# Concern and Continuity in the Care of Cancer Patients and their Carers: a multi-method approach to enlightened management

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***Report for the National Co-ordinating Centre for NHS Service Delivery and Organisation R&D (NCCSDO)***

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The report statistician was Shahed Murad from the Royal Free and University College Medical School.

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# *Executive Summary*

## Introduction and background

Cancer will affect one in three people at some time in their lives. Five-year survival has increased over the last 30 years and cancer has become a chronic illness during which patients must live with uncertainty and the threat of recurrence. There are five important stages in the so called 'cancer journey', in which there are potential breaks in care. These are:

1. initial diagnosis
2. end of first treatment
3. remission
4. relapse
5. referral to specialist palliative care.

Continuity of care has been defined in a number of ways by health professionals. Its core components are continuity of information about patients, an ongoing relationship with one or two key professionals, cross boundary and team consistency and a co-ordinated approach to care. However, we have little information on how patients and their families experience good 'joined-up' care, whether their experiences accord in any way with these service models and whether experienced continuity matters in terms of clinical and service outcomes.

## Objectives

The objectives of the study were:

1. to develop a fine grained understanding of patients', close persons' and professionals' views of and ideas about continuity of care in cancer
2. to translate key elements of continuity into a quantitative research tool
3. to identify associations between continuity of care and satisfaction and to understand the effects of psychological status, expressed needs for care, spiritual belief, quality of life and coping strategies on these associations
4. to model change in continuity and satisfaction over time and across transitions in cancer care
5. to determine whether such transitions in care predict change in perceived continuity after adjustment for potential confounders.

# The study

Patients with breast, lung or colorectal cancer were recruited from three London cancer networks at each of five transitions in care. The study had two parts:

1. Cross-sectional qualitative study
   - patients recruited from general practice, their nominated close persons and health care professionals were interviewed.
2. Quantitative study
   - data from part 1 were used to derive quantitative measures to explore continuity of care prospectively over twelve months in five cohorts of patients recruited from secondary care (at each of five transitions in care) with the same cancers, and their close persons.

## *Analysis*

We compared demographic, clinical and social differences between patients in each phase of treatment and in each cancer group using descriptive statistics at baseline and each follow-up; this was repeated for close persons. Responses to our questions on experienced continuity of care derived from qualitative data were entered into a common factor analysis, one for patients and one for close persons. In our analysis of the prospective study we imputed patient data where missing and compared our analysis in imputed and complete data. We conducted multivariable analyses at baseline and examined our data for change over time. We then examined the pattern of movement or transitions of patients from one treatment phase to another. To deal with the clustered nature of our data, we undertook a multilevel model analysis with two levels. We explored the impact of:

1. continuity scores on satisfaction, psychological status, needs for care and quality of life
2. any transition between treatment phase on perceived continuity.

## *Main findings at baseline*

From our qualitative data, we found that experienced continuity was a complex concept determined by factors such as the quality of the first appointment with secondary services, communication with the family and professionals; information giving by professionals; patients' and close persons' ability to share treatment decisions; the effectiveness of health administrative systems; patients' personalities and family dynamics. Patients' reactions to their illnesses and how they shared information within their families were critical to whether or not continuity could be achieved. People with cancer needed to be active partners in their care according to their own personal coping styles. There was little mention of needing a named co-ordinator of care or needing to see the same health professional each time. Giving information depended on patients' capacity to receive it and establishing a relationship of trust with the patient very early in the initial clinical contact appeared to be crucial in setting the tone for future consultations.

These qualitative data enabled us to develop 20 statements that quantified a broad concept of experienced continuity of cancer care that incorporated users' (and close persons') perceptions of how the services delivered care and information, their sense of control and the quality of their informal support. Two statements were later dropped as they were not universally applicable to all respondents. An exploratory factor analysis of responses to the remaining 18 statements in the patients' data revealed that 11 items making up three factors were important in explaining the latent concept underlying our questionnaire. A similar exploratory factor analysis for these 18 statements in close persons revealed a similar latent structure.

At baseline, positive experiences of continuity of care were significantly associated with higher satisfaction with services, lower needs for care, better quality of life and less psychological distress. Close persons' perceptions of high continuity of care for patients were also associated with higher satisfaction but the association was much weaker than for patients. Their perceptions of high continuity of care for patients were also associated with their own (better) quality of life, less psychological distress and stronger spiritual beliefs. Those close persons who were more involved in helping with the patients' needs and care tended to perceive continuity less favourably than those less involved.

## Main findings

Over the 12 months of the study, patients' perceptions of continuity of care were positively associated with satisfaction with services over time, after adjustment for potential confounding influences. However, the relationship was non-linear. This remained the case after adjustment for close person's perceptions of continuity and their psychological status. High experienced continuity also predicted lower physical and psychological health needs for care, better quality of life and less psychological distress over the 12 months of the study. Transition in phase of treatment (for example remission to relapse) was not associated with any change in perceived continuity.

## Conclusions

Our data would suggest that experienced continuity is an outcome of service delivery that has a distinct character to the process models proposed by professionals. It has an impact on satisfaction with care, needs for care, quality of life and psychological status. Patients can play a distinct role in their own care and recognition of these and seeking to strengthen them is fundamental to health care delivery.

## Recommendations

1. Professionals in cancer services should make sure that patients have as much information as they require about their current treatments and what to expect in the future.
2. Greater attention should be paid to patients' families and close persons in terms of:
   - family dynamics

- their attitudes to and knowledge about the illness
- their involvement.

3 Given its association with better health status and lower needs for care, cancer professionals should address the patient experience of continuity at interdisciplinary meetings, whatever form they take locally.

4 Addressing continuity should take account of current Department of Health policy initiatives that are evolving rapidly in the cancer field.

5 We should distinguish between models of continuity that are delivered in health services and the experience of continuity reported by patients.

5 New ways should be developed to identify patients at risk of poor continuity of care.

6 Patients and close persons should be given the opportunity to assess their experiences of continuity and seek greater service support if it is lacking.

7 Existing or newly developed models of continuity of care are audited against service and clinical outcomes.

# *The Report*

## Section 1 About the study

### *1.1 Project management and staffing*

The principal investigator was Michael King of the Royal Free and University College Medical School. The 38 month study commenced on 1 September 2002 and completed on 31 November 2005 (including a one month no-cost extension).

Two RA1A research assistants (end spinal point 11) were employed throughout the study. A more junior RA1A (end spinal point 9) was employed from month eight to month 38. A statistician was employed on grant enhancement money obtained from the North Central London Research Consortium (NoCLoR) to undertake the main analysis. A project steering group has met at regular monthly intervals. Core members of the group were Michael King, Louise Jones and Irwin Nazareth, with input as required from Alison Richardson, Adrian Tookman, Christina Mason, Robert Blizard and Alison Jones.

### *1.2 Aims and objectives*

As recommended by the Medical Research Council for the development of complex interventions in Health Services Research (MRC, 2000) we set out to conduct the pre-clinical and phase 1 evaluations of a new complex intervention to ensure continuity of cancer care. Our overall aims were to:

1 Describe the physical, emotional, social and spiritual status of patients and close persons as treatment evolves from diagnosis to palliation of cancer.

2 Examine professionals' perceptions of the structures and processes that enhance continuity of care.

3 Identify transitions in care that for patients and close persons are associated with a sense of abandonment by services and low satisfaction.

The detailed objectives were to:

i) Develop a fine grained understanding of patients', close persons' and professionals' views of and ideas about continuity of care in cancer.

ii) Translate key elements of continuity into a quantitative research tool.

iii) Identify associations between continuity of care and satisfaction and to understand the effects of psychological status, expressed needs for care, spiritual belief, quality of life and coping strategies on these associations.

iv) Model change in continuity and satisfaction over time and across transitions in cancer care.

v) Determine whether such transitions in care predict change in perceived continuity after adjustment for potential confounders.

## *1.3 Theoretical background*

### 1.3.1 Concepts of continuity in health care provision

Continuity of care is a concept that is elusive and difficult to define. The central element of continuity is defined in the NHS SDO-commissioned scoping exercise (Freeman *et al*, 2000) as: 'the experience of a co-ordinated and smooth progression of care from the patient's point of view (experienced continuity). It has been proposed that, to achieve this, there should also be continuity of information, cross-boundary and team continuity, flexibility in response to patient need (flexible continuity), care from as few professionals as possible (longitudinal continuity) and a main contact person so that patients can establish and maintain a therapeutic relationship (relational or personal continuity).' More recently and since this study began, the Canadian Health Services Research Foundation (Centre for Health Services, 2006) reviewed the current literature and expanded on Freeman et al's scoping ideas (2000). They now described three types of continuity:

1 Informational continuity
 — the use of information on past events and personal circumstances to make current care appropriate for each individual;

2 Management continuity
 — a consistent and coherent approach to the management of a health condition that is responsive to a patient's changing needs;

3 Relational continuity
 — an ongoing therapeutic relationship between a patient and one or more providers.

In addition, they described continuity as the degree to which a series of discrete health care events is experienced as coherent and connected and consistent with the patient's medical needs and personal context; it is distinguished from other attributes of care by two core elements—care over time and the focus on individual patients. The emphasis on each type of continuity differs depending on the type and setting of care. Most recently, Haggerty *et al* (2003) conducted a critical review of interpersonal continuity of care and care outcomes. They defined interpersonal continuity as the aspect of care related to the ongoing relationship between an individual doctor and patient. However, they also identified persistent methodological challenges in both defining and measuring continuity and were uncertain that such continuity uniformly improves care. It is important to realise, however, that these published models of continuity are not theoretical in terms of their origins, constituents or function. They are not based on a coherent theory in the same way that ethical principles are conceived of in sociology (Tipton, 2002) or in which behaviour theory underpins cognitive behaviour therapy (Tipton, 2002). Published models of continuity of care are simply useful categorical descriptions of what is thought to constitute continuous care from a health service or professional perspective.

Recent changes in organisation of the UK's health care and working practices have altered the ways in which patients can access care and has made continuity of increasing interest and importance. In 2006, NHS Direct became the commonest first contact point for all patients seeking non-routine help. Changes in the delivery of primary care have made booking of appointments with GPs more complicated in some practices, more streamlined in others. The new GP contracts have altered out-of-hours provision. In secondary care, the enforcement of European Working Time Directives has led to shift pattern working for junior doctors so that staff with varying levels of experience are responsible for patients during hospital stays and there is a higher turnover of doctors manning outpatient clinics.

### 1.3.2 The NHS Cancer Plan, co-ordination of services and research

The concept of supportive care in Britain for patients with cancer is now a priority. In response to the NHS Cancer Plan (Department of Health, 2000), attempts have been made to provide better co-ordination of care within cancer services. Cancer networks have been set up across the UK to develop and implement the so called 'hub and spoke' mechanism of care as defined by Calman and Hine (1995). This enables all cancer patients to be treated by a multidisciplinary team which has specific expertise in their particular cancer. Individual tumour boards composed of local specialists work to provide up to date and integrated care by working to agreed clinical guidelines and attempting to respond to National Institute for Health and Clinical Excellence (NICE) recommendations (as set out in the range of cancer service 'improving outcomes' guidance – see www.guidance.nice.org/type) within the confines of local resources. Within this framework, supportive and palliative care networks are being established to co-ordinate and improve both end of life care and to work with cancer networks to improve supportive care earlier in the disease. Coterminous with service networks, a chain of 34 cancer research networks has been established by the National Cancer Research Network, under the co-ordination of the National Cancer Research Institute based in Leeds. Each network is multidisciplinary, draws together local specialist practitioners and is composed of a series of tumour-specific boards which regularly review local practice, respond to NICE guidance, review treatment guidelines and initiate audit activity. Allocated a sum per head of population, each network puts in place research nurses and data managers in cancer centres and cancer units within its geographical area. The remit of these research staff is to recruit participants to research studies that have been approved by the National Cancer Research Institute. When the institute was established in 2001, the aim of this process was to increase recruitment to clinical trials by 10 per cent within three years. This target has been exceeded. Most approved studies have been randomised trials of drug treatments, many of which are integral to best practice; recruitment to approved multi-method studies has been less common and staff are often less familiar with recruiting to such studies.

### 1.3.3 Continuity in cancer care

Cancer will affect one in three people at some time in their lives. It is a disease that is often perceived to lead to an early, possibly painful death. Despite increased public awareness and public health prevention schemes, a diagnosis of cancer retains a degree of stigma and ability to shock. However, five-year survival has increased over the last 30 years (Coleman, 1999) and recent improvements have been seen, particularly in breast and colorectal cancer. As a result, cancer has become a chronic illness during which patients must live with uncertainty and face the threat of recurrence. Despite many more living with cancer, little is known about experiences and needs beyond the treatment experience. Cancer treatments are often intensive and disruptive to patients' lives. Depression frequently goes undetected and may be difficult to distinguish from appropriate anxiety and sadness (Lees and Lloyd Williams, 1999). Patients must cope with the stress of consulting numerous professionals as many treatment regimes are complex, involving surgery, chemotherapy and radiotherapy. Anxiety may reduce patients' understanding of information and their needs for access to information will fluctuate during the course of their disease (Fleissig, 2000). A number of studies have suggested that quality of life in treatment is closely related to quality of care of treatment (Costain *et al*., 1999); that patients are reassured by clear evidence of team work (National Cancer Alliance, 1996); that continuity of care is of paramount importance (*ibid*); and that guidance in getting help is essential (Nelson, 2000). Patients and professionals agree on the need for better communication, continuing contact with specialists, contact telephone numbers to use when things go wrong and easy access to specialist nurses (Farell and Lewis, 2000).

NICE guidance on supportive and palliative care for adults with cancer (2004) calls for the development of mechanisms to promote continuity of care within service delivery and recommends that patients' and carers' views are taken into account in developing and evaluating cancer and palliative care services. A number of systematic reviews of effective cancer care have been published (NHS Centre for Reviews and Dissemination, 1996; 1998; 1999; 2000a; 2000b). Core service recommendations for continuity of care are:

1. Palliative support and specialist care should be integral to patient management from the outset.
2. Rapid and efficient communication systems are needed for liaison and cross-referral between all levels of service.
3. Policies should be in place for the provision of verbal and written information to patients and key personnel should have training in communication skills.
4. Information giving should take account of patients' preferences for information, which should be personalised or tailored to need.
5. Patients should be offered the opportunity to be involved in decisions about their care.

These recommendations indicate that we also need to be aware of the preferences for care expressed by patients and their families.

Recent Department of Health initiatives (since 2000) aimed at improving cancer care have led to considerable changes in service delivery. Improved multidisciplinary working within secondary care has led to the formation of multidisciplinary team meetings (MDMs). These meetings aim to be held weekly by each team providing a cancer service and are tumour-specific. Present are core members of the multidisciplinary team: oncologists, surgeons, pathologists, radiologists, clinical nurse specialists and when appropriate allied health care professionals and palliative care. All new referrals are discussed and treatment plans are proposed and ongoing cases are reviewed. The meetings are busy and many important clinical decisions are made. Due to time constraints and large numbers of referrals many multidisciplinary team meetings are focused on the primary treatment plans. This is reinforced by the mandatory requirement for trusts to meet the cancer targets: the two week wait and the so-called '31/62 day' target (Department of Health, 2002). The latter target is designed to ensure that once cancer is suspected, referral, diagnosis, assessment and staging are all accomplished within 31 days. Within a further 31 days (or a total of 62 days from initial suspicion of cancer) the first course of treatment should have commenced. There is wide variation in the degree of administrative support that is available.

### 1.3.4 Concepts of transitions in cancer care

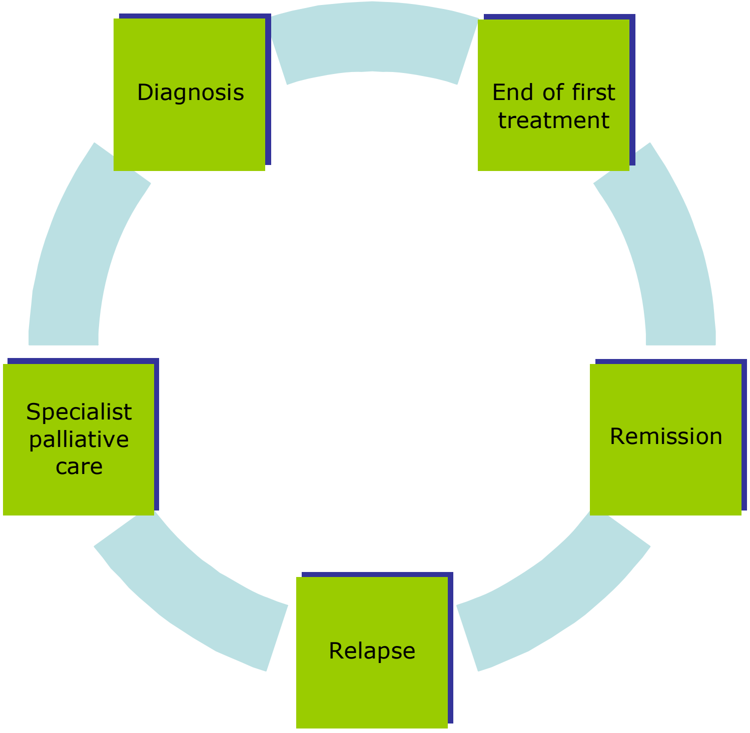
There are five recognised points in the experience of the cancer patient, or so-called 'cancer journey' where there are marked changes in the patient experience (Farell and Lewis, 2000; Morse and Fife, 1998), see Figure 1. We do not claim that these are the only times of change, but they are nevertheless recognised by many clinicians as key points when continuous care might be in jeopardy. These are:

1. Initial diagnosis, defined as within four weeks of receipt of diagnosis and before specific treatment begins.
2. End of first treatment, when first treatment is defined as the treatment plan agreed at the multidisciplinary team meeting.
3. Remission, defined as having been clinically disease free for a minimum of six months.
4. Relapse, defined as first recurrence of cancer of original cell type leading to re-presentation to secondary services.
5. Referral to specialist palliative care, which may occur at any time during illness, but usually when symptoms are severe or the terminal phase is anticipated.

The first hurdle is passed by recognising that cancer is suspected by the patient or the doctor, which is often after a period of undiagnosed ill health. Timely referral to specialist secondary services is now encouraged by the two week cancer waiting times target. Sometimes cancer is an incidental finding during the course of investigation or treatment of another disease. Diagnosis is usually followed by complex multimodality treatment programmes which may lead to remission or movement straight to palliative care. Both cure and remission are phases that can be associated with complex physical and psychosocial needs. The term survivorship is often applied to patients in this phase and there is often a significant need for supportive care.

**Figure 1 Transitions in cancer care**

Those who enter remission may either recover completely or eventually relapse. This may be followed by further treatment and recovery or referral to specialist palliative care. It is at these points that continuity of care, as experienced by patients and their families across the primary secondary care interface and between health care professionals might be expected to be vulnerable.



Since the inception of our study, the NHS has introduced new cancer waiting time targets (Department of Health, n.d.). Guidelines for GPs to make urgent referral for suspected cancer have been published and a maximum two-week waiting time for an outpatient appointment from receipt of referral is now in place. The guidelines and two-week waiting time have aimed at improving clinical outcomes. In 2005 new Government targets for speeding up the diagnostic and treatment process were developed, the so-called '31/62 wait' described in Section 1.3.3. The most recent 31/62 day waiting time targets have been implemented since this study was completed.

### 1.3.5 Mapping experiences of care: patients and close persons

How patients and families experience a cancer diagnosis and the course of disease depends on their circumstances, personalities, the stage of the disease, services available and needs for care. Core service recommendations for continuity of care indicate that we need to be aware of the preferences for care expressed by both patients and their families (National Institute for Health and Clinical Excellence, 2004). The Cancer Services Collaborative *Improvement Partnership* programme has been conducting surveys of service delivery in selected tumour types to identify blocks to services and aid service improvement. Since April 2001 all 34 cancer networks in England have been taking part in the programme. It encourages local clinical teams to examine their services and supports them to make significant improvements by redesigning the way that care is delivered. Its aim has been to improve the experience of care and outcomes for patients with suspected or diagnosed cancer by optimising core delivery systems across the whole pathway of care. Primary medical care became part of the *Improvement Partnership* programme in 2002. The main targets are to reduce the time from initial GP referral for suspected cancer to first definitive treatment to 62 days, increase the number of 'booked' appointments to improve patient certainty and choice, and increase the number of patients who are cared for by a full cancer services team (multidisciplinary team). It has three priorities:

1. early diagnosis - focusing on early diagnostic pathways
2. communication - professional to professional and professional to patient and carer
3. supportive care throughout the pathway - focusing on information for patients, cancer registers and co-ordination of the pathway.

Primary care is considered a 'cross tumour area' because of its impact on all cancers. The *Improvement Partnership* programme is working with the cancer networks and the Department of Health's Cancer Action Team to ensure patients' and carers' experiences of cancer care are improved.

Despite these service innovations, we still have little data on how patients experience continuity of care. Those that do exist have mostly arisen from cross-sectional studies and little research has integrated the views of professionals, examined the needs of people close to patients, taken into account how needs change with disease progression, or considered how service transitions affect satisfaction and outcome.

### 1.3.6 The Medical Research Council's framework for the development and evaluation of complex interventions

In this report, we present findings of our research that follows recommendations of the MRC framework for the development of complex interventions (MRC, 2000). Our data constitute the pre-clinical or theoretical phase for developing and evaluating an intervention. Our eventual aim is to develop and test an intervention to enhance continuity of cancer care. At this stage, we have examined the concepts inherent in continuity of care, constructed a quantitative measure to assess it and examined how it changes with time and treatment transition. The four steps of the MRC framework are:

1. Pre-clinical or theoretical phase
    - The aim of this phase is to establish the theoretical basis for the effects of the planned intervention. This may be formal theory of individual or organisational behaviour or it may be informal evidence regarding organisational constraints or types of patients' or health professionals' beliefs that promote or inhibit behavioural change. This phase of assessing theory and evidence may identify in preliminary form the kind of intervention needed and the study design.
2. Phase I or modelling
    - This phase develops an understanding of the intervention and its possible effects. It involves defining an intervention's components and how they inter-relate and how active components of a complex package may relate to either proxy or final outcomes. Modelling refers

to the potential for paper-based analyses, computer simulations or economic modelling. It may also include qualitative testing through focus groups, preliminary surveys, case studies, or small observational studies.

3 Phase II or exploratory trial
  - In phase II different components of the intervention can be varied to see what effect each has on the intervention as a whole. Evidence can be obtained on a theoretically expected treatment effect, and appropriate control groups, outcome measures, estimates of recruitment for a main trial and other requirements of a trial identified. This phase enables testing of alternative forms of an intervention.

4 Phase III or definitive trial
  - This is the definitive randomised controlled trial to evaluate a complex intervention and requires attention to standard issues of adequate power, randomisation and blinding (where feasible), appropriate outcome measures, informed consent and other standard features of well designed trials.

5 Phase IV or long term surveillance
  - The final step is a separate study to establish the long term and real life effectiveness of the intervention. The application of an intervention outside a research context may be tested and rare or long term adverse events identified. This stage is likely to involve an observational study.

## *1.4 Ethics*

### 1.4.1 Ethical approval

Ethical approval for the qualitative component of the study was obtained from the Camden and Islington Local Research Ethics Committee in September 2001. Ethical approval for the quantitative study was obtained from Trent Multi-centre Research Ethics Committee (MREC) on 2 January 2002 (reference MREC/01/4/059). Under the terms of the MREC approval, relevant local research ethics committees were informed of the study.

### 1.4.2 Informed consent

Potential patients for the baseline qualitative study who were recruited from primary care were identified by general practice managers from general practice registers, approached by a member of the practice team and their permission sought to pass their contact details to the research team. A member of the research team then contacted the patient by telephone, explained the study, arranged a meeting and obtained informed consent. Close persons and professionals nominated by these patients were approached initially by patients to seek permission for their details to be passed to the research team who then contacted the close person by telephone, arranged a meeting and obtained informed consent. Nominated health care professionals were approached directly by the research team. Patients for the prospective study who were recruited from secondary care were first introduced to the study by clinical staff and research nurses affiliated to the National Cancer Research Network (NCRN). They gave written consent for their contact details to be passed to the research team. A member of the team then contacted them by telephone, sent them detailed information about the study and arranged a meeting to explain the study further and obtain informed consent. Each patient was also asked to nominate a close person who might also participate. After close persons had been approached by the patient and had agreed for their contact details to be passed to the research team, a member of the team then contacted close persons by telephone, sent them detailed information about the study and arranged a meeting to explain the study further and obtain informed consent. Patients who could not nominate a close person at the time of recruitment were asked at each follow up interview if they had decided on a nominee who could then be approached. All patients and close persons gave fully informed consent before taking part in this research and were made fully aware that they were free to withdraw from the study at any time.

### 1.4.3 National Cancer Research Institute approval

Funded by the Department of Health, this study was approved by the National Cancer Research Institute and formed part of their national portfolio of approved studies. Recruitment data were sent monthly to the institute’s co-ordinating centre and included on their database. Recruitment to the study was assisted by research staff from the National Cancer Research Network based in the three London networks.

The participating cancer networks and NHS trusts were:

1 North Central London Cancer Network
   - Royal Free Hampstead NHS Trust
   - University College London Hospital NHS Trust
   - Whittington Hospital NHS Trust
   - North Middlesex University Hospital NHS Trust

2 North East London Cancer Network
   - St Bartholomew’s and the London NHS Trust
   - Newham University Hospital NHS Trust
   - Homerton University Hospital NHS Trust

3 South East London Cancer Network
   - Guy’s and St Thomas’ Hospital NHS Trust
   - The Princess Royal University Hospital, Bromley Hospitals NHS Trust
   - Queen Elizabeth Hospital NHS Trust, Woolwich.

Members of the research team liaised closely with cancer network managers and senior local cancer research network staff before and during recruitment. Administrators from the National Cancer Research Network provided support in registering the research with local research and development departments in each participating NHS trust within their network.

## *1.5 Study design*

Measuring experienced continuity is challenging as there are few continuity measurement tools available, there is confusion between measurement of service continuity and measurement of how that service is experienced by patients, and most centre on general practice care (see Section 6.3.4). Because of uncertainty and debate about current concepts of continuity of care, we decided to use a grass roots approach to elucidate what patients, close persons and health professionals consider of importance in their experiences of continuity of care. As noted above, although several current models of continuity of care are considered as 'theoretical' in terms of their development, in the main they are descriptive categories (Centre for Health Services and Policy Research, 2006; Haggerty *et al*, 2003). To accord them the status of theory may be premature. Examples of theory-driven concepts are those underlying behavioural approaches to clinical care, especially those applied to changing behaviours such as smoking, excessive eating or depressive thoughts. These behavioural models of care were derived from theories of physiological function as described by Pavlov and behavioural theories as originally conceived by Skinner (1953). None of the existing concepts of continuity of care are rooted in theory; rather they are based on professionals' opinions of what constitutes continuity. Furthermore, few have taken into account the user or carer perspective. We decided to develop ideas of continuity based on the user view of what mattered. Thus, we did not approach patients and close persons with the aim of validating any particular model of continuity. In this report, we present findings of pre-clinical and theoretical work according to the MRC framework for the development of complex interventions. Our aim was to address with patients, close persons and professionals the issues that relate to patient care and in particular to continuity. We asked patients and those closest to them, as well as key professionals, to tell us about their experiences and used this information to devise a prospective phase I study in which we modelled how continuity changes with treatments and time. To do so, we recruited representative cohorts of patients and close persons in each of five phases in cancer care in order to investigate for up to one year their individual behaviour and interactions with health service organisations. In this way we aimed to model changes in perceived continuity and satisfaction with care as patients move through different aspects of cancer care. While we were already aware of many of the mechanisms by which cancer services are delivered, by following a grass roots approach and examining continuity of care from user and provider perspectives, we aimed to develop a greater understanding of the factors that affect patient and carer experience of care. Our findings have enabled us to begin to model our intervention that will be tested in a phase II trial in future work. Phase II work has received additional funding from NHS SDO Programme and commenced in July 2006; it will continue for 18 months.

### 1.5.1 Pre-clinical phase

The project took place in two parts.

In part 1, we undertook an eight month cross-sectional qualitative study of patients recruited in general practice in two London primary care networks: the North Central London Research Consortium (NoCLoR, formerly NoCTeN) and the South London Research Network (StarNet).

#### *Methods*

**Participants:** Patients with breast, lung or colorectal cancer and their nominated close persons were recruited in five phases of care, namely diagnosis, end of first treatment, remission, relapse and referral to palliative care. The roles of close persons vary according to the patients' phase of treatment and the term 'carer' was not thought to be applicable, for example, when the patient was in remission. Potential patients were identified by practice managers from general practice registers. We used general practice for this baseline qualitative study to ensure that we recruited as wide a sample of people with cancer as possible and not just those on secondary care cancer registers. Each potential recruit was approached by a member of the practice team and their permission sought to pass their contact details to the research team. A member of the research team then contacted the patient, explained the study and obtained informed consent. For ethical reasons the practice team could not record patients who wished not to take part and thus we could not establish clear response rates. Patients were interviewed once at a venue of their choice; most interviews occurred in patients' homes. All interviews were audio-taped. Each patient also nominated:

1. a person close to them (close person)
2. one primary health care professional
3. one secondary health care professional, who the patient judged had provided them with most support during their illness.

These nominees were approached by the research team and also undertook recorded interviews. Interviews with professionals were either conducted by telephone or face to face. When one health care professional was nominated by several patients, those patients were all discussed in a single interview with that health care professional.

**Interviews:** In all interviews with patients, close persons, or health care professionals the main focus was on the patient's *longitudinal* experiences of cancer and cancer services. This encompassed the period up to and including the patient presenting his/her symptoms, through diagnosis, treatment and, where appropriate, remission, relapse, further treatments and experience of palliative care. Interviewers used a series of topic guides to ensure they kept to themes of interest for the study, namely how consistently information was communicated to the patient and close person; whether patients felt they received a timely and consistent service; the manner in which this helped them deal with the cancer within the context of their lives, both past and future and the physical and emotional impact of the illness and its treatment on patients and those close to them. Although in patient and close person interviews the word 'continuity' was avoided in order not to lead participants or impel us to define it for them, interviewers strived to keep the focus on linked up and consistent services. In close person interviews, further attention was paid to the impact of the patient's cancer on the close person him/herself, while health care professionals were asked to offer their opinions on the points at which continuity in service provision in cancer care might be improved. All interviews lasted no more than 45 minutes, were audio-taped and transcribed verbatim (qualitative interview schedules, Appendix A).

**Analysis of the qualitative data:** Each interview was independently analysed and coded by two researchers. In the event of disagreement the coding was discussed and agreed by consensus. We undertook a thematic analysis using N-Vivo (Neuendorf, 2002). The procedure began with the task of theme identification, where three researchers independently noted any themes that were emerging in randomly selected transcripts. There then followed a process of designing and piloting a coding framework based on these emergent themes. The proposed framework was tested on transcripts and, based on its effectiveness with regard to the data and its usability as assessed by the researchers, revised for further testing. The coding frameworks were finalised following the third iteration of this process (Appendix B). All interview transcripts were then independently dual-coded using these frameworks. In the event of disagreements, mutually agreeable codes were negotiated between researchers. A survey of a representative sample of the data found a mean rate of disagreement in codes of 9.1 per cent. The codes were then transferred to QSR NVivo v1.2, thus allowing this substantial dataset to be interrogated in a more manageable fashion.

We then used the data for those cases where there were four interviews (that is, patient, close person and primary and secondary care professionals) to conduct a case study analysis. The themes independently derived from the interview with the person with cancer and the three informants were triangulated by five member of the research team (IN, LJ, AI, HA & AR) to draw clear ideas on experiences of continuity based on these four perspectives (Stake, 2000). Once this was achieved for each individual case, the emerging themes from all seven cases were brought together to develop concepts on continuity of cancer care based on these cases.

# Section 2 The study: part I

## *2.1 Results for part 1*

### 2.1.1 Patient characteristics

Twenty eight patient interviews were available for analysis (Table 1). Twelve were women with breast cancer (mean age 58 years), nine were patients with colorectal cancer (five female, mean age 67 years) and seven were patients with lung cancer (four female, mean age 71 years).

Although our original target was 30 patients, after the completion of 28 patient interviews, no new themes were emerging. Patients were included in the study even if they were unable to nominate either a close person or either health care professional at that time. We felt that inclusion of such data was an important finding.

## *2.2 Thematic analysis framework*

### 2.2.1 Patient interviews

The following section outlines the emergent themes from the patient interviews.

***Patient experiences of care were overshadowed by events surrounding diagnosis.***

1 Delays in diagnosis: These were experienced both in primary and secondary care. Patients experienced regret when GPs failed to appreciate the seriousness of their symptoms and referrals for investigation and to secondary care were delayed.

> *It was by chance that I went back to my practice in May of 2001 about something totally unconnected and I said by the way I never got my colonoscopy appointment.*
>
> (Patient 4)

2 Manner in which the diagnosis was given: Many patients reported a poor experience of receiving their diagnosis for the first time, although it was not certain whether this reflected the shock of receiving the diagnosis rather than the communication skills of the health care professional involved.

> *The way she told it was not very nice, very blunt, you know, very conveyor belt, oh another one got it and it was a bit upsetting........ it went a little bit over my head.*
>
> (Patient 11)
>
> *I find it difficult to recall the terrible things in life.*
>
> (Patient 2)

**Table 1 Details of patients, close persons and professionals interviewed in the baseline qualitative study**

| Tumour type; patient ID number | Treatment phase | Sex and age | | Close person<br>n/i = not interviewed | Primary HCP | Secondary HCP | Complete interviews (number) |
|---|---|---|---|---|---|---|---|
| Colorectal 1 | 1 | M | 58 | Daughter | GP | CNS | 4 |
| Colorectal 2 | 2 | M | 56 | Friend | GP | Surgeon | 4 |
| Colorectal 3 | 3 | M | 69 | Wife | GP | Senior staff nurse | 4 |
| Colorectal 4 | 4 | F | 59 | Husband | GP | Aromatherapist | 4 |
| Breast 5 | 3 | F | 60 | Daughter | GP | Oncologist | 4 |
| Breast 6 | 3 | F | 68 | Friend | GP | CNS | 4 |
| Breast 7 | 5 | F | 56 | Husband | GP | CNS | 4 |
| Lung 8 | 5 | F | 72 | Friend | GP | - | 3 |
| Colorectal 9 | 3 | F | 68 | Daughter | - | Stoma nurse | 3 |
| Breast 10 | 2 | F | 55 | Colleague | GP | - | 3 |
| Breast 11 | 4 | F | 71 | Daughter | GP | - | 3 |
| Lung 12 | 1 | M | 71 | Partner | - | - | 2 |
| Lung 13 | 1 | F | 76 | Friend | - | - | 2 |
| Lung 14 | 3 | M | 67 | Wife | - | - | 2 |
| Lung 15 | 3 | F | 82 | Daughter | - | - | 2 |
| Lung 16 | 5 | F | 67 | Husband (n/i) | - | CNS | 2 |
| Lung 17 | 5 | M | 65 | Partner (n/i) | - | CNS | 2 |
| Colorectal 18 | 4 | F | 83 | Friend (n/i) | GP | - | 2 |
| Breast 19 | 1 | F | 41 | Friend | - | - | 2 |
| Breast 20 | 2 | F | 69 | Husband | - | - | 2 |
| Breast 21 | 3 | F | 49 | - | GP | - | 2 |
| Breast 22 | 4 | F | 68 | - | GP | - | 2 |
| Breast 23 | 5 | F | 67 | Husband | - | - | 2 |
| Colorectal 24 | 5 | F | 73 | - | - | - | 1 |
| Colorectal 25 | 5 | F | 76 | Daughter (n/i) | - | - | 1 |
| Colorectal 26 | 5 | M | 59 | Wife (n/i) | - | - | 1 |
| Breast 27 | 1 | F | 52 | - | - | - | 1 |
| Breast 28 | 4 | F | 42 | Friend (n/i) | - | - | 1 |

*Note: in six cases close persons were nominated, but not interviewed. HCP = health care professional; CNS = clinical nurse specialist.*

3 Effect on engagement with care: A poor experience at first contact with services cast a long shadow over the patient's trust and confidence in the services and in health care professional involved in their care.

> *She (the consultant) just went on…it was like she was on auto-pilot because she went on to explain heredity and the genetics of breast cancer….it wasn't what mum needed to hear…I really don't think to say to someone – you should fear the worst -…..the first thing that came into my head was that mum was going to die….you are left to your own interpretations. When we saw the surgeon, I felt a bit more confident, and questions I asked he answered. The GP started seeing her once a week…it was good to have someone totally separate, if there was something she could not say to me or the medical staff…..I think my mum slipped through the net a few times.*
>
> (Patient. 5, Close person)

### *Impact of treatments*

Most patients agreed to undergo conventional medical treatments such as surgery, radiotherapy and chemotherapy. Attending hospitals for such treatment programmes was time-consuming and debilitating.

> *As I say I could cope with my illness and that but I just felt so, really and truly tired, never felt like that in my life before, really tired out and the doctor kept saying to me, don't you, don't think, you're body's gone through a terrific thing, I can't understand this bit but he said, you know that operation, your body will, you know, you've had a tumour there, you've gone through such trauma your mind, and I can't understand all that about it and I said this is what's happened, why am I feeling so tired? I mean I don't do much much of the day, I might potter in the garden, you know.*
>
> (Patient 5)
>
> *Oh yes it had a severe impact. I couldn't even cut a slice of bread for ages, for months. I couldn't have gone home to my flat alone. I couldn't have fed myself, my mum was here.*
>
> (Patient 19)
>
> *I do know that there's something internally although I'm now going to the toilet it's the other thing of whether the side effects of the radiotherapy weaken the sphincter muscles so if I go out I have to wear an incontinent pad and sometimes I just have to rush to the toilet very quickly and sometimes I make it, sometimes I don't. Most of the time I can control it, but sometimes it just bubbles up and comes out and there's nothing you can do about it.*
>
> (Patient 2)

During active treatment, trust and confidence in service providers, particularly in secondary care, was very important. A small proportion of patients supplemented their conventional treatments with complementary therapies such as aromatherapy or massage.

> *In a way it was a challenge to try and deal with it and I tried to do everything I could to fight it and to do my best. Because you feel not very empowered in hospital and if you do all these alternative things, eating vitamin C and doing a bit of that you feel you are contributing towards your health.*
>
> (Patient 27)

> *Well it's just that they offer counselling, all kinds of therapies, massage, yoga they offer a huge range of complementary therapies which is what you need… In Germany for instance you would have a surgery and then go into a rehabilitation clinic for a couple of weeks or even longer.*
>
> (Patient 19)

### *Maintaining a feeling of normality and sense of self*

Many patients reported a need to maintain a sense of connection with how their lives had been before the diagnosis. Returning to normal daily activities between treatments was of great importance. While patients were keen to know where to find help should they need it, it was also important for them to forget the illness. This may reflect a need for a sense of discontinuity.

> *She still puts her make-up on every day, she still dresses as well as she can, does her hair and her nails, yeah. Yes, and I've said from the neck up you don't look any different she doesn't but I mean, she's just disappearing.*
>
> (Patient 8 close person)
>
> *It seems as though there's an atmosphere of uncertainty that you've both addressed by saying life continues as normal so if I establish a normal pattern then life becomes more certain.*
>
> (Patient 13 close person)
>
> *Yes. We carry on as normal as possible. I think that's probably what I mean to say.*
>
> (Patient 13)

### *Relationships with the family*

Existing relationships and roles within the family strongly affected responses to illness. Patients and close persons experienced shifting roles and often desired to protect each other. Changes in actual and perceived family dynamics, often shaped by past and present experiences of illness, affected their attitudes to illness and in turn their engagement with and continuation in care. Over a long relapsing and remitting illness, family events and fears for the future influenced attitudes to illness.

> *I'm sure he does worry about lots of things, I mean, he's worrying about dying, he's worrying about what's going to happen to me, I think he's worried about his two sons, nineteen and twenty-two, you know.*
>
> (Patient 12 close person)

### *Information and service related issues.*

How services responded; whether patients' records, test results, X-rays and scans were available; and what professionals appeared to remember about their cases all influenced their perceptions of care and continuity of that care.

> *They've got the notes, but not the (X-ray) films… between chemotherapy and radiotherapy and all those different consultations… and moving from one hospital to another, I don't think all the notes moved across properly….there does seem top be regular written communication between hospital and GP, but sometimes takes several weeks to happen…letters to the GP from the hospital are less reliable and slower (than from GP to hospital).*
>
> (Patient 7)

### *Trust, confidence and making a connection*

The availability of a main contact person appeared to be crucial in generating trust. Usually this professional was the GP in primary care, while in secondary care the clinical nurse specialist and sometimes the oncologist was the professional with whom a particularly strong relationship had been established.

> *The doctor (GP) was brilliant at communicating… could ask a million questions and he would answer every one… I used the doctor as a counsellor really…*
>
> (Patient 5)

## 2.2.2 Close person interviews

Eighteen close person interviews were available; eight nominated by patients with breast cancer, five by those with colorectal cancer and five by those with lung cancer. Seven were spouses or partners of patients, five were adult children (all daughters), five were described as friends, and one as a colleague (see Table 1). A total of 24 patients were able to nominate a close person, but when approached for interview, six of these were unavailable because of practical difficulties in arranging appointments. Close persons described both their perceptions of the patients' experiences of care and the impact of the illnesses on their own lives.

The following section outlines the emergent themes from the close person interviews.

### *Practical issues*

Close persons often took responsibility for ensuring that hospital appointments were kept and that treatment delays were reduced to a minimum. Many close persons spent time researching information sources, such as the internet.

> *We have to use mini-cabs because we can't park anywhere (near the hospital).*
>
> (Patient 9 close person)
>
> *A lot of the time we weren't given much information… needed leaflets.*
>
> (Patient. 4 close person)

### *Emotional responses to patient's diagnosis*

Some close persons expressed strong emotional responses to the patient's illness that were often not revealed to the patients themselves. While patients were generally more accepting of their diagnoses, close persons tended to show more anger at perceived delays to care and scepticism about and lack of confidence in health care providers.

> *We wanted a second opinion… to try to decide how much we could trust them (the routine doctors)… what's difficult is the waiting… it is quite a shock at the time to be told these things, it's very hard to take in all the information.*
>
> (Patient. 4 close person)

#### *Effect on close person's life*

Close persons, who were often either family members or closely connected to the direct family, described altered family dynamics as a result of the illness and consequent shifts in roles within the family. The impact was most evident around diagnosis and end of first treatment and in the phase of end of life care. Some close persons described being made more aware of their own risk of developing cancer.

> *My sister couldn't really handle it, my brother couldn't speak to me… I felt like I was facing it on my own… my sister doesn't like hospitals, so they pushed me forward to go to appointment (with mum)… weekends were worst, if my mum went to my brother's, they hadn't told their children that mum had had the operation, so if mum went down there she couldn't mention anything.*
>
> (Patient 5 close person)

### 2.2.3 Health care professional interviews

Some health care professionals were nominated by several patients and these patients were discussed in a single interview with health care professionals.

#### *Primary health care professionals*

The only key professionals nominated by patients with all cancer types were GPs. Fifteen out of the 28 patients did not nominate a primary health care professional, five with breast cancer, four with colorectal cancer and six with lung cancer (Table 1). Responses from GPs were varied; some had a special interest in cancer (one was a Macmillan GP facilitator), others showed great commitment to their patients and bridged the gaps between primary and secondary care by exercising considerable personal effort.

#### *Secondary health care professionals*

Ten out of the 28 patients nominated a secondary health care professional. Five patients nominated their clinical nurse specialist, one a senior staff nurse, one a stoma nurse, one an aromatherapist, one a surgeon and one an oncologist (Table 1). Eighteen patients (nine with breast cancer, four with colorectal cancer and five with lung cancer) did not nominate a secondary health care professional.

### 2.2.4 Emergent themes for primary and secondary care professionals

Not all health care professionals could recall individual patients and thus were not able to give detailed information. However, from the remainder the following themes emerged:

#### *Advocacy*

GPs often found themselves in the role of patient advocate. Patients would consult them between hospital appointments to ask questions and discuss future treatment decisions and the likely course of the illness. GPs also reported having to chase up appointments with secondary care to ensure timely referrals.

> *I had anxious phone calls from the husband and (the patient) herself… I had eventually to put more pressure on the house officer…. saying this is not acceptable, you can't just say we can't find the notes so we're not operating.*
>
> (Primary health care professional to Patients 3, 4 and 9)

### Trust and continuity

Clinical nurse specialists were aware of the key nature of their role for many patients. They acknowledged the problems surrounding how diagnoses were given by professionals and received by patients and stressed the importance of the success of initial contact in establishing a relationship of trust.

> *I think, yeah, people can be quite cagey, not meaning to be, the doctors, but they will not commit themselves because it's as long as a piece of string and you could be on one end or you could be on the other end and the doctors won't commit themselves because they don't want the patients to hold them to that whereas I said to [Patient X] that I know exactly why she wants to know it and I said to her don't hold me to it but at the moment you're in the middle of that piece of string and at any moment you could go to either end and she accepted that. I think if you just say things in a different way so that they understand better.*
>
> *It could be time constraints, it could be anything but on the other hand that's why people like me have a job because that's what we do – they (patients) see the doctor and we (clinical nurse specialists) translate essentially.*
>
> (Clinical nurse specialist, breast)

### Time

Almost all health care professionals mentioned their frustration over insufficient time in clinical consultations, which limited their ability to provide the kind of service that they would wish.

> *The reality of what happens in secondary care is that it's quite reductionist… each person deals with their bit…. if you've got time to do it, that's one of the things in general practice, you can act as that person who co-ordinates each strand.*
>
> (Primary health care professional to Patients 3, 4 and 9)
>
> *Now you have people that never phone you, you have people that phone you every now and again for something big and it takes you a long time to sort it out because it's big and then you get the people that phone you three times a week for little things but equally take up the length of time, um, and obviously new patients can take a long time. The ones that take the most sort of time are the ones that have metastatic disease because it's harder, it's all the dying and the symptoms and the, even if they're not dying they think they're going to die. In an ideal world, there'd be two of me, so that you could do everything properly, you could do everything properly and you would have time to do all the things you don't have time to do.*
>
> (Clinical nurse specialist, breast)

## 2.3 Case study analysis

In three cases we interviewed only two, in six cases only one, and in five cases none of the nominated informants. This occurred either because the person with cancer did not identify an informant or because the identified informant declined to participate. This left seven patients for whom we identified and interviewed all three nominated co-informants (see Box 1).

Thus we had data from seven sets of four interviews (patient, close person and primary and secondary care professionals) in which we were able to undertake a detailed case study analysis. Key themes emerging from each case study were combined to develop overarching concepts of factors influencing continuity of cancer care.

### 2.3.1 Themes arising from the case study analysis that defined continuity of care

These data provided a glimpse of cancer care from four simultaneous aspects. Patients and close persons often had different perceptions of continuity, determined by their personality, family dynamics and ability to share and communicate treatment decisions with their primary and secondary care professionals. The latter two groups also had particular views depending on their knowledge of and insight into the patients and their families and their own ability and time to provide good care. A brief history of each case interviewed is provided below. The people referred to in italics were the key informants identified by the person with cancer who was interviewed.

**Box 1 Case histories**

**Case 1:** 58-year-old professional man who was recently diagnosed with colorectal and prostate cancer who adopted the attitude of 'not being ill'. His wife and daughter were being treated for depression. He did not tell his *daughter* about the diagnosis of cancer but did tell his wife and sister. Nevertheless, his daughter had already guessed he had cancer but was unable to openly discuss this with him. As time went by, he was able to tell her about his illness and include her in decision-making. Both of them felt that this was a positive step. The diagnosis of two cancers at the same time, resulted in case 1 receiving conflicting guidance on management from the specialist consultants. The *clinical nurse specialist* and the *GP* served as the facilitators between the two disciplines, urology and surgical gastroenterology.

**Case 2:** 56-year-old single, socially isolated, unemployed gay man. His had only two close friends who he seldom met. He did, however, speak to them regularly on the telephone. He initially presented with abdominal pain and was referred to hospital for investigations. These were said to be normal. A year later after moving house, he experienced the same severe pain and was coaxed by *his friend*, to visit his new GP. He saw a locum GP who referred him to the local hospital. He failed to receive an appointment as the letter went astray. As his symptoms worsened, he visited the surgery several months later and consulted with another *GP* who urgently referred him to hospital where he was found to have colorectal cancer. The *consultant surgeon* conducted extensive surgery and this was followed by radiotherapy. These treatments made him weak and left him with sexual dysfunction. His sexuality was a most important part of his life and his persistent sexual dysfunction made it seem to him that 'this was the end'.

**Case 3:** 60-year-old married musician living with his *wife*. He was diagnosed with colorectal cancer and was in remission at the time of the interview. Although he initially delayed visiting his *GP* following persistent rectal bleeding, he felt that his access to private medical care ensured that he received quick and quality treatment. The radiotherapy following surgery, however, left him weak and tired. He felt well supported by the *oncology nurse* who he said was 'worth her weight in gold'. He seldom discussed the prognosis of his illness with his wife. This proved problematic as she was preoccupied by his impending death. She was of the opinion that his illness had put her life on hold. He got a lot of comfort from his family who visited him every weekend. He said that his finances were in disarray and his death would create difficulties for the family.

**Case 4:** 56–year-old teacher with advanced colorectal cancer and liver metastasis living with her *husband* and two children aged 15 and 18 years. She initially consulted her *GP* with pelvic pain and he wrote a referral to the surgeon at the local hospital. She did not, however, get an appointment. She returned six months later with the same symptoms and rectal bleeding. She was now referred urgently and found to have colorectal cancer. Following this she was the victim of a series of hospital administrative problems that almost resulted in her surgical treatment being cancelled. Case 4 and her husband were distressed by their experiences and both saw a counsellor to help them through the emotional difficulties that the cancer had brought to their lives. She gained a lot of support and strength from her *aromatherapist* whom she saw in hospital.

**Case 5:** 60-year-old divorced woman with breast cancer in remission. Her *GP* referred her soon after detecting a breast lump. The hospital consultant who assessed her told her to 'fear the worst'. This she interpreted as a diagnosis of terminal cancer. This miscommunication between the patient and the consultant and the latter's inability to clarify specific questions posed by her together with a long wait for her biopsy results and followed by a six-week wait for radiotherapy treatments proved to be frustrating and led to her becoming anxious and depressed. Nevertheless, she developed a good rapport with the *oncologist*. She also saw her GP regularly. He started her on antidepressants after she expressed ideas of suicide to him. She presented her brightest side to her children and depended heavily on her *eldest daughter* who facilitated her contact with the health services and ensured that no treatment gaps occurred. The other children, however, were a lot less supportive.

**Case 6:** 68–year-old widowed woman who lived on her own. Her only close contact was her *friend* who was nominated as next of kin. At the times of interview she had recently experienced a relapse of breast cancer that was discovered on mammography. She then waited for two weeks for confirmation of the diagnosis of recurrence. This was very distressing. She was given little information on her prognosis or treatment plans but was admitted to hospital for a surgical lumpectomy and auxiliary clearance, She was discharged the day after surgery. Post-operatively she developed a wound infection and a lymphocoele. She sought help from her *GP* and the senior *breast nurse,* was her main hospital contact. She was generally self sufficient but sought emotional support from her friend. Her friend was displeased with the level of support offered to her by the medical profession.

**Case 7:** 55-year-old teacher who lived with her *husband* and had widespread bony metastasis of her breast cancer diagnosed 12 years ago. Her *GP* was of the opinion that although she was aware of her imminent death, she was poorly prepared for it. She said that she wanted her son to complete university before she died. She seldom spoke to her husband about the future nor did she or her husband share the details of her illness with her son. She had chemotherapy treatment offered to her by the *oncologist*, who she trusted. She also relied heavily on her GP who she felt went out of his way to support her through her illness.

### 2.3.2 Analysis of main themes

Six main themes emerged from analysis of these seven case studies as follows:

### The patients' personality

This had both an historical and ongoing influence on perceptions of continuity and experiences of care. Patients' personalities vary and affect coping styles and preferences for care. Patients who actively took control of their care were more able to influence continuity than those who were disengaged and/or depended on the medical professionals to take charge of their illnesses. For example, Case 1's ability to take control of the situation was a key factor in influencing good continuity of care.

> Interviewer: *Was the information they gave you easy to understand?*
>
> Case 1: *I made a point of discussing it till I did. I took a view early on that I needed to know as much about this in order to help the decision-making process, particularly as we had two primary sites, so I kept asking questions until I got the answers I understood.*
>
> Case 1's GP: *He's a pretty kind of intelligent and motivated guy – he finds out what he needs to find out. He doesn't have that many questions, sticks to his medicines, turns up to his appointments. I really don't think the cancer services or the staffing there is sort of the level where they could give him the information that he wanted. So a lot of it he found online or by reading or by talking to me, some of it he came to me to ask. If I had to make any criticism about his care it would be that it would probably have been nice if he'd had more time to spend with them to ask some of these questions.*

### The patient's family

Existing family roles and shifting family dynamics with onset of illness in one of its members had a profound and ongoing effect on continuity of care. Most participants were unable to have a frank discussion with their family about the diagnosis and the long-term impact of their illness. People with cancer and their nominated close person often expressed different opinions. Continuity is affected by existing family dynamics and communication within the family; these factors may change with the onset of illness. Case 3 relied heavily on his family for support.

> Interviewer: *Did that have any knock-on repercussions, did you feel isolated or anything?*
>
> Case 3: *Not really because we've got a very close family and children and grandchildren always around here every weekend at least so there's nothing like that for cheering you up.*

However his wife was unable to share with him her own distress:

> Interviewer: *Before you actually found out the diagnosis was cancer one of the possibilities you considered?*
>
> Case 3's wife: *Yes.*
>
> Interviewer: *And did you discuss that between you?*
>
> Case 3's wife: *It was more private.*
>
> Interviewer: *Why didn't you discuss it?*
>
> Case 3's wife: *I wasn't sure that (Case 3) wanted to. In fact I felt that he didn't want to. Yes. I'm quite sure that he thought the same as me, that it was cancer but…. no we didn't discuss it very much.*

### *Treatment decisions shared between professionals and patients*

The extent of information sharing is dependent on patient preferences and the quality of communication that is possible. There were differences in the patients' and clinicians' perspectives of what constituted acceptable waiting times between appointments, undergoing investigations and getting results and treatments. Patients' involvement in treatment decisions facilitated continuity of care whereas inability to clarify uncertainties emerging from consultations or current and past clinical experiences hampered continuity. The six-week wait for radiotherapy following surgery made case 5 depressed and suicidal. She visited her GP who did not share with her the clinical reasons for this delay.

> Case 5::*I was waiting for the radiotherapy to start, cos you have to wait and I was lucky I had to wait six weeks, some people wait three months… And that was a worry when that started what could I expect? How was I going to be? And I went round to my GP and I did sit there and for some reason I said to him I feel so suicidal, I don't think I can face this and I think that's when he suggested the Prozac. But I apologised to him after… cos I would never do anything like that… cos of how it would hurt my children.*
>
> Case 5's GP: *Well depression and anxiety are sort of bread and butter of general practice we see it a lot and also miss quite a bit. So from my perspective it wasn't a problem. But it was a problem for her but it was all mixed up in the fact that she had just been diagnosed with cancer and had just had her operation. The first time I met her she was still bruised from her procedure and they were delaying radiotherapy until she healed a bit more, and that was getting to her, she wanted them to just get on with it.*

Similarly Case 6 waited for two weeks for the results of her investigations. Medically neither of these delays resulted in adverse outcomes but this together with conflicting opinions from different secondary care staff on her treatment did cause uncertainty that later defined and shaped the patient's experiences of continuity.

> Interviewer: *What's your opinion on the quality of care you've received?*
>
> Case 6: *I think I received very good care. I consider myself lucky, the way that it was spotted so early and the team… They really seem to be professional, they're very good.*
>
> Case 6's friend*: as usual, prognosis, you know, one person seemed to be saying oh well it's absolutely wonderful and other people seemed to be saying tut-tut, you know, so it was very muddling.*
>
> Interviewer: *There was a conflict of information?*
>
> Case 6's friend: *Tremendous. There was a conflict about what to expect after the operation. She really didn't have a clue. There appeared to be big areas of problems about treatment. And I don't think, and again I'm only giving by my perspective, nobody sat down with her. I did… I said, well come on let's look at it, if you have chemo it'll be like this, if you have radiotherapy… but I don't think anybody did that. I was very surprised at her discharge after the operation from the hospital. I was so surprised. I actually think that they let her out a lot too soon. I turned up and went to where her bed was and she wasn't there. I rang her at home from the hospital and she was very cross because I think they'd said, well you can go soon so she'd said, well I'll go now which again is very much how she deals with things. I think they should've prevented her. They just said to me, well she seemed a bit cross, is she upset?*

### *Communication between primary and secondary care*

Some patients reported up to date, timely information transfer across the primary/secondary care interface. Others reported that their GPs had not received information on recent treatments and therefore were unable to discuss the details or side effects with them. Communication was hampered by loss of initial referral letters and delay in information transfer from secondary to primary care. This resulted in treatment delays and a gap in information transfer across the primary/secondary interface. In two instances (Cases 2 and 4) the initial referral letter from the GP to the hospital went astray.

> Interviewer: *You've spoken about the quality of care you received not necessarily being the best at the start from the point of view of loss of notes and....*
>
> Case 4: *I feel it was lack of communication. I feel the technical side is wonderful and in my letter to the chief executive i said I think the expertise is wonderful and they were just let down by the admin and the clerical. That's the feeling I had. I think the surgeon was wonderful but why didn't I get the appointment?*

### *The health care professionals*

**The patient's GP:** All seven cases nominated their GPs as the key primary care professional facilitating continuity but close informants did not always share this view. Case 5 consulted her GP when she felt suicidal and was grateful for the support she received despite the fact that he did not explore the reasons behind her anxieties (see 'Treatment decisions shared between professionals and patients', above). Her daughter, however, was less convinced about the GP's input.

> Interviewer: *What is it about the GP that you think was particularly good?*
>
> Case 5's daughter: *I think he reassured my mum. To be honest with you I haven't got as much faith in the GP as my mum has. I think it's my mum's generation that respect GPs and even sometimes the information is given – I think mmmm... bit [of a] strange thing to say but it reassured my mum and the bottom line was it helped her.*

The GP was the key person that provided medical support and continuity to Case 7. He answered all her queries and offered care even when he was on holiday and at weekends.

> Case 7: *He's involved with the palliative care stuff so probably I'm getting more help than I otherwise would. He is very committed so he's come very regularly and visited me at home, particularly when I was in a bad way, to make sure I was all right, phoning me up and coming round.*
>
> Interviewer: *Is that important?*
>
> Case 7: *Oh yes*
>
> Interviewer: *Do you feel if there is a problem he'd be your best contact?*
>
> Case 7: *Yes. I wouldn't want to abuse that. There was one point when I did feel very in need. I phoned him up at some inappropriate time and said 'help!'. I didn't want to, obviously there's a limit as to what you can ask him to do. He just came out and sorted out a whole big problem for me, which was brilliant!*

**The patient's clinical nurse specialist:** four of the seven cases reported contact with specialist nurses and nominated them as their key secondary care informant. Case 3 found temporary nurses on the hospital wards unpleasant, and 'sour and incompetent'.

> Interviewer: *Was there any particular nurse you would seek out if you needed information?*
>
> Case 3: *An Australian woman, she was really worth her weight in gold.*
>
> Case 3's clinical nurse specialist: *You've got a whole class structure in hospitals which is something that I'm not used to and I don't handle very well, that's how miscommunication happens I think where you've got the doctors not telling people at the coal face things and people at the coal face often a bit too nervous to actually go and say things.*
>
> Interviewer: *What are the things that are currently undermining joined up cancer care?*
>
> Clinical nurse*: No qualified nursing staff. My job for example has been advertised six times in the last two and a half years and I'm still here. I have been offered it seventy thousand times. Six thousand pounds they've spent on the advert and nobody applied… because it's quite a stressful field… you'll find that people staying in it, every two or three years need a break, so then you're losing somebody for twelve months while they go off and do something else, if they ever come back.*

**The patient's hospital specialist:** Three of the seven cases nominated their hospital consultants as their secondary care informants. The existence of a long-term relationship with the same professional facilitated continuity of care. GPs were well regarded and patients relied on them to make an early diagnosis, facilitate speedy referrals to secondary care, inform their treatment decisions, explain existing treatments and act as their advocates. Surgeons, junior doctors and temporary nurses were not so favourably regarded but clinical specialist nurses and oncologists did contribute to continuity.

Case 7 disliked contact with junior doctors that inspired little confidence, as they showed poor understanding of her clinical condition.

> Interviewer: *When you have your consultations is it usually the oncologist that you see?*
>
> Case 7: *More often than not, but sometimes it will be a registrar. You tend to prefer it if it's the consultant because you have a continuity of understanding as to what's going on with her and you have a relationship over the years. It's always difficult seeing a registrar who you've never met before and it's obvious that very often they've had a quick flip through the notes and they don't really know what it is about because they've been lumbered with this patient.*

Case 4 felt that the surgeon failed to offer her any hope when diagnosed with a liver metastasis and yet this was treated surgically.

> *He said 'well your liver's too small, the good lobe is too small' and the oncologist tried to say 'well there are things we might try'. But I left that meeting, my husband was with me, we both felt this is real despair. The second time was when I saw another liver surgeon after I'd had the embolisation and they did a scan to see how much the left lobe had grown and he said, 'I do have to tell you that it looks like your left lobe hasn't grown enough, so I don't think we'll be able to operate, but we don't have a volumetric study and as soon as we have that I'll get back to you' and he did within 24 hours, he rang me up to say they'd looked, they'd had the volumetric study it was 31 per cent not 40 per cent but [Surgeon X] could do it… the difference between a so-called curative approach and – I hate the term palliative – how would you define palliative?*

> (Case 4)

### *The hospitals' administration system*

These were frequently regarded as central to the even delivery of care both within secondary care and across the primary/secondary care interface. The existing administrative systems within the NHS were often seen as inadequate resulting in lost referral letters, misplaced clinical records and unreliable appointment systems that led to treatment delays and poor continuity.

> *She forever seemed to be waiting to see this doctor or that doctor. She didn't seem to be clear as to who and what these different doctors were and what their job was, what their function was, what was the significance of seeing this one as opposed to that one. This is again, as you say, entirely mediated through her but it sounded like a mighty muddle.*
>
> (Case 6's friend)

Another example comes from Case 7:

> Interviewer: *When you have your consultations do they always have your notes?*
>
> Case 7: *Once or twice when I first changed from [hospital 1] to [hospital 2], I don't think all the notes moved across properly. Once or twice they've got the notes but not the films. I guess between chemotherapy and radiotherapy and those different consultants. But I understand they work together and have a joint consultation. I think that sometimes caused a delay. One of the difficulties is that they're short of staff sometimes or they have a mixture of permanent staff and agency staff.*

## *2.4 Derivation of questionnaires from part I data*

A set of questionnaires was developed from these qualitative data for use in part II, the prospective study (see Section 3), in which patients and close persons were interviewed every three months for up to one year. Questions for patients were designed to capture experiences of care at baseline and since the last interview. In addition to standardised instruments measuring needs for care, psychological and spiritual status and quality of life (see Section 3.2), we designed questions addressing key themes on continuity and preferences for styles of care that had arisen from the thematic framework and case study analyses of the qualitative data. Questions for close persons mirrored the questions in the patient questionnaires; as well as assessing their own psychological and spiritual status and quality of life, we asked them about their perceptions of *the patients'* experiences of illness and the content and continuity of treatment. We also asked about the close person's sense of emotional and practical involvement in the patient's illness and whether they felt able to cope with the roles they were required to fulfil. We explored whether such roles had changed each three months.

# Section 3 The study: part II

## 3.1 Study design

This was a 12 month prospective cohort study which used two main methods.

### 3.1.1 Quantitative prospective study

We recruited participants from secondary care cancer centres and cancer units across the North Central, North East and South East London cancer networks. Our target was to recruit 250 patients and 250 nominated close persons. We aimed to recruit patients with each cancer type (breast, lung or colorectal cancer) at each of five transitions in care. In order to maximise our likelihood of achieving our target numbers, to simplify recruitment methods for clinical staff, and to ensure an even spread across tumour type, transitions in care and networks, we aimed to recruit two patients with each cancer type at each of the five transitions in care in each network. To achieve this, we aimed to recruit two patients with each cancer type (six patients) at each of the five transition phases from each network, an approximate total of 270 (which was slightly higher than our original target of 250). As the study had received approval from the National Cancer Research Network, staff in each local network and clinical nurse specialists introduced the study to consecutive patients attending outpatient clinics that met the study criteria for each transition in care required. Each patient recruited was asked to nominate a close person to take part in the study. If patients were unable to nominate a close person, they were not excluded from the study, but we asked at each follow up point if a nominee had become available.

#### *Follow-up*

Patients and close persons were interviewed every three months for up to one year.

### 3.1.2 Qualitative prospective study

We also conducted a small scale, prospective qualitative study recruiting from secondary care, in which to understand in more detail how perception of continuity changed with treatment phase. We aimed to recruit a total of 15 patients and 15 nominated close persons, five from each cancer network sampled from tumour types and transitions in care. Participants undertook in-depth interviews lasting no more than 45 minutes at three points over one year. The interviews were loosely structured; interviewers used a guide schedule composed of 10 open-ended questions about experience of care (Appendix E). Interviews were audio-taped and transcribed and were conducted at baseline, six and 12 months after recruitment.

## 3.2 Patient and close person interview schedules for quantitative prospective study

The detailed schedules can be seen in Appendices C and D.

### 3.2.1 Patient questionnaire booklet

This was in ten parts. Part 1 comprised standard socio-demographic questions. Parts 2 to 5 comprised questions derived from the qualitative data as follows:

#### Part 2 Events over the preceding three months

We explored the nature of patient's contacts with health care services and whether their emotional and physical health had changed. Specific questions were then asked on information, management and relationship aspects of continuity of care at the most recent service visit. Patients were asked whether their medical team were well informed about their care and had access to their medical notes and investigation results, and whether a main contact person had been available to them in secondary care.

#### Part 3 Continuity of care

Twenty statements were developed from the qualitative data that patients, close persons and professionals considered determinants of comprehensive, joined-up, long term care (Table 2). The core research team at that stage of the project (MK, LJ, IN, AI and HA) discussed in detail each main theme arising from the qualitative data and successively shaped them into statements that best represented each theme. This process was discursive and needed considerable time and thought. Once a skeleton set of statements were derived they were circulated to the project steering committee and clinician colleagues for further modification. We stress that we did not begin with a theoretical model but sought to turn patients', their close persons' and nominated professionals' views on experiences of continuity into a simple and understandable form. Our aim in the prospective, quantitative phase of the study was to take the main themes on experienced continuity that arose from the narratives and see how they predicted other important outcomes over one year. It was decided that the simplest method to present the ideas would be a Likert format in which patients selected one of five possible responses to each statement ranging from 'strongly agree' to 'strongly disagree'. High scores reflected positive experiences. On their content/face validity nine statements accorded with the sorts of issues discussed in published models of continuity (items 1, 2, 3, 4, 5, 6, 7, 8, 18, 19, 20, Table 2), namely receiving appropriate time and attention as well as information about what to expect in the future; and having confidence that nothing had been overlooked. Although professionals may not regard the other items as directly linked to their notions of the delivery of continuous care, there is no reason to expect that they should; rather they were concepts that arose repeatedly from the qualitative data on *experienced* continuity. For example, the attitudes and involvement of close persons could determine whether or not care was timely, taken up appropriately and continuous. This moves away from the idea that continuity of care is a onesided concept that is simply delivered by health professionals. This theme will be returned to later in the presentation and discussion of results.

**Table 2 Statements about continuity of care**

| Item | Statement |
|---|---|
| 1 | I have received enough time and attention from the cancer services |
| 2 | I do not see the cancer services often enough |
| 3 | I am getting consistent information about my illness from health care staff |
| 4 | I frequently have to chase up cancer services to get things done |
| 5 | I have been well informed about what my treatment will involve over the next few months |
| 6 | I am aware of what side-effects to expect from my cancer treatments |
| 7 | I have been told what to expect in terms of my overall health over the next few months |
| 8 | I feel out of touch with the cancer services between appointments |
| 9 | I feel able to cope with minor complications that may arise |
| 10 | I am coping well between my appointments with the cancer services |
| 11 | I have difficulty accepting the limitations my health places on my life |
| 12 | I am well supported by non-medical services e.g. home help, social services etc |
| 13 | I have received sufficient advice on which financial benefits I can claim |
| 14 | I feel supported by the people closest to me |
| 15 | I feel my friends and relatives are able to help me cope with my illness |
| 16 | I am worried about the emotional state of the people closest to me |
| 17 | I feel I depend too much on my friends or relatives |
| 18 | I have received some misleading information from the cancer services |
| 19 | I am content that I have received a full medical examination with regard to my cancer |
| 20 | I am worried that some things may have been overlooked |

### *Part 4 Preferences for care*

The qualitative study also revealed a number of personal styles of managing illness and its associated treatments that might impact on how patients experienced continuity of care. These involved styles of communication with health care professionals and family members, information disclosure, involvement in decision making and preferences for choice of medical staff, treatments and place of care. Thus, we are able to derive 14 statements on preferred styles of care that were presented in semantic differential format. Participants were asked to choose a point (0-10) between two polar (opposing) statements indicating their preference for each of 14 styles of care (Appendix C). The 14 statements had an internal consistency (Cronbach’s alpha) of 0.69 and no single item removal enhanced this significantly. Scoring on statements 1-4, 7-9 and 10-14 were reversed so that a higher mean score indicated full engagement (that is, a wish to be in control and fully informed and involved in decision making), and a lower score indicating a degree of disengagement (that is, a desire for clinical decisions to be left primarily in the hands of professionals and for respondents to have minimal involvement in services and treatment decisions).

#### *Part 5 Questions specific to each phase of care*

This section comprised a series of statements that also arose from the qualitative data with respect to specific issues at each phase of care. Patients chose from five responses ranging from strongly agree to strongly disagree. The numbers of statements varied with each phase; there were nine at diagnosis, eight at end of first treatment, seven while in remission, 10 on relapse and six statements on referral to specialist palliative care. These are not analysed in this report.

#### *Part 6 Overall satisfaction*

As there was no standardised tool available for assessing satisfaction with cancer treatments, we constructed visual analogue scales (each scored 0-10, a high score indicating high satisfaction) for satisfaction on one general and five specific dimensions: 1) Overall satisfaction; 2) Continuity of care; 3) Supportive care; 4) Information needs; and 5) Quality of communication. We also asked on question on the participant's general confidence in care providers.

Parts 7 to 10 consisted of standardised questionnaires addressing care needs, psychological status, quality of life and spiritual beliefs:

#### *Part 7 Needs for care*

The *Supportive Care Needs Survey* (SCNS – see Bonevski *et al*, 2000; Steginga *et al*, 2000) was developed in Australia. It measures current met and unmet needs in the following domains: psychological, health service and information needs, physical and daily living needs, patient care and support and sexuality.

#### *Part 8 Quality of life*

The Euroqol (EuroQol Group, 1990) is a well standardised measure of quality of life.

#### *Part 9 Psychological status*

The 28 item *General Health Questionnaire* (GHQ-28) is a well known, standardised measure of general psychological distress (Goldberg and Williams, 1988) that was designed as a screening tool for common mental disorders (mainly anxiety and depression) in community settings.

#### *Part 10 Spirituality and religious belief*

The self-report version of the *Royal Free Religious and Spiritual Beliefs Interview* (King *et al*, 1995; 2001) is a brief questionnaire that examines religious affiliation and practice, and spiritual beliefs whether or not in the context of religion. For those who report spiritual beliefs, a score can be derived that measures strength of that belief.

### 3.2.2 Close persons' questionnaire booklet

Parts 2 to 6 and 9 to 10 of the close persons' questionnaire mirrored questions from the patient schedule but were adapted to enquire about the close person's perspective on the patient's care and experiences. However, Parts 7 and 8 focused on close persons' specific issues:

#### Part 7 Personal involvement

The first section of this part consisted of 20 statements about the extent of the close person's involvement in the patient's care, with a choice of three responses (scored 0-3), 'not at all', 'occasionally' or 'frequently' (Appendix D). It was derived for the study based closely on work in this area (Thomas *et al*, 2002). The second explored close person's feelings about coping with the patient's illness. It consisted of eight statements for each of which there was a choice of five responses ranging from 'strongly agree' to 'strongly disagree'.

#### Part 8 Quality of life

The *Caregiver Quality of Life Index - Cancer* (CQOLC) *Scale* is a self-administered rating scale designed to assess quality of life issues in family caregivers of patients with cancer (Weitzner *et al*, 1999). The scale has 35 items, each employing a five-point Likert-type response scale with scoring on each item ranging from 0 to 4. Items 4, 10, 12, 16, 22, 23, 27, 28 and 34 are reversed, meaning high scores reflect lower quality of life. The score range for the instrument is 0-140.

## 3.3 Analysis and results

### 3.3.1 Data management

Data were collected using pen and paper questionnaires and entered electronically throughout the project. However, at the end of the study a 10 per cent random check on the accuracy of data entry was carried out and data were entered again for any section of the interview with a greater than one per cent error rate. Each interview was in 10 sections and each was conducted five times. Thus, of the 50 sections checked in the patient database, eight had error rates of more than one per cent requiring the data to be re-entered. Of the 50 sections checked in the close person database, nine had error rates of more than one per cent requiring the data to be re-entered.

### 3.3.2 Statistical analysis

The prospective study followed patients as they progressed through phases of treatment or remission. Our aims were to examine the structure and content of our quantitative concept of continuity of care and identify how patients' and close persons' scores on this concept of continuity at each treatment phase would change as they moved through their experience of disease over the 12 months of the study. We also aimed to understand how perceived continuity predicted outcomes such as satisfaction with services, psychological status and quality of life. We began data collection with patients at five main phases of their illnesses, as we wished to ensure that all phases were experienced by one cohort of patients in the limited time course of the study and anticipated that some would cross to at least one different phase.

We tested whether successive cohorts were equivalent at the same phase of illness in order to explore the heterogeneity of experience of our sample and therefore of our collected data.

### Cross-sectional analysis

We compared demographic, clinical and social differences between patients in each phase of care and in each cancer group using descriptive statistics both at baseline and each follow-up point. Similar analyses were conducted with close persons' data. Our aim was to examine the cross-sectional relationships between experienced continuity of care and other variables in each of the five phases of illness. We evaluated whether or not the pattern of these relationships was different at different phases of the illness (that is, whether it displayed heterogeneity).

### Examination of the structure and content of our measures of continuity

Responses to our questions on perceptions of continuity of care derived from the qualitative data were entered into a common factor analysis. Separate factor analyses were undertaken in patients and close persons. A simple structure was revealed by varimax rotation; items with factor loadings of greater than 0.5 (estimated using the method of maximum likelihood) were retained.

### Multivariable analyses at baseline

To examine the relationship in patients between continuity of care and satisfaction with services we first calculated the standardised regression coefficient of the association between them. The standardised regression coefficient estimates the impact on satisfaction of one standard deviation change in the continuity score. We then adjusted this coefficient by including other covariates in the model which were selected using the backwards elimination procedure and a level of significance of 0.2 for retention in the model. However, some of the variables such as study design (for example cancer network) and demographic variables were retained in the regression model as they were thought *a priori* to be central to this analysis. Questionnaire variables were eliminated by backwards elimination until a final model was reached. We also explored the relationship between continuity of care and other outcomes, such as SCNS needs for care and GHQ-28 score, while adjusting for study design and demographic variables.

### Examining change over time

We first examined rates of attrition; loss to follow up was due both to drop-out from the study and to the death of the patient. We then examined the pattern of movement of patients in terms of the number and types of transitions from one phase to another occurring at any point over the follow up period. In understanding the effect of transition between illness phases on perceived continuity we assumed that whether or not a transition occurred took priority over when or between which phases that transition occurred.

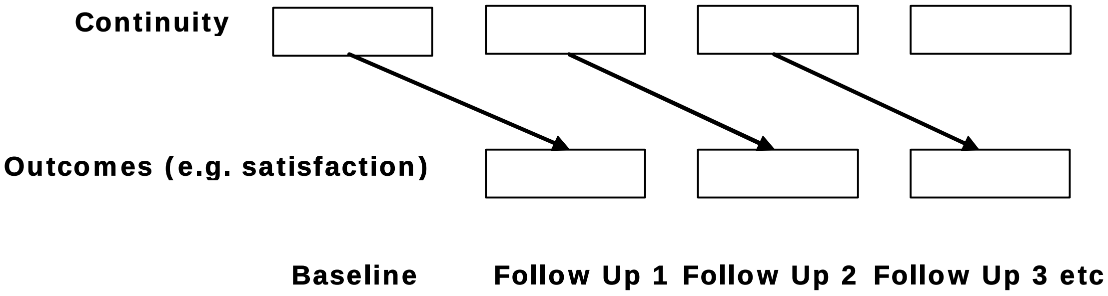
1 In order to deal with the clustered nature of our data (repeated measures in the same patients) we undertook a multilevel model analysis with two levels, time period nested within patients and a

random intercept. The parameters in the multilevel model were estimated using the method of maximum likelihood. We explored the impact of 1) continuity scores on satisfaction, psychological status, needs for care and quality of life; and 2) any transition between treatment phase, on perceived continuity. Within our multilevel model we examined the effect of adjusting for covariates that were fixed at the patient level and also time-varying covariates. Fixed covariates included were the design of the study (cancer network, tumour type, phase of treatment and time periods) and socio-demographic variables (sex and ethnicity). In our examination of the impact of continuity on satisfaction over time, we also adjusted for the time-varying variables of health needs (SCNS), quality of life (Euroqol) and psychological status (GHQ-28). We also tested phase of treatment as a time varying covariate. A model without explanatory covariates was estimated to examine the individual effects of continuity of the dependent variable (for example satisfaction), after which we fitted models that included other single covariates of interest. A final model was fitted that included all possible explanatory variables. Finally, in further multilevel models we examined whether the changes over time we observed in patients were affected by adjustment for *close person's* scores on perceived continuity and psychological status. In this way, we were able to examine whether close person's perceptions and status affected patient's sense of continuity and its outcome in terms of satisfaction, needs for care, quality of life and psychological status.

2 Another approach to the multilevel model analysis of the association of experienced continuity with variables such as satisfaction and psychological status is to model all variables (except demographic variables such as age and gender) as time dependent and in a time lag in which each experienced continuity score is related to each (repeated) outcome measure one time point later (see Figure 2).

This model fits most closely to a predictive model in which we assess whether continuity of care scores predict other outcomes at each subsequent follow-up point.

**Figure 2 Time lag model**



### *Missing data*

Missing data pose an analytic challenge to the validity and precision of epidemiological studies. Long established 'complete case' methods, in which a participant with any missing value is dropped from the analysis, may lead to systematic bias in that patterns of association are different in those participants remaining. The reduction in sample size available for analysis leads to reduced statistical power and consequent over-fitting of the models. Multilevel model analysis is able to include cases even if all the follow-up data are not available and is valid for data that are missing at random. However, this is rarely the case because of features of the study design. For example, participants in phase 5 (palliative care) may find it harder to complete assessments than participants in phase 1 (diagnosis).

Fifty six per cent of patients had at least one missing variable at any point in the study. Thus we first explored the pattern of missing data by creating a missing indicator for each of the outcomes and fitting a multilevel logistic regression model to identify those baseline variables that were associated with this indicator (Table 1a).

**Table 3 Statistically significant associations between missing outcomes and key baseline variables**

| | **Phase** | **Network** | **Site** | **Gender** | **Ethnicity** | **Period** | **Any transition** |
|---|---|---|---|---|---|---|---|
| Continuity score | | 0.006 | | | | <0.001 | |
| Satisfaction score | <0.001 | | 0.030 | | | <0.001 | 0.04 |
| SCNS | | | | | | | |
| - Physical and daily living needs | <0.001 | | 0.003 | | | <0.001 | |
| - Psychological needs | <0.001 | | 0.010 | | | <0.001 | |
| - Sexuality needs | <0.001 | | 0.027 | | | <0.001 | |
| - Patient care & support needs | <0.001 | | 0.010 | | | <0.001 | |
| - Health system and info needs | <0.001 | | 0.042 | | | <0.001 | |
| Euroqol | | | | | | | |
| Euroscore | <0.001 | | | | | <0.001 | |
| Thermostat | <0.001 | | | | | <0.001 | |
| GHQ-28 | <0.001 | | | | | <0.001 | |
| Spirituality | <0.001 | | | | | <0.001 | |

*Note: SCNS = Supportive Care Needs Survey; GHQ = General Health Questionnaire (28 item)*

Treatment phase, network, treatment site, follow-up point (period) and transition from one treatment phase to another were found to be significantly associated with ‘missingness’ of our main outcomes. All the regression models in this study were adjusted for these variables to satisfy the missing at random assumption in multilevel modelling.

We used multiple imputation to estimate missing health service data in the patient data set but did not impute missing demographic data at follow-up interviews as these could be carried forward from the baseline. Multiple (five) complete datasets are derived based on a statistical model for the missing values, given the observed data. Each of the imputed datasets is then analysed using standard methods and valid inferences are obtained by combining these estimates appropriately. We used a technique called 'imputation by chained equations' (ICE) in Stata 9 (Royston, 2004; 2005a; 2005b; van Buuren *et al*, 2006). However, in the case of the longitudinal data we used 'mi macro' in MLwiN (www.missingdata.org.uk) which provides a general framework for imputing and analysing multilevel data sets with missing observations under the assumption of missing at random (MAR). A multivariate response multilevel model is fitted, with the responses being the variables with missing data. This uses a Bayesian approach with non-informative priors to fit the model and then draws imputations from the posterior of this distribution. A multilevel model was separately fitted to each of the five imputed datasets. As in the analysis of baseline data, the regression coefficients and the corresponding standard errors were combined by averaging the coefficients across the models and applying Rubin's rule to obtain the correct standard error (Schafer, 1999). This part of the analysis was conducted in an Excel spreadsheet as a Stata programme for combining results from imputed ICE datasets is not available yet for multilevel models.

In view of the considerable amount of missing data in the close persons' dataset (for example see Table 14), we decided not to impute data in their analyses, with one exception, namely when multilevel model analysis in patients were adjusted for close persons' variables (see Table 18).

All analyses were conducted using Stata version 9.

# Section 4 Results

## 4.1 Background

Patients and close persons were recruited between May 2003 and July 2004 and final follow-ups were completed by August 2005.

### 4.1.1 Patients' data at baseline

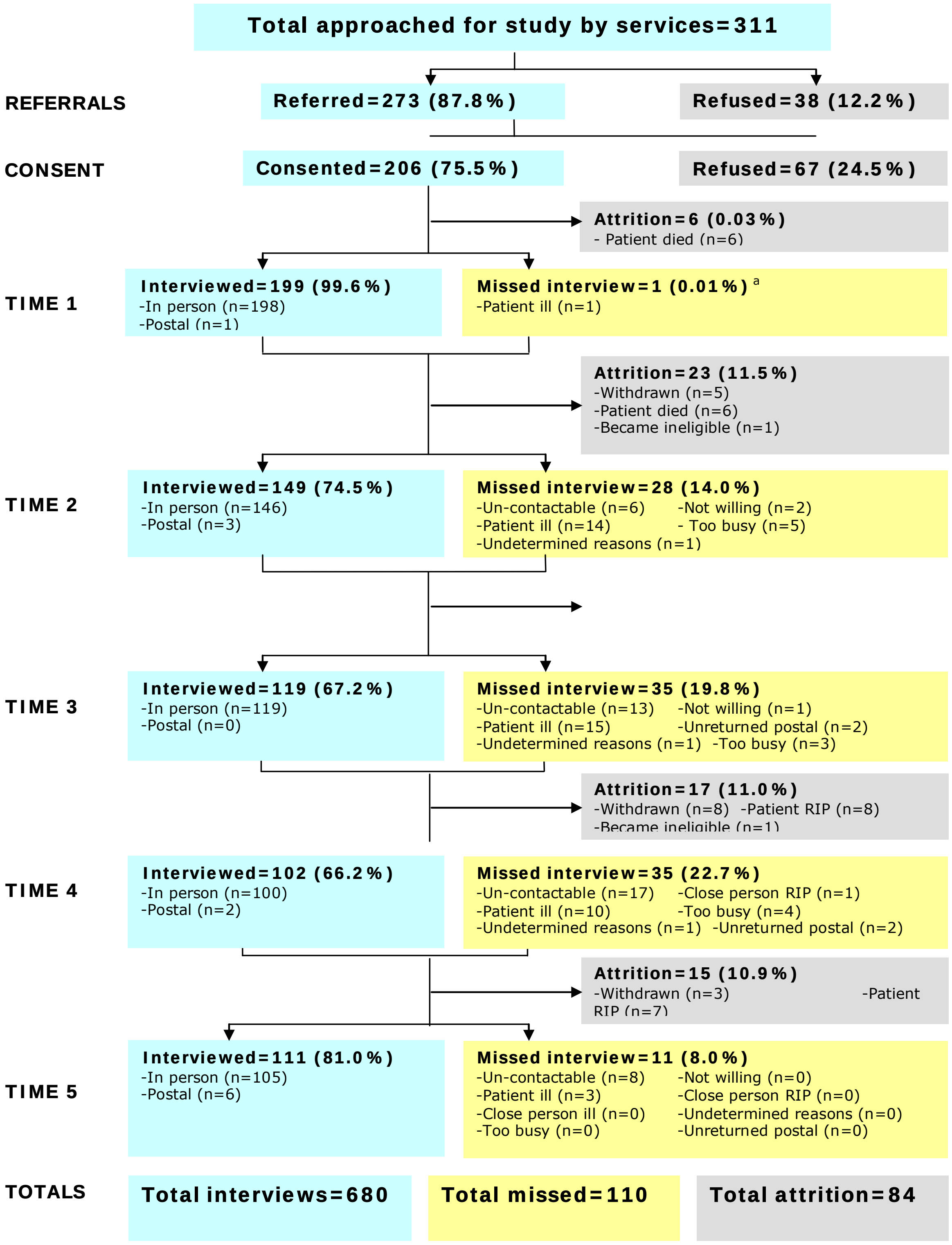
***Response rates***

The flow of patients (and close persons) through the study is shown in Figures 2 and 3. Two hundred and seventy-three patients were nominated by health professionals in the three cancer networks (103, 78 and 92 in each network), of whom 206 agreed and 67 refused to take part. However, a further seven of those who agreed were not eventually interviewed, leaving 199 (73 per cent) who eventually took part.

***Characteristics of the population***

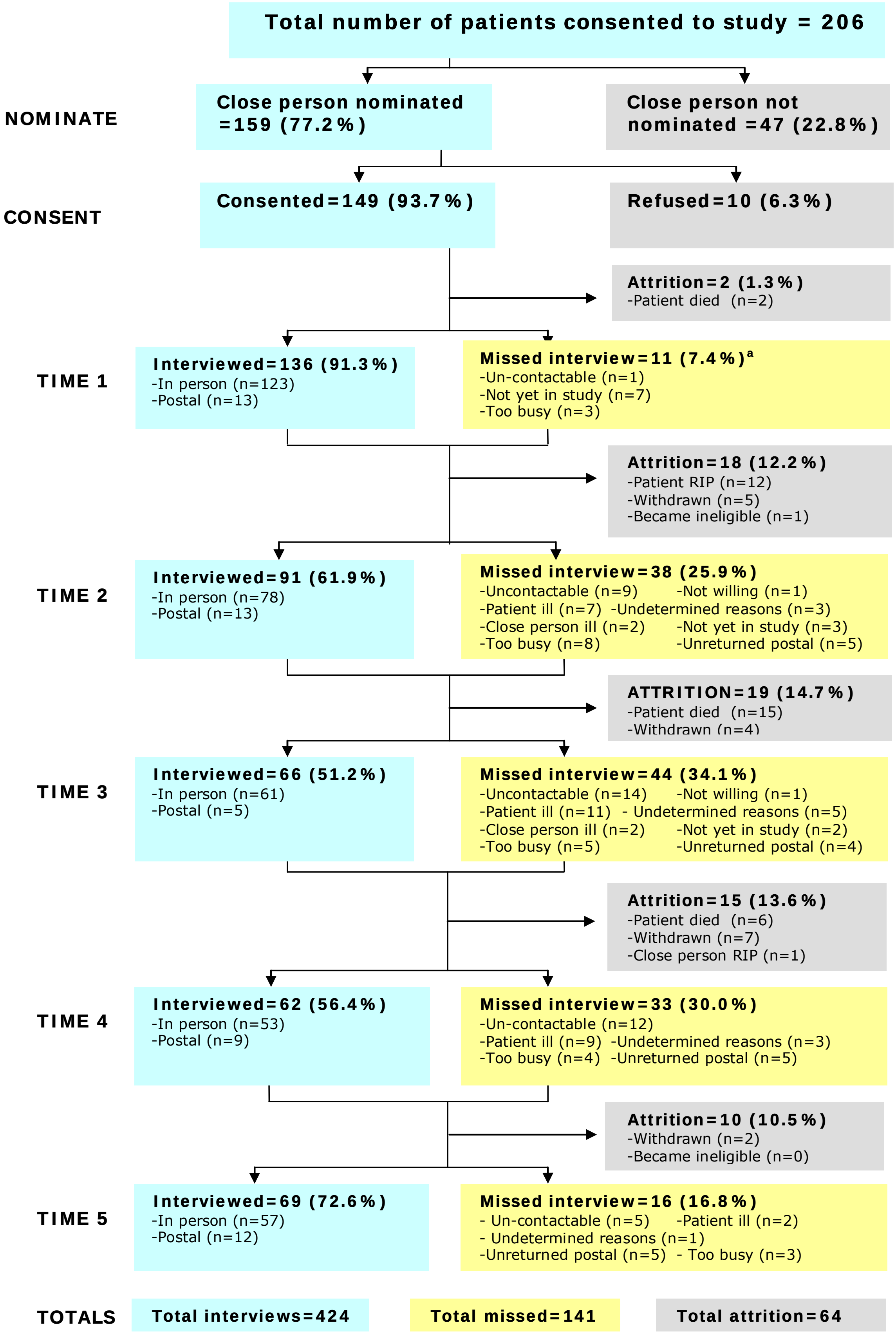
A demographic breakdown of the patients participating is shown in Tables 4 and 5. Women predominated because of the breast cancer group. There were no significant differences between patients in the five phases of illness in terms of social or demographic factors and whether or not they were able to nominate a close person for interview (Table 4). However, breast cancer patients were younger, less likely to live with a partner and were of higher social class (Table 5).

**Figure 3 Flow diagram of patient pathways through study**



*Note:* [a] *This patient did not enter the study at a later point because they subsequently died. Therefore 199 patients participated in the study at some point.*

**Figure 4 Flow diagram of close person pathways through study**



*Note: [a] Of these 11, data were collected on 9 at a later time-point. 145 close persons participated in the study at some point. The remaining 2 close persons did not enter the study at a later point because the patient subsequently died.*

## Table 4 Patient characteristics by treatment phase at baseline

| | Treatment phase | | | | | | | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | All (N=199) | | | Phase 1 Initial diagnosis (N=45) | | | Phase 2 Completion first treatment (N=48) | | | Phase 3 Remission (N=46) | | | Phase 4 Relapse (N=27) | | | Phase 5 Specialist palliative care (N=33) | | | p value |
| | N | M | SD | N | M | SD | N | M | SD | N | M | SD | N | M | SD | N | M | SD | |
| Age in years | 191 | 61.2 | 11.8 | 45 | 60 | 11.1 | 43 | 60.3 | 11.1 | 45 | 61.2 | 11.6 | 25 | 61.7 | 13.2 | 33 | 63.2 | 13.4 | 0.810 |
| | N | | % | N | | % | N | | % | N | | % | N | | % | N | | % | |
| Gender | | | | | | | | | | | | | | | | | | | |
| - male | 63 | | 31.7 | 14 | | 30.4 | 15 | | 32.6 | 13 | | 27.7 | 11 | | 42.3 | 10 | | 29.4 | 0.765 |
| - female | 136 | | 68.3 | 32 | | 69.6 | 31 | | 67.4 | 34 | | 72.3 | 15 | | 57.7 | 24 | | 70.6 | |
| Marital status | | | | | | | | | | | | | | | | | | | |
| - single | 35 | | 17.6 | 11 | | 23.9 | 7 | | 15.2 | 8 | | 17.0 | 6 | | 23.1 | 3 | | 8.8 | |
| - married/co-habiting | 121 | | 60.8 | 27 | | 58.7 | 30 | | 65.2 | 24 | | 51.1 | 17 | | 65.4 | 23 | | 67.7 | 0.190 |
| - formerly married[a] | 41 | | 20.6 | 8 | | 17.4 | 7 | | 15.2 | 15 | | 31.9 | 3 | | 11.5 | 8 | | 23.5 | |
| Household (lives with) | | | | | | | | | | | | | | | | | | | |
| - alone | 56 | | 28.1 | 15 | | 32.6 | 11 | | 23.9 | 18 | | 38.3 | 5 | | 19.2 | 7 | | 20.6 | |
| - spouse/partner only | 77 | | 38.7 | 15 | | 32.6 | 15 | | 32.6 | 16 | | 34.0 | 13 | | 50.0 | 18 | | 52.9 | 0.520 |
| - anyone else | 62 | | 31.2 | 15 | | 41.3 | 19 | | 41.3 | 12 | | 25.5 | 7 | | 26.9 | 9 | | 26.5 | |
| Socio-economic class | | | | | | | | | | | | | | | | | | | |
| - group A[b] | 111 | | 55.8 | 18 | | 39.1 | 29 | | 63.0 | 27 | | 57.5 | 15 | | 57.7 | 22 | | 64.7 | 0.137 |
| - group B[c] | 74 | | 37.2 | 22 | | 47.8 | 16 | | 34.8 | 18 | | 38.3 | 10 | | 38.5 | 8 | | 23.5 | |

**Table 4 continued**

| | | | Treatment phase | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | All (N=199) | | Phase 1 Initial diagnosis (N=45) | | Phase 2 Completion first treatment (N=48) | | Phase 3 Remission (N=46) | | Phase 4 Relapse (N=27) | | Phase 5 Specialist palliative care (N=33) | | p value |
| Ethnicity | | | | | | | | | | | | | |
| - White British | 150 | 75.4 | 33 | 71.7 | 36 | 78.3 | 36 | 76.6 | 19 | 73.1 | 26 | 76.5 | |
| - any other white background | 18 | 9.1 | 4 | 8.7 | 3 | 6.5 | 6 | 12.8 | 2 | 7.7 | 3 | 8.8 | |
| - Black/Black mixed background | 15 | 7.5 | 5 | 10.9 | 2 | 4.4 | 2 | 4.3 | 3 | 11.5 | 3 | 8.8 | 0.497 |
| - Asian/Asian mixed background | 6 | 3.0 | 1 | 2.2 | 0 | 0.0 | 3 | 6.4 | 2 | 7.7 | 0 | 0.0 | |
| - any other background | 8 | 4.0 | 3 | 6.6 | 4 | 8.7 | 0 | 0.0 | 0 | 0.0 | 1 | 2.9 | |
| Nomination of close person | | | | | | | | | | | | | |
| - yes | 161 | 82.6 | 40 | 88.9 | 32 | 71.1 | 38 | 80.8 | 38 | 92.3 | 27 | 84.4 | 0.397 |
| - no | 32 | 16.4 | 5 | 11.1 | 12 | 26.7 | 8 | 17.0 | 8 | 7.7 | 5 | 15.6 | |

*Note:[a]Formerly married = separated, divorced or widowed; [b]Group A = SES I, II and IIIn; [c] Group B = SES IIIm, IV, V and housewife/househusband*

**Table 5 Patient demographics by tumour type**

| | | | | ------------------- | | | | Tumour type | | ------------------ | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | All (N=199) | | | Breast (N=69) | | | Colorectal (N=65) | | | Lung (N=65) | | | p value |
| | N | M | SD | N | M | SD | N | M | SD | N | M | SD | |
| Age in years | 191 | 61.2 | 11.8 | 69 | 55.3 | 11.7 | 59 | 64.5 | 12.1 | 63 | 64.5 | 9.1 | <0.001 |
| | N | | % | N | | % | N | | % | N | | % | |
| Gender | | | | | | | | | | | | | <0.001 |
| - male | 63 | | 31.7 | 0 | | 0.0 | 30 | | 46.2 | 33 | | 50.8 | |
| - female | 136 | | 68.3 | 69 | | 100.0 | 35 | | 53.8 | 32 | | 49.2 | |
| Marital status | | | | | | | | | | | | | |
| - single | 35 | | 17.8 | 15 | | 22.1 | 11 | | 16.9 | 9 | | 14.1 | |
| - married/co-habiting | 121 | | 61.4 | 42 | | 61.8 | 43 | | 66.2 | 36 | | 56.3 | 0.254 |
| - formerly married[a] | 41 | | 20.8 | 11 | | 16.2 | 11 | | 16.9 | 19 | | 29.7 | |
| Household (lives with) | | | | | | | | | | | | | |
| - alone | 56 | | 28.7 | 19 | | 28.8 | 13 | | 20.0 | 24 | | 37.5 | |
| - spouse/partner only | 77 | | 39.5 | 18 | | 27.3 | 32 | | 49.2 | 27 | | 42.2 | 0.010 |
| - anyone else | 62 | | 31.8 | 29 | | 43.9 | 20 | | 30.8 | 13 | | 20.3 | |
| Socio-economic class | | | | | | | | | | | | | |
| - group A[b] | 111 | | 60.0 | 53 | | 81.5 | 30 | | 50.0 | 28 | | 46.7 | <0.001 |
| - group B[c] | 74 | | 40.0 | 12 | | 18.5 | 30 | | 50.0 | 32 | | 53.3 | |
| Ethnicity | | | | | | | | | | | | | |
| - White British | 150 | | 76.1 | 49 | | 72.1 | 47 | | 73.4 | 54 | | 83.1 | |
| - any other whitebackground | 18 | | 9.1 | 5 | | 7.4 | 7 | | 10.9 | 6 | | 9.2 | |
| - Black/Black mixed background | 15 | | 7.6 | 5 | | 7.4 | 6 | | 9.4 | 4 | | 6.2 | |
| - Asian/Asian mixed background | 6 | | 3.0 | 4 | | 5.9 | 1 | | 1.6 | 1 | | 1.5 | 0.360 |
| - Any other background | 8 | | 4.1 | 5 | | 7.4 | 3 | | 4.7 | 0 | | 0.0 | |

**Table 5 continued**

| | All (N=199) | | Tumour type<br>Breast (N=69) | | Colorectal (N=65) | | Lung (N=65) | | p value |
|---|---|---|---|---|---|---|---|---|---|
| Nomination of close person | | | | | | | | | |
| - yes | 161 | 82.6 | 55 | 80.9 | 55 | 87.3 | 51 | 79.7 | 0.732 |
| - no | 32 | 16.4 | 12 | 17.7 | 8 | 12.7 | 12 | 18.7 | |

*Note:[a]Formerly married = separated, divorced, widowed; [b]Group A = SES I, II and IIImn; [c]Group B = SES IIIm, IV, V and housewife/househusband*

### *The factor structure of our measure of continuity of care*

Two of the 20 questions (12,13) on perceived continuity of care were discarded before undertaking further analysis, as a significant proportion of participants found they did not apply to them (Table 6). When all 18 remaining questions were entered into a common factor analysis, 11 grouped into three factors that were named (i) service quality (eight statements); (ii) sense of control (one statement) and; (iii) informal support (two statements) [see Table 6]. However, this factor structure was unstable and changed with each restriction on the analysis. Thus, we regarded the three factor solution as exploratory only and continued the analysis with mean scores on all 18 items of the continuity measure. The 18 items had high internal reliability (Cronbach's Alpha 0.87) and no single item removal improved on this. Thus they could be summed and used as a single score. Scores on questions 1, 3, 5-7, 9, 10, 14, 15 and 19 were reversed so that a high total score mean high experienced continuity.

### *Decision on further analysis of the 18 statements*

At this stage in the analysis we needed to decide how to carry forward our broad and patient driven concept of experienced continuity. The continuity questions that arose from the qualitative data covered a number of ways in which patients and their close persons experienced consistent care. We decided to retain all 18 statements and use them as a total score in the prospective analysis. As noted above, on face validity nine resonated with traditional models of continuity of care. Furthermore, factor 1 in the factor analysis concerned elements such as consistent information, consistent time and attention and feeling in touch with services. The inclusion of other statements on coping and connections with families broadened the concept of experienced continuity of care. For example, coping between appointments may mean that a patient carries a reassuring model of 'joined up care' in his or her mind that helps him or her to manage when not in touch with a team. Good relationships within families when secrets between family members are not a problem also mean that communication with professionals may be facilitated. As seen in our qualitative case study analyses, when patients kept secrets from family members this often prevented joined up care because family members were unable to support patients to make decisions about treatments or attend outpatient appointments. Conversely when patients shared information with family members about their illnesses, this facilitated communication between professionals and proactive attempts to resolve uncertainties about their care. Finally all 18 items showed high internal consistency implying that they were measuring related concepts. Thus we decided to continue the analysis and examine to what degree all 18 questions were associated with other factors including satisfaction, psychological status and needs for care.

**Table 6 Continuity of care factors – patients**

| | Item[a] | Loading[b] |
|---|---|---|
| | ***Factor 1: Cancer service quality*** | |
| 1 | I have received enough time and attention from the cancer services | **0.61** |
| 2 | I do not see the cancer services often enough | **- 0.53** |
| 3 | I am getting consistent information about my illness from health care staff | **0.53** |
| 5 | I have been well informed about what my treatment will involve over the next few months | **0.76** |
| 6 | I am aware of what side-effects to expect from my cancer treatments | **0.76** |
| 7 | I have been told what to expect in terms of my overall health over the next few months | **0.55** |
| 8 | I feel out of touch with the cancer services between appointments | **- 0.54** |
| 19 | I am satisfied that I have received a full medical examination with regard to my cancer | **0.56** |
| | ***Factor 2: Sense of control*** | |
| 10 | I am coping well between my appointments with the cancer services | **- 0.56** |
| | ***Factor 3: Informal support*** | |
| 14 | I feel supported by the people closest to me | **1.00** |
| 15 | I feel my friends and relatives are able to help me cope with my illness | **0.71** |
| | ***Items excluded due to factor loading<0.5*** | |
| 4 | I frequently have to chase up cancer services to get things done | |
| 9 | I feel able to cope with minor complications that may arise | |
| 11 | I have difficulty accepting the limitations my health places on my life | |
| 16 | I am worried about the emotional state of the people closest to me | |
| 17 | I feel I depend too much on my friends or relatives | |
| 18 | I have received some misleading information from the cancer services | |
| 20 | I am worried that some things may have been overlooked | |
| | ***Items excluded from factor analysis [c]*** | |
| 12 | I am well supported by non-medical services e.g. home help, social services etc | |
| 13 | I have received sufficient advice on which financial benefits I can claim | |

*Note: [a] Items are scored on a five point scale from 0=strongly agree to 4=strongly disagree; [b] Items with factor loading < 0.5 were not retained;[c] Items 12 and 13 were excluded from the factor analysis due to the large number of patients who stated that these items were 'not applicable'.*

### Clinical, psychological and spiritual status

The principal differences in clinical needs, and psychological and social status between patients in the cancer illness phases were as follows:

1. Lowest needs for care on the *Supportive care needs survey* were recorded in patients in remission
2. Quality of life was lowest after relapse and during palliative care.
3. Psychological status was most robust in remission and worst at relapse (Table 7).

Satisfaction with services did not differ significantly with phase of illness, but there was a trend for it to be highest when in remission.

**Table 7 Questionnaire data by phase of cancer treatment at baseline**

| | | | | Treatment phase | | | | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | All (N=199) | | | Phase 1 Diagnosis (N=46) | | | Phase 2 Completion first treatment (N=46) | | | Phase 3 In remission (N=47) | | | Phase 4 On relapse (N=26) | | | Phase 5 Specialist palliative care (N=34) | | | p value |
| | N | M | SD | N | M | SD | N | M | SD | N | M | SD | N | M | SD | N | M | SD | |
| ***Continuity of care*** | | | | | | | | | | | | | | | | | | | |
| Score on 18 statements [range 0-72] | 181 | 51.8 | 9.9 | 45 | 52.1 | 9.3 | 41 | 50.8 | 12.9 | 41 | 52.1 | 7.9 | 24 | 53.2 | 6.1 | 30 | 51.0 | 11.4 | 0.879 |
| Patient preferences | | | | | | | | | | | | | | | | | | | |
| Preferences [range 0-160] | 188 | 86.3 | 17.8 | 44 | 89.7 | 14.0 | 44 | 84.5 | 19.2 | 46 | 88.8 | 20.0 | 26 | 83.5 | 16.8 | 28 | 85.6 | 18.1 | 0.397 |
| Satisfaction | | | | | | | | | | | | | | | | | | | |
| Satisfaction [range 0-50] | 191 | 41.7 | 8.8 | 42 | 41.5 | 8.8 | 46 | 39.3 | 9.9 | 46 | 44.0 | 6.3 | 26 | 43.6 | 6.8 | 31 | 40.8 | 10.8 | 0.086 |
| ***Supportive care needs (SCNS)*** | | | | | | | | | | | | | | | | | | | |
| Physical and daily living needs [0-100] | 194 | 11.7 | 4.7 | 44 | 12.0 | 4.4 | 45 | 11.6 | 4.4 | 46 | 9.4 | 4.1 | 27 | 12.7 | 5.2 | 33 | 13.4 | 4.6 | 0.001 |
| Psychological needs [0-100] | 186 | 21.4 | 8.8 | 44 | 21.3 | 9.5 | 44 | 22.8 | 7.9 | 45 | 18.6 | 7.9 | 25 | 25.0 | 10.7 | 28 | 20.6 | 7.2 | 0.037 |
| Patient care & support needs [0-100] | 193 | 11.6 | 3.7 | 44 | 12.8 | 4.3 | 46 | 12.2 | 4.2 | 47 | 9.9 | 2.7 | 26 | 11.7 | 3.3 | 30 | 11.6 | 2.9 | 0.003 |
| Health system +info. needs [0-100] | 184 | 21.8 | 6.9 | 42 | 23.8 | 8.2 | 46 | 24.5 | 8.4 | 47 | 19.1 | 4.9 | 25 | 21.9 | 3.7 | 24 | 19.5 | 4.6 | <0.001 |
| Sexuality needs [0-100] | 193 | 4.3 | 2.4 | 44 | 4.7 | 2.3 | 45 | 4.0 | 2.0 | 47 | 4.3 | 3.1 | 25 | 4.3 | 3.1 | 32 | 4.2 | 2.2 | 0.727 |
| ***EUROQOL*** | | | | | | | | | | | | | | | | | | | |
| Euroqol ED5D [range: -0.59-1.00] | 196 | 0.67 | 0.5 | 46 | 0.73 | 0.23 | 46 | 0.73 | 0.23 | 47 | 0.78 | 0.13 | 26 | 0.64 | 0.28 | 31 | 0.36 | 1.1 | 0.001 |
| Euroqol Thermometer [range 0-100] | 190 | 66.6 | 18.9 | 43 | 64.3 | 20.7 | 45 | 69.5 | 16.4 | 45 | 74.8 | 15.8 | 26 | 60.8 | 20.3 | 31 | 58.7 | 18.1 | 0.001 |

**Table 7 continued**

| | | | | Treatment phase | | | | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | **All (N=199)** | | | **Phase 1**<br>**Diagnosis (N=46)** | | | **Phase 2**<br>**Completion first treatment (N=46)** | | | **Phase 3**<br>**In remission (N=47)** | | | **Phase 4**<br>**On relapse (N=26)** | | | **Phase 5**<br>**Specialist palliative care (N=34)** | | | **p value** |
| | N | M | SD | N | M | SD | N | M | SD | N | M | SD | N | M | SD | N | M | SD | |
| ***General health (GHQ)*** | | | | | | | | | | | | | | | | | | | |
| GHQ total [range 0-28] | 173 | 6.3 | 0.4 | 43 | 7.2 | 0.8 | 39 | 6.9 | 0.9 | 43 | 4.1 | 0.8 | 20 | 8.5 | 1.5 | 28 | 5.7 | 0.9 | 0.001 |
| GHQ | | | | | | | | | | | | | | | | | | | |
| - non-case | 92 (53.2%) | | | 16 (37.2%) | | | 22 (56.4%) | | | 31 (72.1%) | | | 9 (45.0%) | | | 14 (50%) | | | 0.022 |
| - case | 81 (46.8%) | | | 27 (62.8%) | | | 17 (43.6%) | | | 12 (27.9%) | | | 11 (55.0%) | | | 14 (50%) | | | |
| ***Spirituality*** | | | | | | | | | | | | | | | | | | | |
| Spirituality scale score total [0-60] | 187 | 16.1 | 15.3 | 44 | 18.4 | 17.6 | 41 | 15.6 | 13.2 | 46 | 15.5 | 16.3 | 25 | 18.6 | 15.3 | 31 | 12.6 | 13.3 | 0.503 |

### *Relationship between differing concepts of continuity*

In order to evaluate how our concept of experienced continuity related to the recently published models of how to provide service continuity (Haggerty *et al*, 2003), we examined replies to three key questions on service quality at their last service visit (Box 2). Most participants answered affirmatively to each question, which meant that the questions did not discriminate well between participants on continuity of this nature. Approximately four fifths of patients reported that basic aspects of provided continuity (such as medical teams being informed and up-to-date and there being a main contact person) were in place, at least for the preceding three months. Nevertheless, mean scores on experienced continuity were higher in those who reported having a main contact person (mean difference 4.6, t=2.3, p=0.02), and there was a similar trend for higher scores in those who considered their medical team up to date with their situation (mean difference 5.5, t=1.9, p=0.07).

**Box 2 Questions on information, management and relationship aspects of continuity of care at the most recent service visit***

1 Were the medical team up to date with your situation? Yes/No

2 Have you had a main contact person at the hospital over the last three months? Yes/No

3 Did your medical team have access to your most recent:

a. Notes Yes/No/Unsure

b. Scans Yes/No/Unsure

c. Blood tests Yes/No/Unsure

d. X-rays Yes/No/Unsure

*Based on Haggerty et al (2003)

The replies were as follows:

| | | | | | |
|---|---|---|---|---|---|
| Q1 | Yes | 91% | Q3b | Yes | 86% |
| Q2 | Yes | 83% | Q3c | Yes | 89% |
| Q3a | Yes | 92% | Q3d | Yes | 89% |

### *Experienced continuity of care and patient and illness characteristics*

Mean scores on experienced continuity of care did not vary significantly with tumour type, phase of treatment, hospital base, sex, age, ethnicity or marital status. These simple comparisons are likely to be confounded and are considered again later in our multivariable analyses. Nevertheless, the lack of variation in experienced continuity with phase of treatment was evidence against the possibility of significant heterogeneity in our data and suggested the five cohorts could be considered as a whole. This point is returned to in the multilevel model analysis.

### *Relationship between experienced continuity of care and satisfaction with services*

There was a strong relationship between continuity of care and satisfaction scores at baseline (second column, Table 8). A standardised regression coefficient of 0.63 means that an increase of one standard deviation in continuity score increased satisfaction by 0.63 standard deviations. Although adjustment for potential confounding reduced the size of the coefficient to 0.37, it remained statistically significant (Table 8). The imputed data were similar but with a higher standardised regression coefficient in the final model.

**Table 8 Multivariable regression model of continuity of care on satisfaction with services (baseline data)**

| Predictors (n) | Unadjusted standardised regression coefficient B for satisfaction (95% CI) | Standardised regression coefficient B in final model* (95% CI) | Unadjusted standardised regression coefficient B for satisfaction (95% CI) | Standardised regression coefficient B in final model* (95% CI) |
|---|---|---|---|---|
| | Data with complete information | | Imputed data | |
| Continuity of care score | 0.63 (0.52, 0.74) | 0.37 (0.22, 0.53) | 0.62 (0.51, 0.71) | 0.49 (0.37, 0.61) |
| ***Study design variables*** | | | | |
| Cancer network | | | | |
| - 1 | | baseline | | baseline |
| - 2 | | -0.41 (-0.74, -0.07) | | -.19 (-0.46, 0.07) |
| - 3 | | -0.27 (-0.59, 0.05) | | -.11 (-0.38, 0.17) |
| Tumour type | | | | |
| - breast | | baseline | | baseline |
| - colorectal | | -0.07 (-0.41, 0.27) | | 0.11 (-0.17, 0.38) |
| - lung | | 0.46 (0.15, 0.79) | | 0.50 (0.22, 0.78) |
| Treatment phase | | | | |
| - diagnosis | | baseline | | baseline |
| - end of first treatment | | -0.14 (-0.49, 0.22) | | -0.09 (-0.40, 0.22) |
| - remission | | 0.06 (-0.29, 0.41) | | 0.03 (-0.29, 0.35) |
| - first relapse | | 0.34 (-0.07, 0.74) | | 0.16 (-0.20, 0.51) |
| - palliative care | | 0.19 (-0.22, 0.61) | | -0.057 (-0.41, 0.30) |

**Table 8 continued**

| Predictors (n) | Unadjusted standardised regression coefficient B for satisfaction (95% CI) | Standardised regression coefficient B in final model* (95% CI) | Unadjusted standardised regression coefficient B for satisfaction (95% CI) | Standardised regression coefficient B in final model* (95% CI) |
|---|---|---|---|---|
| | **Data with complete information** | | **Imputed data** | |
| ***Demographic variables*** | | | | |
| Gender | | | | |
| - men | | baseline | | baseline |
| - women | | 0.09 (-0.21, 0.39) | | 0.14 (-0.10, 0.39) |
| Ethnicity | | | | |
| - White | | baseline | | baseline |
| - non-White | | -0.16 (-0.44, 0.12) | | -0.18 (-0.42, 0.07) |
| ***Questionnaire variables*** | | | | |
| Supportive care needs survey | | | | |
| - health system and information needs | | -0.26 (-0.41, -0.12) | | -0.28 (-0.45, -0.11) |
| - sexuality needs | | 0.17 (0.05, 0.29) | | 0.13 (0.02, 0.24) |
| Euroqol | | | | |
| - Thermostat | | 0.15 (0.00, 0.30) | | 0.09 (-0.05, 0.22) |

*Note: *Study design and demographic variables were retained in the regression model as they were thought a priori to be key to this analysis. Questionnaire variables were eliminated by backwards elimination until a final model was reached; CI = confidence interval*

### Associations between continuity of care and clinical/functional status

Higher scores on experienced continuity were associated with lower physical daily living needs and lower psychological needs (SCNS), higher quality of life (Euroqol) and lower psychological distress (GHQ-28). These associations were little affected by adjustment for study design and socio-demographic factors or when imputed data were analysed (Table 9).

**Table 9 Associations with scoring on continuity of care (total score on all 18 continuity statements) in patients at baseline**

| | Data with complete information | | Imputed data | |
|---|---|---|---|---|
| **Association** | **Unadjusted * standardised regression coefficient (B) (95% CI)** | **Adjusted standardised B (95% CI)** | **Unadjusted * standardised regression coefficient (B) (95% CI)** | **Adjusted standardised B (95% CI)** |
| Preference for style of care | 0.09 (-0.06, 0.25) | 0.10 (-0.05, 0.25) | 0.13 (0.03, 0.24) | 0.12 (0.02, 0.22) |
| Physical and daily living needs (SCNS) | -0.30 (-0.40, -0.12) | -0.26 (-0.40, -0.13) | -0.28 (-0.42, -0.14) | -0.28 (-0.41, -0.15) |
| Psychological needs (SCNS) | -0.40 (-0.55, -0.25) | -0.42 (-0.56, -0.28) | -0.43 (-0.56, -0.29) | -0.42 (-0.55, -0.30) |
| Euroqol score | 0.35 (0.23, 0.47) | 0.19 (0.09, 0.29) | 0.37 (0.24, 0.51) | 0.35 (0.22, 0.48) |
| Euroqol thermometer | 0.39 (0.25, 0.53) | 0.38 (0.25, 0.52) | 0.39 (0.26, 0.53) | 0.39 (0.25, 0.53) |
| GHQ-28 score | -0.42 (-0.57, 0.27) | -.45 (-0.59, -0.30) | -0.46 (-0.59, -0.32) | -0.43 (-0.56, -0.30) |
| Spiritual score | 0.02 (-0.14, 0.19) | 0.08 (-0.08, 0.24) | 0.02 (-0.40, 0.17) | 0.08 (-0.07, 0.23) |

*Note: * adjusted for treatment phase, cancer network, type of tumour, sex and ethnicity; CI = confidence interval; SCNS = Supportive Care Needs Survey*

### 4.1.2 Close persons' data at baseline

The flow of close persons through the study is shown in Figure 3.

***Socio-demographic characteristics***

145 close persons were recruited of whom 51 per cent were women and 68 per cent were spouses or partners of patients and 32 per cent were other relatives or friends (Tables 10 and 11). There were no significant differences in close persons' characteristics between any of the phases of treatment (Table 10). However, men predominated as close persons to women with breast cancer and this was not explained by their being more likely (than in other cancers) to be spouses or partners. Furthermore, close persons for patients with colorectal cancer were slightly older than those in the other two cancer groups (Table 11).

**Table 10 Close persons' characteristics by patients' treatment phase at baseline**

| | | | | **Patients' treatment phase** | | | | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | **All (N=145)** | | | **Phase 1**<br>**Diagnosis (N=35)** | | | **Phase 2**<br>**Completion of first treatment (N=38)** | | | **Phase 3**<br>**In remission (N=27)** | | | **Phase 4**<br>**Relapse (N=21)** | | | **Phase 5**<br>**Palliative care (N=34)** | | | **p value** |
| | N | M | SD | N | M | SD | N | M | SD | N | M | SD | N | M | SD | N | M | SD | |
| Age in years | 141 | 56.8 | 14.4 | 33 | 55.8 | 13.8 | 35 | 55.0 | 15.5 | 28 | 56.6 | 13.7 | 20 | 59.3 | 12.5 | 25 | 58.8 | 16.6 | 0.783 |
| | N | | % | N | | % | N | | % | N | | % | N | | % | N | | % | |
| Gender | | | | | | | | | | | | | | | | | | | |
| - male | 70 | | 49.0 | 14 | | 41.2 | 20 | | 54.1 | 14 | | 50.0 | 9 | | 45.0 | 13 | | 54.2 | 0.808 |
| - female | 73 | | 51.0 | 20 | | 58.8 | 17 | | 45.9 | 14 | | 50.0 | 11 | | 55.0 | 11 | | 45.8 | |
| Marital status | | | | | | | | | | | | | | | | | | | |
| - single | 15 | | 10.7 | 3 | | 9.4 | 4 | | 10.8 | 4 | | 14.3 | 1 | | 5.0 | 3 | | 13.0 | |
| - married/co-habiting/was married† | 125 | | 89.3 | 29 | | 90.6 | 33 | | 89.2 | 24 | | 85.7 | 19 | | 95.0 | 20 | | 87.0 | 0.910 |
| Household (lives with) | | | | | | | | | | | | | | | | | | | |
| - alone | 11 | | 8.3 | 4 | | 12.9 | 2 | | 6.1 | 3 | | 11.1 | 0 | | 0 | 2 | | 9 | |
| - spouse/partner only | 74 | | 54.1 | 15 | | 48.4 | 16 | | 48.5 | 16 | | 59.3 | 14 | | 73.7 | 13 | | 59.1 | 0.599 |
| - anyone else | 47 | | 35.6 | 12 | | 38.7 | 15 | | 45.4 | 8 | | 39.6 | 5 | | 26.3 | 7 | | 31.8 | |
| Socio-economic class | | | | | | | | | | | | | | | | | | | |
| - group A[a] | 84 | | 65.1 | 21 | | 65.6 | 20 | | 58.8 | 13 | | 59.1 | 14 | | 70.0 | 16 | | 76.2 | 0.682 |
| - group B[b] | 45 | | 34.9 | 11 | | 34.4 | 14 | | 41.2 | 9 | | 40.9 | 6 | | 30.0 | 5 | | 23.8 | |

**Table 10 continued**

| | Patient's treatment phase | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | **All (N=145)** | | **Phase 1 Diagnosis (N=35)** | | **Phase 2 Completion of first treatment (N=38)** | | **Phase 3 In remission (N=27)** | | **Phase 4 Relapse (N=21)** | | **Phase 5 Palliative care (N=34)** | | **p value** |
| Ethnicity | | | | | | | | | | | | | |
| - White British | 109 | 78.4 | 21 | 63.6 | 30 | 83.3 | 22 | 81.5 | 16 | 84.2 | 20 | 83.3 | |
| - any other White background | 15 | 10.8 | 5 | 15.2 | 3 | 8.3 | 4 | 14.8 | 0 | 0.0 | 3 | 12.5 | |
| - Black/Black mixed background | 10 | 7.2 | 5 | 15.2 | 2 | 5.6 | 1 | 3.7 | 1 | 5.3 | 1 | 4.2 | |
| - Asian/Asian mixed background | 3 | 2.2 | 1 | 3.0 | 0 | 0.0 | 0 | 0.0 | 2 | 10.5 | 0 | 0.0 | 0.289 |
| - any other background | 2 | 1.4 | 1 | 3.0 | 1 | 2.8 | 0 | 0.0 | 0 | 0.0 | 0 | 0.0 | |
| Relationship to patient | | | | | | | | | | | | | |
| - spouse or partner | 98 | 68.1 | 20 | 58.8 | 26 | 70.3 | 17 | 64.3 | 16 | 80.0 | 18 | 72.0 | 0.543 |
| - relative or friend | 46 | 31.9 | 14 | 41.2 | 11 | 29.7 | 10 | 35.7 | 4 | 20.0 | 7 | 28.0 | |

*†= separated, divorced or widowed; [a] = SES I, II and IIIn; [b] = SES IIIm, IV, V and housewife/househusband*

**Table 11 Close persons' demographic characteristics by patients' tumour type**

| | | | | Tumour type | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | **All (N=145)** | | | **Breast (N=52)** | | | **Colorectal (N=47)** | | | **Lung (N=46)** | | | **p value** |
| | N | M | SD | N | M | SD | N | M | SD | N | M | SD | |
| Age in years | 141 | 56.8 | 14.4 | 51 | 54.0 | 14.1 | 45 | 61.2 | 13.7 | 45 | 55.4 | 14.5 | 0.040 |
| | N | | % | N | | % | N | | % | N | | % | |
| Gender | | | | | | | | | | | | | |
| - male | 70 | | 49.0 | 39 | | 76.5 | 19 | | 41.3 | 12 | | 26.1 | <0.001 |
| - female | 73 | | 51.0 | 12 | | 23.5 | 27 | | 58.7 | 34 | | 73.9 | |
| Marital status | | | | | | | | | | | | | |
| - single | 15 | | 10.7 | 8 | | 15.7 | 3 | | 6.7 | 4 | | 9.1 | |
| - not single† | 125 | | 89.3 | 43 | | 84.3 | 42 | | 93.3 | 40 | | 90.9 | 0.511 |
| Relationship to patient | | | | | | | | | | | | | |
| - spouse or partner | 98 | | 68.1 | 33 | | 63.5 | 34 | | 73.9 | 31 | | 67.4 | 0.538 |
| - relative or friend | 46 | | 31.9 | 19 | | 36.5 | 12 | | 26.1 | 15 | | 32.6 | |
| Socio-economic class | | | | | | | | | | | | | |
| - group A[a] | 84 | | 65.1 | 33 | | 70.2 | 28 | | 63.6 | 23 | | 60.5 | 0.627 |
| - group B[b] | 45 | | 34.9 | 14 | | 29.8 | 16 | | 36.4 | 15 | | 39.5 | |
| Ethnicity | | | | | | | | | | | | | |
| - White British | 109 | | 78.4 | 35 | | 71.4 | 35 | | 77.8 | 39 | | 86.7 | |
| - any other background | 30 | | 21.6 | 14 | | 28.6 | 10 | | 22.2 | 6 | | 13.3 | 0.198 |

*Note: † = married/co-habiting/was married; [a] = SES I, II and IIIn; [b] = SES IIIm, IV, V and housewife/househusband*

### *The factor structure of the measure of continuity of care in close persons*

Close persons gave their view of continuity as experienced by patients. The questions were exactly those concerning continuity that patients answered but this time from the perspective of close persons. As for patients, two questions were removed from further analysis because they did not apply to all respondents (Table 12). The remaining 18 questions were entered into a common factor analysis and the latent structure was similar (Table 12), but not identical, to that for patients' own ratings of experienced continuity (Table 6). In the case of close persons, item 10 did not stand alone but was included in the main factor on cancer service quality. A second factor concerned being informed about what the future held and the third was exactly the same as for patients and concerned informal support. Because of the relatively low numbers of close persons taking part, this factor analysis was regarded as exploratory only and the full 18 item scale scores used in the remainder of the analysis. The 18 items had exactly similar internal reliability to the patient's version (Cronbach's Alpha 0.87) and no single item removal improved on this. As for patients, scores on questions 1, 3, 5-7, 9, 10, 14, 15 and 19 were reversed so that a high total score meant high experienced continuity. Close person's continuity scores were generally lower than patients (Tables 7 and 13). Although close persons' experienced continuity did not vary significantly between phases of the patient's illness at baseline, there was a trend for lowest scores to occur when patients were receiving palliative care (Table 13). There was a significant correlation between patients' and close persons' experienced continuity scores (coefficient 0.50, $p<0.0001$).

**Table 12 Continuity of care factors – close persons**

| | Item | Loading |
|---|---|---|
| | ***FACTOR 1: Cancer service quality*** | |
| 1 | My friend or relative receives enough time and attention from the cancer services | 0.77 |
| 2 | He/she does not see the cancer services often enough | -0.72 |
| 3 | He/she is getting consistent information about their illness from health care staff | 0.58 |
| 4 | He/she frequently has to chase up cancer services to get things done | -0.57 |
| 8 | He/she feels out of touch with the cancer services between appointments | -0.72 |
| 10 | He/she is coping well between appointments with the cancer services | -0.70 |
| 18 | He/she has received some misleading information from the cancer services | -0.61 |
| 19 | He/she has received a full medical examination with regard to their cancer | 0.59 |
| | ***FACTOR 2: Information about the future*** | |
| 5 | He/she is well informed about what their treatment will involve over the next few months | 0.77 |
| 6 | He/she is aware of what side-effects to expect from their cancer treatments | 0.60 |
| 7 | He/she has been told what to expect in terms of their overall health over the next few months | 0.61 |
| | ***FACTOR 3: Informal support*** | |
| 14 | He/she is being supported by the people closest to them | 1.00 |
| 15 | His/her friends and relatives are able to help them cope with the illness | 0.59 |
| | ***Items excluded due to factor loading<0.5*** | |
| 9 | He/she is able to cope with minor complications that may arise | |
| 11 | He/she finds it difficult to accept the limitations their health places on life | |
| 16 | He/she is worried about the emotional state of the people closest to him/her | |
| 17 | He/she is too dependent on my friends or relatives | |
| 20 | He/she is worried that some things may have been overlooked | |
| | ***Items excluded from factor analysis [c]*** | |
| 12 | He/she is being well supported by non-medical services e.g. home help, social services etc | |
| 13 | He/she receives enough advice on which financial benefits that can be claimed | |

*Note:[a] Items are scored on a five point scale from 0=strongly agree to 4=strongly disagree; [b] Items with factor loading < 0.5 were not retained; [c] Items 12 and 13 were excluded from the factor analysis due to the large number of patients who stated that these items were 'not applicable'.*

### *Close persons' clinical, psychological and spiritual status*

Close persons' satisfaction with services (Table 13) was similar to that of the patients (Table 7). There was a trend in close persons however, for satisfaction to be highest in remission and lowest in palliative care (Table 13). Close persons were involved with patients to a similar degree throughout the phases of treatment. Unfortunately there were considerable missing data on the *Caregiver quality of life scale* with only 52 participants completing all questions. Exploring these data we found that many participants had omitted one or two questions (particularly one on sexual function). Close persons were most psychologically distressed when patients were diagnosed and least distressed when patients were in remission. Spiritual belief did not differ across the treatment phases.

**Table 13 Close persons' questionnaire data by patient's treatment phase at baseline**

| | | | | Phase of cancer at first interview | | | | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | **All (N=145)** | | | **Phase 1 Diagnosis (N=34)** | | | **Phase 2 Completion first treatment (N=39)** | | | **Phase 3 In remission (N=27)** | | | **Phase 4 On relapse (N=21)** | | | **Phase 5 Specialist palliative care (N=24)** | | | **p value** |
| | N | M | SD | N | M | SD | N | M | SD | N | M | SD | N | M | SD | N | M | SD | |
| ***Continuity of care score*** | | | | | | | | | | | | | | | | | | | |
| Score on 18 statements [range 0-72] | 124 | 48.6 | 10.1 | 29 | 48.9 | 11.6 | 31 | 46.9 | 9.8 | 25 | 51.9 | 8.2 | 19 | 50.9 | 7.5 | 20 | 44.4 | 11.2 | 0.083 |
| ***Person preferences*** | | | | | | | | | | | | | | | | | | | |
| Preferences [range 0-160] | 117 | 83.5 | 17.2 | 29 | 85.3 | 15.8 | 33 | 83.6 | 18.7 | 22 | 83.0 | 18.0 | 18 | 84.1 | 15.4 | 15 | 19.7 | 19.2 | 0.894 |
| ***Satisfaction*** | | | | | | | | | | | | | | | | | | | |
| Satisfaction [range 0-50] | 128 | 40.0 | 10.0 | 30 | 40.5 | 10.9 | 32 | 38.1 | 11.0 | 25 | 43.8 | 5.4 | 19 | 41.8 | 8.2 | 22 | 36.1 | 2.2 | 0.063 |
| ***Personal involvement*** | | | | | | | | | | | | | | | | | | | |
| Part A [range 0-40] | 112 | 16.0 | 7.5 | 26 | 16.5 | 7.0 | 30 | 17.4 | 8.4 | 21 | 13.2 | 7.4 | 16 | 17.4 | 7.1 | 19 | 15.1 | 6.7 | 0.307 |
| Part B [0-24] | 122 | 16.5 | 3.8 | 29 | 16.1 | 3.6 | 32 | 15.7 | 3.9 | 23 | 18.8 | 2.8 | 18 | 16.2 | 3.2 | 20 | 15.8 | 4.5 | 0.022 |
| ***Caregiver quality of life*** | | | | | | | | | | | | | | | | | | | |
| Caregiver quality of life [range 0-140] | 52 | 50.1 | 17.5 | 12 | 53.4 | 16.5 | 15 | 50.8 | 16.5 | 8 | 38.5 | 11.8 | 8 | 47.1 | 21.6 | 9 | 57.4 | 16.1 | 0.215 |
| ***GHQ*** | | | | | | | | | | | | | | | | | | | |
| GHQ total [range 0-28] | 114 | 5.1 | 5.2 | 27 | 7.9 | 6.3 | 28 | 4.0 | 4.3 | 25 | 3.0 | 4.4 | 14 | 5.9 | 4.9 | 20 | 4.7 | 4.8 | 0.008 |
| GHQ | N | | % | N | | % | N | | % | N | | % | N | | % | N | | % | |
| - non-case | 71 | | 62.3 | 12 | | 44.4 | 19 | | 67.9 | 20 | | 80 | 8 | | 57.1 | 12 | | 60.0 | 0.109 |
| - case | 43 | | 37.7 | 15 | | 55.6 | 9 | | 32.1 | 5 | | 20 | 6 | | 42.9 | 8 | | 40.0 | |

**Table 13 continued**

| | | | | Phase of cancer at first interview | | | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | All (N=145) | | | Phase 1 Diagnosis (N=34) | | | Phase 2 Completion first treatment (N=39) | | | Phase 3 In remission (N=27) | | | Phase 4 On relapse (N=21) | | | Phase 5 Specialist palliative care (N=24) | | | p value |
| ***Spirituality scale*** | N | M | SD | N | M | SD | N | M | SD | N | M | SD | N | M | SD | N | M | SD | |
| Spirituality scale score total [0-60] | 82 | 21.0 | 12.6 | 20 | 23.8 | 14.4 | 18 | 21.4 | 12.7 | 17 | 20.9 | 12.2 | 13 | 18.1 | 10.7 | 14 | 19.4 | 13.0 | 0.761 |

### Relationship between continuity of care and satisfaction with services

There was a significant relationship between experienced continuity of care as rated by close persons and their satisfaction scores at baseline (Table 14), but the relationship was weaker than that for patients (Table 8). Adjustment in the case of close persons had little impact on this association.

**Table 14 Regression models for satisfaction with services – close persons**

| | **Unadjusted Std B (95% CI)** | **Adjusted Std B (95% CI)** |
|---|---|---|
| Continuity score | 0.18 (0.15, 0.22) | 0.19 (0.15, 0.22) |
| ***Study design variables*** | | |
| Cancer network | | |
| - 1 | | Baseline |
| - 2 | | -0.02 (-0.10, 0.06) |
| - 3 | | 0.01 (-0.07, 0.09) |
| Type of tumour | | |
| - breast | | Baseline |
| - colorectal | | 0.001 (-0.08, 0.1) |
| - lung | | 0.04 (-0.05, 0.13) |
| Treatment phase | | |
| - diagnosis | | Baseline |
| - end first treatment | | 0.001 (-0.09, 0.09) |
| - remission | | 0.02 (-0.08, 0.11) |
| - first relapse | | 0.0003 (-.099, 0.10) |
| - palliative care | | -0.05 (-0.15, 0.06) |
| ***Demographic variables*** | | |
| Gender | | |
| - male | | Baseline |
| - female | | 0.02 (-0.05, 0.09) |
| Ethnicity | | |
| - White | | Baseline |
| - non-White | | 0.02 (-0.06, 0.10) |

*Note: Study design and demographic variables were retained in the regression model as they were thought a priori to be central to the analysis. Because of lower power this analysis did not adjust for questionnaire variables, as was possible in the patients' analysis; CI = confidence interval*

### Associations between close persons' perceptions of continuity of care, their involvement in care and their own health status

As was the case for patients, close persons' own preferences for style of care were not associated with their perceptions of experienced continuity *for patients* (Table 15). After adjustment for potential confounders (treatment phase, network, tumour type, sex and ethnicity), close persons' perceptions of continuity of care for patients was associated with their own (better) quality of life and (lower) psychological distress. In addition, close persons who perceived that patients were receiving good continuity had higher spiritual scores, indicating stronger beliefs. Finally there was a strong association between the close person's personal involvement in the patient's daily needs and his or her perceptions of how continuous care was for patients. The negative sign for the standardised regression coefficient in Table 15 indicates that the *greater* their involvement in the patient's care, the lower their view of continuity provided by services. However, after adjustment for treatment phase, cancer network, tumour type, sex and ethnicity this association fell just short of statistical significance.

**Table 15 Associations with continuity of care scores in close persons at baseline**

| Continuity of care | Association (number of close persons in adjusted model) | Unadjusted Standardised B (95% CI) | Adjusted Std. B* (95% CI) |
|---|---|---|---|
| ***Score on all 18 continuity statements*** | Preference for style of care (n=109) | 0.11 (-0.08, 0.30) | .07 (-0.14, 0.28) |
| | Personal involvement – part A (n=103) | -0.30 (-0.50, -0.09) | -0.23 (-0.47, 0.01) |
| | Care giver quality of life score (n=50) | -0.64 (-0.88, -0.40) | -0.65 (-0.94, -0.36) |
| | GHQ28 score (n=101) | -0.45 (-0.65, -0.26) | -0.52 (-0.73, -0.30) |
| | Spiritual score (n=73) | 0.09 (-0.13, 0.30) | 0.27 (0.02, 0.51) |

*Note:* * *= adjusted for treatment phase, cancer network, type of tumour, sex and ethnicity; CI = confidence interval*

### 4.1.3 Results of the prospective study

The flow of patients through the study, together with those lost by attrition or death, is shown in Figure 2. Participants lost at one follow-up point were not always lost completely from the study, occasionally returning at a subsequent point.

#### *Transitions between treatment phases*

Table 16 shows the movement of patients between phases over the 12 months of the study from baseline to final follow-up. Some of the patients who were lost to follow up at any one time point were again available for interview at a later follow up. To our knowledge, 81 people made at least one transition between treatment phases during the study. Most change occurred when people moved between diagnosis, first treatment and remission and the majority of interviews took place with people who began in or entered remission during follow-up. One person moved back from palliative care into remission and four moved from first relapse into a further remission.

**Table 16 Transition of 199 patients from baseline to final follow-up**

| **Baseline** | | | **Phases at first follow-up (n=148)** | | | | | | **Phases at second follow-up (n=119)** | | | | | | **Phases at third follow-up (n=102)** | | | | | | **Phases at final follow-up (n=111)** | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **Phase*** | **N** | **Lost / died** | **1** | **2** | **3** | **4** | **5** | **Lost / died** | **1** | **2** | **3** | **4** | **5** | **Lost / died** | **1** | **2** | **3** | **4** | **5** | **Lost / died** | **1** | **2** | **3** | **4** | **5** |
| 1 | 45 | 10 | 21 | 14 | | | | 8 | 4 | 10 | 1 | | | 0 | | 5 | 2 | | | | | | | | |
| 2 | 48 | 12 | 2 | 28 | 5 | 1 | | 10 | | 13 | 18 | | 1 | 5 | | 3 | 17 | | | | | 3 | 6 | 2 | 1 |
| 3 | 46 | 7 | | | 36 | 3 | | 4 | | | 36 | 1 | | 13 | | 1 | 51 | | | 4 | | | 69 | 1 | |
| 4 | 27 | 5 | | | | 20 | 2 | 9 | | 1 | 2 | 11 | 1 | 3 | | | 1 | 9 | | 1 | | | 1 | 8 | |
| 5 | 33 | 17 | | | | | 16 | 11 | | | 1 | | 6 | 5 | | | | | 4 | 2 | | | | | 4 |
| Rejoined | | | | | | | | | 3 | 1 | 7 | 1 | 1 | | | 3 | 3 | 1 | 2 | | | | 12 | 3 | 1 |
| **Total** | **199** | **51** | **23** | **42** | **41** | **24** | **18** | **42** | **7** | **25** | **65** | **13** | **9** | **26** | | **12** | **74** | **10** | **6** | **7** | | **3** | **88** | **14** | **6** |

*Note:* * = ***Phase1****:Initial diagnosis,* ***Phase2****: Completion treatment,* ***Phase3:*** *Remission,* ***Phase4*** *Relapse,* ***Phase5*** *Specialist palliative*

### *Association between continuity, transitions in treatment and satisfaction*

Experienced continuity of care did not change significantly over time (per follow-up point, standardised B -0.01, 95% CI -0.06, 0.03). There was also no significant association between continuity and a transition from any treatment phase to another (standardised B -0.25; CI -0.51, 0.01). In our first multilevel model we examined the relationship between scores on our measures of continuity and perceived satisfaction with services. Satisfaction decreased slightly but significantly in the cohort over the 12 months (expressed by time period in Table 17). The relationship between continuity and satisfaction seen in the cross-sectional analysis at baseline (after adjustment for study design, sex, ethnicity and questionnaire scores on needs, quality of life and psychological status – see Table 8), held across the follow-up periods. The magnitude of the standardised regression coefficient seen at baseline changed very little, indicating that the positive relationship between continuity of care and satisfaction held over time. When the analysis was repeated in the imputed data sets the magnitude and direction of the relationship between continuity and satisfaction remained the same.

**Table 17 Multilevel multivariable regression models for patients' satisfaction with services**

| Predictors | Data with complete information | | Imputed data | |
|---|---|---|---|---|
| | Including baseline treatment phase | Including baseline treatment phase | Including baseline treatment phase | Including time changing treatment phase |
| | **Std B (95% CI)** | **Std B (95% CI)** | **Std B (95% CI)** | **Std B (95% CI)** |
| Continuity score | 0.32 (0.25, 0.39) | 0.32 (0.23, 0.39) | 0.32 (0.23, 0.39) | 0.33 (0.25, 0.40) |
| ***Study design variables Ɵ*** | | | | |
| Cancer network | | | | |
| - 1 | baseline | baseline | baseline | baseline |
| - 2 | -0.07 (-0.26, 0.11) | -0.1 (-0.27, 0.07) | -0.1 (-0.27, 0.07) | -0.13 (-0.30, 0.05) |
| - 3 | -0.05 (-0.25,0.13) | -0.02 (-0.20, 0.16) | -0.02 (-0.20, 0.16) | -0.05 (-0.22, 0.13) |
| Tumour type | | | | |
| - breast | baseline | baseline | baseline | baseline |
| - colorectal | 0.05 (-0.14, 0.24) | 0.04 (-0.15, 0.23) | 0.04 (-0.15, 0.23) | 0.02 (-0.16, 0.20) |
| - lung | 0.31 (0.10, 0.51) | 0.37 (0.16, 0.58) | 0.37 (0.16, 0.58) | 0.33 (0.13, 0.53) |
| Treatment phase | | | | |
| - diagnosis | baseline | baseline | baseline | baseline |
| - end of first treatment | -0.08 (-0.28, 0.12) | -0.03 (-0.24, 0.17) | -0.03 (-0.24, 0.17) | -0.03 (-0.21, 0.15) |
| - remission | 0.09 (-0.13, 0.32) | 0.08 (-0.15, 0.30) | 0.08 (-0.15, 0.30) | 0.16 (-0.03, 0.35) |
| - first relapse | 0.09 (-0.17, 0.36) | 0.25 (-0.001, 0.51) | 0.25 (-0.001, 0.51) | 0.19 (-0.06, 0.44) |
| - palliative care | 0.01 (-0.32, 0.34) | 0.09 (-0.19, 0.37) | 0.09 (-0.19, 0.37) | 0.13 (-0.12, 0.39) |
| ***Demographics variables Ɵ*** | | | | |
| Gender | | | | |
| - male | baseline | baseline | baseline | baseline |
| - female | 0.03 (-0.16, 0.23) | 0.01 (-0.17, 0.19) | 0.01 (-0.17, 0.19) | -0.03 (-0.19, 0.13) |

**Table 17 continued**

| Predictors | Data with complete information | | Imputed data | |
|---|---|---|---|---|
| | Including baseline treatment phase | Including baseline treatment phase | Including baseline treatment phase | Including time changing treatment phase |
| | Std B (95% CI) | Std B (95% CI) | Std B (95% CI) | Std B (95% CI) |
| Ethnicity | | | | |
| - White | baseline | baseline | baseline | baseline |
| - non-White | -0.04 (-0.22, 0.14) | -0.06 (-0.23, 0.11) | -0.06 (-0.23, 0.11) | -0.07 (-0.22, 0.10) |
| ***Questionnaire variables$*** | | | | |
| Supportive Care Needs Survey | | | | |
| - health system and information needs | -0.03 (-0.04, -0.02) | -0.26 (-0.33, -0.18) | -0.26 (-0.33, -0.18) | -0.25 (-0.32, -0.17) |
| - sexuality needs | 0.03 (-0.04, 0.09) | 0.05 (-0.02, 0.12) | 0.05 (-0.02, 0.12) | 0.05 (-0.02, 0.11) |
| Euroqol | | | | |
| - Thermostat | 0.10 (0.03, 0.16) | 0.10 (0.03, 0.17) | 0.10 (0.03, 0.17) | 0.09 (0.03, 0.15) |
| Time period # | -0.07 (-0.12,-0.03) | -0.002 (-0.04, 0.03) | -0.002 (-0.04, 0.03) | -0.03 (-0.07, 0.01) |
| Any transition* | | | | |
| - no | Baseline | | | |
| - yes | 0.12 (-0.05, 0.30) | 0.18 (-0.01, 0.37) | 0.18 (-0.01, 0.37) | 0.18 (0.02, 0.03) |
| Intercept Ω | 0.49 | -0.22 | -0.22 | -0.13 |
| Between patient variance | 0.10 | 0.11 | 0.11 | 0.11 |
| Within patient variance | 0.26 | 0.26 | 0.26 | 0.26 |

*Note: Random intercept multilevel model with two levels, time period nested within patients; # Time period is considered as continuous (1-5); * Transition is binary, 1 if at least one transition, 0 for none; $ vary over time; Θ do not vary over time; Ω This describes* *the overall standardised mean of satisfaction across the five time points when all covariates are set to zero; Allowing cancer phase to vary over time reduces between and within patient variability only slightly.*

Finally, in order to examine the impact of *close persons'* perceptions of continuity as well as their psychological status *on outcomes in the patients*, we adjusted the multilevel model for close persons' perceptions of continuity and their psychological status, also at each time point (Table 18). This further adjustment had a small effect on the size of the standardised regression coefficient for the relationship between continuity and satisfaction in patients (Table 18). The greatest impact appeared to arise from the close person's psychological status (GHQ28). It also means that close persons' psychological status had an impact on patients' satisfaction with services. In these analyses we cannot assume that the nature of the relationships found were linear. When we adjusted the model further by adding a quadratic term to the analysis, this revealed that the relationship between continuity and satisfaction was not completely linear over the values of the continuity score. Plotting this relationship showed a curvilinear relationship in which increases from low levels of continuity led to the greatest increase in satisfaction, while the impact of increasing continuity scores from higher start points had much less impact on satisfaction.

**Table 18 Multivariable regression models for satisfaction with services adjusting for close persons' information over 12 months**

| **Predictors** | **Data with complete information** | **Imputed data** |
|---|---|---|
| | **Std B (95% CI)** | **Std B (95% CI)** |
| Continuity score (linear term) | 0.27 (0.16, 0.39) | 0.34 (0.11, 0.55) |
| Continuity score (quadratic term) | -.10 (-0.16, -0.03) | 0.10 (-0.01, 0.21) |
| ***Study design variables ϴ*** | | |
| Cancer network | | |
| - 1 | baseline | baseline |
| - 2 | -0.005 (-0.24, 0.23) | 0.03 (-0.22, 0.28) |
| - 3 | 0.001 (-0.23, 0.23) | 0.11 (-0.16, 0.38) |
| Tumour type | | |
| - breast | baseline | baseline |
| - colorectal | 0.21 (-0.06, 0.47) | 0.10 (-0.11, 0.30) |
| - lung | 0.31 (0.04, 0.58) | 0.34 (0.10, 0.59) |
| Treatment phase | | |
| - diagnosis | baseline | baseline |
| - end of first treatment | 0.14 (-0.11, 0.39) | -0.08 (-0.35, 0.20) |
| - remission | 0.38 (-0.01, 0.78) | 0.17 (-0.15, 0.51) |
| - first relapse | 0.16 (-0.21, 0.53) | 0.09 (-0.23. 0.40) |
| - palliative care | -0.12 (-0.63, 0.40) | 0.21 (-0.16, 0.58) |
| ***Demographics variables ϴ*** | | |
| Gender | | |
| - male | baseline | baseline |
| - female | 0.15 (-0.10, 0.41) | -0.06 (-0.30, 0.18) |
| Ethnicity | | |
| - white | baseline | baseline |
| - non-white | -0.04 (-0.30, 0.23) | -0.19 (-0.43, 0.06) |
| ***Close person variables +*** | | |
| Close person's continuity score | 0.04 (-0.06, 0.14) | 0.08 (-0.07, 0.24) |
| Close person's GHQ28 score | -0.10 (-0.19, -0.01) | 0.001 (-0.08, 0.08) |
| Time period # | 0.01 (-0.04, 0.06) | -0.03 (-0.08, 0.02) |
| No of transitions * | | |
| -No | baseline | baseline |
| -Yes | 0.18 (-0.18, 0.53) | 0.13 (-0.06, 0.31) |
| Intercept Ω | -0.59 | -0.28 |
| Between patient variance | 0.26 | 0.14 |
| Within patient variance | 0.54 | 0.69 |

*Note: Random intercept multilevel model with two levels, time period nested within patients; # Time period is considered as continuous (1-5); * Transition is binary, 1 if at least one transition, 0 for none; ϴ do not vary over time; Ω This describes the overall standardised mean of satisfaction across the five time points when all covariates are set to zero; + although we have not imputed close person data for other analyses, for completeness, we have done so here.*

### 4.1.5 Association between continuity and clinical/ functional outcomes

In the second multilevel model analysis we examined the relationship between continuity and other outcomes in patients. Baseline findings (Table 9) held across the 12 months of the study. That is, high perceived continuity was significantly associated with lower physical, daily living and psychological needs for care (according to the *Supportive care needs survey*), higher quality of life, and lower likelihood of psychological distress (Table 19). Adjustment for a changing phase of treatment had little impact, which is further evidence against the possibility that there was significant heterogeneity in our sample.

**Table 19 Multilevel models of the associations with scoring on continuity of care in patients**

| | **Results from MLM including only baseline treatment phase** | | **Results from MLM, including time changing treatment phase*** | |
|---|---|---|---|---|
| **Association** | **Adjusted* Std. B (95% CI)** | | **Adjusted* Std. B (95% CI)** | |
| | **Complete data** | **Imputed data** | **Complete data** | **Imputed data** |
| SCNS Physical and daily living needs | -0.35 (-0.43, -0.28) | -0.48 (-0.55, -0.41) | -0.35 (-0.42, -0.27) | -0.48 (-0.55, -0.40) |
| | Positive period effect, no transition effect | | Positive period effect, no transition effect | |
| SCNS Psychological needs | -0.44 (-0.52, -0.35) | -0.55 (-0.64, -0.49) | -0.43 (-0.51, -0.35) | -0.55 (-0.63, -0.46) |
| | No period or transition effect | | Positive period effect, no transition effect | |
| Euroqol score | 0.19 (0.11, 0.27) | 0.36 (0.28, 0.44) | 0.19 (0.12, 0 .27) | 0.34 (0.26, 0.42) |
| | No period or transition effect | | No period or transition effect | |
| Euroqol thermometer | 0.28 (0.19, 0.37) | 0.31 (0.22, 0.40) | 0.29 (0.20, 0.38) | 0.31 (0.21, 0.40) |
| | Negative period effect , no transition effect | | Negative period effect, no transition effect | |
| GHQ-28 score | -0.37 (-0.46, -0.28) | -0.51 (-0.60, -0.42) | -0.37(-0.46, -0.28) | -0.51 (-0.59, -0.42) |
| | No period or transition effect | | No period or transition effect | |

*Note:MLM = Random intercept multilevel model with two levels, time period nested within patients; Adjusted for treatment phase, cancer network, tumour type, number of transitions, sex and ethnicity;# Direction of change in covariates time period and transition that are not shown on this table; CI = confidence interval; SCNS = Supportive care needs survey; GHQ = General Health Questionnaire.*

### 4.1.6 Lagged analysis of the impact of continuity of care on clinical and other outcomes

In our final analysis of the prospective, quantitative data, we modelled all variables (except demographic characteristics such as age and gender) as time dependent and in a time lag in which each experienced continuity score is related to each (repeated) outcome measure one time point later. We adjusted the analysis for possible confounders as indicated (Table 20). This model fits most closely to a predictive model in which we assess whether continuity of care scores predict other outcomes at each subsequent follow-up point. Table 20 shows that in the complete data set total score on the 18 continuity questions at each time point in the study was significantly predictive of all supportive care needs (as measured by the *Supportive care needs survey*) in complete and imputed data sets. This finding was similar to those reported earlier in that higher continuity predicted lower needs for care. Continuity did not predict psychological or spiritual outcomes. However, there was a trend for an association with the Euroqol thermostat score in which higher continuity predicted higher quality of life.

**Table 20 Lagged analysis* showing multilevel regression coefficients for continuity score on other outcomes**

| | **Complete data coefficient (95% CI)** | **Imputed data# coefficient (95% CI)** |
|---|---|---|
| **Satisfaction score** | **0.04 (-0.06, 0.14)** | **-0.15 (-0.24, -0.06)** |
| Supportive Care Needs Survey | | |
| - physical and daily living needs | -0.16 (-0.24, -0.08) | -0.19 (-0.36, -0.01) |
| - psychological needs | -0.14 (-0.24, -0.05) | -0.15 (-0.27, -0.03) |
| - health system and information needs | -0.32 (-0.41, -0.23) | -0.28 (-0.39, -0.17) |
| - sexuality needs | -0.12 ( -0.20,-0.05) | -0.19 (-0.31, -0.07) |
| - patient care and support needs | -0.20 (-0.29, -0.11) | -0.15 (-0.25, -0.05) |
| Euroqol | | |
| - Euroscore | -0.05 (-0.14, 0.03) | 0.04 (-0.08, 0.16) |
| - Thermostat | 0.09 (-0.01, 0.19) | 0.07 (-0.04, 0.18) |
| GHQ-28 | -0.04 (-0.13, 0.05) | -0.06 (-0.16, 0.04) |
| Spirituality | 0.02 (-0.05, 0.09) | 0.02 (-0.11, 0.16) |

*Note:* after adjustment for baseline outcome, treatment phase, treatment site, network, period and transition from one treatment phase to another; # mean regression coefficients arising from the five imputed data sets; GHQ = General Health Questionnaire.*

# Section 5 Prospective qualitative study

## *5.1 Background*

We aimed to recruit a small sample of patients and close persons in each of the treatment phases and with each of the three cancers. The target totals were 15 patients and 15 nominated close persons spread across tumour types, networks and phases of illness. This element was intended to provide qualitative prospective data to ensure that our quantitative measures were not missing any vital component of continuity that might emerge over time and had not been teased out in the preparatory study based in general practice.

### 5.1.1 Method

Patients were identified in secondary care by clinical nurse specialists and National Cancer Research Network staff across the three cancer networks and approached to gain consent for their details to be passed to the research team who contacted them to explain the study, obtain formal valid consent and arrange appointments for interview. Participants agreed to be interviewed on a maximum of three occasions over 12 months, at six month intervals. Interviews were transcribed verbatim and analysed for thematic content by two members of the research team who did not undertake the interviews. The coding framework from the general practice qualitative study was used to check emerging themes, and any new themes were noted, in particular, themes emerging from consecutive interviews.

### 5.1.2 Interview schedules

Interviews were more open ended, with fewer prompts, in order to allow flexibility and allow exploration of themes that might have been overlooked in other parts of the study. The interview schedule guide is shown in Appendix E

## *5.2 Results*

Significant problems were encountered in achieving our target sample of 15 patients and 15 close persons. This was due partly to the priority placed on recruitment to the quantitative study by National Cancer Research Network staff and partly due to study fatigue in the cancer networks. Although eight patients were recruited at baseline, follow up interviews were only achieved in three cases, one at Time 2 (6 months) and one at Time 3 (12 months). Attrition at Time 2 was due to death (1), poor health (1), withdrawal from the study (1), being lost to contact (3), or late entry to study (1). Further attrition at Time 3 was due to death (1) and late recruitment (2). Close person interviews at baseline were available for the two patients who participated in more than one interview.

**Box 3 Case histories**

Patient A, a 70-year-old lady, was recruited from the North-East London Cancer Network. She had been diagnosed with colorectal cancer and was interviewed at the end of first treatment (baseline) and again six months later. A third interview was not possible at twelve months as she had by then died. Her daughter was nominated as close person and was also interviewed at baseline only.

Patient B, a 71 year old lady was recruited from the South-East London Cancer Network. She had been diagnosed with breast cancer and was interviewed at baseline and after twelve months. It was not possible to contact her at the six month follow up point. Her daughter was nominated as close person and was interviewed at baseline only.

All emergent themes from both patient and close person interviews were covered in the cross sectional analysis coding framework. However, the two rating researchers agreed that there were some differences in emphasis raised in the longitudinal interviews, particularly the adjustment to illness over time and fears for the future. The strongest themes are summarised below.

### 5.2.1 Contact with services and transitions in care

In both cases, the first contact with services at the time of diagnosis was good, and this set the scene for future relationships with clinicians. Information transfer was good for both patients and close persons and both patients felt able to cope between appointments having good knowledge of a contact person at the hospital. Both patients had other medical problems, and received good interdisciplinary care over time.

For Patient A, the transition from hospital to home was very difficult:

> *I was nowhere near ready to face things......the support stopped when I came out of hospital.*

Considerable practical support was needed in order to cope at home at the end of first treatment. She experienced considerable delays in accessing timely support from social services having to wait up to five weeks for assessment for aids to daily living within the home:

> *I knew I couldn't do it on my own... the welfare workers said you mustn't try to shower on your own, we'll come in to assess you... .it was five weeks before they came... it's only giving you help when you are past the stage when you need it most.*

### 5.2.2 Adjustment to cancer and maintenance of sense of normality

After the end of treatment, both patients tried hard to carry on their lives as normal. Patient B was able to get back to work, but encountered the problem of low energy levels over a long period. Patient A made adjustments to her daily routine:

> *I've had to slow down a lot... I'm never going to get back to where I was.*

Even if feeling physically better, the knowledge of possible recurrence is always present and is a source of anxiety:

> *Once you've got cancer, life's never the same again.*
>
> (Patient B)
>
> *Once you know you've got cancer…it's never going to go out of your mind… try to make the most of each day as it come….feel like different person.*
>
> (Patient A)

### 5.2.3 The patient's personality and family relationships

Patient A appears to have always acted to attempt to protect her family. Although herself very afraid, she was anxious not to transmit this to the family:

> *Fear…. how would my family cope…. would I manage alone.*

She already suspected that she had cancer at the time of her diagnosis and remained strong so as not to worry her daughter who said:

> *I can remember her beforehand, just sort of mentioning it, trying to prepare me without saying out loud, listen you know I've got cancer don't you.*

However, later in the illness, Patient A became more unwell and vulnerable. Rather than ask for a lot more help from the family she relied for emotional support on a close friend. Her daughter acknowledged and respected this:

> *She hated having to ask us for help.*

Patient B appears to have relied on her daughter to help her through the period of initial diagnosis:

> *Mum worries…. I tried to calm her down before we had a definitive diagnosis and a forward plan.*
>
> (Close person, Patient B)

Patient B found it difficult to talk to her own mother about having cancer since this was not an acceptable subject for discussion with the older generation:

> *She's 86, I don't talk to her… did try to tell her everything that was happening, to keep her informed and then I suddenly realised she hadn't taken it in at all…. She obviously hadn't understood.*

# Section 6 Discussion

## *6.1 Main findings*

### 6.1.1 Main findings at baseline

The narrative accounts of patients with cancer, as well as those of the people closest to them and the professionals treating them revealed that experienced continuity was a complex concept determined by factors such as the quality of the first appointment with secondary services, communication with the family and professionals; information giving by professionals; patients' and close persons' ability to share treatment decisions; the effectiveness of health administrative systems; patients' personalities and family dynamics. In particular it showed that patients' reactions to their illnesses and how they shared information within their families could have an impact on whether important aspects of continuity such as communication with professionals could be fully achieved. It also showed that people with cancer needed to be active partners in their care according to their own personal coping styles. There was little mention of needing a named co-ordinator of care or needing to see the same health professional each time, which may simply reflect that these are aspects of provided continuity, whereas we were measuring how continuity was experienced at the patient level. Nevertheless, the GP was generally regarded as a key primary care professional for ensuring unbroken care but confusion sometimes occurred over the key person in secondary care and poor communication increased this uncertainty. Giving information depended on patients' capacity to receive it and establishing a relationship of trust with the patient very early in the initial contact appeared to be crucial in setting the tone for future consultations*.* Many participants felt that improving health service administrative processes could go a long way toward improving experienced continuity of cancer care.

These qualitative data enabled us to quantify a broad concept of experienced continuity of cancer care that incorporated users' (and close persons') perceptions of how the services delivered care and information, as well as their sense of control and the quality of their informal support. An exploratory factor analysis in the patients' data revealed that 11 items making up three factors were important in explaining the latent concept underlying our questionnaire. However, this factor structure was unstable and thus all 18 items of the scale were retained for the remainder of the analysis. A similar exploratory factor analysis in close persons revealed a similar latent structure.

At baseline, patients' perceptions of experienced continuity of care were significantly associated with higher satisfaction with services, lower needs for care, better quality of life and less psychological distress. Close persons' perceptions of high continuity of care for patients were also associated with higher satisfaction but the association was much weaker than for patients. Their perceptions of high continuity of care for patients were also associated with their own (better) quality of life, less psychological distress and stronger spiritual beliefs. Those close persons who were more involved in helping with the patients' needs and care tended to perceive continuity less favourably than those less involved.

### 6.1.2 Main findings in our prospective analysis over 12 months

Patients' perceptions of continuity of care were positively associated with satisfaction with services over time, after adjustment for potential confounding influences. However, the relationship was non-linear. This remained the case after adjustment for close person's perceptions of continuity as well as their psychological status. High experienced continuity was also associated with lower physical and psychological health needs for care, better quality of life and less psychological distress at each follow-up point over the 12 months of the study. Transition in phase of treatment (for example, remission to relapse) was not associated with any change in perceived continuity, although comparatively few patients moved between phases of illness over the 12 months of the study. These associations over 12 months were less extensive in our lagged analysis which was the toughest test of whether experienced continuity at each time point could predict psychological, personal (for example, satisfaction) and clinical outcomes three months later. Continuity scores in the lagged analysis were associated with subsequent health care and information needs (derived from the *Supportive care needs survey*) but not with psychological status, quality of life or spirituality.

One or two new themes emerged from the qualitative prospective study. One patient described the concept of major difficulty in moving between phases of illness which supports our theory of the possible impact of transitions in care. Both cases reflect the problems of living with cancer after the end of treatment, the efforts that are required to regain a sense of normality and the constant fears for the future that a cancer diagnosis still fuels.

## *6.2 Strengths and limitations of the research*

Our conception of experienced continuity arose from our in-depth discussions with patients, people closest to them and health care professionals. It may be argued that our broad focus risked diluting theoretical concepts of continuity (for example treatment from a key professional in one place over time) with patients' and close persons' other concerns, such as service quality and informal support. However, it is likely that patients and close persons have different priorities than professionals when they experience 'joined up' care. These issues are discussed more fully in the subsequent section. Although patient recruitment was close to target, it was more difficult to recruit close persons, partly because not all patients were willing or able to name someone and partly because not all nominated close persons agreed to participate. Thus our analyses linking patients' and close persons' views were limited in statistical power. Recruitment to the prospective qualitative study was much lower than expected and the results should be treated with caution. Those patients who did participate may have been particularly motivated to convey their stories because of individual problems that they wished to highlight, or because of their particular personalities.

The data on the five cohorts enabled us to examine the cross-sectional relationship between continuity and outcome at each of the five stages of illness. The lack of variation in continuity and satisfaction scores with phase of treatment at baseline suggested that there was little heterogeneity in the patient sample. This finding enabled us to consider the patients as one cohort, even though they started from differing treatment points. The lack of impact of adjustment for (changing) phase of treatment in the analysis of prospective data also supported this.

Our multilevel models enabled us to examine the associations observed at baseline between perceived continuity of care and satisfaction, needs for care, quality of life and psychological status over the follow-up period of the study. Without a prospective analysis it is impossible to be certain whether the links between lower experienced continuity and lower satisfaction, quality of life and psychological status observed in this study are due to the effects of illness or to pre-existing difficulties in the individuals comprising this study population. By taking a multilevel approach to the analysis of our prospective data, we also took account of the clustering in the data within patients over time, and thus avoided an overly optimistic assessment of the relationship between continuity and our other outcomes. We are aware, however, that we could not account for a further level of clustering at the level of cancer network. Three levels (or even nine at the level of hospital) may be insufficient for a meaningful multilevel model. We also strove to avoid over-fitting of our models of the relationship between continuity and other outcomes. Nevertheless, our use of multivariable imputation gave us greater power to repeat our multivariable analysis with more precise estimates.

In our analyses (particularly the lagged analysis), we have used the term 'predict' when describing the relationship between continuity at one point in the prospective study and satisfaction and other outcomes at another. By this we do not intend to imply that we have developed a predictive model from which we can estimate future satisfaction on the basis of experienced continuity. This is because:

1 residual confounding is possible
2 it is probable (given the repeated measures of our analysis) that we are over-fitting the estimates of the association between experienced continuity and satisfaction.

The same caveat applies to the associations over time between experienced continuity and other clinical and functional outcomes.

The main weakness of the study is the rate of attrition, which was in part inevitable due to death or increasingly severe illness. This was envisaged at the outset, and to some extent the analyses conducted with the imputed data sets indicate that the impact of missing data on our main findings was not profound. Missing data was a particular problem in close persons and for this reason we did not embark on full scale data imputation (except in our adjustment for close person data in our ML models in table 16). For multiple imputation to be reliable, a number of conditions must hold. First, the missing data must be missing at random. Although not the case here, adjustment in the model for the major predictors of missing data compensated for this to an extent. A further weakness is that even though we followed up participants over 12 months, transitions in treatment phase occurred most often in patients recruited at diagnosis or first treatment. Although this reflects the chronic nature of many cancers, it limited the extent to which we could examine the impact of transition on continuity of care. Over the course of 12 months, the majority of patients we first interviewed at diagnosis and end of first treatment had passed into remission. Of those who were patients recruited in remission, more than half remained in remission at final follow up. Finally, we must emphasise that although the study took in a very wide geographical area with considerable variation in socio-economics conditions and health services, the findings apply to the London area and may not be generalisable beyond that, particular in terms of the primary/secondary care interface.

## 6.3 Measures of continuity of care

It was no surprise that the content of some of the statements in our measure of experienced continuity should differ from concepts of continuity proposed by health professionals. The models of continuity debated in the published literature (Centre for Health Services and Policy Research, 2006; Haggerty *et al*, 2003) are professional descriptions of ‘joined up’, consistent and integrated health care. However, our brief was not to study these components in any detail; rather, it was to explore and define continuity as *experienced* by users and their close persons. In so doing we have described an *outcome* and not a *process* of service provision. Our concept of experienced continuity arose from qualitative work with patients and nominated close persons in the first phase of research and was subsequently developed into the 18 questions applied in our quantitative, prospective study. They describe how patients and close persons experience joined-up, integrated care. This outcome will not exactly mirror the components of continuity understood at the level of the service professional. It is not a description of the process (continuity of care) so much as a measure of the outcome (namely how such continuity is perceived or experienced by users). To use a metaphor, a cognitive behaviour therapist employs a number of evidenced-based actions to help a patient understand their thought processes and recover from depression. The patient experiences the care delivered in a number of ways, most of which result in his or her feeling better and having the confidence to take up his/her usual life again. The patient’s experience is one of regaining hope, coping better and feeling more positive - it is not encapsulated by a description of the process of care delivered by the therapist, most of which he/she would not understand. In our study, patients experienced consistent care in terms of sufficient knowledge about their illness and its prognosis, a belief that they can get ready access to services, a confidence that they can manage when not in touch with services, an assurance (or otherwise) that their families can cope, and so forth. They did not discuss joined up care, good communication between services or having the same key person to contact. Their description is simply different; it is the *outcome* we call experienced continuity. Thus, of necessity, patients, close persons (and some professionals) embrace wider issues in their discernment of continuity than simply whether or not they see the same professional and whether or not that professional is up to date with their treatment history. This may also be because in cancer care, such basic features of continuity are already in place for the great majority of patients. It is also important to keep in mind that in care of cancer, as opposed to other conditions, the potentially life threatening nature of the diagnosis instils fear. Such fear may render some patients and their families particularly keen to engage with clinical services in order to secure their best chance of curative treatment or early detection of recurrence. Thus, simple issues such as having a regular contact person over periods of time may be necessary but *insufficient* as an overall indicator of patients' experienced continuity. Experienced continuity of cancer care appears to be a multifaceted notion that undoubtedly contains informational and relational elements but also involves a dimension in which patients are enabled to cope between service contacts. The latter in turn puts pressure on patients' informal networks and how effectively those close to them are coping. The question about *coping between appointments* (Item 10, Table 6), which stood alone as the second factor of our common factor analysis in patients, seems to be an important indicator of whether or not services are experienced as consistent and continuous. Coping between appointments may mean that a patient carries an image of 'joined up' care in his or her mind that helps him or her to manage when not in touch with a team. Although there are many factors that may affect coping, by adjusting for treatment phase, cancer network, type of tumour, sex and ethnicity in our multivariable models, we managed to isolate to some extent the relationship between continuity and these other outcomes. We note, nevertheless, that having a main contact person and knowing that health professionals are up to date with one's history were linked to higher scores on our measure of continuity. What our results appear to indicate, however, is that experienced continuity goes well beyond these factors.

How patients cope between appointments is also linked to the concept of self-management and how to engage patients in their health care. Our results suggest that if experienced continuity is to be achieved we need to develop interventions that address the development of these skills in patients, as a self-management disposition will encourage coping. Despite a strong policy commitment in the UK to patient-centred care, patients' roles as active partners in their health care are insufficiently recognised and supported by health care professionals (Coulter, 2006). In her analysis, Coulter chose to examine six indicators of engagement, namely quality of doctor-patient communication, access to alternative sources of information and advice, provision of preventive care and advice, informed choice of provider, risk communication and involvement in treatment decisions, support for self-care and self-management.

Lastly, irrespective of predefined professional models of continuity of care, the global concept of continuity that emerged from our data demonstrated a strong relationship with satisfaction of care, needs for care and most clinical outcomes at baseline and this was further observed in our lagged analyses for specific care needs and quality of life. These findings are encouraging and merit a fuller exploration of the concepts that have emerged from our study.

### 6.3.1 How patients and close persons experience continuity

Perceived service quality and continuity are difficult to tease apart. As already discussed, professionals tend to regard continuity in terms of ensuring the same professional is involved and providing consistent information. However patients appear to have broader concerns about longitudinal stability (regardless of whether or not the same professional is involved), information on what will happen in the future, their ability to cope and their relationships with those close to them. Thus continuity may not be a 'package' that professionals can necessarily *offer,* so much as an interaction between the care setting, the professionals' management and patients' beliefs and attitudes about those close to them. Our results indicate that continuity can be facilitated but only *provided* to a certain extent. For example, if patients have difficulty communicating their beliefs and fears about their cancer to people close to them and do not involve them in their treatments, their continuity of care may be placed in jeopardy. Promoting involvement and a sense of engagement in their care might be the best way to ensure clinicians help patients to help themselves. It is worrying therefore that Coulter concluded in her international analysis (King *et al*, 2001) that the UK is not performing well when it comes to involving patients in their care and thus it is hard to avoid the conclusion that health care is delivered in a more paternalistic fashion in the UK than in the other countries studied (USA, New Zealand, Canada, Germany, Australia).

### 6.3.2 The role of close persons and families

Our data have drawn attention to the role of the family in continuity. Shifting roles within the family and a desire for family members to protect each other from distress may impact on experienced continuity. Families in which members feel supported and connected, while at the same time able to express their own individuality, are better able to adapt to changes (Kemp, 1995). Most research into family dynamics in cancer has focused on end of life issues, palliative care and bereavement (Kissane and Bloch, 2002) and little attention has been paid to their role in how patients experience continuity. Receiving the diagnosis of a potentially life threatening illness has a major impact on people's attitudes to time, purpose in life, sense of inclusion and planning for the future. Family members may experience guilt, tension, anger and distrust that make it difficult for them to support each other easily (Kristjanson and Ashcroft, 1994). Our results indicate that patients worry about how much they depend on those close to them, as well as how those close persons are coping themselves. They also indicate that psychological distress in close persons can affect patients' perceptions, for example satisfaction with services. These findings indicate that the patient and close person form a dyad with each influencing the other to some extent. We shall be able to explore this in greater detail in subsequent analyses. Kissane and Bloch (2002) describe three key dimensions of family functioning: cohesiveness, conflict and expressiveness. Cohesiveness describes the family's ability to function as a team and when this element is high it buffers any reduction in other dimensions of functioning. A family's ability to resolve conflict reflects its capacity to adapt and one that is low in expressiveness of thought and feeling is thought to function less well. As we have shown, cancer is increasingly experienced as a chronic disease and family members may experience several developmental transitions with subsequent problems of adjustment (Shapiro, 2002). Thus, the way a family functions may, to at least some extent, determine continuity of services for patients and the ways in which they engage in care.

Thomas and colleagues (2002) used qualitative and quantitative methods in a three-year study to explore the care-giving experiences of 262 informal carers for people with cancer. They found that additional care work demands were an important feature of informal carers' experiences but that this varied with the stage of the patient's disease and the presence of either co-morbidity in patients or morbidity in carers. Carers of either sex worked hard to manage their emotions as well as those of the patient. They felt a sense of responsibility to be 'strong' and 'positive; and to maximise the sense of normality in the lives of both the patient and themselves. Our data show that close person's psychological status affects how patients experience continuity and whether or not they are satisfied with services. They also show that close persons judge continuity in somewhat less favourable terms than patients and that the more intimately they become involved in care, the lower their opinion of continuity. This last finding suggests that close persons' views are less immediately influenced than patients' by the immediate impact of symptomatic treatments and the need to depend on professional staff. Consequently close persons may be less ready to please in their making their estimations.

### 6.3.3 The relationship between patients' and close persons' views

The evidence on the relationship between patient and carer experiences of cancer care comes mainly from studies that have compared patients' views on end of life care with carers' proxy views collected after bereavement (Kissane and Bloch, 2002). The evidence suggests that carers' proxy views on the quality of services and on observable symptoms compare well with patients. Agreement is poorest for patients' subjective experiences, such as pain, anxiety and depression. Data collected in a large regional study in England of 1858 relatives or close friends and neighbours 10 months after deaths from cancer (Addington-Hall and McCarthy, 1995) showed that informal caregivers' satisfaction is mainly determined by service characteristics (for example patient and carer having the same GP); attributes of both patients and informal caregivers (for example when caring was rewarding rather than a burden) also play an important role.

### 6.3.4 Coming to a consensus

There have been several attempts to review and consolidate the many concepts of continuity of care that have been described across all health services(Haggerty *et al*, 2003; Fletcher *et al*, 1984; Saultz, 2003); Saultz and Lochner, 2005). However, all have been defined by professionals. Continuity has been regarded as a hierarchical concept that requires informational continuity before longitudinal and interpersonal continuity can be realised. Informational continuity is defined as an organised collection of medical and social information about each patient that is readily available to any health professional caring for that patient. It requires a systematic process that allows access to and communication about this information among those involved in the care. Longitudinal continuity is when each patient has a 'medical home' in which he or she receives most health care in an accessible and familiar environment from an organised team of providers. Interpersonal continuity describes the ongoing relationship between the patient and one health professional whom the patient knows by name and whom he or she has come to trust. The professional assumes personal responsibility for the patient's overall health and arranges cover when away. Other facets of continuity that have been described are geographical continuity which means care is continuous across several sites such as the office, home, and hospital; interdisciplinary continuity which ensures that the patient's history is known even when a wide range of services spanning the traditional medical specialities is required; and family continuity in which providers regard the health problems of other family members as part of the overall picture of care for their patient (Saultz, 2003; Saultz and Lochner, 2005).

Despite these complex, top-down models, most empirical research has used simple models, usually focused on whether or not patients see the same health professional who reviews and co-ordinates their care and for how long that relationship is maintained. This has been the case in medical treatments such as asthma (Love *et al*, 2000), but also particularly in general practice care (Mainous *et al*, 2001; Nutting *et al*, 2003). Nevertheless, there have been a number of attempts to design instruments to measure more complex concepts of continuity of care. At least one measure has been developed for use in patients with terminal illness (McCusker, 1984). This instrument poses four questions on continuity of care as part of an overall scale on satisfaction and preferences in patients in long term and end of life care. The four questions concern professionals' knowledge of the patient's history of care and whether or not patients see the same doctor. However, the questions had low internal consistency and seemed to be measuring two distinct dimensions of care. At least two self-report questionnaires have been developed in primary medical care (Chao, 1988; Falvo and Smith, 1983) and one in diabetes care (Gulliford, 2006). The first of these concerns the ongoing patient-family physician relationship based on five theoretical dimensions of continuity: chronological, geographic, interdisciplinary, interpersonal, and informational (Chao, 1988). Items developed by the author to cover these dimensions were assessed for face validity by a board of family physicians. A principal components factor analysis of this perception of continuity scale revealed two factors, the first concerning the structure of health care delivery (for example wanting appropriate referrals) and the second dealing with the interpersonal relationship between physician and patient (for example doctor knows about family problems). A measure of single provider continuity was made from the patients' charts. Although satisfaction and perceived continuity scores were correlated, neither was correlated with a simple, chart-based measure of continuity. The second questionnaire concerns dimensions of satisfaction and rapport between patients and physicians (Falvo and Smith, 1983). It is a patient-rated scale about the patient-physician interaction that concerns 17 key issues such as being treated respectfully and taking account of individuals' needs when prescribing. The items arose from structured discussions with patients and were gradually refined with feedback from patients and physicians. Test-retest reliability was assessed on only 23 patients but appears to be satisfactory (0.76). Gulliford *et al* have recently devised a 19 item measure of perceived continuity that was developed from professionals' models of continuity and tested in qualitative and quantitative work in Type 2 diabetes. It has acceptable internal and test-retest reliability but does not appear to be predictive of clinical outcomes.

## 6.4 Does continuity matter?

Our results suggest that our concept of experienced continuity of care has a significant impact across the time course of the study, not only on satisfaction with care but also (and arguably more importantly) on health outcomes such as needs for care, psychological status and quality of life. This remained the case after adjustment for potential confounders of these associations, such as cancer type and cancer service network. Thus, experienced continuity seems to be closely linked to important health outcomes and these relationships require more investigation. However, we did not confirm that transitions between phases of treatment (for example remission into relapse) altered the underlying perception of continuity. There did not appear to be a sense of 'abandonment'.

Although a recent review article (Saultz and Albedaiwi, 2004) examining evidence for the relationship between interpersonal continuity of care and outcomes such as patient satisfaction suggests that it is difficult to determine whether continuity leads to satisfaction or the other way round, there are now several longitudinal and experimental studies that also suggest that experienced continuity leads to particular health and social outcomes. However, as already emphasised, most concern one-dimensional measures of continuity such as whether or not patients see the same health professional who reviews and co-ordinates their care and for how long that relationship is maintained. At least one such prospective study in 256 patients with Type II diabetes linked increased continuity with better glycaemic (HBA1) control (Parchman *et al*, 2002). However, as mentioned in Section 6.3.4, Gulliford *et al* did not find an association between their carefully developed measure of experienced continuity and patient clinical outcomes in Type II diabetes. Desire for continuity also varies with the nature of the patient and their circumstances. Longitudinal studies in general practice suggest that older patients with less education and worse health, and who visit the practice more often, value continuity conceptualised simply as co-ordinated care from one doctor over time (Nutting *et al*, 2003).

Most randomised trial evidence for the benefit of enhancing continuity of care arises from obstetric practice. A Cochrane review of two randomised trials in obstetric services (Hodnett, 2000) involving 1815 women compared care co-ordinated in each patient by one midwife (high continuity) with that provided by a number of physicians and midwives (low continuity). Women in the high continuity arms of the trials were less likely to be admitted to hospital in the antenatal period, more likely to attend antenatal education classes, less likely to require analgaesics during labour, more likely to appreciate their antenatal, intra-partum and postnatal care and less likely to have episiotomies. Newborns were less likely to need resuscitation. However the women in the high continuity arm of the trial were more likely to suffer vaginal or perineal tears. Similar positive outcomes in obstetric care were found in a review of seven randomised control trials involving over 9000 women (Waldenstrom and Turnbull, 1998). In the cancer field, there are also indications that continuity in terms of a regular clinician and a regular site for treatment are associated with higher rates of uptake of screening for cervical cancer (O'Malley *et al*, 1997). There is also evidence from a Medicare database in the USA that continuous, regular primary care provision leads to earlier detection of cancer (Reid and Rozier, 2006).

## 6.5 Implications for services

Continuity and quality of service delivery extend across the interface between primary and secondary care. Although some cancers are discovered as incidental findings during treatments in secondary care for other causes, many are first suspected by patients at home, or on consultation with their GPs. In order to encourage the efficiency and reliability of timely referral and accurate diagnosis, the Government has recently set new target limits on waiting times from primary care referral to specialist appointment and from the specialist's decision to treat to first definitive treatment (Department of Health, n.d.). However, changes in general practice organisation are also important in ensuring better quality of care. The new general medical services contract was introduced in April 2004 and offered substantial payments for practices that provide high quality patient care. Quality of care is assessed using a set of indicators that make up the *Quality and outcomes framework* (QOF). The indicators in the QOF cover four domains:

i clinical care

ii practice organisation (practice records, information for patients, education and training, practice management and medicines management)

iii patient experience

iv additional services.

The first section of the QOF, the clinical indicators, relates to 10 chronic conditions, one of which is cancer. This section requires that GPs maintain a register of all people with cancer in their practice and conduct annual clinical review on each of them. The second section on practice organisation relates to general (not cancer specific) information provision and communication between the patient and the general practice team. The third section measures patients' experience of the practice and is assessed through a patient-completed questionnaire about general aspects of access to clinical care; the organisation of appointments within the practice; and more specific issues relating to telephone and face to face contacts with receptionists, the patients' personal experiences of consulting with the doctor and their overall satisfaction with the clinical care provided. With the exception of the first clinical indicator, none of these measures focus on specifically cancer. Our results suggest that the main problems encountered by patients with cancer were communication difficulties across the primary/secondary interface. There was little dissatisfaction with the care provided by general practice teams. The delivery of clinical care for cancer across the primary secondary interface remains a neglected area of service delivery and general medical service initiatives such as QOF will do little to address the gaps in care identified in our study. Further research and planning are needed on this aspect of service delivery and organisation.

Much work has been done in cancer networks to improve standards and provide training in the breaking of significant news to patients and their families and keeping them informed about their care. Communication skills courses for all health care professionals, including consultants, are currently being considered for implementation across the UK (Fallowfield *et al*, 2003; Jenkins and Fallowfield, 2002). An increasing number of services are being supported by full time clinical nurse specialist posts. However, funding for these is distributed locally and there is considerable competition when allocating resources in many NHS trusts. For the commoner cancers such as those in this study, clinical nurse specialists are often in post; for the less common cancers many such posts are unavailable or unfilled. Clinical nurse specialists remain the primary point of contact for patients and often are the main providers of information on services for both patients and their families. Communication between health care professionals continues to improve with increased multidisciplinary working and the growing numbers of multidisciplinary team meetings at which all patients are regularly discussed. These meetings, together with information from referral targets and other sources, are an important source for of data collection for achieving the new Government targets aimed at reducing waiting times to definitive diagnosis and treatment (see Section 1.3.3 for an explanation of the '31/62' target). Improved multidisciplinary communication will ensure patients are given consistent information in a timely fashion by professionals familiar with their clinical condition and associated personal circumstances. Guidelines for secondary care to use electronic hospital discharge summaries, the speedy transfer of information to GPs including the use of facsimile or email to communicate a cancer diagnosis within 24 hours should improve communication with primary care and enable easier access to information for patients and their GPs.

## 6.6 Links between continuity of care and other patient and close person factors

Despite work in the UK and Canada that attempts to define and develop measures to assess continuity of care, the concept remains complex. Our analyses indicate that experienced continuity of care varies with patients' and close persons' characteristics such as age and psychological status and whether or not they wished to be actively involved in the treatments offered. Although patients' perceptions of continuity of care did not vary with phase of treatment, there was a suggestion from our baseline results that close persons experienced continuity at its lowest in palliative care. However, their psychological status was also worst at this phase of illness and (as our other prospective results suggest) this may have impacted on their perceived continuity. In the final phase of illness increased co-operation between primary, secondary and tertiary care services would be of particular value to patients. Supported by the Department of Health's End of Life Care initiative (Department of Health, 2006), current pilot work on the expanding the introduction of the Macmillan Gold Standards Framework that is being conducted in some cancer networks, the increasing introduction of the

Liverpool Pathway for the Care of the Dying for use by community-based palliative care teams and the strengthening of links between service providers via palliative and supportive care networks may be catalysts in improving co-ordination of end of life care. End of life networks, and initiatives such as the Marie Curie-led Delivering Choice programme currently being piloted and evaluated in Lincolnshire, Tayside and Leeds, aim to improve co-ordination and delivery of care for dying patients to enable them to receive appropriate support to die in the place of their choice.

Our evidence suggests that services cannot play a full part in ensuring continuity without knowing more about how patients relate to their families and close friends. Continuity is unlikely to be achieved without an adequate understanding of patients' needs and preferences and factors that influence them. Oncologists focus on the complexities of multimodality treatment and need support in these aspects of care; routine use of assessment tools might enhance this process. Our findings respond to the call for the development of mechanisms to promote continuity of care published in the UK's NICE guidance on supportive and palliative care for adults with cancer (National Institute for Health and Clinical Excellence, 2004) and are supported by recent work on needs assessment tools (Richardson *et al*, 2005). Careful assessment of patients' needs and circumstances is fundamental to understanding patients' experiences and developing an effective care response.

## 6.7 Continuity and transitions in treatment

Recent innovations to improve co-ordination of care have focused on home care at the end of life (Gysels and Higginson, 2004). Little research has assessed the impact of continuity across the course of cancer treatment. We did not confirm our clinical observation that transition in treatment leads in some patients to a sense of abandonment by services. There were no differences in patients' perceptions of continuity between treatment phases at baseline, nor did the prospective data indicate any significant change in perceived continuity after transitions in care. This may be due to an artefact in our study; transitions that predominated were mainly from diagnosis or treatment to remission. Furthermore, our approach assumes that continuity of care is always important to service users and takes little account of the potential benefits of less continuous care. An emerging theme in the UK's supportive care strategy (National Institute for Health and Clinical Excellence, 2004) is about how to support and follow up patients in remission. If, as our data suggest, these patients have minimal needs then follow-up might often best take place in primary care with the support of specialist nurses. However, our finding that patients' psychological status was best and needs for care lowest in remission might also suggest that many patients are content to be relatively disengaged from health care services, free to forget their illness and get on with normal life. Status during remission is of particular importance since many more people are living longer with cancer. Imposing professional models of continuity that involve regular contact and support, may risk reminding people and their families that they are ill and prevent them re-engaging with daily living. Although regular contact and support provide patients and close persons with an opportunity to discuss their fears and concerns, it should certainly not be regarded as a panacea;

for many of them, each check up will bring with it anxiety and fear of relapse (Cox and Wilson, 2003). This fear can lead to difficulty in taking up life again in the community in which they live and work (Breaden, 1997). Furthermore, such follow-up can be a costly ritual for many patients that does little that is clinical effective (Brada, 1995). While we have shown that easy access to a contact person in secondary care is likely to increase confidence, many patients also express the wish to return to a sense of normality in their lives. This dilemma may have particular relevance to services that are planning rehabilitation programmes to support patients re-engaging with daily living immediately post treatment and managing their lives after moving to palliation. There is a large literature on cancer survivorship and many rehabilitation programmes focus on the use of exercise for those in recovery and those in the palliative phase (Stevinson and Fox, 2006). Day care provision for patients with advanced disease provides supportive care in the form of exercise programmes, group therapies, complementary therapies and counselling. It is a challenge for these services to access patients with significant physical, psychological or social needs, while at the same time encouraging patients to re-engage with normal activities of daily living when appropriate. Saultz and Lochner (2005) throw doubt on the desirability of continuity of care as an outcome and suggest the possibility that transient discontinuity might improve care by allowing new insights into the process of diagnosis and management. Whilst family doctors assume that interpersonal continuity is desirable, there remains scarce evidence that it is *always* of value to patients.

## 6.8 Implications for research

Our data would suggest that experienced continuity is an outcome of service delivery that has a character distinct from the process models proposed by professionals. It has an impact on satisfaction with care, needs for care, quality of life and psychological status. Our measure of experienced continuity may serve as a valuable indicator of the delivery of continuity of care. Additionally, patients could use the measure to play a distinct role in their own care through recognition of issues arising from the experience of continuity. These are fundamental to health care delivery. We need further examination of the meaning of such factors as ‘coping between appointments’, the contribution of patients’ personalities and self efficacy, and/or whether or not our suggestion that coping is a proxy measure of their confidence that the service will consistently meet their needs is a valid one. We also need to develop theoretical models of experienced continuity that explain its nature and variation. In further work with multidisciplinary teams that is planned in the next funded phase of our work due to commence in 2006 we shall will attempt to identify those patient circumstances in which perceived continuity and satisfaction are weakest. Our aim is to evaluate our concept of experienced continuity in clinical settings.

# Section 7 Conclusions and recommendations

## *7.1 Conclusions*

1 Experienced continuity of care is a multifaceted outcome that requires more than basic consistency in health care personnel and record keeping.

2 Experienced continuity is of necessity different to current models of continuity in service provision.

3 Experienced continuity of care involves historical knowledge of the patient and family, information sharing, knowledge of what to expect in the future, ability to cope between appointments, and the informal support of others.

4 Patients and close persons play an interactive role with health care professionals in ensuring continuity and recognition of this and seeking to strengthen their role is fundamental to health care delivery.

5 High levels of experienced continuity of cancer care confers benefits in terms of satisfaction and health outcomes.

6 Our measure of experienced continuity may serve as a valuable indicator of the delivery of continuity of care.

7 Multidisciplinary team meetings are currently a forum for clinical decision making and care planning and may provide a setting in which to address continuity of care directly.

## *7.2 Recommendations*

1 Professionals in cancer services should make sure that patients have as much information as they require about their current treatments and what to expect in the future.

2 Efforts to improve continuity would benefit from greater attention to patients' families and close persons in terms of:
- family dynamics
- their attitudes to and knowledge about the illness
- their involvement.

3 Given its association with better health status and lower needs for care, cancer professionals should address the patient experience of continuity at interdisciplinary meetings, whatever form they take locally.

4 Addressing continuity should take account of current Department of Health policy initiatives that are evolving rapidly in the cancer field.

5 We should distinguish between models of continuity that are delivered in health services and the experience of continuity reported by patients.

5 New ways should be developed to identify patients at risk of poor continuity of care.

6 Patients and close persons should be given the opportunity to assess their experiences of continuity and seek greater service support if it is lacking.

7 Existing or newly developed models of continuity of care are audited against service and clinical outcomes.

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# *Appendices*

## Appendix A Qualitative interview schedules

This appendix sets out the qualitative interview schedules produced for part I of the study:

i patient and close person interview schedules

ii health care professional interview schedule.

**Patient questionnaire - part I qualitative study**

### *Background information*

Name:

Age:

Sex:

Contact details:

Diagnosis:

*Relevant* medical history:

*Relevant* family medical history:

### *Statement of thanks and brief outline of study*

Thank you for agreeing to this interview.

We're looking at the best ways to improve the quality of care and support people receive…but we're also interested in finding out about the emotional and practical issues that affect people during their illness.

We would like to hear about your experiences, both good and bad. This will help us find out what works and what doesn't and will be very useful to us in improving health care services.

We're interested in hearing about your experiences since diagnosis…particularly what is happening in your life now.

The interview will take about 45 minutes and please don't feel you have to answer any questions that you don't feel comfortable with.

Also feel free to ask me questions at the end. I'm not a medical doctor but a researcher, and so unfortunately I won't be able to answer any specific questions about treatment.

As I said in the letter, at the end we will be asking you to think about a friend or relative who gives you support …so that we can also talk to them about their experiences…

And we will also ask about the two health workers who have been most helpful—the one who you met through your GP (it might be, for example, the practice nurse, district nurse, counsellor, the GP themselves or anyone who has been the most helpful)—and the one from the hospital, (who might be a doctor, nurse, physiotherapist, chemotherapist or whoever). This is so we can ask them about their job and how they see health care.

## *Consent and confidentiality*

Thank you for letting us ask about your experiences. Can I just check that you're still happy to go ahead and talk with us… [SIGN CONSENT FORM] … if at any time you decide you don't want to participate any further…then that is ok too.

We would also like to remind you that we would like to tape the interview; this will save us writing lots of notes and missing things that you say which are important

And as far as confidentiality goes…everything you say will be completely confidential and will not be discussed with anyone, including the medical staff or your family members.

## *Background information*

Before we start can I just ask:

- Do you have a living partner, and do you have any children?

- Do your friends and relatives live near by?

- How close is the hospital - is it easy to get to?

- How close is the GP - is it easy to get to?

- And lastly, what is your occupation, and are you still working?

## *Diagnosis*

This first section is about your diagnosis…and so I'd like to start by asking you a few quick questions about your diagnosis:

1. Who told you about your diagnosis, and was the information given in person?

2. Did they spend enough time talking with you about the diagnosis?

3. Was the information easy to understand?

4. Was there too little or too much information about things such as illness, treatment, medications and support services?

5. What went through your mind during those first few days after diagnosis?

## *Emotional issues and uncertainties*

**Question:** We all know that living with illness can be difficult at the best of times… and this section is about some of the emotional difficulties that you might have experienced over the past few months… so I'd like to ask…what are your main worries at the moment?

**Primary prompts:**

Are there times when you are:

Other people we spoke to said they were:

- Worried about what might happen in the future?
- Worried about the changes that are happening to them?
- Worried about not being in control anymore?
- Worried about the way their body looked?
- Worried about their family/partner/children?
- Worried about pain?
- Worried about finances?

**Positive prompt:**

Which persons were most helpful?

**Question:** How have these worries been affecting your everyday life?

**Primary prompts:**

Are there any times of the day that are worse than others e.g. in the morning, evening or at night – why?

Can you remember any weeks that were particularly bad – why?

Are things generally better or worse at weekends - why?

**Question:** Do these worries stop you from doing things?

**Primary prompts:**

Some people said that they:

- Feel a lack of motivation
- Just don't feel like getting out of bed in the morning
- Are you the sort of person who tends to accept things, or do you fight things?
- If you could change one thing what would it be?

**Positive prompt:**

What things helped with these worries?

## *Treatment, perceptions and expectations*

**Lead in:** The next section is about the kinds of treatment you've received and the expectations you had of it beforehand…

**Question:** What treatment have you had?

**Primary prompts:**

What about the quality of care you have received?

Has it been better or worse that you expected – Why?

Were you worried about treatment?

What treatment were you expecting…chemotherapy, surgery, injections etc?

Has treatment been like you expected - if no, how have things been different from how you imagined?

Has treatment ever got too much - if yes, who helped you keep going?

Have you ever considered stopping treatment - if yes, why?

Does it seem like treatment keeps stopping and starting, or does it seem like you're always being treated for something?

Could you give us a few words that would describe your experiences?

Are there days when you:

- Feel like not taking your medication?

- Feel like not going for appointments/ treatment - if yes, why?

- Feel disorientated…especially before or after treatment?

**Question:** If someone you knew got diagnosed with the same thing, what would you tell them:

**Primary prompts:**

- in regards to the emotional experience that they are going through?

- in regards to treatment and services?

Have you tried any alternative therapies?

How much support have you have received - from GP, Hospital and family?

If you could change one thing about health care services, what would it be?

**Positive prompts:**

What things have you learnt about yourself?

Has your life changed for the better in any way?

## *Communication*

**Lead in:** I would now like to ask about communication…especially your experiences of good and bad communication, so that we can find out ways of making communication easier…

**Question:** Some people have told us that they have found it difficult to approach medical staff and discuss things with them…whilst other people said that they have had few problems finding staff and discussing things with them. We'd be very interested to hear of your experience of communicating with medical staff.

**Primary prompts:**

Do you often get the opportunity to ask questions?

Was information clear?

Do you find people generally communicate in plain English - and who doesn't?

Are there things that still have not been explained to you?

Have there been times when someone has talked to you, but you still felt none the wiser afterwards?

What piece of information was most confusing?

Were there any language problems and barriers?

***Who do you approach when you want to find out information about your illness?

Who are the most approachable members of staff?

***What things do you talk about with other patients - do you find this useful?

**Positive prompts:**

Who gave the best information?

Why did they give the best information?

**Question:** This is a difficult time for everyone concerned: yourself, your friends and family….and as we know, talking with friends and family can sometimes be difficult…and so if it's ok we'd like to ask you how it has been discussing things with your family and friends.

**Primary prompts:**

How have things been when talking with your husband, partner, wife?

What things do you discuss with family?

Have you stopped seeing your friends?

What things do you discuss with friends?

What things do you discuss with children?

What things are difficult to discuss?

Is there anyone outside of family who you can turn to?

**Positive prompt:**

Who do you find it easy to talk with?

## *Emotional disruption*

**Lead in:** I'd like to talk a little bit more about some of the emotional issues…often illness gets people down.

**Question:** could you tell us a little bit about the kinds of feelings you've been having?

**Primary prompts:**

Are there times when you:

- just wanted to give up - if yes, when and why?
- felt all alone - if yes, when and why?
- felt like not seeing anyone - if yes, when and why?
- felt overwhelmed - if yes, when and why?
- suffered from low self esteem etc - if yes, when and why?
- felt it wasn't worth taking care of your appearance?
- worried about the next few months?
- worried about dying alone?

**Positive prompt:**

What helps when you're feeling fed up?

Question: Are there any times that you've felt depressed or left in the dark…?

**Primary prompts**

When was the worse time:

- Before, during or after diagnosis?
- Before, during or after treatment?
- Which were the times when you felt like things were getting better?
- What kinds of support did you already have?
- What support did the medical services offer?
- Has anyone suggested going to see a counsellor?
- What support have you had to go and find yourself?
- Would you like to join a support group?

**Question:** Could you also tell us a bit about those times when things are going well…?

***Who has been most supportive, and why?

## *Physical issues (optional for stage 5)*

**Lead in:** We've now reached the last section…and I'd like to talk to you about some of the physical problems you are experiencing.

Question: Illness takes a physical toll…what are the biggest physical problems you have had to deal with?

**Primary prompts:**

Fatigue and tiredness - what times are better or worse?

Disruption of sleep

***How have you coped with the disruptions?

Who would you contact if your physical condition suddenly got worse?

**Positive prompt:**

What would make things better?

Question: What things have you found most difficult, and is there anything you can't do anymore?

**Primary prompts:**

Do you have problems:

- caring for yourself?
- carrying out everyday chores?
- being dependent on others:
- With mobility - including getting to shops, making hospital appointments etc - also expense involved.

How is it affecting:

- your social life?
- your work?

**Positive prompt:**

Can you suggest any techniques that other people might use to help them cope?

**Wrapping-up**

OK that's most of the interview over…before we finish is there anything you think is important that we haven't talked about? …and so I'd just like to end by asking you - what are your hopes for the future?

**Ending the interview**

Thank you very much…and I hope I haven't taken up too much of your time. The information you have given us is going to be extremely useful in helping us to improve care. Please feel free to ask any questions about the study…

Turn off tape recorder, answer any questions and then ask:

- the patient to nominate a friend or relative and ask the patient to contact them
- for the names and contact details of the nominated health care workers
- if it's ok to make a follow up call and outline purpose of the call:

We'd like to telephone you in a couple of days…firstly to check if it's ok to talk to the person close to you…but also because there may be things that you think about after I've gone. We all know the feeling when you suddenly remember something that you wished you'd said at the time…and so if anything comes up just jot it down for when I call.

[Arrange a time to contact.]

**After interview**

- ECOG assessment
- Add any relevant notes and information

**Close person questionnaire - part I qualitative study**

### *Aims of questionnaire:*

The emphasis of this questionnaire moves towards the significant persons in the patient's life…partners, friends, family and so forth…who may or may not be active as carers. It is an open question as to the extent to which the focus of this questionnaire should remain on the patient's experiences or shift towards the significant person's own needs, and in turn how these relate to continuity. The basic structure is the same as the 'patient questionnaire' and is primarily meant to get people talking—in a non threatening way—about issues that are of interest and relevance. Thus none of the questions or phrasings are cast in stone and we should use those that seem most appropriate to the person's situation and also remember to pick up on the person's own terminology when phrasing questions.

### *Background information to be collated on phone before interview*

Name:

Sex:

Relationship to patient:

### *Background information to be collated at beginning of interview*

Age:

Occupation:

Relationship to patient:

Length of time known to patient:

Approximate amount of time person spends with patient per week:

### *Statement of thanks and brief outline of study*

Thank you for agreeing to this interview.

We're looking at the best ways to improve the quality of care and support patients and their families/the people close to them receive…but we're also interested in finding out about the emotional and practical issues that affect families/close persons during illness.

We would like to hear about how your life has changed since [name of patient] was diagnosed… about some of the emotional and practical issues you have had to cope with …and about how things are now.

Hearing about your experiences, both good and bad, will be very useful to us in improving health care services…and will help us ensure that close friends and relatives, like yourself, are being given adequate support.

The interview will take about 45 minutes, and please don't feel you have to answer any questions that you don't feel comfortable with.

Also feel free to ask us questions at the end. I'm not a medical doctor and so unfortunately I won't be able to answer any specific questions about treatment.

## *Consent and confidentiality*

Thank you for letting us talk to you about your experiences. Can I just check that you're still happy to go ahead and talk with us […SIGN CONSENT FORM…] If at any time you decide you don't want to participate any further…then that is ok too.

We would also like to remind you that we would like to tape the interview - this will save us writing notes and missing things that might be important. I think we also mentioned that we are trying to talk with everyone on their own.

And as far as confidentiality goes…everything you say will be completely confidential and will not be discussed with anyone, including [name of patient], the medical staff or other family members.

## *Background information*

Before we start can I ask:

- How long have you known [name of patient]?
- Do you live nearby, and is it easy to visit them at home?
- Is it easy to visit them when they are in hospital?
- How much time do you usually spend with [name of patient] per week?
- And lastly, are you currently working and what is your occupation?

## *Diagnosis*

I'd like to start by asking a few questions about the time when [name] was diagnosed.

1 Did you accompany [name] when they were first referred to hospital?

2 Were you with [name] when they were told of their diagnosis?*

* if yes:

a did the medical staff spend enough time talking about the diagnosis?

b did they communicate clearly?

c was enough information given in regards to illness, treatment, medications and support services?

* if no:

- did [name] tell you about their diagnosis themselves?

3 What went through your mind during those first few days after [name] was diagnosed?

## *Emotional issues and uncertainties*

Lead in: We all know that illness can be difficult at the best of times…and this section is about some of the emotional difficulties that you might have experienced over the past few months whilst living with/ being friends with/ being married to [name]…this will help us understand about the major difficulties you are [both] experiencing and how to help people through them…

**Question:** And so I'd like to ask - what are your main worries at the moment?

**Primary prompts:**

Are there times when you are:

Other people we spoke to said they are:

- Uncertain about what might happen to your friend/partner?
- Worried about the changes that are happening to them?
- Worried that you aren't able to do anything?
- Worried about not knowing how to care for them?
- Worried about not being able to cope yourself?
- Worried about their/your finances?

**Positive prompt:**

Which persons have so far been most helpful?

**Question:** How have these worries been affecting your everyday life?

**Primary prompts:**

Has your:

- family life/social life been greatly affected?
- tolerance level (or motivation) been affected?

Are there times when you:

- feel like taking time off work?
- don't feel like looking after/being with your friend?

Do you like to take charge of the patient, or do you let them do things for themselves?

Are there any days that are worse than others – why?

Are things generally better or worse before or after the person goes for treatment?

Can you remember any weeks that were particularly bad – why?

**Positive prompts:**

What things helped with these worries?

If you could change one thing, what would it be?

## *Treatment, perceptions and expectations*

Question: The next section is about people's expectations…and the sorts of things you thought would happen when [patient's name] was diagnosed.

Having someone close to you suddenly fall sick is stressful…looking back, has being a carer/friend been easier or more difficult than you expected?

**Primary prompts:**

How much support have you received from GP, hospital, family etc?

What things have been more difficult than you expected – why?

What things have been easier than you expected – why?

Have you had to encourage them to go for treatment – how?

Have you ever wanted to tell them to stop having treatment?

What words would you use to describe your experiences?

**Positive prompts:**

If you could change one thing about the health care services, what would it be?

What things have you learnt about yourself?

Question: If someone else was diagnosed with the same thing, what would you tell them:

**Primary prompts:**

- in regards to the emotional experience of living with illness?
- in regards to treatment and services?

Question: What would you tell their husband/ wife/ friends etc:

**Primary prompts:**

- in regards to what they are going through?
- in regards to what they should expect?
- in regards to seeking support and services?

## *Communication*

**Lead in:** I would now like to ask about communication…especially your experiences of good and bad communication, so that we can find out ways of making communication easier…

**Question:** Some people have told us that they have found it difficult to approach medical staff and discuss things with them…whereas other people said that they have had few problems finding staff and discussing things. We'd be very interested to hear of your experiences of communicating with medical staff.

**Primary prompts:**

Do you have much contact with medical staff?

Do you often get the opportunity to ask questions?

Do you find people generally communicate in plain English - and who doesn't?

Are there things that still have not been explained to you?

Have there been times when someone has talked to you, but you still felt none the wiser afterwards?

Which piece of information was most confusing?

Were there any language problems or barriers?

Who are the most approachable staff?

Which things do you talk about with other patients' friends and relatives - do you find this useful?

**Positive prompts:**

Who gave the best information?

Why did they give the best information?

**Question:** This is a difficult time for everyone concerned: yourself, your friends and family…and so if it's ok, we'd like to ask you how it has been discussing things with your family and friends.

**Primary prompts:**

How have things been when talking with [name]?

What things do you discuss with other family members?

What things do you discuss with friends?

What things do you discuss with children?

What things are difficult to discuss?

Is there anyone outside of family you can turn to?

**Positive Prompt:**

Who do find it easy to talk with?

## *Emotional disruption*

**Lead in:** I'd like to talk a little bit more about some of the emotional issues…

**Question:** Are there any times that you've noticed [name] has seemed depressed or left in the dark…?

**Primary prompts**

When was the worse time:

Before, during or after [name]'s diagnosis?

Before, during or after treatment?

Is there one time that sticks in your memory as being a bad time?

Which were the times when it seemed like things were getting better?

What support did the medical services offer?

**Positive prompt:**

Who has been most supportive - and why?

Question:…could you also tell us a little bit about the kinds of feelings you've been having?

**Primary prompts:**

Are there times when you:

just wanted to give up - if yes, when and why?

felt alone - if yes, when and why?

felt like not seeing anyone - if yes, when and why?

felt overwhelmed - if yes, when and why?

felt worried about the next few months?

What kinds of support did you already have?

What support have you had to go and find yourself?

Would you like to join a support group?

**Positive prompt:**

What helps when you're feeling fed up?

## *Physical issues*

**Question:** We've now reached the last section… being friends with/caring for someone also takes a physical toll… and so I'd like to ask you - what things have you found most difficult about living with/ being friends with someone with illness, and is there anything you can't do anymore?

**Primary prompts:**

Do you have difficulty with:

- caring for the patient?
- everyday routines?
- dependency on others:
- restrictions on time and/or mobility, including getting to shops, making hospital appointments etc

What impact has it had:

- on your social life?
- on your work?

**Positive prompt:**

Can you suggest any techniques that have been useful or that other people might use to help them cope?

**Question:** what are the biggest physical issues you yourself have had to deal with?

**Primary prompts:**

Disruption of sleep:

- Fatigue and tiredness
- How have you coped with the disruptions?

**Positive prompt:**

What would make things better?

## *Wrapping-up*

OK, that's most of the interview over…before we finish, is there anything you think is important that we haven't talked about? …and so I'd just like to end by asking you - what are your hopes for the future?

## *Ending the interview*

Thank you very much…and I hope I haven't taken up too much of your time. The information you have given us is going to be extremely useful in helping us to improve care. Please feel free to ask any questions about the study…

Turn off tape recorder, answer any questions and then ask if it's ok to make a follow up call and outline the purpose of the call:

We'd like to telephone you in a couple of days…as there may be things that you think about after I've gone. We all know the feeling when you suddenly remember something that you wished you'd said at the time…and so if anything comes up, just jot it down for when I call.

[Arrange a time to call.]

**Schedule for health care professional interviews – part I qualitative study**

You were recently nominated by [name of patient(s)] as the person they found most helpful in regards to their primary/secondary care during the NHS Service and Delivery Organisation continuity in cancer care study that is currently taking place across the North, North East and South East London cancer networks. Consequently we would like to conduct a short interview (10-15 minutes) to discuss your views on how continuity in cancer care can be improved. More specifically, we would like to ask:

What went well in regards to [name of patient]'s health care and treatment?

Is there anything that you or the health care services could have done better in regards to their treatment?

Without breaking confidentiality, could you give an example of a patient who has received poor health care and explain why you think this was the case?

What do you think are the major issues that are currently undermining continuity in cancer care?

We can conduct these interviews in person or over the telephone at a time that is most convenient to you, and we would like to tape them if possible. If you are particularly interested in the issues raised by this study we can arrange for a more extended interview.

# Appendix B Qualitative analysis framework

This appendix sets out the framework developed for the qualitative analysis:

i patient coding framework

ii close person coding framework

iii information on people with cancer and nominated interviewees.

### i Patient coding framework

| | | |
|---|---|---|
| B<br>Patient's background/ history/ situation | B1<br>Social | Education; economic; cultural; religious; age; sex |
| | B2<br>Medical | Other illnesses and health problems; General state of health |
| | B3<br>Practical | Transport; location/distances |
| | B4<br>Physical health | General state and changes; restrictions; pain/discomfort; adaptations |
| | B5<br>Emotional responses | General state and changes; continuity/discontinuity of self; body image; non-cancer issues; perception of past and future; response to events/transitions; maintenance/ change of lifestyle; proactive/passive personality; coping strategies; organising for future; response to events/transitions; maintenance/ change of lifestyle; proactive/passive personality; coping strategies; organising for future |
| P<br>Primary care | P1<br>Pre-diagnosis | Background to initial contact; clinical investigations |
| | P2<br>Communication | Overall communication (manner, information); contact time (frequency, length of consultations); questions (opportunity, knowledge base); points of breakdown |
| | P3<br>Service organisation | Organisation and co-ordination of services; Accessibility of services; Waiting times (appointments, treatment, results) |
| | P4<br>Support | Met needs; unmet needs |
| | P5<br>Decision making | Options; health care professional involvement; other persons' involvement; Knowledge base |
| | P6<br>Impact of treatment | Physical effects; emotional effects; coping strategies; attitudes to treatment |

| | | |
|---|---|---|
| S<br>Secondary care | S1<br>Pre-diagnosis | Background to initial contact; clinical investigations |
| | S2<br>Communication | Overall communication (manner, info);<br>Contact time (frequency, length of consultations); questions (opportunity, knowledge base); points of breakdown |
| | S3<br>Service organisation | Organisation and co-ordination of services; accessibility of services; waiting times (appointments, treatment, results) |
| | S4<br>Support | Met needs; unmet needs |
| | S5<br>Decision making | Options; health care professional involvement; other persons' involvement; Knowledge base |
| | S6<br>Impact of treatment | Physical effects; emotional effects; coping strategies; attitudes to treatment |
| R<br>Relationships | R1<br>Interactions between close person and patient | Communication; level/type of contact; attitudes and reactions; changes in relationship |
| | R2<br>Interactions that patient and close person have with other people | Communication; level/type of contact; attitudes and reactions; changes in relationship |
| O<br>Other issues | | Alternative/complementary therapies; non-medical services |

### ii Close person coding framework

| | | |
|---|---|---|
| B<br>Patient's background/ history/ situation | B1<br>Social | • Education<br>• Economic<br>• Cultural<br>• Religious<br>• Age<br>• Sex |
| | B2<br>Medical | • Other illnesses and health problems<br>• General state of health |
| | B3<br>Practical | • Transport<br>• Location/distances |
| | B4<br>Physical health | • Response to events/transitions<br>• Maintenance/change of lifestyle<br>• Proactive/passive personality<br>• Coping strategies<br>• Organising for future<br>• General state and changes<br>• Continuity/discontinuity of self<br>• Body image<br>• Non-cancer issues<br>• Perception of past and future<br>• Abandonment / isolation |
| | B5<br>Emotional responses | • General state and changes<br>• Restrictions<br>• Pain/discomfort<br>• Adaptations |
| P<br>Primary care | P1<br>Pre-diagnosis | • Background to initial contact<br>• Clinical investigations |
| | P2<br>Communication | • Overall communication (manner, info)<br>• Contact time (frequency, length of consultations)<br>• Questions (opportunity, knowledge base)<br>• Points of breakdown<br>• General preferences |
| | P3<br>Service organisation | • Organisation and co-ordination of services<br>• Accessibility of services<br>• Waiting times (appointments, treatment, results)<br>• General preferences |

| | | |
|---|---|---|
| | P4<br>Support | • Met needs<br>• Unmet needs |
| | P5<br>Decision making | • Options<br>• Health care professional involvement<br>• Other persons' involvement<br>• Knowledge base |
| | P6<br>Impact of treatment | • Physical effects<br>• Emotional effects<br>• Coping strategies<br>• Attitudes to treatment |
| S<br>Secondary care | S1<br>Pre-diagnosis | • Background to initial contact<br>• Clinical investigations |
| | S2<br>Communication | • Overall communication (manner, info)<br>• Contact time (frequency, length of consultations)<br>• Questions (opportunity, knowledge base)<br>• Points of breakdown<br>• General preferences |
| | S3<br>Service organisation | • Organisation and co-ordination of services<br>• Accessibility of services<br>• Waiting times (appointments, treatment, results)<br>• General preferences |
| | S4<br>Support | • Met needs<br>• Unmet needs |
| | S5<br>Decision making | • Options<br>• Health care professional involvement<br>• Other persons' involvement<br>• Knowledge base |
| | S6<br>Impact of treatment | • Physical effects<br>• Emotional effects<br>• Coping strategies<br>• Attitudes to treatment |
| R<br>Relationships | R1<br>Interactions between close person and patient | • Communication<br>• Level/type of contact<br>• Attitudes and reactions<br>• Changes in relationship |
| | R2<br>Interactions that patient and close person have with other people | • Communication<br>• Level/type of contact<br>• Attitudes and reactions<br>• Changes in relationship |

| | | |
|---|---|---|
| O<br>Other issues | | - Alternative/complementary therapies<br>- Non-medical services |
| Bc<br>Background:<br>Close persons | B1c<br>Social | - Education<br>- Economic<br>- Cultural<br>- Religious<br>- Age<br>- Sex |
| | B2c<br>Medical | - Other illnesses and health problems<br>- General state of health |
| | B3c<br>Practical | - Transport<br>- Location/distances |
| | B4c<br>Emotional responses | - Response to events/transitions<br>- Maintenance/change of lifestyle<br>- Proactive/passive personality<br>- Coping strategies<br>- Organising for future<br>- General state and changes<br>- Continuity/discontinuity of self<br>- Body image<br>- Non-cancer issues<br>- Perception of past and future<br>- Abandonment / isolation |
| | B5c<br>Physical health | - General state and changes<br>- Restrictions<br>- Pain/discomfort<br>- Adaptations |
| Pc<br>Primary care: impact on close persons | P2c<br>Communication | - Overall communication (manner, info)<br>- Contact time (frequency, length of consultations)<br>- Questions (opportunity, knowledge base)<br>- Points of breakdown<br>- General preferences |
| | P4c<br>Support | - Met needs<br>- Unmet needs |
| | P5c<br>Decision making | - Options<br>- Health care professional involvement<br>- Other persons' involvement<br>- Knowledge base |

| | | |
|---|---|---|
| Sc<br>Secondary care:<br>Impact on close persons | S2c Communication | • Overall communication (manner, info)<br>• Contact time (frequency, length of consultations)<br>• Questions (opportunity, knowledge base)<br>• Points of breakdown<br>• General preferences |
| | S4c Support | • Met needs<br>• Unmet needs |
| | S5c Decision making | • Options<br>• Health care professional involvement<br>• Other persons' involvement<br>• Knowledge base |
| | S6c Impact of treatment | • Physical effects<br>• Emotional effects<br>• Coping strategies<br>• Attitudes to treatment |

## iii Information on the people with cancer and their nominated interviewees

| Transition point | Colorectal | Breast |
|---|---|---|
| **Diagnosis** | Case 1 | |
| Patient | 58 year old male<br>Management consultant | — |
| Close person | Daughter | |
| Primary care professional | GP | |
| Secondary care professional | Clinical nurse specialist | |
| **At completion of primary treatment** | Case 2 | |
| Patient | 56 year old male<br>Unemployed | — |
| Close person | Friend | |
| Primary care professional | GP | |
| Secondary care professional | Surgeon | |
| **In remission** | Case 3 | Case 5 |
| Patient | 69 year old male<br>Musician | 60 year old female<br>Retail shop assistant |
| Close person | Wife | Daughter |
| Primary care professional | GP | GP |
| Secondary care professional | Senior staff nurse | Oncologist |
| **In relapse** | Case 4 | Case 6 |
| Patient | 56 year old female<br>Housing officer | 68 year old female<br>Civil service |
| Close person | Husband | Friend |
| Primary care professional | GP | GP |
| Secondary care professional | Aromatherapist | Clinical nurse specialist |
| **Palliative care** | | Case 7 |
| Patient | — | 55 year old female<br>Headmistress |
| Close person | | Husband |
| Primary care professional | | GP |
| Secondary care professional | | Oncologist |

# Appendix C Quantitative study: patient measures

This appendix contains the patient questionnaire booklet used in part 2 of the prospective quantitative study, for all five recruitment phases.

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**Patient questionnaire booklet**

**Name:**

**Contact details:**

**Interview date:**

**Sex:** Male Female

**Age:**

**GP details:**

**Civil status** (e.g. single, married, cohabiting etc)

**Who lives with you in your home?**

**Do you have children?** (if yes, please provide number and ages)

**Occupation:**

**Are you currently in employment?** Yes No

**Is this work full or part time?** FT PT

**At what age did you leave school, college or university?**

**Do you have any qualifications (please state)?**

**Which of the following best describes your ethnic group?**

White British White Irish Other white background (please specify)

Black Caribbean & White Black African & White Asian & White

Black or Black British Caribbean African Asian or Asian British

Indian Pakistani Bangladeshi Chinese

Other ethnic group (please specify):

**Country of birth:**

**If born outside UK, how long have you lived in UK?**

**What is your first language?**

**Where treated** (please list if more than one place)

**Responsible consultant:**

**Please estimate the time between your first noticing something was wrong and receiving your diagnosis:**

**Estimated date of diagnosis:**

**Do you think the illness was detected as quickly as it should have been?**

Yes No

**If not, why not?**

**Were you told your diagnosis face to face?**

Yes No

**If yes, by whom? If no, how?**

**Do you think:**

(i) The diagnosis was given in a sensitive manner: Yes No

(ii) Enough time was taken: Yes No

(iii) The right type of information was given: Yes No

(iv) There was enough privacy: Yes No

(v) There was a suitable professional to talk to afterward: Yes No

**Was a friend or relative with you when you were told of your diagnosis?**

Yes No

**Have you ever had** (tick as appropriate):

Radiotherapy

Chemotherapy

Alternative therapy (please specify)

Counselling

Palliative care

Refused any treatment (please specify)

Other (please specify)

**Are you receiving treatment for any other illnesses or medical conditions (e.g. high blood pressure, diabetes, depression)?**

**If yes:**

Please state which illness(es)

Are you attending a hospital clinic for this/these?

**Are you currently receiving any state benefits (e.g. Disabled Living Allowance, Attendance Allowance, Income Support, Housing Benefit)?**

Yes No

**If yes, please state:**

**Do you have private health care insurance?**

Yes No

## Part two: What has happened over the last three months?

**Overall how has your *physical health* seemed over the last three months?**

Much worse A little worse About the same A little better A lot better

**Overall how has your *emotional state* seemed over the last three months?**

Much worse A little worse About the same A little better A lot better

**How much contact have you had with your friends and relatives over the last three months?**

Much more A little more About the same A little less A lot less

**Overall how are you coping over the last three months?**

Much better A little better About the same A little worse Much worse

**If working, roughly how many days have you taken off work over the last three months because of your illness?**

**If *not* working, roughly how many days over the last three months have you not been able to carry out your usual duties because of your illness?**

**Please estimate how many times you have been to hospital over the last three months:**

**When did you last visit the hospital?**

**Were you an in patient or an out patient?**

Inpatient Outpatient

**Were the medical team up to date with your situation?** Yes No

If no, which service was not up to date?

**Did your medical team have access to your most recent:**

| | | | |
|---|---|---|---|
| **Notes** | Yes | No | Unsure |
| **Scans** | Yes | No | Unsure |
| **Blood tests** | Yes | No | Unsure |

**X rays** Yes NoUnsure

**Overall, in the last three months has the health care you have received seemed:**

Same Better Worse

**Have you had a main contact person at the hospital over the last three months?** Yes No

**If yes, who (e.g. consultant, nurse specialist etc)?**

**Which of the following have you seen over the last three months?**

Nurse specialist

District nurse

Palliative care doctor/nurse

Consultant oncologist

Surgeon

Radiotherapist

Private doctor

Respite care

Other (please state)

GP

Counsellor

Home help

Night sitter

Alternative therapist (please state)

Social worker

Support group

Religious leader

None

**What services and treatments have you received over the last three months?**

- Radiotherapy
- Chemotherapy
- Alternative therapy (please specify)
- Counselling
- Palliative care
- Refused any treatment (please specify)
- Other (please specify)

**Are you on any treatment now?**

Yes No

**If yes, please state:**

## Part three: Managing the illness

*Please circle the answer that best describes your experience of being a cancer patient*

**i I have received enough time and attention from the cancer services**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**ii I do not see the cancer services often enough**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**iii I am getting consistent information about my illness from health care staff**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**iv I frequently have to chase up cancer services to get things done**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**v I have been well informed about what my *treatment* will involve over the next few months**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**vi I am aware of what *side-effects* to expect from my cancer treatments**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**vii I've been told what to expect in terms of my *overall health* over the next few months**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**viii I feel out of touch with the cancer services between appointments**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**ix I feel able to cope with minor complications that may arise**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**x I am coping well between my appointments with the cancer services**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**xi I have difficulty accepting the limitations my health places on my life**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**xii I am well supported by *non-medical services* e.g. home help, social services etc**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**xiii I have received sufficient advice on which financial benefits I can claim**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**xiv I feel supported by the people closest to me**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**xv I feel my friends and relatives are able to help me cope with my illness**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**xvi I am worried about the emotional state of the people closest to me**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**xvii I feel I depend too much on my friends or relatives**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**xviii I have received some misleading information from the cancer services**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**xix I am content that I have received a full medical examination with regard to my cancer**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**xx I am worried that some things may have been overlooked**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

## Part four: My preferences

For each statement, please circle the number which best describes your preferences NOW

GENERALLY, I PREFER…

| | | |
|---|---|---|
| Direct communication even if news is bad | 1 2 3 4 5 6 7 8 9 10<br>↔ | To be protected from bad news |
| A thorough discussion of my current health | 1 2 3 4 5 6 7 8 9 10 | Just to be told the fundamentals |
| To discuss my illness with my friends and family | 1 2 3 4 5 6 7 8 9 10 | Not to discuss my illness with my friends and family |
| To carry out my usual duties and routines | 1 2 3 4 5 6 7 8 9 10 | Not to carry out my usual duties and routines |
| Frequent, short appointments | 1 2 3 4 5 6 7 8 9 10 | Less frequent, longer appointments |
| To see the same doctor even if less convenient | 1 2 3 4 5 6 7 8 9 10 | To see a different doctor if it is more convenient |
| To be treated at a specialist centre even if this means travelling | 1 2 3 4 5 6 7 8 9 10 | To have little involvement in decisions about my treatment |
| To have the strongest treatment, even if this is very uncomfortable | 1 2 3 4 5 6 7 8 9 10 | To have less strong treatment but be more comfortable |
| Generally to be treated at home | 1 2 3 4 5 6 7 8 9 10 | Generally to be treated in hospital |
| To plan for the future | 1 2 3 4 5 6 7 8 9 10 | To deal with things as they arise |
| To ask for help from my friends and family | 1 2 3 4 5 6 7 8 9 10 | To wait until help is offered by them |
| For my friends and relatives to be more involved in my day to day life | 1 2 3 4 5 6 7 8 9 10 | For my friends and relatives to be less involved in my day to day life |
| To be in charge | 1 2 3 4 5 6 7 8 9 10 | For my friend or relative to be in charge |

## Part five: Key issues in my life - Transition 1:

**Learning I had cancer had a big impact on my life**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**Becoming a cancer patient has been difficult for me**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**My progression from diagnosis to treatment was well organised**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**I received important information about my illness promptly**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**My cancer diagnosis has had a big impact on my close friends and family**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**I had enough time to consider my options before starting treatment**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**I have considered not having any treatment**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**I am considering alternative treatments**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**I am not sure what questions to ask the medical team**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

## Part five: Key issues in my life - Transition 2:

**I have been able to live a normal life whilst undergoing treatment**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**I spend a lot of unnecessary time waiting for treatment**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**I have found treatment overwhelming**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**I have considered stopping my treatment**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**My treatment has caused disruption to my friends and relatives' lives**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**My progression from treatment to discharge was well organised**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**I am uncertain about what palliative care services do**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**I need more help from palliative care services**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

## Part five: Key issues in my life - Transition 3:

**I felt relieved once my treatment finished**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**I have not been able to get back to my normal routines**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**I now feel free of cancer**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**I am worried that cancer may return**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**I feel out of contact with medical services**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**I have been able to resume work**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**I have been able to get back to normal with my family and friends**

Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree

## Part five: Key issues in my life - Transition 4:

**I have been able to live a normal life whilst undergoing treatment**

Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree

**I spend a lot of unnecessary time waiting for treatment**

Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree

**I have found treatment overwhelming**

Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree

**I have considered stopping my treatment**

Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree

**My treatment has caused disruption to my friends and relatives' lives**

Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree

**I have received the same standard of health care as during earlier stages of the cancer**

Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree

**I am finding it harder to cope now than during earlier stages of the cancer**

Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree

**My friends and relatives are finding it harder to cope now than during earlier stages of the cancer**

Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree

**I am uncertain about what palliative care services do**

Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree

**I need more help from palliative care services**

Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree

## Part five: Key issues in my life - Transition 5:

**I need palliative care**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**I need more help from palliative care services**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**I would still like to receive cancer treatment even if it only has a small chance of working**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**I would have benefited from seeing palliative care services earlier**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**My quality of life means more to me than living longer**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**It helps to be around people whose illness is at a similar stage to mine**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

## Part six: Overall satisfaction

In this section we are asking about your overall views of your care so far. Please choose a number along each line that best describes the way you feel.

**1. Overall, have you felt satisfied with your health care?**

Dissatisfied 1 2 3 4 5 6 7 8 9 10 Satisfied

**2. Overall, have you been satisfied with how the different parts of your health care (e.g. chemotherapy, radiotherapy, surgery) have been co-ordinated?**

Dissatisfied 1 2 3 4 5 6 7 8 9 10 Satisfied

**3. Overall, have you been satisfied with the level of support provided by the health care services?**

Dissatisfied 1 2 3 4 5 6 7 8 9 10 Satisfied

**4. Overall, do you feel satisfied with the information you received about your illness?**

Dissatisfied 1 2 3 4 5 6 7 8 9 10 Satisfied

**5. Overall, have you felt satisfied with the way health care professionals communicate with you?**

Dissatisfied 1 2 3 4 5 6 7 8 9 10 Satisfied

**6. Overall, have you felt confident in the health care professionals looking after you?**

Dissatisfied 1 2 3 4 5 6 7 8 9 10 Satisfied

## Part seven: Supportive care needs survey

INSTRUCTIONS

To help us plan better services for people diagnosed with cancer, we are interested in whether or not needs which you may have faced as a result of having cancer have been met.

For every item on the following pages, indicate whether you have needed help with this issue within the last month as a result of having cancer. *Put a circle around the number which best describes whether you have needed help with this in the last month.* There are 5 possible answers to choose from:

**1 = No need:** **Not applicable**

This was not a problem for me as a result of having cancer.

**2 = No need:** **Satisfied**

I did need help with this, but my need for help was satisfied at the time.

**3 = Some need:** **Low need for help**

This item caused me little concern or discomfort. I had little need for additional help.

**4 = Some need:** **Moderate need for help**

This item caused me some concern or discomfort. I had some need for additional help.

**5 = Some need:** **High need for help**

This item caused me a lot of concern or discomfort. I had a strong need for additional help.

**For example:**

| **In the last month what was your level of need for help with:** | --No need-- | | -------Some need------ | | |
|---|---|---|---|---|---|
| | NA | Satisfied | Low need | Moderate need | High need |
| 1. Being informed about things you can do to help yourself to get well | 1 | 2 | 3 | [✓ 4] | 5 |

If you put the circle where we have, it means that you did not receive as much information as you wanted about things you could do to help yourself get well, and therefore needed some more information.

| **In the last month what was your level of need for help with:** | --No need-- | | -------Some need------ | | |
|---|---|---|---|---|---|
| | NA | Satisfied | Low need | Moderate need | High need |
| 1. Pain | 1 | 2 | 3 | 4 | 5 |
| 2. Lack of energy/tiredness | 1 | 2 | 3 | 4 | 5 |
| 3. Feeling unwell a lot of the time | 1 | 2 | 3 | 4 | 5 |
| 4. Work around the home | 1 | 2 | 3 | 4 | 5 |
| 5. Not being able to do the things you used to do | 1 | 2 | 3 | 4 | 5 |
| 6. Anxiety | 1 | 2 | 3 | 4 | 5 |
| 7. Feeling down or depressed | 1 | 2 | 3 | 4 | 5 |
| 8. Feelings of sadness | 1 | 2 | 3 | 4 | 5 |
| 9. Fear of the cancer spreading | 1 | 2 | 3 | 4 | 5 |
| 10. Worry that the results of treatment are beyond your control | 1 | 2 | 3 | 4 | 5 |
| 11. Uncertainty about the future | 1 | 2 | 3 | 4 | 5 |
| 12. Learning to feel in control of your situation | 1 | 2 | 3 | 4 | 5 |
| 13. Keeping a positive outlook | 1 | 2 | 3 | 4 | 5 |
| 14. Feelings about death and dying | 1 | 2 | 3 | 4 | 5 |
| 15. Changes in sexual feelings | 1 | 2 | 3 | 4 | 5 |
| 16. Changes in your sexual relationships | 1 | 2 | 3 | 4 | 5 |
| 17. Concerns about the worries of those close to you | 1 | 2 | 3 | 4 | 5 |
| 18. More choice about which cancer specialists you see | 1 | 2 | 3 | 4 | 5 |
| 19. More choice about which hospital you attend | 1 | 2 | 3 | 4 | 5 |
| 20. Reassurance by medical staff that the way you feel is normal | 1 | 2 | 3 | 4 | 5 |
| 21. Hospital staff attending promptly to your physical needs | 1 | 2 | 3 | 4 | 5 |

| | | | | | |
|---|---|---|---|---|---|
| 22. Hospital staff acknowledging, and showing sensitivity to, your feelings and emotional needs | 1 | 2 | 3 | 4 | 5 |
| 23. Being given written information about the important aspects of your care | 1 | 2 | 3 | 4 | 5 |
| 24. Being given information (written, diagrams, drawings) about aspects of managing your illness and side-effects at home | 1 | 2 | 3 | 4 | 5 |
| 25. Being given explanations of those tests for which you would like explanations | 1 | 2 | 3 | 4 | 5 |
| 26. Being adequately informed about the benefits and side-effects of treatments before you choose to have them | 1 | 2 | 3 | 4 | 5 |
| 27. Being informed about your test results as soon as feasible | 1 | 2 | 3 | 4 | 5 |
| 28. Being informed about cancer which is under control or diminishing (that is, remission) | 1 | 2 | 3 | 4 | 5 |
| 29. Being informed about things you can do to help yourself to get well | 1 | 2 | 3 | 4 | 5 |
| 30. Having access to professional counselling (e.g. psychologist, social worker, counsellor, nurse specialist) if you, family or friends need it | 1 | 2 | 3 | 4 | 5 |
| 31. To be given information about sexual relationships | 1 | 2 | 3 | 4 | 5 |
| 32. Being treated like a person not just another case | 1 | 2 | 3 | 4 | 5 |
| 33. Being treated in a hospital or clinic that is as physically pleasant as possible | 1 | 2 | 3 | 4 | 5 |
| 34. Having one member of hospital staff with whom you can talk to about all aspects of your condition, treatment and follow-up | 1 | 2 | 3 | 4 | 5 |

## Part Eight: EUROQOL

Please answer by placing a tick in the box which best describes your health *today*

**1 Mobility**

I have no problems in walking about ☐
I have some problems in walking about ☐
I am confined to bed ☐

**2 Self care**

I have no problems with self care ☐
I have some problems washing or dressing myself ☐
I am unable to wash or dress myself ☐

**3 Usual activities**
*(e.g. work, study, housework, family or leisure activities)*

I have no problems performing my usual activities ☐
I have some problems performing my usual activities ☐
I am unable to perform my usual activities ☐

**4 Pain/discomfort**

I have no pain or discomfort ☐
I have moderate pain or discomfort ☐
I have extreme pain or discomfort ☐

**5 Anxiety/depression**

I am not anxious or depressed ☐
I am moderately anxious or depressed ☐
I am extremely anxious or depressed ☐

**Compared with my general level of health over the past 12 months, my health today is (please tick one box):**

Better ☐
Much the same ☐
Worse ☐

To help people say how good or bad a health state is we have drawn a scale (rather like a thermometer) on which the best health state you can think of is marked 100 and the worst health state is marked 0. We would like you to say on this scale how good or bad your own health is today, in your own opinion.

Please do this by drawing a line from the box below to whichever point on the scale says how good or bad your health is today.

**YOUR OWN HEALTH STATE TODAY**

**Best imaginable health state**

**100**

**90**

**80**

**70**

**60**

**50**

**40**

**30**

**20**

**10**

**0**

**Worst imaginable health state**

## Part nine: General health questionnaire 28

We should like to know if you have had any medical complaints and how your health has been in general, over the past few weeks. Please answer ALL the questions on the following pages by circling the answer which you think most nearly applies to you. Remember that we want to know about present and recent complaints, not those that you had in the past. It is important that you try to answer ALL the questions.

**Have you recently…**

| | | | | |
|---|---|---|---|---|
| **A1. Been feeling perfectly well and in good health?** | Better than usual | Same as usual | Worse than usual | Much worse than usual |
| **A2. Been feeling in need of a good tonic?** | Not at all | No more than usual | Rather more than usual | Much more than usual |
| **A3. Been feeling run down and out of sorts?** | Not at all | No more than usual | Rather more than usual | Much more than usual |
| **A4. Felt that you are ill?** | Not at all | No more than usual | Rather more than usual | Much more than usual |
| **A5. Been getting any pains in your head?** | Not at all | No more than usual | Rather more than usual | Much more than usual |
| **A6. Been getting a feeling of tightness or pressure in your head?** | Not at all | No more than usual | Rather more than usual | Much more than usual |
| **A7. Been having hot or cold spells?** | Not at all | No more than usual | Rather more than usual | Much more than usual |

| | | | | |
|---|---|---|---|---|
| **B1. Lost much sleep over worry?** | Not at all | No more than usual | Rather more than usual | Much more than usual |
| **B2. Had difficulty in staying asleep once you are off?** | Not at all | No more than usual | Rather more than usual | Much more than usual |
| **B3. Felt constantly under strain?** | Not at all | No more than usual | Rather more than usual | Much more than usual |
| **B4. Been getting edgy and bad tempered?** | Not at all | No more than usual | Rather more than usual | Much more than usual |
| **B5. Been getting scared or panicky for no good reason?** | Not at all | No more than usual | Rather more than usual | Much more than usual |
| **B6. Found everything getting on top of you?** | Not at all | No more than usual | Rather more than usual | Much more than usual |
| **B7. Been feeling nervous and strung up all the time?** | Not at all | No more than usual | Rather more than usual | Much more than usual |

| | | | | |
|---|---|---|---|---|
| **C1. Been managing to keep yourself busy and occupied?** | More so than usual | Same as usual | Rather less than usual | Much less than usual |
| **C2. Been taking longer over the things you do?** | Quicker than usual | Same as usual | Longer than usual | Much longer than usual |
| **C3. Felt on the whole you were doing things well?** | Better than usual | About the same | Less well than usual | Much less well |
| **C4. Been satisfied with the way you've carried out your task?** | More satisfied | About the same as usual | Less satisfied than usual | Much less satisfied |
| **C5. Felt that you are playing a useful part in things?** | More so than usual | Same as usual | Less useful than usual | Much less useful |
| **C6. Felt capable of making decisions about things?** | More so than usual | Same as usual | Less so than usual | Much less capable |
| **C7. Been able to enjoy your normal day-to-day activities?** | More so than usual | Same as usual | Less so than usual | Much less than usual |

| | | | | |
|---|---|---|---|---|
| **D1. Been thinking of yourself as a worthless person?** | Not at all | No more than usual | Rather more than usual | Much more than usual |
| **D2. Felt that life is entirely hopeless?** | Not at all | No more than usual | Rather more than usual | Much more than usual |
| **D3. Felt that life isn't worth living?** | Not at all | No more than usual | Rather more than usual | Much more than usual |
| **D4. Thought of the possibility that you might make away with yourself?** | Definitely not | I don't think so | Has crossed my mind | Definitely have |
| **D5. Found at times you couldn't do anything because your nerves were too bad?** | Not at all | No more than usual | Rather more than usual | Much more than usual |
| **D6. Found yourself wishing you were dead and away from it all?** | Not at all | No more than usual | Rather more than usual | Much more than usual |
| **D7. Found that the idea of taking your own life kept coming into your mind?** | Definitely not | I don't think so | Has crossed my mind | Definitely has |

## Part ten: Spirituality

These questions concern your religious and spiritual beliefs. Please try to answer them even if you have little interest in religion.

By religion, we mean the actual practice of a faith, e.g. going to a temple, mosque, church or synagogue. Some people do not follow a religion but do have spiritual beliefs or experiences, for example they believe that there is some power or force other than themselves that might influence their life. Some people think of this as God or gods, whilst others do not. Some people make sense of their lives without any religious or spiritual belief.

**1. Therefore, would you say that you have a *religious* or *spiritual* understanding of your life?** (Please tick one)

| | | | |
|---|---|---|---|
| Religious | ☐ | Both religious and spiritual | ☐ |
| Spiritual | ☐ | Neither religious nor spiritual | ☐ |

If you have NEVER had a RELIGIOUS or SPIRITUAL BELIEF, please leave the following questions blank

**2. How strongly do you hold to your religious/spiritual view of life? Circle the number that best describes your view.**

| | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| Weakly held view | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | Strongly held view |

**3. Do you have a specific religion?**

I do not observe a religion (go to question 6) ☐

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| Moslem | ☐ | Jew | ☐ | Hindu | ☐ | Jain | ☐ |
| Sikh | ☐ | Christian | ☐ | Buddhist | ☐ | Baha'i | ☐ |
| Confucian | ☐ | Shinto | ☐ | Spiritualist | ☐ | Parsi/Zorastrian | ☐ |
| Rastafarian | ☐ | Other | ☐ | | | | |

**4. How important to you is the practice of your belief (e.g. private meditation, religious services) in your day-to-day life? Please circle the number on the scale which best describes your view.**

| | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| Not necessary | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | Essential |

**5. How often do you attend services or prayer meetings or go to a place of worship?**

Never

Less than once a year

Once a year but less than once a month

Once a month but less than once a week

Once a week or more

**6. Do you believe in a spiritual power or force other than yourself that can *influence* what happens to you in your day-to-day life? Please circle the number on the scale which best describes your view.**

| | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| No influence | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | Strong influence |

**7. Do you believe in a spiritual power or force other than yourself that enables you to *cope* personally with events in your life? Please circle the number on the scale which best describes your view.**

| | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| No help | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | A great help |

**8. Do you believe in a spiritual power or force other than yourself that influences world affairs e.g. wars? Please circle the number on the scale which best describes your view.**

| | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| No influence | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | Strong influence |

**9. Do you believe in a spiritual power or force other than yourself that influences natural disasters, such as earthquakes, floods? Please circle the number on the scale which best describes your view.**

| | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| No influence | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | Strong influence |

**10. Do you communicate in any way with a spiritual power, for example by prayer or contact via a medium?**

Yes No Unsure

# Appendix D Quantitative study: close person measures

This appendix contains the close person questionnaire booklet used in part 2 of the prospective quantitative study, for all five recruitment phases.

### Close person questionnaire booklet

**Part one: Demographics (only to be collected at first interview)**

**Name:**

**Contact details:**

**Interview date:**

**Sex:** Male Female

**Age:**

**GP details:**

**Civil status** (e.g. single, married, cohabiting etc)

**Who lives with you in your home?**

**Do you have children?** (if yes, please provide number and ages)

**Occupation:**

**Are you currently in employment?** Yes No

**Is this work full or part time?** FT PT

**What age did you leave school, college or university?**

**Do you have any qualifications (please state)?**

**Which of the following best describes your ethnic group?**

White British White Irish Other white background (please specify)

Black Caribbean & White Black African & White Asian & White

Black or Black British Caribbean African Asian or Asian British

Indian Pakistani Bangladeshi Chinese

Other ethnic group (please specify):

**Country of birth:**

**If born outside UK, how long have you lived in UK?**

**What is your first language?**

**What is your relationship to the person (e.g. friend, partner etc):**

**How long have you known him or her?**

**How near to him or her do you live?**

**Do you think his or her illness was detected as quickly as it should have been?**

Yes No

**If not, why not?**

**Were you there when he or she was told their diagnosis?**

Yes No

**If no, how did you find out?**

**If yes, do you think:**

(i) The diagnosis was given in a sensitive manner: Yes No

(ii) Enough time was taken: Yes No

(iii) The right type of information was given: Yes No

(iv) There was enough privacy: Yes No

(v) There was a suitable professional to talk to afterward: Yes No

**Have you *ever* provided care for someone with a serious illness before?**

Yes No

**In the last year have you been caring for any other people with a serious illness?**

Yes No

**Are *you* receiving treatment for any other illnesses or medical conditions (e.g. high blood pressure, diabetes, depression)?**

**If yes:**

Please state which illness(es)

Are you attending a hospital clinic for this/these?

**Are you currently receiving any state benefits (e.g. Disabled Living Allowance, Attendance Allowance, Income Support, Housing Benefit)?**

Yes No

**If yes, please state:**

## Part two: What has happened over the last three months?

**Overall how has your friend or relative's *physical health* seemed over the last three months?**

Much worse A little worse About the same A little better A lot better

**Overall how has your friend or relative's *emotional state* seemed over the last three months?**

Much worse A little worse About the same A little better A lot better

**How much contact has she/he had with friends and relatives over the last three months?**

Much more A little more About the same A little less A lot less

**Overall how has your friend or relative been coping over the last three months?**

Much better A little better About the same A little worse Much worse

**How frequently are you in contact with your friend or relative?**

Every day, 2 or 3 times a week

Once a week

Once a fortnight

Once a month

Less than once a month

**What is your usual form of contact with your friend or relative? (please circle one)**

you live with them you visit them at home you visit them in hospital

they visit you at home you meet in a public place telephone

letter email.

**If *working*, roughly how many days have you taken off to help or care for your friend or relative over the last three months?**

**If *not working*, how many days over the last 3 months have you taken out of your usual routine to help or care for your friend or relative?**

**Please estimate how many times you have accompanied your friend or relative to hospital over the last three months:**

**Did the medical team seem up to date with your friend or relative's situation?**

Yes No

**If no, which service was not up to date?**

**Overall, in the last three months has your friend or relative's health care seemed:**

Same Better Worse

**Has your friend or relative had a main contact person at the hospital over the last three months?**

Yes No

**If yes, who (e.g. consultant, nurse specialist etc)?**

**Which of the following have you had contact with concerning your friend or relative's illness over the last three months?**

Nurse specialist
District nurse
Palliative care doctor/nurse
Consultant oncologist
Surgeon
Radiotherapist
Private doctor
Respite care
Other (please state)
GP
Counsellor
Home help
Night sitter
Alternative therapist (please state)
Social worker
Support group
Religious leader
None

**Have *you* used any of the following to help you cope with the stresses of your friend or relative's illness?**

Counsellor Support group Alternative therapist GPReligious leader

Other (please state)

## Part three: How is your friend or relative coping?

The following section is about your friend or relative. Please circle the most appropriate answer.

**i My friend or relative receives enough time and attention from the cancer services**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**ii He/she does not see the cancer services often enough**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**iii He/she is getting consistent information about their illness from health care staff**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**iv He/she frequently has to chase up cancer services to get things done**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**v He/she is well informed about what their *treatment* will involve over the next few months**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**vi He/she is aware of what *side-effects* to expect from their cancer treatments**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**vii He/she has been told what to expect in terms of their *overall health* over the next few months**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**viii He/she feels out of touch with the cancer services between appointments**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**ix He/she is able to cope with minor complications that may arise**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**x He/she is coping well between my appointments with the cancer services**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**xi He/she finds it difficult to accept the limitations their health places on life**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**xii He/she is being well supported by *non-medical services* (e.g. home help, social services etc)**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**xiii He/she receives enough advice about which financial benefits can be claimed**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**xiv He/she is being supported by the people closest to them**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**xv His/her friends and relatives are able to help them cope with their illness**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**xvi He/she is worried about the emotional state of the people closest to him/her**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**xvii He/she is too dependent on friends and relatives**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**xviii He/she has received some misleading information from the cancer services**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**xix He/she has received a full and proper medical examination with regard to their cancer**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**xx He/she is worried that some things have been overlooked**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

## Part four: My preferences

For each statement, please circle the number which best describes your preferences NOW

GENERALLY, I PREFER…

| | | |
|---|---|---|
| Direct communication even if news is bad | 1 2 3 4 5 6 7 8 9 10<br>↔ | To be protected from bad news |
| A thorough discussion of my friend or relative's current health | 1 2 3 4 5 6 7 8 9 10 | Just to be told the fundamentals |
| To discuss my friend or relative's illness with them | 1 2 3 4 5 6 7 8 9 10 | Not to discuss my friend or relative's illness with them |
| To carry out my usual duties and routines | 1 2 3 4 5 6 7 8 9 10 | Not to carry out my usual duties and routines |
| For my friend or relative to have frequent, but shorter appointments | 1 2 3 4 5 6 7 8 9 10 | For my friend or relative to have less frequent but longer appointments |
| For him/her to see the same doctor even if it is less convenient | 1 2 3 4 5 6 7 8 9 10 | For him/her to see a different doctor if it is more convenient |
| For him/her to be treated at a specialist centre even if this means travelling | 1 2 3 4 5 6 7 8 9 10 | For him/her to be treated locally even if this is not a specialist centre |
| To be fully involved in decisions about his/her treatment | 1 2 3 4 5 6 7 8 9 10 | To have little involvement in decisions about his/her treatment |
| For him/her to have the strongest treatment, even if this is very uncomfortable | 1 2 3 4 5 6 7 8 9 10 | For him/her to have less strong treatment but be more comfortable |
| For him/her generally to be treated at home | 1 2 3 4 5 6 7 8 9 10 | For him/her generally to be treated in hospital |
| To plan for the future | 1 2 3 4 5 6 7 8 9 10 | To deal with things as they arise |
| To wait until I am asked for help | 1 2 3 4 5 6 7 8 9 10 | To offer help without being asked |
| To be more involved in my friend or relative's day to day life | 1 2 3 4 5 6 7 8 9 10 | To be less involved in my friend or relative's day to day life |
| For my friend or relative to be in charge | 1 2 3 4 5 6 7 8 9 10 | To be in charge myself |
| To discuss his/her illness with others who are close to them | 1 2 3 4 5 6 7 8 9 10 | Not to discuss his/her illness with others who are close to them |
| To discuss my own situation with my friends and family | 1 2 3 4 5 6 7 8 9 10 | Not to discuss my own situation with my friends and family |

## Part five: Key issues in my friend or relative's life - Transition 1:

**My friend or relative's cancer diagnosis had a big impact on their life**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**Becoming a cancer patient has been difficult for them**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**His/her progression from diagnosis to treatment was well organised**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**He/she receives important information about their illness promptly**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**His/her diagnosis has had a big impact on their close friends and family**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**He/she had enough time to consider the options before starting treatment**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**He/she has considered not having treatment**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**He/she has considered alternative treatments**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**He/she is not sure what questions to ask the medical team**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

## Part five: Key issues in my friend or relative’s life - Transition 2:

**My friend or relative has been able to live a normal life whilst undergoing treatment**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**He / she spends a lot of unnecessary time waiting for treatment**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**He / she has found treatment overwhelming**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**He / she has considered stopping my treatment**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**His / her treatment has disrupted his / her friends and relatives’ everyday life**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**His / her progression from treatment to discharge was well organised**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**He / she is uncertain about what palliative care services do**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**He / she needs more help from palliative care services**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

## Part five: Key issues in my friend or relative’s life - Transition 3:

**My friend or relative felt relieved once their treatment finished**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**My friend or relative has not been able to get back to their normal routines**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**He / she now feels free of cancer**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**He / she is worried that cancer may return**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**He / she feels out of contact with medical services**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**He / she has been able to resume work**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**He / she has been able to get back to normal with their family and friends**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

## Part five: Key issues in my friend or relative's life - Transition 4:

**My friend or relative has been able to live a normal life whilst undergoing treatment**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**He / she spends a lot of unnecessary time waiting for treatment**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**He / she has found treatment overwhelming**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**He / she has considered stopping their treatment**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**His / her treatment has disrupted his / her friends and relatives' everyday life**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**He / she has received the same standard of health care as during earlier stages of the cancer**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**He / she is finding it harder to cope now than during earlier stages of the cancer**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**His / her friends and relatives are finding it harder to cope now than during earlier stages of the cancer**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**He/she is uncertain about what palliative care services do**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**He/she needs more help from palliative care services**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

## Part five: Key issues in my friend or relative's life - Transition 5:

**My friend or relative needs palliative care**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**He/she needs more help from palliative care services**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**He/she would still like to receive cancer treatment even if it only has a small chance of working**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**He/she would have benefited from seeing palliative care services earlier**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**His/her quality of life means more to them than living longer**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**It helps him/her to be around people whose illness is at a similar stage**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

## Part six: Overall satisfaction

*In this section we are asking about your overall views of your friend or relative's care so far. Please choose a number along each line that best describes the way you feel.*

**1. Overall, have you felt satisfied with the health care your friend or relative has received?**

Dissatisfied 1 2 3 4 5 6 7 8 9 10 Satisfied

**2. Overall, have you been satisfied with how the different parts of your friend or relative's health care (e.g. chemotherapy, radiotherapy, surgery) have been co-ordinated?**

Dissatisfied 1 2 3 4 5 6 7 8 9 10 Satisfied

**3. Overall, have you been satisfied with the level of support provided by the health care services?**

Dissatisfied 1 2 3 4 5 6 7 8 9 10 Satisfied

**4. Overall, do you feel satisfied with the information provided to your friend or relative about their illness?**

Dissatisfied 1 2 3 4 5 6 7 8 9 10 Satisfied

**5. Overall, are you satisfied with the way health care professionals communicate with your friend or relative?**

Dissatisfied 1 2 3 4 5 6 7 8 9 10 Satisfied

**6. Overall, have you felt confident in the health care professionals looking after your friend or relative?**

Dissatisfied 1 2 3 4 5 6 7 8 9 10 Satisfied

**7. Overall, are you satisfied with the way health care professionals communicate with you?**

Dissatisfied 1 2 3 4 5 6 7 8 9 10 Satisfied

## Part seven: Personal involvement

*In the last three months my role has involved…*

**Providing physical care (e.g. washing and bathing)**

*not at all occasionally frequently*

**Helping them with basic medical tasks (e.g. changing bandages)**

*not at all occasionally frequently*

**Giving medication**

*not at all occasionally frequently*

**Providing financial support**

*not at all occasionally frequently*

**Providing domestic support (e.g. shopping, cleaning)**

*not at all occasionally frequently*

**Providing transport**

*not at all occasionally frequently*

**Providing emotional support**

*not at all occasionally frequently*

**Helping them deal with health care professionals**

*not at all occasionally frequently*

**Giving advice**

*not at all occasionally frequently*

**Encouraging them to use medical services**

*not at all occasionally frequently*

**Discouraging them from doing too much**

*not at all occasionally frequently*

**Ensuring they keep appointments**

*not at all occasionally frequently*

**Taking care of complications that arise**

*not at all occasionally frequently*

**Asking medical staff questions on my friend or relative's behalf**

*not at all occasionally frequently*

**Helping my friend or relative make sense of medical information**

*not at all occasionally frequently*

**Chasing up medical services (e.g. making appointments, getting results)**

*not at all occasionally frequently*

**Finding out information from other sources (e.g. internet, books)**

*not at all* *occasionally* *frequently*

**Helping my friend or relative deal with their social life (e.g. other friends and family)**

*not at all* *occasionally* *frequently*

**Supporting or caring for other people who are ill**

*not at all* *occasionally* *frequently*

**Providing support for other family members**

*not at all* *occasionally* *frequently*

*In the last three months I have felt…*

**Able to help my friend or relative cope with their illness**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**Unsure how best to support my friend or relative**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**Found it difficult to discuss things with my friend or relative**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**Felt responsible for my friend or relative's well being**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**Worried about the effects the cancer treatment is having on my friend or relative**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**His / her illness has meant I cannot live my normal life**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**The cancer services have expected too much of me**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

**My friend or relative has expected too much of me**

| | | | | |
|---|---|---|---|---|
| Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |

## Part eight: Care giver quality of life

*Below is a list of statements that other people caring for loved ones with cancer have said are important. Please read each item and circle the response which most applies to you during the past few weeks.*

*During the past few weeks:*

**1. It bothers me that my daily routine is altered**

not at all a little bit somewhat quite a bit very much

**2. My sleep is less restful**

not at all a little bit somewhat quite a bit very much

**3. My daily life is imposed upon**

not at all a little bit somewhat quite a bit very much

**4. I am satisfied with my sex life**

not at all a little bit somewhat quite a bit very much

**5. It is difficult to maintain my outside interests**

not at all a little bit somewhat quite a bit very much

**6. I am under a financial strain**

not at all a little bit somewhat quite a bit very much

**7. I am concerned about accessing financial benefits that may be available**

not at all a little bit somewhat quite a bit very much

**8. My economic future is uncertain**

not at all a little bit somewhat quite a bit very much

**9. I fear my loved one will die**

not at all a little bit somewhat quite a bit very much

**10. I have more of a positive outlook on my life since my loved one's illness**

not at all a little bit somewhat quite a bit very much

**11. My level of stress and worries has increased**

not at all a little bit somewhat quite a bit very much

**12. My sense of spirituality has increased**

not at all a little bit somewhat quite a bit very much

**13. It bothers me limiting my focus day to day**

not at all a little bit somewhat quite a bit very much

**14. I feel sad**

not at all a little bit somewhat quite a bit very much

**15. I feel under increased mental strain**

not at all a little bit somewhat quite a bit very much

**16. I get support from my friends and neighbours**

not at all a little bit somewhat quite a bit very much

**17. I feel guilty**

not at all a little bit somewhat quite a bit very much

**18. I feel frustrated**

not at all a little bit somewhat quite a bit very much

**19. I feel nervous**

not at all a little bit somewhat quite a bit very much

**20. I worry about the impact my loved one's illness has on my children or other family members**

not at all a little bit somewhat quite a bit very much

**21. I have difficulty dealing with my loved one's changing eating habits**

not at all a little bit somewhat quite a bit very much

**22. I have developed a closer relationship with my loved one**

not at all a little bit somewhat quite a bit very much

**23. I feel adequately informed about my loved one's illness**

not at all a little bit somewhat quite a bit very much

**24. It bothers me that I need to be available to chauffeur my loved one to appointments**

not at all a little bit somewhat quite a bit very much

**25. I fear the adverse effects of treatment on my loved one**

not at all a little bit somewhat quite a bit very much

**26. The responsibility I have for my loved one's care at home is overwhelming**

not at all a little bit somewhat quite a bit very much

**27. I am glad that my focus is on getting my loved one well**

not at all a little bit somewhat quite a bit very much

**28. Family communication has increased**

not at all a little bit somewhat quite a bit very much

**29. It bothers me that my priorities have changed**

not at all a little bit somewhat quite a bit very much

**30. The need to protect my loved one bothers me**

not at all a little bit somewhat quite a bit very much

**31. It upsets me to see my loved one deteriorate**

not at all a little bit somewhat quite a bit very much

**32. The need to manage my loved one's pain is overwhelming**

| | | | | |
|---|---|---|---|---|
| not at all | a little bit | somewhat | quite a bit | very much |

**33. I'm discouraged about the future**

| | | | | |
|---|---|---|---|---|
| not at all | a little bit | somewhat | quite a bit | very much |

**34. I am satisfied with the support I get from my family**

| | | | | |
|---|---|---|---|---|
| not at all | a little bit | somewhat | quite a bit | very much |

**35. It bothers me that other family members have not shown interest in taking care of my loved one**

| | | | | |
|---|---|---|---|---|
| not at all | a little bit | somewhat | quite a bit | very much |

## Part nine: General health questionnaire 28

We should like to know if you have had any medical complaints and how your health has been in general, over the past few weeks. Please answer ALL the questions on the following pages by underlining the answer which you think most nearly applies to you. Remember that we want to know about present and recent complaints, not those that you had in the past. It is important that you try to answer ALL the questions.

**Have you recently…**

| | | | | |
|---|---|---|---|---|
| **A1. Been feeling perfectly well and in good health?** | Better than usual | Same as usual | Worse than usual | Much worse than usual |
| **A2. Been feeling in need of a good tonic?** | Not at all | No more than usual | Rather more than usual | Much more than usual |
| **A3. Been feeling run down and out of sorts?** | Not at all | No more than usual | Rather more than usual | Much more than usual |
| **A4. Felt that you are ill?** | Not at all | No more than usual | Rather more than usual | Much more than usual |
| **A5. Been getting any pains in your head?** | Not at all | No more than usual | Rather more than usual | Much more than usual |
| **A6. Been getting a feeling of tightness or pressure in your head?** | Not at all | No more than usual | Rather more than usual | Much more than usual |
| **A7. Been having hot or cold spells?** | Not at all | No more than usual | Rather more than usual | Much more than usual |

| | | | | |
|---|---|---|---|---|
| **B1. Lost much sleep over worry?** | Not at all | No more than usual | Rather more than usual | Much more than usual |
| **B2. Had difficulty in staying asleep once you are off?** | Not at all | No more than usual | Rather more than usual | Much more than usual |
| **B3. Felt constantly under strain?** | Not at all | No more than usual | Rather more than usual | Much more than usual |
| **B4. Been getting edgy and bad tempered?** | Not at all | No more than usual | Rather more than usual | Much more than usual |
| **B5. Been getting scared or panicky for no good reason?** | Not at all | No more than usual | Rather more than usual | Much more than usual |
| **B6. Found everything getting on top of you?** | Not at all | No more than usual | Rather more than usual | Much more than usual |
| **B7. Been feeling nervous and strung up all the time?** | Not at all | No more than usual | Rather more than usual | Much more than usual |

| | | | | |
|---|---|---|---|---|
| **C1. Been managing to keep yourself busy and occupied?** | More so than usual | Same as usual | Rather less than usual | Much less than usual |
| **C2. Been taking longer over the things you do?** | Quicker than usual | Same as usual | Longer than usual | Much longer than usual |
| **C3. Felt on the whole you were doing things well?** | Better than usual | About the same | Less well than usual | Much less well |
| **C4. Been satisfied with the way you've carried out your task?** | More satisfied | About the same as usual | Less satisfied than usual | Much less satisfied |
| **C5. Felt that you are playing a useful part in things?** | More so than usual | Same as usual | Less useful than usual | Much less useful |
| **C6. Felt capable of making decisions about things?** | More so than usual | Same as usual | Less so than usual | Much less capable |
| **C7. Been able to enjoy your normal day-to-day activities?** | More so than usual | Same as usual | Less so than usual | Much less than usual |

| | | | | |
|---|---|---|---|---|
| **D1. Been thinking of yourself as a worthless person?** | Not at all | No more than usual | Rather more than usual | Much more than usual |
| **D2. Felt that life is entirely hopeless?** | Not at all | No more than usual | Rather more than usual | Much more than usual |
| **D3. Felt that life isn't worth living?** | Not at all | No more than usual | Rather more than usual | Much more than usual |
| **D4. Thought of the possibility that you might make away with yourself?** | Definitely not | I don't think so | Has crossed my mind | Definitely have |
| **D5. Found at times you couldn't do anything because your nerves were too bad?** | Not at all | No more than usual | Rather more than usual | Much more than usual |
| **D6. Found yourself wishing you were dead and away from it all?** | Not at all | No more than usual | Rather more than usual | Much more than usual |
| **D7. Found that the idea of taking your own life kept coming into your mind?** | Definitely not | I don't think so | Has crossed my mind | Definitely has |

## Part ten: Spirituality

These questions concern your religious and spiritual beliefs. Please try to answer them even if you have little interest in religion.

By *religion*, we mean the actual practice of a faith, e.g. going to a temple, mosque, church or synagogue. Some people do not follow a religion but do have *spiritual* beliefs or experiences, for example they believe that there is some power or force other than themselves that might influence their life. Some people think of this as God or gods, whilst others do not. Some people make sense of their lives without any religious or spiritual belief.

**1. Therefore, would you say that you have a *religious* or *spiritual* understanding of your life?** (Please tick one)

| | | | |
|---|---|---|---|
| Religious | ☐ | Both religious and spiritual | ☐ |
| Spiritual | ☐ | Neither religious nor spiritual | ☐ |

If you have *NEVER* had a *RELIGIOUS* or *SPIRITUAL BELIEF*, please leave the following questions blank ☐

**2. How strongly do you hold to your religious/spiritual view of life? Circle the number that best describes your view.**

| | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| Weakly held view | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | Strongly held view |

**3. Do you have a specific religion?**

I do not observe a religion (go to question 6) ☐

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| Moslem | ☐ | Jew | ☐ | Hindu | ☐ | Jain | ☐ |
| Sikh | ☐ | Christian | ☐ | Buddhist | ☐ | Baha'i | ☐ |
| Confucian | ☐ | Shinto | ☐ | Spiritualist | ☐ | Parsi/Zorastrian | ☐ |
| Rastafarian | ☐ | Other | ☐ | | | | |

**4. How important to you is the practice of your belief (e.g. private meditation, religious services) in your day-to-day life? Please circle the number on the scale which best describes your view.**

| | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| Not necessary | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | Essential |

**5. How often do you attend services or prayer meetings or go to a place of worship?**

Never

Less than once a year

Once a year but less than once a month

Once a month but less than once a week

Once a week or more

**6. Do you believe in a spiritual power or force other than yourself that can *influence* what happens to you in your day-to-day life? Please circle the number on the scale which best describes your view.**

| | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| No influence | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | Strong influence |

| | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| **7. Do you believe in a spiritual power or force other than yourself that enables you to *cope* personally with events in your life? Please circle the number on the scale which best describes your view.** | | | | | | | | | | | |
| No help | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | A great help |
| **8. Do you believe in a spiritual power or force other than yourself that influences world affairs e.g. wars? Please circle the number on the scale which best describes your view.** | | | | | | | | | | | |
| No influence | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | Strong influence |
| **9. Do you believe in a spiritual power or force other than yourself that influences natural disasters, such as earthquakes, floods? Please circle the number on the scale which best describes your view.** | | | | | | | | | | | |
| No influence | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | Strong influence |
| **10. Do you communicate in any way with a spiritual power, for example by prayer or contact via a medium?**<br>Yes No Unsure | | | | | | | | | | | |

# Appendix E Researcher guide for part 2 qualitative interviews (patients and close persons)

Whilst there will be more flexibility in these interviews and it is not desirable to work to a very structured framework, please ensure that you are confident that the following areas have been considered before ending the interview:

1 The background circumstances (physical, psychological, social, past experience of illness) of the patient/ close person at the time the diagnosis is made or symptom is discovered.

2 The social and family relationships that are current and how these might have shifted in course of disease or since earlier interview.

3 Communication with health care professionals, maintenance of this care and whether there is a feeling of being known to services or whether histories and/or personal circumstances have to be repeated 'as new' on each occasion.

4 Personal trust, confidence and sense of connection with services and service providers.

5 The nature of the role of patient or close person in maintaining health care….is this active or passive, is there a desire to be connected to or disconnected from services long term?

6 What are the main issues in the life of patient or close person - are these related to the patient's health or are other events dominating? How does this shift/evolve at subsequent interviews?

### *Main themes during the interview*

A Background to diagnosis – why & how did you present?

B What happened next? Various stages e.g. treatment, remission, relapse

C Main sources of support (Clinical nurse specialist? GP? Support groups? Friends? Family?)

### *Ending questions*

1 Overall, impact on trust and confidence of medical services - why so?

2 Main concern/biggest issue facing right now and any thoughts on how to be addressed

3 Any advice patient/close person can give to someone in similar position? (regarding dealings with health care professionals, family etc)

### *General points running throughout the interview*

1 Communication

2 Information - amount, clarity, timing

3 Impact (personal and others)

4 Changes in relationships with
- family

  - medical services

5 Needs – met/unmet.

## Disclaimer

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## Addendum

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Addendum:

This report was amended on 29th September 2011 to update the correct copyright statement and/or correct the publication date. The content of the report has not been changed.