

Consultation response

Ref: 3111

Equity and Excellence: Liberating the NHS Age UK response to the NHS White Paper

5 October 2010

All rights reserved. Third parties may only reproduce this paper or parts of it for academic, educational or research purposes or where the prior consent of Age UK has been obtained for influencing or developing policy and practice.

Name: Ruthe Isden
Email: ruthe.isden@ageuk.org.uk

Age UK
Astral House, 1268 London Road
London SW16 4ER
T 020 8765 7200 F 020 8765 7211
E policy@ageuk.org.uk
www.ageuk.org.uk

Age UK is a charitable company limited by guarantee and registered in England (registered charity number 1128267 and registered company number 6825798). The registered address is 207-221 Pentonville Road, London N1 9UZ.

Age UK is the new force combining Age Concern and Help the Aged. We are a national charity and social enterprise working to transform later life in the UK and overseas. Our vision is of a world in which older people flourish. We aim to improve later life for everyone through our information and advice, services, products, training, research and campaigning.

Introduction

When the original plan for the NHS was unveiled it was breath-taking in the bold scope of its aspiration. It envisaged a society where people did not die prematurely from preventable causes or live in pain and dependency for the want of medical attention. While both science and society have changed enormously since 1948 – and with it our expectations and aspirations – the basic principles still stand. The NHS at its best provides everyone with security and peace of mind that in times of ill-health, at their most vulnerable, they will be provided with the care and support they need. At no time is this security more valuable than in older age, where the likelihood of disability, disease and long term ill-health are considerably higher than at other times in our lives. To misquote a sporting legend, for older people the NHS isn't a matter of life and death, it's far more important than that.

The NHS unfortunately does not always live up to this ideal. It does not always provide the care people they need; many older people still die from preventable causes or suffer in pain and ill-health unnecessarily. The record of the NHS in treating patients as individuals, with their own needs, wants and aspirations, and not as conditions or processes is underwhelming. Instead people are too often made to feel devalued and a burden on the very people who should be caring for them. People interacting with the NHS can find it impossibly bureaucratic and inflexible, where process and lack of coordination leave them fighting to get the help they desperately need. It is also still a deeply inequitable system that continues to consider second or even third rate good enough for older people in our society. It is clear that the NHS can, and should, do better for older people. These reforms represent a real opportunity to tackle some of the long term problems that have beset the system, it should not be wasted.

While the NHS reforms will impact on everyone to a greater or lesser extent, they are likely to be most keenly felt by older people. People over 65 make up 60% of admissions in NHS hospitals and those with two or more long-term conditions account for the majority of adult bed days¹. 39% of all people over 65 have a limiting long-standing illness and the proportion increases as people get older². Older people are at further risk from mental health conditions with depression affecting 22% of men and 28% of women aged 65 or over³. Consequently, many older people are living with multiple health conditions and increased health need through physical frailty. Taking into account the fact that people are living longer – leading to a higher prevalence of people with long-term conditions – the proportion of older people

¹ Oliver, D., "*Acopia*" and "*social admission*" are not diagnoses: why older people deserve better, J R Soc Med 2008; 101: 168-174

² The estimate is for the UK, based on Great Britain data from the General Lifestyle Survey 2008, Office for National Statistics, 2010

³ Depression is defined as a high score on the GDS10 (Geriatric Depression Scale) inHealth Survey for England 2005: Health of older People, IC NHS 2007

accessing health and social care services living with multiple conditions, requiring complex care, will only continue to increase. Older people in fact represent the largest patient cohort for the NHS and failing to get the system right will have far reaching consequences. Indeed, getting it right for older people is fundamentally about getting it right for everyone. Poor communication by health professionals, lack of joined up care, service gaps and unsafe practice have a high impact on older people as high service users, but everyone suffers when poor practice is allowed to proliferate unchallenged.

Age UK aspires to an NHS which truly meets the needs of older people; treating older people with respect and dignity, seeking through treatment and prevention to deliver the best health and wellbeing outcomes possible for each individuals, involving people in where and how their care will be managed and, overall, providing security and peace of mind in times of crisis. It is against these criteria that Age UK has assessed, and will continue to assess, the progress of the NHS and the reforms proposed by the White Paper. Structures and processes are important the test of their achievement, however, is whether they can successfully support a vision of society in which everyone, including older people, can aspire to good health and quality of life.

In developing our response to the White Paper, Age UK has undertaken a series of listening events with older people and commissioned a survey of older people's attitudes on issues raised by the reforms. This response seeks to represent those views and highlight key areas of concern and consideration for improving the care of older patients within the scope of the system proposed.

Key points and recommendations

Managing to protect older people

- Age UK believes the immediate future poses huge challenges for the NHS which are set to test the organisation to its limits. Given that many of the planned reforms are untested and the effectiveness of the system as a whole unknown, we would urge caution in proceeding to undertake wholesale change on such a tight timetable.
- The services provided by the NHS are vital for people in later life and any disruption, even temporarily, could prove disastrous. Age UK wants to see a robust process for monitoring the impact of NHS reforms on older patients to ensure that the quality and effectiveness of day-to-day NHS care is not adversely impacted during this time of immense transition.

Old age does not justify second rate care

- The reform of commissioning proposed in the White Paper provides an opportunity to address serious inequity in the way that NHS services are commissioned and delivered. Age UK believes there is a clear imperative to raise the profile of age equality issues within commissioning and champion reform, including:

- a detail strategy setting out how the Commissioning Board intends to fulfil its responsibilities to implement age equality legislation;
 - incorporate specific monitoring on age equality into the wider obligations for GP consortia to account for progress on health inequalities;
 - the appointment of an older people's champion to the NHS Commissioning Board to support the development and implementation of an older people's strategy.
- Age UK is deeply concerned that the NHS outcomes framework will solidify and extend ageism rather than deliver improvement in health outcomes. We are extremely alarmed to note that indicators used to measure mortality and cancer survival rates, for example, do not capture data within older age groups.
 - In the development of the funding formula for consortia and in determining capitation and contractual payments, it is imperative that the Commissioning Board undertake a thorough review of demographic factors and, in taking account of the prospective burden of disease, ensure the prevalence of multiple conditions and frailty is incorporated into any new funding formula.
 - In reforming and extending the use of tariffs, CQUIN and payment by results we believe it is imperative that the NHS Commissioning Board take into account the prevalence of multiple conditions and frailty when designing tariff systems, putting in place a robust process for designing and reviewing, the impact of tariffs systems on older patient care.

Implementing meaningful choice and personalisation

- Successfully achieving the goal of 'no decisions about me without me' will require a significant cultural shift in the NHS, starting with a strategy for identifying best practice and improving training for healthcare professionals in the necessary skills to effectively support shared decision-making.
- Age UK is concerned that the 'information revolution' will be far from inclusive as Government seems to envisage the internet as the primary source of information. We would welcome the opportunity to engage at an early stage of development to ensure it is accessible for older people.
- Increasing reliance on private and third sector organisations to provide information and advice raises issues of accuracy and appropriate expertise in interpreting and delivering information. Age UK believes Government should learn from the experience of the financial sector and introduces a degree of quality assurance through regulation and kitemarking.
- Advocacy and support services will play a very important role in supporting patients within the envisaged new system. Age UK believes it should not be provided in an ad hoc and unregulated way. Those providing advocacy services should be required to operate according to a code of conduct and agreed standards of practice.

- To ensure all patients are able to access advocacy and support local authorities should be under an obligation to commission suitable services from providers able to demonstrate they meet the criteria to practice.
- Older people surveyed were fairly sceptical about the role of choice and competition in improving the quality of health services, with focus group participants expressing concern that it will severely disadvantage those who are unable or unwilling to travel distances to access alternative providers, leading them to receive 'second rate' care.
- Monitor, working in collaboration with the NHS Commissioning Board and local consortia, needs to develop a robust market stimulation strategy with specific emphasis on encouraging new providers and provider innovation in less well served areas and reduces barriers to market entry.

Patient and public engagement

- Age UK is keen to see the role of patient and public engagement significantly strengthened within the reforms. We believe that the quality and effectiveness of patient and public engagement activities undertaken by commissioning consortia should be routinely assessed as part of the commissioning framework and supplemented by quality standards.

Delivering high-quality care

- In order to encourage and support consortia, and other networks of professionals, to deliver seamless, integrated care for patients we believe that the commissioning framework, guidance and NICE quality standards should adopt a fully integrated care pathway approach.
- GP consortia should be supported by the introduction of regional clinical directors, working under the Commissioning Boards, championing excellence in commissioning and facilitating the development of collaborative initiatives across consortia and service boundaries.
- In order to ensure that the distribution of GP consortia do not embed inequalities, we believe that before authorising consortia the NHS Commissioning Board ought to undertake an equality impact assessment.
- Age UK would like to see a full review of PCT and SHA functions, in consultation with stakeholders, to ensure that all relevant functions and responsibilities will be appropriately continued within a reformed system.
- Age UK welcomes a commitment to improving the regulatory environment for research, but we are concerned that the continuation of so many clinical trials to routinely exclude older participants will limit the positive impact that this could have for an ageing population.
- Age UK are keen to see a strategy whereby the views of patients and the public can be inputted into research priorities.

Accountability and performance management

- In addition to financial incentives within the GP provider contract to participate in the consortia and achieve improvements, Age UK is extremely keen to see robust assessment processes and appropriate levers put in place for the Commissioning Board to identify and address weaknesses in commissioning performance.
- In order to ensure GP consortia are held accountable to local communities as well as the Commissioning Board, we propose that all consortia boards include mandatory, and not tokenistic, representation from patients, the public and the local authority.
- We would like to seek assurances that all such providers commissioned by the Board will be appropriately performance managed to ensure that patients are not being offered second rate or unsafe services.

No quality without safety

- Age UK is seeking assurances that CQC model of assessment and risk analysis will be updated to reflect the new environment, and in particular methods of replacing data previously intended to be supplied by PCTs.
- In order to achieve '*a culture of open information, active responsibility and challenge*' we suggest that Government carefully considers the international evidence, from countries such as New Zealand, and the recommendations of the final report of the Scottish Parliament into establishing a no-fault compensation scheme in Scotland.

1. Managing change to protect older patients

The pace of change within the NHS nonetheless is proceeding at an alarming rate. The breadth and depth of reform being proposed by the White Paper is particularly striking when set against the concurrent challenges the service faces in achieving the level of productivity and capacity gains necessary to effectively meet future demand. Even with current levels of NHS spending guaranteed we know that rising need risks outstripping finite resources, severely compromising standards of care, if the process of productivity reform is not well managed. To account for demographic change alone the NHS will need to realise an additional £1.1 - £1.4 billion a year⁴. However, this will not necessarily meet the needs of growing numbers of people with multiple conditions and complex health needs accessing health services. In addition to which, the NHS may also find itself in the position of contending with the knock on effect of spending cuts in other areas, most notably social care. The immediate future, therefore, poses a huge challenge to the NHS which, in its totality, is set to test the organisation to its limits. Given that many of the planned reforms are untested and the effectiveness of the system as a whole unknown, we would urge caution in proceeding to undertake wholesale change on such a tight timetable.

⁴ Appleby, J., Crawford, R., Emmerson, C., *How cold will it be? Prospects for NHS funding:2011-2017*, King's Fund, 2009

The process of change is extraordinarily difficult for any organisation, let alone one as complex as the NHS and with as many functions and responsibilities. We cannot expect the process of change to always run smoothly nor can transition to new arrangements be achieved without robust planning and the full engagement and commitment of staff. We are concerned that current Government plans are moving too quickly without demonstrating sufficient strategic planning or the support and engagement of NHS staff. Low staff morale and high turnover at such a crucial time can only impact adversely on patient care.

Older people with complex health needs risk finding themselves at the centre of a perfect storm in the coming years. For these people the services the NHS provides are vital and any disruption to their care or loss of service, even temporarily, would prove disastrous and potentially fatal. Consequently, Age UK wants to see a robust process put in place for monitoring the impact of these changes on older patients to ensure that the quality and effectiveness of day-to-day NHS care is not adversely impacted during this time of immense transition.

2. Old age does not justify second rate care

Old age does not justify second rate care, yet this is all too often what older people receive. Ageism is still attitudinally and structurally embedded within the NHS to such an extent that it is costing lives and condemning older people to a life of pain and dependency⁵. There is no excuse for the continuation of outdated attitudes and practice that causes so much preventable suffering for older people and their families. Therefore, while we were pleased to see an explicit public commitment by Government to promoting equality and implementing the ban on age discrimination in NHS, we feel that this commitment is not enough. We believe that the reform process offers a unique opportunity to eradicate the serious barriers older people face in accessing high-quality care and achieving optimum health outcomes. It is imperative the opportunity to tackle inequitable gaps in service, address unhelpful ageist professional attitudes and redress the funding imbalance is not lost.

Commissioning reforms and service gaps

The reform of commissioning proposed in the White Paper provides an opportunity to address serious inequity in the way that NHS services are commissioned and delivered. We are well aware that many services of primary benefit to older people, such as falls prevention, incontinence and audiology, are under-funded and under-prioritised by commissioners⁶. We are also aware that older people face discrimination in accessing mainstream services, as for example mental health

⁵ The Centre for Policy on Ageing produced two reports for the Department of Health reviewing existing evidence on the extent to which ageism is prevalent within the NHS. The reports concluded that although instances of direct and explicit age discrimination had fallen significantly since the introduction of the National Services Framework for Older People in 2001, indirect discrimination and inequity remained, highlighting a wide range of issues including; poorer treatment outcomes, inequitable funding patterns and underinvestment in services for older people, ageist attitudes in clinical decision making and poorer patient experience. Centre for Policy on Ageing, *Ageism and age discrimination in primary and community healthcare in the UK* (2009) and *Ageism and age discrimination in secondary health care in the UK* (2009)

⁶ P67 Centre for Policy on Ageing, *Ageism and age discrimination in primary and community healthcare in the UK* (2009)

services⁷. In addition to which, there are simply service gaps for many older people. To provide but one example, the CQC have recognised the shortfalls in the level of care older people in care homes are launching a large scale review. Many primary care practitioners, including GPs, do not see care homes as within their scope of work and will often attend on an ad hoc basis rather than as part of condition management regime. However, many older people expressed little confidence at our listening events that the proposed reforms would in fact address equity in service provision and, in some cases, feared further barriers would be established.

Age UK believes there is a clear imperative to raise the profile of age equality issues within commissioning and champion reform. As a result, we want to see the NHS Commissioning Board set out a specific strategy detailing how it intends to fulfil its responsibilities to implement age equality legislation and tackle wider ageism in the commissioning and delivery of services. The priorities and improvement measures set out in the strategy should be clearly reflected in the commissioning framework, and underpinning guidance and quality standards, set out by the Board to hold GP commissioning consortia to account. The commissioning strategy should also, as part of its wider obligation to monitor progress on health inequalities, specifically monitor age equality. To support the development and implementation of such a strategy we believe that it is vital Government appoint an older people's champion to the NHS Commissioning Board.

Treatment outcomes

There is an urgent need to address serious inequity in treatment outcomes for older people. A recent report commissioned by the Department of Health concluded that *'evidence of under-investigation and under-treatment of older people in cancer care, cardiology and stroke is so widespread and strong that, even taking into account confounding factors such as fragility, co-morbidity and polypharmacy, we must conclude that ageist attitudes are having an effect overall impact on investigation and treatment levels'*⁸. When set in the context of the UK's comparatively poor record on mortality rates for older people in many treatable disease areas, as for example cancer,⁹ this is damning indeed. Older people are being condemned to an early death by outdated ageist attitudes and clinical decision-making. Yet those fears expressed by older people that the reforms would fail to address this sort of inequity seem set to be realised. In fact, Age UK is deeply concerned that the NHS outcomes framework will simply solidify and extend ageism rather than deliver improvement in health outcomes. In particular, we are extremely alarmed to note that the indicators proposed to monitor progress in improving outcomes for cancer, stroke and heart disease – the priority areas identified for improvement within domain one – only collect data up to the age of 74. Given the serious issues around under-investigation and under-treatment identified, we fear that excluding older people from indicators will at best fail to generate improvement and may in fact exacerbate the problem as resources are targeted at younger age groups.

⁷ Depression affects 22% of men and 28% of women aged 65 or over according to the inHealth survey for England. Yet the Royal College of Psychiatrists estimates that 85% of older people with depression receive no help at all from the NHS (Royal College of Psychiatrists press release, 29 October 2009). Depression is defined as a high score on the GDS10 (Geriatric Depression Scale) inHealth Survey for England 2005: Health of older People, IC NHS (2007):

⁸ p57 Centre for Policy on Ageing, *Ageism and age discrimination in secondary health care in the UK* (2009)

⁹ p42 *ibid*

We will be responding in detail to the Department of Health's consultation on the proposed NHS outcomes framework and will raise our specific concerns about the framework and supporting indicators and will make recommendations for change.

Equity in funding

NHS expenditure is largely based on historic funding patterns that have not always accounted for or increased in line with the needs of an ageing population. A review for the Department of Health recently stated "*current services often reflect historic patterns, whilst demand, need and aspirations of local people change*".¹⁰ Furthermore, evidence also suggests that current patterns of NHS spending are inequitable toward older patients. Indeed, despite being the largest patient cohort within the NHS, there is considerable underinvestment in the services that benefit older people most¹¹, as for example incontinence services.

In future the NHS Commissioning Board will be responsible for allocating budgets to commissioning consortia and determining the contractual weighting of funding to primary care dentists, GP practices, community based pharmacies and primary ophthalmic services. In the development of the funding formula for consortia and in determining capitation and contractual payments, it is imperative that the Commissioning Board undertake a thorough review of demographic factors and the prospective burden of disease to ensure funding decisions are being based on an up to date profile of the population served. However, we also believe that this will not solve equity issues all together. A significant factor in developing and delivering services for older people is prevalence of multiple conditions and frailty; we believe that measures of both should be incorporated into a new formula. Prevalence of multiple conditions and frailty should also be reflected in the allocation of funding to the Public Health Service and local authority public health budgets.

The White Paper is also seeking to reform and extend the use of tariffs, CQUIN and payment by results. Age UK is concerned that the current tariff system establishes barriers to integrated service delivery and creates perverse incentives within the system. We also believe that they do not reflect the increased complexity of treating older patients, who are likely to be frail and have multiple conditions, requiring complex care and additional support, such as step down discharge services. Consequently, we believe it is imperative that the NHS Commissioning Board take into account these factors when designing tariff systems and put in place a robust process for designing and, more importantly regularly reviewing, the impact of tariffs systems on older patient care.

3. Implementing meaningful choice and personalisation

The NHS has not traditionally been very successful in listening to patients, involving them in making decisions about their care or providing much by way of choice. Yet

¹⁰ Carruthers, I., Ormondroyd, J., *Achieving age equality in health and social care*, Department of Health (2009)

¹¹ p67 Centre for Policy on Ageing, *Ageism and age discrimination in primary and community healthcare in the UK* (2009)

we know that failing to do so causes a great deal of distress to so many older patients¹². Treating patients as people first and foremost, with their own individual fears, concerns and experiences – something which most definitely does not diminish with age – must be at the heart of the NHS and embedded within practice of all health professionals. Achieving these aims is both a matter of challenging prevailing attitudes towards older people within the NHS and the ‘one size fits all’ approach to care. Choices, however, must be meaningful, provide older patients with options they genuinely value, and be supported by accessible and trustworthy information and decision-making aids. The Government acknowledges within the White Paper that there is still a way to go towards realising these aims and eliminating the barriers that currently exist.

Shared decision-making

The commitment to shared decision-making set out in the White Paper is a deeply welcome one. There is good evidence that patients who are well-informed about their condition and involved in making choices about their care and treatment experience enhanced treatment outcomes¹³. In addition to the improvements shared decision-making can deliver in terms of care, we consider it to be central in treating patients with respect and dignity. We are also aware that there is a long way to go before the full benefits can be realised, however.

The interaction between healthcare professional and individual patient is clearly at the heart of implementing genuine shared decision-making. Yet the NHS is frequently poor at listening to patients and supporting engagement in their care. Many older patients highlight poor communication on the part of care professionals as a strong contributor to poor healthcare experiences and in feeling devalued¹⁴. Older people also raise specific concerns that they are treated differently because of their age. Successfully achieving the goal of ‘*no decisions about me without me*’ will require a significant cultural shift in the NHS, starting with a strategy for identifying best practice and improving training for healthcare professionals in the necessary skills to effectively support shared decision-making.

Provision of accessible and trustworthy Information

Information and advocacy, however, are pre-requisite in effectively exercising choice and being able to become more fully engaged in treatment. Age UK remains concerned that patients could make uninformed decisions unless these supporting services are available. Indeed, providing patients with more information about everything from the quality of service providers to their own health records to treatment options is one of the central pillars of the reforms. This ‘information revolution’, however, looks set to be far from inclusive as Government seems to envisage the internet as the primary source of information. Existing initiatives, as for example NHS Choices, are also largely solely accessible online, while the uncertainty over the future of NHS Direct and its call centre functions compound concerns.

¹² Ipsos Mori, *Aspirations for healthcare amongst older people*, Age Concern Report (2009)

¹³ pp5-6, Age UK et al, *How to deliver high-quality, patient-centred, cost-effective care*, ed. The King’s Fund (2010)

¹⁴ Ipsos Mori, *Aspirations for healthcare amongst older people*, Age Concern Report (2009)

Older people are the largest patient cohort within the NHS and have some of the most complex health needs. The gains to be made from more effectively managing the health of older people with long term and multiple conditions is where some of the greatest scope for efficiency and health improvement is to be made. Yet 64% of over 65's have never been online¹⁵. The need to ensure accessibility is acknowledged but the White Paper proceeds to describe almost exclusively electronic means. We note that Government intends to publish an information strategy later this year, Age UK would welcome the opportunity to participate at an early stage in its development to ensure that the needs of the older service users are appropriately addressed.

The White Paper also makes reference to the role of third sector organisations in disseminating information to groups who may otherwise find it difficult to access. Many third sector organisations already do a huge amount of important work in supporting patients, and their carers, providing them with information and advice. However, increasing reliance on third parties raises an issue around accuracy and appropriate expertise in interpreting and delivering information. There is a wealth of health information available in the public arena, much of it very good but still a significant amount of it bogus. We are very concerned that many older people will find themselves excluded from access to information from sources widely recognised and trusted, such as the NHS, and find little guidance to assist them in locating alternative reliable sources. We believe the Department needs to learn from the experience of other sectors in disseminating important information and advice, such as the financial capability work carried out by the Financial Services Authority and the Consumer Financial Educational Body (CFEB). Experience to date in the financial sector shows both the considerable challenge of using information and advice to improve consumer outcomes and the potential for doing so if innovation of approach is combined with more traditional methods of intervention and regulation¹⁶. As the experience of the financial sector suggests, information and education alone will not be sufficient. We also recommend introducing a degree of quality assurance through regulation and kitemarking. This will help guide patients to appropriate and reliable sources and feel confident in the information being received. For example, the Personal Finance Education Group runs an accreditation scheme for materials and resources aimed at schools.

Advocacy and support

In addition to ensuring that information is suitably accessible, there will still be a need to support individuals, their families and carers, to exercise choice and make decisions about their care. For those patients who face additional barriers – as a result of physical or cognitive disability, language barriers, poor literacy etc. – to accessing information and making decisions about their care, or who may require on-going support to manage their health effectively, advocacy and support services can play a hugely beneficial role. Advocacy is also critical for vulnerable patients to

¹⁵ Office for National Statistics (2009). 'Internet Access: Households and individuals 2009'. Office for National Statistics website.

¹⁶ Two general models for population-wide behaviour change have emerged in recent years: interventions that aim to change behaviour by providing information, education and tangible incentives; and interventions that change behaviour by changing the environment within which the person acts. Policy-makers attempting to change behaviour need to understand how the reflective and automatic systems work, and how they affect behaviour. The report suggests that the most effective policies will be those that combine more traditional interventions: regulation, information and education, with the creation of contexts and environments that encourage the automatic system to support behaviour change. *Transforming Financial Behaviour*, Consumer Finance Education Body (2010)

challenge poor care or decisions that they do not agree with so that they can successfully resolve those issues. The role of advocates is given further significance within these reforms as a result of the emphasis placed on patient choice and competition in delivering quality improvement. A survey of older people's views commissioned by Age UK clearly demonstrated that many people in later life have serious concerns that the competition model will not be successful in delivering improvements in their care¹⁷. At our listening events older people expressed particular anxiety about the additional burden of having to make choices when their health was going through a period of crisis. As a result, many feared that this could lead to them accessing poorly performing services. We are deeply concerned that older people with complex needs, crosscutting health and social care services, will be at a serious disadvantage in making meaningful choices about their care and obtaining the best health outcomes without appropriate advocacy and additional support. The White Paper acknowledges the need for these services but proposes little by way of solutions, however.

The White Paper does make the suggestion that local authorities could commission Healthwatch to fulfil a support and advocacy function as part of their role as local consumer champion. There is also clear indication that Government expects the third sector to adopt a significant role in providing support. While we believe that both may offer excellent facilities to patients, we urge a note of caution. Firstly, to a greater extent it is the role of the healthcare professional to provide information and advice to patients as a core part of facilitating shared decision-making. Evidence across a range of conditions suggests that patients are likely to be most responsive to information about their care and condition when a healthcare professional guides them through the relevant information and helps them to apply it to their individual circumstances.¹⁸ So while we agree there is an important role for wider advocacy and support, this should complement, rather than replace, the core responsibilities of healthcare professionals to support their patients. Secondly, given the important role this type of advocacy and support may play in a reformed NHS, it should not be provided in an ad hoc and unregulated way. As with the appropriate dissemination of information, we believe Government should learn from the experiences of other sectors. Those acting as advocates should have a recognised role and be required to operate according to a code of conduct and agreed standards of practice. There should be appropriate mechanisms to investigate complaints, and if necessary bar an individual from fulfilling this role. We believe this is of particular importance if patients are to be encouraged to share their medical records. To ensure all patients are able to access this type of support we also believe that local authorities should be under an obligation to commission suitable services from providers able to demonstrate they meet the criteria to practice.

Real choice in services

Choice in healthcare is valued by older people, particularly choice around how their care is managed and the environment in which they receive care¹⁹. Older people are considerably more sceptical, however, about the role of choice and competition in

¹⁷ 57% of respondents strongly or slightly agreed with the statement '*standards of care would get worse if health services had to compete for patients*', TNS Healthcare Omnibus Survey, October 2010

¹⁸ p5, Age UK et al, *How to deliver high-quality, patient-centred, cost-effective care*, ed. The King's Fund (2010)

¹⁹ Ipsos Mori, *Aspirations for healthcare amongst older people*, Age Concern Report (2009)

improving the quality of health services²⁰. The quantity and quality of services available locally forms a large part of this scepticism. Older people at our listening events were deeply concerned that a competitive model where patients are expected to 'vote with their feet' will severely disadvantage those who are unable or unwilling to travel distances to access alternative providers, leading them to receive 'second rate' care. This was of particular concern in rural areas where many people already feel disadvantaged by a lack of local provision.²¹ Many already have to travel long distances to access services and did not believe providers would be willing to open more local settings. In fact, they feared that greater independence and less strategic oversight of the services framework would motivate providers to consolidate further into single large sites, reducing choice and access still further.

Implementing genuine choice of provider and driving quality through competition is entirely dependent on there being a vibrant local provider market. Lack of providers operating in a local market undermines the principles underpinning the competitive model, as neither patient choice nor commissioning decisions have much leverage to influence the behaviour of dominant providers in relation to either the quality or type of services on offer. The Health Select Committee identified this imbalance of power and lack of levers on the part of commissioners as one of the key weakness of PCT commissioning in their 2010 report²². In an attempt to address the problem the World Class Commissioning Framework identified a specific role for PCTs in stimulating their local provider market. However, the White Paper does not set out any solutions as to how this same problem will be overcome in the future, where commissioners seem set to become smaller relation to providers. Monitor is assigned limited responsibilities regarding opening up the social market to competition, however, we believe that there is a clear need to go further. Monitor, working in collaboration with the NHS Commissioning Board and local consortia, needs to develop a robust market stimulation strategy with specific emphasis on encouraging new providers and provider innovation in less well served areas and reduces barriers to market entry.

4. Patient and public engagement

Patient and public engagement in local healthcare provision is an extremely important component of developing an NHS that is responsive at a local level to the needs of patient. Commissioning consortia and health and wellbeing boards will have a duty of patient and public involvement which, as the White Paper acknowledges, is not something which has been done particularly effectively in the past. We are

²⁰ 57% of respondents strongly or slightly agreed with the statement '*standards of care would get worse if health services had to compete for patients*', TNS Healthcare Omnibus Survey, October 2010

²¹ Nearly one-quarter of all people living in remote rural areas are more than 6km from the nearest GP, compared with 2% of people in nonremote rural areas; 54% of people in remote rural areas are more than one hour travel time from a hospital, compared with 38% in non remote rural areas. Mapping the level of need: assessing the social exclusion of older people in rural areas, Report for Cabinet Office Social Exclusion Task Force (2009)

²² p35 "The evidence we received indicated that, even in the absence of the factors so far identified, PCTs would still struggle to make an impact as commissioners since there is a seemingly perennial imbalance of power between providers and commissioners. When the purchaser/provider split was introduced it was intended that purchasers would have the power that customers are supposed to have in real markets, where "the customer is king." However, it is often argued that, in practice, power has mainly resided with NHS providers." House of Commons Health Select Committee enquiry into Commissioning, fourth report of session 2009-10 (January 2010)

pleased to see that, though the process of reform, Government intends to look at the existing mechanism for strengthening public engagement.

The overall reforms, however, place a great deal of emphasis on the market to drive quality and deliver 'what patients want' and, to a lesser extent, the role of democratic mechanisms through the local authority. While we believe that each of these methods can play an important part in influencing commissioning decisions they are not a substitute for robust patient and public engagement. In addition to which, while organisations as Healthwatch, representing the consumer interest, can provide very valuable feedback it cannot act as the sole conduit of patient views.

The purpose of patient and public engagement, as distinct from patient choice or organisational accountability, is to employ a wide range of methods to ensure that the needs and aspirations of all sections of the community are fully understood within commissioning and service design. Indeed, it is vital that the views of hard-to-reach groups such as frail older people, those with life-limiting conditions, or those with cognitive impairment are properly recognised within this process. Older people in our listening events also expressed particular concern that relying solely on public involvement in formal networks, as for example patient panels or lay board representatives, would not adequately ensure that the views of older people were heard²³. Concerns centred on the barriers to participation that many older people face in becoming actively involved in their community²⁴ and a perception that attempts to influence decision-making locally was ineffective²⁵. As a result, Age UK is particularly keen to see the role of patient and public engagement significantly strengthened within the reforms. We believe that the quality and effectiveness of patient and public engagement activities undertaken by commissioning consortia should be routinely assessed as part of the commissioning framework and supplemented by quality standards.

5. Delivering high-quality outcomes

Effective service planning and commissioning is central to delivering a health service as complex and multifaceted as the NHS. Understanding and meeting the comprehensive health needs of millions of people is no small undertaking. Yet ineffective commissioning within the NHS has continued for far too long. Older people have suffered as a result of the system's failure to properly promote integrated services, join-up care and to collaborate and communicate effectively. Immense physical and emotional distress has too often been the result as older patients have been shunted around the system without anyone taking proper responsibility for their care.

²³ Survey results also suggested that current awareness of current formal engagement mechanisms, such as PALs, LINKs, and patients panels was relatively low. In addition to which 51% of respondents strongly or slightly disagreed with the statement '*I would like to play a role in deciding which NHS services should be provided in my local area*'. TNS Healthcare Omnibus Survey, October 2010

²⁴ Research suggests that over 1 million people over 50 consider themselves to be socially excluded from society. Age Concern, *Out of sight, out of mind: social exclusion behind closed doors* (2007)

²⁵ The Citizenship Survey 2009-10 showed that older people were less likely than younger groups to feel they could influence decisions locally and nationally. *Citizenship Survey:2009-10*, Department for Communities and Local Government (July 2010)

Older people, however, expressed serious reservations during our listening events that the reforms and GP commissioning will be particularly effective in solving these problems. In some cases fearing that, contrary to the principles around which the reforms are based, many GPs either do not have sufficient understanding of the needs of older people²⁶ or display ageist attitudes. Participants also expressed concerns that GP commissioning would impact adversely on patient care, with GPs having less time to spend with their patients²⁷, and did not want to see them taking on further managerial roles. Age UK has commented in depth on the proposed reform to the commissioning system in response to the *Commissioning for Patient consultation*, however, there are three further issues we would highlight.

Service planning and integration

One of the most significant challenges that the proposed White Paper reforms may pose is to service integration and collaboration. For older people likely to experience multiple conditions, frailty and have complex, cross-cutting health and social care needs, the delivery of coordinated and seamless services is a high priority. Indeed it is often the lack of communication and collaboration leading to a disjointed patient journey that creates the greatest barriers for older people to achieving high quality outcomes. Collaborative models, including case management, follow up and coordination between primary, secondary and social care services are vital.²⁸ However, we are deeply concerned that increased market competition and the loss of strategic oversight by PCTs (who often played a key role in driving forward these initiatives) may discourage such collaboration and the development of integrated models of working, such as managed clinical networks, which have proved so successful in delivering a seamless care pathway to the patient. Age UK is concerned that it will become increasingly difficult to adopt such approaches in future as we are doubtful, at this stage, that commissioning consortia would have the leverage or capacity to implement them.

Consequently – in order to encourage and support consortia, and other networks of professionals, to deliver seamless, integrated care for patients – we believe that the commissioning framework, guidance and NICE quality standards should adopt a fully integrated care pathway approach. Consortia commissioners should be encouraged to commission and contract fully integrated services, incentivising providers to collaborate in delivering care. This should also be supported by the introduction of regional clinical directors, working under the Commissioning Board, championing excellence in commissioning and facilitating the development of collaborative initiatives across consortia and service boundaries. This approach would also help to ensure that gaps in service provision and disjointed provision across consortia boundaries were identified and addressed.

Establishing GP commissioning consortia

²⁶ Only 40 % of GPs will have received any postgraduate training in the care of frail older people with multiple pathologies. Centre for Policy on Ageing, Ageism and age discrimination in primary and community healthcare in the UK (2009)

²⁷ This view was also echoed by the results of a survey commissioned by Age UK into the attitudes of older people where 34% of respondents strongly or slightly agreed with the statement 'I am worried that services for older people's health and care in my area would get worse if my GP had more control over which services are available' and 51% of respondents strongly or slightly agreed with the statement 'I am worried that if my GP took on new responsibilities for local NHS budgets, they would spend less time on my healthcare'. TNS Healthcare Omnibus Survey, October 2010

²⁸ P3, Age UK et al, How to deliver high-quality, patient-centred, cost-effective care, ed. The King's Fund (2010)

Age UK is concerned about the laissez faire approach to forming GP commissioning consortia. While we support local flexibility in determining new working arrangements, we believe care should be taken to ensure that new consortia are not formed in such a way that either compromises their ability to strategically manage service provision or ghettoises disadvantaged areas. Getting right the geographical spread and the population mix of each consortia area will inevitably be a challenge and unlikely to deliver perfect arrangements. However, in a risk pooling system it is important to ensure that the mix of population need is balanced, even within a weighted funding model. Furthermore, if people have complete choice over GP provider it will be important to take account of how cross-boundary patient flows may distort population based assumptions. The Commissioning Board has already been assigned the power to regulate the geographical spread of consortia, we believe that before authorising consortia they also ought to undertake an equality impact assessment.

Transition of commissioning functions

The White Paper is seeking a radical review and redistribution of management functions and responsibility within the NHS. While we acknowledge that simplification may well be overdue, it is important to recognise that the delivery of comprehensive health service is an extremely complex undertaking and does require robust management. We are concerned that the NHS Commissioning Board risks having too many responsibilities and areas of work previously handled by PCTs and SHAs. As there is currently no clarity on the size and regional reach of the Commissioning Board, it is unclear how it will practically fulfil its responsibilities to monitor commissioning consortia performance or manage strategic commissioning of regional services, or indeed whether other key functions such as appealing decisions and complaints could fall between the cracks. Furthermore, we are concerned that not all of those important functions and responsibilities have been transferred to a suitable home. We would like to see a full review of PCT and SHA functions, in consultation with stakeholders, to ensure that all relevant functions and responsibilities will be appropriately continued within a reformed system.

The role of research

Age UK was particularly pleased to note the commitment within the White Paper to promoting research and evidence based practice. We particularly welcome proposals to review regulation surrounding clinical research and trials, and hope that the AMS review will encourage more medical research to continue in the UK. However, although improving the regulatory environment for research will prove beneficial, we are concerned that the continuation of so many clinical trials to routinely exclude older participants will limit the positive impact that this could have for an ageing population. In addition to which, without a commensurate commitment to research funding the improvements realised may also be limited. The emphasis on the use of research to improve clinical outcomes is also deeply welcome. We are concerned, however, that there needs to be improved discussion with stakeholders of how knowledge transfer can be improved within the NHS to ensure that research findings make a real difference and have high impact on patient care.

We are pleased to see that NICE has been given a role in advising the NIHR on research priorities in order to support the development of quality standards. However, mainstream thinking in research indicates that not only experts but 'research users'

should be fully involved in the setting of research priorities. The FUTURAGE project is a case in point. It is developing a road map for ageing research in the EU and has integrated the views of older people into its priority development, so that future research is not 'expert driven' but society led'. We are, therefore, keen to see a strategy whereby the views of patients and the public can be inputted into research priorities.

6. Accountability and performance management

Accountability, to patients and public, is central for an organisation that has responsibility for spending billions of pounds of public funds and maintaining the health of a nation. It is also important to patients to ensure that they feel able to influence the way in which the NHS is run. Currently decisions about the services that directly affecting the quality of life of older people lack transparency. It is in part that lack of accountability within the system in the past that the White Paper reforms are seeking to address now. However, accountability is not simply a matter of democratic control. Accountability within the system for performance, outcomes and finance is also vital, this requires clear mechanism for performance management.

Accountability and performance management of GP commissioning consortia

Age UK has serious reservations surrounding the accountability of the proposed GP commissioning consortia. We believe that mechanism for both upwards accountability to the Commissioning Board for performance and management of finance is unacceptably weak. We are also unconvinced by current proposals to establish downwards accountability via local authorities.

Lack of appropriate and transparent levers within the NHS to address poorly performing commissioners has long been a recognised problem. While the Commissioning Board has responsibility for assessing consortia commissioning performance and ensuring it achieves against the commissioning framework, and in turn the outcomes framework, there is no indication of what levers the Board may have. Although the consultation *Commissioning for Patients* acknowledges that the Board will '*need powers to intervene in the event a consortium is unable to fulfil its duties or where there is a significant risk of failure*'²⁹ we remain concerned that there is a lack of clarity about what sanctions and powers the Commissioning Board will have to address poor performance. The intention is to provide financial incentives within the GP provider contract to participate in the consortia and achieve improvements. Financial incentives provide a carrot but where is the stick for failing consortia? As a result, Age UK is extremely keen to see robust assessment processes and appropriate levers put in place for the Commissioning Board to identify and address weaknesses in commissioning performance.

Downwards accountability of the consortia to patients and the public is also fairly weak. The proposals for local authorities to undertake scrutiny of health service provision through health and wellbeing boards will, we believe, have limited impact. Although there is a duty to consult and a responsibility to collaborate with local

²⁹ p10, *Liberating the NHS: Commissioning for Patients*, Department of Health (2010)

authorities, medical service commissioning is exclusively the preserve of the consortia and the NHS Commissioning Board. We believe that this will continue to ensure that accountability flows for commissioning decisions flows upwards and not down to the local population. In turn this undermines the principles of localised commissioning set out in the White Paper. In order to address this imbalance, we propose that all consortia boards include mandatory, and not tokenistic, representation from patients, the public and the local authority.

Performance management of NHS Commissioning Board contracted providers

The White Paper identifies a number of services that it considers would be more effectively commissioned at a national level by the Commissioning Board, including GPs, dentistry, community pharmacy, primary ophthalmic service and national specialised services. While we have no particular comment regarding these commissioning arrangements, we do have concern around appropriate performance management and inspection. PCT commissioners and contract managers, supported by specialist practice advisors, undertook primary responsibility for ensuring that local providers fulfilled the terms of their contracts and met all relevant standards. Where a provider was delivering an unsatisfactory or unsafe service to patients it was largely the role of the PCT to work with them to improve. There would be significant questions regardless about how a remote national body, with limited regional presents, would be able to effectively manage such a large number of individual providers. However, we are particularly concerned to note within the White Paper that the NHS Commissioning Board '*will not manage providers*'³⁰. We would like, therefore, to seek assurances that all such providers commissioned by the Board will be appropriately managed to ensure that patients are not being offered second rate or unsafe services.

7. No quality without safety

Government has, rightly, identified safety as being a priority for the NHS. Indeed, there can be no quality without assurance of safety and adherence to the basic principle of healthcare that it should do no harm. The heartbreak and suffering for patients who experience failures of the healthcare system and who may be left in long-term physical and mental distress is utterly unacceptable. As is allowing a system to continue which allowed the horrific failings that occurred in Mid-Staffordshire hospital to go unaddressed for so long. Older patients are also often rendered more vulnerable than through diminished physical or mental capacity. We believe it is a core Government responsibility to ensure that horrific failings in safety and the abuse of patients trust does not occur, therefore, it is vital that a robust system of checks and balances is put in place.

Care Quality Commission registration and monitoring

Building on the issues we have raised in relation to the appropriate performance management of providers commissioned directly by the NHS Commissioning Board, we have concerns regarding the fitness of the current CQC assessment process. The

³⁰ p30, *Equity and Excellence: Liberating the NHS*, Department of Health (2010)

CQC registration plays a hugely important role in providing a guarantee to patients that the services they are accessing are safe and quality assured. However, the current CQC assessment and monitoring model is risk-based and relies on a plethora of information and data generated throughout the system upon which it can draw to make a risk assessment. Currently much of that information is generated through the precise PCT performance management and health and safety regimes described above. Once PCTs have been abolished, we believe that there is a risk that reliable collection of this information will be lost. Consequently, we are seeking assurances that CQC model of assessment and risk analysis will be updated to reflect the new environment.

Increasing transparency and safety

While we deeply welcome the commitment made within the White Paper to establish '*a culture of open information, active responsibility and challenge*'³¹ we also recognise this is a huge undertaking and will require really challenging prevalent culture and practice within the NHS. We do not think, therefore, it will be sufficient to simply monitor safety through the outcomes framework as there are clear conflicts around full and accurate reporting. There is evidence, however, that introducing a full no-fault compensation scheme can have significant benefits in eliminating defensive blame culture and fostering greater transparency and accountability³². Where there is no need to 'prove' clinical negligence evidence suggests patients are better able to seek redress and an apology should something go wrong and healthcare professionals feel significantly less defensive in admitting and learning from mistakes or service failure. We suggest that Government carefully considers the international evidence, from countries such as New Zealand, and the recommendations of the final report of the Scottish Parliament into establishing a no-fault compensation scheme in Scotland.³³

³¹ p4 *ibid*

³² The Chief Medical Officer published a consultation in 2003 seeking views on the reform of the compensation scheme in England. Within it he highlighted the greater willingness of clinicians operating in those countries with a no-fault compensation scheme to appropriately report adverse incidents and discuss them more openly with patients. Donaldson L. *Making Amends*, Department of Health consultation (2003)

³³ An expert group, chaired by Sheila Madean, director of the Institute of Law and Ethics in Medicine at Glasgow University is due to report into the feasibility of introducing a no-fault compensation scheme in Scotland by October 2010.