and the social workers who were evenly balanced (n=27, 50%) ($\chi^2=10.893$, $p<0.001$). Time available for direct user contact was rated as adequate by most respondents in the psychiatrist, psychologist and OT group (n=32, 58%) and inadequate by nurses (n=26, 51%) and social workers (n=27, 63%) ($\chi^2=12.012$, $p<0.05$).

IT equipment

Within CMHTs alone, the availability of IT equipment and accommodation for users in the community were considered inadequate. A greater proportion of respondents thought that direct funding was inadequate, more so in the social work (n=24, 67%)

than the PPO (n=19, 45%) and nursing (n=13, 38%) groups ($\chi^2=9.845$, $p<0.05$). By contrast, availability of wards for referral was rated as adequate by the majority within the PPO and nursing groups (PPO n=29, 75%; nursing n=23, 50%) and as inadequate by a narrow majority in the social work group (n=19, 50%) ($\chi^2=10.650$, $p<0.05$). The PPO group was more likely to consider the availability of beds for user referral inadequate ($\chi^2=12.011$, $p<0.05$).

Staffing support

In CMHTs alone, most respondents rated auxiliary support as inadequate. Use of agency or bank staff was rated as low by more than half of the respondents within the nursing group (n=21, 55%) but only seven (18%) within the social work group; within the PPO group opinion was divided, with one third of the respondents (n=13, 33%) rating this as high and the same proportion as low ($\chi^2=13.827$, $p=0.008$).

There were statistically significant differences between the professional groups regarding use of locum staff. Only 23% of the PPO group rated this as high compared to 57% of the social work group ($\chi^2=23.478$, $p<0.001$). Similarly, staff turnover was rated as low by more than half the nursing group (n=24, 56%) but far fewer of the social work (n=9, 22%) and PPO (n=14, 30%) groups ($\chi^2=12.080$, $p=0.017$). Staff sickness was rated as low by more than half the nursing group (n=26, 58%) compared to just over a third of the social work (n=15, 37%) and PPO (n=16, 35%) groups ($\chi^2=9.703$, $p=0.046$).

Achieving continuity of care

Communication

Within CMHTs, communication was rated as effective between teams, leaders, users, carers and outside agencies by the majority of respondents, and there were no differences between professional groups. Similar proportions rated consultation between staff and senior managers as effective and ineffective.

Teamwork

Most CMHT respondents rated team support, team working, skill mix, specialist teams, decision-making and multi-disciplinary recording as effective in relation to continuity. There were some statistically significant differences between professional groups, with 94% of the PPO group (n=51) and 93% of social workers (n=40) but only 81% of nurses (n=42) giving this rating (χ^2=16.009, p<0.005).

Barriers and facilitators – Team Working and Decision-making

For CMHTs alone, most staff rated team support, maintenance of multi-disciplinary records and team decision-making as facilitators of continuity of care, with no differences between professional groups. While most respondents rated integrated team working as a facilitator, psychiatrists, psychologists and OTs were more likely to do so (PPO n=54, 100%; social workers n=38, 90%; nurses n=41, 80%; χ^2=14.780, p<0.01). Similar differences were found for team skill mix (PPO n=52, 96%; social workers n=37, 90%; nurses n=37, 73%; χ^2=13.617, p<0.01) and the development of specialist teams (PPO n=36, 71%; social workers n=19, 45%; nurses n=32, 48%; χ^2=15.167, p<0.01).

Barriers and facilitators – Team Communication

For CMHTs alone, with the exception of consultation between team and senior management, respondents within all professional groups rated all categories of communication as facilitators of continuity of care. In relation to consultation with senior management, this was rated as a barrier to continuity of care by most. There were no statistically significant differences between professional groups.

Disclaimer

Addendum

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