Age discrimination in health and social care

Introduction

Why look at age discrimination?
Primarily because older people themselves are concerned. Over the last year, the national media have regularly featured highly disturbing cases of patients being denied treatment or good quality NHS care because of ageist attitudes.

However these cases usually come to light only when the individuals concerned or their families complain. The true extent of the problem remains unclear. For instance is age discrimination the result of particular practitioners’ behaviour or does it run through policy and practice in a systematic way?

The Secretary of State for Health recently announced the development of new standards to outlaw age discrimination in the NHS. However, to be effective, standards (or any other proposed strategy) must address the reality of age discrimination as it is experienced by older people and their families.

What is age discrimination?
Age discrimination results from ageism which is a form of prejudice. Despite the fact that the majority of older people describe themselves as being in good health (less than one per cent of the older population is in hospital at any one time), older people tend to be stereotyped as a homogenous group characterised by passivity, failing physical and mental health and dependency.

Such views are observable in society generally but also among health and social care professionals, who may have more frequent contact with older users with complex health needs. Ageist attitudes are not inevitable however, the recent Better Government for Older People pilot schemes were notable in promoting more positive attitudes towards older people by local authority staff.

Age discrimination can be direct, which occurs when a person is treated less favourably because of their age. But discrimination can also occur indirectly, that is, when care is offered in such a way that older people are disadvantaged because they are disproportionately affected.

Discrimination occurs at many levels, from the system-wide (see Box) to the individual.

It is worth stressing that discrimination is not necessarily unfair, indeed, positive discrimination is a well established mechanism for addressing inequalities in health. For example, people over 60 are entitled to free prescriptions and eyesight tests and the process of allocating resources for health and social care is weighted by the proportion of older people resident in the local population.

The lack of intermediate care: an example of indirect age discrimination
The pressure to minimise inpatient lengths of stay can have adverse consequences for patients who take longer than average to recover from surgery or illness especially where intermediate care or other community-based recuperative or rehabilitative services are limited. Older patients especially those living alone are at greatest risk.
Context

In general terms, money spent on the NHS and social care services will benefit older people because older people are major consumers of care.

The fact that adult NHS and social care services are largely (and increasingly) utilised by older people suggests that services are responding at some general level to an ageing population.

However, it does not necessarily follow that services are designed with older people’s needs in mind or that age discrimination is rare.

Discrimination in the NHS

The NHS has evolved to provide an enormous range of services, encompassing early intervention, prevention and screening, diagnosis, referral, treatment, therapy and palliative care. Health care is delivered by a wide range of qualified health professionals, support staff and care workers. Service provision is also shaped by managers, commissioners and local and national policy. A review of the literature suggests that age discrimination occurs across the service and at different levels, but also that it appears under various guises, and is sometimes, arguably, justified.

Do older people get access to health care as quickly as other patients?

The right to health care on the basis of need and clinical ability to benefit is a tenet of the NHS. And this is evident in various policy statements and guidelines, for instance, the General Medical Council’s guidelines for doctors includes the following: “a patient’s lifestyle, culture, beliefs, race, colour, gender, sexuality, age, social status, or perceived economic worth [should not] prejudice the treatment you provide or arrange”.

However, some services apply explicit age restrictions.

Screening

Women aged between 20 and 64 are called at least once every five years for a cervical smear test to detect pre-cancerous abnormalities. Women aged between 50 and 64 are currently called every three years for breast screening. Breast screening invitations will be extended to all women up to the age of 70 by 2004. Breast screening is also available to women over these ages who self-refer.

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2 Good medical practice, GMC, paragraph 13.
It is worth noting that:

- population screening requires considerable investment in staff and resources. For example, the breast screening programme is constrained by the availability of radiologists and radiographers.
- the stated aim of screening is to reduce mortality and ill health by detecting problems at an early stage (before symptoms appear), perhaps many years before cancers or abnormalities become life threatening.
- screening itself will harm some individuals, for example, through over treatment. In the case of breast mammography, the accuracy of the test improves in older age groups.

Cervical Screening

Mortality from cervical cancer has fallen markedly since the introduction of national screening in the late 1980s. Women who have had a negative smear history before exiting the programme are at very low risk of subsequently developing the disease. There is little consensus that this programme should be extended to older women, especially as the proportion of the target population screened has risen over time.

Breast Screening

Breast screening is more controversial. At the time of its introduction, the UK programme was groundbreaking and experimental. It was unclear whether the benefits seen in screening trials would be realised in a national programme. A decade of experience has proven the programme to be successful, attractive to women (although uptake does decline with age) and positive research findings have prompted the Government to extend the upper age limit to 70.

Some commentators have argued there was sufficient evidence to do this earlier and questioned whether the time taken to review the upper age limit was related to resource constraints or perhaps, ageist assumptions about the benefits of screening older women.

The effectiveness of calling women over 70 for breast screening is more difficult to assess although one estimate suggests that 1500 lives could be saved annually if the programme was extended to all older women in the UK. The Government is unlikely to extend the programme further without funding more detailed research on the issue. There are no current plans to do this.

Whether or not 70 is ultimately proven to be an appropriate age cut-off, there is a case for setting explicit age criteria for routine screening in principle. If the programme can not be shown to be of overall benefit to women in older age groups, then it is difficult to justify the costs (not just economic) associated with a population-wide intervention.

Physiological health and life expectancy vary enormously between individuals of course and many women may, very reasonably, wish to take advantage of breast screening into very old age.

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2. G Sutton, Will you still need me, will you still screen me when I’m past 64 *BMJ* 1997; 315: 1032-3.
4. I am grateful to Julietta Patnick for this personal communication.
While self-referrals are generally increasing, the overall rate remains very low. A recent survey commissioned by Age Concern highlighted widespread lack of awareness amongst older women about the risks of contracting breast cancer and availability of screening.

These findings may reflect a general lack of information available to older women. But the very existence of an explicit upper age limit for routine screening may be inherently misleading. It may also contribute to more general anxiety about age discrimination in the NHS.

### Over-75 Health Check
Age limits can positively discriminate in favour of older patients, for example, all registered patients over 75 are offered an annual primary care health check.

However, the over-75 health checks tend to be unpopular with GPs who feel that the additional workload they generate is not justified. This view is not borne out by some studies which suggest that, when consistently applied, the checks can result in increased referrals and uncover unmet need.

That these checks are held in some disregard is interesting. It is possible that indirect ageism on the part of practice staff might be a factor, for example, if the importance of treating ‘low level’ health problems is undervalued in this age group.

### Discretionary Age Limits
Some services operate with upper age limits which may not be openly publicised but which are real barriers nevertheless. Assessing the extent of such practice is difficult. A recent survey of a representative sample of GPs found that many claimed to be aware of upper age limits a range of services including heart bypass operations (34%), knee replacements (12%) and kidney dialysis (35%). Some well-documented examples of such age limits are summarised below.

<table>
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<th>Cardiac Care</th>
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<td>Twenty per cent of cardiac care units in 1991 operated upper age limits and 40% had an explicit age-related policy for thrombolysis despite the fact that research suggests that older people may derive the most benefit from this treatment.</td>
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A recent review of cardiac rehabilitation found that where programmes had been established, upper age limits were fairly common. (In a sample survey in 1994, 40% of programmes operated age limits, a finding consistent with earlier research.)

Explicit age limits in cardiac care may become less common as the National Service Framework for coronary heart disease is implemented. The NSF makes it clear that effective cardiac care should be available to all patients able to benefit.

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8 J McGarry & A Arthur, Can over-75 health checks identify unmet need? *Nursing Standard* 1999; 13: 37-9. Note that not all studies report positive findings, particularly where over-75 checks have been assessed according to how many relatively severe health problems are identified.
The 1999 National Confidential Enquiry into Perioperative Deaths considered postoperative care in a high dependency unit (HDU) to be commonly indicated for surgical patients over 90.\textsuperscript{12} Despite this, in their detailed review of the cases of 944 very old patients who died following surgery, only four per cent had been admitted to an HDU. Attempting to reconcile this difference, the enquiry team noted that 28 surgeons (in the course of providing the enquiry with case details) reported upper age limits for the high or intensive care facilities in their hospitals.

The most of UK health services are not explicitly rationed but older people may nevertheless be treated differently or have to wait longer for treatment.

Older people are sometimes viewed negatively by GPs because they are perceived to generate a disproportionate amount of work (for example through home visits, greater prevalence of chronic disability and so on). The shift from long-stay NHS care to residential homes has increased demand from an increasingly ill and disabled section of the population. Residents of nursing and residential homes may have difficulty accessing mainstream primary care for this reason.

Many carers have little contact with formal health services such as district nursing although they feel they would benefit from this.\textsuperscript{13}

Older people may not be offered the same treatment. For example, health and lifestyle advice is not always offered to older people although many older people are unaware that their lifestyles are unhealthy.\textsuperscript{14} Similarly, certain conditions seem to be less visible in the elderly. For example, mental health problems in older people are often misdiagnosed or unrecognised in the community. In a recent survey, 16\% of GPs had not referred older patients primarily because of their age.\textsuperscript{9}

\begin{itemize}
\item The national breast and cervical screening programmes are relatively unusual in explicitly discriminating against older (and younger) women
\item Age limits for routine screening for these diseases are justifiable, but lack of awareness of the availability of breast screening on request is a problem
\item The breast screening programme is being extended in response to scientific evidence
\item Upper age limits may have unintended consequences on women’s attitudes to risk
\item The extent of local, discretionary or covert age barriers to care is difficult to assess and less open to debate
\item Age limits are perceived by GPs to apply to many health services in the UK despite little evidence to support such practice and in the face of guidelines to the contrary
\item It tends to be unclear from the literature why age limits are imposed, (for example, as a response to severe demand pressures, or whether older people are believed to be less likely to benefit from care)
\item New guidance (for example, the National Service Frameworks) may have an impact on discretionary age barriers
\end{itemize}

\textsuperscript{12} National Confidential Enquiry into Perioperative Deaths, Extremes of age NCEPOD, 1999.
\textsuperscript{13} M Henwood, Ignored and invisible? Carers’ experience of the NHS Carers National Association, 1998.
\textsuperscript{14} P Little, Who is targeted for lifestyle advice? A cross-sectional survey in two general practices British Journal of General Practice 1999; 49: 806-10.
Older people are less likely to be accepted for treatment for end stage renal failure than younger patients and particularly so in the UK (although acceptance rates also decline with age internationally).

However, New and Mays argued that it is impossible to support claims of age discrimination made on the basis of this data, because, at the general level, age is statistically associated with clinical ability to benefit. Furthermore, they could find no consistent pattern in the way that older people are treated across Europe.

The authors gave careful consideration to the literature on need for renal replacement therapy. Although, overall UK treatment rates did appear to be in line with current guidelines, they concluded that need was not an objective concept and estimates of need and treatment norms are not stable over time. In other words, there is no obvious ‘right’ level of acceptance for treatment against which to measure recent UK experience. More detailed research is needed.

Turner and et al, undertook a wide-ranging review of cancer services. Patterns of diagnosis, treatment and survival differ between younger and older age groups in the UK and elsewhere and the difference is not convincingly explained by comorbidity in older patients (although this is clearly a factor).

The authors found that the effects of cancer treatments in older people are not well understood (because older patients have traditionally been excluded from trials), however, the notion that many treatments are not tolerated well by older people is not always borne out by the available research. Additionally, American studies of patient preferences have found that most older patients would choose aggressive treatment if this improved survival and that older patients may cope better psychologically with a cancer diagnosis than other age groups.

Although suggestive rather than conclusive, it seems that older people may not always be offered the best treatment available for their cancer.

A major survey of 12,000 patients with injuries admitted to 20 Scottish hospital A&E departments found that excess mortality in older patients was higher than expected even accounting for comorbidity and ‘frailty’.

Older patients were much less likely than younger counterparts with similar injuries to receive appropriate treatment, for example, intensive care or referral for specialist investigation. The authors also found that the medical staff did not always recognise the life-threatening nature of apparently ‘moderate’ injuries in older patients.

These findings are especially alarming because a high proportion of emergency admissions are made by older patients through A&E departments in the UK.

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The 'Postcode Lottery'

Some treatments are rationed in some health authority areas. For example, a recent survey of health authorities found that Aricept (and similar drugs) for Alzheimer’s disease are not routinely available on the NHS in many areas. These drugs have proven (if non-curative) benefit for a proportion of patients in the early stage of the disease. The cost is around £1000 per patient pa. Patient organisations argue that these drugs have a major impact on quality of life for sufferers and carers and enable patients to remain at home for longer (offsetting the costs of institutional care). The majority of patients with dementia are older people and the ‘postcode lottery’ for Aricept is sometimes argued to be a form of age discrimination. The question is, are treatments of comparable efficacy and cost provided more readily for conditions affecting younger patients?

Priority for Cardiac Surgery

Hughes and Griffiths recorded a series of cardiac catheterisation case conferences at which cardiologists discussed potential candidates for surgery with the consultant cardiothoracic surgeon. The researchers found that in many case conferences, the age of the patient (and other social factors such as social position) appeared to influence the outcome. However, rather than explicitly exclude or disadvantage patients, age was used tacitly to position patients on the waiting list. Decisions were rationalised in terms of technical feasibility. Age tended to be only explicitly acknowledged as an important factor in decision-making in cases where patients were young.

Implicit rationing: key points

- There is evidence across a range of services that older people may be denied treatment offered to younger patients. Only a few examples have been presented here.

- However, in many cases the evidence is not conclusive, because age discrimination is difficult to prove from aggregate or routine data. NHS performance monitoring tends to focus on geographical inequalities rather than social, racial or intergenerational inequities.

- Discrimination may also be difficult to assess at the individual patient level because ageist decision making is sometimes very subtle.

Do older people receive the same quality of care as younger patients?

In 1988 an independent investigation into acute hospital care in 1998 found both good practice and also evidence of negative attitudes towards older people and inadequacies in care provided on some general acute wards. In some instances hospitals were failing to meet even basic standards of nutrition or personal hygiene for older patients, causing great distress to patients and their relatives and adverse outcomes. Given the number of patients who are over 65 admitted to general wards, these results are disturbing.

Black and ethnic minority older people may also be at risk of racial discrimination in the NHS. Sometimes this is direct, for example, there is some evidence that medical staff accustomed to eurocentric norms, (for example in the way that patients describe symptoms and comply with

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advice) can perceive patients from black and ethnic minorities negatively.\(^{20}\) Additionally, mainstream health services are not always sensitive to the needs of black and ethnic minority patients. Good advocacy services for example have been relatively slow to develop in the NHS.

Language is often used by staff and professionals in such a way as to be patronising or even insulting to older people. A common example, is addressing older people by their first names, a practice which many older people find disrespectful.\(^{21}\)

### Would older people be better served if health care rationing was more explicit?

There have been calls to make the NHS more rational in its rationing. However, it is not necessarily the case that older people would be better served by a more transparent system. Firstly, some commentators have called for age to be a rationing criterion in its own right. Perhaps the best known of these arguments is the ‘fair innings’ argument.\(^{21}\) This holds that all citizens should have the right to a notional ‘fair innings’. Younger people (and older people who have had a disadvantaged life) should be given priority for health care treatments. Some commentators have gone further arguing that there should be an age after which people are not offered life-extending treatments at all. However, explicit age-based rationing is controversial and, even if practicable, is highly unlikely to be politically acceptable in the UK.

In the main, proponents of explicit rationing mechanisms tend to advocate a general utilitarian approach, that is, their aim is to maximise the health benefits obtainable from available (limited) resources for a given population. This is fine in principle but the practice discriminates against older people because of the way in which health benefits tend to be measured - in terms of ‘quality adjusted life years’ (QALYs).

There are several ways in which QALYs discriminate against older people. Firstly, because older people have lower life expectancies, health interventions in older age groups generate fewer ‘life years’ than interventions in younger age groups. Secondly, years lived in disability are given lower weight than years lived in full health. This discriminates against people with chronic disabilities and illness (many of whom will be older people). Finally, QALYs do not capture the breadth of outcomes that may be especially important to older people such as, independence, or the impact of an intervention on carers and family.

Research into public support for rationing is mixed. Public attitudes surveys in the UK have found that many people would support a system which prioritised the young.\(^{22}\) Other studies have found that the public tend to prioritise people who are severely ill (regardless to an extent, of clinical ability to benefit); identifiable individuals, and seek a system which is ‘fair’.\(^{23}\) Experiments have also shown that the public values are open to manipulation.

In the UK, the National Institute of Clinical Excellence (NICE) is the most prominent explicit rationing mechanism. NICE uses cost-effectiveness analysis to appraise drugs and health technologies but it has a remit to consult relevant patient groups as part of each appraisal. It will be interesting to see whether it can successfully address equity issues through this process.


Age discrimination and social care

Our review of the literature of age discrimination and social care is still at an early stage. Age discrimination in social care is a more difficult analytical concept since much social care is selectively provided, that is, older disabled people tend to receive services primarily designed for older people from a ring-fenced budget.

Do older people get access to social care as quickly as younger people?

Since 1993, access to state supported social care is provided if older, disabled people or carers are assessed as meeting the criteria for help drawn up by their social services department. The right to assessment is enshrined in the Disabled Persons (Services, Consultation and Representation) Act 1986 but there is no right to state supported social care services even if a person is assessed as having a need. Research has suggested that social workers and social services departments actively attempt to ration assessments although the researchers did not distinguish between older and younger disabled people.  

Direct Age Discrimination

It is not clear whether older people are disadvantaged in relation to younger disabled adults in terms of access. (Although there is some anecdotal evidence of disabled adults who on reaching their 65 birthday, find that their package of care has been cut and access to some services withdrawn.)

Long Term Care

Age discrimination is perhaps most evident in the way that long term care needs have increasingly become the responsibility of social services departments rather than the health service. Continuing care services which were once provided free in long stay hospitals have shifted to the residential and nursing home sectors. There is no clear boundary between health and social care needs but state support for long term residential care is subject to a means-test which takes into account the capital value of people’s homes if they are home owners.

Older people who have to contribute financially to their personal care, face a form of indirect age discrimination because while the system applies to disabled people with long term care needs generally, older people make up the majority of people affected. The Government has recently announced that all nursing care will be provided free regardless of where that care is located but the anomaly will remain for help with tasks like washing and feeding.

Charging

A further consequence of the shift towards community care is that social services departments are serving populations with greater levels of complex disability within fixed budgets. A result has been that free services tend to be restricted to clients in the most severe need. Older people with ‘low level’ needs and carers may have little access to state-supported care until they reach crisis point. One third of local authorities have charging policies which can leave users with less to live on than basic income support levels. Older people are particularly likely to be sensitive to the stigma associated with means-testing.

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Do older people get the same quality of care as younger people?

There is evidence to suggest that older people are more likely to receive poorer quality care than other social care clients.

Commissioning

A recent report on services commissioned for older people by social services departments found that expectations of services at this strategic level were generally low when compared to services for other groups. Low expectations on the part of commissioners contrasts with older people’s aspirations for independence, dignity and the chance to live as normal a life as possible.

Negative Attitudes

Older people can experience negative attitudes from social care staff either in residential settings or in their own homes. At the extreme older people are at risk of various forms of abuse. Older people suffering from dementia are especially vulnerable.

It should be noted that younger people with severe learning or behavioural difficulties, people who are mentally incapacitated and children are also ‘at risk’ but the population of older people who are reliant on formal (or informal) care is larger.

Services for black and ethnic minority older people

Social services have a universalist approach to service provision which can disadvantage black and ethnic minority older people. Take up of social services among some black and ethnic minorities has traditionally been low but this seems to reflect considerable unmet need and lack of awareness about available services. Research suggests that generally black and ethnic minority elders would prefer to take advantage of mainstream service provision rather than separate services (although this is not always the case) but they may have specific needs which need to be addressed.

In considering the quality of social services, it is worth noting that both social services and the social security systems were never established to provide a comprehensive service in the way that the NHS was conceived. The social welfare systems were designed to act as a safety net, particularly for the poor. The legacy of this system for an ageing society is difficult to quantify but the fact is that many services are currently provided for older people, that social care professionals and staff would not want to rely on themselves.

27 C Gazder That’s the way the money goes: inspection of commissioning arrangements for community care services, Social Services Inspectorate, The Stationery Office, 1999.
Why are older people treated differently?

Older people are not valued as highly as younger people

- Research suggests that younger people do not value older people’s quality of life as much as older people themselves do. This is hugely important given professional power and gatekeeping. For example, studies of ‘do not resuscitate’ decisions suggest that relatively inexperienced junior doctors do not always make appropriate decisions on behalf of their patients. Guidelines (recently reiterated by the Government) stress the importance of consultant-led decision-making in conjunction with discussion with patients and their families.

- Older people and very old people in particular may be judged to have had a ‘fair innings’ and thus be less deserving of limited health and social care resources.

- Sociological studies of medical consultations suggest that health and social care professionals modify the information, advice and interventions they provide according to the ‘social distance’ that exists between themselves and their patients or clients. Under this theory, older people, people with severe disabilities or mental health problems, people from different ethnic backgrounds and different social class may be treated less favourably.

- Older people are frequently viewed as passive and dependent in our culture. Economic activity tends to be the normal measure of achievement and younger members of society may be given greater priority for treatment. This view of older people as a burden on society is not well founded however. Older people, by definition, are the entire UK population who happen to have reached a particular age.

- It may be that younger patients feel better able to argue for priority for services (for example, if their livelihood is jeopardised by ill-health). Older people have traditionally been relatively acquiescent in their relationships with professionals. As younger cohorts age, such attitudes may change. Political parties in the UK are beginning to acknowledge the power of the older vote.

Older people’s needs are not always well understood

- Health problems in the older population may be characterised as normal aspects of ageing. (This is perhaps understandable as there is little consensus over what level of physical limitation is in fact, normal in older age, and the prevalence of disability has not remained fixed over time). Fatalism and low expectations about what services and interventions can achieve for older people are evident in both acute and community health and social care services. Low expectations on the part of commissioners and providers will be self-fulfilling. Similarly, low expectations of older people’s mental capacity, produces inappropriate and infantilising behaviours.

- Historically, clinical trials and medical research tended to exclude older patients. Although this is changing (certainly in relation to centrally funded clinical trials), knowledge about the impact of treatments on older people is often poor and older patients may be unfairly denied access to some interventions as a result. Conversely, older patients are at greater risk of complications particularly, through drug interactions, which are not tested in trials of younger subjects.
Organisational factors

- Work with older people is not seen to be attractive. Pay levels tend to be very low for care workers and assistants. The proportion of staff who are qualified tends to be lower than with other patient groups. Career prospects, for example nurse consultant positions tend to be associated with high-technology specialties such as intensive care medicine.

- The health service in particular is modelled on acute disease pathways. Chronic conditions present a particular challenge for a system organised around the district general hospital and its component specialties. Doctors may feel uncomfortable dealing with conditions that they can not ‘cure’.

- Joint working between the NHS and social services departments has proved to be very difficult to achieve well. Older people, are particularly disadvantaged by poorly co-ordinated services, for example, equipment stores.

Summary

This briefing note is based on a review of the research literature and a series of meetings with key stakeholders in older people’s health and social care provision.

While there are many examples of excellent care for older people in the UK, the review has revealed evidence of unfair age discrimination in health and social care. A wide range of services are implicated.

There is clear evidence that some services have operated explicit age restrictions which have little justifiable clinical basis.

Age discrimination is more often covert and subtle and is implicit in a general lack of priority for older people’s services. Discrimination is sometimes difficult to separate from other issues around, gender, poverty, ethnicity and the way in which people with disabilities and long term illness are treated.

This paper was produced as part of a wider project on age discrimination being undertaken at the King’s Fund. Future work will explore the options for tackling ageism in health and social care.

For further information about work on age discrimination in health and social care at the King’s Fund, please contact Emilie Roberts or Janice Robinson on 020 7307 2523.