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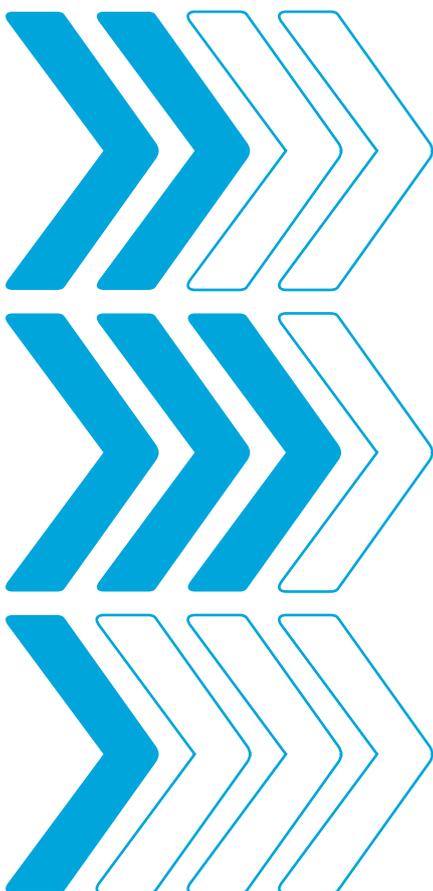
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Continuity of care for older hospital patients

A call for action



Key messages

- Continuity is fundamental to high-quality care. Without it, care is unlikely to be clinically effective, safe, personalised, efficient or cost-effective. Breakdowns in continuity of care put patients at risk, cause duplication and add avoidable costs to both health and social care.
- This paper focuses on the experiences of older people with multiple health problems, and particularly on their experiences *inside hospital*. Continuity is especially important for these older patients because: they are more likely to spend time in hospital and to be in hospital for longer; if they are frail, a stay in hospital can be life-changing; and, regrettably, in some hospitals and some wards older patients are exposed to unacceptable standards of care.
- The national inpatient surveys provide objective data on patients' experiences but not on how it feels to the patients. We have presented case studies from carers, which reflect commonly reported concerns and vividly exemplify the impact that poorly co-ordinated care can have.
- Patients and carers experience problems with care planning, communication and co-ordination. Their stories show that breakdowns in continuity cause patients to lose trust; however, ordinary human respect, kindness and consideration shown on a personal level has a disproportionately positive impact on patients' and carers' overall sense of their experience.
- The obstacles to continuity of care for older patients in modern hospitals are systemic and complex. Issues include: the volume of work in hospital; the ordinary routines that govern the working days (and nights); the culture of care in the hospital as a whole and in teams; the levels of training and skill of the workforce; and the values of the staff. Engagement of senior staff and board members with frontline staff and with patients and carers is also critical.
- In the short term, a number of interventions can help to improve continuity of care. We outline practical models and methods for improving continuity of care and make recommendations for frontline and senior executives.

Foreword

Everyone wants patients to receive consistent, reliable, high-quality care, and most health workers think that this means providing patient-centred care with compassion. So why does it not feel like that for so many patients in our hospitals today? Must they trade in low-tech human values for high-tech, effective treatment? Surely not – but too many recent public reports and inquiries have highlighted the problem for it to be a few chance encounters. This paper draws on objective data and patients' stories; it is honest, and, yes, we have a problem; but it is also timely and welcome because it offers some explanations rather than excuses or soul-searching, and suggests a collective way forward.

Its focus is on hospitals, but the principles are general. Patients and their carers value continuity of care, which they judge by how it seems to them. Co-ordination among ourselves makes that experience more likely. If we do this successfully, then clinical outcomes and safety improve. This paper presents research evidence to support this, but it then goes on to describe the many trends in modern health care and hospital organisation that seriously challenge our ability to be successful. Of course, at the point of care, it is about individuals; but in a complex situation, careful attention – to the micro- and macro-processes as well as to the prevailing hospital culture – is required to make it more likely that the right things are done and that it feels right to the patient.

There are 'touch points', often transitions of care such as hospital discharges or inter-ward transfers. Minimising unnecessary and unplanned transitions would therefore seem wise, and this paper recommends that providers review how they function with regard to this, including consideration of patients' experiences, albeit that the tools to measure this are so far relatively underdeveloped in the hospital setting.

However, continuity of care is not only about individual relationships: loss at this personal level can be mitigated by consistency of purpose, care plans and effective, timely communication. This paper therefore recommends that we adapt and evolve our basic ways of working, including ward rounds, handovers, record-keeping, multidisciplinary working and more. Useful examples are given where convincing improvement has been achieved in the NHS, with local clinical teams taking the initiative. Guidance is also available from medical colleges and professional associations.

Integration at various levels can support this clinical co-ordination, and this paper calls on senior managers and professional leaders – both local and national – to demonstrate real commitment and support for this. Education and training will be central, but there are implications for research, too: this has only recently become the subject of rigorous study, and we will need more.

To regret that we need this paper is understandable, but pointless. We do, and I commend its reasoning and recommendations to you.

*Professor Finbarr C Martin
President, British Geriatrics Society and Consultant Physician for Older People*

Introduction

This exploratory paper draws attention to an overlooked but important topic: the contribution that continuity of care makes to the quality of care experienced in hospital by patients with multiple health problems aged 70 years and older, and also how it affects the experience of the people closest to them. For the sake of simplicity, we have described the people close to patients as ‘carers’, with apologies to those who dislike the term, preferring to be seen as spouses, relatives, friends or neighbours.

There are many reasons for focusing on the continuity of care of older people with complex health problems and their carers, including the following.

- Most people (65 per cent) admitted to hospital are older than 65 years. At any one time, patients in this group account for the large majority – 70 per cent – of bed days, and some of their number can be found on every ward and in all clinical departments (apart from obstetrics and paediatrics). When we are thinking about quality of care in hospital and older people, we are talking about the predominant experience of patients in hospital in general, not just patients on designated ‘care of the elderly’ wards.
- Many older people with multiple medical problems are also frail. The impact of contact with a hospital – how they come into it, what happens when they are there, and the process of leaving – can determine the direction their life takes thereafter. Their ability to recover their former independence is greatly affected, for better or worse. Too often, for many older people, a stay in hospital is disempowering: the environment itself, the noise, and the routines on the wards overwhelm and undermine them in ways that affect their ability to recover who they were and how they were living before they were admitted.
- There is mounting evidence that the standard of care received by many older patients is unacceptable, and part of that picture is that care is fragmented and lacks continuity (Levenson 2007; Francis 2010; Abraham 2011; Care Quality Commission 2011a). Patients are moved around very frequently – from bed to bed and bay to bay on the same ward, and often from one ward to another. Handovers between professionals and teams are poorly planned and executed, and care is also poorly planned and co-ordinated.
- Patients and staff report the dehumanising experience for patients of being moved around inside hospitals ‘like parcels’ (Goodrich and Cornwell 2008). One woman, describing her feelings about being moved around, even within the space of the ward, said: ‘I feel like I’m being moved around like a parcel, I’m being moved from chair to commode to bed. I feel like a parcel and not a person anymore’ (Maben *et al* 2012).
- There is evidence of discrimination against older people in hospital (Lievesley *et al* 2009). Age-based discrimination has almost disappeared from NHS policy since the 2001 *National Service Framework for Older People* (Department of Health 2001), but it has not gone from practice. In response to survey questions, older people tend to complain less and be less critical than younger people (Lievesley *et al* 2009). Even so, they are less likely than patients in younger groups to describe their care as ‘excellent’ and more likely to say that they felt ‘talked over as though they were not there’ (Care Quality Commission 2011b). There is evidence of ageism among all staff; regrettably the evidence is stronger for doctors than for other professional groups (Lievesley *et al* 2009). Older people have differential access to services: they wait longer than younger people in A&E departments; are less likely to be referred to intensive care or to have surgery following trauma; have less access to palliative care than younger people with cancer; and are investigated and treated less than younger patients for a range of conditions including cancer, heart disease and stroke.

- The National Institute for Health and Clinical Excellence (NICE) is preparing guidance on standards of care of acute inpatients, which is expected to identify continuity of care as important (National Institute for Health and Clinical Excellence 2012b). Once the guidance is published, acute trusts will be required to respond to it.

The scope of this study is limited to what happens inside hospital. It does not look at what happens before people come into hospital, or follow them to their own homes or into residential or nursing care, and so it does not have much to say about continuity of care across sectors or the co-ordination of health and social services in the community. We know that transitions into and out of hospital are critically important to older people's health and well-being, and that for a very long time they have been 'one of the most problematic areas of policy and practice' (Glasby 2003; Ellins *et al* 2012).

Transitions into and out of hospital are much studied and very important, but with the resources available we felt we could not contribute anything new or useful on these topics. Instead, we explicitly focused on the relational, interpersonal and emotional aspects of care, and concentrated on the practical approaches, methods and tools that are deliberately designed to support older people and their carers in hospital. Our particular interest is in NHS hospitals, but we have thrown the net wide in the search for practical tools and methods that can make a difference.

We began the study with a review of the relevant national and international literature and survey evidence published since 2005, plus interviews with experts in the treatment and care of older people, in professional organisations and in voluntary bodies. We also sought advice from a handful of very active carers. We shared the interim findings at a workshop in May 2011, where we also gathered new material (*see* Appendix A). We then revised the report and presented the findings to experts in policy, practitioners, researchers and voluntary sector campaigners at the Sir Roger Bannister Health Summit in November 2011. The discussion at the summit focused on the importance of staff experience as well as that of patients and carers, and brought a greater appreciation of the complex systemic and organisational issues that provoke breaks in continuity of care.

This paper looks at what we know about continuity of care and about the experience of older people in hospital and reflects on why continuity of care is so difficult to achieve in the environment of the acute hospital. In the final section we describe good practice in continuity of care, and the practical models and methods for improving continuity of care that we found coming closest to conforming to those principles.

We believe that real continuity of care cannot be achieved without fundamental change in the way that the NHS as a whole thinks about the role and priorities of the general acute hospital and how it is run. A consensus is beginning to form around the unacceptability of the very poor standard of care of older patients in some hospitals and the need for action. Almost every piece of research and official report on the topic calls for new and different behaviour on the part of hospital leaders; more and better clinical leadership; greater engagement on the part of board members and executive directors with frontline staff, patients and carers; greater priority for clinical quality and safety; and more and better measurement (Carruthers and Ormondroyd 2009; Tadd *et al* 2011; The King's Fund 2011). In effect, a complete transformation in hospital organisation and culture is required, which will take time to achieve. More positively, there is much that can be done quickly to improve relationships and communication between patients, carers and frontline clinical and support staff and that will make a profound difference to patients and relatives. Most of the approaches we recommend do not need to wait for the root and branch change that is needed.

The current situation

What we know about continuity of care

Continuity is fundamental to high-quality care. Without it, the care that is offered is unlikely to be clinically effective, safe, personalised, efficient or cost-effective. Breakdowns in continuity of care put patients at risk, cause duplication and create additional costs to both health and social care (Kohn *et al* 2000; Committee on Quality of Health Care in America, Institute of Medicine 2001; Haggerty *et al* 2003; Freeman and Hughes 2010).

In the United Kingdom, most of the research into continuity of care has been carried out in the primary care and community service setting (Freeman and Hughes 2010). There is relatively little research into continuity of care in social care or in hospital.

The terminology in the literature is confusing: the terms ‘continuity’, ‘co-ordination’ and ‘integration of care’ tend to be used loosely and, although they are related, they are different. We see no need to invent new terminology and offer the following definitions. Courtesy of Haggerty *et al* (2003), we define continuity from the subjective point of view of patients and carers: ‘Continuity is the degree to which a series of discrete health care events is experienced as coherent and connected and consistent with the patient’s needs and personal context.’

Freeman and Hughes (2010) offer a useful distinction between two different aspects of continuity:

- continuity of relationship, which refers to continuous therapeutic relationships with one or more clinicians
- continuity of management, which refers to continuity and consistency of clinical management, including the provision and sharing of information and communication about care-planning, along with co-ordination of the care required by the patient.

The term co-ordination is used here to refer to policies, processes, systems and practical tools that underpin care provision. Bodenheimer (2003) defines co-ordination in these terms as: ‘A function that ensures that the patient’s needs and preferences for health services and information sharing across people, functions and sites are met over time.’

Co-ordination of care is one of the top priorities of the major health charities in the Richmond Group because of the central and determining part it plays in shaping the quality of care (The King’s Fund and the Richmond Group of Charities 2010).

The term integration occurs frequently along with co-ordination, but we see integration as having a different and wider application that is especially relevant to discussions about health and social care (Goodwin and Smith 2011). Fulop and others offer definitions of different aspects or types of integration (Fulop *et al* 2005; Ramsay and Fulop 2008). These include:

- systemic integration: a coherence of rules and policies at all organisational levels
- normative integration: an ethos of shared values and commitments that enables trust and collaboration in delivering care services
- service integration: the effort to bring different steps in a process, parts of an organisation, or professionals in different teams together to deliver a service
- functional integration: the work of non-clinical support and back-office functions, including access and use of information technology, data analysis and electronic patient records
- clinical integration: adherence to clinical guidelines and protocols or to care plans.

Continuity of care matters to everyone, but it ‘becomes increasingly important for patients as they age, develop multiple morbidities and complex problems, or become

socially or psychologically vulnerable' (Freeman and Hughes 2010). The greater the social vulnerability and dependency of an individual, the more weight he or she attaches to continuity of care, which makes it critically important for, for example, young people, asylum seekers and people who are homeless. The salience varies with age, health problem, context, personal circumstances and preferences, but generalisations can be misleading. Patients themselves, and their carers, play a substantial part in securing continuity, working hard to bridge gaps in communication and co-ordination where they occur. It is especially significant to older people because of the way in which the medical problems associated with ageing overlap with other medical problems.

Continuity of care matters to patients and their carers at every step of the journey within the hospital environment, but arrival in A&E or on to a ward and the moment of discharge are often particularly associated with high levels of anxiety and stress. These 'touch points', sometimes called 'moments of truth', are key times and/or places at which people's contact with a service shapes their subjective experience in a global way (Bate and Robert 2006). As a spokesman from one of the national voluntary organisations told us: 'Continuity matters as patients use their experience as a barometer of the service in general, eg, whether information about their care passes between professionals within hospitals or between providers. Good continuity inspires trust and confidence from patients' (interview).

Surprisingly perhaps, given the sheer volume of research in this area, there are no simple, practical measures of continuity of care available, possibly because of the confusion in terminology noted earlier. If we are to improve continuity, it is important to measure it so that we can assess the scale of the problems, understand what is causing them, and begin to overcome them. Experts agree that the most meaningful and practically useful way to do this is to ask patients (Freeman and Hughes 2010).

Surveys comparing the United Kingdom with other international health systems suggest that the UK system is better co-ordinated than most (The Commonwealth Fund 2008, 2010). The United Kingdom tends to do better than the Netherlands, Norway and Sweden, with the United States having the worst record for co-ordination problems.

Commentators generally attribute the better performance of the UK health system to the role of the GP as the provider of primary care and gatekeeper to other services. Although patients with chronic conditions experienced more problems with continuity and co-ordination of care, and little or no improvement in the past five years in all areas surveyed, in the United Kingdom some aspects of co-ordination did improve. For example, the proportion of patients reporting that their regular doctor 'always' or 'often' co-ordinated or arranged care increased from 58 per cent to 68 per cent, as did reports of hospitals contacting the regular doctor following an emergency admission. It is a mixed picture, however: problems involving co-ordination of test results and records diminished a little, for example, but the overall proportion reporting one or more co-ordination problems in the past two years increased from 13 per cent to 19 per cent.

What we know about older people and their experience in hospital

Older people are at greater risk of fragmented care in hospital for a variety of reasons. Analysis by The King's Fund of Hospital Episode Statistics up to 2009/10 (excluding obstetrics, midwifery, learning disability, adult mental illness, child and adolescent psychiatry, forensic psychiatry, psychotherapy, old-age psychiatry and well babies) showed the following.

- **Older people account for the majority of inpatients:** since the turn of the century, the inpatient population has been getting progressively older. In the past 10 years, the proportion of bed days occupied by patients aged 65 years and over has remained stable: the proportion occupied by those aged 65–84 years has fallen (from 48 per

cent to 44 per cent), but the proportion occupied by people aged 85 years or greater has risen (from 22 to 25 per cent). Over the next 10–20 years the trend is expected to continue as the population ages and the absolute number of very old people increases.

- **The length of time a person spends in hospital is directly related to age:** the older you are, the more often you will be in hospital and for longer; the longer you are in hospital, the greater your exposure to risk of physical and/or mental deterioration due to iatrogenic illness and/or injury (Hoogerduijn *et al* 2007; Lafont *et al* 2011). The average length of stay increases directly with age: it is eight days for patients aged 65–74 years; 10 days for patients aged 75–84 years; and 12 days for patients aged 85 years or older. The averages mask very wide variations in actual lengths of stay, however. More than a quarter of patients older than 85 years admitted as emergencies stay for more than two weeks, and about 10 per cent stay for more than a month.
- **Older patients are more likely than others to be readmitted to hospital within a short time of discharge:** readmissions have been rising for the past 20 years for all patients, but rising fastest for patients older than 75 years. In 2006/7, the readmission rate for people younger than 75 years was 9 per cent, but for those older than 75 years it was 14 per cent. There is no evidence that the rise in readmissions is associated with reduced lengths of stay, but there has been a considerable increase in the proportion of emergency readmissions that occur within 0–1 day of the original admission, which suggests that some patients are being discharged too quickly. The older the patient is, the more likely it is to happen more than once in the same year: 7 per cent of patients older than 85 years are readmitted three or more times in one year. On average, patients older than 75 years who are readmitted remain in hospital a further 14 days (Lafont *et al* 2011).
- **They are often moved about within the hospital:** unfortunately, it is impossible to say how many patients are moved between wards after they are admitted, or to comment accurately on the number of times individual patients are moved as the data are not collected. The national patient survey asks patients how many times they moved during their last ‘admission episode’. In 2010, the majority – 63 per cent – reported staying in one ward; 28 per cent moved once; and 8 per cent were in three or more wards. Asked whether their discharge from hospital was delayed, the majority – 60 per cent – said it was not, with 40 per cent saying it was (up by 2 per cent from 2005).

We were given access on an anonymised basis to data from two recently conducted small audits of transfers of care in one NHS trust.

The first audit collected data on 12 patients (10 medical and 2 surgical), most of whom had complex medical problems. All 12 patients were transferred from acute care into rehabilitation settings without the facilitation of a discharge co-ordinator. The results show:

- a mean length of stay of 49 days
- 7/12 patients were moved at least once out-of-hours, 3/12 were moved three times out-of-hours, and 10/12 were moved after 8pm
- patients were not always aware of the reasons for being transferred
- all the patients were transferred between more than one medical team, with the average number of transfers between medical teams being three per patient.

The second audit collected data on 10, mainly orthopaedic, patients who were transferred from the acute hospital to a community hospital, with a discharge co-ordinator arranging all the transfers. The results show:

- all but one of the patients experienced three transfers; one patient had four transfers
- all but one of the patients were aware of the reasons for the transfer and were transferred during the day

- the patients typically came into the emergency department, were transferred first to a medical admissions unit, then to one or more acute wards, and finally to rehabilitation.

What we know about older people and their experience of continuity of care

The main source of data on patients' experience in hospital is the national inpatient surveys that began in 2002. The picture painted by the survey data is considerably less rosy and more nuanced than the one painted by the international surveys we looked at earlier.

In 2010, more than 66,000 patients responded to the national inpatient survey, a response rate of 50 per cent. Just over half the respondents to the survey were aged 66 years or older; 35 per cent were aged between 66 and 80 years; and 16 per cent were older than 80 years (up by 2 per cent since 2002). The survey reflects both the preponderance of older patients and the increase in the size of the population of very old and frail patients. It is based on a representative sample of the patient population in each trust, and results are generalisable (Care Quality Commission 2011b).

In the past decade, written information for patients has improved, but in other respects little has changed in the experiences of patients since the survey began in 2002. The following aspects of care have remained almost static:

- the involvement of patients in decisions about their care: 48 per cent of patients answered 'to some extent' or 'no' (2005–2010 surveys)
- doctors or nurses failed to provide information to carers about looking after the patient (32 per cent said this was the case in 2010)
- staff explaining how to take medication in an understandable way: 25 per cent of patients had not been told or told only 'to some extent' (2009–2010 surveys)
- staff explaining potential medication side-effects: 44 per cent of patients said this had not happened (2010 survey)
- staff providing information about danger signals to watch for after discharge: 38 per cent of patients said this had not happened (2010 survey)
- staff providing a named contact to answer concerns after leaving hospital: 24 per cent of patients reported that this was not given (2010 survey).

Some aspects of experience in hospital have slightly worsened over the period since the survey began, with a small rise in the proportion of patients who said they:

- could not find a member of staff to talk to about worries and fears
- felt that the purpose of their medication was not completely explained in a way they could understand.
- had a delayed discharge
- did not feel enough information was provided about their treatment or condition
- reported that staff often said different things.

Survey data track trends over time and allow us to compare different hospitals. What they do not do is show how patients feel about their experience, the impact it has had on them or the sense they have made of it; for that, we rely on stories. We asked carers currently involved with a very old person with recent experience in hospital to tell us their stories. Below we reproduce (with permission) three such accounts in full to demonstrate the rich insights they afford and to illustrate the striking degree of commonality. We do not claim that the stories are representative, but they do reflect issues that have been picked up by

a great many others, and vividly exemplify the impact on older people and their families that poorly co-ordinated inpatient care can have.

A granddaughter's story

Over the past 20 years, my 92-year-old grandmother has endured the progressive stages of Parkinson's disease. She is now dependent on my 93-year-old grandfather (her main carer) and others for all the activities of daily life.

She has had many hospital admissions, almost always due to problems swallowing, which have meant she requires an intravenous drip to take fluids for short periods. When in hospital she has often become confused or delirious and her condition has worsened, entailing a longer stay. We have tried to ask community nurses to provide the necessary intravenous drip at home to avoid an admission, but the local community nurses are not trained to provide this.

She has had two periods of admission this year. During both periods we found the nursing care to be erratic, and communication between nurses and doctors to be poor. My grandmother had a different nurse each day, even though nurses she had become a little more familiar with were still working on the same ward. The timing of drugs, essential in Parkinsonism, was poor. When the paper drug chart ran out of space for new dates it took nearly the full day for a new chart to be started, causing worry that the drugs due in the interim had not been administered properly. On one occasion, I had to stay late at the hospital to make sure my grandmother received her evening drugs so I could call and reassure my grandfather.

During the first admission, her delirious state meant my grandmother knocked her legs on the bed bars causing bruising and eventually a large haematoma and necrosis of the skin. We were told that no padding or other solution was available. The wounds took six months to heal and required daily, then thrice-weekly, community nurse visits and expensive dressings. We have since seen padding to bed bars used elsewhere and learned (from consultants in the same hospital) that best practice would have been to nurse her in a low bed without bars.

During the second admission, an early discharge failed within 24 hours, possibly due to inadequate medication to quell her delirium. The process of discharge and re-admission caused great distress to both grandparents. They were forced to wait in the discharge lounge for about six to seven hours with no information as to when they might be able to go home. The following morning, realising my grandmother would need to be readmitted as she had again become delirious, my grandfather called the GP, who told him to call the hospital. He spoke to an administrator who said that a consultant would call him back, but several hours later, when the consultant called, my grandparents were already waiting in A&E. Although it was clearly a failed discharge, my grandmother had to go through a lengthy process of tests before she was admitted to a bed late in the evening.

My grandmother was moved twice in the first couple of days. The second move was carried out at 4am. Agitated on being woken, she pulled out her feeding tube. Her dentures were lost in transit and could not be located despite us repeatedly going to ask staff at the ward she had come from. The lack of dentures left her unable to communicate and increased her difficulty with eating. She developed aspiration pneumonia, which could have been in part due to the lack of dentures.

The pneumonia kept my grandmother in hospital for almost a month. By the time she was discharged she was very weak and came home under the palliative care team.

This seemed to improve care co-ordination, in so far as when she was discharged she bypassed the discharge lounge and the ambulance team took her straight from the ward to her bed at home.

The palliative care team instructed the family not to try too hard with feeding and medication regimes and not to get my grandmother out of bed, but my grandfather didn't agree. He acquired replacement dentures and mobilised her. Two months later she could walk a few steps with help, and enjoyed celebrating her 92nd birthday with friends and family.

A daughter's story

My mother was always very active and independent up to her mid-80s, enjoying activities such as book groups, gardening and spending time with her family. Until recently she lived independently next door to my brother. She has now moved to a care home close by.

Six years ago she had community-acquired pneumonia and was admitted to hospital for seven weeks. In hospital she contracted *Clostridium difficile* [infection] and was transferred between six different wards, including gynaecology, which was obviously not appropriate. It was very difficult to find out who was responsible for her care or who knew the most information about her condition. The nurses could only tell us the name of the consultant on-call that day, and the consultants rotated from day to day.

Throughout her time in hospital, staff continually called my mother by the wrong name. She has been called Harriet all her life, but it is her middle name, so her first name is written on all her records. We drew this to the attention of staff on the ward; it was important, especially as she was suffering from episodes of confusion, but it did not stop. Everyday someone from the family would visit her and wipe the wrong name off the whiteboard. On one occasion, after tracking down a registrar responsible for her care, we explained the situation and he wrote, 'likes to be called Harriet' in big letters on the front of her notes, but it still had little effect.

Recently she was very unwell again and confused and disorientated. She was moved between several wards and unsurprisingly contracted norovirus. It had a profound effect: at her most confused and sick we were unable to visit for a week, leaving her isolated and frightened.

Before she was discharged, there was a multidisciplinary case conference including the family, which went well. Unfortunately, despite the positive case conference, her care plan disintegrated and everything happened in a rush. The ward was keen to discharge her because of the norovirus. She was discharged without the family or the GP being told, and no one made sure that the community nurses were asked to do her injections and she did not get a referral for chiropody. The care home was expecting her, but on the day she was discharged they had very little notice. I had to intervene to make sure the ward staff spoke to them. After she was discharged she was very low, emotionally and physically.

She has also had exceptional care. On a recent admission, when I arrived to visit her, the ward sister introduced herself, explained that she was the main contact and even knew my mother's correct name. The atmosphere on the ward was completely different; the nurses were busy and engaged, rather than huddled around reception, they checked on her regularly and introduced themselves before starting treating her.

Overall, she has received the best care from staff who have treated and respected her as a person rather than stereotyping her as an elderly person who's not capable of thinking and doing things for herself.

A wife's story

I became a full time carer for my husband five or six years ago due to his increased dependency and weakness. He has had many hospital admissions because of problems associated with Crohn's disease and with his longer-term steroid medication. His weakness has resulted in many falls, and I have to call an ambulance each time because I cannot lift him. In the community, I have been supported by social services and the local carers' organisation, which is very helpful. There are occupational therapists who assess needs and provide stair-rails, bath aids, wheelchair, commodes, etc, all vital to his care and safety, and there is the district nursing service and the incontinence service. The incontinence service provided pads, etc, but was by far the least helpful and most inefficient service, difficult to get through to by telephone, unhelpful in discussing needs, and very slow in providing much-needed items. Liaison between these various services was poor, and I had to give the same information over and over again.

He spent two periods in hospital, in October 2010 for three weeks, and in January 2011 when he was in for five weeks. His care was inadequate in many areas... In hospital I found it difficult to communicate with the doctors who were in charge. They were not easily available. They did not liaise with [the other hospital where he had been treated]. Medication was stopped or changed without my knowledge. My husband spent longer in hospital than was clinically necessary because of administrative muddles over discharge procedures. The hospital occupational therapist did not liaise properly with district nurses, and my husband's hospital bed was provided at home without a mattress. Discharge protocols clashed. The occupational therapist said he could not order a bed until the discharge date was provided, but the ward manager said the bed had to be in place before a date could be given. This caused my husband great distress and despondency, and he has never fully regained what was lost in his mobility and continence while in hospital.

These stories show a quality of inpatient care that is very variable: it is good some of the time but it is never reliable. They show that patients and carers experience multiple, overlapping problems, with difficulties including:

- the way that nurses organise their work, the culture of the ward, and the way nurses interact with them
- access to consultants and senior medical staff, and communication with doctors
- poor communication between hospital staff and staff in the community
- poor and non-existent care-planning
- the failure of the system to identify a named person responsible for their care and with enough of an overview of what is happening to talk to patients and carers
- the absence of, or failure to adhere to, shared protocols and guidelines
- disruption caused by the patient being moved about inside the hospital.

The stories illustrate how and why breakdowns in the continuity of care – plus the absence of a relationship with professional staff, poor information and opaque or non-existent clinical management – lead patients and carers to lose trust, and the damaging consequences for their health and well-being. They illustrate the precarious and complex arrangements on which households of frail older people depend, and the work carers put into co-ordinating care to prevent breakdowns in continuity and repair them when

they occur. Perhaps most importantly, they also illustrate the well-known phenomenon that, despite any difficulties, ordinary human respect, kindness and consideration shown on a personal level has an extraordinary and disproportionately positive impact on the experience of patients and carers (Ellins *et al* 2012).

The roots of the problems

The obstacles to continuity of care in hospital are systemic and complex. They are rooted in factors deeply embedded in the current design of the health and social care system and the priorities of those who commission acute care and run hospitals. They affect the volume of work in hospital, the ordinary routines that govern the working days (and nights), the culture of care in the hospital as a whole and in teams (microsystems), the levels of training and skill of the workforce, and the values of the staff.

The conceptual framework for understanding the analysis of integration outlined earlier offers a way in to the issues.

Systemic integration

Although we excluded policy from the scope of the study, it is impossible to ignore its impact on older people, carers and services. Policies and rules developed to fix an immediate concern or one part of the system can have unintended consequences that impact on them. Examples include the following.

- For more than a decade, the government's main priorities for the NHS have been to speed up access to A&E, elective surgery and general practice, and improve clinical care for patients with cancer, heart disease, stroke and mental health. Services have improved across the board for cancer, heart disease and stroke patients, but less for older patients with those conditions than for others (Lievesley *et al* 2009).
- The different rules governing payment in health and in social care result in patients and carers being caught between hospital staff and social care workers who are at loggerheads (Ellins *et al* 2012). The *National Service Framework for Older People* (Department of Health 2001), which was designed to redress the balance, did not come with additional funding earmarked to support implementation, as its predecessors had (Oliver 2008).

Fundamentally, the response of the health care system to the changes occurring in the health of an ageing population is inadequate. The system is not geared to meet the needs of the majority and the people who need it most. We need a radical rethink about the role of the acute hospital in meeting the needs of people with long-term conditions and people who are old, with complex health problems, and frail.

Hospitals are dangerous places, and it is vital to avoid unnecessary admissions and develop better services for older people in the community and in their own homes. It is, however, a mistake to think that this will completely solve the problems in hospitals. It is neither desirable nor possible to keep all frail, older people out of hospital all of the time: there will always be a need for some to access the diagnostics, treatment and care that can be provided only by an acute hospital.

For more than a decade, hospitals have been under pressure from a variety of sources: legislation, changes in medical education, and the drive to contain costs have all exacerbated problems in relation to continuity of care.

The European Working Time Directive, coupled with changes in medical education, have radically altered the way doctors work together. Consultants used to work in firms, with junior doctors working for them on six-month rotations. Today, they mostly belong to a consultant team that has teams of junior doctors on four-month rotations. Maben found that: 'Consultant physicians spoke of not getting to know their junior staff because of the new rotation system so that [senior house officers] were only in one place for four months. Junior medical staff spoke of isolation, high workload and the need to debrief with peers' (Maben *et al* 2012).

The coincidence of reduced hours of work, shift-working and the movement into teams has disrupted old methods of communication between doctors, and made it more difficult for professionals working with the same patient to keep in touch with each other. In the absence of easy and frequent face-to-face contact between people, the quality of the communication at handover and in patient records is paramount.

To survive financially, hospitals must strive continuously to improve productivity by increasing patient throughput, maximising the use of beds, and reducing lengths of stay. Coupled with the secular reduction in the total number of beds over the past 20 years, it is normal for most hospitals to function at 90–100 per cent occupancy with very little or no spare capacity on the wards. It is often not possible to admit emergency patients straight to a bed in the right place. Typically, patients for admission are transferred from A&E into an assessment unit, from where they are sent home or transferred to the first available bed. If it is on a ward assigned to the wrong specialty, they are moved again, possibly more than once. Other factors contributing to the volume of movement inside hospitals include the shortage of individual rooms for end-of-life care, and the incidence of hospital-acquired infections.

Normative integration

Age discrimination and ageist attitudes are prevalent in hospital (Lievesley *et al* 2009). At a corporate level, the business is organised on the basis of specialties, departments, workforce categories and other management units, not generic patient groups. Ageism means that older people's issues, including continuity of care, rarely get the focus they deserve. The hospital is not designed around their needs in terms of workforce, the physical environment, the organisation of the day or attitudes towards visitors.

A recent major study (Tadd *et al* 2011) of the care of older patients on acute wards found that people in charge and frontline staff almost unanimously held the view that hospital is 'the wrong place' for older patients, especially older patients who have mental health problems. Despite the fact that, as we have seen, the majority of patients in hospital are old, they are seen as not belonging, and therefore less entitled to be there. Hospitals are felt to be 'right', apparently, only for patients who are acutely ill and can be treated, and the hospital culture therefore merely tolerates older and frail patients, who are referred to pejoratively as 'inappropriate admissions', 'bed-blockers' and 'social admissions': dehumanising terms that both reflect and shape staff attitudes and behaviours.

Attracting health professionals to work with older people is a problem in most disciplines in all advanced economies.

People have not insisted on a change in priorities. We all like medical gizmos and demand that policy-makers make sure they are paid for. They feed our hope that the troubles of the body can be fixed for good. But geriatricians? Who clamours for geriatricians? What geriatricians do – bolster our resilience in old age, our capacity to weather what comes – is both difficult and unappealingly limited. It requires attention to the body and its alterations. And it requires each of us to contemplate the course of our decline, in order to make the small changes that can reshape it. When the prevailing fantasy is that we can be ageless, the geriatrician's uncomfortable demand is that we accept we are not.

(Gawande 2007)

Professional values reflect the values of the wider society, and old age specialties in medicine and nursing lack status, are perceived as unattractive and are hard to recruit to. Of course, there are individuals in all professional groups who are deeply committed to working with older people and who find the work challenging and rewarding, but for doctors, 'the care of older people is seen as unattractive and low status by many,

compounded by the lack of potential for private practice' (Oliver 2008), and it is not a popular nursing specialty. Maben quotes nurses saying care of the elderly wards are 'a dead end part of the service' where 'you can't go far', and 'an area where you aren't picking up skills' (Maben *et al* 2012).

Lack of recognition and lack of ownership of the problems older patients and carers face in hospital mean that older patients are often in the hands of staff who are not trained to care for them and lack the knowledge and skill to do so confidently. Geriatric medicine does not feature prominently in the curricula of many medical schools, and plays only a small part in nurse training. Care of the older person is an optional specialty, not something that is fundamental to the general curriculum. The vast bulk of the physical care of older patients has been delegated to untrained health care assistants who have few if any qualifications. The work is typically labelled 'basic', rather than 'essential'. If it was defined as 'essential', perhaps we would begin to see that it requires both knowledge and skill. The government has announced that from 2013 health care assistants must be trained and employers will be responsible for that training. This may be a step in the right direction, but it will not make a difference without changes in the wider culture in hospital.

Service integration

It is a platitude to say that hospitals are places of silos and hierarchies. Frontline clinical and support staff in departments and wards have surprisingly little face-to-face contact with colleagues in other areas, and professionals do not meet together to plan their work beyond formal multidisciplinary meetings. Managers higher up in the organisation are often better placed to look across whole-care pathways than are the people directly delivering patient care.

If anything, achieving continuity is more difficult today than it used to be as a result of increasing specialisation in both medicine and nursing. Medical sub-specialties, along with both disease- and organ-based nursing specialties, have proliferated – more so in the United Kingdom than in other European countries (General Medical Council 2011). There are 61 approved medical specialties and 34 approved sub-specialties in the United Kingdom, compared with 57 specialties in Sweden (the next closest), and 52 in Ireland, Germany and Romania. Norway has the lowest number with only 30 (General Medical Council 2011).

Specialisation can improve clinical quality and safety, but it has negative consequences when the care from the specialists is poorly co-ordinated. For older people with complex needs, as well as for some other groups of patients, specialisation within the professions brings disadvantages if it is not tempered by access to appropriate generalists and other professionals to ensure a holistic approach is also taken. Geriatricians mainly remain generalists, but not all older patients are cared for by a geriatrician and, in some hospitals and teams, geriatricians lack influence.

Liaison psychiatry or liaison mental health services are designed to support the mental health needs of patients in hospital, particularly those with long-term health needs. These services have been shown to provide a range of benefits, such as improvements in health outcomes and patient experience, while reducing length of stay, readmissions and health care costs (NHS Confederation 2011).

Liaison psychiatry has particular importance for older people within acute care as it provides an integrated approach to addressing their physical and mental health needs. The psychiatric liaison model for older people is being implemented across the country, with differing service models. The common aspects of an effective service include a multidisciplinary team with a range of disciplines, trained in mental health liaison and led by a psychiatric consultant. The service should be embedded in the acute hospital setting

so that staff can work closely with acute staff on general wards and have sufficient time to provide training and education (Working Group for Liaison Mental Health Services for Older People 2005; NHS Confederation 2009).

A recent National Institute for Health Service Delivery and Organisation project (Holmes *et al* 2010) to map the provision of these services in the United Kingdom found that there had been a shift since 2002, away from the traditional hospital consultation model towards psychiatric liaison services, but that provision across the country remained patchy.

In the absence of co-ordinated services and care processes, the quality of the communication between clinicians is paramount. The proliferation of roles and personnel can be bewildering for patients and carers unless the various functions and responsibilities of each team member are carefully explained.

Co-ordinating the contributions of all the different professionals involved with a particular patient requires:

- team leadership
- clarity about the roles and inputs to the team that each individual and professional background brings
- clarity about who is accountable for what and what delegation means
- the availability of members of the team to meet together reliably
- good record-keeping.

In the complex environment of acute hospitals, where patients in the care of a single specialist medical team may be distributed across many wards, and when patients are moved about within and between wards, multidisciplinary meetings are often exceptionally difficult to organise and thus rarely occur.

Some hospitals try to strengthen continuity and reduce delays in clinical decision-making through medical scheduling. Some have opted for 'consultant of the week' (or fortnight) schemes, where the consultant is based on the ward for the whole period with his or her medical colleagues taking over duties in clinics and elsewhere. Others link a geriatrician to every acute ward, or have geriatricians in teams offering specialist advice to other disciplines. There are pros and cons to all of these various schemes. So long as the goals of greater continuity and fewer delays are agreed, each hospital can find the solution that best suits its medical workforce and patient population profile. A scheme that works well in one hospital will not necessarily work in all.

Functional integration

The quality, speed and reliability of information and communication systems are fundamental to continuity. Most acute trusts do not yet offer access to electronic medical records to all staff throughout the hospital. Many professional staff have little or no access to computer terminals to review care plans, record care and communicate with each other.

Records continue to be mainly handwritten and paper-based. It is normal for different professionals working with one patient each to keep their own records, for those various records to be kept in different places, and for parts of the record not to be available out of hours. Nurses complain about the burden of paperwork and about having to complete complex paper-based patient assessments that frequently do not contribute to patient care, but at the same time it is normal for nurses to re-do the paperwork when a patient arrives in their area, rather than relying on an assessment carried out by a colleague in another part of the hospital.

Patients and carers complain that staff take action or ask them to provide more information before checking for themselves what information has already been recorded. They also complain about having to repeat personal details and answer the same questions, and worry that behind this phenomenon is the possibility that ‘no-one knows, or cares, who I am.’ They become worried if the people they meet cannot give them an overview of the plan of care and when different people tell them different things.

Electronic records can play a significant part in contributing to the continuity of care and ensuring that care is better co-ordinated. A study of the Hospital at Night scheme, introduced after the European Working Time Directive was implemented, concluded that electronic handover improves information transfer, improves continuity and helps to reduce medical errors (Raptis *et al* 2009).

Clinical integration

Ageist attitudes and professional values that reflect them have direct consequences for the quality of clinical care. They have shaped an approach to the medical care of older people in which it is acceptable for the standards of care and procedures to differ from those applied to the medical care of other age groups. Oliver (2008) coins the term ‘therapeutic nihilism’ to describe the phenomenon of older patients being admitted to hospital and treated without proper diagnosis and assessment, with the result that treatable problems such as incontinence, depression and delirium are normalised and go untreated. “The customary diagnostic rigour, which we have been trained to apply as standard, can be mysteriously replaced by “therapeutic nihilism.” (Oliver 2008).

There is no excuse for treating older patients as a group differently from younger patients. The National Institute for Health and Clinical Excellence has published guidelines and quality standards relating to the care of older patients, notably on falls (National Institute for Clinical Excellence 2004), critical illness rehabilitation (National Institute for Health and Clinical Excellence 2009) incontinence (National Institute for Health and Clinical Excellence 2007), dementia (National Institute for Health and Clinical Excellence and the Social Care Institute for Excellence 2006), delirium (National Institute for Health and Clinical Excellence 2010), stroke (National Institute for Health and Clinical Excellence 2008), chronic heart disease (National Institute for Clinical Excellence 2003) and end-of-life care for adults (National Institute for Health and Clinical Excellence 2012a). These should be made available to and implemented by all health professionals who work with

adults in hospital.

Practical solutions

Practices that promote continuity of care

The evidence on continuity of care for people with long-term conditions, mental health problems and/or who need end-of-life care is the same, with the essential requirements being (Freeman and Hughes 2010):

- a named key worker available 24/7
- a care plan
- a complete medical record, ideally held electronically
- multi-skilled carers, whether their background be nursing or an associated care professional
- generalists working alongside specialists.

From interviews with experts and carers, for inpatient acute care we would add:

- a named professional capable of having an overview of the case and who is accountable for the care plan
- information for patients and carers about the times when the accountable person is available to answer questions and discuss the care plan
- training for all staff in the care of older patients, including care of patients with cognitive impairment
- cognitive assessment of all older patients to diagnose delirium, dementia and depression
- operational plans to reduce the number of times the same patient is moved around a hospital
- operational plans to mitigate the effect of movements, including policies on out-of-hours transfers
- use of checklists for essential information to support communication with patients and carers
- email and telephone contact between consultants and GPs
- email and telephone contact between ward-based staff and their community-based counterparts.

The distinction between continuity of relationship and continuity of management is analytically helpful but, in practice, efforts to promote continuity of care do not fit into neat categories. Initiatives aimed at strengthening relationships have knock-on benefits for clinical quality, and initiatives aimed at improving communication with patients help patients and carers with the work they do to bridge the gaps in services.

We found two types of initiative to promote continuity of care.

- Interventions aimed at a single aspect of continuity, for example, communication or relational care. Interventions in this group can be relatively complex, but what distinguishes them is that as long as frontline staff have the support of their immediate manager, they can implement them.
- Interventions aimed at promoting continuity of care from the beginning to the end of the patient's journey. These kinds of changes usually take a long time and need the support of very senior clinical and operational leaders over sustained periods.

Interventions aimed at promoting one aspect of continuity

There are several practical tools in use in the United Kingdom to strengthen continuity of communication between professionals and patients, and professionals and carers. Typically, these are simple, paper-based documents or forms for patients or carers to complete, giving professionals information about the patients' lives outside the hospital and their individual preferences. The idea is that the provision of this information empowers patients and carers because they can urge professionals to refer to it, and it helps the professionals by giving them a sense of who their patients are outside the medical setting.

One such tool that has been tested and is easily available is *This is Me*, a leaflet for patients and/or their carers to complete before patients go into hospital (Alzheimer's Society/Royal College of Nursing 2010). *This is Me* provides a snapshot of the patients' normal lives outside the care setting, detailing their habits, interests, likes and dislikes. Simple and practical, it was first developed by the Northumberland Acute Care and Dementia Group at Northumberland Health Care Foundation NHS Trust, and was launched by the Alzheimer's Society with the support of the Royal College of Nursing in February 2010.

We looked for examples of interventions designed to strengthen relationships between patients, carers and professionals in the United Kingdom but struggled to find any. In the United States, Planetree, a not-for-profit organisation that promotes patient-centred care, has published material on two practical methods of strengthening relationships between patients, carers and staff (Frampton *et al* 2008). Both are the product of a fundamental philosophy of care that expects professionals to include the patient – and whomever else the patient wishes – in care-planning and decision-making.

Partners in Care

This programme is a deliberate effort to enhance the role patients and their relations play in patients' hospital care. Patients nominate a member of their social network as their 'care partner'. The goal is for the personal, emotional, physical and psychological needs of patients to be met by allowing and encouraging their normal support system to be involved in their care during their hospital stay, while respecting and protecting patients' sense of dignity and independence.

The way Partners in Care works is that a primary nurse responsible for the patient has an initial discussion with the patient and the nominated care partner to gauge the patient's interests and preferences. Within 48 hours of admission, the members of the multidisciplinary health care team hold a collaborative care conference with the patient and care partner to discuss diagnosis, treatment and post-hospital care needs.

The role of the ward-based nurse after the conference is typically to provide the care partner with education and training, so that he or she can participate in routine care activities with the patient such as: personal care, menu selection, assistance with meals, monitoring fluids, reading, writing and other diversions, mouth care, dressings, catheter and drain care, and mobilisation. The role of the care partner is explicitly not to replace the nursing care but to enhance it.

Patient and family-centred ward rounds and clinics

The difference between family-centred ward rounds and family-centred clinics is that the ward round is held at the patient's bedside, the clinic away from it. The purpose of both is to promote an open exchange of information and ideas between the patient, the patient's family and the professionals involved. Careful attention is paid to respecting the wishes of the patient and family members about issues to do with confidentiality, privacy and the degree of involvement wanted.

The family is told the times of the rounds/clinics and introduced to the members of the care team. The roles of the members of the care team, and the professionals' expectations of the part that family members will play are explained.

The aim is to give the family the opportunity to ask questions, to receive information and provide additional, new information, to review the care plan and to discuss plans for discharge. At the end of the session, the professional checks whether there are last-minute concerns and explains how any additional information will be relayed to the family.

It is possible that the hospitals that have implemented the Planetree model, with its emphasis on patient-centred care, are exceptional in the United States as well as in the United Kingdom, and that the lack of published examples of relationship-building interventions in the United Kingdom does not indicate a profound philosophical/cultural difference between US and UK hospitals. It is also possible that there is greater awareness and respect for patients' autonomy in the United States because patients are viewed more as active consumers.

Interventions aimed at promoting continuity across the care pathway

From the patient's perspective, management continuity is about knowing:

- that he or she has a care plan
- that clinical care is consistent with that plan
- who to speak to if there are any problems.

There are many ways in which patients and families can be empowered in and around their hospital stays. Despite the impact of physical and mental frailty, it should not be assumed that patients are incapable or unwilling to be more involved in their own care, although some will need support from their families or other advocates to help them to do so.

In the United Kingdom and elsewhere, continuity is achieved by bringing an additional patient-navigator or patient-advocate into the system. The Stroke Association's Life After Stroke Services model, for example, provides stroke survivors, families and carers with information, support and assistance (Stroke Association 2012). It helps ensure that their needs are being met, and helps them come to terms with life after stroke. Co-ordinators direct clients towards other services that can meet their needs and help them to achieve their goals. They seek to develop strong links with all the sources of support available, bridging and navigating across systems and organisational boundaries. The work is led by the needs and goals of the client.

The service usually covers the time from early recovery and adjustment, giving personalised information on the ward, through to up to a year after stroke. Being a supportive presence throughout to both the stroke survivor and his or her carer, staff are trusted to help with the emotional consequences of stroke, and can make important early interventions to prevent crises developing.

One such scheme is the Hospital-Based Carer Support Worker (HCSW) provided by Carers Leeds and funded by Lloyds TSB Charitable Trust. The HCSW aims to provide information, advice and confidential support to all carers within the hospital setting. This may include visitors, patients or paid staff that have a caring role at home. The challenges faced by Carers Leeds' HCSW are common to many hospitals where the sheer size and complexity of the organisation and its policies and procedures present difficulties knowing where to go to follow up certain issues raised by carers.

The main carer issue that has faced the HCSW in Leeds concerned the discharge procedure. Patients and carers do not always know where to go for help and they can become lost in the world of care plans, benefits, home care services, enablement and medication. Carers Leeds' HCSW helps carers 'through the system' to enable them to feel more confident and assured when their caring role starts for them at home (interview).

In Pennsylvania, in the United States, Naylor and colleagues have developed and refined a model of care to address the unmet needs of hospitalised older people and to improve outcomes after discharge (Naylor 2002, 2004; Naylor *et al* 2009). The model relies on an advanced practice nurse (APN) with gerontological expertise to do comprehensive discharge-planning. The APN tailors post-discharge services to the patient and provides follow-up care by telephone and home visits.

The intervention is notable for its emphasis on identifying patients' and caregivers' goals, individualised care plans developed and implemented by APNs in collaboration with patients' physicians, educational and behavioural strategies to address patients' and caregivers' needs, and co-ordination and continuity of care across settings. Naylor and colleagues have evaluated the intervention for its effect on costs and outcomes, to identify the patient groups for whom it is effective, and to define the intensity and duration of services necessary to improve outcomes.

The scale and complexity of the changes needed to deliver co-ordinated care to patients using existing staff alone can be seen in the examples below from Leeds and the Royal Bolton Hospital.

Leeds Hospital Mental Health Team for Older People

In 2006, in response to rising lengths of stay among older patients with dementia, delirium or depression, hospitals in Leeds chose to move from a traditional psychiatric consultation model to a psychiatric liaison service, the Hospital Mental Health Team for Older People (HMHTOP).

The HMHTOP is a service for those aged 65 years and older provided by the mental health trust – the Leeds and York Partnership NHS Foundation Trust – and physically located on the site of the Leeds Teaching Hospitals NHS Trust.

The team provides a quick referral service to:

- identify and assess older people with serious mental health needs within general acute care
- manage the effects of physical health on mental health
- provide training and support to hospital staff caring for older people with mild dementia and delirium on their wards.

It operates seven days a week, between 9am and 5pm, and comprises a consultant psychiatrist, senior house officer in psychiatry, several band five and six nurses, an occupational therapist and administrative support. This multidisciplinary approach brings together staff with a range of skills, and every member of the team is trained to carry out assessments.

On any given day, the team operates on an *ad hoc* basis, receiving referrals from departments throughout the hospital trust. Most referrals come from care-of-the-elderly wards, but oncology, orthopaedics and surgical wards are increasingly referring patients to the service as well.

Once a referral form is received, the administrator checks whether the patient is known to the mental health trust. Cases are assigned to team members in the morning, and then assessments are carried out with the patients using a standard assessment pack. Staff use this time to speak to the patient, his or her family, carers and staff members to build up a detailed picture.

Later in the day, the morning's cases are reviewed at a multidisciplinary team meeting. The findings from the assessment are summarised, and diagnoses are discussed as a group. While this is going on, notes of the assessment are entered into the patient's electronic record. Patients are often referred back to their GP for a follow-up, but a

significant proportion are referred on to inpatient psychiatric wards (largely due to difficult dementia) or memory clinics or signposted towards information about dementia, for example.

Providing education and training to staff across the trust is another key function of the HMHTOP. As the service is designed to integrate mental and physical health, team members work closely with general staff to ensure that appropriate referrals are made and to provide advice about managing patients with low-level dementia, delirium and depression on the wards – ensuring, for example, that older patients are kept sufficiently hydrated as dehydration can exacerbate or cause delirium.

The creation of the HMHTOP was funded by the Department of Health as part of the two-year Leeds Partnership for Older People's Programme pilot between 2006 and 2008. This pilot evaluation found that length of stay significantly decreased for patients with dementia as a primary or secondary diagnosis compared with the general patient cohort (Godfrey 2009). HMHTOP has also increased the number of referrals by 87 per cent, from only 200 per year in 1999, and now accounts for two-fifths of all mental health referrals in Leeds.

The majority of their patients are diagnosed with delirium, dementia or both, and over 60 per cent are older than 80 years. Interestingly, three-quarters of their patients are new to the mental health trust, suggesting that the service is picking up a high proportion of previously undiagnosed conditions.

Respiratory gateways at the Bolton NHS Foundation Trust

At the Royal Bolton Hospital, the aim has been to achieve a continuous, co-ordinated and reliable care experience for patients. Since 2005, the Bolton NHS Foundation Trust has committed significant resources to an organisation-wide strategy to improve the quality of services using so-called 'lean' methodology. A large number of clinical staff have trained in the principles and techniques of quality improvement and are familiar with rapid improvement events, process mapping, observations of practice and activity analysis. The trust executive knows that it takes time to prepare improvement ideas and that it is essential for clinical teams to take time away from clinical work to monitor and develop improvement plans together.

In 2009, the Royal Bolton Hospital identified respiratory services as being a priority for quality improvement. At the outset, services in Bolton were thought to be good locally. Like services for patients with chronic conditions all over the country, different combinations of personnel treated patients with respiratory problems in different settings. These included:

- two inpatient wards
- specialist nurses for asthma, lung cancer, tuberculosis, chronic obstructive pulmonary disease and long-term oxygen therapy
- nurse-led clinics
- pulmonary rehabilitation
- a hospital-at-home service
- outpatient services.

The team that led the work to improve the respiratory pathway comprised a respiratory nurse specialist, a matron and two medical consultants supported by quality improvement specialists. They created what they called a 'patient gateway', underpinned by the principle of 'one decision flow'. Put simply, this means having the right team members, with the right information, present at the right time to make the decisions required to add value to the patient's journey by eliminating entirely delays, errors, duplication and non-patient-related variation. The idea is that every day that the patient is in hospital, it is absolutely

clear what actions are being done and by which members of the team, with the result that the patient can be treated and discharged without delay.

Over a period of 18 months, the respiratory service improved clinical outcomes and achieved a much-improved experience of continuity (see Table 1).

Table 1 Changes in outcomes for respiratory patients, 2009–11

| Measure | 2009–10 | 2010–11 | Change (%) |
|--|--------------------|--------------------|------------|
| Mortality* | 119 | 91 | -23.0 |
| Length of stay | 8.9 days | 6.9 days | -23.0 |
| Readmissions | 9.5% | 8.5% | -10.5 |
| Escalation to intensive care unit | 101 patients | 64 patients | -34.0 |
| Home visits by respiratory specialist nurse | 269 (July–January) | 410 (July–January) | +34.0 |
| Respiratory specialist nurse time on wards seeing patients | 26.25 | 52.5 | +50.0 |

Notes: *hospital standardised mortality ratio

Source: Bradley *et al* (2011)

One patient is quoted as saying: ‘I have been a patient here for 30 years, care has always been good. But the changes now on the ward are marvellous, you see a consultant every day, you know what is going on and can action things sooner if necessary’ (Bradley *et al* 2011).

Behind the scenes, the modifications that made the improvements possible included:

- all consultants’ job plans were reviewed and changed to allow daily review of patient care
- consultants were rostered to work on the wards continuously for a period of two weeks
- daily morning ward rounds
- daily multidisciplinary board rounds (meetings at the white board)
- ward rounds at 4pm on Fridays to make decisions before the weekend
- respiratory nurse specialists’ roles were changed from disease-based to patient-based allocation for all respiratory patients
- the respiratory nurse specialist service was made available seven days per week
- changes were made in the way that junior doctors and nurses work together
- separate rounds for medication were instituted.

The chief executive of the trust described the changes thus:

Within respiratory services, there may be five consultants. Ours each do a two-week ward duty, during which time they do not do routine clinics. These doctors are responsible for all the respiratory patients for that fortnight. That offers most patients continuity, but where they experience a changeover of consultant, the plan continues. This is being rolled out across the hospital. We have done complex care wards, cardiology, gastroenterology, orthopaedic and respiratory.

(Interview)

The scale of the challenge to the usual ways of working in acute hospitals, and of the changes that individuals and teams had to make to deliver a co-ordinated respiratory service cannot be underestimated. For that reason, we cannot simply recommend the Bolton approach as the solution everywhere. Before they are ready to tackle the

fundamental improvements required to co-ordinate care, hospital leaders need to be satisfied that they have the foundations in place. These include:

- the will among leaders at senior and ward level and the determination and persistence to see the changes through over time
- knowledge of improvement methods and techniques
- a realistic time horizon for planning and implementation: transformation does not occur quickly
- a willingness to allow the team to take risks
- really good communication within clinical teams
- measurement and analytical capability that can be used by the team.

Better information and metrics

If continuity of care and co-ordination of services are to happen, much more work needs to be done on measures, including measures that assess patients' experience of continuity and the impact of interventions designed to improve it. It is surprising to discover how little work has been done to date on this important topic, and probably fair to say that the measurement of continuity of care is underdeveloped. This may, in part, reflect a lack of consistency about the definitions of continuity of care and co-ordination of care.

The situation is not improved by the existence of separate outcome frameworks for the NHS and social care, which do nothing to promote an overview of people's journey through the system and, indeed, encourage an organisational rather than patient-focused view of performance. Organisations are not currently judged on how successful they are at providing continuity of care, but this should be the case.

In the United Kingdom, the questionnaires used by the national patient surveys of clinical conditions (such as stroke, heart disease and cancer), of some patient groups (women using maternity services), and for community rehabilitation provide a good basis for designing survey instruments that can measure continuity of care.

In the United States, recognised measures include Coleman's CTM-3 and CTM-15 (Coleman *et al* 2005, 2007). The CTM-3, completed at a home visit, has three statements, the CTM-15 has more. The CTM-3 statements are:

- The hospital staff took my preferences and those of my family or caregiver into account in deciding what my health care needs would be when I left hospital.
- When I left the hospital, I had a good understanding of the things I was responsible for in managing my health.
- When I left the hospital, I clearly understood the purpose of taking each of my medications.

In the United States, the Picker Institute is promoting the concept of 'Always Events' as a positive tool (Picker Institute 2012). The flip-side of the coin from 'Never Events' – incidents that should never occur during the delivery of patient care – Always Events are seen as an exciting way to promote better communication and better care transitions, being 'aspects of the patient and family experience that should always occur when patients interact with health care professionals and the delivery system', as ascertained through focus groups composed of patients, families and frontline caregivers (Picker Institute 2012).

The Picker Institute has identified four criteria that should guide the selection of Always Events. They are:

- significant: patients should have identified the experience as important
- evidence-based: the experience should be known to be related to the optimal care of and respect for the patient
- measurable: the experience should be sufficiently specific so that whether it occurred can be accurately and reliably determined
- affordable: the experience should be able to be achieved by any organisation without substantial renovations, capital expenditure or the purchase of new equipment or technology.

At this stage of development, the Picker Institute is funding two-year demonstration projects based on a range of Always Events. When the programme ends, it will produce a guide to lessons learned and tools to support future adopters.

In the United Kingdom, the Department of Health has begun to follow the US lead by issuing, in 2011, a list of 25 Never Events that providers must report and that are linked to financial penalties (Department of Health 2011). The list was updated in 2012 (Department of Health 2012).

Although better metrics are important, it is also vital to recognise the value of qualitative data and informal feedback. Clinical staff and managers could learn a great deal about how to improve continuity from asking patients and carers about their experience and posing questions as simple as:

- Is there anything else I can do for you?
- Do you know whom to contact when you need to?
- Do you have their name and number?
- Do you have the information you need about your drugs?
- Do you have the information you need about what will happen next?
- Is there any information I can help you with?

Patients and carers often hang back from asking questions, but they are a rich source of service intelligence for those who tap into it.

While there is scope to develop better metrics, it is also important to acknowledge that qualitative data can contribute to service assessment.

Conclusions and recommendations

Continuity and the co-ordination of care are fundamental to high-quality, cost-effective health care. In the context of acute care, the risks of fragmentation and breakdown in care co-ordination are high, especially for older patients.

The scale of the problem and the number affected is unknown, but it is quite clear that a very great many older and very old patients are receiving sub-optimal care. Too many patients and carers do not know 'who is in charge' of the patient's care, who they can talk to about it, and how to get answers to their questions.

Relatively small changes in practice can significantly strengthen patients' and carers' relationships with clinicians and contribute to greater consistency of clinical management. Solving the deep and systemic problems that underlie many of the problems, however, requires the commitment of the senior leadership of the hospital, a deliberate strategic intent, clear aims, investment in and knowledge of service improvement methods, a willingness and persistence to pursue the goals over months and, if necessary, years, and the capability to measure and monitor the changes.

Our recommendations are presented below.

Recommendations

| Patients and carers | Frontline clinical and support staff | Senior executives and board members |
|--|---|--|
| Patients and carers should receive high-quality care that is appropriate for their needs in all clinical areas | Should have confidence in their own level of knowledge and skill in relation to the medical care of older people | Should develop and implement a hospital-wide strategy for high-quality care for frail, older patients with complex medical problems that promotes continuity of care |
| Patients and carers should always know the name of the person in charge who will be able to answer questions and discuss the care plan | Should introduce themselves to patients and carers by name and explain their role | Should consider whether a dedicated care co-ordinator is needed in complex cases, and make sure that a named professional is responsible and accountable for every patient |
| Patients and carers should always know when and how to get hold of the lead professional | <p>Should agree who is the named professional in charge and give that name to the patient and carer</p> <p>Should agree when and how the lead professional will be available, and make sure that patients and carers know the details</p> <p>Team members should make sure that the lead professional is aware of changes in the patient's plan</p> | Should make sure that patients and carers know when and how to get in touch with that named professional |
| Patients should be invited to nominate a partner in care | Should invite patients to name their partners in care and invite those people to be more closely involved with the care plan | Should pilot and implement partners-in-care schemes on the wards |
| Patients and carers should have the opportunity to complete a <i>This Is Me</i> document or a suitable alternative | Should use a <i>This Is Me</i> document or a suitable alternative | Should review patient documentation to ensure <i>This Is Me</i> or a suitable alternative can be adopted |
| Older frail patients should be moved in hospital as little as possible, and never out-of-hours for non-clinical reasons | <p>Should avoid moving older and frail patients unless it is clinically necessary</p> <p>Should not move frail, older people out-of-hours for non-clinical reasons</p> | <p>Should regularly audit the number of transfers that occur internally, the reasons they occur, and at what time of day</p> <p>Should aim to reduce the number of transfers occurring internally</p> <p>Should prohibit the movement of frail, older people out-of-hours for non-clinical reasons</p> |
| Patients should be looked after by people who are appropriately trained to care for them | | Should ensure all staff receive training in the care of older people |
| Patients should know how to give feedback about their experience of services and should feel that it will be welcomed | Should invite feedback from patients and carers, and act on it | Should invite formal and informal feedback from patients and carers about continuity and the quality of care, and act on it |

Appendix A Individuals interviewed for this study

| | |
|--------------------------|---|
| Conor Burke | Chief Executive, Redbridge Primary Care Trust |
| Jane Buswell | Consultant nurse |
| Professor Cyril Chantler | Chairman, UCL Partners |
| Amanda Cheesley | Long-Term Conditions Nursing Adviser, Royal College of Nursing |
| Gilly Crosby | Director, Centre for Policy on Ageing |
| Natasha Curry | Fellow, The King's Fund |
| Lesley Doherty | Chief Executive, Royal Bolton Hospital NHS Foundation Trust |
| Ruth Eley | Independent consultant, former Programme Head Older People, Department of Health |
| Dr Sam Everington | General practitioner |
| Diana Forster | Carer |
| Liz Fradd | Independent consultant |
| Tom Gentry | Policy Adviser, Health Services, Age UK |
| Nick Goodwin | Senior fellow, The King's Fund |
| Pippa Gough | Independent consultant |
| Dr Nori Graham | Emeritus Consultant in the Psychiatry of Old Age, Royal Free Hospital |
| Nicky Hayes | Consultant Nurse Adviser on Older People, Royal College of Nursing |
| Richard Humphries | Senior fellow, The King's Fund |
| Professor Steve Iliffe | Professor of Primary Care for Older People |
| Louise Lakey | Senior Policy Officer, Policy and Public Affairs, Alzheimer's Society |
| Professor Finbarr Martin | President, British Geriatrics Society |
| Dr Jacqueline Morris | Dignity Champion, British Geriatrics Society |
| Kieran Mullan | Head of Engagement and Strategy, the Patients Association |
| Shilpa Ross | Fellow, The King's Fund |
| Professor Iqbal Singh | Consultant Physician in Medicine for the Elderly |
| Karin Tancock | Professional Affairs Officer for Older People, College of Occupational Therapists |
| Jeremy Taylor | Chief Executive, National Voices |
| Rachel Thompson | Dementia Project Manager, Royal College of Nursing |
| Sue Wallace-Bonner | Operational Director, Halton Borough Council |

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