Promoting Continuity of Care for People with Severe Mental Illness

whose needs span primary, secondary and social care
A multi-method investigation of relevant mechanisms and contexts

prepared by

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Executive Summary

Background

Continuity of Care was identified by the National Co-ordinating Council of the new National Co-ordinating Centre for NHS Service Delivery and Organisation R & D (NCCSDO) as one of their first priorities, after a national listening exercise in 1999. In 2000, a scoping exercise recommended mental health as a priority area needing review of existing research and reported that little was known about the actual experience of patients. Accordingly the NCCSDO commissioned this research project where review of existing literature would be interpreted with reference to field studies of mental health care in the NHS.

Aims

- To find out and understand mechanisms that enhance continuity of care for people with severe mental illness.

- To comment on the contexts where these mechanisms operate.

Method

A systematic literature review was undertaken. In parallel the team carried out four case studies, visiting NHS mental health care units in two English provincial sites and two London sites. In addition, a consensus enquiry of experts including researchers, practitioners, managers and representatives of users and carers (a restricted Delphi exercise) was undertaken.

Findings

The literature review confirmed the findings of the scoping study: that to date there has been relatively little investigation of the continuity of care experienced by patients and carers. The limited available evidence emphasises the importance of flexible response to patients' needs with professionals able to step outside institutional limits and act in enabling and advocacy roles.

Considering continuity of contact (longitudinal continuity), assertive community treatment has the strongest evidence base. There is

evidence that less intensive programmes such as the Care Programme Approach and Community Mental Health Teams are successful in maintaining contact with patients, but this is less convincing for improvements in outcome or for cost savings. It is possible to improve continuity of care in terms of contact with and knowledge of a service over a period of time but this has not so far been shown to affect outcomes.

The field studies have highlighted how enthusiastic local champions can innovate and reach out to users but also the endless challenges of staff turnover and limited resources. User views have again emphasised the importance of individual relationships and of professionals being trusted and being willing to 'go the extra mile'. Each of the sites showed how a service boundary or barrier could be crossed but only one site crossed more than one boundary at once.

The Delphi study of experts illustrated a wide awareness of the potential for improvement – for example, in crossing the boundary between primary and specialist care – but experts pointed out how difficult it was to realise such visions on a wide scale.

Implications for service

While Community Mental Health Care Teams are a fact in today's NHS there is no good evidence that they have done more than maintain the status quo in terms of care received.

Field evidence and expert opinion suggest that the way teams function may be more relevant to improving care than their composition.

Rapid staff turnover is inimical to continuity of the care experienced by patients. So far there is no evidence that resource shortages can be significantly mitigated by attempts to improve continuity of care.

More involvement of users in care planning and delivery is a promising but as yet unevaluated means of improving care in a cost-effective way. It is to be hoped that it will lead to better satisfaction from patients and more relevant activity by professionals.

Bridging the boundary between primary and specialist mental health care is particularly challenging. An imaginative range of initiatives is indicated.

Implications for research

Detailed study of user and carer experience of the care of severe mental illness is a wide-open field for researchers.

Where possible this should be combined with the evaluation of the effects of novel methods of care delivery on outcomes.

Continuity of care is a complex, multi-element relational concept. Meaningful study therefore involves careful definition of one or more elements and multi-method assessment of what must usually be a complex intervention with many possible outcomes, some of which will be perverse.

Operational measures of continuity of care relevant to the experiences of patients and carers need to be developed. These need to be tested with and assessed by clinicians and managers with service responsibility.

Better continuity of information through modern electronic systems has obvious potential but early studies suggest this may not be easy to apply. How to integrate these powerful systems into professional practice to give best advantage to patient care is an important outstanding question. The primary/secondary mental health care boundary would seem to be a suitable focus for intervention studies.

The crucial feature of the care of severe mental illness is the ability of the service to cope with patients' changing needs over time, in particular to engender trust and to be available in crises. Evaluations therefore need to cover a long time scale to be convincing.

The Report

Introduction

Continuity of care was one of nine priority themes identified in a national listening exercise carried out in 1999 by the new National Co-ordinating Centre for NHS Service Delivery and Organisation R & D (NCCSDO) (Fulop *et al.*, 2000). In 2000 a scoping exercise was undertaken to map existing research and define a field of appropriate research (Freeman *et al.*, 2001). The scoping exercise identified the need for a number of systematic reviews of continuing care processes for specific groups of patients, including those with mental health problems. It also highlighted the scarcity of research into the continuity of care actually experienced by patients. Accordingly the NCCSDO called for bids for a short research project where a systematic literature review was evaluated in the light of field studies of current practice in the care of patients with severe mental illness. As a research team drawn from both clinical and sociological disciplines we decided to undertake a Delphi study in addition to reviewing the literature and undertaking four small ethnographic field studies. The resulting range of input from informed experts would add a useful extra perspective to the understanding of continuity of care in severe mental illness.

Continuity of care for people with severe mental illness

Severe mental illnesses (SMI) are a group of primarily psychotic disorders that are, by definition, long term and associated with impaired social functioning (Ruggieri *et al.,* 2000). Continuity of care for patients who experience SMI has assumed particular significance because of several important historical, clinical and political factors. These include:

* *deinstitutionalisation* – rather than hospitals attempting to meet the health and social needs of patients, this task is now taken on by a range of primary and secondary health and social care providers

* the *clinical features of psychosis* – people with SMI may lack insight into their condition and be reluctant to seek help or actively avoid contact with services

* *concerns about untoward incidents* involving people with SMI – repeated official inquiries have linked incidents to failures to co-ordinate patient care.

These factors are operating in the context of specific increased emphasis on a patient-oriented National Health Service.

The significance of continuity of care was recognised in the National Service Framework for Mental Health, which states that 'delivering continuity of care for as long as it is needed' should be a guiding principle in planning and delivering mental health services (Department of Health (DoH), 1999).

Aims of the project

To find out and understand mechanisms that enhance continuity of care for people with severe mental illness and comment on the contexts where these mechanisms are applicable.

The research team and the steering group

Expertise of the research team included specialist psychiatry (M. Crawford), mental health services research (MC and T. Weaver), sociology/anthropology (J. Low), library skills (E. de Jonge) and general practice (G. Freeman), with specific recent experience of assessing users' views on their mental health care (MC and TW). Consultant members of the steering group contributed additional expertise in management and sociology (E. Ferlie), anthropology (I. Robinson), mental health social work (J. Schneider), and mental health services research (P. Tyrer).

The three study elements

1 Literature review

(Summary – for full report see Appendix 1.)

Introduction and aims

We undertook a qualitative review of the literature on continuity of care
for people with SMI in order to address five related questions:

1   How has continuity of care for people with SMI been defined?

2   How do service users and their carers perceive continuity of care?

3   What are the obstacles and barriers to providing continuity of care
     for people with SMI?

4   How can these obstacles be overcome?

5   What are the effects of providing improved continuity of care?

Methods and findings

Methods used for this review are detailed in Appendix I. They involved
identifying literature through a search of electronic databases, an
examination of grey literature, and contact with experts in the field. Two
reviewers independently rated abstracts of papers generated in this way
and decided whether to obtain the complete article. Articles were
included if they addressed one of the aims of the study. Papers for
inclusion in the review were categorised according to the type of paper,
the question(s) they addressed, and the elements of continuity of care
included in the paper (see Section 3 of Appendix 1). A total of 1763
abstracts were identified and 445 full reports inspected; 91 addressed
the study questions and these form the basis of this review.

Question 1 How has continuity of care for people with SMI been defined?

Many reports refer to, but do not define continuity of care. Some of
those that do imply that it is primarily about avoiding periods when
patients lose contact with services (Department of Health, 2001). The
success with which services are able to continuously monitor patients is
usually included as part of the definition of continuity of care (Bachrach,
1981). This was one element identified by Johnson and colleagues
(Johnson *et al.*, 1997).

Their complete list was:

*   continuity of service provision

*   extent of breaks in service delivery

*   continuity of contact with particular professionals

*   implementation of plans for services

*   co-ordination with primary care services

*   co-ordination with informal carers and with formal carers outside the specialist mental health services.

They measured this subsequently by counting the number and length of 'gaps' in patient contact with services (Bindman *et al.*, 2000). Definitions of continuity of care for people with SMI also emphasise the importance of the linking hospital and community services (Bass and Windle, 1972). This theme was further developed by Bachrach, who defined continuity of care as 'the orderly, uninterrupted movement of patients among the diverse elements of the health delivery system' (Bachrach, 1981). Bachrach also highlighted the close relationship between accessibility of services and the extent of continuity of care. Patient knowledge of how to access services has been used as an indicator of the quality of continuity of care for patients with SMI (Bindman *et al.*, 2000).

Many reports that use the term continuity of care in relation to patients with SMI do not state what they mean by this term. Those that do emphasise the need to provide care over a long period of time and avoid gaps in service provision. Accessibility of services, co-ordination of care between different professionals and between professionals and informal carers, especially during periods of transition such as following discharge from hospital, have also been highlighted.

Question 2 How do service users and their carers perceive continuity of care?

The scoping study recommended placing patient experiences of continuity of care at the heart of their definition (Freeman *et al.*, 2001). We identified several papers that emphasised the need to consider patient and carer views of the continuity of care and one study that attempted to measure it (Bindman *et al.*, 2000). However, in all these studies it is assumed that patients view continuity of care in the same way that service providers do.

Several important studies have sought to identify the views of service users and carers about the quality of care they receive. While these reports have not reported specifically on continuity of care, many of the issues raised relate to the organisation of services and the ease with which services can be accessed. Such studies have highlighted the availability of crisis services (Rose, 2001) and the value of continuing relationship with one person over time (Crosland, 2001) as being of particular importance. We are aware of only one published study that specifically set out to identify continuity of care from the perspective of

service users (Ware *et al.*, 1999). In this study patients identified the ability of service providers to step outside their prescribed role and to help patients anticipate and manage potential problems as essential ingredients of continuity of care.

As yet, relatively little is known about how patients and carers perceive continuity of care for severe mental illness. This lack of knowledge is a major obstacle to the development and evaluation of services that aim to enhance experienced continuity of care.

Question 3 What are the obstacles and barriers to providing continuity of care for people with SMI?

A variety of factors related to patients and patterns of service delivery can prevent patients receiving adequate continuity of care. Some patients do not want to maintain contact with service providers, either because of impaired insight or dissatisfaction with care that is offered (Wasylenki *et al.,* 1985). Patients with SMI are highly mobile (Lamont *et al.,* 2000) and continuity of care can breakdown when patients move and contact is not made with local services.

Problems in communication between different services disrupt continuity of care. Important boundaries include those between inpatient and community settings, primary and secondary health services (Bindman *et al.*, 1997) and social workers and health care professionals. Misplaced assumptions about information required by different groups of professionals and the roles of staff in these different settings can also disrupt continuity of care (Lima and Brooks, 1985).

Informal carers may find it difficult to learn about arrangements being made to manage patients' problems. Assumptions about what carers are able to provide can lead to failures in continuity of care (Tessler and Gamache, 1994).

Staff turnover and staff taking on key worker responsibilities while in rotational training posts lead to frequent changes in key worker and this reduces continuity of relationships (Bindman *et al.*, 2000). Obstacles to providing cross-boundary continuity following discharge from hospital include pressures of work, staff shortages and a lack of clarity about discharge procedures (Durgahee, 1996).

High levels of mobility, dissatisfaction with care and impaired insight all reduce the likelihood of patients keeping contact with services. Pressures of work, staff shortages and lack of operational policies impair continuity across boundaries. Misplaced beliefs about the role of informal carers may also damage patients' continuity of care. The assumption that patients always want continuity of care has not been tested and is unlikely to apply in all cases.

Question 4 How can these obstacles be overcome?

Several important changes to services, including the introduction of care management and the Care Programme Approach were introduced in the

belief that they would improve continuity of care for patients with SMI (Shepherd, 1990; DoH, 1990). While it has been argued that these changes have increased longitudinal and relational continuity of care, we have been unable to find research evidence to support these claims. Controlled trials of alternative forms of community care have compared drop-out rates between those receiving experimental and standard forms of treatment. Such studies may provide an indication of the level of continuity of contact provided by these services. A systematic review of case management versus standard care reported 30 per cent lower drop-out rate among those receiving case management (Marshall *et al.*, 2001). Reductions in drop-out rate of 12 per cent with management by Community Mental Health Teams (CMHTs) (Tyrer *et al.*, 2001), 49 per cent with assertive community treatment (ACT) (Marshall and Lockwood, 2001), and 35 per cent with crisis intervention (Joy *et al.*, 2001) have also been reported, all compared with standard care.

While it was argued that introduction of case management would improve continuity of care between primary and secondary services (Schwab *et al.*, 1998), observational evidence suggests that use of primary care services was not influenced by the introduction of case management (Bjorkman and Hansson, 2000) and most GPs are unaware of the identity of the key workers of the patients they treat (Bindman *et al.*, 1997). Early indications are that patient-held shared care records may not prove to be an effective way to enhance informational continuity of care for patients with SMI (Warner *et al.*, 2000). Interventions aimed at helping to prepare patients for their discharge from hospital may be valued by patients, but their impact, if any, on enhancing transitional continuity of care has not been explored.

Several important changes to the way that services are provided for patients with severe mental illness were introduced in the belief that they would improve the continuity of care that patients receive. But the impact of the introduction of these changes on experienced continuity has not been fully explored. Comparisons of drop-out rates between experimental treatments and standard care derived from controlled trials provide a crude indication of (longitudinal) continuity of contact with patients.

Systematic reviews of case management, community mental health teams and crisis intervention all show that patients who receive these forms of intervention have lower drop-out rates than those who receive standard care. Trials of assertive community treatment (ACT) show the greatest impact on reduction in drop-out rates. ACT is the only recent intervention to influence other outcomes such as employment and accommodation status, independent living, and cost reductions.

Question 5 What are the effects of providing improved continuity of care?

Several reports that we examined suggested that failure to provide continuity of care contributes to early re-admission to hospital (Ramon,

1994) and untoward incidents such as homicide and suicide (Sheppard, 1996; DoH, 2001). Evidence to support these claims comes from case–control studies. These have identified reductions in level and frequency of contact with service providers (Appleby *et al.*, 1999), change of consultant, unplanned discharge from hospital, and a significant care professional on leave (King *et al.*, 2001), as important risk factors for suicide among people in contact with psychiatric services. These studies cannot address whether decreased continuity of care affects the likelihood of suicide or simply the time at which it occurs. We are unaware of experimental evidence to suggest that interventions that improve quality of continuity of care can affect the number of untoward incidents. The rarity of such incidents would make studies logistically complicated and very expensive.

Most studies that evaluate the impact of changes in the organisation and delivery of care for people with SMI have not attempted to define continuity of care or measure any element of it. An exception is the cohort study by Bindman and colleagues (2000) in which simple baseline quantitative measures of elements of continuity were used to examine effects on social and psychiatric outcomes 20 months later. This study reported no change in these outcomes but this finding may have resulted either from inability to measure the most relevant elements of continuity or from confounding factors, such as deteriorating mental health leading to increased continuity of care but poorer health and social outcomes.

Such problems may be overcome by experimental studies in which the effects of confounding variables can be reduced through randomisation. We are unaware of research that has set out to manipulate the level of any element of continuity of care that patients receive and then assess its effects on health or other outcomes. Such work would be ethically acceptable because of genuine doubt consequent on the lack of evidence up to now that continuity of care substantially affects outcomes.

If we were to accept that interventions which are associated with decreased drop-out rates are in effect improving some elements of continuity of care, then the reviews of assertive community treatment (ACT) and community mental health teams (CMHTs) should command attention. These report reduced rates of hospital admission from systematic reviews of ACT and CMHTs, suggesting that these interventions may reduce the need for inpatient treatment. However, evidence from controlled trials of case management which found decreased rates of drop-out but increased rates of hospital admission suggests that the relationship between longitudinal continuity of care and use of inpatient services is not a simple one.

There is widespread belief that failure to provide continuity of care may increase the likelihood of untoward incidents and evidence from observational studies suggests that it may increase the likelihood of suicide. Experimental studies are needed in order to explore the effects of continuity of care on health and social outcomes. While there is some

evidence to suggest that interventions that increase intensity of contact with patients may reduce their subsequent use of inpatient services, there is as yet no experimental evidence about the effects of changing the quality of continuity of care that patients experience.

Conclusions

Implications for current service provision

It is important that those involved in co-ordinating care are fully aware of the particular problems that arise when patients change address and move from inpatient to outpatient care. Helping patients anticipate and manage potential problems is likely to be valued by patients and improve the quality of care they receive.

Misplaced assumptions about the role of informal carers and primary care workers may reduce the quality of continuity of care that patients receive.

- Case management, community mental health teams and crisis intervention probably decrease the likelihood that patients lose contact with services. Assertive community treatment may be a particularly effective way to maintain the connection between patients and services.

- Reduction in drop-out rates, however desirable, should not be taken as synonymous with improvement in patients' perceptions of the quality of the continuity of care they receive. Little is known about this.

Areas where further research is required

Operational measures of continuity of care relevant to the experiences of patients and carers need to be developed. These need to be tested with and assessed by clinicians and managers with service responsibility.

The impact of future changes in service delivery and organisation for people with SMI should include assessment of patient and carer perceptions of the continuity of care they receive.

The effects of interventions that are aimed at standardising procedures and practices need to be checked for their effects on providing care that is tailored to the needs of individual patients and is flexible.

Interventions that can help to provide continuity of care at the point of discharge from hospital and improve co-ordinating care between primary and secondary services need to be developed and evaluated.

Elements of continuity are components of a wider experience of care received over time and severe mental illness tends to be chronic. They therefore need to be assessed in long-term studies using multiple methods to assess interactions between other elements of care such as technical expertise and accessibility.

2 Field studies

(Summary – for full report see Appendix 2.)

Introduction and aims

These studies were undertaken to provide evidence to contrast with that available from the English-language literature. There was time to visit four sites in the study period and so these were chosen as examples of what is possible rather than what is normal. The sites were selected from lists of Beacon sites and from those specified in the National Service Framework for Mental Health (DoH, 1999). In view of the scarcity of evidence about continuity of care as actually experienced by service users, we were particularly interested in attempts to involve patients and their carers in the delivery and planning process. Our other main interest was in continuity of care across the main institutional boundaries, namely between specialist mental health and social care and between specialist care and primary care. Although the number of sites was limited we were also keen to study two services outside London, though as London's mental health care problems are so extensive (Johnson *et al.*, 1998) we make no apology for choosing the other two within London.

The aims of these studies, therefore, were to:

- report the rationale of these innovative services as understood by those working there

- sample some day-to-day working to assess how much observed process reflected the aspirations of the service.

The two principal areas of interest were ways of maximising *cross-boundary continuity* and evidence of genuine user involvement in the care process with respect to *experienced continuity*.

Method

The field studies were carried out ethnographically by JL in discussion with TW and GF (see Appendix 2 for methods and references). The research questions were pursued through site visits, telephone calls, e-mail, internal documentation, published work, focus groups, observation of team work in practice, and interviews off site. Each site was visited, but the trajectory of research through each site varied, with a particular focus on documenting and understanding the day-to-day processes operating. Most of the data were gathered through detailed field notes, supplemented by audiotapes when appropriate.

Findings

Study Site A: Service user representation in a home treatment service

The service

This service had been established on the initiative of local professionals against a background of shortage of traditional services, specifically of inpatient beds. It also was a response to a demand from a well-organised user group.

There were two important innovative features:

1   a philosophy of *equal worth for all members* of the multidisciplinary team and the creation of *trust between clients and team members*

2   early establishment of a *full-time post to represent the user* at all levels of service planning and delivery; this was the service user development worker – the postholder was not professionally qualified or experienced but was paid at an equivalent rate.

It is also important that the service is not confined to office hours but is 'always open' with staff on site from 9 a.m. to 9 p.m. on working days and on call out of hours.

Observations

These comprised interviews with key team members, including the service user development worker, and direct observation of a routine full team meeting. JL was also able to visit an unusual local branch of MIND run entirely by local users and ex-users.

Findings

Highlights were the democratic teamworking and good communication across the specialist/social care boundary (cross-boundary continuity). The *mechanism* for this was the membership of the team and the scope of its work. The context was the philosophy of key members and the stability of team membership – the original leaders were still in post. Turnover has been low and hence clients have been able to establish trust and therapeutic relationships with both individuals and perhaps with the team as a whole (*relational continuity*).

Comment

This appears to be a well-motivated and relatively well-resourced group. It is an example of what many community mental health teams may aspire to. As such it should be able to bridge the boundary between medical and social care. However, while the informal relationship and links with primary care appeared good, there was no evidence that this service was especially close to or interdependent with primary care. Team members felt inhibited by the relatively large number of small general practices in the area. Indeed some interviewees remarked that

long-established links between individual GPs and consultant psychiatrists cut across their efforts to be the main portal of entry to specialist services in Bradford.

The strong user voice was noteworthy. It would be very interesting to follow up the experience of a sample of users in detail over two to three years and compare this with the experience and perceptions of a group having care from a comparably resourced CMHT but without this emphasis on user representation.

Study Site B: Experienced contextual continuity in a women's crisis centre

The service

This is a residential service in London for women, providing an alternative to hospital admission. It was developed from the views and experiences of women service users and professionals. There is round-the-clock staff support and residents may stay up to four weeks with a range of treatments on site. Children can accompany their mothers. Staff are drawn from a range of professional groups, including nursing, psychology and social work, but these are not translated into *roles* in the team.

Observations

Much of the material for this site was generated during site visits while work continued in the centre. Interviews were also carried out on site, on the job, and off site with key staff and residents and the contract GP. A focus group was also conducted.

Findings

Many 'admissions' are self-referred. The existence of this informal service allows patients to judge when they need residential care in a crisis. Assessment aims to be holistic, in particular being sensitive to the woman's own context. The nature of the centre as a retreat or 'cocoon' is valued as an important aspect of therapy and care. There is great emphasis on listening and communication. The key feature of therapy is sensitive negotiation of the agreement plan. The unit does have stated ground-rules for the behaviour of residents. If these are consistently broken then residents can be moved on. The ability to do this is deemed an important feature of the service. Use of this facility has to be negotiated with other local mental health services. Residence in the unit does not exclude ongoing contact with other services, either primary care or specialist, and so it is not quite analogous to inpatient care.

There are two implications for continuity here. The first is in the dimension of experienced continuity with emphasis on the woman's social context. The crisis centre offers a fixed physical place (in contrast to the Home Treatment Team in the first site) but works effectively to produce continuity in the psychological space. In addition, the House is neither locked nor remote, and residents can maintain links with normal life and other health and social services.

The second clarifies a particular dimension of informational continuity. The project maintains links with contemporary Health Service provision and practice, but has invented a novel boundary between itself and medical expertise. The lack of a formal nursing position in the team reveals a gap in continuity that nursing staff would normally have to cover. As the crisis centre does not hold medical records, the different kinds of medication prescribed by the psychiatrist, the GP, or any other specialist medical input are not known to each other unless the woman herself relates the information. The attached GP anticipates a solution to this in the future rollout of information technology.

Comment

This is an unusual and attractive service embodying a strong user-centred philosophy with particular emphasis on the circumstances of individual women. *Relational continuity in context* is thus potentially very strong. Staff report much time and effort spent on informal networking and liaison with other professionals. They are particularly interested in *informational continuity* (but see above) and insist that communication should be of high quality, honest and relevant. This is important but seldom emphasised in discussion of patient-held records or record linkage between professional groups. It implies that use of this unusual resource (the crisis centre) is best preceded by accurate assessment.

The observations about the unit's policy on discharging residents who break their agreement plan indicate its ability to control its workload and

conditions. This is a facility that would be envied by many mental health teams.

It is noteworthy that there are no reported special links with primary care other than the special service provided twice a week by the centre's attached GP.

These observations cannot allow us to estimate the total contribution of this service to the whole local mental health service network. Emphasis on the experience and wants of the user seem likely to lead to good experienced continuity because of the ability of the service to liaise directly across boundaries on an individual advocacy basis. The facility for self-referral (subject to availability of space) offers particular scope for flexible continuity.

Study Site C: Integrating services in a rapidly changing environment

The service

This is an example of a Community Mental Health Team working across the health care/social care boundary and is closely integrated into both services. As in Site A, the team aims to be the normal single portal of entry to specialist mental health and social services. In this London setting, the boundaries of mental health trusts have not been coterminous with those of health authorities or of primary care groups or trusts. In addition, (again like Site A) it has not seemed practicable to build on existing links between general practitioners and psychiatrists.

Observations

Data were gathered through observation of a multidisciplinary team meeting, interviews, telephone conversations, policy documentation, and 'following the action'. The experience of this field study led the research to quite separate aspects of the mental health provision, and gave the impression of highly alienated 'City' life.

Case histories

Three contrasting case histories illustrate the service in action in a variety of ways and crossing different boundaries. These illustrated mobile patients who were needing general medical as well as mental health and social care. There was a referral from a general practitioner, interface with housing department, police, neighbours, and the voluntary sector. There was discussion of forced entry to a patient's home.

Comment

This study probably seems much more recognisable to those at the sharp end of inner-city mental health care. There are repeated cross-boundary continuity issues as the various elements of health and other services, extending way beyond social work, try to communicate with each other. There are examples of staff turnover even in this very limited observation

period. The ability of the service to concentrate on the patient's experience is severely constrained by a combination of high caseload and relative lack of resources. The further combination of high patient mobility and wide variety of potential players means even longitudinal continuity demands a very dedicated key worker or small key team with an acceptable caseload. Relational continuity needs at least minimal longitudinal continuity combined with added time and skill.

Informational continuity is interesting and largely informal. There is considerable scope for limited and possibly misleading information to assume the status of fact. Some of this could be improved by well-integrated health and social service records but the networks reported here extend far more widely than any system currently envisaged.

Study Site D: Mental health liaison: a primary care-based option

The service

The mental health service in this Midland town consists of existing Community Mental Health Teams (including social workers and so crossing this boundary) managed with a specific commitment to liaise with primary care – in particular, with general practices. There had been a long-standing drive to reduce interprofessional barriers within the teams. Earlier, many general practices had had attached community psychiatric nurses but it was not possible to continue resourcing this. The new pattern was to link each member of the CMHT with a group of practices and leave it to the group to determine when and how often they would meet. Thus primary care teams are now directly working with CMH team members of contrasting professional backgrounds.

An additional feature has been wider networking of the service with educational providers and with the pharmaceutical industry. There has been a local core curriculum for mental health offering multi-professional education and fostering teamwork.

As this was the only study site to emphasise links with primary care we decided to concentrate fieldwork on a primary care-based mental health team led by a local GP.

Observations

Key members of the team included the GP leader, three nurses (the liaison community psychiatric nurse, a primary care mental health practice nurse and a community (general) nurse), and a counsellor. The GP was one of a group of doctors, each of whom had a special clinical interest; in this case it was mental health. The primary care mental health team relied on the practice's paperless computer record system (Vision).

Observations included interviews with team members centred on individual client stories. In addition the Beacon site manager was

interviewed. The subject matter emphasised mechanisms of teamwork and remarked on the specific circumstances (context).

Findings

These committed team members gave striking examples of how they crossed professional boundaries in a variety of settings. In one example a practice-based nurse applied dressings to the chronic wound of a patient with a mental health and substance abuse problem on the premises of a local psychiatric unit. The team reported close interpersonal liaison and good knowledge of a local community of manageable size and identifiable extent.

Comment

This group offered the only example of a specialist mental health care team able to cross both the social work and the primary care boundaries. This showed how flexible and imaginative teamworking could enhance cross-boundary continuity. Members were able to get close enough to clients to be able to offer genuine relational continuity and their internal communication was good enough for this to be relational with the team as well as with individuals. Informational continuity was maximised in this setting by a common computerised record system. Again, stability of team membership was noteworthy.

Unfortunately no one example offered everything we were looking for and this one, admirable in so many ways, seemed to lack evidence of a dedicated users' perspective. While this flexible community-based service is certainly close to the user it is strongly professionally driven and informed. It is debatable how much value would be added by more user input and this is a suitable topic for further enquiry.

Discussion

These field studies offer some tantalisingly brief glimpses into the reality behind the rhetoric as it appears at locality rather than strategic level. In studies of this kind and scope it is not possible to assess the contribution of elements of continuity of care to the whole pattern of care given and received. In particular there is no information on the contribution of these local teams to the total package of mental health care in their area.

That said, there are lessons to be learned about the meaning of elements of continuity of care in the field. The colour of these limited examples can only hint at the variety of care patterns and informal initiatives that happen within the summary data of large-scale studies assessing the effects of, say, CPA or ACT.

Cross-boundary continuity has been addressed by the creation of multidisciplinary teams bridging specialist mental health care and social work. The reports from Sites A and C give a flavour of how these teams can profit from the mix of professional backgrounds and the ability to

cross traditional boundaries within the team. It is not possible to judge what difference this has made to the users but the apparent high professional morale is likely to improve standards. Crossing the boundary with primary care is a more difficult task. The long tradition of the separation of mental from general health care continues even in 2001 with the creation or continuation of mental health trusts which are not co-terminous with the new primary care trusts. The primary care-based mental health team in Site D is an excellent example of a complete rethink of mental health care in the UK context. Here there is a feel of crossing the general/mental health boundary as well as the primary/specialist one. This example prompts the question of whether such a team could take on the range and severity of problems being faced by their colleagues at Site C in inner London.

Informational continuity is a recurrent element at all four sites. This was most explicit at the community-based Site D with its shared multi-professional computer-based record. Systems common to mental health and social care were implied in the CMHT examples at Sites A and C. What all three of these studies highlighted was the salience of informal information and personal verbal contacts, some of which extended across many further boundaries such as employment, housing, police and general health care. The picture reminds us that a computerised formal record cannot convey the wealth of contextual detail implicit in direct verbal contact, but also that informal messaging risks distortion as it is forwarded and re-interpreted – in other words, there is a risk of gossip assuming the status of fact.

Flexible continuity and longitudinal continuity are hard to assess in one-off visits, which are essentially cross-sectional.

Good flexible continuity in the sense of care varied in scope to suit the user's changing needs is implied by the crisis centre (Site B) system of careful individual reassessment shared with the user at each 'admission'. Other teams might wish to offer this but their ability to do so may be compromised by unsupportable caseloads.

Longitudinal continuity is about the user/client's repeated contact with the same professional or team. Here staff turnover was implied by the Site C visits, as well as the challenges posed by user mobility. Thus longitudinal continuity with a team is more practicable than with an individual in the inner-city context.

Personal or relational continuity expresses the extent to which the process of interchange between user and professional (individual or team) is therapeutic in itself. While some minimal degree of repeated contact (longitudinal continuity) is necessary, this is not sufficient, and interpersonal skills and empathic attitudes are necessary as well as appropriate interventions. The degree of relational continuity offered at the four study sites can be perceived by the emphasis of the various stories – how much they were personally focused on individual users and their contexts. Here, there is congruence between the amount of focus on user perspective and also the direct reporting of individual contacts.

The Site A study reports a strong philosophy of user focus manifest both within the professional structure and outside it in the local branch of MIND. The Site B process clearly gives great emphasis to personal relationships and so potentially offers good personal continuity. The story from Site D, though professionally oriented, reports considerable familiarity with the individual user over time. Only in the Site C account, with its impression of constant flux of both users and professionals within a high workload, was the feeling of relational continuity absent.

These studies have repeatedly emphasised the importance of local context, both of services and of the lives of users. It may be helpful here to postulate contextual continuity as a subset or at least a closely related element of relational/personal continuity.

Once again, the conclusion has to be that the gold standard is the experience of the user. These field studies have examined the process of the various contributory elements of continuity. Assessment of experienced continuity means going and studying users, which will happen in a different part of the NCCSDO's programme.

3 Delphi study

(Summary – for full report see Appendix 3.)

Introduction

Delphi studies aim to obtain a consensus view on a given issue from a group of experts, or appropriately experienced individuals (Delbecq *et al.*, 1986; Jones and Hunter, 1995). This aim is achieved through administration of a series of structured questionnaires accompanied by feedback of summarised findings from earlier responses in iterative fashion.

We included a Delphi study in this research in order to give an extended perspective on the possible gap between research practice as reported in the literature and the snapshots of practice in a locality that we expected to gain from the field studies. As far as possible, the interim findings of the literature review and the field studies would inform later stages of our Delphi study. To keep this manageable within the six-month study period, the exercise was restricted to two rounds.

Aims and method

Our aims were to:

- assess the extent to which the generic scoping study definition of continuity of care was found relevant to the care of people with severe mental illness and to modify this definition as appropriate

- identify factors perceived to promote or inhibit elements of continuity of care for people with severe mental illness

- identify mechanisms with potential to enhance continuity of care and to assess their perceived utility

with reference to a panel of provider stakeholders, service users and informal carers.

A panel of respondents was identified and recruited collectively by the research team. Potential respondents were identified because they were members of an important stakeholder group and had a record of involvement in academic and/or policy-oriented debate concerning the development of care services for people with severe mental illness. The groups were:

- service users

- carers

- psychiatry

- social work

- psychology/ psychotherapy

- general practice

- NHS and Social Services Management.

We identified key authors from our literature review, practitioners involved in National Service Framework 'Beacon sites', and invited other nominations from our steering group. There were 24 panel members. The response rate to Round 1 was 20/24 (83 per cent) and to Round 2 10/24 (42 per cent). (The two rounds are described in Appendix 3.)

Findings

Definition

Most aspects of the scoping study definition (see Appendix 3 Figure 2, Definitions 1 and 2) were supported, particularly the primacy of the experience of the user when assessing continuity of care. The comments of the Delphi panel led us to clarify and expand the definition in a draft for Round 2. The changes were a response to increased emphasis on the social context of care, the special needs of patients with severe and enduring mental illness over the longer term, the need for consistency of therapeutic programme, and the importance of recognising wider boundaries with the voluntary sector, with carers and with professions beyond medicine (in its general sense) and social work.

Factors inhibiting continuity and some proposed remedies

Primary/specialist care boundary

The panel was generally agreed that continuity across this boundary (or the lack of it) is a major issue. Respondents were agreed that there was tremendous potential in primary care but that primary care practitioners varied, both in their skills and in their motivation in caring for people with severe mental illness. Thus the potential is unrealisable on an area-wide basis.

There was general support for local educational initiatives in helping address this issue and for improved electronic communication systems. Overall support was only borderline for more radical measures such as establishing joint posts and primary care placements.

Health/social care boundary

Here, there was strong support for joint working and integrated services. However, there was less consensus on the extent to which this could be driven, and concern – particularly from professionals outside medicine – that their specific contribution might become undervalued. Respondents reminded us of the contrasting cultural values and practices of medicine and social work and some feared that some current initiatives for integration were sidelining rather than addressing the teamworking challenges implied. They also mentioned the complexity of care networks beyond medicine and social work that included more boundaries than could be contained within a multidisciplinary team. But if teams became too large they risked becoming unresponsive to variation in the individual user's needs.

Staff turnover

Staff turnover and implied 'burnout' was specified by respondents as the biggest challenge to delivery of continuity to be experienced by users, with particular adverse effect on longitudinal, relational and flexible elements. Unsupported staff with excessive workloads would inevitably deliver routine rather than user-sensitive care.

Here, there was a spread of support for measures to enhance job satisfaction and hence retention of staff, particularly support (for example, through supervision and mentoring) and team-building exercises.

Enhancement of continuity: user involvement

Out of a range of suggestions here, the two gaining highest support were, first, to maintain and enhance a range of therapeutic options (including talking therapies, art and drama) and, second, to increase opportunities for user involvement. At the other end of the scale the option of greater investment in a range of day care options received relatively little support.

The interest in service user involvement was considered at two levels: the service planning level and the care of the individual. There was cogent and specific support for involvement of users through dialogue in service planning and development. But there was surprisingly little emphasis on user involvement at the individual level in responses from the Delphi panel.

Discussion

The aims of the Delphi study were to develop a definition of continuity of care that was relevant to the care of people with severe mental illness, and to identify factors perceived to promote or inhibit continuity of care and mechanisms with potential to enhance it. We did this with reference to a panel of provider stakeholders, service users and informal carers. Delphi studies are usually employed to work towards some operational consensus on an issue. While our study has certainly helped define areas of broad agreement, it has also served to map out and highlight contentious areas around which various stakeholders hold unresolved discordant views. As a strict Delphi exercise it was incomplete, limited by a low response to Round 2.

We believe that there is utility in this output. Any opportunity to extend this project beyond the two rounds our timetable permitted would help to further clarify these themes. One disappointing aspect of the study has been the low response to Round 2. Notwithstanding these problems and limitations, we feel the Delphi study has been a useful addition to the investigation. It has raised important new questions while also informing our thinking about what continuity of care means and how it may be enhanced. The following points summarise the main lessons.

1   The generic definition of continuity of care, developed by the preceding scoping exercise, requires modification before it has

relevance to the special circumstances of mental health care. Our work with the Delphi panel has taken us some way forward. The suggestion of inclusion of continuity of social context into our definition, to describe the need for services to 'sustain a person's preferred social and personal relationship in the community and enhance quality of life', has been supported by service users and other stakeholders. It is also illustrated in our field studies, particularly in Site B (Appendix 2). However, some difficulties remain unresolved. These centre on the ethics of informational continuity and achieving genuine user-centred meanings for longitudinal and long-term continuity.

2   The position of primary care emerges as a key development area. The gulf between the important potential role for primary care (which the panel wanted to see) and the more limited role that was realistically possible in current circumstances was strikingly apparent and almost unanimously shared by all sections of the panel.

3   The panel felt that progress towards the integration of secondary health and social care was fundamentally important. Most recognised that progress was being achieved, but also that difficult inter-agency and interdisciplinary relations still needed to be resolved. While there was no consensus on the way forward, there was nevertheless a majority view in favour of removing both agency and disciplinary boundaries rather than attempting to better manage the interface between different organisations.

4   Key problems were identified. Most significantly perhaps, workforce issues affecting staff turnover within specialist care was identified as a major challenge. Improved staff retention was seen as a fundamental to achieving continuity of care. Supervision, training, team building, mentorship and work sharing were some of the key mechanisms identified by the panel that could address this problem.

5   Finally, if we are to work towards enhancements to continuity of care that are both user-centred and valued by users, we are going to have to achieve far more in terms of user involvement. Other concurrent work undertaken by members of the research team[1] has highlighted how difficult progress with user involvement has been for many trusts. We are conscious that the Delphi exercise has tended to confirm the ubiquity of these difficulties. While some of the Delphi panel were passionate about the value and importance of user involvement, certain professional interests were vague about its meaning and role. There is no other single issue that has so clearly exposed the inability of this brief two-stage exercise to approach consensus. Further work should be urgently undertaken to develop mutual understanding about user involvement, particularly at individual level and a clearer view about how to achieve this.

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[1] Work in progress by MC, TW and others with NHSE (LRO) Organisation and Management R&D Funding: *User involvement in the planning and delivery of healthcare*.

Overview of findings

Definition

There is general agreement about the pre-eminent importance of considering continuity of care issues from the perspective of users' and patients' experience (experienced continuity). However, the Delphi study has usefully highlighted misunderstanding of certain elements of the generic definition from the scoping study (see Appendix 3, Figure 2) and clarified where it should be expanded for relevance in the mental health care setting. The field studies have added useful context. In particular, our Delphi experts emphasised:

- the long-term care aspect of longitudinal continuity in severe mental illness

- that continuity is experienced in an individual's social context

- that personal and relational continuity should be part of a consistent care programme

- that flexible continuity adjusting to an individual's changing needs should be part of a consistent care programme

- the challenging scope of cross-boundary continuity, including between professionals and carers and between health care professionals and groups such as the police, housing departments and employment agencies

There was also a consensus that the needs of informational continuity would not be met only by an electronic patient-held record.

Accordingly we now propose an amended definition (Figure 1).

Figure 1 Proposed continuity of care definition (for general application, including the care of severe mental illness)

A minimum definition of continuity of care should include the following elements:

- the experience of a co-ordinated and smooth progression of care from the service users' point of view (*experienced continuity*)

To achieve this central element the service needs to:

- provide one or more named individual professionals with whom the service user can establish and maintain a consistent therapeutic relationship (*relational, personal and therapeutic continuity*)

- ensure that care is provided by as few professionals as possible, consistent with need and uninterrupted for as long as the service user requires it (*longitudinal continuity*)

- be flexible and adjust to the changes in a person's life over time in their own personal and social context (*flexible continuity*)

- have *effective communication*:
  (a) based on excellent information transfer following the service user (*information continuity*)
  (b) between professionals working in statutory and non-statutory agencies, working in primary and secondary care, and with the service user and their informal care networks (*cross-boundary and team continuity*).

User perceptions and involvement in continuity of care

The relative dearth of literature in this area, noted in the scoping study, was confirmed. Delphi panel members were keen to involve users in service planning and operation but seemed less interested in users' individual involvement in their own care. The field studies showed some of the challenges in realising both aspects of user involvement. Site A had brought in and valued a user representative at an early stage. At Site B the key feature is individually negotiated patient agreements. User involvement was much less evident at the other centres.

We suggest that genuine user involvement represents a culture change for NHS professionals, going beyond what has been needed, for example, in joint working with social work colleagues. As such it may hold the key to delivering genuine improvements in experienced continuity of care. Any outcome experiments of interventions to improve elements of continuity should preferably include and assess some form of user involvement.

The concept of flexible continuity, including continuity in the patient's social context, reminds us that continuity is not necessarily at the top of the patient's menu at all times. Patients may sometimes wish for a new start or for a second opinion not biased by previous assessments. In addition, users' needs vary over time and what is good for the service

(for example, concentration of specialised expertise at one site) may not suit the user's wish for a convenient accessible local service.

What inhibits continuity?

Here the three study arms gave congruent evidence. Qualitative observational evidence suggested that experienced relational continuity depends on sufficient professional time and hence resources. Beyond this, the professional's skills and perhaps motivation in tailoring care to the individual's particular needs are also relevant. Negative patient perceptions and failure to identify with treatment regimens may explain loss of contact with mental health services.

The field studies suggest that the scale of the boundary issue between specialist and primary care is large and the Delphi panel offers some explanation. Everyone is agreed that primary care has much to offer and the Site D field study gives a flavour of this in action. However, two serious problems inhibit progress.

First, the wide variation in primary care (specifically general practice) skill and motivation to engage in close partnership in the care of people with severe mental illness and, second, the logistical problems involved in liaising with many different practices. This is accentuated in inner cities where practices tend to be small. It is tempting to speculate whether GP participation in Community Mental Health Teams activity has insufficient immediate pay-off for either party to overcome the difficulty in achieving it. The benefits are instead general, longer term, and involve issues beyond mental health. It is easier to postpone them. Further study could elucidate the perceived rewards and the opportunity costs involved in crossing this boundary.

Finally, there was evidence, particularly from the field studies and the Delphi study, that boundary issues extend beyond the fields of medical and social work. They particularly involve linkage with carers and relatives, as well as wider areas such as housing and the police. Attempting to include all boundaries is likely to lead to large, unwieldy (and hence unresponsive and inflexible) service units.

Improving continuity

There is most evidence about continuity across the boundary between health and social care. The main community team care approaches all seek to bridge this boundary by including it within the team. Many studies have tried to assess how effective these approaches are in reducing drop-out rates and discontinuity gaps. The field studies illustrate two CMHTs which show contrasts in philosophy, composition, morale and community setting. The issue of underlying resource is implied rather than measured and it would take far more sophisticated study to understand the relative contributions of management and leadership skills, staff training and experience and financial resources. But there is a clear view from the field studies and the Delphi study that rapid staff turnover is the enemy of personal/relational and probably of experienced continuity. The Site D field study shows how a small mixed group of professionals, imaginatively led, can cross traditional demarcation lines with ease when allowed to develop their own solutions on the ground over time.

Benefits of improved continuity

There is surprisingly little firm evidence that improving any element of continuity of care has an immediate and direct effect on improving hard outcomes. In the USA context, where the discontinuity of standard care can be real and serious, specific outreach programmes may of themselves offer big improvements in continuity, leading to much improved coordination with less duplication and cost. In the UK the NHS already offers a basic minimum of continuity, including some shared records, well-established methods of communication, and free access to care for all. Here, therefore, outreach programmes may tend to identify more problems and hence incur new costs. This has made the assessment of interventions to improve continuity difficult. However, interventions that have been studied such as ACT, CPA and CMHTs are so broad in scope that we cannot be confident that elements of continuity have indeed been altered. More specific interventions are needed.

Serious outcomes such as suicide and homicide are so rare that conventional research trials of interventions are logistically impossible. The suggestive observational evidence that suicide may be increased by non-availability of key staff is tantalisingly inadequate on its own and invites larger-scale inquiry.

We can be more confident that better personal and relational continuity lead to improved patient and staff satisfaction and that improved informational continuity at least reduces frustration and delay. These 'process outcomes' may be considered worth having in themselves. Imaginative research is needed to find out whether they can lead to more tangible benefits such as improved team functioning and fewer untoward incidents.

Our overall conclusion, therefore, is that research in this area has so far been inhibited by the rarity of precise definition and, following from this, a lack of specific measures of important elements of continuity which are generally relevant to improving health outcomes for people suffering from severe mental illness. Developing such measures and applying them to assess the effects of specific, generalisable interventions that modify elements of continuity of care offers hope of improving our understanding.

Implications for service

- While Community Mental Health Care Teams are a fact in today's NHS there is no good evidence that they have done more than maintain the status quo in terms of care received.

- Field evidence and expert opinion suggest that the way teams function may be more relevant to improving care than their composition.

- Rapid staff turnover is inimical to continuity of the care experienced by patients. So far there is no evidence that resource shortages can be significantly mitigated by attempts to improve continuity of care.

- More involvement of users in care planning and delivery is a promising but as yet unevaluated means of improving care in a cost-effective way. It is to be hoped that it will lead to better satisfaction from patients and more relevant activity by professionals.

- Bridging the boundary between primary and specialist mental health care is particularly challenging. An imaginative range of initiatives is indicated.

Implications for research

Detailed study of user and carer experience of the care of severe mental illness is a wide-open field for researchers.

Where possible this should be combined with the evaluation of the effects of novel methods of care delivery on outcomes.

Continuity of care is a complex, multi-element relational concept. Meaningful study therefore involves careful definition of one or more elements and multi-method assessment of what must usually be a complex intervention with many possible outcomes, some of which will be perverse.

Operational measures of continuity of care relevant to the experiences of patients and carers need to be developed. These need to be tested with and assessed by clinicians and managers with service responsibility.

Better continuity of information through modern electronic systems has obvious potential but early studies suggest this may not be easy to apply. How to integrate these powerful systems into professional practice to give best advantage to patient care is an important outstanding question. The primary/secondary mental health care boundary would seem to be a suitable focus for intervention studies.

The crucial feature of the care of severe mental illness is the ability of the service to cope with patients' changing needs over time, in particular to engender trust and to be available at crises. Evaluations therefore need to cover a long timescale to be convincing.

Appendix 1

Report of the literature review
(led and reported by Mike Crawford and Eccy de Jonge)

Introduction

Continuity of care was identified as a research priority by the Service Delivery and Organisation (SDO) Research and Development programme as part of a national listening exercise conducted in 1999 (Fulop *et al.*, 2000). A subsequent scoping exercise combined a literature review with a conceptual analysis in order to generate a definition of continuity of care and identify areas where further research was required (Freeman *et al.*, 2001). One of the recommendations of this report was that a more detailed examination of literature be conducted with reference to specific groups of patients, one of which was people with severe mental illness (SMI). Severe mental illnesses are a group of primarily psychotic disorders that are, by definition, long term and associated with impaired social functioning (Ruggieri *et al.*, 2000). Continuity of care for patients who experience SMI has assumed particular significance because of a several important historical, clinical and political factors.

The organisation of services for people with SMI underwent radical transformation during the second half of the 20th century. De-institutionalisation resulted in patient care being transferred from hospital to predominantly community settings. Where a single organisation – the asylum – had previously attempted to meet the health and social needs of patients, this task was to be taken on by a range of primary and secondary health and social care providers. From an early stage it was realised that providing continuity of care for patients would be central to their receiving high-quality community care (Audit Commission, 1986).

In addition to having long-term and complex needs, people with SMI may experience impaired insight. This means that at times when a person is least well they may be reluctant to seek help or actively avoid contact with services. Ambivalence or rejection of contact with services further complicates the delivery of continuity of care (Wasylenki *et al.*, 1985).

Continuity of care for patients with SMI has been highlighted by a Confidential Inquiry (Department of Health (DoH), 2001) and in several official inquiries into untoward incidents involving people with mental illnesses (Sheppard, 1996). These documents have linked the occurrence of fatal incidents with failures of service providers to deliver continuity of care. While such incidents are rare, they are widely publicised and have

had a major influence on policy and legislation affecting the lives of people with SMI (Secretary of State for Health, 1999).

For a variety of reasons continuity of care is considered an essential element of the provision of services for people with SMI. The significance of continuity of care was recognised in the National Service Framework for Mental Health, which states that 'delivering continuity of care for as long as it is needed' should be a guiding principle in planning and delivering mental health services (DoH, 1999). In this context we undertook a comprehensive qualitative review of the literature on continuity of care for people with SMI.

Aims

We aimed to identify national and international literature on continuity of care for people with SMI. We used information from these papers in order to address five related questions:

1   How is continuity of care for people with SMI defined?

2   How do patients and their carers perceive continuity of care?

3   What are the obstacles and barriers to providing continuity of care for people with SMI?

4   How can these obstacles be overcome?

5   What are the effects of providing improved continuity of care?

Methods

Search strategy

We identified papers for possible inclusion in the study by combining an electronic search of databases, a search for grey literature and contact with experts in the field. Electronic databases searched comprised medical (Medline 1966 onwards, Embase 1988, PsychINFO 1967, AHMED 1988), nursing (CINHAL 1982) health care management (HMIC and HELMIS 1983) and social science (Web of Science – Social Science Citation Index). We conducted an electronic search of the Cochrane Library, a database of systematic reviews, and searched for grey literature using SIGLE (a database maintained by the European Association for Grey Literature (EAGLE) that contains unpublished material such as reports, documents and pamphlets as well as PhD and other university theses).

We used MeSH headings and free text searches related to SMI (for example, psychosis, schizophrenia, bipolar disorder) combined with terms related to continuity of care. We anticipated that many papers that discussed aspects of continuity of care for patients with SMI would not use this phrase so the search included a variety of terms derived from the broad definition of continuity of care included in the report produced by the scoping exercise (Freeman *et al.*, 2001). Lists of the MeSH

headings and terms for free text searchers are listed later in this appendix. Searches were restricted to papers published in English between 1966 and October 2000.

Experts were identified by generating a list of authors of papers on continuity of care from the Reference Manager file containing details of 453 abstracts obtained from the electronic search of databases; 19 authors on this list had published three or more papers on the subject of continuity of care. We wrote to all 19 with a request that they send us references or copies of papers or unpublished reports on continuity of care for patients with SMI. Three experts responded to this request, sending us 36 papers of which 10 met the inclusion criteria and had not been identified by the electronic search (see Appendix 4 References).

Selection criteria

Several different definitions of severe mental illness have been produced (Ruggieri *et al.* 2000). For the purpose of this study we used a narrow definition based on that produced by the American Psychiatric Association (1987). This meant that papers were included if they described care for patients with non-organic psychoses such as schizophrenia and manic depressive psychosis. We excluded papers that focused on patients with personality disorders, neuroses and other mental disorders. Papers were included if they described continuity of patient care (either explicitly or implicitly) but papers that explored aspects of quality of care not related to continuity of care were excluded.

Two researchers (E. de Jonge and M. Crawford) independently examined titles and abstracts of papers that were initially identified and full text articles were obtained for all papers except those where it was clear from the title and abstract that they did not address the study aims. Further papers were then excluded if examination of the full text of articles showed that they did not address the aims of the study. Details of all papers were entered into Reference Manager (Reference Manager, 2000) in order to assist with subsequent categorising and processing of data.

Qualitative analysis

Papers for possible inclusion in the review were examined by one of two reviewers (EdJ and MC) who completed a coding sheet (included at the end of this appendix). Papers were described by type (editorial or discussion paper, qualitative research, observational study, experimental investigation or review), the study aim or aims addressed, and the element of continuity of care that was the main focus (if any). A global rating for each paper was awarded and used to exclude papers which, on detailed inspection, did not address the study aims or provide information which it was felt should be highlighted in the subsequent report. Three reviewers (EdJ, MC and G. Freeman) each took a lead in examining groups of papers classified by one of the five study aims. The reviewers

presented initial findings of their part of the review to the steering group, giving an opportunity for reviewers to give feedback prior to producing draft reports. A proportion of papers addressed more than one of the study aims; these were copied and forwarded to the reviewers working on these different sections.

Findings

Having searched 10 electronic databases, we identified 1763 papers for possible inclusion in the review. Of these, 1328 were excluded because either the paper was a duplicate of one identified from one of the other searches or because examination of the title and abstract revealed that the paper did not address study aims. The remaining 435 papers, together with 10 papers obtained from contact with experts, were examined and coding sheets were completed. This led to the exclusion of a further 360 papers. Information gathered from the remaining 91 papers forms the basis of the remainder of this report.

Definition of continuity of care

A recent scoping exercise (Freeman *et al.*, 2001) identified six generic elements of continuity of care:

1   *experienced continuity* – the experience of co-ordinated and smooth progression of care from the patient's point of view

2   *continuity of information* – excellent information transfer following the patient

3   *cross-boundary and team continuity* – effective communication between professionals and services and with patients

4   *flexible continuity* – to be flexible and adjust to the needs of the individual over time

5   *longitudinal continuity* – care from as few professionals as possible, consistent with other needs

6   *relational or personal continuity* – to provide one or more named individual professionals with whom the patient can establish and maintain a therapeutic relationship.

The present systematic literature review aimed to explore the way in which the term 'continuity of care' had been applied in relation to the care of people with SMI. We were keen to identify differences in content or emphasis of the dimensions included in the definition of continuity of care found in the scoping report. While all the papers selected for the review establish factors that lead to, promote or effect continuity of care, less than a dozen papers aim to clarify or define how continuity of care relates specifically to SMI. The following is an analysis of definitions of continuity of care, specifically applicable to those with SMI.

In general, continuity of care refers to a collection of criteria to evaluate the use of services, from therapy and medication to work, employment and housing (Tessler and Gamache, 1994; Bachrach, 1983), and the

provision of these services in an organised manner over time (Bass and Windle, 1972; Systema *et al.,* 1997). Although Tessler and Gamache sought to examine and define continuity of care as the relation between family members (both patient and carer) and professionals, they argue that 'continuity of care' lacks a clear definition, sometimes referring to 'accessibility' of health care provisions, and other times as synonymous to 'quality of care', limited to meaning contact with professionals in post-hospitalisation aftercare programmes.

Bachrach defines continuity of care as experienced continuity which is both cross-boundary and flexible, fitting the categories 1, 3 and 4 identified above (Bachrach, 1983). In addition, Bachrach argues that continuity of care must be 'longitudinal' which, in contrast to the definition given above, simply recognises that patients with SMI require long-term treatment. The need to provide patients with SMI with a long-term care plan aims to avoid repeated readmission to hospital after discharge – the 'revolving door syndrome'. While it is generally agreed that treatment should concentrate on the needs of the individual, continuity of care requires an interdisciplinary approach – that is, social service provision as well as medical supervision.

Continuity of care takes into consideration *flexibility*, identified in category 4, *relational continuity* identified in 6 and *communication* identified in 3. But effective communication involves patient-tracking and follow-up procedures, as maintained in 2. Communication is seen as a major factor in preventing the revolving-door syndrome.

The main elements described in Bachrach's early paper (Bachrach, 1983) were recognised as important in the scoping exercise. All these various categories can be subsumed under the notions of 'connectedness' and 'openness'; patients are not restricted to receiving care only in an institutional setting and so avoid being categorised inappropriately or being coerced into receiving unwanted 'care'. However, a problem arises between offering service provision on demand – taking a flexible approach which is chosen by the patient – and allowing the patient (or carer) to discontinue care whenever it seems ineffectual or unwanted (Bachrach, 1983).

Bachrach thus adds an additional term, which she calls 'psychological access' (Bachrach, 1986). This recognises that the patient may lack the assertiveness and communication skills necessary to understand and navigate the system, so ensuring continuity of care requires that patients be educated and encouraged to use the services provided. A further issue that has practical implications for continuity of care is financial access. In the USA, where patients have to pay for service provision, there is no universal entitlement to psychiatric care, or to medical insurance. Thus the issue of social and state responsibility is identified as crucial to ensuring continuity of care, given that most patients come from economically deprived backgrounds (Bachrach, 1983). Finally, Bachrach identifies 'geographic access' as a major contributor to providing continuity of care – the patient must be able to access

services locally, or at least be able to reach the locus of care provision. Bachrach identifies this as a major problem in the USA, especially in rural areas that have an inadequate transport system but a large 'catchment area' (Bachrach, 1986).

Wasylenki and colleagues concentrate on the practical implications of providing continuity of care which is recognised as a therapeutic relationship on which a patient can rely over time (category 6) (Wasylenki *et al.*, 1985). Continuity of care is ensured by a continuity of quality service provision for patients, to avoid both the 'revolving-door syndrome' and the problem of care being the sole responsibility and decision of the patient himself or herself. Like Bachrach, Wasylenki *et al.* recognise that the patient may not always be capable of making decisions in his or her best interests, or want to receive 'care'. The solution is the establishment of a relationship between one or several professionals to ensure that adequate care is provided (categories 5 and 6). The main component of continuity of care lies within a system where one person, the key worker or case manager, works closely with the patient and takes responsibility for his or her service provision. Case managers or key workers assess the patient's needs, plan specific goals and activities for the patient to achieve, refer or transfer the patient to appropriate services, and monitor the patient's progress as well as acting as advocates — ensuring the patient receives equal rights, housing, and medical care (Tessler and Gamache, 1994). The key worker or case manager has the responsibility of staying in touch with the patient and ensuring that care is maintained, reporting back to psychiatric services and other social bodies at regular review meetings.

One of the main challenges to providing continuity of care occurs between inpatient and outpatient psychiatric care (Nazareth and King, 1992). Special reference must therefore be made to connect the patient's treatment in hospital to community treatment and social functioning. Continuity of care should aim to resolve the 'revolving-door syndrome' so that patients become part of the community rather than reliant on a hospital system in which they feel more secure than in the 'outside' world where the procurement of housing and welfare benefits may prove daunting to the patient, who may end up lost in the system (Nazareth and King, 1992; Nelson *et al.*, 2000).

Johnson and colleagues reviewed previous literature and developed an operationalised definition of continuity of care (Johnson *et al.*, 1997). These consisted of six dimensions of continuity (whether patients remain in contact with services, extent of breaks in service delivery, implementation of plans for services, co-ordination with primary care services and co-ordination with formal and informal carers). These measures were then used to rate the level of continuity of care among a cohort of patients with SMI in order to explore the effects of continuity of care on health and other outcomes (Bindman *et al.*, 2000) (see 'Effects of continuity of care for patients with SMI', below).

To summarise – for those with SMI, continuity of care must rest on the following principles.

- Care must be available over a long period of time.

- People must be treated individually.

- Care must be flexible.

- Case managers and key workers are viewed as the principal providers of care and should be held accountable for providing continuity of care.

- Obstacles to providing care must be recognised and overcome.

Continuity of care from the perspective of patients and carers

Several important surveys have sought to identify the views of service users and carers about the quality of care they receive. While these reports have not reported specifically on continuity of care, many of the issues raised relate to the organisation of services and the ease with which service can be accessed.

In a national survey of 345 carers of people with schizophrenia who were in contact with the National Schizophrenia Fellowship carers rated 'regular contact with a key worker' as being the single most valuable component of service provision (Hogman and Pearson, 1995). While continuity of care was not raised as an issue, respondents stated that they needed better information about who they could contact if a crisis arose and about other aspects of care, and they wanted more contact with all those professionals involved in providing services for the person they cared for. The need for more information and access to services 24 hours a day was also highlighted by a survey of 112 family carers conducted by the Sainsbury Centre for Mental Health (Shepherd *et al.*, 1994). A common concern of carers that was more directly related to continuity of care was that there should be 'improved service co-ordination and communication by professionals'. Concerns about the availability of crisis services also rated highly among the needs of 64 carers in a cross-sectional survey of four mental health teams in England (Schneider *et al.*, 2001). The authors reported a non-statistical significant trend towards carers in areas where health and social services worked more closely being less concerned about the availability of backup services. Tessler and Gamache (1994) also explored the relationship between continuity of care and the views of carers about the service they received: 305 families' carers were interviewed before and after the person they cared for had been discharged from hospital. Using a measure of carer burden developed for the study, the researchers examined factors associated with carer burden. The carers of patients who were judged to have received high levels of continuity of care did not experience lower levels of carer burden.

Views of service patients, collected at both a local and national level, show a high degree of consistency. While continuity of care has not been

raised directly, patients repeatedly ask for more information about their treatment and care and for quicker and more responsive help at times of crisis (Rogers *et al.*, 1993). Data collected from patients through user-focused monitoring involving 500 patients in West London (Rose, 2001) emphasised the need for crisis planning. A survey of 23 service users in London, which focused on arrangements for care programming, suggested that patients particularly value the relationship with their care manager and the report concluded that services should recognise the importance of ongoing continuous relationships between patients and their key workers (Beeforth *et al.*, 1994). Qualitative data collected about 32 patients with SMI in a general practice setting confirmed the importance that patients place on their ability to build a continuing relationship with one person over time; concerns were expressed by patients involved in the study concerning repeated changes in physicians and the need to give repeated accounts of their previous problems and treatment (Crossland, 2001).

We are aware of only one study that aimed to directly examine patient perspectives of the continuity of care they received. This project, conducted in two community mental health centres in Boston, USA, used qualitative research methods in order to identify 'mechanisms of continuity' from the perspective of service users and providers (Ware *et al.*, 1999). By combing data from participant observation and in-depth interviews with 16 patients and 16 health care workers, Ware and colleagues were able to identify six mechanisms for enabling continuity of care to occur. These were:

- *pinch hitting* (when individual service providers step outside their prescribed role)

- *trouble-shooting* (when providers anticipate potential problems and move to address them before they develop)

- *smoothing transitions* (where workers try to minimise the impact of changes in service provision)

- *creating flexibility* (where attempts are made to adapt to meet particular needs of individual clients)

- *speeding the system up* (helping patients access appropriate services by liaising with colleagues in different components of services)

- *contextualising* (where service providers who have known the client over a long period of time help others working with clients to reframe problems in a way that recognises previous gains).

These observations are based on a synthesis of findings from both service providers and service users, and data presented in the papers do not allow the reader to separate the views of each group. While some of these items are similar to dimensions of continuity of care defined by service providers, they suggest that patients experience continuity of care through being helped to plan how to manage crises and having a relationship with workers who are 'prepared to go the extra mile'.

Obstacles to providing continuity of care

The following factors have been identified as the main obstacles to providing continuity of care:

- financial costs not met by local or government authorities (Lima and Brooks, 1985)

- lack of inter-agency communication and collaboration (Lima and Brooks, 1985; Durgahee, 1996)

- lack of training and support (Lima and Brooks, 1985; Durgahee, 1996; Nazareth and King, 1992)

- absence of keyworkers' consent to take responsibility or to understand the nature of their role (Durgahee, 1996)

- absence of responsibility and accountability in general, specifically in the move between institution and community-based care (Anonymous Panel, 1994)

- burden of responsibility placed too heavily on patients/ families living in unsupervised settings (Tessler and Gamache, 1994)

- legislative barriers preventing transfer of funds from health and social care services (Parker and Gordon, 1998).

Demographic factors associated with loss of patient contact with services include younger age, unemployment, social isolation and residence in inner city areas (Tehhrani *et al.*, 1996). People who are more mobile and have frequent changes of address are also less likely to keep in contact with services (Lamont *et al.*, 2000). Patients may choose to avoid contact with services if they feel that available care would not be of help to them (Sharma *et al.*, 1995). In a US cross-sectional survey of people with SMI who had dropped out of contact with services, the most common reasons given by respondents for not maintaining contact were that they did not feel they had problems that required treatment or that they wanted to solve the problems they had on their own (Kessler *et al.*, 2001).

Data from cohort studies suggest that those who do not maintain contact with services are also those judged to have the greatest needs (Fischer *et al.*, 2001; Killapsy *et al.*, 2000). This observation underpins a series of service developments that have attempted to reduce the likelihood of patients losing contact with services (see 'Factors that promote continuity of care', below).

Deficits in continuity of service provision have been reported during the period when patients are discharged from inpatient services. Observational studies in Virginia, USA, demonstrated that patients who had short admissions and those who were discharged to services outside the local area were less likely to be followed up (Farrell *et al.*, 1996; Farrell *et al.*, 1999). Organisational factors such as lack of administrative support and problems reconciling differences in working practices between inpatient and community services have been highlighted as obstacles to delivering continuity of care at the time of discharge from

hospital (Christianson *et al.*, 1991). Problems of high staff turnover have been highlighted as an obstacle to providing continuity of personal care in community settings (Holloway *et al.*, 1991).

Factors that promote continuity of care

The major theme emerging from literature on factors that promote continuity of care for people with SMI concerns the evaluation of interventions and policies aimed at increasing longitudinal continuity of care. Policy initiatives that make individual health care professionals responsible for co-ordinating patient care are intended to reduce the likelihood that patients will lose contact with services. While there has been considerable discussion about the effects that such policies *should* have on patient care, few have attempted to quantify their effects.

Promoting relational and longitudinal continuity of care

Throughout the literature that we examined there has been emphasis on patients remaining in contact with the same professional. This principle underpins two key service developments that have aimed to improve the quality of care for patients with SMI: case management and the care programme approach. Case management was introduced in Britain in the late 1980s and sought to enhance continuity of care by making a named individual – the care manager – responsible for co-ordinating the care of patients with SMI (Shepherd, 1990). Providing continuity of care was also one of the stated aims of the Care Programme Approach, in which a named individual – the key worker – has the task of providing patients with accessible services and maintaining contact with the patient as long as it is required (DoH, 1990). Of course, this emphasis on care co-ordination by one individual assumes that their relationship with the client or patient will necessarily be productive and therapeutic. We found no studies testing this assumption.

While it has been argued that the introduction of case management and providing patients with named key workers should increase longitudinal and hence perhaps relational continuity of care (Davies, 1981), we have not been able to find evidence to support this assertion. A retrospective examination of 100 patient records by Bindman and colleagues suggested that even in long-established community teams there is low longitudinal continuity of care (Bindman *et al.*, 2000). In this study, conducted in south London, patients had a change in key worker approximately every eight months. The same study demonstrated that patients whose key worker was a junior doctor had lower longitudinal continuity than those whose key worker was another member of the team (one key worker every 5.6 months compared to one key worker every 9.5 months). The reason for this difference was that junior doctors were on 'rotational' placements every six months, and it seems reasonable to conclude that where patients have key workers who are in training they will have lower longitudinal continuity.

We identified further papers that described the development of innovative services that have, among other aims, tried to increase longitudinal continuity of care. Unfortunately, when evaluating the effects of these services their impact on longitudinal continuity has often not been measured (for example, Rosenheck *et al.*, 1995). A retrospective examination of case notes of 20 patients with SMI who were taken on by key workers during the initial implementation of the Care Programme Approach demonstrated that the number of contacts with professionals rose by 55 per cent over the following two years (Feeney *et al.*, 1998) but total numbers of service contacts do not measure longitudinal continuity reliably. Other studies have contrasted the drop-out rate of patients receiving experimental and standard treatments using randomised controlled trials. Statistically significant reductions in drop-out rate have been reported in trials of case management (Tyrer *et al.*, 1995). Observational evidence suggesting that 'crisis teams' can achieve high levels of longitudinal continuity of care has also been tested experimentally (Mezzina and Vidoni, 1995).

Four systematic reviews have examined the effects of a range of interventions on whether or not patients with SMI maintain contact with services. These have examined the effects of case management (Marshall *et al.*, 2001), community mental health teams (CMHTs) (Tyrer *et al.*, 2001), assertive community treatment (ACT) (Marshall and Lockwood, 2001) and crisis intervention (Joy *et al.*, 2001) on drop-out rates, and compared these with drop-out rates for patients in receipt of standard care. The systematic review by Marshall and colleagues identified 10 randomised controlled trials comparing case management with standard care, of which six reported drop-out rates. These trials attempted to follow up patients for between 12 and 18 months and a meta-analysis demonstrated that those receiving case management had a small but statistically significant reduction in the drop-out rate (equivalent to an odds ratio of 0.7, 99 per cent CI = 0.5 to 0.98). A systematic review of CMHTs versus standard care (based around hospital outpatient departments) identified five controlled trials, all of which examined drop-outs as a measure of longitudinal continuity of care (Tyrer, 1998). A meta-analysis of data from these studies demonstrated that CMHT management was associated with a 12 per cent lower drop-out rate. Not all patients that were included in these studies had SMI but it is of note that the one which was restricted to patients with psychotic illnesses was also the one showing the greatest difference in drop-out rate (Burns *et al.*, 1993).

The systematic review of ACT versus standard care by Marshall and Lockwood (2001) identified 20 trials for inclusion in a meta-analysis. Of these, 18 included data on drop-out rates. These studies followed patients for between 6 and 24 months. Those who were treated with ACT had lower drop-out rates (equivalent to an odds ratio of 0.51, 99 per cent CI = 0.37 to 0.7).

The systematic review of crisis interventions identified five trials, all of which compared drop-out rates. Those treated using crisis intervention

were more likely to remain in contact with services at 12 months (odds ratio 0.65, 95 per cent CI = 0.44 to 0.96).

Numerous studies have explored the effects of psycho-education for patients with SMI. These interventions involve exploring factors that the patient believes are important in helping them stay well and providing them with information and support in order to encourage healthy living. While the effects of psycho-education have been explored in experimental studies, their effects on patient- or provider-defined continuity of care have not been explored (NHS Centre for Reviews and Dissemination, 2000).

Promoting cross-boundary or interprofessional continuity of care across service interfaces

Patients with SMI are often in contact with several different services, and the difficulties patients face in accessing these services have often been highlighted (DoH, 1999). The three services that patients are most likely to be in contact with are primary and secondary medical care and social services, and it is relationships between these three services that are most often discussed in the literature.

Interface between psychiatry and social services

By definition, patients with SMI have both mental health and social needs. Ensuring cross-professional continuity of care between medical and social services is considered to be a basic requirement of community care (Barnes, 1995). It has been argued that cross-professional continuity of care can be improved by combing social workers, nurses and social workers in multidisciplinary teams (Holloway *et al.*, 1991). Measuring the effectiveness of cross-professional continuity of care is not straightforward and as a result studies exploring the effects of multidisciplinary team working have tended to examine other aspects of continuity of care, such as longitudinal continuity of care (see previous section). Sytema and colleagues compared services received by patients with SMI in Groningen (Netherlands) and Verona (Italy) in order to explore differences in the way that services based on institutional care and community mental health teams worked (Sytema *et al.*, 1997). These authors suggest that the higher percentage of patients in Verona who use multiple services is evidence of joint working and a flexible approach to providing care. They attribute this to the greater level of cross-professional continuity of care in community mental health teams.

Interface between primary and secondary care

While methods to enhance communication and liaison at the interface between general practice and psychiatric care services have received considerable attention, findings from most studies do not relate directly to patients with severe mental illness. The majority of patients with mental health problems who seek help from GPs have anxiety and depression. Interventions aimed at integrating the work of GPs and

psychiatrists usually include only a small proportion of patients with SMI (Tyrer, 1984). Despite this, a GP with an average-size case list will provide care for about four patients with schizophrenia and as many as 30 per cent of patients will not be in contact with secondary care services (Harvey *et al.*, 1996).

Patients with SMI have higher levels of contact with GPs than other patients (Nazareth *et al.*, 1993). However, the majority of these consultations are limited to repeat prescriptions or the administration of depot medication (Bellack and Mueser, 1986). A survey of 369 GPs in south-west London suggested that most wanted psychiatrists to be responsible for providing management for SMI but 90 per cent were happy to take primary responsibility for the physical health care of patients (Kendrick *et al.*, 1994). These findings are supported by a survey of 58 GPs in south-east London who rated their level of involvement in the care of 81 patients with SMI as 'low' (Bindman *et al.*, 1997). The Royal College of General Practitioners has produced guidance on the role that GPs should play in caring for people with SMI (Ryall *et al.*, 1990), but evidence suggests that most GPs continue to feel uncertain about what this role should be (Bindman *et al.*, 1997).

Given the role that case managers have in co-ordinating the care of patients with SMI, it has been argued that care managers could help to enhance cross-professional continuity of care by accompanying patients to appointments with primary care physicians, and by making sure that relatives and other health care professionals are aware of the patient's physical health needs (Schwab *et al.*, 1998). While helping to liaise with primary care physicians was highlighted as part of the role of case managers in a new service in Dunedin (New Zealand), cross-professional continuity of care was not included as part of their subsequent evaluation of this service (Wood and Anderson, 1994). Levels of contact with GPs were monitored as part of an evaluation of the introduction of care management in Lund (Sweden). Use of primary care services by 176 patients with SMI was no greater in the 18 months after being taken on for case management than they had been in the 18 months prior to the introduction of this service (Bjorkman and Hansson, 2000). The survey by Bindman and colleagues in south-east London suggested that GPs were less likely to be sent a letter by outpatient psychiatrists when the patient had a key worker and GPs could correctly identify key workers for only 24 per cent of their patients (Bindman *et al.*, 1997). A study by Kendrick and colleagues in south-west London attempted to encourage GPs to become more active in the management of patients with SMI by providing training in the use of a brief structured interview schedule which they suggested should be used on a six-monthly basis. Effects of this intervention were examined in a randomised controlled trial. While GPs who underwent training were more likely to make changes to the depot medication of patients registered with them, and refer them to local community services, these GPs believed the schedule was too time-consuming and rarely used it at the frequency that was suggested (Kendrick *et al.*, 1995).

While CPA meetings provide the basis for co-ordinating the care of patients with SMI, GPs are rarely if ever able to attend (Schneider *et al.*, 1999; Bindman *et al.*, 1997).

Promoting transition across the interface

While people with SMI may have to negotiate many important transitions in the course of their contact with services, the literature that we identified focused almost entirely on the transition between hospital and community services. Much of this work concerned the discharge of patients who had spent many years in psychiatric hospital during the period when services in Western Europe and North America were based on institutional care (Tessler and Mason, 1979; Gooch and Leff, 1996). Following the establishment of community-based care for people with SMI, research has continued to explore factors that affect continuity of care for patients who experience shorter periods of inpatient treatment at times of crisis. Observational studies in Virginia (USA) demonstrated that patients living in rural areas were more likely to receive services following discharge from hospital than those living in urban areas (Farrell *et al.*, 1996). Subsequent work by the same team explored other factors associated with receipt of aftercare following discharge from hospital (Farrell *et al.*, 1999). Patients who had short admissions and those who were discharged to services outside the local area were less likely to be followed up. A cohort study of 1077 patients in 21 Italian centres suggested that when patients were lost to follow-up this was most likely to occur in the period immediately following their discharge from hospital (Barbato *et al.*, 1992).

Commentators discussing factors that enhance continuity of care following discharge from hospital emphasise the need to begin discharge planning in the early phase of the admission to hospital (Tuzman and Cohen, 1992; Forchuk *et al.*, 1998). Ensuring that inpatient staff, such as psychiatrists, also play an active role in teams that provide community services has also been recommended as a way of improving transitional continuity of care (Sainsbury Centre for Mental Health, 1998). Observational evidence from Stockholm (Sweden) suggests that the development of sectorised services helps to promote continuity of care of patients discharged from hospital to community services (Lindholm, 1983). Advocates of alternatives to hospital admission argue that they avoid some of the problems of transitional continuity of care by reducing divisions between outpatient and inpatient services (Spoelstra and Fitzgerald, 1996; Ledbetter and Batey, 1981). In their cross-sectional comparison of services provided to patients in contact with CMHT-based care in Verona and institution-based care in Groningen, Sytema and colleagues reported that patients in Verona were more likely to be seen by the community team within two weeks of their discharge from hospital (Sytema *et al.*, 1997).

The results of a 'participatory research project' aimed at improving patient compliance with discharge plans reported that patients and staff valued the introduction of a series of measures aimed at supporting

patients in the transition between hospital and community settings (Bostelman *et al.*, 1994). These measures included educating patients and carers about aftercare arrangements, telephone contact with patients within 48 hours of their discharge from hospital, and giving them information about a telephone help-line. While the results of the intervention were not quantified, the authors commented that carers had often been unwilling or unable to attend meetings. Hochberger and Fisher-James argued in favour of didactic group work to prepare patients for discharge from psychiatric services in New Jersey (1992). Nursing staff and social work support organised groups of patients to support each other and to reinforce the importance of taking medication and keeping a positive attitude as they approached discharge from the services.

Promoting informational continuity of care

Concerns have repeatedly been expressed about problems in sharing information about patients between primary and secondary services (Sheppard, 1996). In an attempt to facilitate the process of sharing information between primary and secondary care, the requirements that GPs have for written information have been explored. Recommendations about the content of letters sent to GPs based on a review of the literature (Strathdee, 1996) and a survey of GPs (Walker and Eagles, 1994) reached similar conclusions. GPs stated that they were keen to receive information that was in a concise format. They wanted to know what the patient's diagnosis was, what information the patient was given about their condition and to be provided with a summary of the tasks that GPs and secondary services would take responsibility for.

Patient-held shared care records have been advocated as a way of facilitating communication between patients and those involved in their care (Essex *et al.*, 1990). However, a systematic review of shared care records for people with SMI failed to find experimental evidence that supported their use (Henderson and Laugharne, 2001). A subsequent randomised controlled trial of shared care records has suggested that patients with psychotic illnesses are less likely to use shared care records than those with non-psychotic mental disorders (Warner *et al.*, 2000). Use of shared care records was reported to be low among both patients and health care professionals, and 39 per cent of patients reported having lost their records during the 12-month period of the study.

Effects of continuity of care for patients with SMI

Several reports that we examined suggested that failure to provide continuity of care contributes to early re-admission to hospital (Ramon, 1994) and untoward incidents such as homicide and suicide (Sheppard, 1996; Reith, 1998; DoH, 2001). Evidence to support these claims comes from case–control studies that have identified reductions in level and frequency of contact with service providers (Appleby *et al.*, 1999), change of consultant, unplanned discharge from hospital and a significant

care professional on leave (King *et al.*, 2001), as important risk factors for suicide among people in contact with psychiatric services. These observational studies cannot address whether decreased continuity of care affects the likelihood of suicide or simply the time at which it occurs. We are unaware of experimental evidence to suggest that interventions that improve quality of continuity of care can affect the number of untoward incidents. The rarity of such incidents would make studies logistically complicated and very expensive.

Most studies that evaluate the impact of changes in the organisational and delivery of care for people with SMI have not attempted to define or measure continuity of care. A notable exception to this is the cohort study by Bindman *et al.* (2000) in which baseline measures of continuity of care were used to examine effects on social and psychiatric outcomes 20 months later. This study reported no change in these outcomes but this finding may have resulted from confounding factors, such as deteriorating mental health leading to increased continuity of care but poorer health and social outcomes.

Such problems may be overcome by experimental studies in which the effects of confounding variables can be reduced through randomisation. We are unaware of research that has set out to manipulate the level of continuity of care that patients receive and measure its effects on health or other outcomes.

If we are prepared to accept evidence from interventions which are associated with decreased drop-out rates as being those which provide improved quality of continuity of care, then reports of reduced rates of hospital admission from systematic reviews of ACT and CMHTs would suggest that increased continuity of care may reduce the need for inpatient treatment. However, evidence from controlled trials of case management, which found decreased rates of drop-out but increased rates of hospital admission, suggests that the relationship between longitudinal continuity of care and use of inpatient services is not a simple one.

Discussion

It is widely recognised that a variety of patient and service factors make delivering continuity of care to patients with SMI a challenging task. While there has been considerable interest in the concept of continuity of care for some years, it is only recently that attempts have been made to clarify the meaning of this term and quantify the level of continuity of care that patients receive. This has made identifying and reviewing published literature on this topic a difficult task. Many papers that used the term 'continuity of care' do not define the term but alluded to the concept of continuous monitoring or contact with services. Other papers, which did not use the term continuity of care, provided important information about aspects of cross-boundary and cross-professional continuity of care. In an attempt to overcome this problem we used a wide variety of search terms related to the different dimensions of

continuity of care, but papers which did not use these terms or refer to continuity of care may not have been included in this review. Poor response from experts in the field whom we contacted, and time constraints which limited our ability to identify and examine important references in the papers that we obtained, mean that we are unable to claim that this review is fully comprehensive.

However, over 1700 abstracts were examined and when we cross-checked the papers that we identified with those identified by the scoping exercise (Freeman *et al.*, 2001), we were encouraged to find that none of those in the scoping exercise that discussed continuity of care for patients with SMI had been 'missed'.

In line with the earlier scoping study findings (Freeman *et al.*, 2001) one of the most striking findings of this review is the relative absence of literature that explores service users' perceptions of the care that they receive. A consensus has begun to emerge that whichever components are included, patient and carer perceptions must lie at the heart of future attempts to measure the quality of continuity of care that services provide (Adair *et al.*, 2001). It will not be possible to explore policies or practices that enhance continuity of care until ways to assess such perceptions have been developed.

While such definitions by academics have brought clearer theoretical understanding, they have not always mapped on to methods of measurement. Adair emphasises that development of valid and reliable definitions from the perspective of clients and service managers should remain a high priority for researchers (Adair C– personal communication).

Several reports highlight a lack of consensus about the role that different service providers in different settings should play in order to ensure that patient care is integrated. What role do GPs have in providing care for people with SMI? Is it the responsibility of inpatient or community workers to co-ordinate care at the time of a discharge from hospital? Additional consideration of these important issues may help to improve the co-ordination of patient care and may improve patient perceptions of the quality of continuity of care they receive.

Paradoxically, ensuring that systems for co-ordinating patient care are standardised may reduce the opportunity for professionals to provide flexible care in which they are able to 'step outside their prescribed role' – an element of continuity of care that patients may particularly value (Ware *et al.*, 1999). Engaging patients who are reluctant to have contact with services is a key component of efforts to provide continuity of patient care. The effects that changes in key worker have on this process need to be explored further.

It seems probable that patients are more likely to remain in contact with services when these are provided by CMHTs operating in close liaison with social services within defined catchment areas. Patients who move away from their previous address challenge this 'sectorised' way of providing services. There is clear evidence that the period following

discharge from hospital is a time when patients are particularly vulnerable. Only limited evidence has been found in this review to support the notion that systems for co-ordinating care improve the quality of continuity of care that patients receive. However, it is important that those involved in co-ordinating care are fully aware of the particular problems that arise when patients change address and move from inpatient to outpatient care. Helping patients anticipate and manage potential problems is likely to be valued by patients and improve the quality of care they receive.

Discussion of continuity of care for people with SMI has tended to focus on the continuity of contact. While maintaining regular contact with service providers is an element of continuity of care, it may not be the most important one in determining thecontinuity of care actually experienced. Further consideration needs to be given to patients' experiences in order to enable quality of care for people with SMI to be assessed and improved. Better understanding is needed of how patients and carers experience ongoing therapeutic relationships with key workers and other professionals over time. How important is this in relation to other issues such as resources and speed of access? How much can good information transfer, using modern technology, compensate for the need to encounter a number of different professionals? Is relational discontinuity an inevitable feature of care systems which are short of funding and resources?

It is noteworthy that this body of literature assumes that continuity of care is always and perhaps necessarily good. The scoping study had pointed out that for some patients, particularly perhaps patients with mental health problems, continuity may not be wanted (Freeman *et al.*, 2001, Section 9.3). Patients may desire a fresh start or a confidential second opinion, without reference to their known medical history. There is also an inherent conflict in the idea that successful therapy for severe mental illness can mean the ability to live independently and hence free of the surveillance inherent in a caring system designed to anticipate and prevent relapse.

The scoping study also pointed out that care may need to be flexible over time and that there is potential conflict between the desire of professionals to concentrate expertise in tertiary centres and the wishes of patients to have local accessible care (Freeman *et al.*, 2001, Sections 8.2.2 and 9.2). This issue was highlighted by our Delphi experts in Appendix 3.

Conclusions

Many reports that use the term 'continuity of care' in relation to patients with SMI do not define it. Those that do so emphasise the need to provide care over a long period of time and avoid gaps in service provision. Accessibility of services and co-ordination of care between different professionals and between professionals and informal carers, especially during periods of transition such as following discharge from

hospital, have also been highlighted. Relatively little is known about how patients and carers perceive continuity of care and how they might prioritise its various elements. This lack of knowledge is a major obstacle to the development and evaluation of services that aim to enhance experienced continuity of care.

High levels of mobility, dissatisfaction with care, and impaired insight all reduce the likelihood of patients maintaining contact with services. Pressures of work, shortages of staff and lack of operational policies impair cross-professional and cross-boundary continuity of care. Misplaced assumptions about the role of informal carers may also damage patients' continuity of care. Although several important changes to the way that services are provided for patients with SMI were introduced in the belief that they would improve the continuity of care that patients receive, the impact of the introduction of these changes on continuity of care has not been fully explored.

Comparisons of drop-out rates between experimental treatments and standard care derived from controlled trials provide a crude indication of continuity of contact with patients. Systematic reviews of case management, community mental health teams, and crisis intervention all demonstrate that patients who receive these forms of intervention have lower drop-out rates than those who receive standard care. Trials of assertive community treatment show the greatest impact on reduction in drop-out rates. There is a widespread belief that failure to provide continuity of care may increase the likelihood of untoward incidents and there is some observational evidence that it increases the likelihood of suicide. Experimental studies are needed in order to explore the effects of continuity of care on health and social outcomes. While there is some evidence to suggest that the intensity of contact with patients affects their subsequent use of inpatient services, experimental studies which have set out to examine the effects of changing the quality of continuity of care that patients experience have not been conducted.

Implications for current service provision

* It is important that those involved in co-ordinating care are fully aware of the particular problems that arise when patients change address and move from inpatient to outpatient care. Helping patients anticipate and manage potential problems is likely to be valued by patients and improve the quality of care they receive.

* Misplaced assumptions about the role of informal carers and primary care workers may reduce the quality of continuity of care that patients receive.

* Case management, community mental health teams and crisis intervention probably decrease the likelihood that patients lose contact with services. Assertive community treatment may be a particularly effective way to maintain the connection between patients and services.

- Reduction in drop-out rates, however desirable, should not be taken as synonymous with improvement in patients' perceptions of the quality of the continuity of care they receive. Little is known about this.

Areas where further research is required

- Operational measures of continuity of care relevant to the experiences of patients and carers need to be developed. These need to be tested with and assessed by clinicians and managers with service responsibility.

- Evaluation of the impact of future changes in service delivery and organisation for people with SMI should include assessment of patient and carer perceptions of the continuity of care they receive.

- The effect of interventions that are aimed at standardising procedures and practices need to be checked for their effects on providing care that is tailored to the needs of individual patients and is flexible.

- Interventions that can help to provide continuity of care at the point of discharge from hospital and improve co-ordinating care between primary and secondary services need to be developed and evaluated.

- Elements of continuity are components of a wider experience of care received over time, and severe mental illness tends to be chronic. They therefore need to be assessed in long-term studies using multiple methods to assess interactions between other elements of care such as technical expertise and accessibility.

Details of MeSH headings used

Table A1.1 EMBASE

Mental health	Continuity of care	Other
Psychosis	Organisational and management	Mental health service
Schizophrenia	Patient care	Teamwork
Manic depressive psychosis	Health care quality	Health care policy
	Conformational transition	Maladjustment
	Health care delivery	Health programme
	Phase transition	Medical decision making
	Health care planning	
	Long-term care	
	Health care	
	Primary medical care	
	Longitudinal study	

Table A1.2 MEDLINE

Mental health	Continuity of care	Other
Psychotic disorders	Continuity of patient care	Patient care team
Schizophrenia	Delivery of health care	Interprofessional relations
Bipolar disorder	Health care quality	Social adjustment
Borderline personality disorder	Health services needs and demand	Community health nursing
	Primary health care	Health services research
	Primary nursing care	Medical records system
	Health care planning	Hospitalisation
	Long-term care	Patient satisfaction
	Patient care planning	Case management
	Primary medical care	Community mental health programmes
	Managed care programmes	Inter-institutional relations
	'Referral and consultation'	Rural health services
	Longitudinal studies	Attitude of health personnel
	Health transition	Information systems
	'Discontinuity'	Patient advocacy
		Legislation and jurisprudence

Table A1.3 PsychINFO

Mental health	Continuity of care	Other
Manic depression	Continuity of care	Psychiatric hospital programmes
Schizophrenia	Health care delivery	Client attitudes
Schizoaffective disorder	Health care utlilisation	Community services
Psychosis	Health care services	
	Quality of care	
	Primary health care	
	Health care psychology	

Table A1.4 The King's Fund: HMIC and HELMIS

Mental health	Continuity of care	Other
Severe mental illness	Patient-centred care	Mental health service
Schizophrenia	Care management	User involvement
Psychotic illness	Care planning	Performance evaluation
Persistent mental illness	Continuity of care	Case management
	Continuity of patient care	Interprofessional relations
	Mental health services	
	Care programme approach	
	Continuing care	
	Quality assurance health care	

Literature coding sheet

A ID Reference number

B Type of paper

1	Editorial/commentarydiscussion paper ❑	2	Qualitative research ❑
3	Observation study (with numerical data) ❑	4	Systematic review ❑
5	Experiment (trial/randomised/RCT) ❑		❑

C Area or question addressed *(tick more than one if needed)*

1	Definition of continuity of care ❑	2	Users' or carers' views ❑
3	Factors that lead to or promote continuity of care ❑	4	Obstacles to providing continuity of care ❑
5	The effects (+ve or −ve) of continuity of care ❑		

D The element of continuity of care addressed in the paper
   (tick more than one if needed)

1	Relational continuity of care (seeing the *same* professional) ❑	2	Longitudinal continuity of care/gaps (patient remains in contact with services) ❑
3	Continuity between GP and hospital (secondary care) services ❑	4	Continuity between hospital (secondary) and social care ❑
5	Informational continuity of care (information sharing/joint records) ❑	6	Co-ordinating care with informal carers (i.e. family/relatives) ❑
7	Experienced continuity of care (perspective of patients/users) ❑	8	Transitional continuity (e.g. between inpatient and outpatient settings) ❑
9	Other (please state)		

E Global quality rating

1 Paper provides clear and detailed information that *should be highlighted*   ❑

2 Paper provides useful information that *should be included*   ❑

3 Paper has relevant information that *should be considered for inclusion*   ❑

4 Paper does not address study questions and *should be excluded*   ❑

General comments and details of any reference cited in the report that needs to be chased may be added to the reverse of this sheet.

Appendix 2

Four field studies
(undertaken and reported by Janet Low)

Introduction

The field visits were done in such a way as to get as close as possible to the real action of mental health work in four different contexts. The material is ethnographic in character, and is informed by discourse and narrative studies (see for example Latour, 1987; Latour and Woolgar, 1979; Woolgar and Pawluch 1985; Woolgar 1991).This method was chosen in response to the aim of the NCCSDO to maintain a focus which did not exclude the perspective of the person who suffers from mental health problems (for an account of the method of symmetry see Callon 1986).

The NCCSDO is seeking to understand the complex organisational issues of managing health care, and at the same time to maintain a central focus on the human subject who is in need of that care. Keeping the person at the centre of attention is by no means simple: as soon as people begin to engage with the various parts of the organisation, they find themselves partly transformed into pseudo-organisational actors. In the field of mental health, a person may find themselves transformed into a patient (in relations with their doctor), a client (in relations with social work services), and a user (when they are relating in some way to management). Sometimes doctors and social workers have to be more like managers, and the person in care becomes a user almost at the same time as being a client and a patient. In practice, these kinds of complexities are, ideally, managed seamlessly. Nevertheless, it is important to have an idea of the underlying structures that underpin the current complex practices. This report tries to consider the people who become patients, clients and users while addressing the people who are professional clinicians and managers. So, in reading this report, I need to rely on you to hold on first and foremost to the idea of people taking up different positions in relation to each other. In this way, I aim to show how it might be possible to hold the organisational pressures at bay for long enough to allow for a 'patient'-centred account to be made.

Research in the field – selecting cases and choosing methods

We selected three of the Beacon Sites listed by the Department of Health in early 2001. The selection was made after reading through the brief descriptions, choosing sites according to whether they mentioned the three main 'boundaries' encountered by people with severe mental illness (primary/secondary, health/social care, individual/institution). The fourth site was selected from the National Service Framework Document for Mental Health Care (Department of Health (DoH), 1999) because it featured these three care boundaries. No attempt is made to generalise from these case studies, nor to make comparisons between them other than to illustrate conceptual points.

Research methods used include interviews, observation, and 'following the actors' (Latour, 1987). The data is wholly qualitative, falling into the categories of discursive (what people said to me, or suggested I read), descriptive (what I observed), and ethnographic (description of aspects of the social structure, or culture, of each site). These sites were selected to examine elements of continuity of care in action rather than the sites themselves, hence they are not named.

Field Study A
Service user representation in a home treatment service

Introduction

This home treatment service (HTS) was established in 1996 in a city to provide intensive support in the community for adults suffering acute mental health crises. The impetus to develop the service came through three channels:

1   *institutional crisis:* excess of demand over supply on the local inpatient units

2   *user demand:* the well-organised and highly active presence of articulate user organisations in the city that wanted better community-based crisis support

3   *limits to professional practice:* innovative and committed medical staff wanted to address some of the structural problems of mental health care service delivery.

The Community Health Trust, in conjunction with Social Services, decided to take the opportunity to try something new. They appointed an experienced senior psychiatric nurse, and a consultant psychiatrist, who also happens to be a qualified anthropologist and philosopher, to get together and develop a version of Home Treatment for the locality.

These team leaders claim that their greatest innovation has been in terms of the philosophy of care at the heart of the team's operation. The policy of the team is to focus on establishing trust between professionals and service users. One element in achieving this was the introduction of an entirely new position in the mental health team, the service user development worker. The person who filled it was an ex-user of services, someone who might elsewhere have found himself categorised as 'a long-term sufferer of severe mental illness'. This person, Mr S, was still in post when I visited the site – five years on.

A second element was an overall policy that the HTS called 'non-medical models of the mind'. This was intended to change the way staff spoke with each other, and with the people they were engaged to care for. The emphasis, then, was away from medical discourse of diagnosis, and towards the words of the person in need of some kind of help – how they spoke about their experience would be the raw material that staff would work with.

These two elements of the HTS's policy reveal mechanisms and contexts that, as we will see, became crucial for future operational success and created the conditions for continuity of care on a number of levels. In particular, they created conditions for new relationships across two of the major boundaries: health/social care and individual/institution.

The service user development worker: his role in relational continuity

Mr S comments that the hierarchy in the team is operationalised in a fairly democratic way. However, he is aware that there is still an underlying tendency for everyone to defer towards clinical expertise. In fact, he says, this is something that is becoming stronger at the moment. He comments on the arrival of two medically qualified members in the team, one a general practitioner, the other a senior house officer in psychiatry. These two participate very actively in the team meetings, usually from the position of medical experts. With the original consultant now working part-time, there is a shift in emphasis back towards the 'medical model of the mind'.

Normally Mr S does not see himself as a support worker, and so does not actively work with the clients of the team. Nor does he see himself as an advocate. He argues that, at policy level, advocates should be independent of the organisational structure in order to be effective. However, at tactical level, he described an exception where he made good use of the role. It was the case of a young woman whose state of mind often led her to inflict harm on her body. This case illustrates the challenge of the boundary between the organised teams of people employed to care, and the individual person who becomes the object of that care.

This young woman experienced increasing levels of distress during the process of care. This placed a high strain on the relationship between the nurse in question and the woman in care, and an impasse was reached. There was a failure in communication between these two women, one of whom is part of an organised team, while the other is there because she is experiencing intolerable mental distress to the point where she inflicts harm on herself. The impasse between the nurse and the patient/client soon became a part of the pathology, and contributed towards the pressure to self-harm. Mr S became involved at this point.

His contribution was to borrow the model of advocacy, and place himself in the structure more as an 'outsider'. His aim was to represent the woman's position in team meetings. He traded on his position as 'insider', drawing on the relationships of trust that had been laid down over time, in order to build a relationship through which communication could recommence. He found this a tough challenge. He says that he probably owes much to the support of one of the team leaders.

The key event in this single case history happened at the team's equivalent of a case conference. A meeting had been set up between the young woman, the social worker and the consultant psychiatrist. Mr S stressed that both the social worker and the psychiatrist are thoroughly committed to the principle of user involvement, both are very good at listening to the patient or client and to taking their words seriously. Both have a commitment to minimum use of medication, and have a very sensitive and minimal approach to using any of the sections of the Mental Health Act. Even so, the fact of their institutional

positions, and the combined power that this organisational relationship gives to them, made the meeting impossibly threatening to the woman. She was overwhelmed by the situation. The solution that Mr S and the team arrived at was for him to meet the woman first, and then go to the meeting and speak on her behalf. Again, this strategy met with success in so far as the impasse was resolved, communication regained, and the possibility for care delivery reinstated.

This case brings out two aspects of continuity of care in the field of mental health.

1   It illustrates how quickly the system of care can enter into the pathology and worsen the very problem it was trying to help. The potential loss of the patient's trust may directly lead to self-harm, their disengagement from the process of care, or an escalation in the level of force required to keep them in the system.

2   Each professional group of people, such as nurses, doctors, social workers, advocates, has its own theories which attempt to explain these kinds of phenomena (by which I mean the woman in distress), and each theory carries with it implications for action. In this case, the theory of the advocate was proven to be effective, in that it decreased the suffering in the woman at risk.

Thus, effective teamwork with a specific user perspective directly enabled the patient to trust the care team: the patient's experienced continuity of care was enhanced. This was a form of relational continuity – timely intervention by a team member enhanced the patient's therapeutic relationship with the team as a whole. This allows us to question the notion that relational continuity necessarily means care meditated through one key worker (see 'Factors that promote continuity of care' in Appendix 1).

Field Study B
Experienced contextual continuity in a women's crisis centre

The idea of contextual continuity, that is continuity of social context, arose from initial responses to our Delphi exercise (see Appendix 3). It is additional to the elements listed in Appendix 1 under 'Definition of continuity of care' and is illustrated in this case study.

Outline of the service

This centre is a service for women in mental health crisis and provides an alternative to admission to psychiatric hospital in London. It is set in a house that can accommodate up to 12 women and four children in safe, appropriate and dignified accommodation. The centre was designed, developed, and based on the views and experiences of women service users and the professionals who work with them. The staff provide 24-hour support and assessment, a short-term residential stay (up to four weeks), and a range of service options and treatments.

While at the centre women residents have access to a local GP who visits the project (this is a special arrangement and is an innovation for the project). Great emphasis is given to empowering the women who use the centre (emphasising the user's voice), and to sustaining their way of life and their ways of living as much as possible during the stay (this provides the basis for good contextual continuity as well as experienced continuity). This means that centre's staff are prepared, willing and able to work alongside whichever community workers are involved in the care. This could include CPNs and mental health social workers and psychiatrists, but also voluntary bodies, family members and other privately arranged carers.

Relationships with other parts of the health and social care network are also supported off site. If a woman has an ongoing relationship with psychiatric services, this is supported and attention is paid to maintaining the longitudinal continuity and therapeutic consistency in this dimension. That relationship is maintained off site, and the level of support can be varied along a flexible continuum. All the residents are managed within the Care Programme Approach. The project has made continuity of care a high priority in a number of interesting and innovative ways (again, see 'Definition of continuity of care' in Appendix 1).

The impetus to establish the crisis house came about eight years ago. It was user-led and gained the support of the local authority. There was already an excellent voluntary sector crisis house locally, so people in the area could see what they wanted to create. The preparation for the project was thorough and included public meetings to give feedback and to incorporate people's wishes at the design stage. Like the previous case, this project began well, with support from key levels in the local economy of mental health care – including that of users. There was an

extensive period of consultation and planning: at the right time and place, with the right people acting from the most useful positions. So, it should be no surprise that the project took off successfully and has been up and running with many of the same staff for over six years now, giving a stable therapeutic community.

Staff, referral, assessment of clients

None of the staff is employed on the basis of their profession, although many of them do have psychology, nursing and social work qualifications and experience in their backgrounds. The manager, for example, has been a ward manager in the past, and has plenty of experience of mental health nursing in NHS contexts. This pattern of employment promotes the possibility for integrating the user's voice into the process of care, and for reorganising the social/health care boundary as well as the primary/secondary boundary.

Many house residents are self-referred. This emphasises the user as an 'expert' deciding on their need for care, and signals that her experience of the care given here is paramount. Other referrals come from professionals both from within the health and social care network, and from projects outside this NHS/Social Services structural boundary.

When a referral comes in, it triggers an established process. The process is supported by paperwork which provides a structure for the content of an assessment. The form maps out the stages of a routine, and the key topics of interest, it also designates a Time (capital T) in which to reflect and understand. It also provides a Space (capital S) to include other people's ideas and thoughts. (The form is reproduced at the end of this section.)

The assessment stage aims to gather together several people's views on the case and represents a commitment to providing contextual continuity to the woman and to paying attention to the relationship*s* that might exist in her own personal care network. For example: what is it that makes this a crisis? Can the person manage at home? Has everything else been thought of – children, work, personal relationships and personal priorities? What are the risks involved? Might there be violence, or other forensic issues? It is important, here, to pay attention to the contextual continuity of the woman, but also to establish the institutional continuity too. It is the way that these two different things are brought together that makes this project so interesting.

There is a potential contradiction between maintaining a person's contextual continuity and providing a secure institutional framework. The previous case study – the home treatment service – illustrates one approach to this when they make their institutional structure stretch out to the various people and deliver treatment directly into their homes. Something different is happening here: this Crisis House also scores highly on maintaining contextual continuity, but it does this within a clear physical space. One staff member even described it as a 'cocoon,

protected from the outside world'. So, how does this project support contextual continuity?

The House workers encourage the women who reside with them to keep believing in themselves as women. That is, they emphasise their position as mothers, wives, professionals – whatever they are in their regular lives. Thus they reduce the opportunities for people to think of themselves chiefly as patients, or as objects of care. An ongoing commitment is made to maintain the social contextual continuity in the mind of the woman. There are two distinct steps to this process:

1   listening to what she says and the way she says it

2   acting on the leads she gives by forging links to them that can be used to sustain the connections with her life.

There are three distinct areas of skill at work here: listening, responding, and judging when and how to move between those two things. This judgement is part of the expertise built up in the project and transferred between the women who work there: it is a product of continuity within a therapeutic team.

Although no-one at the House made this statement about themselves, it seems to me that Hegel (1977) would find this project interesting. His conceptualisation of the master/slave dialectic is shown at work here. People who find themselves in positions of mastery in relation to knowledge – for example in medical settings (especially in high-status positions such as consultants) – also find that others seem to spontaneously relate to them from a subservient position. This can manifest in hostility as well as submission. Problems may follow – especially in mental health care where the relationship can become part of the pathology itself. What seems to be evident from the work at the House is that they have configured their network in such a way as to reduce the possibilities of a 'pooling' of mastery – it is kept moving through the network, and effort is made to disperse it as quickly as it gathers. When it works, it decreases the tension and reduces the severity of the symptoms. This is why the organisational form of treatment is of such central concern to the clinical disciplines in mental health care.

The assessment form (included at the end of this section) shows how the team establishes the elements of the woman's social network into the process of care (contextual continuity) and it provides the foundations of care to be grounded in her own account, her own experience of the process (experienced continuity*)*. The form is an instrument of informational continuity. It represents a process of transformation that sets out from one kind of data (the personal account) and moves into specific areas of professional concern.

We can see that the professional care dimensions have not been surrendered in the process; this is represented through the questions about risk. The first priority, however, is given to the ways in which the woman herself understands these risks and what she knows about the

ways in which the crisis manifests itself. This section elicits information that will be useful in preparing the workers to anticipate particular problems and to alert them to special ways that might be appropriate when working with the woman.

In the Fourth Report of the Select Committee on Health (House of Commons Select Committee on Health, 2000), there is a special section on the problems of defining mental disorder (especially paragraphs 24–28). One implication of this is the need for professionals to remain open to the possibility of pathways that still function in the person's life. These 'pathways' may provide vital routes out of the crisis and need to be supported and built upon. The assessment form in use at the House illustrates several moments in the process where staff look for signs of these trails. It is especially clear in questions 10 11, and 14. This practice represents an element in the process of providing flexibility in the care process; this in turn creates the conditions for good-quality care to take place, which in turn increases the chances of good continuity through a number of channels.

It is important that the assessment form be understood as a paper trace of a set of actions at a particular place in a longer process. The form, together with the mode of operation, produces the possibility of an '*intéressement*' – a mode of relation which emphasises the willingness of the individual woman to join in the process offered by the particular network (Callon, 1986).

This therapeutic tool appears to be an effective way of involving the woman in her own progress so that she makes effective links with the staff. She is thus encouraged to mediate her own experience of continuity of care.

By holding off the manifestations of the institution, the members of staff are able to show the woman that it is worth her while to use the service. It is part of the process that offers a 'configured' place for her to join into a productive relationship with the network.

> *The form is about the information that we need, but is not supposed to be the questions that we ask. We want to know what their story is in their words, or the words of their friends. We might say, for example, 'what is it that your friend would say' if that helps to bring more information to light.*

(House worker)

Risk assessment is a critical question where institutions and individuals might find themselves in conflict. Staff try to address this question quite openly at the assessment. They might ask the woman how she usually expresses her anxiety, whether she has ever hit someone, or does she shout, for example. These questions mark the beginning of a process of negotiation that results in a signed agreement between resident and staff. The institution has formulated several kinds of actions that would be acceptable to the project, and has established these as part of the organisational routine.

The agreement enshrines six of these:

> *One of the specific tools that we have at the House is the Agreement Plan. It is central to our internal continuity of care. It is the script. It includes our assessment and the woman's voice too.*

(*op. cit.*)

Agreement Plan: Resident and Staff

1 You can expect to have a member of staff allocated to you 24 hours a day who will offer all the assistance they can.

2 You can expect to be treated respectfully by staff and in a response to your individual needs.

3 You can request individual time with specific staff members and have access to groups held within the project.

4 Your named worker and other staff will assist you in making plans for your life after leaving the House. Below is a space for you and our workers to make agreement plans specific to you.

5 We ask you not to drink alcohol or use unprescribed drugs while you are staying at the project. If you return to the project smelling of alcohol or under the influence of either drugs or alcohol, your place here will be reviewed.

6 The project has a philosophy of equality towards all people. We do not find any discriminatory behaviour, abuse, or violence acceptable. Your place will be reviewed if either of the above occur.

Cross-boundary continuity

The Crisis House is part of a more extensive network of mental health care managed by the local health authority. The essence of the House is its ability to maintain the subjectivity of the women who seek refuge there. It can be seen as something which 'staves off' for as long as possible the dreadful objectifying tendency that occurs at moments of maximum severity of mental health crisis. In other words, when it becomes difficult to the point of impossibility to relate to the woman as a human subject, she becomes an object in the relationship. For example:

> *We can move people on if we want to. For example, one woman smelled so badly and would not engage in any of our attempts to change her, we eventually had to get her out of here, onto somewhere else.*

(Senior house worker)

This woman had clearly changed from subject to object. It had become possible to 'move her on', which is not the same as to 'invite her to go'. It is not difficult to imagine (especially if you have ever worked in an acute ward), that the arrival of this particular smelly object would have been met by a team of nurses (together with a bath full of soapy water), prepared to engage bodily with their new object of care to begin the process which would (one hopes) turn it back into a recognisable human subject. It is important to remember that each element in the network of care must have a strategy to cope with excessively difficult moments in the care of extreme mental health problems. Even the acute ward can move people on, often to intensive care or specialist units. These

elements of continuity between different sections in the overall network of care are critical. Where there is a short circuit, it is the responsibility of staff – and especially of senior staff – to initiate processes that might generate solutions.

The House cannot afford to 'move on' too many difficult cases, or it will weaken its position in the overall scheme of care, both in terms of relations with potential clients, and with professionals in other parts of the network.

The boundaries may be tested at different levels (for example, between professional organisations and between individual and institution). I was aware of a particular 'trial of strength' going on between a CPN (community psychiatric nurse) in a local CMHT (community mental health team) and the House. Here is the way it was represented to me during a group meeting with the work team.

> I think there is a misconception about what we offer. People outside either have too high expectations, or too low. For example, there is a CPN, someone we have worked with for quite a long time, and who really should know about what we do. She is currently expecting us to administer someone's depot injection. She said that in her experience, it has happened before here, she said 'you do employ nurses', and I said, 'yes, but we're not employed as nurses'. So I went on, 'I've been here long enough to know that that hasn't happened here'. I don't think she liked that, but I was surprised she didn't know, she's visited us many times.

The House functions in some ways as an acute ward in the local care network, but with significant differences that raise questions about the definition of severe mental illness. The House cannot invoke sections of the Mental Health Act, and cannot hold people against their will. It follows, therefore, that the staff cannot physically restrain any of the residents in order to medicate them. There is no psychiatrist on the payroll at the House. The women who are qualified as nurses are not employed as nurses: the position of 'nurse' does not exist in the structure of the House. These are two elements of policy that can be 'finessed' by local tactics – the House manager and her team can employ people who have nursing qualifications and experience into the 'worker' positions in the employment structure. They can engage psychiatrists as advisers, either formally or informally. They can welcome investigations by psychiatric research teams, and so on.

All these are elements and possibilities for building continuity between the various parts of the overall mental health care teams – cross-team continuity, informational continuity – which can be useful for improving the experience of continuity of care for particular patients/clients/women.

A further issue of informational continuity

The House has negotiated with a local general practice to provide regular (twice-weekly) attendance and emergency call out for physical problems in the House. The residents can thus potentially receive care from at least three sources, their personal GP, the House GP, their personal

psychiatrist, and sometimes also other specialist care. There is no mechanism to co-ordinate these three prescribers. The absence of a formal nursing role in the project removes one traditional method of continuity (the nurse would supervise the medication). During the interview with the House GP, we discussed the potential for the NHS Net to overcome this problem. In the meantime the problem remains one to be juggled *ad hoc*.

Finally, this quote, from the manager of the House, demonstrates that although the House has only a short history, the challenges it faces in crossing institutional boundaries are familiar.

If people working in the other teams could admit their anxiety, admit their limits, it would be a much easier job to do [taking referrals from other professionals]. If someone is phoning up to get you to take in a new admission, they don't say 'I'm off on holiday, but I'm really worried that she won't cope on her own'; instead they tell you about the extremes of the woman's problem! If they spoke about their own limits, at least then you can make some sensible decisions, based on the true picture. If they make it into a symptom of the patient, you spend ages trying to find out what is really going on, and the person in the middle suffers doubly.

**JK Mental Health NHS Trust
Assessment form for residency at LM Crisis House**

Date and time:

Name:

Staff name and title:

Presenting needs:

1 from the woman's point of view

2 from relative, friend or worker point of view.

Past history and mood:

3 Experiences in the past that she feels, or that others feel, have contributed to her present circumstances or feelings.

4 How does she communicate her distress? Does she have people in her life whom she trusts?

5 Ask about any cultural or spiritual beliefs she would like to talk about.

Level of risk

6 Has she ever resorted to extreme methods to express her emotions/feelings? Explore suicidal ideas and self-harm.

7a Ask if she had any thoughts or feelings about harming others and has she ever acted on those.

7b Has she got any problems with the use of alcohol or drugs, now or in the past?

Perception of events

8 Does she suffer with any worrying thoughts or disturbing thoughts, e.g. that someone will harm her, or are there other preoccupations?

9 Any experiences which are interfering with her ability to concentrate/function in her usual capacity, e.g. hearing voices, anxiety, lack of sleep?

Resources

10 Areas where the woman feels she is coping and managing, e.g. taking the children to the childminder, or studying.

11 Social circumstances/housing, finances, work and study – again ask what is working and what is not. What is already helping with these areas? (Gather information about important others, both personal and professional.)

Physical

12 Any physical factors which are causing concern? Changes in sleep pattern, eating pattern?

13 Any known physical problems (go to medical assessment form if these may need further exploration and intervention affecting stay at the project): ask about allergies. GP would be contacted routinely. Medication taken for any condition. Name and use.

Children

14 Women with parental responsibility: any information women want to offer regarding their children?

  (a) Does she feel able to maintain supervision for her children?

  (b) What does she feel she needs in terms of support to enable her to do this?

  (c) Who, if anybody, does she share parenting responsibilities with and what is their view?

  (d) Does the referrer support the parent's view? If not, give reasons.

  (e) Is she aware of the project's guidelines and responsibilities regarding children?

Contact social services (date and time)

Is there an allocated worker?

Is the child/children known?

In what capacity?

Contact made

At this point take a break for all parties to have time to consider action to be taken. Project staff may wish to consult others at this point.

[The last page of the document is a formalised and detailed set of decisions which configure the route to the next stage of care. It is a page for the worker to use to address the formal organisational consequences of the assessment, including sign-offs.]

Field Study C
Integrating services in a rapidly changing environment

Introduction

This field report differs from the other three in that the service that is its object of study is not so clearly associated with a place of practice. For practical reasons, I have chosen to focus the report on a single team meeting of one community mental health team (CMHT). The research visits included a number of interviews with different people, including a service user representative. For the purpose of this report, however, I have chosen to present only a fraction of these data in order to make what I consider to be the most important point.

The team in question meets regularly in a room in a building in the grounds of a London hospital. CMHTs are an established feature in mental health care across the country; there is a structure and a protocol, a manager, and a system of record keeping. However, the clinical work of the team – face to face with patients, clients or users – is very highly dispersed. This team differs from others in that it is a kind of 'meta-team', consisting of members who represent other teams of workers.

We chose to include it as one of our four case studies on the strength of the recommendation it received in the NHS National Service Framework document for Mental Health (DoH, 1999). The NSF document had commended the service for its work under Standards 4 and 5, that is for effective services for people who are suffering severely with mental illness. It was especially interesting to us because the service was being praised for successfully integrating health care and social care.

In the other three case studies, it was easy to discover each level of policy-maker. There were clear positions of responsibility, and clear pathways to other levels, clear links to other kinds of service. Even though the projects were 'nested' in complex networks, it was possible to find the boundaries and to know their relative places in the hierarchy. This case presented difficulties on this point.

My method of 'following the actants' (actors – see Latour, 1987) also led me away from the site (institutional and geographical). On two separate occasions I found myself at local police stations, and interviewing police officers about their part in the work of controlling people who were clearly suffering greatly from mental health problems. There would have been a third time, but on that occasion I was interrupted on my way: I was required to stop at a 'frontier' (boundary). This boundary was manifested by the operations manager for Mental Health Services at the hospital – I had found an instance of the institutional limit, the organisational frontier, of the mental health system of care.

The CMHT manager had told me of the success they had achieved in integrating their service across the health and social care boundaries. The team works with common supervisory and disciplinary procedures, and is developing common contracts and complaints procedures. The health care staff are trained in care management assessment, and have access to social care budgets. From the team manager's point of view, he is confident that he is delivering a seamless service across health and social care at the point of delivery. But, he added, there are major institutional barriers that split managerial hierarchies between health and social care. These barriers have serious implications for the ability of the CMHT to make its own policy and delegate its team members with responsibility for tactical manoeuvring. From this point of view the CMHT is severely disabled, institutionally speaking. This, in part, begins to explain the close presence of the police force.

The policy and procedures within which this CMHT operates were 'jointly agreed' between a mental health NHS trust, which covers four local areas represented by three different local authorities, and the Social Services of one of those authorities. That is a complicated arrangement with physical geography bearing no simple relation to organisational forms. This arrangement itself is relatively new, had been preceded by other combinations, and was looking forward to an, as yet unspecified, change in the near future.

At the level of health and social care, the organising principles are becoming clearer, and perhaps we can look forward to a period of settlement. At the time of my research visit, this pot was still furiously boiling away: staff were 'looking forward' to a revolutionary change via the national policy to pushing the emphasis away from health authority level to that of the primary care trust. To recap: the CMHT works in a context which is being defined by national government health policy, local government social care policy, special local government policies for London, and the local police service. The CMHT is exposed to policy making which is of a different order to its work.

The work of the team, expressed in a formal statement of aims, is to:

1   be the major point of access for the specialist assessment of people with mental health problems living in the area

2   co-ordinate and deliver care to people with severe and long-term mental health problems

3   promote collaborative relationships with partner agencies providing mental health services in the local community.

In this context of organisational complexity and change, it is difficult to assess the team's own contribution to elements of continuity of care. A higher organisational level of continuity at the policy and strategic levels seems necessary first. My interviews were full of information about the dissolution of service units and teams, and the regular re-emergence of different forms and different regimens of naming. High levels of staff turnover had become a mundane fact of life. Not only was it difficult to keep up with the names of senior posts, but it was also difficult to

remember the names of the incumbents. Alongside this, the (upward) dynamics of the local property market had led to a series of disruptive relocations.

Continuity in action

How has this team managed to be singled out for praise when it operates in the eye of such a storm? How does the local population cope with such a high degree of uncertainty and change? Three examples illustrate the work of the team on one day in the summer of 2001.

The meeting is organised to allow an open discussion: a flow of information. The team manager does not manage the meeting itself: his job is to manage the context which makes the meeting possible. The meeting is run by a Chair, a position not a person. The people who make up the team take it in turns to occupy the chair and to be responsible for maintaining the meeting as a forum for discussion and decision making. The team is based on a number of specialist areas, and these are represented by team members. The team can invite representatives from other specialist functions to join in at different stages of the meeting as and when necessary.

The meeting can be thought of as a mechanism that operates in two phases. The first phase is the establishment of a forum into which the participants come as representatives of their *functional* role in the institution. The second phase is the improvisation on the occasion, where a level of specialist knowledge (a theoretical level, if you like) is brought to bear on the questions posed by the reports on various people who are either already in care, or are presented for possible care. The meeting itself is a melting-pot of possible outcomes as all the 'stakeholders' contribute their knowledge and propose tactical manoeuvres on behalf of the absent patient or client. I felt it was possible to see this meeting in principle as one whose business is to set clinical policy and strategy, but in practice it carries this out at the level of tactics because the environment is so uncertain.

My request to sit in on the meeting was welcomed, and permission was granted by the team members – I was grateful for this level of professional generosity and openness.

Here is a list of those present on this particular day. I have arranged it as a list: it does not represent the pattern of seating, but reflects the hierarchy that I inferred from the dynamics at play.

Present at the meeting:

> Dr A: consultant psychiatrist
>
> Dr K: clinical assistant
>
> Dr X: locum senior house officer
>
> K1: clinical practices manager (acute wards at local hospital) (manager of the community mental health team)

SA: acting senior social worker (soon to be leaving for a job elsewhere)

SB: social worker

SC: social worker

N1, community psychiatric nurse (CPN): Assertive Outreach
(N1 took the Chair. The allocated Chair for today's meeting was off sick, and N1 took up the burden with a sigh.)

N2, CPN

OT: occupational therapist, who is here because she runs the day hospital.

student nurse, here because she is shadowing the CPN.

locum social worker

[short visit from Rapid Response Team, Home Treatment.]

Absentees on this day included a family therapist (part-time, attends every second meeting) and a clinical psychologist.

The agenda includes:

- Allocation of new referrals

- Feedback issues from Crisis

- Rapid response

- Day-patient lists and inpatient lists

- Arranging CPA meetings

- Social work/ASW issues

- Allocation of future Chairs.

A number of cases are discussed, three of which particularly illustrate continuity issues.

Case A

A young woman who was 20 weeks pregnant raised questions about which specialist team should be responsible for her care. It seemed more important to consider that she was pregnant than that she was suffering mental health problems. Continuity across disciplinary boundaries has to clearly designate a first team to which a second expertise can then be added. Second to this is the question of which geographic team she should be assigned to; this woman was circulating among her personal social network, which covered much of southern England.

Case B

A different issue is raised by a 39-year-old man, known already to the day hospital and to the outpatient department where he has been attending for depot injections. News has arrived via a number of sources (housing office, police, neighbours) that he is breaking into his neighbours' flats, and causing some disturbance with his behaviour. There is also talk about fax messages to the Prime Minister. This case illustrates

the nature of information and the informal mechanisms through which it arrives.

Case C

A young man currently planning to move from the 'non-statutory' therapeutic community where he lives to less intensive accommodation. His social worker wants to accompany him on a visit to see alternative accommodation. This would encourage relational and longitudinal continuity. However, owing to staff shortages the social work team leader has to intervene at this point to 'forbid' the locum social worker from pursuing this line. He insists that the non-statutory organisations do this work themselves. This 'insistence' may well introduce 'barriers' which may hinder continuity across this boundary in future; in this case it stopped it dead.

Experienced continuity

Experienced continuity in all three cases is in question. The process of referrals (continuity between teams, the handing over of patient plus notes and information) raises many questions: the first two cases in particular seem to be very much out there on their own. The use of the police as part of the team who will 'admit' Case B suggests that they too should be represented on the CMHT.

The man in Case C had, from the health services point of view, already become an 'ex-user'. As he prepares to move away from the Fellowship House into 'less intensive' accommodation, he drops even further away from the process of care when the social work team disengages from him. It is possible to imagine that he will be all right, but this will test trust across the CMHT boundary with non-statutory groups.

Continuity of information

The nature of the raw information is perhaps a striking feature of these cases. It comes in through a number of channels, each with its own way of structuring both the form and content, but also with its own ways of communicating. This requires the team to reorient themselves each time to the different kind of information, and to weigh it carefully with different scales. This often leads the team to revalue the 'information' to its basic level of a 'sign' that prompts an investigation from within the team itself, who can then produce information which is more appropriate to its own ways of communication and understanding. The informal nature of cross-boundary information is highly problematic in being open to alternative interpretations.

Cross-boundary continuity

Three boundaries are involved.

- Case A: information must pass over geographic 'frontiers', and across the physical/mental health care boundary.

- Case B: direct information from the police (a very specific moment in a longer chain of communication, involving complaints received by the police from other members of the public), information from a social worker via a link with a housing officer. This information has already been associated with the team's own memory (in the form of notes and experience) of this particular man and his previous relationship with outpatient departments.

- Case C: the boundary with non-statutory mental health projects, which in this case is being carried out by the locum social worker. These are institutionally weak links in the chain, easily broken off when subjected to any tension.

Inter and intra-team continuity

Our definition includes team continuity: I have split this into two elements in order to be clearer about the issues involved. The CMHT is a kind of meta-team that contains representatives of a number of other teams. In this way, intra-team continuity (the ongoing sustenance of the CMHT) becomes a mechanism of inter-team continuity.

Flexible continuity

Flexibility according to the users' needs means giving up team involvement: Case C shows how this dimension of continuity overlaps with cross-boundary continuity. (See discussion of contextual continuity.)

Longitudinal continuity

The categories, specialisms, and distribution of care in the service manifest themselves in institutional boundaries: crisis teams, rapid response teams, social care teams, primary care teams, etc. Longitudinal continuity is, largely, already foreclosed by this current policy of care.

Comment

In the process of investigating this field study I was presented with a vast array of data. In deciding how to write the report of it, I have chosen to exclude almost all of it in order to concentrate only on the most important element. In my opinion, our concepts seem inadequate to deal with the levels of complexity that these people are working with, and it would be inappropriate to try to judge the team on these terms.

The people who are bearing even more of the pressure, however, are, of course, the local population, none more so than those deemed least able to – people who are already suffering high levels of mental 'dis-ease'.

This site makes a considerable contrast with the first two. It operates on a large scale in a particularly complex urban environment. The effects of repeated organisational change are palpable and the scale of staff turnover is discouraging to those working 'in the field'. The concept of

abolishing the boundary between health and social care is admirable, but this brief observation shows how the execution may not necessarily realise the intentions of policy-makers. Whether this is due more to inadequate resources or to flawed implementation cannot be determined at such a brief visit, but the question is posed.

Field Study D
Mental health liaison: a primary care-based option

Introduction

This Beacon site was selected because it was trying to bridge the gap between primary and secondary mental health care. It aimed to strengthen the liaison between all the sections of local primary, secondary and community health care teams behind a common goal. The initial step in the strategy was to establish this as an idea through a training initiative. The second step was structural, looking to develop working links through jobs and organisational mechanisms. The site visit was at this level, and took place in a thriving general practice in a Midland town. The site visit focused on the work of the mental health team.

Beacon status was awarded for the initial work that addressed county-wide provision, to:

- focus on the care of severely mentally ill people within primary care

- identify practice needs for education, training and supervision

- develop a core curriculum for training

- foster a team approach to communication within and between services

- provide additional practical resources to primary and secondary care teams

- share experiences of good practice and identify areas of need

- provide practice-based education and to build teamworking

- encourage multiprofessional multi-agency working (including access to community and voluntary rescues and patient intervention)

- identify necessary changes in service delivery, and to integrate the CPA system.

The Beacon site manager (H) was a driving force in this project. H had been a general practice receptionist, a practice nurse, and a mental health nurse over the last 10 years and had therefore brought considerable breadth of experience from both primary and secondary care to the new venture. She was also determined to create the conditions for making improvements to mental health care provision.

By the time I visited the site, Beacon funding had finished. The local strategy was now moving beyond the initial training initiative, seeking ongoing funding.

The idea of a network that operates by attracting and enrolling many different kinds of actor is particularly useful in this context. The climate of change in health care delivery has created a loose organisation that

can be very fluid. The actors in this network and the relationships between them are in flux and subject to many changes.

There appear to be two forces at play in the context of this developing network: the specific history of local service provision, and the grand policy initiatives launched by various coalitions. Looking at the scene from this point of view allows us to take account of the weight of local resources, and the pull of ideas and desires. For example, the NHS Framework Document provides a kind of magnet into the future by setting out objectives for mental health care. These have been used by ambitious local players to rally local resources and to generate action at ground level. The Defeat Depression Campaign initiated by the Royal College of Psychiatry in the early 1990s provided another important opportunity to mobilise actors and forge new links at local level. What we seem to be witnessing are the beginnings of a new area of expertise. Depression and anxiety are in the process of becoming new areas for specialist attention at local primary care level.

The focus of the net-builders began by establishing a new set of ideas and skills in people's minds. As we have said, the first step was a training initiative. This in itself involved a strategic network, which went beyond the boundaries of the NHS Institution. Especially important were the Depression Care Training Centre, which runs out of the local university college, and also the senior product manager of 'WXYZ Laboratories' – a company that manufactures and sells medication for easing mental health problems. Also involved are the Director of Mental Health Services, the patient services manager in the community mental health services, and the role of mental health facilitator in primary care. We can see that the network flows over a number of institutional boundaries and takes root in local opportunities.

Continuity of care

Crossing these care boundaries has not always been straightforward. For example, in the recent history of health provision there was a move to place CPNs in GP surgeries. Shortly after the establishment of this, the strategy changed, and CPNs were withdrawn. This created a 'wall of resentment' among the GP community. From our point of view, this would constitute a barrier to continuity of care. It interrupts the professional relationships and will therefore create conditions for poor informational continuity, you could even understand it as the establishment of cross-boundary (dis)continuity.

Cross-boundary continuity is also illustrated positively in this field study: GPs in Northamptonshire want nurses to work with them in their surgeries and maintain the integrity of their expertise.

> *They wanted an on-site community mental health nurse. They didn't even want a social worker, or an occupational therapist! They only know what community mental health nurses do (ha ha).*

In this case, I found that the debate about what constitutes mental health, and therefore what kind of care can be delivered, is being

conducted within the framework of general practice. Expertise is developed and delivered primarily through nursing positions with the one exception of a part-time counsellor. Continuity of care can now be generated: having established the framework of a team of experts within the practice, responsibilities can be clearly identified, and any transfer of care can be accounted for. The primary care team has settled the debate on mental health for itself, and is now in a position to develop the necessary channels for maintaining continuity of care between itself and other parts of the health care system.

What happens in other parts of the county

What we did was divide the members of each community mental health team and allocated them several practices to key-work. This is what they call a 'relationship consultation model'.

The key worker gets a contract where they agree with the surgery that they will come to weekly or monthly meetings (and that's totally down to the primary care team – some of them only want them to come in once a month to their main monthly meeting; some of them want them every week).

There was no way we could go in and impose a model.

So we've gone along with what they [GPs] wanted, and we plan to go back in January to see if they feel the relationship has developed. Do they feel more confident? Do they feel they can phone up more easily? Can they be sure they know who is looking after which person, and they can feel that all these things are measured?

The site visit

Our enquiry follows the thread into one particular general practice in the town. The key player here is Dr S. He has been a GP with the practice for about 10 years. He has a personal passion to improve mental health care at primary care level, and he explains his choice with biographical details. In fact, Dr S had once trained as a counsellor, believing that this would form the basis of consultation with patients in general practice. He was quick to discover that you could not make much progress in that way within the structural constraints of general practice. So he decided to switch his tactic and became instrumental in establishing two counsellors within the practice. This was in the days of fundholding. One counsellor had to go when fundholding finished, but one is still there today, a valued member of a team that now provides a strong network for mental health care.

The second key actor in this local network is the liaison CPN. This position is a crucial one in the ensuing success, but it exists against the grain. When CPNs were withdrawn from GP surgeries, this CPN resisted. The working relationships established in the practice, and a series of local negotiations with the CMHT, were strong enough to convince the main actors that this was worth supporting.

Two more key actors are in the form of the integrated nursing project (in this case a district nurse), and the primary care mental health practice nurse. Each of these three nurses occupies a position that is funded through a different stream, and these are available through the skilled work of Dr S in the financial dimension of the net. Each one of these nurses had a specific function to implement a different kind of change. Each of these projects engaged the postholder in another network of people across institutional boundaries at different places. For example, the primary care mental health practice nurse has a partner nurse in another practice on the other side of town. And the link CPN is also part of one of the CMHTs.

After speaking with four out of the five people who make up the surgery mental health team (the counsellor was unavailable) it was clear that there was an extremely strong social organisation network of which they were a part. Each person took the trouble to point out the many different features of teamworking, mutual respect, and the supportive attitudes that made up the work experience at the surgery. Everyone who works there is acknowledged as a member of the team. Hierarchies clearly exist, and the GPs are evidently the core of this system, but there were many other layers at play in the complex network of work relationships that allowed information, knowledge, and support to flow wherever it was needed.

An instructive case of continuity

During an interview with the Integrated Nursing Project nurse (we will refer to her as 'T'), I encountered a beautiful example of care that is instructive for our project. The example concerns a man who had attempted to commit suicide by injecting a dangerous substance into his arm. The suicide attempt failed, but it set him on a trajectory through the system that illustrates the particular challenge that severe suffering of mental illness poses to any mechanistic conceptualisation of 'continuity of care'.

The substance he injected did not travel through his veins, but remained where it entered and caused such damage to his arm that the A & E staff had to cut it out. This left a very large hole in his arm, which required regular specialised dressing. This one act turned this man simultaneously into two kinds of object in need of NHS care. Each object was part of a different network of care: psychiatric and medical. Can they coexist?

During his stay in the acute unit, he was visited each day by a team of district nurses from his GP surgery. One of the team is T, the Integrated Nursing Project nurse. T told us that she was one of three nurses who visited him each day to dress the wound. Their work varied in intensity as the wound made its recovery. They carried out this work in the specialised psychiatric hospital, at his home upon discharge, and at his mother's home during his visits to her. This demonstrates the way that contextual continuity was sustained by these nurses. In the course of this specialised physical care, these nurses would also, of course,

converse with their patient. In this way they also bore some of the burden of work generally carried out in psychiatric teams. They acted as pivots between GP, psychiatry, and specialist medicine.

T was quite clear that this work was difficult work, and that it was only possible to accomplish it without strain because of the established context of the practice. There appear to be three main threads to this context:

1   specialised psychiatric knowledge entered the network in this practice, through the CPN

2   structured group meetings, and the informal social network, provided plenty of channels to process information and the stress that arose from the work

3   the computerised record system fortified the system and gave everyone confidence that responsibilities were being discharged.

The local preconditions for continuity of care in a team

• The link CPN had spent a number of years building relationships between the surgery staff and the community mental health teams. This gradually contributed to an increase in the knowledge of the surgery on mental health issues.

• The routine lunch-time training sessions for all staff in the practice had enabled colleagues to get to know the kinds and levels of expertise that each of them possessed, and established a context in which professional relationships could flourish.

• The regular team meetings, which encourage staff to speak about critical incidents and dispel stress and anxiety, as well as to share expertise and knowledge.

• The unstinting support of the lead GP, who is constantly networking and finding financial support to keep his team together.

• The daily practice of coffee time for all members of staff at the practice, which allows intricate networks among all levels of staff to be established.

• The computerised information system that supports the specialists in communicating their clinical material.

• The long-term commitment to knowledge-based practice among the GPs.

• The time spent in producing plans, protocols and pathways, for any new venture.

• The recognition of the importance of planning and review.

• The annual summer and Christmas social events.

Concluding remarks

Lessons for continuity of care are at a very rudimentary level concerning the importance of local teamwork in a stable and supportive framework with a number of local champions. This enables individual professionals to devise and implement local and often informal mechanisms of offering several elements of continuity, particularly across boundaries, but also showing how good teams can offer relational continuity. The importance of local mechanisms and enterprise has been emphasised by Cook *et al.* (2000). These local snapshots encourage us to imagine the variety lying beneath the summary data in large-scale studies of CPA and ACT (see Appendix 1, 'Effects of continuity of care for patients with SMI').

This final case also illustrates the groundwork that needs to be done to establish a new domain of expertise in primary care. Here we can see the gradual expansion of the idea that depression and anxiety are things that *can* be treated outside specialist mental health care teams. It is also the beginning of a realisation that they *should be* treated.

A kind of buffer zone seems to be in the process of creation. The clinical concepts are loose enough to draw new members of the public into the gaze of the medical experts. These experts can now maintain a low level of routine care for a large number of people who would otherwise have been expected to cope on their own. The provision of this kind of care, and the existence of the network of expertise allow the nursing and counselling staff to initiate care early in the process when simple routine services can make a great deal of difference. This is preventive work, whose true effects cannot be accurately measured.

Appendix 3

Delphi study
(led and reported by Tim Weaver)

Introduction

There are three striking aspects about the empirical work and debate about continuity of care: first, the absence of any shared definition of what continuity of care means; secondly, a lack of clarity about the factors that inhibit continuity of care; thirdly, the paucity of evidence about mechanisms that enhance continuity of care and their outcomes. We decided to implement a Delphi study to investigate these themes.

What is a Delphi study?

In its traditional form, Delphi studies aim to obtain a consensus view on a given issue from a group of experts, or appropriately experienced individuals (Delbecq, 1986; Jones and Hunter, 1995). This aim is achieved through administration of a series of structured questionnaires accompanied by feedback of summarised findings from earlier responses (See Figure A3.1). This iterative process is designed to achieve informed opinion development and to facilitate increased levels of agreement on an issue and ultimately a level of consensus sufficient to form a basis for action (Sackman, 1975). Delphi methods are recognised as useful in situations where there may not be any consensus. This may be because of the lack of scientific evidence, the existence of contradictory evidence, or alternatively the controversial or complex nature of the issue. However it may be applied, Delphi methods tend to be employed to assess the extent of agreement and may be used to resolve disagreement and develop consensus.

Delphi studies have been recognised as an effective method of structuring communication and debate around complex problems in health care (Jones and Hunter, 1995) and recent examples include work in the field of community psychiatry (Fiander and Burns, 2000). Delphi techniques do not require that participants meet face to face; indeed one of their principles is usually that members of the panel remain anonymous to one another. Its advantages therefore include the ability to engage panels of experts cheaply, without geographical limitations on the sample. (Pill, 1971; Rowe *et al.*, 1991) This also means that service users, who may be marginalised in focus groups, can be included as equal partners. This was a major consideration for us, given our desire to

include service users as active and equal participants in our investigation.

Aims

Our aims were to:

- assess the extent to which the generic scoping study definition of continuity of care was found relevant to the care of people with severe mental illness and to modify this definition as appropriate

- identify factors perceived to promote or inhibit elements of continuity of care for people with severe mental illness

- identify mechanisms with potential to enhance continuity of care and to assess their perceived utility

with reference to a panel of provider stakeholders, service users and informal carers.

Method

Design

The study aims were pursued through a two-stage survey. Given our brief timetable of six months and the need to integrate this work with literature review and fieldwork, we had to restrict the study to two rounds. The Round 1 questionnaire was therefore developed within the research team and informed by our ongoing literature review. Delphi studies frequently employ quantitative techniques to measure the strength and range of opinion. However, we employed a modified approach using open questions in the first round. At Round 2, the research team summarised the responses to Round 1 and drafted a feedback report along with a second questionnaire. Group members were asked to respond to, and evaluate, ideas and issues included in the summary report through the second-round questionnaire. The Round 2 questionnaire used a mix of open questions and quantitative measures using items generated by the open questions in Round 1 (Figure A3.1).

Figure A3.1   Delphi study process

```
┌─────────────────────────┐
│    Review literature     │
└─────────────────────────┘
             │
┌─────────────────────────┐    ┌────────────────────────────────────────┐
│ Define research questions│────│ • What is CoC in context of care for SMI?│
└─────────────────────────┘    │ • What promotes or hinders CoC?          │
             │                 │ • What mechanisms might enhance CoC?      │
             │                 └────────────────────────────────────────┘
┌─────────────────────────┐    ┌────────────────────────────────────────┐
│   Recruit Delphi group   │────│                                          │
└─────────────────────────┘    └────────────────────────────────────────┘
             │
┌─────────────────────────┐    ┌────────────────────────────────────────┐
│ Round 1 of Delphi study  │────│ • Critically assess definition of CoC.   │
└─────────────────────────┘    │ • Qualitative 'open' questions re. factors│
             │                 │   that hinder / promote CoC in relation to │
             │                 │   primary care, health & social care,      │
             │                 │   multi-disciplinary teamwork, user        │
             │                 │   involvement.                             │
┌─────────────────────────┐    └────────────────────────────────────────┐
│  Analyse panel responses │────│                                          │
└─────────────────────────┘    └────────────────────────────────────────┘
             │
┌─────────────────────────┐    ┌────────────────────────────────────────┐
│  Re-formulate research   │────│ • Assess revised definition of CoC       │
│   questions for Round 2  │    │ • Obtain ratings for utility of potential│
└─────────────────────────┘    │   mechanisms influencing CoC             │
             │                 └────────────────────────────────────────┘
┌─────────────────────────┐
│ Feedback Round 1 findings│
│   Distribute Round 2     │
│     questionnaire        │
└─────────────────────────┘
             │
┌─────────────────────────┐
│   Analyse results for    │
│  agreement and degree of │
└─────────────────────────┘
             │
┌─────────────────────────┐
│   Disseminate findings   │
└─────────────────────────┘
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The panel

Given the predominantly qualitative analysis we proposed, we felt that a relatively small panel was appropriate. A panel of respondents was identified and recruited collectively by the research team. Potential respondents were identified because they were members of an important stakeholder group and had a record of involvement in academic and/or policy-oriented debate concerning the development of care services for people with severe mental illness. We identified key authors from our literature review and practitioners involved in National Service Framework 'Beacon sites', and invited other nominations from our steering group. We initially approached a total of 40 people of whom 24 agreed to participate in the study (the panel). In June 2001, we sent Round 1 questionnaires to this latter group, of whom 20 (83 per cent) returned completed forms. The respondents represented the following key stakeholder groups: service users, carers, psychiatry, social work, psychology/psychotherapy, general practice, NHS and Social Services management. We sent the second questionnaire to the panel in September 2001 and received ten responses (42 per cent). Eight of these had completed the questionnaire, the ninth provided an extensive written response and the tenth gave a brief response.

Analysis

Our analysis addressed the study aims as follows.

First, we coded the responses we received to questions about the appropriateness and comprehensiveness of our definition of continuity of care. These responses were assessed by two internal raters (J. Low and T. Weaver) and classified as either 'consistent with (an element of) the definition', 'providing grounds for modification of (an element of) the definition' or 'a new element'. We then drafted provisional modifications to the definition for the Round 2 questionnaire and the process was then repeated.

A tabulation was made of responses to open questions in Round 1 that asked the panel to identify mechanisms with potential to promote continuity of care. This initial analysis generated a list of items. These were grouped around key themes (notably primary care, health and social care and multidisciplinary working) and included in a series of quantitative questions at Round 2. We asked the panel to rate each mechanism in one of three ways.

1   We asked respondents to rate the potential of mechanisms to impact positively or negatively upon continuity of care using Likert scales.

2   Where a large number of items were nominated at Round 1 in relation to a specific issue (e.g. minimising staff turnover) we asked respondents to identify the intervention strategy with the highest potential for positive impact, relative to other listed items.

3   Where the mechanisms identified at Round 1 were mutually exclusive, we asked the panel to select one from alternative strategies we presented.

Analysis of these themes at Round 2 involved calculation of mean scores and measurement of the proportion of respondents favouring nominated intervention strategies.

Findings

Defining continuity of care

In the first round we invited the panel to comment on a definition of continuity of care that had been developed through the scoping study (Freeman, 2001). Figure A3.2 shows that this generic definition gave primacy to patients' experienced continuity – and that five other elements contributed to this experience.

At Round 1, the panel was asked to comment on the comprehensiveness and appropriateness of this definition to the care of people with severe mental illness (SMI). We found that the panel strongly supported the primacy of the service users' perspective (experienced continuity). However, several members of our panel drew attention to unique characteristics of mental illness (and its clinical management) that were not adequately acknowledged by this generic definition.

Figure A3.2 Developing a definition of continuity of care

Definition 1 *Generic definition based on the scoping study (Freeman, 2000)*

A minimum definition of continuity of care should include the following elements:

- The experience of a co-ordinated and smooth progression of care from the patients' point of view (**experienced continuity**).

To achieve this central element the service needs:

- excellent information transfer following the patient (**continuity of information**)

- effective communication between professionals and services and with patients (**cross-boundary and team continuity**)

- to be flexible and adjust to the needs of the individual over time (**flexible continuity**)

- care from as few professionals as possible, consistent with other needs (**longitudinal continuity**)

- to provide one or more named individual professionals with whom the patient can establish and maintain a therapeutic relationship (**relational or personal continuity**).

Definition 2 *Revised definition based on Round 1 responses to Definition 1*

A minimum definition of continuity of care should include the following elements:

- the experience of a co-ordinated and smooth progression of care from the service users' point of view (**experienced continuity**) which should sustain a person's preferred social and personal relationship in the community and enhance quality of life **(continuity of social context)**

To achieve these central elements the service needs:

- to provide one or more named individual professionals with whom the service user can establish and maintain a consistent therapeutic relationship (**relational, personal and therapeutic continuity**)

- to ensure that care is provided by as few professionals as possible, consistent with need (**longitudinal continuity**)

- to be flexible and to adjust to the changes in a person's life over time (**flexible continuity**) and to provide uninterrupted care for as along as the service user requires it (**long-term continuity**)

- **effective communication**:
  (a) based on excellent information transfer following the service user (**information continuity**)
  (b) between professionals working in statutory and non-statutory agencies, working in primary and secondary care, and with the service user and their informal care networks (**cross-boundary and team continuit*y***).

'Severe mental illness' is not a diagnosis. Rather it is a term used to refer to populations often defined in terms of both diagnostic criteria (such as schizophrenia, manic depression) and information about case history and problem severity (for example, duration of illness, frequency of inpatient admission). People who meet these mixed criteria may be a heterogeneous group and experience a range of problems. Severe mental illness can be 'enduring' (though it may also be episodic) and may impact profoundly and in multiple ways on the everyday lives of sufferers. The panel felt that these characteristics meant that experienced continuity for the service user may depend on success in achieving many differing elements of continuity of care and that responding appropriately to changes over time in the clinical and social circumstances of sufferers was a critical factor affecting experienced continuity. There was particular concern that the many service users with episodic patterns of illness lost contact with services all too easily and had difficulty re-establishing therapeutic relationships. (An absence of flexible continuity which undermined long-term continuity.)

It was for these reasons that a significant number of our panel expressed the view that experienced continuity for mental health patients amounted to much more than the 'seamless' service implied by the generic definition. To many of our panel, experienced continuity of mental health care also embraced the need to maintain, and not to disrupt, people's social and personal relationships.

After analysis of the first round responses we decided to propose a revised definition of some elements of continuity of care. We introduced 'continuity of social context' into our definition to describe the need for services to 'sustain a person's preferred social and personal relationship in the community and enhance quality of life'. There were two other significant findings.

- Some of the terms in our original, generic definition had different or broader meanings in the context of mental health care. Panel members felt that consistency of therapeutic approach should be an additional aspect of relational or personal continuity. Secondly, the need for specialist mental health services to work with non-specialist, non-statutory and informal care providers was also noted as an aspect of cross-boundary and team continuity.

- The panel also felt that the enduring nature of severe mental illness needed to be explicitly recognised. We proposed the term long-term continuity in Round 2 for this reason.

At Round 2 we fed back these findings and asked the panel to re-assess the comprehensive and appropriateness of the revised definition. Although relatively few of the panel responded, there was a strong consensus among these respondents that the revised definition was comprehensive. However, questions were raised about appropriateness.

- Some felt our definition of information continuity focused too much upon communication between professionals. The imperative to communicate effectively with patients is absent from the definition.

Moreover, there was a feeling that our definition implied that perfect continuity of information involved full exchange of clinical information. This needed to be challenged, as there were instances where, ethically, information should not be communicated between professionals.

• Greater clarity was also requested about the meaning of longitudinal continuity and its distinction from long-term continuity.

What influences continuity of care at the interface between primary care and secondary health and social care services?

Primary care

At Round 1 we asked the panel what aspects of mental health care should be the responsibility of GPs (and their primary health care teams). We also asked whether the division of clinical responsibility between primary and secondary care tended to enhance or detract from elements of continuity of care.

It was apparent from the responses of users and carers that they wanted GPs to have a significant role in management. They valued the GPs' local accessibility, the absence of stigma and the potential of traditional 'family' GPs to understand the history and context of a person's illness. Significantly, statutory services were seen as often lacking this latter attribute because of their fragmentation and also because of high rates of staff turnover. These characteristics of primary care were seen as having potential to promote relational, personal and therapeutic continuity and longitudinal, long-term and flexible continuity, together with continuity of social context. However, most of the panel felt this potential was not widely realised. There was recognition from all groups represented on the panel (including GPs) that while some GPs were willing and able to work with people with severe mental illness, many others were either unwilling or unable.

Moreover, respondents from both primary and secondary care noted the practical difficulty for GPs of becoming more involved in care-planning processes that operate in secondary care (cross-boundary) and of establishing effective mechanisms for information exchange (continuity of information). Consequently, there was a gap between the roles that respondents felt it was realistic for the majority of GPs to perform (such as physical care, monitoring and administration of medication), and those which they wanted to be performed by GPs with appropriate skills (such as long-term monitoring, relapse detection).

At Round 1 we asked the panel to identify mechanisms with potential to enhance continuity of care. Mechanisms identified in relation to primary care fell into three main categories: training, communication and joint working.

At Round 2 we asked respondents to rate nominated items using a 5-point Likert scale. Table A3.1 shows that all respondents felt that training initiatives (such as more mental health training for medical students, joint training between professions, user/carer input into training) had potential for positive impact on continuity of care. There was also a similar consensus about the positive potential of improved electronic forms of communication.

Table A3.1 Round 2 panel ratings of the potential impact on continuity of care (CoC) of interventions nominated at Round 1 (valid cases = 8)

	Mean score *	Mode	Range (high, low)
Primary care-level interventions			
Training			
Improve and extend the training in mental health care for all medical students	1.6	2	(2, 1)
Provide more joint training between professional groups: GPs, psychiatrists, social workers, nurses ,etc.	1.6	2	(2, 1)
Include mental health service users and their carers in the design and delivery of training	1.6	2	(2, 1)
Communication			
Provide and improve electronic forms of communication between primary and secondary care	1.3	1	(2, 1)
Joint working			
Give primary care greater responsibility for the organisation and co-ordination of services	0	1	(1, −2)
Establish posts in primary care with responsibility to link/liaise with secondary mental health services	0.9	0	(2, -1)
Establish more posts in primary care settings for specialist mental health workers (e.g. CPNs or social workers)	0.1	0	(2, -2)
Locate more specialist community mental health teams or activity (e.g. CPA meetings) within primary care premises	0.5	0	(2, -1)
Organisational and service-level interventions			
Maintain and enhance range of therapeutic options (e.g. provide talking therapies, art and drama therapy, OT, etc.)	1.6	2	(2, 1)
Increase opportunities for user involvement	1.6	2	(2, 0)
Give greater priority to finding and supporting appropriate job opportunities	1.5	2	(2, 0)
Improve communication between statutory services and providers of services in the independent sector	1	1	(2, 0)
Develop shared information technology	1	1	(2, 0)
Implement principles of Assertive Community Treatment (i.e. team-based case management with assertive outreach)	1	0	(2, 0)
Greater devolution of decision making to nurses, social workers and other 'frontline' professionals	0.9	1	(2, 0)
Greater investment in a range of day-care options	0.3	1	(2, −2)

* Items were rated on the following scale:
2 = major potential for positive impact on CoC
1 = some potential for positive impact on CoC
0 = unlikely to have any positive or negative impact on CoC
−1 = some potential for negative impact on CoC
−2 = major potential for negative impact on CoC

However, items relating to joint working proved more contentious. The items 'establishing specialist mental health worker posts in primary care', 'more posts in primary care settings for specialist mental health workers', 'more specialist community mental health teams or activity within primary care premises' and giving primary care 'greater responsibility for organisation and co-ordination' all received both positive and negative ratings from different respondents. Overall mean scores showed that the panel felt these items were most likely to have a neutral or marginally positive impact on continuity of care for people with severe mental illness.

Health and social care

At Round 1 we asked the panel a series of question about the interface between health and social care. We asked how each of the following was perceived to be impacting upon continuity of care:

1   the separation of health care delivery and the purchasing and delivery of social care.

2   current integration of NHS and Social Service functions under the Care Programme Approach (CPA)

3   the development of multidisciplinary teams (MDTs).

A strong consensus emerged that that closer working between health and social care was necessary and important to achieving continuity of care. Both users and carers agreed that multidisciplinary teams had improved experienced continuity, mainly through improved cross-boundary and team continuity across the interface of health care and social care. Some of the panel defined the importance of integration in terms of it being a basis for achieving care that, although described differently (for example, comprehensive, holistic), appeared to embrace a wider and more person-focused conception of care. This recognised the service users' need to retain or improve their status in a preferred social context *(continuity of social context).*

However, most of the panel recognised that positive cross-boundary working relationships between health and social care could be difficult to achieve. This was because of the differences in professional knowledge, legal status, statutory powers and casework practice. Several respondents acknowledged a tension between the medical and social models of mental health care. Some felt this could undermine the effective functioning of teams, while others observed that existing tensions had been magnified by the introduction of MDT's in a climate of financial stringency. Success was thought to vary widely across the country. Most acknowledged that mental health professionals needed the support of strong management and supervision arrangements in order to manage the stresses and uncertainties that characterise much mental health casework.

Staff turnover and 'burn-out'

Respondents representing most stakeholder groups also expressed concerns that experienced continuity for service users was difficult to attain if care staff felt they were unsupported, undervalued and carried the burden of unrealistic and unsustainable expectations in a difficult financial, organisational and professional context. Several respondents made explicit reference to 'burn-out' and the high rates of staff turnover as a major problem for services and one of the major negative influences upon continuity of care. Turnover of staff was seen as undermining relational, personal and therapeutic continuity, and longitudinal continuity.

There was agreement about the need for working at the interface between health care and social care to be improved and recognition that the progress towards closer working of health care and social care had delivered some (if not all) potential benefits. However, some divergent views were expressed about the direction and value of further progress. The differing views expressed crystallised around two themes.

1   *What organisational and management structures were most appropriate to support multidisciplinary working?* There was some support for the idea of removing organisation boundaries between health care and social care and creating various forms of unified management at the team level. However, some respondents were more cautious about such change and noted the differing 'cultures', organisational structures and geographical boundaries of local government and the NHS. Some mental health clinicians on the panel were wary about the implications of trying to improve the working of MDTs through organisational integration. A number of respondents also pointed to the extreme complexity of local service provision. They noted two main factors:
    • the increasingly diverse mixed economy of statutory, independent and informal providers of care and the importance of this mixed economy in providing creative responses to individual needs
    • key factors that contribute to a person's experience of continuity of social context remaining outside the influence of medical and social care agencies as currently configured (for example, employment opportunities).

Hence, experienced continuity of care was affected by the operation of cross-boundary issues other than those arising in relation to local authority Social Services and the NHS.

2   *How should case work practice develop in the context of multidisciplinary working?* There were two contrasting positions, that:
    • MDTs may function better if workers developed common skills and competencies
    • MDTs should work to harness the specialist roles and skills associated with professions without convergence in the skills bases of different disciplines.

Some (though not all) who subscribed to this second position argued that disciplinary boundaries were positive and needed to be retained in order to maintain independence, innovation and therapeutic diversity. Respondents who expressed this latter view represented social work, psychology/psychotherapy and also health and social service management.

We investigated the issue of cross-boundary working and multidisciplinary working at Round 2 by asking the panel if they agreed or disagreed with a series of statements representing views expressed at Round 1. The responses showed that a majority felt the removal of institutional and disciplinary boundaries would enhance continuity of care.

With regard to the interface between NHS and local authority Social Services, five out of seven respondents felt that removal of organisational and management boundaries between health care and social care was most likely to improve working at the interface between health care and social care. Five out of seven respondents also agreed that continuity of care would be improved if mental health workers (for example, nurses, social workers) developed more common skills and competencies.

One of the key problems acknowledged above, and to which respondents repeatedly referred, was that of staff turnover. As one of the service users on the panel put it:

> *… the simple truth is the service you deliver is only as good as the people involved.*

At Round 1, panel members made a number of suggestions about how staff retention could be improved. At Round 2 we asked the panel to rate these mechanisms (Table A3.2).

Table A3.2 shows that there was particularly strong support for improved clinical supervision, mentoring and peer support; more joint working and team building; more interdisciplinary and in-service training; more emphasis upon team-based responsibility for management of patients; greater patient contact and less bureaucracy; and greater user involvement.

Table A3.2 Round 2 panel ratings of the importance of mechanisms to improve staff retention (valid cases = 8)

	No. of panel members indicating item was an important factor	No. of panel members indicating item was the single most important factor
More clerical support for frontline staff	1	
Stronger MDT management		
Less bureaucracy, more direct patient contact	2	1
Greater emphasis upon team building	4	
More in-service training /personal development	2	1
More emphasis on personal safety of staff		
Devolve more decision making to CMHT and ward management	1	
More emphasis upon team-based responsibility for management of patients	2	2
More joint, interdisciplinary training	3	1
Removal of pay differentials between professions	1	
Agreed limits to caseload size	2	
Improve clinical supervision /mentoring /peer support	5	1
More resources to services (e.g. day care) that support frontline casework	1	1
Developing user involvement (including involvement in care provision).	2	1

Organisational and service-level interventions with potential to enhance continuity of care

At Round 1 the panel identified a number of organisational and service-level interventions, which were felt to have potential to enhance continuity of care. At Round 2 we asked the panel to rate these using the same 5-point Likert scale described above.

Table A3.1 shows that most items were rated positively by a majority of respondents. The item receiving the highest overall rating was 'maintain and enhance the range of therapeutic options (e.g. provide talking therapies, art and drama therapy, occupational therapy etc.)'. Interestingly, 'greater investment in a range of day-care options' scored the lowest rating overall, with a mean score of 0.3 ('marginal positive impact').

One further item rated highly was 'increased opportunities for user involvement'. This issue was the focus of a series of questions at Round 1. We asked the panel whether the practice of user involvement had had, or might have, a positive or negative impact upon elements of

continuity of care. There was a consensus that forms of user involvement could be important mechanisms for improving continuity of care. Most respondents focused upon models of user involvement that involved some form of dialogue or consultative process, whereby the members of self-advocacy user groups contributed to the decision-making process of service planning or management. All these approaches are based to some extent on a similar rationale – that by involving the recipients of service in decisions about the way services are managed and delivered, the care provided to all users is more likely to be experienced as high quality and appropriate.

However, user involvement may also operate at the level of the individual and can describe various strategies for improving experienced continuity by empowering service users to make choices about, or have influence over, the care they receive. There was surprisingly little emphasis upon user involvement at the individual level in the panel's responses, and respondents were generally vague about the scope, method and outcomes of user involvement.

Conclusions

1   The generic definition of continuity of care, developed by the preceding scoping exercise, requires refinement to make it relevant to the special circumstances of mental health care and accessible to its practitioners. Our work with the Delphi panel has taken us some way forward. The suggestion of inclusion continuity of social context into our definition to describe the need for services to 'sustain a person's preferred social and personal relationship in the community and enhance quality of life' has been supported by service users and other stakeholders. However, some difficulties remain unresolved. These centre on the ethics of informational continuity and achieving genuine user-centred meanings for longitudinal and long-term continuity.

2   The position of primary care emerges as a key development area. The gulf between the important potential role for primary care (which the panel wanted to see) and the more limited role that was realistically possible in current circumstances, was strikingly apparent and almost unanimously shared by all sections of the panel.

3   The Delphi panel felt progress towards the integration of secondary health care and social care was fundamentally important. Most recognised progress was being achieved but also difficult inter-agency and interdisciplinary relations still needed to be resolved. While there was no consensus on the way forward, there was nevertheless a majority view in favour of removing both agency and disciplinary boundaries rather than attempting to better manage the interface between different organisations.

4   Key problems were identified. Most significantly perhaps, workforce issues affecting staff turnover within specialist care was identified a major challenge. Improved staff retention was seen as a fundamental

to achieving continuity of care. Supervision, training, team building, mentorship and work sharing were some of the key mechanisms identified by the panel that could address this problem.

5   If we are to work towards enhancements to continuity of care that are both user-centred and valued by users, we are going to have to achieve far more in terms of user involvement. Other concurrent work undertaken by members of the research team[2] has highlighted how difficult progress with user involvement has been for many trusts. We are conscious that the Delphi exercise has tended to confirm the ubiquity of these difficulties. While some of the Delphi panel were passionate about the value and importance of user involvement, certain professional interests were vague about its meaning and role. There is no other single issue which has so clearly exposed the inability of this brief, two-stage exercise to approach consensus. Further work should be urgently undertaken to develop mutual understanding about user involvement, particularly at individual level, and a clearer view about how to achieve this.

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[2] Work in progress by MC, TW and others with NHSE (LRO) Organisation and Management R&D Funding: *User involvement in the planning and delivery of healthcare*.

Appendix 4

References

The following is a complete list of the papers included in the analysis. It includes some references that have not been cited in the text.

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Addendum

This report was amended on 28th September 2011 to update the correct copyright statement and/or correct the publication date. The content of the report has not been changed.