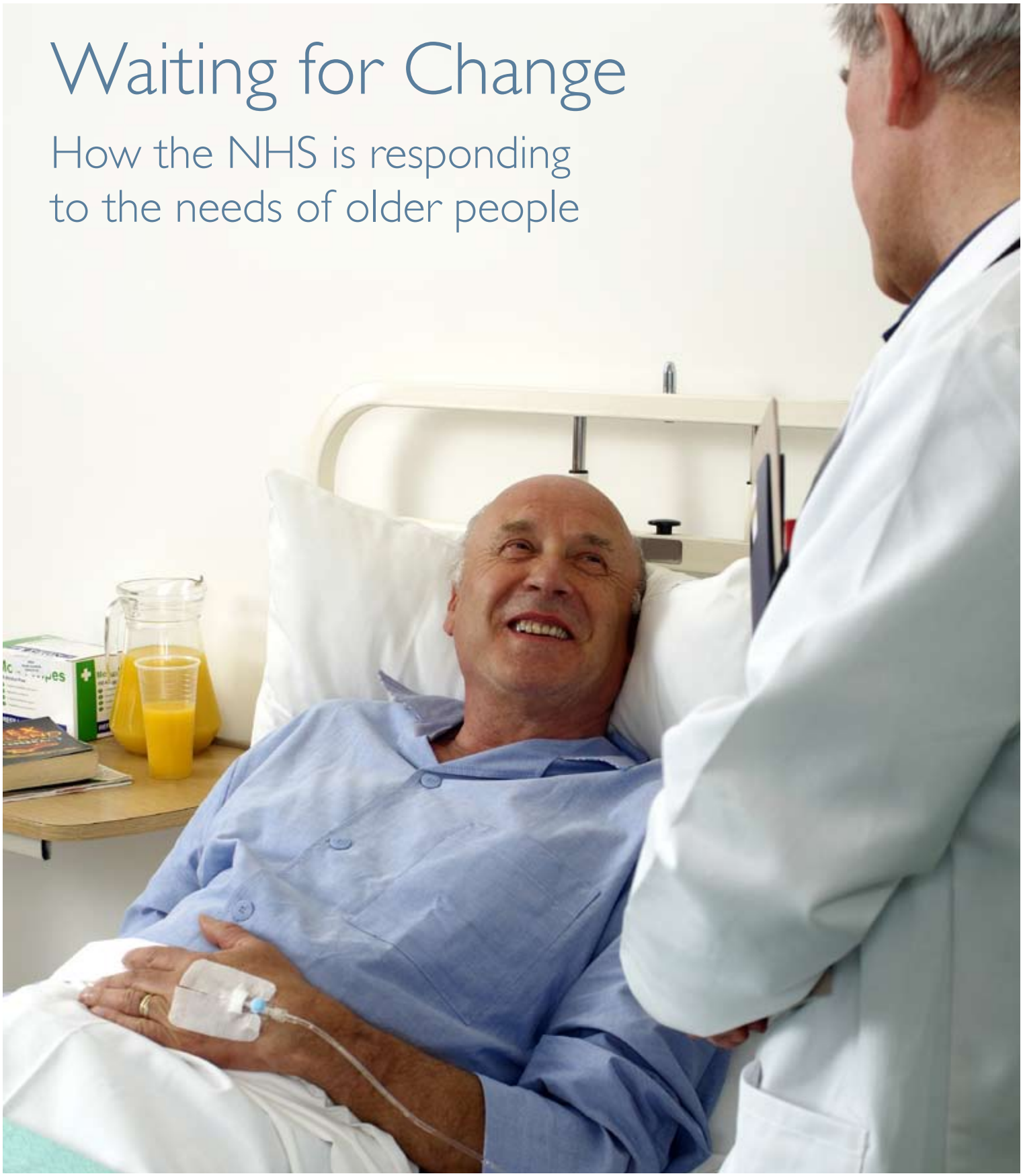
AGE Concern

HELP THE AGED
WE WILL

Waiting for Change

How the NHS is responding to the needs of older people



Summary

Quality continues to be an organising principle for healthcare. All political parties are committed to the view that the NHS should be 'world-class'. But what does this mean in practice?

We commissioned Ipsos MORI to explore the concept of quality with those people who use healthcare services the most – older people. We asked the research team to focus in particular on those whose voices are often heard least – people approaching the last years of their life, who often have multiple and complex conditions requiring intense support.

Following 20 face-to-face interviews, Ipsos MORI outlined a series of high-level preferences expressed by this sub-group of highly vulnerable older people.

Healthcare in the community

1 Face-to-face, personalised, flexible appointments

2 To retain control in their home

3 Respect for preferences and belongings

4 Company and the opportunity to be listened to

5 Proactive healthcare and support

Healthcare in hospital

6 Choice and control over daily routines

7 A 'connected' relationship between staff and patients

8 Maintenance of privacy in hospital

Healthcare across all settings

9 Joined-up care

Although there is virtually nothing in this list that is new, these simple aspirations have still not been realised. For the second half of this project we evaluated how far health policy and practice is from delivering quality as defined by those who use and need the services the most.

On the basis of this research and analysis we have made key recommendations to ensure that our healthcare system delivers the kind of service that the frail older people who use it say they want most.

Professionals must:

- listen to older people whose homes they visit and respect their choices and directions, particularly in relation to how they like things to be done, in order that they do not feel excluded and powerless;
- recognise the importance of human interaction and relationship-centred care, and never underestimate the social aspects of healthcare;
- proactively signpost older people on to centres of expertise where they can get the information and support they need, to ensure that every interaction with a healthcare professional is an opportunity to link people into wider support networks;
- be aware that co-morbidities are a reality for many: micro-management of conditions without regard for individuals' other health issues is likely to be ineffective. Training, development and revalidation of healthcare professionals must reflect this.

Healthcare providers must:

- build on skills developed in pre-registration training, develop healthcare professionals' skills and competencies in enabling older patients to manage their own health wherever possible;
- ensure that healthcare professionals entering older people's homes have readily available information on a range of entitlements, support and social opportunities in the local area – for example, befriending schemes;
- consider hosting services such as benefits advice in healthcare settings such as GP practices or health centres;
- recognise the importance of healthcare professionals going beyond clinical tasks to enable individuals to exercise choice and

control: this ranges from choosing treatments to practicalities such as placing food within easy reach of an individual so that they are able to eat; it may help to involve families wherever possible;

- prioritise and report openly on those quality issues which matter to older people, through, for example, Quality Accounts and NHS Choices;
- ensure hospital staffing ratios take into account adequate staff to deliver personal and intimate care in a way which ensures fundamental privacy;
- collecting more and better feedback from older patients and learn from it to improve their systems, processes and working cultures.

The Care Quality Commission must:

- hold to account healthcare providers working in the community for the behaviour of healthcare professionals working in patients' homes;
- reinforce in guidance that service users should be involved throughout the process of making decisions on treatment options and hold providers to account where this is shown not to have happened.

Professional regulators and representative bodies must:

- reinforce the importance of relationship-centred care throughout health workforce standards. These must be further promoted by the Royal Colleges and representative bodies.

The Government must:

- ensure that drives to promote choice in primary care and general practice do not exclude those who need it most; older people must be supported to make choices in the way which suits them; information and advocacy services will be essential to making this work;
- ensure that future reconfigurations of GP services – and specifically commitments to remove practice boundaries – preserve continuity of care and the option of care in the home;
- look urgently at how GPs are remunerated for their services to care homes: it should be the responsibility of PCTs to ensure that all individuals in their area can exercise their entitlement to be registered with a GP of their choice regardless of their housing tenure and that this service is provided free to the patient;
- ensure that any roll-out of personal health budgets for older patients living in the community is deferred until after detailed evaluation has taken place and implemented only where the benefits are clear;
- provide clear strategy and sustained funding for information and advice;
- review the implementation of the Mental Capacity Act, in its widest sense, across health and social care to ensure that steps are taken to improve awareness of the Act and that the principles are incorporated in everyday practice;
- stand by its commitment to hold hospitals to account for failing to deliver single-sex accommodation;
- disseminate learning from pilot programmes such as Partnerships for Older People so that all areas are able to focus attention on better co-ordination of care, particularly at hospital discharge;
- robustly support the implementation of care plans to ensure that health professionals, providers and commissioners are fully prepared to use them to tailor and co-ordinate healthcare to meet individuals' needs; implementation should also be carefully monitored, with particular attention to older patients' experience, to ensure that progress genuinely reflects need.

Introduction

More of us are living longer and the fastest-growing proportion of the population in England is the over-85s. Their number is predicted to double in the next 25 years and to treble in the next 35.[1]

It is not news that older people are the largest users of most healthcare services. People over 65 occupy almost two-thirds of general and acute hospital beds[2] and are more likely to visit the GP[3] than younger adults. However, their needs rarely appear to be at the heart of NHS decision-making or delivery.

The NHS is facing significant budgetary pressures, although delivering high-quality services remains a fundamental organisational principle, as clearly stated in Lord Darzi's review of the NHS, *High Quality Care for All*. Given the rise in numbers of the oldest old, it is essential to understand what quality means for this group.

We commissioned Ipsos MORI to explore the concept of quality with those people who use healthcare services the most: older people. We asked the research team to focus in particular on those whose voices are often heard least – people approaching the last years of their life, who often have multiple and complex conditions requiring intense support. Ipsos MORI carried out 20 in-depth interviews with older people who had recent experience of using health services, the majority of whom were over the age of 80.

The purpose of this exercise was to gauge qualitatively what this group of vulnerable older people value in a health service. Ipsos MORI then translated these values into a series of high-level aspirations for healthcare.[4]

This report presents those aspirations. In addition, Age Concern and Help the Aged has taken each aspiration and carried out its own detailed analysis on the extent to which these aspirations are being met by policy and practice.

Two overarching conclusions can be drawn out of this work:

1 Older people are more concerned that their needs are met than who delivers the support. When asked about healthcare at home, interviewees clearly did not always distinguish between health and social care support. This is likely to reflect confusion over how the two systems interact.

2 If the NHS is serious about delivering quality, it needs to get to grips with patients' real experiences rather than make presumptions about what matters. It needs to focus not only on what is done (and is easily measurable) but how it is delivered, and seek ways of valuing this. When asked about waiting times, for example, an ongoing political preoccupation, those interviewed reported that waiting times for outpatient appointments and Accident and Emergency admission were less of a concern than the time inpatients can spend waiting for a response to the call button. Often, politicians and professionals focus on what they think is important while ignoring those issues by which patients really judge a service.

[1] National Population Projections 2006-based, Office for National Statistics, 2008

[2] *Living Well in Later Life: a review of progress against the National Service Framework for Older People,* CSCI, Audit Commission, Healthcare Commission, 2006

[3] *Health Survey for England 2005: health of older people,* The NHS Information Centre for Health and Social Care, 2007

[4] Ipsos MORI presented ten aspirations for healthcare; however, two of these ('demonstrate awareness of the holistic care package' and 'co-ordinated care to help patients navigate the system') appeared very similar so we have combined the two into the aspiration 'joined-up care'

Healthcare in the community

1 Face-to-face, personalised, flexible appointments

Findings from our research

Older people value continuity and want to see the health professional that they know and trust. However, mobility difficulties and lack of transport can prevent them from getting to a GP surgery. Having a face-to-face appointment is important for care tailored to the individual, and sometimes this will need to be in the form of a home visit.

Progress report

- The older a patient is, the more likely they are to say they have a preferred doctor. And older patients are more likely to see their preferred doctor: 72 per cent of people aged over 85 say they always or almost always see their preferred doctor, while only 38 per cent of 18- to 24-year-olds say this is the case.[5]
- The percentage of GP consultations undertaken as home visits has dropped from 9 per cent in 1995 of to 4 per cent in 2008.[6] Older people's experiences of trying to arrange a home visit for themselves or for someone else are mixed. More than one in ten of those who had arranged a home visit had found this difficult. Another 3 per cent of older people who had not arranged a home visit said that they had not been aware that they could ask for one.[7] One couple participating in our research, neither of whom was unable to leave the house, described getting to the GP as a 'physical impossibility'. However, they did not feel their GP was readily able to come out on home visits.

[5] *GP Patient Survey 2008/2009: national report for the Department of Health*, Ipsos MORI, 2009

[6] Research database, University of Nottingham and EMIS, quoted in *Pharma Times*, 3 September 2009

[7] Age Concern, *Primary Concerns*, 2008

'We've had this all the time we've had her. She's always been very difficult about coming out, hasn't she? "You're taking up my valuable time."' Male, Hillingdon

Access to primary care has been the focus of significant attention in the last couple of years and GP availability and accessibility has come under scrutiny. The Next Stage Review of the NHS announced investment in 152 GP-led health centres – one for every PCT in the country. The objectives included improving access to and integration between health services, although actual specifications for what they should look like have been left to local decision-making.

The expansion of choice has become a dominant organising principle of NHS services, with moves to extend choice into primary care and specifically promote choice of GP.

The Government's focus on access to primary care is admirable. However, the big-ticket policy items are unlikely to have a large positive impact on those who use and need health services the most – frail older people.

Older people do not necessarily want to shop around for healthcare. They place significant value on the ability to make appointments to see a trusted individual at a time and in a place that is convenient, which may be their home if necessary.

'The buses only run at certain times round here… I don't drive so I wish the surgeries would understand this more and help to make appointments easier to attend.' Male, Ross-on-Wye

Furthermore, the ability to make an informed choice is not available to many. Only 36 per cent of people over 65 have ever used the internet.[8] Yet, increasingly, the expectation is that patients will become confident consumers of healthcare based on knowledge they have acquired online.

At the extreme, care home residents are very often actively denied choice. Some practices are reluctant to register residents, or insist that residents must all have the same GP and are not permitted to carry over their existing registration.

[8] *Internet Access 2009: households and individuals*, ONS, 2009

Many homes have established retainer contracts with practices to encourage provision, with some GP practices charging up to £24,000 per year for core NHS services.[9] These additional costs are inevitably passed on to those residents who fund their own care, which effectively denies them their right to free NHS healthcare.

What needs to be done?

The Government must:

1 Ensure that drives to promote choice in primary care and general practice do not exclude those who need it most and that older people are supported to make choices in a way which suits them. Information and advocacy services will be essential to making this work.

2 Ensure that future reconfigurations of GP services and specifically commitments to remove practice boundaries preserve continuity of care and the option of care in the home.

3 Look urgently at how GPs are remunerated for their services to care homes. It should be the responsibility of PCTs to ensure that all individuals in their area receive their entitlement to be registered with a GP of their choice regardless of their housing tenure and that this service is provided free to the patient.

2 Retaining control in their own homes

Findings from our research

Many older people receive health services in their own home. Although invaluable, this support should complement rather than smother older people's capacity to help themselves in order that they retain their independence and a feeling of control. Control is particularly vital for older people in their own homes as this is generally perceived as being the last area over which they are able to assert it.

'I've always done everything in this house myself – decorating, plumbing, fitting kitchens, whatever. I could turn my hand to it and not only did I do it for us but I did it for all these old ladies that we used to look after, and we used to take them on holiday and do all sorts of things like that. Then, all of a sudden you can't do it any more.' Male, Hillingdon

Progress report

- Over two-thirds (67 per cent) of people aged 85 and over in the UK have a disability or limiting long-standing illness. For those aged 65–74 the figure is 40 per cent, and for people aged 75–84 it is 55 per cent.[10]
- Yet 55 per cent of people aged 18–64 expect to be living independently when they are 80 years old.
- In 2008, 30 per cent of primary care patients were not involved as much as they wanted to be in decisions about their care and treatment.[11]

Policy initiatives, including the National Service Framework for Older People and the White Paper for Community Services, *Our Health, Our Care, Our Say,* have promoted person-centred care, whereby the patient is empowered and involved. The NHS Constitution enshrines the *'right to be involved in discussions and decisions about your healthcare, and to be given information to enable you to do this'* and pledges that the NHS will *'work in partnership with you, your family, carers and representatives'*.

Older people want to remain independent in later life. However, many suffer from disability or long-term health conditions which demand some form of medical or social assistance. The Government is in favour of providing that support closer to home, a move which we welcome. In addition, older people also want to maintain control as much as possible.

Policy initiatives, including the National Service Framework for Older People and the White Paper

[9] Care homes: getting to grips with GP retainers, *Health Service Journal*, 2009

[10] *Family Resources Survey 2007/8*, Department for Work and Pensions, 2009

[11] *National Survey of Local Health Services*, CQC, 2008

for Community Services, *Our Health, Our Care, Our Say*, have promoted person-centred care, whereby the patient is empowered and involved. The NHS Constitution enshrines the '*right to be involved in discussions and decisions about your healthcare, and to be given information to enable you to do this*' and pledges that the NHS will *'work in partnership with you, your family, carers and representatives'*.

The piloting of personal health budgets takes the empowerment agenda to its logical extreme, promoting the patient as the main locus of decision-making.

And yet, many patients still feel partially excluded from the decision-making process, indicating that the paternalistic model of health care still persists. Treatment and support should start by looking at what the older person wants to achieve and assisting them to do so rather than applying a disease management model. More could be done to capitalise on older individuals' understanding of their own condition, their capacity to manage it and even their ability to support others going through a similar experience, through models such as peer support.

On the other hand, the evidence suggests that few older people welcome complete control of the public resources available to meet their needs. The evaluation of individual budgets in social care suggested that in contrast to other groups, older people with budgets reported lower psychological well-being than those using traditional services and did not appear to want the *'additional burden'* of planning and managing their own support in this way.[12] We need to get the balance right between an empowered patient exercising control and one who is anxious with the burden of decision-making.

What needs to be done?

1 **The Government** must ensure that any roll-out of personal health budgets for older patients living in the community is deferred until full evaluation has taken place and their impact fully assessed.

2 Building on skills developed in pre-registration training, **healthcare providers** must develop healthcare professionals' skills and competencies in enabling older patients to manage their own health wherever possible.

3 **Healthcare professionals** visiting older people at home must listen to them and respect their choices and directions, particularly in relation to how they like things to be done in order that older people do not feel excluded and powerless.

3 Respect for preferences and belongings

Findings from our research

Any health worker entering a service user's home must respect the way they like things to be done, including the use of their belongings.

Progress report

- In 2008 61 per cent of clients reported that the care worker always did the things that they

[12] *Evaluation of the Individual Budgets Pilot Programme: final report*, Glendinning, C., Challis, D., Fernandez, J., Jacobs, S., Jones, K., Knapp, M., Manthorpe, J., Moran, N., Netten, A., Stevens, M. and Wilberforce, M., Social Policy Research Unit, University of York, York, 2008

wanted done, while 1 per cent said they never do the things they want done.[13]

It is hard to quantify behaviours which are fundamentally about basic respect and politeness when visiting a person's home. It is however easy to overlook such courtesies when a healthcare professional has many demands on their time.

'When I would ask him to make a cup of tea, I always make sure they know I like the kettle to be emptied first and fresh cold water put in, as my doctor said this was good for my health… but the same person will still come in and heat up the same water right in front of me. I am the one that needs to drink it, and it's my home.' Male, Luton

Within the Transforming Community Services agenda, there is a drive to reconfigure community health services, starting with PCTs separating their provider and commissioner functions. This could result in multiple provider organisations from the public, private and third sectors operating in an area, mirroring what has happened in social care. Healthcare workers could be employed by one of a range of organisations.

Draft regulations and guidance from the Government and the CQC state that service providers are expected to be *'considerate and respectful to the person'*. This is something we welcome. However, as the market for community health services fragments, it will be difficult to oversee the implementation of a common set of standards. We need smart ways for the PCT and the regulator to hold providers to account, based on the actual experiences of patients – not only for the standards of clinical care but also the extent to which they treat patients and their belongings with respect.

What needs to be done?

- The Care Quality Commission must hold healthcare providers working in the community to account for the behaviour of healthcare professionals working in patients' homes.

[13] *Personal Social Services: home care users aged 65 or over, England – councils with adult social services responsibilities tables, provisional, 2008–9*, Information Centre for Health and Social Care, 2009

4 Company and the opportunity to be listened to

Findings from our research

Older people can feel lonely or isolated. Contact with health and care workers can offer a much-needed form of interaction, and friendly conversation is often welcome.

Progress report

- One-person households are projected to overtake married couple households by 2030.[14]
- 11 per cent of people aged 65+ say they are lonely.[15]
- In response to a 2007 Age Concern survey 29 per cent of respondents aged 50+ said they saw friends and 36 per cent said they saw family a few times a month or less.[16]

'One of these ladies – she is absolutely marvellous and she just comes in sometimes . . . "Oh, you're still breathing. I'll come in for five minutes."' Female, Hillingdon

There is a welcome emphasis in policy on quality of care and maintaining dignity. The Government's dignity challenge outlines ten characteristics of a service which respects an individual's dignity and includes a challenge to 'act to alleviate people's loneliness and isolation'. However, there is little hard evidence relating to the impact on services and whether the reality for patients has changed. Indeed, healthcare workers often adopt a task-oriented approach to healthcare rather than developing a positive relationship with the patient.

The links between social isolation and mental and physical health are well documented[17] but health services are not well set up to deal with problems associated with social detachment.

Solving this cannot lie exclusively with health services. But services should not exacerbate social isolation. Injecting some humanity into interactions

[14] *Focus on Families,* ONS, 2007

[15] ICM Research survey for *One Voice,* 2008

[16] *Lifeforces Survey,* Age Concern Research Services, 2007

[17] *Mental Capacity and Well-being*, Foresight, 2008

and recognising an individual's identity beyond their ill-health could make a big difference. Equally, health workers could play a key role in signposting individuals to wider social and leisure opportunities as a way of promoting mental well-being.

Clearly, many healthcare professionals do go the extra mile and this must be recognised. However, social interaction should not be simply an optional extra but a core part of ensuring the overall well-being of the frailest users of NHS services.

What needs to be done?

1. **Healthcare professionals** must recognise the importance of human interaction and relationship-centred care. Social aspects of healthcare should not be underestimated.
2. **Healthcare providers** must ensure that healthcare professionals entering older people's homes have readily available information on a range of accessible social opportunities and activities, such as befriending schemes, in the local area.

5 Proactive healthcare and support

Findings from our research

Older individuals are often unaware of what is available to them and may need help and support to understand and access what is on offer. Information, advice and outreach are key to making this work.

Progress report

- Of those who reported that they had a long-standing medical condition and needed support, 45 per cent said that they had 'definitely' received enough support from local services or organisations to help them to manage their condition. A further 29 per cent said that they had received support to 'some extent', but over a quarter (26 per cent) said that they had not received any.[18]

[18] *National Survey of Local Health Services*, Care Quality Commission, 2008

'I would like to have more say about my health, but I don't really know what is available. How can I ask for help if I'm not sure what I need?' Female, Luton

Older people with long-term conditions will regularly have to make decisions about their care or will need to access a range of support to enable them to live independently. Unfortunately, too often older people and their families experience difficulties in accessing the right information at the right time in order to make decisions and access care.

Internet-based information and advice such as NHS Choices excludes the majority of older people, who are not online. Telephone-based services can be off-putting for those who find it difficult to conduct lengthy and complex calls.[19] The format of information and advice is therefore often inaccessible to those who need it most. And yet, in spite of government recognition of their importance, funding for information and advice services which go beyond telephone/internet is uncertain and fragmented.[20]

'I don't complain much … but to be honest I don't have much experience with the NHS, so I don't really know what to ask for anyway.' Female, Ross-on-Wye

An additional problem is that many older people are unaware that they are missing out on entitlements or support that could make their lives easier. Often this results in them accessing services in a crisis.

Every contact with a health professional should be an opportunity to link the individual in with entitlements and appropriate support. Health professionals should be fully aware of local information and advice services and should signpost older patients on whenever possible.

However, a survey of local Age Concern information services suggested that the NHS is missing opportunities to connect people with the advice they need. Only 19 per cent of users of these advice services were referred via a health

[19] *Hanging on the Telephone: CAB evidence on the effectiveness of call centres*, Citizens Advice, 2004

[20] *Transforming Lives: tackling poverty and promoting independence and dignity through information and advice*, Age Concern, 2008

professional (even though 89 per cent of the users reported disabilities or chronic and multiple health conditions which required contact with health professionals).[21]

What needs to be done?

1 **The Government** must provide a clear strategy and sustained funding for information and advice.

2 **Healthcare professionals** must proactively signpost older people on to centres of expertise where they can get the information and support they need to ensure that every interaction with a healthcare professional is an opportunity to link people into wider support networks.

3 **Healthcare providers** should also consider hosting services such as benefits advice in healthcare settings such as GP practices or health centres.[22]

[21] Ibid.

[22] See *Just What the Doctor Ordered,* Age Concern, 2008, for examples of this in practice

Care in hospital

6 Choice and control over daily routines

Findings from our research

An unfamiliar and busy acute care environment can make patients feel lost and uncomfortable, impeding recovery. Older people should be able to preserve familiar aspects of their daily routine such as when they take medications or the kind of food they like to eat.

Progress report

- Busy hospitals are getting busier. Some 14.1 million people were admitted to hospital in 2008/9[23] – an increase of 600,000 people on the previous year.
- Although average length of hospital stay is falling, many older people can expect to stay a week or more in hospital. An individual admitted for a fall, for example (one of the top reasons for admission), can expect to stay for an average of 8.2 days.[24]
- In 2008 96 per cent of people reported having somewhere to keep their personal belongings on the ward but 65 per cent of respondents could not lock that space.[25]
- 22 per cent of people were not always offered a choice of food.[26]

'When I was in the ward it was actually quite scary … It's so foreign to me and having staff there who both respect your routine but also tell you what's going to happen to you makes all the difference.' Male, Luton

[23] *Provisional Monthly Hospital Episode Statistics for Admitted Patient care and Outpatient Data, April 2008–May 2009*, NHS Information Centre, 2009

[24] *HES on Falls*: NHS Information Centre http://www.heson-line.nhs.uk/Ease/servlet/ContentServer?siteID=1937&categoryID=1071 last accessed 25 September

[25] *Survey of Adult Inpatients 2008*, Care Quality Commission, 2009

[26] Ibid.

Clearly, a hospital stay represents a severe disruption to an individual's daily routine. In the commotion of a hospital ward it can be hard for an older person to maintain their sense of identity and control. Some participants in our research found it upsetting not to have pills on time or not to have food offered that they could eat. Yet patients feel better when they can remember and relate to important people, events and things.[27]

'Sometimes something as small as asking me when I usually take my pills or what I normally drink with them means a lot to me.' Female, Luton

At present the emphasis in hospitals is very much on throughput and completing essential clinical tasks, which leaves very little time and space in which older people can keep hold of familiar aspects of their life or control their experiences. Apparently small things, such as being able to wear their own clothes and having somewhere to store their own belongings, could make a big difference.

NHS policy now recognises that it is no longer satisfactory to treat people as numbers and that a good patient experience is intrinsic to the success of an overall care package. The NHS's Next Stage Review included patient experience as one of three key domains of quality to be promoted. The Department of Health's dignity challenge states that services which respect dignity should *'enable people to maintain the maximum possible level of independence, choice and control'*. However, the few indicators we have suggest that for many this vision is far from reality.

The rhetoric about quality needs to be made real, especially for those who use hospital services most – older people. New ways must be found of valuing and incentivising the behaviours in hospitals which older people want. This cuts across all staff, from porters and cleaners through nurses to consultants.

[27] An investigation of the components of best nursing practice in the care of acutely ill hospitalized older patients with coincidental dementia: a multi-method design, Tolson, D., Smith, M., Knight, P., *Journal of Advanced Nursing*, 1999; 30(5):1127–36.

What needs to happen?

1. **Healthcare providers** must recognise the importance of healthcare professionals going beyond clinical tasks to enabling individuals to exercise choice and control. This ranges from choosing treatments to wearing their own clothes. Involving family wherever possible may help.
2. **Healthcare providers** must also prioritise and report openly on those quality issues which matter to older people, through, for example, Quality Accounts and NHS Choices.

7 A 'connected' relationship between staff and patients

Findings from our research

Communication based on mutual respect and understanding engenders trust and supports good decision-making. Taking the time to understand the person behind the patient will further enhance the therapeutic partnership between patient and practitioner.

Progress report

- In 2008 47 per cent of people said that they were not involved (or were only partly involved) as much as they wanted to be in decisions about their care and treatment in hospital.[28]
- 20 per cent of people did not always have trust and confidence in the doctors treating them; this figure rose to 25 per cent when respondents were talking about nurses.[29]

'I suppose it's nice to have the doctor call you by your first name, but when they are half your age and just talk to you like you're a child it doesn't really make me trust in what they are saying … You can do both, can't you?' Male, Luton

A good relationship extends much further than ticking off standard questions to obtain a person's

[28] *Survey of Adult Inpatients 2008*, Care Quality Commission, 2009

[29] Ibid.

medical history and carrying out observations in circumstances which make the patient feel a passive recipient of care. Patients, and where relevant their families or representatives, need to be wholly involved in discussions or decision-making.

We are awash with policy which reinforces the message that patients are partners in care and their wishes should be respected. Workforce standards for health professionals such as Tomorrow's Doctors and the nursing code of conduct contain statements such as *'Doctors have a duty to listen to patients and respond to their concerns and preferences'*[30] and *'Make the care of people your first concern, treating them as individuals and respecting their dignity'*.[31]

However, the practical realities of achieving a good relationship are not addressed in these high-level statements. Moreover, cognitive or sensory impairment can result in behaviour that challenges staff or creates communication difficulties and few healthcare professionals are appropriately trained to deal with this. Yet up to half of older people in hospital may have cognitive impairment, including dementia and delirium.[32] Some 28 per cent of people aged 65+ have difficulties with their eyesight[33] and 55 per cent of people aged 60+ are deaf or hard of hearing.[34]

Both the End-of-life Care and the Dementia strategies emphasised the need to develop communications skills in the workforce, including involving patients in decisions about care, but words need to be translated into action.

The Mental Capacity Act (MCA) was also a significant step forward. The legislation enshrines the common law principle that it must be assumed that people have capacity unless it is established that they do not. All practicable steps must be taken to help a person make a decision, and if

someone else is having to make a decision because a person is unable to do so, it must be in his or her best interests. Participation must be encouraged, taking account of past and present wishes and in consultation with carers and others who know the person well. However, there are question marks over the extent to which the MCA has been implemented or has had an impact on quality of care.

'I have an inquisitive mind and I want to be involved. It's my body and I want to be involved in what's being done to me.' Male, Hyndburn

What needs to be done?

1. **Professional regulators** and **representative bodies** must reinforce the importance of relationship-centred care throughout health workforce standards. These must be further promoted by the Royal Colleges and representative bodies.
2. The **Care Quality Commission** must reinforce in guidance that service users should be involved throughout the process of making decisions on treatment options and hold providers to account where this is shown not to be the case.
3. **Government** must review the implementation of the Mental Capacity Act in its widest sense across health and social care to ensure that steps are taken to improve awareness of the Act and to see that the principles are incorporated in everyday practice.

[30] *Tomorrow's Doctors*, GMC, 2009

[31] *Nursing Code of Conduct*, NMC

[32] *Who Cares Wins: improving the outcome for older people admitted to the general hospital*, Royal College of Psychiatrists, 2005

[33] *General Household Survey*, 2001

[34] RNID website factsheet

8 Maintenance of privacy in hospital

Findings from our research

Older people should never feel embarrassed or humiliated in hospital. Staff can do a great deal to reassure them that personal or intimate care is not a burden. In addition, the environment should support privacy but not at the expense of interaction. Older people often prefer the company of others on a ward rather than the isolation of a single room. However, this is only the case when sharing accommodation with the people of the same sex.

Progress report

- In 2008 24 per cent of people reported sharing a sleeping area with a member of the opposite sex when they were first admitted to a bed on a ward while 30 per cent of people reported using the same bathroom or shower as patients of the opposite sex.[35]
- In 2008, 30 per cent of inpatients say they were not always afforded enough privacy when discussing their condition or treatment.[36]
- About 12 per cent said they were not always given enough privacy when they were being examined or treated.[37]
- Only 9 per cent of patients were asked to give their views on the quality of care.[38]

'Dealing with your husband is a private thing, isn't it? And you're stuck in a bed next to somebody who is snoring and, to be honest, all the bodily functions and what not – some men don't care, do they? ... It's like having your private life invaded by a complete stranger and I can't deal with anything like that.' Female, Salford

Privacy in a hospital is fundamental. Lack of privacy in mixed-sex wards was raised by many witnesses in the Joint Committee on Human Rights report on the human rights of older people in healthcare as a potential violation of Article 8.[39]

After many years of political commitments on privacy and mixed-sex accommodation, the NHS needs to get this right. In early 2009 the Government launched a welcome programme to 'all but eliminate' mixed-sex accommodation. This includes financial penalties for hospitals who fail to tackle the problem, a £100 million privacy and dignity fund to help hospital trusts make the transition and a greater focus on measuring and improving patient experience with regard to mixed-sex accommodation.[40]

However, maintaining privacy clearly extends much further than the bricks and mortar of mixed-sex accommodation. The extent to which older patients are afforded privacy when discussing their treatment or personal affairs is also dependent on timely and respectful behaviour from staff. Older people also report feeling humiliated and embarrassed when staff do not respond to calls for assistance in getting to the bathroom on time.

'I was not mobile at all when I was in hospital … I called and called for someone to come and take me to the toilet, but after almost 20 minutes of waiting I embarrassed myself in my bed … I see staff all the time in hospital – it's not that there is no one around.' Male, Luton

While some of this depends on having staffing ratios which enable intimate care to be carried out with privacy and respect, much depends on the approach of individual healthcare professionals. Trust boards need to focus their attention on developing cultures and practices which meet patient expectations around privacy. This demands accepting and responding to feedback from patients, something at which the NHS is currently poor. From ward to board it should never be acceptable to undermine an older patient's privacy.

[35] *Survey of Adult Inpatients 2008*, Care Quality Commission, 2009

[36] Ibid.

[37] Ibid.

[38] Ibid.

[39] *The Human Rights of Older People in Healthcare*, Joint Committee on Human Rights, Eighteenth Report of Session 2006–7, Volume I: Report and Formal Minutes

[40] *Financial penalties for hospitals who fail to tackle mixed-sex accommodation*, Central Office of Information release, 2009

'I didn't like being in a single room… They actually forgot to deliver my dinner one night… and I had no one to chat to. I felt isolated.' Female, Ross-on-Wye

There is of course a fine line between protecting privacy and promoting isolation. Many of the older people we asked liked the social aspects of being in a ward when they needed to be. While single rooms are the preference for some, they clearly are not the answer for all.

What needs to be done?

1 **The Government** must hold hospitals to account for failing to deliver single-sex accommodation.

2 **Healthcare providers** must ensure that hospital staffing ratios allow for adequate staff to deliver personal and intimate care in a way which ensures fundamental privacy.

3 **Healthcare providers** must also collect more and better feedback from older patients and learn from it to improve their systems, processes and working cultures.

Healthcare across all settings

9 Joined-up care

Findings from our research

Older people's health and care needs should be assessed holistically. Professionals should work together both to ensure that the appropriate package of services is created and that the patient is informed of every stage of the care process.

Progress report

- In 2008, 8 per cent of patients reported that when they first saw the health professional they were referred to, he/she did not seem to have all the necessary information about them or their condition.[41]
- Some 57 per cent of inpatients reported that they did not receive copies of letters sent between hospital doctors and their family doctor.
- Although 84 per cent of inpatients reported that they were involved in decisions about their discharge from hospital, 30 per cent reported that they were involved only to some extent.[42]
- In 2008 three in five respondents to a BMA survey reported that there was not appropriate continuity of care for older patients accessing health and social care.[43]

'If you're only given medication and not information, then you leave feeling the same. You still don't know what is wrong with you. You don't trust them.' Male, Hillingdon

Many older people suffer from several health conditions, both physical and mental, which often

[41] *National Survey of Local Health Services*, Care Quality Commission, 2008

[42] *Survey of Adult Inpatients 2008*, Care Quality Commission, 2009

[43] *Survey of Members' Views of Care of the Elderly*, BMA, 2008

require the intervention or support of multiple professionals or agencies.

However, the system is poorly set up to manage multiple needs simultaneously. Health professionals are trained and developed in a way which privileges speciality expertise – the career path for doctors under Modernising Medical Careers, for example, requires that they choose a speciality after only two years of qualified medical practice. This can encourage a blinkered approach to an individual's overall health, with a tendency to treat individual symptoms or conditions separately rather than collaborating to provide a good overall service. Yet our research showed that where healthcare professionals took the time to help the patient beyond the confines of their particular specialism, this was seen as excellent care.

Older patients' journey through the system is also often poorly managed. This includes transitions between wards in a hospital, between the hospital and home, and simply navigating care in the community. Between 1998–9 and 2006–7 the number of emergency re-admissions within a month of discharge from hospital for people aged 75+ rose by 69 per cent.[44] Good co-ordination of care at discharge must surely underpin attempts to reverse trend. This includes involving people in decisions about their care, giving them the right information and support at discharge, and keeping them in the communication loop.

Attempts to co-ordinate services better have had some successes. Providing a person-centred and integrated response for older people was one aim of the Partnerships for Older People pilots. The national evaluation has indicated some positive outcomes, including reduced emergency admissions. However, there is little sense of how the learning from the POPPs pilots will translate into better co-ordinated practice universally. Our new research found that visits at home appeared to be well co-ordinated for those who suffered from one long-term condition (e.g. cancer or stroke) but for those with 'no specifically serious diagnosis', while none the less very frail, barriers appeared to be preventing them from getting the care they required at home.

The NHS Next Stage Review announced that by June 2010 all those with long-term conditions will have been offered a personalised care plan. This could make a big difference providing that the plans are genuinely tailored to older people's multiple and fluctuating needs. However, recent research suggests that care plans as they are instituted today are only moderately effective (and, in some cases, ineffective) at achieving gains for patients and that there is a need for more resources and training for health professionals if the initiative is to be successful.[45]

What needs to be done?

1. **The Government** must disseminate learning from pilot programmes such as Partnerships for Older People so that all areas are able to focus attention on better co-ordination of care, particularly at hospital discharge.
2. **The Government** must robustly support the implementation of care plans to ensure that health professionals, providers and commissioners are fully prepared to use them to tailor healthcare in a co-ordinated way to individual's needs. The implementation should also be carefully monitored, looking in particular at older patients' experience, to ensure that progress genuinely reflects need.
3. **Professionals** must be aware that co-morbidities are a reality for many. Micro-management of conditions without regard for individuals' wider health circumstances is likely to be ineffective. Training, development and revalidation of healthcare professionals must reflect this.

[44] Information Centre NHS http://www.nchod.nhs.uk/

[45] *Planning Care: a national survey of health advocacy groups*, report prepared for the Royal College of Nursing and National Voices by PatientView, 2009

Astral House, 1268 London Road
London SW16 4ER
T 020 8765 7200 **F** 020 8765 7211
www.ageconcern.org.uk

207–221 Pentonville Road
London N1 9UZ
T 020 7278 1114 **F** 020 7278 1116
www.helptheaged.org.uk

From spring 2010, we will be called Age UK

Age Concern England (charity number 261794) has merged with Help the Aged (charity number 272786) to form Age UK, a charitable company limited by guarantee and registered in England: registered office address 207–221 Pentonville Road, London N1 9UZ, company number 6825798, registered charity number 1128267. Age Concern and Help the Aged are brands of Age UK. The three national Age Concerns in Scotland, Northern Ireland and Wales have also merged with Help the Aged in these nations to form three registered charities: Age Scotland, Age NI, Age Cymru.

Printed on FSC certified paper using wood and mixed products from well-managed forests and other controlled sources. ID8556 12/09