

The care of frail older people with complex needs: time for a revolution

The Sir Roger Bannister Health Summit, Leeds Castle

Author: Jocelyn Cornwell

March 2012

In November 2011, The King's Fund invited academics, practitioners, policy-makers and representatives from patient and voluntary organisations to discuss the care of very old frail people with complex health problems (see the full list of participants and terms of reference in Appendix 1). Mindful of the work of others (NHS Confederation, the Local Government Association and Age UK 2012; The Mid Staffordshire NHS Foundation Trust Inquiry 2009), we focused exclusively on what could be done to build the confidence of vulnerable older patients with complex needs and their carers in the quality of care in hospital and at home. This report summarises the discussion, including recommendations framed in relation to levels of authority in the health and social care system. The King's Fund is very grateful to the trustees of Leeds Castle for making the summit possible and to summit members for their contributions.

KEY MESSAGES

- People in the UK are living longer, but many are living with one or more long-term medical conditions, and for a significant number, advancing age brings frailty. Although we have seen staggering improvements in medicine in the past 25 years, many of our health professionals were educated and trained for a different era.
- Successive governments have recognised the complexity of this problem and introduced policies and guidance for the care of older people. However, the great urgency is to turn the rhetoric of personalised care into the reality of everyday care and practice in relation to frail older people.
- Older people's services do not have high societal status and are not generally considered attractive options for professionals. The majority of staff providing the physical and emotional care for older people in hospital and at home have few qualifications, are on low pay and have poor working conditions.
- The quality of interactions and relationships between frail older people and professional caregivers is shaped by the team and the organisational 'climate' of care. Effective managers and staff working in a supportive organisational context could remedy many of the problems encountered by patients and carers in both their own homes and hospital.
- Actions can be taken at different levels of the system to deal with this issue, but we believe that the responsibility for quality of care and outcomes for patients is firmly located at the level of the team. The main purpose of decisions and actions taken at other levels of the system should be to enable frontline staff to do their work.

INTRODUCTION

Background

People in the UK are living longer, but not necessarily healthier, lives. The proportion of people who are very old is growing fastest: there are currently three million people over 80, and this number is expected to almost double by 2030. There are more people over 90 year on year; the number of centenarians has risen 50 per cent since 2002. This should be cause for celebration; contrary to popular belief, ageing is not inevitably associated with failing health but varies individually. In self-reports, the majority of people over 80 say they are satisfied or very satisfied with their health (Oliver 2012), and that certain aspects of cognitive performance improve.

For many older people, however, advancing age is associated with frailty, which is not a diagnosis, but is a useful term that describes the state of 'limited functional reserve' or 'failure to integrate responses in the face of stress,' which explains the commonly used term 'geriatric giants'; 'functions such as staying upright, maintaining balance and walking are more likely to fail, resulting in falls, immobility or delirium. A small insult can result in catastrophic loss of function' (Rockwood and Hubbard 2004). Common co-morbidities such as dementia also contribute to frailty. About 750,000 people in the UK currently have dementia, and the number is expected to double in the next 30 years (Department of Health 2009).

As we age we tend to use health and social services more. The majority of patients in hospital and in the community are over 75. The average age of hospital patients is now over 80, and in one hospital, a recent a one-day census of patients in medical beds found the average age was 82 years old, with 10 per cent of the patients over 90 (Tadd *et al* 2011). The median age of patients admitted with hip fracture is 84, of whom one in three have dementia, one in three suffer delirium and one in three never return to their former residence (British Orthopaedic Association and British Geriatrics Society 2007). Most patients over 85 go to hospital because of an emergency, and stay on average for about 12 days (The King's Fund analysis of Hospital Episode Statistics 2009/10). The older the patient the more likely s/he will remain in hospital for longer (Cornwell *et al* 2012).

The majority of people nursed at home and who get help with activities of daily living such as washing, dressing and eating are 75 or older. Older patients account for more than half the caseload of district nurses: in 2004, district nurses looked after 470,000 patients aged between 75 and 84, and 383,000 aged 84 and older (Department of Health 2004). Another half a million (around 453,000) people receive home care from social services; 84 per cent of them are over 75 (The Information Centre 2010b). Around 2.5 million people over 75 also have some kind of informal care at home from close family members, neighbours and friends. A quarter of carers are themselves 65 or older (The Information Centre 2010b).

Successive governments have made older people's services a priority, most recently with the Equality Duty in the Equality Act (2010) dealing with age discrimination in health and social care coming into legal force. We have policies and guidance in abundance: there has been a National Service Framework (NSF) for older people for more than a decade (Department of Health 2001); there is a National Dementia Strategy (Department of Health 2009), and the National Institute of Health and Clinical Excellence (NICE) has produced guidance and quality standards for the so-called 'geriatric syndromes' including: instability (guidance on falls) (National Institute for Health and Clinical Excellence 2004); immobility (rehabilitation and post-acute care) (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 2006) and confusion (delirium) (National Institute for Health and Clinical Excellence 2010). Nevertheless, it is painfully clear that the health and social care system is failing older people with complex needs and other vulnerable patients including people with learning disabilities (Mencap 2012). The great urgency is to turn the guidance and rhetoric of personalised care into a reality of everyday care and practice (Goodrich and Cornwell 2008).

Challenges

We should say at the outset that most patients in hospital and recipients of home care rate their experience positively (The Information Centre 2010a), and that it is evident that all the professions involved are lucky enough to attract a great many individuals with a vocation to work with older people. Recently, however, there has rightly been a great deal of public concern about both hospital nursing and the care of older people at home (Care Quality Commission 2011; Abraham 2011; Equality and Human Rights Commission 2011) and inevitably, the summit concentrated on the problems and challenges in caring for older frail patients.

The model of acute care unsuited to patients with complex needs

The physical environment, working practices and care processes of acute hospitals geared to the model of acute medical care presuppose that the main task of the hospital is treatment and cure. However, care pathways and performance targets for waiting times and access to elective procedures are either irrelevant or actively obstructive to high-quality care for patients with complex conditions. These patients need reliable holistic (bio-psychosocial) assessment; multi-disciplinary care planning; advance planning to avoid predictable emergencies; care co-ordination; excellent nursing; excellent communication and collaborative relationships between staff, patients and carers. Too often what they get is: late and missed diagnosis; no care planning; unpredicted (but eminently predictable and therefore avoidable) events followed by unplanned interventions; lack of access to specialists and diagnostics; sometimes lack of access to generalists; lack of information; poor communication; lack of continuity, and poorly informed and sometimes unsympathetic interactions with professional staff.

Older people's care lacks social and professional status

Caring for older people does not have high social status and is not generally considered an attractive option for professionals. There are problems recruiting to older people's services in all sectors. Geriatric medicine is the largest medical specialty in the UK, but although consultant numbers in all specialties have risen sharply since 2002, the growth in the number of geriatricians has been slower than in other specialties (Centre for Workforce Intelligence 2011). According to the British Geriatrics Society, the UK needs around 50 per cent more geriatricians to cope with current demand (Centre for Workforce Intelligence 2012). Alongside consultants, the number of nurses has also increased sharply since 2002, particularly in hospitals, but wards that care for older people with complex conditions, including dementia, generally struggle to recruit and keep the best staff. Despite the fact that on all hospital wards (apart from obstetrics and paediatrics) many patients are older, there has not been enough recognition of the impact this has on nurses' workloads, and on care of the elderly wards the patient-to-nurse ratios and the skill mix (the ratio of qualified to unqualified nurses) of nurses tends to be lower than on other medical wards (Ball and Pike 2009).

Poor working conditions

Much greater attention needs to be paid to the working conditions of nurses, care assistants and home care workers. In hospital and at home, the majority of staff providing the physical and emotional care for older people have very few qualifications, are on low pay and have low

social status, and there is widespread acceptance of these very poor working conditions that would be unthinkable for staff in other areas of health care. In the community, the number of district nurses is falling and there is concern that the workforce is ageing (Dunkley and Haider 2011). District nurses are being replaced by general qualified nurses and care assistants and, indeed, untrained care assistants deliver most care in patients' own homes. Among social workers, personal lists are diminishing, and there is a very high volume of paperwork associated with every encounter, resulting in much of their work being carried out on the phone.

Failure of education and training to keep pace with changing needs

Although medicine has seen staggering developments in the past 25 years and there is evidence that geriatric assessment specialist care improves clinical outcomes (Ellis *et al* 2011), far too often, illness and disability in older people is normalised, older patients' medical problems are not investigated properly, and pain in older patients is overlooked (Lievesley *et al* 2009). We need to see a revolution in the education and training of current and future staff so that staff are equipped to care for the majority of the patients they are there to serve.

Despite the fact that nursing frail older people with complex needs requires knowledge and skill, as well as empathy, emotional reserve and common sense, there is no specialist qualification in nursing care for older adults. The government has announced that there will be minimum standards for training and a code of conduct for health care support workers and adult social care workers (Department of Health 2011), but we are a long way away from seeing a common standard of care specifically for older people. Some training requirements are generic – such as protection and care of the human dignity and spirit of vulnerable people, for example, and skills in communicating and working in partnership with patients and carers – others are specific to older people – such as awareness and treatment of depression, delirium and dementia.

The nature of the work and the need for support

The work of caring for older patients with complex needs is hard and testing – physically, psychologically and emotionally. Since it is invariably described in the press and elsewhere as 'basic' rather than 'essential', with the implication that it requires no knowledge or skill, is it any wonder if it is seen by some nurses as 'a route to nowhere' (Maben *et al* 2012)? Doctors may enjoy a greater sense of autonomy and control than nurses because they are able to walk away from patients, but for nurses and care assistants working anything between 8 and 14-hour shifts, the physical and emotional impact of the work can be immense. Responding to call bells, or paying a home visit, is rewarding when the patient can articulate his/her needs, the needs are easily met and s/he is grateful. But this is not always the case. In hospital, patients with dementia and delirium may disturb other patients, or may be challenging and difficult to keep calm and safe. In hospital and at home, changing a doubly incontinent patient and remaking the whole bed requires the effort of two people. Sometimes patients are unresponsive, and beds need to be changed again almost immediately. Situations like this are manageable if nothing else is happening and other patients do not need attention at the same time. But if time is constrained, other staff are unavailable or unco-operative, other patients who need help have to wait, which in turn adds to the sense of pressure and to nurses' sense of failure.

Without education or training in the care of older people and first-class leadership and support, care staff working with frail older patients, and with patients who are cognitively impaired, will become demoralised and may feel resentful. Care staff in teams that lack support, do not work co-operatively, and do not have a positive ethic of care, will eventually learn to cut themselves

off from patients and to behave in ways that de-personalise them. If the physical or emotional stress is prolonged, they will be at risk of burn out, and may become withdrawn and lose the capacity to empathise and care altogether (Firth-Cozens and Cornwell 2009). In the community, many care assistants know their clients personally and repeatedly go the extra mile for them but contractually they may be scheduled to spend time conducting only functional activities. If clients need anything unexpected, or the care assistant feels that they would like to do something for them that is outside the prescribed programme, the care assistant cannot respond.

RECOMMENDATIONS

Summit participants took the view that the health and social care system has been slow to adapt to the needs of increasing numbers of frail older people who make up the bulk of service users. A revolution is needed in the care and treatment of older people through the education, training and support of frontline staff and by valuing the role of team leaders. The keys to shaping the quality of interactions and relationships between frail older people and professional caregivers lie in the team or 'micro-system' and the organisational 'climate' of care. Effective managers working in a supportive organisational context could remedy many of the problems encountered by patients and carers in both their own homes and hospital.

In the light of these observations, the summit's recommendations aim to enable and to require frontline clinical and support staff to provide care that consistently and reliably meets predefined standards for clinical quality, safety and quality of experience. The summit recommends that the responsibility for quality of care and outcomes for patients is firmly located at the level of the team /micro-system, along with control over the resources the team needs. The main purpose of decisions and actions taken at other levels of the system should be to enable the front line to do its work.

Recommendation 1: For team leaders

In order to create adequately resourced, high-performing and sustainable professional teams with a strong ethic of care and staff support, the Summit recommends that the position of team leader /ward manager has higher status in the wider organisation, opportunities for education and career progression, and remuneration that reflects the value, complexity and importance of the role.

Team leaders should be as closely involved with all aspects of patients' care as possible. In hospital, this makes it likely the team leaders will be ward managers not doctors. The role of the medical consultant is to lead the patient's planning and delivery of medical care, to take responsibility for the quality of the medical care and to work with the team leader to achieve consistency of clinical management. Consultants are rarely sufficiently closely involved with all aspects of the patient's care and its co-ordination to act as team leaders. In domiciliary services, the team leader will be the immediate supervisor or manager of a team of care assistants and social workers.

Great attention needs to be given to leadership and management skills. Team leaders and ward managers should be a positive role model for all staff, including staff from different professional disciplines. They should play a full part in recruiting to their own team and have control and influence over the resources they need to care for patients, including, for example, equipment and its upkeep, the physical environment of care, and both the quality and quantity of supplies such as food, drinks and linen. All care staff, and team leaders especially, have a

moral obligation to speak up if organisational policies, rules and working practices cause harm to patients or prevent staff providing care to an appropriate standard, and should be enabled and required to do so.

The core aspects of team leaders' roles are the same in hospital and in the community. Team leaders should be responsible for delivering care to agreed standards for clinical quality, patient safety and patient experience. They should be expected to advocate upwards on issues that impact on care quality, such as staff numbers, the mix of skills and the quality of the physical environment. They should be responsible for making absolutely clear to their team what they expect in terms of care quality, should articulate what good care looks like, and should formally and informally monitor outcomes. Not everything that matters can be measured and as well as using patient feedback, they should take time simply to observe the care being given in their area.

Team leaders should demonstrate positive and caring attitudes towards patients, and welcoming and responsive attitudes towards carers and visitors. They should set out deliberately to enhance patients' and carers' influence and control over care, and should search for innovative methods – such as the use of patient passports, for example, and documents such as 'This is Me' to help with this (Alzheimer's Society and Royal College of Nursing 2010). They should actively explore new ways to re-engage staff with patients' subjective experience, reminding them of the need to see the person in the patient. They should make sure patients and carers know when and how to reach them, and should listen, and expect team members to listen, to patients and carers, keep them well informed and act on their feedback.

The climate of care in the team is critically important. Team leaders should create a climate of mutual respect in which it is unacceptable for members of the team to be unco-operative or to say 'that is not my job' or 'that is not my patient'. They should ensure all clinical and support staff have a common goal, share the same values, and have an attitude of mutual respect. They should be fully involved and responsible for selection – and, if required, de-selection – of team members and for ensuring team members are competent and safe to practise. Part of this requires monitoring levels of staff stress, fatigue and exhaustion.

Consistently high-quality care requires commitment. Team leaders must actively talk to their team about care processes, goals of care and how to improve them and be able to access training for team members to reinforce and support care goals. They should celebrate and praise good care wherever it is exemplified and challenge poor practice but should also be prepared to tackle poor attitudes and behaviour toward patients and colleagues, and to challenge cynicism.

Recommendation 2: For senior leaders

Senior leaders in provider organisations should acknowledge that frail older people with multiple health conditions are core service users and should define explicitly what must be done to meet their particular needs. Key to this will be development action plans that direct the attention of personnel at all levels to support the work of frontline teams and that judge the performance of managers at every level in relation to their contribution to quality of care. They should use information on staff engagement and satisfaction to assess the performance of teams and micro-system managers.

Senior leaders of provider organisations should ensure agendas of board and executive team meetings devote time to discussions of patient care, safety and experience.

The care of frail older people with complex conditions will improve only with deliberate intent and planning (Bohmer 2011). Senior leaders should plan integrated pathways of care for older patients with complex needs, with the aim of reducing the unpredictability that characterises so much of their care. They should specify care pathways in detail and in advance; the pathways should include plans for geriatric assessment, care planning, transitions of care and how transitions are to be handled. Recognising that vulnerable people with complex needs are not well served by current arrangements, leaders should include mechanisms such as key contacts, patient advocates, and support workers who can help patients and carers navigate transitions between different parts of the care system. The care pathways should specify the numbers of staff and the qualifications and training they need to deliver the care for frail older people to a good standard; the specification should be refreshed at regular intervals. All staff working with adults should receive training in the generic aspects of care of older patients and in how to care for people with delirium and dementia.

Since there is no point in making plans that do not deliver, the plans should specify the measures of service quality and feedback from patients and carers that will be used to monitor the service, should include arrangements to ensure patients with dementia (who may not be able to complete questionnaires) and their carers are included. Senior leaders should invite local voluntary groups who advocate for older people and carers to review standards of care, and make sure they themselves know what is going on getting out and observing services being delivered, and using local groups and /or mystery shoppers as well as patients and carers for formal and informal feedback. They should ensure older people are systematically included as partners in education and training, in service design and improvement and in governance structures.

The organisation should support a positive climate of care at team level. This means creating a just culture to support reporting of quality and safety issues, ensuring that organisational priorities and/or decisions do not unintentionally translate into poor care in patients' homes or on the wards. They should explicitly recognise and thank staff for the care they provide, acknowledge the physical and emotional work involved and put in place mechanisms for staff support. They should challenge ageism, ban pejorative and de-humanising language about older people or carers, make absolutely clear what kinds of attitudes, behaviour and language they expect, and take action when unacceptable behaviour occurs.

How senior leaders themselves work matters almost as much as what they say and do. They should adopt a style of leadership that is directive when it needs to be, but which also encourages organisational learning and reflective practice. They should regularly spend time with frontline teams, quietly observing them at work and taking time to listen and respond to their concerns about issues impacting adversely on standards of patients' care.

Recommendation 3: For professional bodies

The quality of care depends on having well-educated and trained staff in sufficient numbers. The summit recommends that professional bodies and those bodies responsible for education and training, revalidation and appraisal develop strategies to change perceptions of older people's services and to create the future workforce that older people need.

Most people entering health and social care want to look after people, and only decide the specific group they want to care for in the course of their training. The summit considers that education and training bodies have not adjusted to the fact that older people's care is core business. Medical schools should be teaching future doctors not to denigrate older people's

care as 'social work medicine', but to value the part they can play in leading and planning complex care.

The summit recommends that the bodies responsible for undergraduate and postgraduate education and for continuing professional development education and training should develop professional attitudes towards older people. The summit recommends those bodies review current curricula and teaching methods against the skills and knowledge base required to build a workforce that values prevention of avoidable disability, is appropriately sensitive to dependency and is competent to help people cope with physical and mental deterioration. The curriculum, teaching methods and work placements should teach professional students to value older people, and provide them with the knowledge, attitudes and skills they need to work effectively in multi-disciplinary teams. Experiential methods can help students put themselves in their patient's shoes.

Recommendation 4: For policy-makers, government, the NHS Commissioning Board

National leaders in government and the Department of Health, on the NHS Commissioning Board, the Care Quality Commission and Monitor are a long way away from frontline clinical care but they determine the priorities and shape the context in which care is delivered. The summit sees the principal task of these organisations as design of the structures and incentives to support the development of the professional workforce and drive better outcomes for frail older people. The summit did not make detailed recommendations in relation to regulation, but saw the tasks of setting standards, developing guidelines and designing measures as best left to NICE and clinical experts.

The summit is also mindful that decisions taken at national level can have unintended consequences and that how national organisations go about their task is as important as what they do. Patients' interests have not commanded the attention they deserve at the most senior levels in recent years; there is a regrettable gulf between NHS clinicians (mainly doctors) and managers, and a widespread culture of compliance and fear that has limited enthusiasm for learning, innovation and improvement (Institute for Healthcare Improvement 2008; Institute for Healthcare Improvement 2008).

For all of these reasons, the summit recommends that national organisations limit the volume and frequency of detailed instructions and guidance issued to health and social care providers because it can distract senior leaders from their task and obfuscate the picture in organisations. The aim should be to set guiding principles not rules and to emphasise the responsibility of senior leaders and clinicians to deliver better outcomes for patients and staff.

The summit recommends that the Department of Health and other national organisations create the conditions for local health communities to develop clear strategies and plans for the care of frail older people with complex needs that define success – as being about prevention, early diagnosis, prevention of avoidable disability and improving patient-reported outcomes, National leaders should also create the incentives for professional bodies, commissioners and others to produce technical and service innovations to improve the care of frail older people, and develop and disseminate the knowledge and skills required in the professional workforce. They should commission research into methods and measures of patient experience that are suitable for using with patients who are cognitively impaired and that will help, and measures that will help to strengthen continuity of care in hospital and across sectors. They should also create and disseminate a repository of good practice examples and case studies.

Recommendation 5: Think tanks, commentators

The problems frail older people experience in relation to the health and social care system have their roots in the wider social culture that does not value old age or older people. If older people had high status and were highly valued, it would be unthinkable to allow frail older people to be largely looked after by low paid staff with few qualifications and little or no training.

We should be glad we are living longer and celebrate the economic, social and medical advances that have led to it. On the whole we do not do that.

The summit believes that it is possible to challenge deep-seated social prejudices towards older people. We have seen it happen in our lifetimes in relation to societal attitudes towards divorce, children born out of wedlock, and homosexuality, and in health and social care, in attitudes towards HIV/AIDS, towards smoking and towards children in care and parents with children in hospital.

Health and social care professionals and the system as a whole can take a lead in changing social attitudes towards ageing and older people and making services for older people dignified and decent places to work and train within. The summit recommends that excellence in the care of frail older people should be a priority for health and social care services, with the concept of human rights a standard point of reference. It challenges policy-makers, think tanks, researchers, health and social care professionals to reflect on the use of language, to reject words such as 'tsunami' and 'unaffordable burden' being applied to the ageing population and to ban words like 'frequent flyer', 'acopia', 'social admission', and 'bed blocker' from the lexicon (Oliver 2008; NHS Confederation *et al* 2012).

References

- Abraham A (2011). *Care and Compassion? Report of the Health Service Ombudsman on ten investigations into NHS care of older people*. Fourth report of the Health Service Commissioner for England; session 2010-2011. HC 778. London: The Stationery Office. Available at: www.ombudsman.org.uk/data/assets/pdf_file/0016/7216/Care-and-Compassion-PHSO-0114web.pdf (accessed on 5 February 2012).
- Alzheimer's Society/Royal College of Nursing (2010). *This Is Me*. London: Alzheimer's Society/Royal College of Medicine. Available at: www.alzheimers.org.uk/site/scripts/download_info.php?fileID=849 (accessed on 5 February 2012).
- Ball J, Pike G (2009). *Past Imperfect, Future Tens: Nurses' employment and morale in 2009*. London: Royal College of Nursing.
- Bohmer R (2011). 'The four habits of high-value healthcare organizations'. *New England Journal of Medicine*, vol 365, p 2045–47.
- British Geriatrics Society (2011). *Quest for Quality: British Geriatric Society Joint Working Party inquiry into the quality of healthcare support for older people in care home: A call for leadership, partnership and quality improvement*. Available at: www.bgs.org.uk/campaigns/carehomes/quest_quality_care_homes.pdf (accessed on 20 March 2012).
- British Orthopaedic Association/British Geriatrics Society (2007). *The Care of Patients with Fragility Fracture*. London: British Orthopaedic Association.
- Care Quality Commission (2011). *Dignity and Nutrition Inspection Programme: National overview*. Newcastle-upon-Tyne: Care Quality Commission.
- Centre for Workforce Intelligence (2011). *Geriatric Medicine: CfWI medical factsheet and summary sheet*. Available at: www.cfwl.org.uk/publications/geriatric-medicine-cfwl-medical-fact-sheet-and-summary-sheet-august-2011 (accessed on 6 March 2012).
- Cornwall J, Levenson R, Sonola L, Poteliakhoff E (2012). *Continuity of Care for Older Hospital Patients: A call for action*. London: The King's Fund.
- Department of Health (2011). 'Scheme to support healthcare assistants unveiled.' Press release. Available at: <http://mediacentre.dh.gov.uk/2011/11/15/scheme-to-support-healthcare-assistants-unveiled/> (accessed on 20 March 2012).
- Department of Health (2009). *Living Well with Dementia: A national dementia strategy*. London: Department of Health.
- Department of Health/National Statistics (2004). *Patient Care in the Community: NHS district nursing summary information for 2003–04, England*. London: National Statistics/Department of Health.
- Department of Health (2001). *National Service Framework for Older People*. London: Department of Health.
- Dunkley L, Haider S (2011). *Workforce Risks and Opportunities: Nursing and Midwifery*. London: Centre for Workforce Intelligence. Available at: www.cfwl.org.uk/publications/workforce-risks-and-opportunities-nursing-and-midwifery (accessed on 21 March 2012).

Ellis G, Whitehead M, Robinson D, O'Neill D, Langhorne P (2011). 'Comprehensive geriatric assessment for older adults admitted to hospital: meta-analysis of randomised controlled trials'. *British Medical Journal*, vol 343, d6553 (accessed on 27 February 2012).

Equality and Human Rights Commission (2011). *Close to Home: An inquiry into older people and human rights in home care*. London: Equality and Human Rights Commission. Available at: www.equalityhumanrights.com/legal-and-policy/inquiries-and-assessments/inquiry-into-home-care-of-older-people/close-to-home-report/ (accessed on 20 March 2012).

Firth-Cozens J, Cornwell J (2009). *The Point of Care: Enabling compassionate care in acute hospital settings*. London: The King's Fund. Available at: www.kingsfund.org.uk/publications/articles/compassionate_care.html (accessed on 20 March 2012).

Goodrich J, Cornwell J (2008). *Seeing the Person in the Patient: The Point of Care review paper*. London: The King's Fund.

Institute for Healthcare Improvement (2008). *Achieving the Vision of Excellence in Quality: Recommendations for the English NHS system of quality improvement*. Submission to the Department of Health. Available at: www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_118552.pdf (accessed on 20 March 2012).

Lievesley N, Hayes R, Jones K, Clark A (2009). *Ageism and Age Discrimination in Secondary Health Care in the United Kingdom: a review from the literature*. London: Centre for Policy on Ageing. Available at: www.cpa.org.uk/information/reviews/CPAAgeism_and_age_discrimination_in_secondary_health_care-report.pdf (accessed on 5 February 2012).

Maben J, Peccei R, Adams M, Robert G, Richardson A, Murrells T (2012). *Patients' Experiences of Care and the Influence of Staff Motivation, Affect and Well-being*. Final report. National Institute for Health Service Delivery and Organisation programme (currently undergoing peer review). Available at: www.netscc.ac.uk/hsdr/projdetails.php?ref=08-1819-213 (accessed on 20 March 2012).

Mencap (2012). *Death by Indifference: 74 deaths and counting – A progress report 5 years on*. London: Mencap. Available at: www.mencap.org.uk/74deaths (accessed on 6 March 2012).

National Institute for Health and Clinical Excellence (2010). *Delirium: Diagnosis, prevention and management*. NICE Clinical Guideline 103. Available at: <http://guidance.nice.org.uk/CG103/NICEGuidance/pdf> (accessed on 27 February 2012).

National Institute for Health and Clinical Excellence (2009). *Rehabilitation after Critical Illness*. NICE Clinical Guideline 83. Available at: <http://guidance.nice.org.uk/CG83/NICEGuidance/pdf> (accessed on 27 February 2012).

National Institute for Health and Clinical Excellence (2007). *Faecal Incontinence: The management of faecal incontinence in adults*. NICE Clinical Guideline 49. Available at: <http://guidance.nice.org.uk/CG49/NICEGuidance/pdf> (accessed on 27 February 2012).

National Institute for Health and Clinical Excellence and Social Care Institute for Excellence (2006). *Dementia: Supporting people with dementia and their carers in health and social care*. NICE Clinical Guideline 42. Available at: <http://guidance.nice.org.uk/CG42/NICEGuidance/pdf> (accessed on 27 February 2012).

National Institute for Clinical Excellence (2004). *Falls: The assessment and prevention of falls in older people*. Clinical Guidance 21. Available at: <http://guidance.nice.org.uk/CG21/NICEguidance/pdf> (accessed on 27 February 2012).

NHS Confederation, the Local Government Association and Age UK (2012). *Delivering Dignity: Securing dignity in care for older people in hospitals and care homes – A report for consultation*. London: NHS Confederation, the Local Government Association and Age UK.

Oliver D (2012). 'Discrimination in health services for older people (UK)'. *International Journal of Medical Ethics* (in press).

Rockwood K, Hubbard R (2004). 'Frailty and the geriatrician'. *Age and Ageing*, vol 33, no 5, pp 429–30.

Tadd W, Hillman A, Calnan S, Calnan M, Bayer T, Read S (2011). *Dignity in Practice: An exploration of the care of older adults in acute NHS trusts*. London: Her Majesty's Stationery Office.

The Information Centre for health and social care (2010a). *Community Care Statistics 2009/2010*. Social Services Activity Report. Available at: www.ic.nhs.uk/webfiles/publications/009_Social_Care/carestats0910asrfinal/Community_Care_Statistics_200910_Social_Services_Activity_Report_England.pdf (accessed on 20 March 2012).

The Information Centre for health and social care (2010b). *Survey of Carers in Households 2009/2010*. The Health and Social Care Information Centre. Available at: www.ic.nhs.uk/webfiles/publications/009_Social_Care/carersurvey0910/Survey_of_Carers_in_Households_2009_10_England_NS_Status_v1_0a.pdf (accessed 29 February 2012).

The Mid Staffordshire NHS Foundation Trust Inquiry (2009). *Independent Inquiry into care provided by Mid Staffordshire NHS Foundation Trust January 2005-March 2009. Vols 1 and 2*. Chair: Robert Francis. London: The Stationery Office. Available at: www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_113447.pdf (accessed on 6 March 2012).

Further Reading

Baillie L (2009). 'Patient dignity in an acute hospital setting: a case study'. *International Journal of Nursing Studies*, vol 46, no1, pp 23–36.

British Medical Association (2011). *The Psychological and Social Needs of Patients*. London: BMA.

Erlen J A (2007). 'The frail elderly: a matter of caring'. *Orthopaedic Nursing*, vol 26, pp 379–82.

Haak N (2009). 'Maintaining privacy and dignity of patients admitted to a district general hospital NHS trust'. *Developing Practice Improving Care*, vol 5, no 2, pp 1–4.

Jacobson N (2010). 'Dignity violation in healthcare'. *Qualitative Health Research*, vol 19, no 1, pp 1536–47.

Kee Y Y, Rippingale C (2009). 'The prevalence and characteristic of patients with "acopia"'. *Age and Ageing*, vol 38, pp 103–5.

Kessler I, Heron P, Dopson S, Magee H, Swain D, Askham J (2010). *Nature and Consequences*

of Support Workers in a Hospital Setting. Final report. NIHR Service Delivery and Organisation programme. Available at: www.netscc.ac.uk/hsdr/files/project/SDO_FR_08-1619-155_V01.pdf (accessed on 16 March 2012).

Lax R (2008). 'Becoming really old: the indignities'. *Psychoanalytic Quarterly*, vol 77, no 3, pp 835–57.

Mangset M, Erling Dahl T, Forde R, Bruun Wyller T (2008). 'We're just sick people, nothing else: factors contribution to elderly stroke patients' satisfaction with rehabilitation'. *Clinical Rehabilitation*, vol 22, pp 825–35.

Oliver D (2008). 'Acopia and "social admission" are not diagnoses: Why older people deserve better'. *Journal of the Royal Society of Medicine*, vol 101, pp 168–74.

Parker S, Fadayevelan R, Lee S (2006). 'Acute hospital care for frail older people'. *Age and Ageing*, vol 35, pp 551–2.

Raleigh V S, Hussey D, Seccombe I, Qi R (2009). 'Do associations between staff and inpatient feedback have the potential for improving patient experience? An analysis of surveys in NHS acute trusts in England'. *Quality and Safety in Health Care*, vol 18, pp 347–54.

Rockwood K, Hubbard R (2004). 'Frailty and the geriatrician'. *Age and Ageing*, vol 33, pp 429–30.

Schneider J, Scales K (2010). *Challenging Care: The role of Health Care Assistants in dementia wards*. Nottingham: School of Sociology, Social Policy and Social Work.

Tadd W, Hillman A, Calnan S, Calnan M, Bayer A, Read S. (2011) *Dignity in Practice: An exploration of the care of older adults in acute NHS Trusts*. NIHR Service Delivery and Organisation Programme. Available at: www.netscc.ac.uk/hsdr/files/project/SDO_FR_08-1819-218_V02.pdf (accessed on 16 March 2012).

Tadd W, Hillman A, Calnan S, Calnan M, Bayer A, Read S (2011). 'Right place - wrong person: dignity in the acute care of older people'. *Quality in Ageing and Older Adults*, vol 12, no 1, pp 33–43.

Tadd W, Calnan M (2009). 'Caring for older people : why dignity matters - the European experience' in Nordenfelt L (ed), *Dignity in care for older people*, Chapter 6 , p119–42, Oxford: Wiley-Blackwell. See also: www.cardiff.ac.uk/socsi/dignity/dignityinpractice/index.html (accessed on 16 March 2012).

Appendix 1

Terms of reference and list of participants in the Sir Roger Bannister Health Summit, Leeds Castle, on 3–4 November 2011.

Terms of reference

The summit focused exclusively on *the quality of the interactions and relationship between frail older people with complex health problems and professional caregivers in hospital and at home* and on recommendations that would:

- build the confidence of frail and vulnerable older people and patients with complex needs and their families/carers in the quality of care at home and in hospital
- ensure professional staff are able to provide effective clinical care in the context of kind, caring and supportive relationships
- prevent fragmentation and discontinuities in care in hospital and between hospital and the patient's home
- strengthen the skills, resilience and confidence of professional staff working with older people in the two settings.

Participants

Professor Richard Bohmer, International Visiting Fellow, The King's Fund
Elisabeth Buggins CBE, DL, Chairman, Birmingham Women's Hospital NHS Foundation Trust
Andrew Chidgey, Head of Policy and Public Affairs and Programme Director, National Dementia Strategy Implementation, Alzheimer's Society
Dr Jocelyn Cornwell Programme Director, The Point of Care, The King's Fund
Professor Jenny Firth-Cozens, Visiting Professor, Imperial College, London
Beverley Fitzsimons, Programme Manager, The Point of Care, The King's Fund
Dr Dee Gallop, General practitioner and Clinical Director, Lincolnshire Partnership Foundation Trust
Joanna Goodrich, Programme Manager, The Point of Care, The King's Fund
Martin Green, Chief Executive, English Community Care Association
Baroness Sally Greengross OBE, Chair of the All-Party Parliamentary Group on Dementia, House of Lords
Professor Chris Ham, Chief Executive, The King's Fund
Julie Hendry, Director of Quality and Patient Experience, Mid-Staffordshire NHS Foundation Trust
Professor Robert Howard, Academic Director for the Mental Health of Older Adults and Dementia, South London and Maudsley NHS Foundation Trust
Professor Jill Maben, Director, National Nursing Research Unit, Florence Nightingale School of Nursing and Midwifery, King's College, London
Professor Finbarr Martin, Consultant Physician and President of the British Geriatrics Society, Guy's and St Thomas' NHS Foundation Trust
Michelle Mitchell, Charity Director, Age UK
Dr Caroline Nicholson, Research Fellow, King's College, London
Professor David Oliver, National Clinical Director for Older People, Department of Health
Flo Panel-Coates, Chief Nurse, Maidstone and Tunbridge Wells NHS Trust
Sir Keith Pearson, Chairman, NHS Confederation
Ruth Poole, Group Clinical Director, Healthcare at Home Ltd
Jeremy Porteus, Chairman, Homes and Community Agency's Vulnerable and Older People Advisory Group
Professor Justine Schneider, Professor of Mental Health and Social Care, Nottingham University
Dr Win Tadd, Reader, Economic and Social Research Council Centre for the Economic and Social Aspects of Genomics, Cardiff University
Dr Mark Temple Acute Care Fellow, Royal College of Physicians

Appendix 2

Campaigns, investigations, guidance and reports drawing attention to the care of older people

- 1997 'Dignity on the ward'. *Observer* newspaper campaign
- 1998 *Not Because They Are Old*. Health Advisory Service inquiry report
- 1999 'Dignity on the wards'. Help the Aged report and campaign
- 2001 *Caring for Older People: a nursing priority*. Standing Nursing and Midwifery Advisory Committee report
- 2001 National Service Framework for Older People. Department of Health
- 2006 *A New Ambition for Old Age: Next steps in implementing the NSF for older people*. Department of Health resource document
- 2006 'Dignity in care' campaign. Department of Health
- 2006 *Dignity in Practice*. SCIE guide 2
- 2006 'Behind closed doors'. British Geriatrics Society campaign
- 2006 'Hungry to be heard'. Age Concern campaign
- 2007 *The Challenge of Dignity in Care - Upholding the rights of the individual*. Help the Aged report
- 2007 *Caring for Dignity*. A national report on dignity in care of older people while in hospital, Healthcare Commission
- 2007 18th report of the Joint Committee on Human Rights
- 2007 Investigation into outbreaks of *Clostridium difficile* at Maidstone and Tunbridge Wells NHS Trust. Healthcare Commission
- 2008 *Spotlight on Complaints*. Healthcare Commission report
- 2008 'Defending dignity: at the heart of everything we do'. RCN campaign
- 2009 *Guidance for the Care of Older People*. Nursing & Midwifery Council report
- 2009 *Patients not Numbers, People not Statistics*. Patients Association report
- 2009 *Counting the Cost: Caring for people with dementia on hospital wards*. Alzheimer's Society report
- 2010 *Listen to Patients, Speak up for Change*. Patients Association report
- 2010 'Still hungry to be heard' campaign. Age UK
- 2010 *An Age Old Problem: A review of the care received by elderly patients undergoing surgery*. National Confidential Patient Enquiry into Outcome and Death report
- 2010 National Audit of Dementia. Royal College of Psychiatrists

- 2010 *Acute Awareness: improving hospital care for people with dementia*. NHS Confederation
- 2010 Independent inquiry into care provided by Mid Staffordshire NHS Foundation Trust January 2005 - March 2009. Chaired by Sir Robert Francis (ongoing)
- 2011 *Care and compassion?* Report of the Health Service Ombudsman on ten investigations into NHS care of older people
- 2011 *Dignity and nutrition for older people*. Series of reports from CQC
- 2011 Living Well at Home Inquiry. All Party Parliamentary Group on Housing and Care for Older People. Chaired by Lord Best
- 2011 *Report of the National Audit of Dementia Care in General Hospitals 2011*. Royal College of Psychiatrists
- 2011 *We have been listening, have you been learning?* The Patients Association, and associated CARE Campaign (with Nursing Standard) November 2011
- 2011 *Close to home: An inquiry into older people and human rights in home care*. Equality and Human Rights Commission
- 2012 *Delivering Dignity: securing dignity in care for older people in hospitals and care homes. A report for consultation*. Commission on Dignity in Care (Age UK, NHS Confederation and Local Government Group) 29 February 2012