

# **Achieving age equality in health and social care**

## **ANNEX**

**To a report to the Secretary of State for Health by Sir Ian Carruthers and Jan Ormondroyd**

**October 2009**

# **Working papers to support “Achieving age equality in health and social care” A report to the Secretary of State for Health by Sir Ian Carruthers and Jan Ormondroyd**

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These working papers provide some background and additional information about the work of the review, especially the work in the South West that has focused on the practical implementation of the legislation. There has been a close collaboration between the analysis of the broad themes at a national level and the work in the South West focusing on specific issues that are of direct relevance to statutory organisations, their partners and service users and carers. This has led the review to both build on existing pieces of work commissioned by the Department of Health and commission further work that will comprise a resource pack to support local implementation of the relevant sections of the Equality Bill.

The annex contains the following sections:

1. Local Engagement Events: a summary of the key themes from the twelve engagement events held in September and October 2009. p 3
2. The Resource Pack: details of the work commissioned from the National Development Team for Inclusion, the Social Care Institute for Excellence and Ros Levenson and colleagues to support local implementation. p 9
3. Indicators: initial ideas on developing a set of indicators in collaboration with the University of West of England. p11
4. Age Explicit Criteria: a summary of initial review of national age explicit criteria within the Department of Health and its Arms Length Bodies. p19
5. Joint Strategic Needs Assessment: summary of a review of local JSNAs by the University of West of England. p21
6. Literature Reviews: key themes from the reviews undertaken by the Centre for Policy on Ageing. p23
7. Cost effectiveness and Quality Adjusted Life Years (QALYs): Discussion of the work with the University of Leeds p26

# 1. Key themes from the Local Engagement Events

## THE AUDIENCE

Audiences for the Local Engagement Events provided a rich mix of professional and non-professional participants. Representatives at the workshops included: managers and clinicians from PCTs, provider trusts and local authorities; third sector organisations such as Age Concern/Help the Aged; LINK members and managers; older people's forums and user networks; organisations representing the needs of people from minority ethnic groups; elected members; and the independent sector. Managerial and clinical representatives included participants at director, strategic and operational levels. Representation from the third sector and independent sectors was typically from managerial level locally. The organisations involved in the development of the toolkit and guidance also participated in their local sessions to ensure good fit with the rest of the project.

## THE PROCESS

The events used case studies to stimulate a discussion about local examples of age discrimination and possible solutions. There was an introduction to the legislation and the session concluded with a focus on prioritising national and local actions to implement the relevant parts of the legislation. A key feature of all the events was the lively and engaged debate from participants which produced many practical and positive contributions. There was a widespread understanding of the principles behind the law, especially the need to "objectively justify" where services did differentiate on the basis of age. Although there was a focus on services for older people, other examples of discrimination were discussed and it was noted that many of the solutions proposed would have a beneficial impact on all age groups as well as help remove discriminatory practice. The case studies helped the groups to focus on outcomes for the people concerned rather than the process, and to distinguish between poor quality delivery and discriminatory practice.

## THE THEMES

### Behaviours and attitudes - the importance of training

Behaviours and attitudes were identified as crucial issues in determining not only whether people felt they were treated fairly but also whether the outcome was non-discriminatory. People gave numerous examples of discriminatory attitudes based on age, summarised in the phrase "what can you expect at your age?" The high incidence of untreated depression in older people and examples of situations when staff "talked over" older people were also quoted as examples of discrimination. The engagement events generated a number of suggestions for addressing behaviours and attitudes, recognising that a change in the law, while critical, would need

to be supported by other strategies. Training in age equality was seen as an essential requirement - not just as part of formal education programmes but also as part of induction and regular updates. Linking into the “dignity and respect” training programmes was seen as being more effective than focusing the messages only through equality work. There was scope to involve the users of services and carers in delivering modules about the needs and aspirations of different age groups, especially of older people in professional training and development, starting at earliest stages of training. Mentoring of clinicians and senior managers was also proposed. The wider ageist attitudes of society were highlighted and it was felt that the health and social care system had a role to play in addressing these. The third sector argued for a role in this area through mediation, advocacy and by representing people’s views to organisations.

### **Strategic commissioning**

Good information on health, care and well-being needs was seen as an essential first step in ensuring that service planning and delivery are fair and proportionate. Again, people with the potential for multiple discrimination such as older prisoners and older people from minority ethnic groups, were seen as particularly important. Commissioning also needed to be informed by data that is broken down and analysed by age.

Public involvement in commissioning decisions was seen as crucial - progress was being made but ending age discrimination provided an additional impetus. Representatives of patient, service user and public groups observed that their role needed to cover both the planning and design stages but also the delivery and evaluation and review stages and that PCTs and LAs needed to use age appropriate means of engaging different groups, especially different communities of older people.

Some current clinical research was seen to exclude older people and people said this should be corrected.

The need to have “joined-up” commissioning between health and social care was highlighted, as were the benefits of integrated working between providers. especially in assessment and in designing and delivering care packages.

### **Personalisation in assessment, referral and care planning**

The engagement events stressed that there were points in people’s journey through the health and social care system where key decisions were made and the priority was to ensure that discrimination at these points was eliminated. These points included assessment by health and social care professionals, where it was crucial that people’s individual needs and situation were taken into account through person centred planning rather than basing decisions on a series of assumptions about the person’s chronological age. A number of participants raised issues that related to the Mental Capacity Act that needed to be seen alongside ending age discrimination. The role of primary care was seen as critical - it often was an entry point to receiving services but also played a on-going role in

providing the necessary information, signalling and supporting appropriate choices. People describe the importance of information being consistent and linked between agencies. At several events older people stressed a frustration at being constantly referred to the internet and they argued that other forms of information should be used as well.

The need for the decision making processes about individual’s care and about organisation’s plans and priorities to be transparent was frequently raised. Although participants believed that there were very few explicit age criteria in their areas, they did feel that there were examples of assumptions being made about which services older people could and could not access. In clinical and care assessments, people needed to be regarded as partners to agree mutual expectations and to support informed choice. In practice, people felt that age was often used by staff to pre-judge what an individual wanted and needed.

These decisions about individual’s care result in organisation wide patterns of service that show different levels of use for different ages. Some of these differences reflected the different needs of people at different stages in their lives. In social care there has been a historical difference in the per capita funding of different age groups, which also tends to pre-determine the range of services people have been offered. Personalisation would have an effect on this, as long as this was combined with a change in behaviours and attitudes. NHS commissioners and providers have rarely looked at the different rates of access across age groups to see if these reflect need.

The same approach should be applied to personal budgets. While not everyone wants direct payments, service users of all ages should always be offered different approaches to personalisation and staff should not assume whether people of a certain age may or may not want it. The engagement events provided both sceptical and positive views of the impact of direct payments but the crucial factor was that people wanted to make choices about their care arrangements for themselves, based on good information.

The role of advocacy and support was stressed many times in the engagement events. While people felt that services should be accessible and easy to navigate, in practice this often was not the case and advocacy was very important, particularly at times of personal stress. The availability of advocacy is critical to this process working well.

Through the discussion of the case studies, we have developed a summary of some of the key aspects of how age discrimination is seen as impacting on the care pathway in health and social care and its implications for improving services in the future.

<b>CARE PATHWAYS</b>		
<b>Social care</b>		
<b>ASSESSMENT</b>	<b>CARE PLAN</b>	<b>IMPLICATIONS</b>

<p>Risk that some assessments of older people focus too much on specific care needs that can be met through existing models of service rather than a comprehensive assessment of the individual and their needs.</p> <p>The availability of advocacy, particularly for older people, and support for decision-making varies greatly.</p> <p>Assessments of older people are less likely to focus on wider social and emotional needs and wants than with adults of working age.</p> <p>Great variation in the assessment of carer's needs.</p>	<p>May focus too narrowly on purchasing practical packages of care that utilise the available services, such as domiciliary care, adaptations, meals provision, reablement, day care, respite care or care home.</p> <p>In recent years the per capita cost of care packages for older people has been lower than for adults of a working age. Though there may be reasons for some difference, participants often felt older people were accessing a different sort of service compared to that available to working age adults.</p> <p>Cost ceilings have been used, formally or informally, when the cost of domiciliary care exceeds a certain amount, triggering the use of care homes.</p>	<p>Assessment should look at the whole person, including their social and emotional needs as well as practical care and support needs. There is a stronger culture of person centred planning, which supports this approach.</p> <p>Care plans should include a wide range of responses from social activities to housing plus a wider range of care and support services. They should be more bespoke. Advocacy should be readily available.</p> <p>Carer assessment needs to be undertaken more consistently</p> <p>Personalisation is seen as a means of addressing the current deficits but this requires behaviour and systems to change and is also likely to require redistribution of resources.</p>
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**Health care**

<b>ASSESSMENT</b>	<b>TREATMENT</b>	<b>IMPLICATIONS</b>
<p>Risk that some older people are not being given a proper diagnosis of their health problems - "old age" and "acopia" are not diagnoses. They want the health professional's assessment to recognise their</p>	<p>Risk of older people not being fully investigated and experiencing a badly designed pathway involving frequent visits to different departments and hospitals. They want to make informed choices about their care and seek age-appropriate</p>	<p>The role of primary care professionals in providing continuity of care and acting as a sort of "care manager". The ability to be referred to either general and specialty services depending on the person's needs at that specific time and not</p>

<p>complex health and wider care needs, including the relevant effects of any co-morbidities. They want to be an equal partner in the assessment process, and not talked over or judgements made because they are currently ill or have recently had an accident and appear frail.</p> <p>Older people can be passive in a consultation and so there is role for advocacy or a supportive friend to help with the assessment and discussion of options.</p>	<p>information.</p>	<p>based on the person's age - sometimes a specialist "care of the elderly" service will be more appropriate but on other occasions the person will be better treated by a specialist acute and mental health professional. Thus the specialised older people's professionals have an important role in acting as "change agents" with other health teams as well as providing services targeted at older people.</p>
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### **Health Promotion and Prevention**

This area was seen as an important means of maintaining people's health and social inclusion and as a way of stressing a positive role for older people and other marginalised groups by acting as volunteers, advocates and enablers for others. The lessons from the local Partnership with Older People's Programmes were mentioned where they had been undertaken locally. This could be actively supported by the third sector and through strategies such as intergenerational working to address ageist attitudes and assumptions. There were concerns that services such as foot care that had an important role in prevention were often regarded as lower priorities than immediate treatment and care services.

### **Beyond health and social care**

The importance of other services outside the remit of the review that impact on people's health, social care and well-being were discussed. These include housing, employment, leisure and, crucially, the benefits system, where people observed that they wanted to understand the justification for age criteria in some existing benefits, such as Disability Living Allowance and Mobility Allowance.

### **Other forms of “unfairness”**

People raised other forms of discrimination that they regarded as linking in with age discrimination.

- **Geographical variation in the availability of services** - People perceived what is commonly called the “post-code lottery” as being closely linked with age discrimination because of the different services that are available not just between PCTs and LAs but also within the larger PCTs and LAs. Because older people were less mobile, they felt that they were often particularly disadvantaged.
- **Dual and multiple discrimination** - the workshops highlighted the interaction between age and other characteristics that could lead to discrimination. In addition to the protected characteristics, such as race, belief and sexual orientation, which are defined in the Bill, many of the workshops emphasised the impact of living in a rural community as a form of disadvantage.
- **Poor quality services** - the groups identified that action on discrimination helps to address the issue of poor quality service for all ages as part of wider service improvement initiatives. They recognised that sometimes it was difficult to separate what was discrimination and what was simply poor service.

### **The legislation**

The events discussed both the ban on age discrimination and the new duty to promote equality. The timescale for introducing the ban in health and social care was discussed and there was a general consensus that there was no reason to delay beyond 2012. In the context of the forthcoming period of tight financial pressures on public services, there was a view that social care and the NHS need to give people confidence that age discrimination is allowed as a form of rationing of services and so it was important that ending age discrimination was about more than just complying with the letter of the law but that the spirit of the law needed to be part of the implementation. The possible role for exemptions to the law was discussed. There was strong support that all differences needed to be “objectively justified” and it was recognised that there could be benefit from having some services that were targeted and tailored for specific age groups.

## 2. The Resource Pack

We were impressed by the feedback we received from the field about the work that followed the National Service Framework for Older People, especially the audit that used the work published by the King's Fund.

We have tested out our ideas with the NHS, Local Authorities and public, patient and service user groups locally across the South West and this has led us to work on a "typical implementation process". This would not be the only way to prepare for the legislation and address wider issues of age equality but organisations have told us that they would find it helpful as a template that they can adapt for local implementation.

Thus we have started work on producing a set of resources that will help Local Authorities and the NHS work with their partners, both private and third sector providers and groups representing the public, service users and carers. This work is being undertaken using the principles of co-production with the different stakeholders and will be tested and improved in the light of the formal consultation processes over the next few months.

The resource pack will complement statutory guidance from the Equality and Human Rights Commission and guidance on the implementation of all aspects of the Equality Bill from the Department of Health.

There are three components to the resource pack:

- **An audit tool on age discrimination** - the National Development Team for Inclusion are co-ordinating the work on a toolkit that will enable local NHS organisations and local authorities to undertake an audit or gap analysis of their position on age discrimination and age equality. This will include a focus on their preparedness for the implementation of the relevant requirements of the new Equality Bill and ideally should be undertaken jointly between health and social care with the full involvement of public, patient and service user groups.
- **Good Practice Guidance for the NHS** - Ros Levenson and colleagues, including Age Concern and Help the aged are co-ordinating the production of guidance for local NHS organisations. The aim is that the guidance will help both commissioning and provider organisations build on the information and insight from using the toolkit and draw up action plans and identify solutions to end age discrimination and promote age equality in their organisations.
- **Illustrative Practice Guide for adult social care departments within local authorities** - the Social Care Institute for Excellence were commissioned by the Department of Health to produce materials that will help local authorities identify, formulate and

promote good practice in encouraging age equality and tackling age discrimination in social work, social care commissioning and service provision.

From the engagement events and other discussions, we believe that the key features of successful local engagement include:

- a) A collaborative approach between health and social care working closely with other statutory agencies and the third and private sectors and with patients, service users, carers and the public.
- b) A clear and systematic approach to understanding the current position and to action planning.
- c) Transparency and openness in identifying issues, agreeing solutions and monitoring progress.
- d) A focus on quality improvement and outcomes rather than compliance with the law.
- e) Integration into core decision making processes and existing policies but remaining explicit about age discrimination as this is the main new provision of the Bill for health and social care.
- f) A strong focus on supporting staff to reflect on their practice and providing education and training to help them understand and respond to people's needs and aspirations.

### 3. Indicators

The need to have high quality, timely, relevant information on age differences and discrimination has been a key theme of the work both nationally and in the South West. Understanding the patterns of services is a key component of all work on equalities but there is potential to have excellent information and intelligence on age related patterns and outcomes because organisations routinely and accurately collect the data of birth of patients and service users. However we note that many existing systems do not explicitly compare the provision between different age groups and try to relate this to need.

We have looked at the existing data on age related services. There have been some excellent national reports on health and well being among older people (the Health and Social Care Information Centre's *Health Survey for Older People* in 2005 and *Indications of Public Health in English Regions for Older People* by the Association of Public Health Observatories in 2008) and we have looked at what these have told us about the South West (for example in *Second Blooming: Towards achieving a healthy and mature population in the South West* by the South West Public Health Observatory in 2005).

We are working in collaboration with the Faculty of Health and Social Care at the University of West of England to produce an indicative list of measures of age differentiation that are potential indicators of age discrimination. The work has drawn on the evidence presented to the review, such as the literature reviews produced by the Centre for Policy on Ageing, and requires further work and discussion. Our main focus has been on services for older people as the evidence indicates this is the main area of discrimination.

The aim of producing a set of indicators is to help NHS organisations and local authorities analyse their current services in relation to age and benchmark their position with to other geographical areas to help identify issues of potential discrimination that need to be addressed. Underpinning the work is the view that it is not possible to use quantitative data to conclusively prove that individuals have been discriminated against or a pattern of service provision is discriminatory but, combined with other quantitative and qualitative data, information can help organisations identify local priorities to action to end age discrimination and be compliant with the new legislation.

The intention is that the indicators can be calculated using data that is already collected and available but by presenting them in an accessible format and using age related ratios, they will be provided as a comparative set, conceptually similar to NHS Comparators. They will need to be updated to enable the NHS and Local Authorities track progress as they prepare for the implementation dates.

We have grouped the indicators under the following headings:

- Social care
- Mental health services
- Prevention, promotion and primary and community health care
- Acute secondary and tertiary health care

Indicators 1 to 5 aim to provide an overview of population characteristics as context to considering levels of need among different age groups in a geographical area. The remaining indicators have been selected to cover three main areas of service delivery:

- screening/assessment/prevention,
- levels of access
- outcomes/quality of life

We have two generic issues that merit further consideration:

- a) should we try to use the same age groupings for all indicators and should we seek to compare with the whole population or between specific age groups? This may not be possible as different data sets use 16 and 18 as the lower age for “adult services” and over 55, 65, 75, 85 and 90.
- b) Should data where appropriate be provided for commissioners and for providers?

<b>1. Context Measures</b>	
<b>1.1</b>	<b>Percentage of the population aged 65+</b>
	<i>Rationale: this helps set the context for the proportion of older people, which the evidence presented to the review shows is the main group to experience age discrimination</i>
	<i>Question: this data is readily available and understood locally so does it add anything? should there be further age splits and is there a need for other population characteristics such as ethnicity - these may help local discussion about dual/multiple discrimination</i>
	<i>The South West has 19% which is the highest percentage of any region in England</i>
<b>1.2</b>	<b>Life expectancy at age 65</b>
	<i>Rationale: this data helps identify the underlying health of</i>

	<i>the population of older people</i>
	<b>Question:</b> <i>there are also estimates of “healthy life expectancy” and “disability free life expectancy” - would these be more helpful in setting the context?</i>
	<b>The South West</b> <i>the expectancy was 16.9 years for men and 20.0 years for women in 2001 and this is also the highest of any English region.</i>
<b>1.3</b>	<b>Cancer and Cardio Vascular Disease mortality rates for people aged 75 or over</b>
	<b>Rationale:</b> <i>These are the two main causes of death in England and the mortality rate for under 75s has been one of the “Vital Sign” indicators</i>
	<b>Question:</b> <i>should the indicator compare the 75+ rate with the average for all ages?</i>
	<b>In the South West</b> <i>the directly standardised rates for over 65s in 2005 were the lowest of any English region for cancer and second lowest for CHD, though the rate for stroke were significantly closer to the national average.</i>
<b>1.4</b>	<b>The percentage of people aged 65 or over who are living in fuel poverty</b>
	<b>Rationale:</b> <i>fuel poverty is a good indicator of wider poverty and in 2006 at a national level, 30% of single pensioners were in fuel poverty.</i>
	<b>Question:</b> <i>should we use a different indicator of poverty?</i>
	<b>In the South West</b> <i>just under 7% of the population are in fuel poverty, which is in the middle of the English regions but below the national average.</i>
<b>1.5</b>	<b>The percentage of people age 65 or over who have recorded at least one fall (in the past 12 months)</b>
	<b>Rationale:</b> <i>Mobility is a major issue among older people and falls are the most frequent and most serious type of accident - over 30% of older people will fall during the course of a year</i>
	<b>Question:</b> <i>as the data is not routinely available, should the age standardised admission rate to hospital be used?</i>
	<b>In the South West</b> <i>the rates in the Health Survey for England 2005 were 24% for men and 29% for women, which were above the England average. The age standardised admission rate to hospital in the SW were also above the England average, with the rate for women being</i>
<b>Indicator Measures</b>	
<b>2. Prevention, promotion, primary and community health services</b>	
<b>2.1</b>	<b>In the smoking cessation service, the percentage of those who set a “quit date” aged 60 or over, compared to the population of people over 60 (with a note of the percentage of those who set a “quit date” over 16 compared to the population)</b>
	<b>Rationale:</b> <i>indicative of attitudes to quality of life for older people and targeting of public health resources.</i>

	<i>Question: as constructed this will allow PCTs to compare the “reach” of the smoking cessation service among older people. However should we consider the success rate, thought this tends to higher among people over 60?</i>
	<i>In the South West the HSE reported a smoking rate among over 65s of 11.7% (below the England average of 12.4%). The rate of those setting “quit date” per 100,000 for over 16s in the south west was not quite double that of over 60s.</i>
2.2	<b>Looking at the population of people aged 65 or over, percentage seasonal influenza vaccine uptake (in the previous 12 months?)</b>
	<i>Rationale: comparator between geographical areas.</i>
	<i>In the South West in 2008-09 the rate was slightly higher than the national average for over 65s and slightly below the rate for those under 65 and defined as at risk.</i>
	<i>Question: should we look at the ratio between over 65 to under 65 at risk?</i>
2.3	<b>The percentage of all excess winter deaths that occur among people aged 65 or over</b>
	<i>Rationale: Excess winter death index is designed to identify the number of deaths above the residual level of mortality and is proportionately higher among older age groups.</i>
	<i>Question: should we simply present the data or should we look at the ratio of older people to all ages? The data varies between years so it is difficult to identify trends - do the ratios remain reasonably constant?</i>
	<i>In the South West the index was 15.7 in 2007-08 for all age and 91.1 for over 85s. This similar to the rate for all English regions but the SW is unusual in having a lower figure for the 75-84 band compared to the 65-74 group.</i>
2.4	<b>The rate per 1000 women aged 65 to 70 who received breast screening in the previous 12 months compared to the rate for 50 to 70.</b>
	<i>Rationale: The screening programme has been shown to reduce mortality and morbidity while a quarter of breast cancers develop in women over 70</i>
	<i>Question: A related issue is the uptake of the offer to request screening in over 70 year olds though we should be able to have data on access for 70-73 year olds as the programme raises the upper age limit</i>
	<i>In the South West the rate per 1000 in 2007-08 was slightly higher in the 65 to 70 age group.</i>
2.5	<b>The percentage of people aged 65 or over who receive NHS footcare services</b>
	<i>Rationale: It is widely felt that there is considerable under provision of podiatry services for older people despite evidence that they can have a major impact on quality of life in reducing mobility. It is difficult to identify discrimination for individuals but the NSF for Older People gave footcare as an example of discrimination.</i>

	<i>Question: there is data on access to NHS chiropody services but this does not include all forms of footcare. Should the indicator compare age groups, though at a national level the rate is highest among the older age groups.</i>
	<i>In the South West the NHS chiropody rate is the sixth of the regions across England in 2004-05</i>
<b>2.6</b>	<b>The percentage of the population aged 65 or over who receive palliative care (including or excluding for cancer?)</b>
	<i>Rationale: older people are less likely to receive palliative care and there are considerable geographical variations in levels of access (CPA review)</i>
	<i>Question: we are not sure what routine data is available on palliative</i>
<b>3. Acute secondary and tertiary health care</b>	
<b>3.1</b>	<b>The average waiting time in Accident and Emergency for people aged 65 or over (compared with people aged under 65?)</b>
	<i>Rationale: While there may be valid reasons for some difference in this measure, there is evidence that older people wait on average 4 times as long as younger age groups (CPA review).</i>
	<i>Question: we are not sure whether there is national data to enable this to be calculated so is there another indicator that should be considering about A&amp;E performance?</i>
<b>3.2</b>	<b>The ratio of the number of hip replacements per 10,000 people aged between 65 and 74 compared with the number per 10,000 people aged 75 or over and the number aged under 65</b>
	<i>Rationale: compares targeting of resources across ages for the same condition/ treatment.</i>
	<i>Question: Would it be better to look at the relative length of the waiting time for patients over 65 compared to the waiting time for under 65s? Should we look at other procedures?</i>
	<i>In the South West the directly standardised admission rate for hip replacement in 2005-06 was the highest of any English region.</i>
<b>3.3</b>	<b>The ratio of the number of women per 1,000 of the population aged 65 or over who have had breast cancer surgery compared with the number per 1,000 of the population aged under 65.</b>
	<i>Rationale: Around 13,000 women over the age of 70 are diagnosed with breast cancer each year in the UK. While younger women routinely have surgery to remove their tumours, those who are older have significantly poorer access to surgery, even when the grade and size of tumour have been adjusted for.</i>
	<i>Question: should the age groups be changed to link with the screening programme?</i>
	<i>In the South West the age standardised rate of breast cancer incidence in 1997 was slightly above the national rate and in 2000 the standardised incidence rates were marked higher for women over 75 than for those aged 50 to 74. Data on the</i>

	<i>surgical rate is available but has not been analysed.</i>
<b>3.4</b>	<b>The average waiting time for cataract treatment among people aged 65 or over compared with people aged under 65</b>
	<i>Rationale: good vision is a key factor in maintaining independence</i>
	<i>Question: the admission rate for cataract surgery from HES is complicated as some admissions are as outpatient procedures so looking at average waiting times might enable the differences in performance for different age groups to be analysed subject to the data being available.</i>
<b>3.5</b>	<b>The percentage of hospital complaints that are primarily concerned with age discrimination</b>
	<i>Rationale: enables comparison between geographical areas.</i>
	<i>Question: the data may be not be consistently recorded and with the new data definitions resulting from the new health and social care complaints system, this data is unlikely to be available</i>
<b>3.6</b>	<b>The percentage of patients over 65 who report experiencing doctors talking the front of the patient as they were not there compared to the percentage for under 65 year olds.</b>
	<i>Rationale: the CPA review showed how this indicator from the National Patient Survey increases for over 65s and marked increased for over 80 year olds</i>
	<i>Question: should the indicator focus on the over 80 year olds (though this may lead to very small numbers when broken down to local organisations) Should another and/or additional questions from the survey programme be used?</i>
	<i>Nationally the results of the survey were that in 2005 for 36-50 year olds the answer "yes often" was 5.95% and 7.0% for over 80 year olds</i>
<b>3.7</b>	<b>The ratio of the number of people per 1,000 of the population aged 85 or over who are admitted to specialist stroke units compared with the number per 1,000 of the population aged under 65 - 84 and the under 65s</b>
	<i>Rationale: older patients, and particularly those over 85, are less likely to be referred for surgical interventions for stroke.</i>
	<i>Question: are these the rights age bands? The national audit uses an indicator of "percentage of patients who spent at least 90% of their stay in a stroke unit" but this is not broken down by age.</i>
	<i>In the South West six of the 17 hospitals in the audit were below the national average of 58% in 2008 audit</i>
<b>3.8</b>	<b>The percentage of hospital emergency readmissions within 28 days of discharge among people aged 65 or over compared to all ages</b>
	<i>Rationale: Although there may be good reasons for the differences, the readmissions figure is higher for older people than for other age groups and varies considerably geographically.</i>
<b>3.9</b>	<b>Compliance with the NICE IVF Guidelines</b>

	<i>Rationale: NICE has issued guidelines on IVF services which PCTs are expected to comply with. Some PCTs have developed different criteria and compliance with the NICE criteria vary.</i>
	<i>Question: data on compliance from around the country is based on occasional surveys of PCTs so it may not be able to answer the question.</i>
<b>4. Mental health services</b>	
<b>4.1</b>	<b>The proportion of people aged 65 or over who are referred to old age psychiatry</b>
	<i>Rationale: The treatment of mental health problems has been identified as an area where older people have lower access to services than other age groups, possibly due to ageism.</i>
	<i>Question: this gives the geographical differences but if the indicator looked at the rate per 1000 population of referral to psychiatry in over 65s compared to 18 to 64, then the indicator might be more focused on age differentiated patterns. Data on should be able to be extracted from the Mental Health Minimum Data Set</i>
	<i>In the South West the age standardised admission rate for mental health is the highest in country in 2005-06.</i>
<b>4.2</b>	<b>The proportion of people aged 65+ with accessing a memory clinic/specialist dementia services?</b>
	<i>Rationale: Dementia is under-diagnosed and the Dementia Strategy recognises the importance of memory clinics in maximising independence and quality of life for people with dementia</i>
	<i>Question: is this a reasonable way of looking at dementia diagnosis rates?</i>
	<i>In the South West the age standardised admission rate for dementia is the second highest in country for men and the third lowest for women (in 2005-06)</i>
<b>4.3</b>	<b>The ratio of the number of people per 1,000 of the population aged under 65 who have been referred for psychological therapies in the last 12 months compared with the number per 1,000 aged 65 or over?</b>
	<i>Rationale: there is some evidence that older people have less access to psychological therapies, despite high levels of reported depression.</i>
	<i>Question: the main data source appears to be related to the coverage of the IAPT (Improving Access to Psychological Therapies) Programme. Does this offer sufficient coverage or are there alternatives and can these differentiate different age groups?</i>
<b>5. Social care</b>	
<b>5.1</b>	<b>The ratio of per capita expenditure by councils on social care for people with care needs aged 65 or over compared with those aged 18 to 64.</b>
	<i>Rationale: There is explicit differential funding of care packages for older people and younger adults with disabilities,</i>

	<i>along with widespread use of cost-ceilings</i>
	<i>Question: should we separate different services and different clients or try to aggregate?</i>
	<i>In the south west rates vary substantially between locations and services but there is not simple regional data.</i>
<b>5.2</b>	<b>The ratio of the rate of carers assessments per 1000 of the population for carers aged 65 or over compared to all adults</b>
	<i>Rationale: serves as a comparator between geographical areas. The role of older people as carers is increasing recognised and yet the number of carer assessments often remains low.</i>
	<i>Question: should the comparison be with all adults, all ages or a specific age group</i>
	<i>In the south west the rate for over 65s in 2007-08 was significantly higher than for the whole population and there was substantial variation between local authorities.</i>
<b>5.3</b>	<b>The ratio of the number of people per 1,000 of the population aged 65 or over who receive a completed local authority assessment, compared with the number per 1,000 of the population aged over 18.</b>
	<i>Rationale: The rate is clearly markedly higher for older people but the variation in the rate between local authorities is substantial.</i>
	<i>Question: should we separate new and existing clients?</i>
	<i>In the south west the assessment rate per 1000 population is more than three times the rate of over 65s than all adults but there are significant variations between local authority areas.</i>
<b>5.4</b>	<b>The ratio of older people who take up individual budgets of all clients compared to working age adults</b>
	<i>Rationale: there is a large variation across councils in the proportion of older people receiving direct payments and there is anecdotal evidence of older people not being offered individual budgets.</i>
	<i>Question: should we use survey data on older people's experience of being offered budgets? We could look at the rate of uptake as a proportion of population but not sure if this would be clearer about the nature of the offer rather than the reported phenomena of older people's general reluctance to take up budgets.</i>

## 4. National age explicit criteria: an initial list

This is an initial list that the review used for its scoping work and analysis on age discrimination. It was produced following discussions within Department of Health and Arms Length Bodies and these organisations will need to revisit it as part of Recommendation 8 in the Review to “assess age based criteria in a transparent manner leading to changes in policy if required”.

### a) Cancer

#### Breast screening:

- Women aged 50 to 70 are invited every three years for breast screening by mammography. This is being extended to 47 to 73.
- Women aged over 70 able to self-refer every three years if they wish. The Department has produced a leaflet with Age Concern to raise awareness of self-referral, which can be viewed at the following link:  
<http://www.cancerscreening.nhs.uk/breastscreen/publications/l-02.html>

#### Cervical Screening:

- Woman aged 25 to 49 is invited for a cervical screening test every three years.
- Women aged 50 to 64 are invited every five years.
- Women aged over 64 are invited if they have never been screened or if their last three tests showed abnormalities.

#### Bowel cancer screening:

The NHS Bowel Screening Programme began in April 2006 and is due to be fully rolled out by December 2009.

The programme has started by:

- inviting men and women aged 60 to 69 to participate every two years;
- enabling men and women aged 70 and over to self-refer every two years.

The CRS has committed the Department to extending screening to men and women aged up to 75 from 2010, and making a decision on screening men and women in their 50s in 2010.

### b) IVF

The NICE fertility guideline recommends IVF for eligible couples where the woman is aged 23-39 years. The guideline is being reviewed, beginning in 2010.

**c) Sperm and egg donation**

Age limits of 18-35 for egg donors and 18-45 for sperm donors are recommended by the Human Fertilisation and Embryology Authority.

Clinics may choose to make exceptions.

**d) Seasonal Flu Vaccination**

People over 65 are able to receive seasonal flu vaccination (other criteria apply for people under 65)

**e) Chlamydia screening programme**

Chlamydia screening programme targets age groups 15-24

**f) Charges**

People over 60 are exempt for prescription charges and sight tests

**g) NHS Health Checks (CVD)**

The programme is aimed at people between 40 and 74 years old at risk from coronary heart disease, stroke, diabetes and kidney disease.

**h) Entitlement to request annual health check for over 75s**

The 1990 GP contract requires GPs to offer patients over 75 an annual health check.

**i) Various indicator sets**

Local indicators for mortality from Cardio-vascular disease and for cancer in under 75 year olds are used. This is in Vital Signs and in the Comprehensive Area Assessment. However it is part of the current Comprehensive Spending Review cycle and so will be reviewed before 2012.

## 5. Joint Strategic Needs Assessment

Our work has also shown that the Joint Strategic Needs Assessment has the potential to set a local framework for creating age equality by focusing on the needs of the local population. The JSNA is a document produced by local statutory organisations setting out the health and care needs of the population. Thus we commissioned the University of West of England to undertake an analysis of the JSNAs and associated documents for all the locations across the South West.

### **Joint Strategic Needs Assessments in South West England: a documentary analysis.**

Since 2007 all primary care trusts and local authorities have a statutory duty to work together to publish a Joint Strategic Needs Assessment (JSNA). The JSNA “is a process that will identify the current and future health and wellbeing needs of a local population, informing the priorities and targets set by Local Area Agreements and leading to agreed commissioning priorities that will improve outcomes and reduce health inequalities” (Department of Health website). The local approach to producing the JSNA varies greatly as do the format of the documents produced.

JSNAs provide an important opportunity to identify age differentiated patterns of need within populations and to plan service delivery in proportion to those needs. In this respect they are an invaluable part of the process of ensuring that services do not discriminate on the grounds of age.

A documentary review was carried out of 13 JSNAs and associated action plans using the south west of England as a case study area in order to explore the extent to which the needs of older people are identified and how those needs are reflected in the commissioning intentions of Local Authorities and Primary Care Trusts.

This review found considerable variation in the way that the needs of older people are identified and addressed. Four authorities stand out as giving older people considerable prominence compared with others through, for example, the development of an ‘Ageing Strategy’. There is also some ambiguity in definitions. While most JSNAs categorise older people as being over 50, the bulk of the discussion and analysis pertains to people over 65 years old, with some reference made to those over 85. The term elderly is still being used in some reports, which seems to indicate a narrow focus on the clinical needs of older people. This contrasts with the broader, more holistic approach to wellbeing, independence and dignity in later life adopted by some authorities.

Six of the areas specifically mention ‘Age Discrimination’ in their JSNAs and/or their action plans. References to equality/inequality were more frequent but these related to general discussions of geographical patterns of deprivation rather than to older people specifically.

Overall it is clear that some areas are in the early stages of thinking about issues to do with ageing. Best practice in this respect is based on compiling appropriate information, being aware of the national policy context, involving older people in service development and taking a person-centred approach to service delivery. We also suggest that identified age-specific needs should be addressed in comprehensive action plans that include targets and timescales.

Faculty of Health and Social Care  
University of the West of England

## 6. Literature Reviews

In all six literature reviews have been commissioned to inform the review.

The Centre for Policy on Ageing has undertaken five literature reviews focusing on the evidence for age discrimination in health and social care. They have drawn upon a range of material including peer-reviewed quantitative and qualitative research, large scale surveys and studies, policy documents, case studies and opinion pieces.

The five studies have focused on older people and covered the following areas:

- Likely costs and benefits of legislation to prohibit age discrimination and potential measures of age discrimination
- Primary and community health services
- Secondary health services
- Social care services
- Mental health services

The sixth review on cost effectiveness analysis is discussed in the next section.

There are a number of cross cutting themes from their work which the CPA have summarised as follows:

### **Ageism and Age Discrimination in Health and Social Care - Summary of key findings**

In 2007 and 2009 the Centre for Policy on Ageing carried out a series of five literature based reviews, commissioned by the Department of Health, to look for evidence of age discrimination in health and social care services in the United Kingdom. The reviews looked at the costs and benefits of age discrimination legislation and at evidence of discrimination in primary health care, secondary health care, mental health care and social care. The following is a brief summary of the main cross cutting themes and issues that emerged from these reviews.

The reviews distinguished between *ageism*, a term first used in the late 1960s to describe an unjustifiable prejudicial attitude of mind towards older people, and *age discrimination*, discriminatory actions, made purely on the basis of age that can be observed and, perhaps, measured. Age discrimination can occur in a variety of ways. *Direct* age discrimination treats two individuals with similar needs differently purely on the basis of their age. *Indirect* age discrimination treats people of all ages the same, not recognising the greater needs of particular age groups so those age groups are disadvantaged. *Institutional* age discrimination is age discrimination written into policies and practice. *Individual* age discrimination is discriminatory action taken by individuals as a result of their own personal ageist attitudes. *Overt* age discrimination is age discrimination that is open

and observable. *Covert* age discrimination is hidden and possibly even subconscious. Institutional age discrimination is likely to be overt. Individual age discrimination is likely to be covert.

Age differentiated behaviour is a well thought out and justifiable difference in treatment by age based on a well developed understanding of age differences. Age differentiated behaviour should not be used as a euphemism for age discrimination.

Partly as a result of policy audits carried out following the publication of the National Service Framework for Older People in 2001 there are very few remaining examples of overt, institutional direct age discrimination in health and social care. The key national examples of age differentiated services are the age cut-offs in screening programmes by invitation, some of which are age discriminatory and others where there is no data to support the current cut-off, the age based organisation and provision of mental health services and the age based organisation and provision of social care services. Arguably, the use of the Quality Adjusted Life Year (QALY) in assessing the overall relative cost effectiveness of treatments that are only or mainly of benefit to older people is also age discriminatory.

Although not explicit and overt, there is widespread evidence of the unjustified differential treatment of older people as a group in both primary and secondary healthcare. The discrimination is mainly covert and results from the cumulative effect of ageist attitudes by individual healthcare workers. Some age discrimination is direct discrimination and manifests itself, for example, in lower rates of referral and more late referrals of older people to specialist care by General Practitioners (GPs), the lower proportion of quality of care indicators met in primary care for geriatric conditions compared with general medical conditions, lower application rates of primary and secondary prevention for older people, lower rates of appropriate surgical intervention for older people and lower rates of appropriate diagnosis and treatment for heart disease, cancer and transient ischaemic attack and stroke for older people, even after issues of frailty and co-morbidity have been taken into account.

Much age discrimination experienced by older people in health and social care is, however, indirect, either through the inadequate provision of services mainly used by older people or the equal application of policies to the disadvantage of older people with greater needs. Hospital discharge policies, equally applied, result in higher rates of emergency readmission within 28 days of discharge for those aged 75+ and the gap is widening. The reduction in GP home visit consultations from 22% in 1971 to 4% in 2006 and the recent reorganisation of out-of -hours services affect older people disproportionately. The late diagnosis and under-diagnosis of dementia, with up to one half of cases going unrecognised and poor quality foot-care services with 58% of older people in need of foot care services having to make private provision are likely indicators of indirect age discrimination in these areas.

Individual ageist attitudes underpin much of the age discrimination observable in health and social care. There is evidence, in secondary health care, that doctors are more ageist than nurses, however ageist attitudes by health and social care staff is a pervasive issue and is likely to reflect ageist attitudes in society as a whole. Although legislation can provide a marker, ageism in health and social care has to be addressed through a longer term programme of intervention in education and training.

Although it is agreed, at national level, by professional bodies and the government, that health, mental health and social care services should be organised and provided on the basis of need rather than age, there is widespread variation in the way services are organised and applied at a local level. Particularly, in mental health services and social care, there is much variation in the degree of age discrimination to be found in the application of policies in different localities.

Although not strictly part of health and social care, related benefit payments such as Attendance Allowance, Disability Living Allowance and Independent Living Funds have age-based cut-offs in their application which may conflict with age discrimination legislation.

To avoid the complications of co-morbidity, older people have often been excluded from clinical trials. The situation is improving but there is still a large knock-on effect in healthcare, with approved drugs not having been tested on older people, so doctors have to either not prescribe or prescribe 'off label'.

Finally, although it has been estimated that to bring older peoples services up to the level of the best, for mental health care alone, would cost £2 billion per year, our view is that national health and social care budgets are largely determined by external factors and, although the elimination of age discrimination may result in a redistribution of funds within healthcare, evidence from other countries indicates that the introduction of age discrimination legislation has little or no long-term effect on the total healthcare budget.

Centre for Policy on Ageing  
October 2009.

## 7. Cost Effectiveness and Quality Adjusted Life Years (QALYs)

During the course of our evidence gathering, the Review heard a number of concerns expressed about the use of Quality Adjusted Life Years (QALYs). Some stakeholders raised specific issues whilst others expressed a general anxiety. This annex presents the Review's thoughts on these issues. It does not have any legal status.

The annex first discusses cost effectiveness, which is an underlying concept from which the use of cost per QALY gained flows. It then looks at refinements to the QALY methodology. Finally, it discusses how NICE uses a QALY methodology to inform its decision making but takes other factors into account. It should be noted that although NICE is the body that is most recognised in terms of applying QALY methodology, other decision-makers including the Department of Health, the Human Tissue Authority and the Joint Committee on Vaccination and Immunisation also use it.

### Cost effectiveness

1. There is a limited pool of resources available for spending on health and social care which means that the system often has difficult decisions to make concerning whether certain treatment or care should be provided to an individual or to anyone at all. The Department of Health, the NHS and local authorities generally consider the cost effectiveness of the care or treatment to inform this decision. If the cost of care or treatment is high relative to its effectiveness then it is less likely to be funded because this would mean that some other more cost effective treatments, which would deliver greater benefits to patients or service users, could not be funded. This does mean that people may be treated differently in terms of provision of specific services.
2. The Review believes that the use of cost effectiveness as an element in decision making is a proportionate means of achieving a legitimate aim. The legitimate aim being sought is the best use of scarce resources available for health care and protection, and application of the evidence on clinical and cost-effectiveness is the proportionate means of achieving it.

#### *Is cost-effectiveness objectively justifiable in principle?*

3. The use of cost effectiveness enables decisions to be made on treatments, based on a view of the benefit of these relative to the cost. In looking at benefit or effect, cost-effectiveness does not consider the characteristics of the population that are benefiting. This means that, when used in isolation,<sup>1</sup> it does not place a higher value on improvements or support of some individuals more

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<sup>1</sup> Usually cost effectiveness is not used in isolation and consideration is given to impacts on specific groups through the use of Equality Impact Assessments or the inclusion of social values in decision making.

than others. Equally, it does not make adjustments where the characteristics of a particular group mean that they will benefit to a lesser degree from care or treatment. i.e. If older people benefit less from a treatment due to their co-morbidities or lower life expectancy then this treatment would be considered less cost effective for older people and hence might not be provided. This arises when a pure approach to cost effectiveness is taken. In practice, many decisions are not made this way - see later discussion.

4. The benefit/effectiveness is considered from the perspective of the overall population which does not know the age of the patient, only the improvement they experience, rather than from the perspective of the individual patient. Hence, the population might consider that a small improvement in a person's condition is of relatively low value (especially when compared with a greater improvement in another person's condition). However, the individual in question might value the small improvement very highly and our approach to cost effectiveness does not take this into account. (It is not clear that individuals in any age group value small improvements more highly than other age groups, though, so this aspect may not have a differential impact.)
5. There are a number of alternative ways of allocating resources that do consider characteristics explicitly. The paper by Persad, Wertheimer and Emanuel, *Principles for allocating scarce medical interventions* considers the main ones.<sup>2</sup> This paper highlights the limitations of all approaches to resource allocation. It faults cost-effectiveness based or "utilitarian" approaches for not taking into account relevant characteristics of patients. However, it expresses a preference for "The Complete Lives" approach to allocation which explicitly bases decisions on age. It argues that this is appropriate because, those fortunate enough to live to old age have benefited when they were young from the greater availability of care at this point. We do not think that such an approach addresses the concerns there might be about cost effectiveness under the new legislation.<sup>3</sup> We consider the limitations of the other approaches described to be more problematic than those posed by cost effectiveness.
6. We therefore think that considering cost-effectiveness is the most appropriate way of allocating resources given the constraints of the healthcare budget.

## Use of QALYs

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<sup>2</sup> Principles for allocation of scarce medical interventions, Govind Persad BS, Alan Wertheimer PhD, Ezekiel J Emanuel MD, *The Lancet*, Volume 373, Issue 9661, Pages 423 - 431, 31 January 2009 [http://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(09\)60137-9/fulltext](http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(09)60137-9/fulltext)

<sup>3</sup> This is similar to the Fair Innings approach. NICE's Citizens' Council considered this approach and rejected it.

7. QALYs are used to compare policies, technologies and drugs against their current standard treatment in the NHS in order to assess the health gain from the intervention. There are many ways to measure effectiveness, but what is required is a measure that can be used across all interventions, so that comparisons can be made with other interventions and a benchmark level (threshold). Hence generic health benefit measures have been developed - normally called the QALY.

#### How QALYs are estimated

A QALY approach “assigns to each period of time a weight, ranging from 0 to 1, corresponding to the health-related quality-of-life during that period, where a weight of 1 corresponds to optimal health and a weight of 0 corresponds to a health state judged to be equivalent to death”.<sup>4</sup> The number of QALYs gained with a particular treatment is calculated by the value given to the quality of life with that treatment multiplied by the length of life achieved with the treatment. A treatment may increase the quality of life for a patient, may extend life or do both. As a result, the use of QALYs as a measure of benefit can be used to compare the benefits of all medical interventions.

#### *Challenges to general approach to using QALYs*

8. As stated above, the duration of benefit is one factor used in assessing a QALY gain. Grimley Evans (1997)<sup>5</sup> has argued that this “indirectly puts different values on individuals according to their life expectancy. Thus citizens are no longer equal and older people in particular are disadvantaged”. However, removing this factor creates what many people would consider a perverse situation that a treatment would be considered of equal effectiveness whether they extended a patient’s life for a day, a week or a year.
9. The other factor used in assessing QALY gain is the amount of improvement to the patient. This factor seems reasonable as it allows for differentiation between treatments with small effects and those with large effects. However, the measured benefit of the treatment may be capped by the person’s long term health state. This could disadvantage disabled and older people as their long term health state is usually below 1 reflecting the limitations placed on them by their disability or co-morbidities. This is a well recognised problem, though in practice, this seldom arises in decisions (see paragraph 17). Furthermore, it is difficult to find a solution to this that does not give rise to other problems.

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<sup>4</sup> Foundations of cost-effectiveness analysis for health and medical practices, Weinstein, M.C. and Stason, W.B. New England Journal of Medicine, 1977, 296:716

<sup>5</sup> The rationing debate: Rationing health care by age: The case against, Grimley Evans, J. BMJ 314:822, 1997

10. A literature review by Edlin et. al.<sup>6</sup> considers various ways of alternatives to the general QALY approach and finds that all have shortcomings and many of the more practical alternatives would give older people even lower priority in resource allocation. They consider procedural theories (Daniels, 1985)<sup>7</sup>, constraining maximisation with an access cut off/ “fair innings” (Dey and Fraser, 2000<sup>8</sup>, Callahan, 1986<sup>9</sup>, Williams, 1999<sup>10</sup>), and incorporating age into the objective function and giving it a weighting (various authors).

#### *Detail of calculating QALYs and assessing value*

11. From our call for evidence, several questions around the estimation of QALYs have been posed. Respondents have requested that further research be done in these areas. This section reviews these issues and the state of current research on them. It also flags where certain adjustments might have unexpected consequences in terms of the treatments that are more likely to be approved. Unexpected consequences often arise because all treatments are assessed on a common basis so adjusting that basis leads to a review of all. Given the fixed budget constraint, if new treatments are approved then other treatments (that might affect the same or different groups of patients) might be used less or not receive funding. In practice, it is difficult to identify what treatments are unfunded or opportunities are forgone as a result of this process.
12. *QALYs don't take into account small improvements of the sort that often occur in older people as the EQ5D is not refined enough.*<sup>11</sup> Euroqol, the group responsible for the EQ5D methodology, is working on EQ5D-5L which describes the extent of a problem at five levels rather than three. The Euroqol group have indicated that a “valuation protocol” now needs to be developed for each country which translates these descriptions of health states into numerical values reflecting how strongly people feel

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<sup>6</sup> Cost-effectiveness analysis and ageism: a review of the theoretical literature, R. Edlin, J. Round, C. McCabe, M. Sculpher, K. Claxton, R. Cookson, June 2008, Leeds Institute of Health Sciences

<sup>7</sup> Just Health Care, Daniels, N. 1985, Cambridge University Press: New York

<sup>8</sup> Age-based rationing in the allocation of health care, Dey, I and Fraser, N. Journal of Aging and Health, 2000, 12:511

<sup>9</sup> Adequate Health care and an ageing society: Are the morally compatible, Callaghan, D, 1986 Daedalus Winter:247-67

<sup>10</sup> Inequalities in health and intergenerational equity, Williams A, 1999, Ethical theory and moral practice, 2:47-55

<sup>11</sup> The EQ-5D is a widely used generic instrument to measure and value health. The EQ-5D descriptive system consists of 5 dimensions: Mobility, Self-Care, Usual Activities, Pain/Discomfort and Anxiety/Depression. Each dimension defines 3 levels, indicating no problems, some or moderate problems, and extreme problems, resulting in a total of 243 (35) unique health states (permutations). The EQ-5D can be used for descriptive purposes and as an instrument to derive health-related quality of life as a single summary index. Brooks R, Rabin R, Charro F de (eds). The measurement and valuation of health status using EQ-5D: A European perspective. Dordrecht, Kluwer academic publishers, 2003

one state compares to another. It is expected that the new measure will be available for use in the next few years.

13. *The cost per QALY gained approach does not take into account the costs borne by carers and social services - or the savings to these groups if the health improves of an individual receiving care.* QALYs currently measure only health benefit associated with the drug or treatment.<sup>12</sup> A number of other parties are recommending that other non-health benefits are taken into account, such as the patient's increased productivity from improved health. If some non-health benefits are taken into account then it is likely to be appropriate that all are, making it difficult to predict how this will change the types of treatment approved. Closer examination reveals a number of complexities and potentially perverse effects. For example, attaching a greater weight to impacts on economic productivity would have the effect of prioritising interventions for adults of working age, effectively deprioritising interventions for older people or for people who are too ill to return to work even with treatment.
14. It is also worth considering how the inclusion of non-health costs and benefits would actually affect health: if treatments were approved that gave considerable external benefits over treatments that gave mainly health benefits then the budget allocated to health could be used up on a lot of non-health spending. In theory, the health budget could be re-imbursed by the other areas that benefited from this spending. However, this does not happen in practice.
15. The Department of Health has held a number of workshops with stakeholders to explore this issue and, following those workshops, has commissioned York University to undertake research in this area. York University is expected to publish a report later this year.

### **Role of NICE**

16. NICE produces guidance on three broad areas of health: public health; health technologies and clinical practice. In order to make sure its recommendations represent good value for money, it uses the best evidence to weigh up costs and benefits. The independent committees who produce the guidance discuss the evidence and make decisions about a particular health topic. NICE committees are made up predominantly of professionals but also include patients and members of the public.
17. In most circumstances NICE does not produce guidance that would result in one person in a particular group of patients being treated less favourably than another: If NICE approves a treatment it is

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<sup>12</sup> Some bodies, such as NICE, take other benefits into account in addition to QALYs. See below.

usually approved for all users who fit any relevant clinical criteria, not just those in a certain age range.<sup>13</sup>

18. Some respondents to the call for evidence thought changes to the approaches taken by NICE were appropriate.
19. *NICE should habitually consider effectiveness of drugs on particular age groups and make recommendations accordingly.* These respondents thought that there were drugs that were more effective in older people than younger people that were not being approved as their effectiveness for the population as a whole was low. However, applying this approach across the board is likely to result in greater differences in treatment offered to people. Whilst this could represent an improvement in cost-effectiveness terms it could mean that the concern about older people and disabled people getting less treatment because of their lower health state, discussed in paragraph 9, would arise for NICE guidance.
20. *NICE should consider the costs borne by carers in its methodology.* NICE considers all *health* benefits of a treatment whether these are experienced by the patient or the carer.<sup>14</sup> Reductions in the cost of caring, for example if less care time was needed, would be included in the economic model as a cost reduction, not as health benefit.
21. Within its methodology, NICE has the ability to weigh social value judgements against the cost per QALY gained values. The independent committee therefore has the ability to determine if drugs or treatments have other characteristics that mean they should be approved.
22. It is also important to consider that NICE produces guidance, rather than binding rules, and that at an individual level clinicians can decide to provide treatments (usually with the approval of their PCT) even where NICE has recommended that they should not normally be made available.

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<sup>13</sup> Guidelines on fertility, osteoporosis, flu vaccination and statins indicate ages at which the treatment is deemed cost effective. Age is used in these circumstances as it is the best indicator of effectiveness.

<sup>14</sup> Though evidence of health benefits to carers is seldom provided.