



Kent Academic Repository

Billings, Jenny R. (2003) *Staff perceptions of ageist practice in the clinical setting: Practice development project*. Project report. Centre for Health Services Studies, Canterbury

Downloaded from

<https://kar.kent.ac.uk/7758/> The University of Kent's Academic Repository KAR

The version of record is available from

http://www.kent.ac.uk/chss/docs/staff_perception_of_ageist_practice.pdf

This document version

UNSPECIFIED

DOI for this version

Licence for this version

UNSPECIFIED

Additional information

Versions of research works

Versions of Record

If this version is the version of record, it is the same as the published version available on the publisher's web site. Cite as the published version.

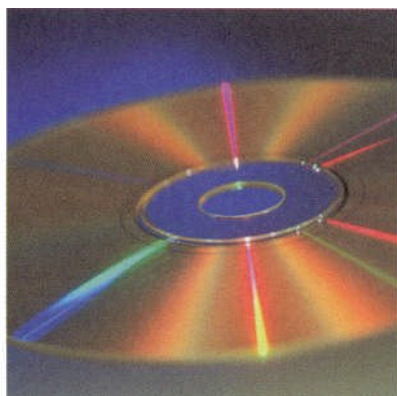
Author Accepted Manuscripts

If this document is identified as the Author Accepted Manuscript it is the version after peer review but before type setting, copy editing or publisher branding. Cite as Surname, Initial. (Year) 'Title of article'. To be published in *Title of Journal*, Volume and issue numbers [peer-reviewed accepted version]. Available at: DOI or URL (Accessed: date).

Enquiries

If you have questions about this document contact ResearchSupport@kent.ac.uk. Please include the URL of the record in KAR. If you believe that your, or a third party's rights have been compromised through this document please see our [Take Down policy](https://www.kent.ac.uk/guides/kar-the-kent-academic-repository#policies) (available from <https://www.kent.ac.uk/guides/kar-the-kent-academic-repository#policies>).

Staff Perceptions of Ageist
Practice in the Clinical Setting:
Practice Development Project



**Jenny Billings,
Research Fellow**

**Centre for Health Services Studies
University of Kent**

June 2003

Centre for Health Services Studies

CHSS is one of three research units of the University of Kent's School of Social Policy, Sociology and Social Research and contributed to the school's recent Research Assessment Exercise 6* rating. This puts the school in the top three in the UK. CHSS is an applied research unit where research is informed by and ultimately influences practice.

The Centre is directed by Professor Andy Aiaszewski and draws together a wide range of research and disciplinary expertise, including health and social policy, medical sociology, public health and epidemiology, geriatric medicine, primary care, physiotherapy, statistical and information analysis. CHSS supports research in the NHS in Kent and Surrey and has a programme of national and international health services research. While CHSS undertakes research in a wide range of health and health care topics, its main research programmes comprise:

- Risk and health care
- Health and social care of vulnerable adults
- Public health and public policy
- Injury prevention and surveillance
- Ethnicity and health care

Researchers in the Centre attract funding of nearly £1 million per year from a diverse range of funders including the ESRC, MRC, Department of Health, NHS Health Trusts and the European Commission.

This report was funded by East Kent Coastal Primary Care Trust, June 2003. It forms part of the national auditing requirements of 2002 needed to take forward Standard 1 of the National Service Framework for Older People.

For further details about the work of the Centre or for more copies of the report please contact:

Peta Hampshire
Executive Officer to the Centre
Centre for Health Services Studies
George Allen Wing
University of Kent
Kent CT2 7NF

Tel: 01227 824057
E-mail: P.R.Hampshire@kent.ac.uk
Fax: 01227 827868
www.kent.ac.uk/chss/

Contents

	Page number
Executive summary	iii
Acknowledgements	vi
1 Introduction	1
1.1 Overview of the literature	2
1.2 Aim of the study	3
1.3 Operational definitions	3
2 Method	4
2.1 Study design	4
2.2 Sample	4
2.3 Instrumentation	6
2.4 Data collection	8
2.5 Data analysis	9
2.6 Ethical issues	9
3 Findings	10
3.1 Access to services	10
3.2 Communication and attitude	13
3.3 Treatment and care	16
3.4 Summary of main points	19
4 Discussion	22
4.1 Client centred care	22
4.2 Clinical priorities	23
4.3 Clinical standards	23
4.4 The role of relatives	24
4.5 Implications for practice	25
4.6 Limitations of the study	26
5 Conclusion	27
6 Recommendations	28
7 References	30
Appendices	32
Appendix 1: Focus group schedule	32
Appendix 2: Participant reference sheet	34
Appendix 3: Questionnaire	35

Tables

	Page number
Table 1: Participants per staff group	6
Table 2: Percentage of overall responses to access to services statements	10
Table 3: Percentage of overall responses to communication and attitude statements	14
Table 4: Percentage of overall responses to treatment and care statements	16

Staff Perceptions of Ageist Practice in the Clinical Setting: Practice Development Project

**Jenny Billings, Research Fellow, Centre for Health Service Studies,
University of Kent**

Commissioned by East Kent Coastal Primary Care Trust

Executive Summary July 2003

This study took place between October 2002 and March 2003. It was commissioned by East Kent Coastal Primary Care Trust in response to the audit requirements for the National Service Framework for Older People Standard 1 "Rooting Out Ageism".

Aim of the Study

The aim of this study was to

- identify and describe the nature of any age discriminatory practice in the clinical setting through the perceptions and experiences of staff working with older people in East Kent
- provide recommendations based on the findings

Method

The study adopted a largely qualitative approach using focus group design. In all, six focus groups were conducted consisting of 57 people from a wide range of health and social service specialisms in East Kent. An aim of the study method was to isolate consensus areas of ageist practice that would facilitate targeted intervention. To assist this, a questionnaire of statements relating to common practice experiences was developed following the first two focus groups. This was completed by the subsequent four focus groups and used as a discussion tool. The questionnaire also provided some loose quantifiable information from these four groups around frequency of perceptions and experiences of ageist practice.

Summary of Findings

Questionnaire Statements

- With reference to the questionnaire statements, most participants had rarely or never experienced age discrimination in relation to accessing services, but a large percentage had often or sometimes witnessed statements concerning attitudes to older people and how they are communicated with. Approximately half of statements about treatment and care were experienced more often than not. The issue of assessing sexuality was seen as the most problematic statement overall, witnessed by 76.3% of participants.

Group Discussions

- Discussion of access to services highlighted perceptions about difficulties of access to specialist units, investigations or treatments being denied or delayed because of age. The care of older people on the wards was also felt to be compromised by the perception that some staff gave it a low priority.

- Perceptions of ageist practice in relation to communicating with older people and attitudes towards them highlighted the use of inappropriate address through poor assessment; frequent exclusion of older people from conversations; the complexities involved in information giving and adopting a non-ageist approach; and, though improving, some instances of labelling from the mental health perspective. Where this latter issue did occur, it was seen to have detrimental effects on diagnosis and treatment. On the ward situation, it was felt that communication issues were more common among 'visiting' staff, such as agency nurses and some doctors.
- With treatment and care, issues relating to the assessment of sexuality were widely debated, highlighting assumptions about sexual activity among older people, and the discomfort and embarrassment experienced from both staff and the older person. This theme was also reflected in debates about resuscitation, where it was acknowledged that client involvement was difficult. Other areas included the lack of client input at joint assessments in mental health, and insufficient time and attention devoted to safe medication of older people because of their age. While some treatment and care decisions could be viewed as ageist, the difficulties making clinical judgements in the face of complex needs was recognised as challenging.
- Not only had insensitive treatment from staff been perceived, but all groups felt that relatives were also instrumental in adopting an ageist attitude. This was manifest as relatives requesting, demanding or questioning access to services, treatment and care without consulting or taking into consideration the wishes of the older person. There was a perception that this may be due to not seeing the full picture of care, and feelings of guilt.
- The issue of discrimination in relation to resources appeared across all areas, felt to promote ageist practice and be disproportionate to need. This occurred with the funding of Rapid Response; discrimination regarding bed availability for mental health patients over 65 years; and non-provision of the Social Services community support team for the over 65s. Lack of staff was felt to be responsible for reduced quality of care such as the limited choices older people had in when they go to bed. While this problem was not felt to be confined to older people, they were seen as the biggest users which enlarged the potential for ageist practice.
- Although there appeared to be several examples of age discrimination in a variety of areas and setting, there was agreement that care received in specialist wards was of a good standard and that improvements had been made in combating unfair or insensitive treatment.

Recommendations

On the basis of the findings, greater choice and control for older people need to be key features of the recommendations, through the role of commissioners and the development of a co-ordinated development programme involving all stakeholders.

Role of commissioners

The role of commissioners is crucial to this process. To address the underlying factors this should include:

- Setting the agenda, making its position on ageism clear and setting clear standards for providers – the ‘zero tolerance’ agenda
- Influencing the environment in which services are delivered – such as planning and the allocation of resources
- Demonstrating openness and communicating clear, explicit values to help shape the expectations and perceptions of service users, relatives and frontline staff

Programme development

A programme of initiatives addressing the main themes needs to draw on models of good practice in the local area and national arena and could include:

- Communications programme developed with and aimed at users around the general standards of service that can be expected – in particular values and standards – this could include targeted material on the ‘difficult’ issues identified by focus groups
- Training and education of staff around issues such as behaviour and communication that uses models of practice that are effective;
- Review of organisational systems impacting on older people’s services from the client perspective;
- Review and development of workable models that will facilitate the engagement of older people and their carers, working towards enhancing client-centred service provision;
- Review of lessons from parallel situation – such as learning of Metropolitan Police from MacPherson (Stephen Lawrence) Inquiry;
- Assessment of resource allocation processes and provision of facilities (including assistive technology) from the client/carer perspective;
- Developing a local accreditation scheme for wards or departments to participate in;
- Communications programme aimed at relatives and carers about expectations and aspirations of services for older people;
- Piloting and evaluating new developments to ensure effectiveness before wider dissemination.

JRB July 2003

Acknowledgements

This study would not have been possible without the willing participants. Grateful thanks therefore go to the many members of staff who gave their valuable time and effort to this study.

Acknowledgement must also be made to Hannah Reid, Development Officer at East Kent Coastal Primary Care Trust, whose plentiful administrative and recruitment skills ensured the smooth running of the project.

Staff Perceptions of Ageist Practice in the Clinical Setting: Practice Development Project

Jenny Billings, University of Kent

1 Introduction

The National Service Framework (NSF) for Older People has meant that, for the first time, the government have provided an approach to the identification and potential elimination of age discrimination in relation to how older people access and use health and social care services (DoH 2001). Standard 1 of the NSF seeks to root out age discrimination and develop a programme of action to address the issues related to unfair or insensitive treatment due to age.

In order to tackle age discrimination effectively, there has been a need to identify the incidence at a local level. Over the past year, health and social care agencies have been auditing and reviewing written policies, and in East Kent, this process has been completed. An interim report by the Department of Health (DoH 2002) provides the results of audits collated across the NHS. In summary, it reports that the audits have shown that only a very small number of policies are explicitly age discriminatory, and that there is considerable variation across the country resulting in lack of consistency. Conversely, action to combat discrimination is already in place in many areas. This is through the establishment of age-related services that have been developed to meet the needs of older people, based on what is effective (DoH 2002).

However, the report states that these audits have raised a number of important issues in relation to age discrimination. For example, it emphasises that age discrimination is a complex issue when relating it to practice. It is generally acknowledged that both individual practitioners and health and welfare agencies discriminate against older people (Tinker 1996; DoH 2001), and such ageism is extremely difficult to combat as it is based on perceptions that have been internalised (Bytheway 1995). This has resulted in a lack of common definition or wider understanding of what it actually means and when it is evident. This is supported within the wider literature, where debates about what constitutes ageism offer no concrete solutions or guidance (Rivlin 1995; Bowling 1996; Williams 1997). As a result, it is difficult to identify ageist practice and therefore hard to take action to root out discrimination effectively at a local level. Ellis (2002) supports this by pointing out that ageism is often an invisible and unchallenged part of day-to-day culture and can result in more hidden or indirect forms of discrimination that are difficult to quantify. He states that tackling ageist practice is challenging but must be about much more than addressing its more obvious form.

Consequent to the findings of the Department of Health's interim report (DoH 2002), a programme has been set out to take the NSF standard forward. A series of action areas include further monitoring and assessment of age-related policies, implementation of guidelines and development of an audit tool to maintain consistency of reporting. Importantly, one of the activity areas concerns workforce development. This incorporates undertaking a further audit to identify staff perceptions of ageism in clinical practice in an effort to reveal and describe the existence of any discrete and less visible aspects of discrimination, with the aim of developing recommendations for intervention. The need for such action is also supported in other published works (Bowling 1999, Ellis 2002). It is this service development action area that has been taken forward by East Kent Coastal Primary Care Trust and is the subject of this report.

1.1 Overview of the Literature

A literature review was conducted to inform the development of the study and a brief overview is provided here. In terms of gaining perceptions of ageist practice from staff, previous research in this area was not found other than minimal anecdotal reports that implicate resources as a factor in the inability to provide adequate care (Buswell 2001). Other publications appear to be largely discussion papers highlighting the potential for ageism in the health and social care arena, and this subject appears to have provoked considerable debate amongst academics and clinicians. This includes broad discussions on the cases for and against rationing by age (Williams 1997; Grimley Evans 1997), and the pros and cons of the outlawing of age discrimination (Scott 2000).

Some publications have focused on a number of specific clinical areas and include empirical research, suggesting ageism in access to specialist services and some treatments, such as breast screening (Sutton 1997), surgery and cardiology (Bowling 1999). The subject of resuscitation and ageism also appears to be controversial in relation to determining its existence and developing policy (Rosenfeld et al 1997; Durrant et al 2002). Another study has demonstrated the exclusion of older people from clinical trials, having serious implications for the efficacy of some treatments on this population group (Bayer 2000). In another area, Ellis (2002) links age discrimination to quality of care of older people, suggesting that there are less evident elements at play with respect to ageist practice, such as how older people are communicated with, attitudes of staff and general care which are much more difficult to bring to the surface. As the interim report implies (DoH 2002), it is these areas that are crucial to identify through staff perceptions in order to begin the process of 'rooting out discrimination' at a local level.

Overall, the literature confirms the importance of this area as a subject for continued investigation, and given the dearth of published work

surrounding staff perceptions, adds weight to the need for this study. It is evident that there is a need to be clear about the range of factors that constitute discrimination in practice.

1.2 Aim of the Study

The aim of this study was to

- a) identify and describe the nature of any age discriminatory practice in the clinical setting through the perceptions and experiences of staff working with older people in East Kent
- b) provide recommendations based on the findings

1.3 Operational Definitions

For the purposes of this study, the description of **age discrimination** as used in the National Service Framework for Older People document will be used:

Age discrimination happens when someone makes or sees a distinction because of another person's age and uses this as a basis for prejudice against, or unfair treatment of that person. (DoH 2001)

Ageist practice refers to the carrying out of unfair or insensitive treatment because of age (Tinker 1996).

2 Method

2.1 Study design

The study adopted a largely qualitative approach using focus group design, as this was seen to be a more suitable medium to explore the complexities of the study topic. The original intention of this study was to conduct a survey of randomly selected staff, with questionnaire development taking place through two initial focus groups with staff. Following these focus groups and the questionnaire construction, the survey approach was deemed insufficiently sensitive and valid an instrument to capture the diversity, richness and complexity surrounding individual interpretation of what constitutes ageist practice. However, the questionnaire was used at subsequent focus groups as a discussion tool, and provided some loose quantifiable information around frequency of perceptions and experiences of ageist practice in various settings. Further explanation of how the questionnaire was developed and used in this context is provided later.

The use of focus groups is well documented in health and social care research (Morgan 1997), used as a means of collecting rich qualitative data in a non-threatening environment by probing issues and exploring experiences from the participant's perspective (Pope and May 2000). Careful facilitation is however needed to ensure equality of involvement and diversity of opinion (Kitzinger 2000) and this process is enhanced by the presence of a second facilitator in order to provide technical support and take notes on the discussion.

In addition to exploring and expanding ideas in the subject area, focus group design is also useful for gaining consensus views of experiences in order to pinpoint specific areas of common agreement for action. This facet of focus group design was particularly useful in relation to this study in order to identify tangible practice issues, and the use of the questionnaire as a discussion tool facilitated this without constraining the accompanying debate.

2.2 Sample

In all, a total of six focus groups lasting one hour were conducted between October 2002 and March 2003 with a total of 57 participants. Numbers of participants per group ranged from four to 11. Each group consisted of workers from the following health and social care sectors (see table 1 for a more detailed breakdown of participants):

Group 1	Community, general practice, voluntary sector (11)
Group 2	Acute general and mental health hospitals (11)
Group 3	Community (9)
Group 4	Acute general hospital (4)
Group 5	Acute general hospital and community (11)

Group 6 General practice and community (11)

Staff were recruited with the assistance of a PCT Development Manager who liaised with senior management in the settings. A number of venues in community and acute settings were organised to attract as many people as possible from all areas in East Kent. The sampling framework was largely purposeful, and staff were included who were currently working with older people for longer than three months. Some period of exposure to the practice situation was required, in order to inform about the study topic, hence the inclusion criteria of three months. In addition, diversity of background was encouraged. Flick (1998) describes this sampling method as credible and appropriate for qualitative research approaches, in order to maximise richness of data in the area under study, and opportunity to participate. Numbers of people ultimately recruited per Primary Care Trust were as follows (includes participation from acute hospitals):

East Kent Coastal PCT	35
Canterbury and Coastal PCT	11
Ashford PCT	6
Shepway PCT	2
Those working across PCTs	3

As the above numbers indicate, recruitment in some PCT areas was more fruitful than in others, despite flexibility with the focus group locations and times. This could be due to the more active involvement of some managers in the recruitment process. However, although not specifically quantified, some of the respondents stated during discussions that they had worked in other areas and were able to bring a wide range of experiences and views from an East Kent perspective to the debate.

Although most people taking part were working in acute or community NHS settings, a range of other qualified and unqualified, junior and senior workers from the voluntary sector, social services, health promotion and education also took part. In addition, within the NHS, specialist services such as continence, cardiac rehabilitation and members of Community Assessment and Rehabilitation teams (CART) and Rapid Response (RR) were also represented. Table 1 provides a breakdown of participation in staff groups. More specific breakdown is not provided due to the small numbers and potential identification of participants, therefore supporting information is provided to give an overview of the spread of representation.

Table 1: Participants per staff group (n=57)

Staff Group	Number (n=57)	Further information
Community Reg. general nurse (n=29, 50.9%) GP practice staff GPs Mental health nurse CART and RR	10 6 5 4 4	This community grouping included district nurses, team leaders, specialist nurses, health care assistants, primary care visitors, practice nurses, practice managers and administrative staff.
Acute Hospital Reg. General nurse (n=21, 35.8%) Mental health nurse Therapists Social Services	15 2 2 2	This included staff working on rehabilitation wards, coronary care, accident and emergency, and stroke units. Staff grades included health care assistants, staff nurses, sisters, team leaders, senior practitioners, matrons and senior management
Other groups (n=7, 13.3%)	7	This includes the voluntary sector (Age Concern and Red Cross), education, administration and health promotion representatives.

2.3 Instrumentation

The instrumentation for this study consisted of

- a) a semi-structured interview schedule (appendix 1)
- b) a participant reference sheet (appendix 2)
- c) a questionnaire (appendix 3)

a) **Semi-structured interview schedule**

As previously explained, the original intention of the study was to develop a survey based on some initial exploratory work with staff. The interview schedule was constructed for this purpose, and proved to be useful in generating relevant and specific examples. Six topic areas derived from previously discussed literature and policy were used to promote discussion:-

- Access to services
- Communication
- Attitude
- Privacy and dignity
- Personal care
- Treatment

Prompts were used within each area to encourage people to express a range of experiences in different situations. Participants were also given the opportunity to offer suggestions for other areas, and to comment on the appropriateness of these areas in relation to age discrimination.

An important feature of this initial exploratory work and the focus groups that followed was to discuss any competing or 'rival' explanations for the practice that was described. This was in order to

anchor the perceptions to true ageist practice as much as possible, to establish credibility of the examples and to gain a degree of consensus among participants about what constituted insensitive or unfair treatment of older people.

b) *Participant reference sheet*

Given the different understandings and high level of complexity of the subject area, a reference sheet was constructed to help focus the participants, as recommended by Kitzinger (2000) in focus group design. It consisted of three main elements:-

- The National Service Framework operational definition of age discrimination
- A list of the six topic areas for discussion
- A set of criteria that participants were asked to use when offering practice examples. It was felt to be important to elicit actual experiences that participants had witnessed themselves in the clinical situation. Participants were therefore asked to provide examples of age discrimination against older people that were first-hand experiences, either seen or heard in the care setting, read in medical notes or heard via an older user or their carer.

c) *Questionnaire*

Experiences recounted by participants in the first two focus groups were developed into statements that were grouped into three sections. The sections were a combination of the original topic areas in the interview schedule; no further areas were suggested by participants;

Section 1: Access to services. This included statements in relation to access to specialist services, investigations, surgery, respite care and recuperative care. A statement relating to the role of relatives in accessing services was also included.

Section 2: Communication and attitude. Statements here reflected information giving, how older people are addressed and the labelling of older people.

Section 3: Treatment and care. These statements related to inappropriate treatment, lack of privacy, assessment and resuscitation.

A five dimension rating scale relating to the frequency with which the statements were experienced ('often' to 'never') was used, in order to gauge an estimation of extent. A 'not applicable' column was added, given the different care contexts of the participants. Each section included a space for comments that participants were encouraged to use in preparation for the discussions that followed.

Two statements were included that were not expressed by the two initial focus group members, but were evident in the literature. These were:-

- Section 1: question 9 'not having cardiac investigations or treatments such as pacemakers because of age' (Bowling 1999)
- Section1: question 10 'not being offered the chance to take part in research, such as entering a clinical trial' (Bayer 2000)

In addition, a further short section was added to elicit information about the participants, namely their work setting and staff group. This information is displayed in table 1.

2.4 Data Collection

Data from focus group discussions were collected in the following ways. With respect to the first two initial focus groups, the semi-structured interview schedule was used to guide and prompt debate, requesting as much specific detail as possible of people's experiences of ageism in the practice setting. With the remaining four focus groups, participants were asked to complete the questionnaire for ten minutes at the start of each session, which then acted as the discussion schedule for the remainder of the sessions. All participants were asked to remember any experiences going back three years and within East Kent NHS or Social Services employment. This time span is based on the desire to capture recent experiences, and on recall accuracy.

For all groups, the participant sheet was referred to at the beginning of each session and reinforced during the session to keep a focus on responses and discussions. However, care was taken not to restrict people unduly to the schedule areas and to limit the scope of experiences. As mentioned, emphasis was placed on a discussion of any rival explanations for the examples given, and gaining some agreement about the authenticity and credibility of the experiences between group members. For those using the questionnaire, the opportunity to remove or add statements depending on the consensus view of their validity in expressing ageist practice was offered.

With respect to data recording, two facilitators were used. One led the discussions and wrote key words used by group members and expressions on a flip chart in full view of the group as discussion progressed. This served to provoke lively debate and helped participants to follow the flow of conversation, contribute and see where consensus could be reached. The other facilitator took more detailed notes of points raised to ensure that as much data was gathered as possible. The presence of this facilitator was explained to participants. Although taped recordings are the preferred method of full data capture (Pope and May 2000), the credibility and accuracy of note taking can be enhanced in the following ways. Firstly, at the end of each session, the recordings were checked with participants, and added to or changed to reflect their true opinions (Flick 1998); secondly, the notes taken by the second facilitator served as a further check to accuracy and depth of data collection.

2.5 Data analysis

Data from the questionnaires were analysed using simple descriptive statistics through frequency distributions, as the small unrepresentative and non-probability sampling technique did not permit a more elaborate approach.

The qualitative data collected from the discussion of the questionnaire were analysed using a content analysis approach as suggested by Flick (1998) which entailed applying a pre-defined thematic template to the data. This template was consistent with the three categories of the questionnaire namely 'access to services', 'communication and attitudes' and 'treatment and care'. Information was then sorted into the themes taking care to remain faithful to the original recorded discussions. As Flick notes, this is a useful way of reducing data into meaningful themes, but can be constraining and artificially represent the data. It is important therefore that categories brought to the data should be repeatedly assessed against them for their relevance, to avoid missing important themes and misrepresentation. Analysts of this approach should use an accompanying open coding system to capture data not fitting into the pre-defined template; this was carried out.

2.6 Ethical Issues

This study was conducted within the model of a National Service Framework audit and service development. Given the sensitive nature of the topic under study, ethical principles were strictly adhered to. This included the following,

- at the start of the sessions a full explanation of the study was given with particular reference to how the findings would be used;
- verbal consent was obtained from group members to record discussions;
- everyone participating in the focus groups were assured that any comments and questionnaire responses would remain confidential and the possibility of identification from a report would be removed;
- ground rules were established in each group whereby discussion of any issues raised in the course of the sessions would not be discussed outside of the group, unless otherwise requested; this was particularly important if participants provided specific identifiable information about an experience;
- participants were informed that they could withdraw from the study at any time;
- permission was gained from all participants for any comments they made to be noted and that they could withdraw any comments at any time.

3 Findings

The findings will be described in relation to the three statement sections of the questionnaire. A table of overall questionnaire responses to statements per section will be provided, these were completed by groups 3 to 6 (n=38). This will be followed by an account of the discussions that took place in all groups. As described, data were collected using written rather than audio methods. As a result, actual quotes cannot be used to substantiate the descriptions. However, some phrases were recorded word verbatim and used in the sections, presented in italics. For auditability purposes, they are referenced using the focus group number and note page.

It is important to note that, while some concerns about ageist practice would appear to exist and have been expressed, the majority of participants agreed that in some areas great strides in the health care of older people had been made in combating unfair or insensitive treatment.

3.1 Access to Services

Table 2: Percentage of overall responses to access to services statements (n=38).

Figures in bold indicate a majority response to 'often' or 'sometimes' witnessed.

Statement	Often %	Sometimes %	Rarely %	Never %	N/A to me %
1. Not being referred to specialist services locally or outside the area, when this is needed	2.6	39.5	36.8	21.1	0
2. Not having surgery despite being fit enough	2.6	18.4	42.1	23.7	13.2
3. Not being referred for investigations such as blood tests, x-rays or scans	7.9	26.3	36.8	26.3	2.6
4. Being excluded from respite care because you are over 65, even if you had it before	5.3	10.5	28.9	36.8	18.4
5. Having difficulties getting some services to see a person who is over 65	13.2	15.8	36.8	26.3	7.9
6. Having problems getting a recuperative care bed if you are over 65	2.6	10.5	34.2	15.8	15.8
7. Relatives urging for an older person to go to a nursing home when it is not appropriate	7.9	57.9	15.8	7.9	10.5
8. Older people having a low priority with respect to medical attention, referrals, surgery or investigations	10.5	26.3	47.4	15.8	0
9. Not having cardiac investigations or treatments such as pacemakers because of age	2.6	15.8	34.2	26.3	21.1
10. Not being offered the chance to take part in research, such as entering a clinical trial (5.3% no answer)	2.6	13.2	18.4	13.2	47.4
11. Having difficulties getting onto a GP list (5.3% no answer)	0	13.2	34.2	21.1	26.3

- 3.1.1 As table 1 indicates, a large percentage of the statement areas had rarely or never been witnessed by the participants, where applicable. This was especially so for access to surgery (2), investigations (3), respite care (4), recuperative care (6), cardiac treatments (9), clinical trials (10) or a GP list (11). In general, most participants had also not experienced difficulties getting services to see people over 65 (4), or older people having a low priority (8). However, the role of relatives in urging for a nursing home placement did appear to have been experienced more frequently.
- 3.1.2 Despite these findings, the discussions revealed some specific areas of concern. There were some incidences reported of older people being denied access to specialist services because of age across all the focus groups, which was felt to have an impact upon choices and control. One example given was of older men with urological problems repeatedly having conservative treatment and being denied surgery with no suitable explanation, despite being otherwise fit. One client was told *"Go home and stop worrying about it"* (1:p.2). Another perception was that older people are offended not to be routinely selected for mammography or cervical screening from a certain age.
- 3.1.3 Other participants had experienced difficulty transferring older people to specialist units outside the area because of an age restriction in the unit's policy. Neurological units were cited as an example. Following an example given by one participant of challenging an age restriction, it was felt in one group that age boundaries imposed on access to services can sometimes be misunderstood as policy, or even be a result of what individuals believe about a policy which becomes common practice. The importance of questioning restrictions was agreed.
- 3.1.4 It was also noted that access to the intensive care unit and coronary care unit can sometimes be limited for older people, especially if an older person is competing with a younger person for a remaining bed. It was felt that decisions about who the most appropriate recipient would be were based on age, quality of life and life expectancy, alongside clinical need. Conversely however, it was noted that some services are recommended for people over a certain age, such as echo-cardiograms for people over 80. Paradoxically, when policies positively discriminate this still does not appear satisfactory, as the perception was that the service is often refused and was thought to provoke unnecessary anxiety. Coupled with this, it was also felt that older people sometimes feel themselves that they are 'too old' to be referred to a specialist service.
- 3.1.5 Participants from the acute setting also expressed particular concerns about priority of care, especially those working on older people's wards. There was the perception that services such as phlebotomy often visited the wards last, with the result that many tests were not

done due to time constraints, ultimately delaying treatment or discharge. Also, there were several examples of how older patients waiting for surgery (mostly hip replacements) were delayed to make way for paediatric or gynaecological cases, which caused distress. It was however acknowledged that medical emergencies should take precedence over a more stable patient, but it is often difficult to strike a balance without appearing to be discriminatory. In some acute areas, efforts were being made to rectify this, such as trauma list management to manage the issue of prioritising.

- 3.1.6 In addition, some participants felt that medical staff were slow to respond to requests to see a patient on an older person's ward (such as long delays in answering bleeps) and a reluctance to contact specialist services. Some staff used their experience of working on a variety of wards to state that such delay was not so evident for younger people. Participants felt that this was due to clinical priorities, in that a younger person in casualty would take precedence on medical time. Others felt that this was more apparent among junior medical staff and could be due to lack of knowledge in how to respond to complex needs of older people. Conversely however, some participants felt that medical staff were quick to refer patients to rehabilitation services on an age basis rather than clinical need, one group felt that this was noticeable from the surgical teams.
- 3.1.7 One area where most participants perceived there to be examples of unfair or insensitive treatment due to age was through encounters with relatives. Statement 7 provoked considerable discussion in all groups, with participants giving examples of how relatives would request for their relative to stay in hospital longer, or urge their older relative to give up their own home for a nursing home place, despite the patient wanting to return home and being assessed as capable. From a community perspective, relatives were noted for sometimes expressing concern that an older person could not cope in their own home, when in fact they could, with some additional help. It was observed that often 'battles' took place, with relatives seeming to withdraw the right for their relative to choose, effectively creating a loss of independence. Another example given was of a relative questioning an older person's need for a pacemaker, stating *"Is it worth it? Can't you let him be?"* (2:p.2). There was a general view that sometimes relatives have a low expectation of an older person's recovery, and see rehabilitation programmes as too intensive and rushed.
- 3.1.8 The issue of resources was also apparent as a determinant of ageist practice and quality of care. It was suggested in one area that GPs were unable to refer older people to the Rapid Response team as there was a charge to the practice for using doctors on call services. Participants stated that GPs would rather admit patients to hospital in certain circumstances. Another issue around the use of dosset boxes for dispensing tablets was also discussed. There was a perception that

pharmacists were reluctant to use dosset boxes due to increased cost, despite the fact that they were felt to be of great benefit to older people.

3.1.9 Continuing with resources and from a mental health perspective, there was the perception that beds were not available for people over 65 with dementia and a functional illness, although beds are being purchased for people under 65 years. This was felt to create a 'two-tier' service insensitive to the needs of older people with mental health problems. In addition, some mental health support team resources cannot be accessed by people over 65 providing a perceived poorer service to those most in need. The fact that services for older people were criterion-based rather than based on need was felt to be a reason for this unfair treatment. Particular concern was expressed around the change from adult to older adult services with mental health clients, in that packages and levels of care change, as well as the care management and who provides. This was felt to result in an inflexible service that did not meet the needs of the client.

3.1.10 From a social services perspective, there were some similar concerns. Participants reported that the community support team is not provided for those over 65. Also, respite care is paid for the carers of disabled people under 65, such as stroke victims, multiple sclerosis, and Parkinson's disease, but not over 65 years, even if they have received it in the past. The perception appears to be that there are fewer resources for those over 65 than under 65, when often the complexity of care increases. Added to this was the concern that older people are not aware of the benefits that they are entitled to. Although this may be the case for other age groups, participants perceived it occurring more often among older people.

3.2 Communication and Attitude

3.2.1 Table 3 below highlights that more than half of participants completing the questionnaire had witnessed insensitive treatment 'often' or 'sometimes' in relation to communication and attitude. Statements encountered most frequently were excluding older people from conversations, sensitive or otherwise (1,7), shouting at older people (2), and being patronising (10). Statements less encountered were information giving about medicines ((8) and labelling older people as 'daft' or 'demented' (9).

3.2.2 Again, discussions in the groups were revealing. Some groups argued that the statements could occur across all age groups, but the consensus view was that they were more likely to happen with older people. With respect to names, there was a general view that there was too little assessment of the preferred way that older people like to be addressed, and this was seen as disrespectful. This was witnessed particularly in acute hospital settings and residential and nursing homes.

Table 3: Percentage of overall responses to communication and attitude statements (n=38)

Figures in bold indicate a majority response to 'often' or 'sometimes' witnessed.

Statement	Often %	Some-times %	Rarely %	Never %	N/A to me %
1. Staff speaking to friends or relatives about the older person in his or her presence, but excluding them from the conversation.	23.7	57.9	5.3	13.2	0
2. Shouting at an older person even if they are not deaf	13.2	47.4	26.3	13.2	0
3. Not fully informing an older person about their condition, treatment and/or care, assuming they wouldn't understand or don't want to be bothered about it.	23.7	39.5	21.1	13.2	2.6
4. Calling an older person 'lovey' or 'duckie' instead of their preferred name	26.3	39.5	21.1	13.2	0
5. Discussing sensitive issues within earshot of the older person but not with them	10.5	44.7	26.3	18.4	0
6. Speaking 'on behalf' of an older person about a matter without making sure of their opinions	15.8	31.6	26.3	26.3	0
7. Discussing personal and sensitive issues with an older person loudly within hearing of other people	10.5	47.4	21.1	21.1	0
8. Not giving enough or appropriate information about medicines – 'just take them'	18.4	23.7	21.1	34.2	2.6
9. Labelling older people as 'daft' or 'demented' if they have a problem understanding	10.5	31.6	15.8	42.1	0
10. Talking to or about older people in a patronising way – treating them like children	10.5	50.0	23.7	13.2	2.6

3.2.3 There was the opinion that staff assume an older person will not mind the use of nicknames, and most groups agreed that this was a particular problem among agency staff, who perhaps were not sufficiently briefed. One group suggested that the tone of the address was often more important than getting the actual name wrong, and that often getting someone's title right (eg Mrs or Miss) was more of an issue to older people. However, a counter view suggested was that there may be regional variations in the acceptability of the more familiar forms of address. One group felt that people from the north would be more likely to prefer being called 'my love' for example. It was agreed that the importance of assessment to gain the older person's preference was paramount.

3.2.4 The issue of exclusion during communication in the absence of any cognitive problems was seen as a particular problem in the hospital setting, with medical and again agency staff seen as less sensitive in this area. An example was given of a consultant talking into a dictaphone at a patient's bedside about his condition, and of an agency nurse pointing to an older person saying "We'll do this one next"

(2:p.3). The issue of exclusion was also seen to be evident in nursing and residential homes, with staff speaking on behalf of older people about a matter without making sure of their opinion. Again, groups perceived there to be issues with relatives, and an example was given of relatives seeming to “*blank*” their elderly relative at the bedside when seeking information from staff (1:p.2).

- 3.2.5 Even when older people are not excluded from the conversation, the general issue of communicating inappropriately to them was a common experience across all groups. Remarks were made about the impact of shouting, and how this can seem as if the member of staff is angry. Although most groups had witnessed older people being spoken to in a patronising way, others suggested that this may be a result of over protection, and not intended to be condescending.
- 3.2.6 The discussions about information giving were wide-ranging, demonstrating the difficulties in achieving the right approach. There was a view from some groups that staff assume the older person would not understand or couldn't be bothered, and that this explained why older people are sometimes not informed about their treatment or condition. Another explanation put forward by some participants was that communication lapses can occur due to pressure on time, professionals' abilities to judge comprehension levels in older people or the person's perceived mental frailty. One group felt that in certain situations, it might be more appropriate to tell relatives first, especially if there is uncomfortable news.
- 3.2.7 While some participants felt that full information was essential, others suggested that in their experience, too much information and the way it is presented could be frightening. An example of information giving in cardiac rehabilitation was given, where older clients had expressed concerns about the terminology used and had experienced difficulties in interpreting information. Conversely, other participants noted that older people were becoming much more informed with better access to information through the media, and therefore required fuller more detailed explanations.
- 3.2.8 A further opinion was that in some cases, older people do not want to know about their illness or diagnosis and this should be respected. A consensus view was that accurate judgements through assessment were required taking into account patient wishes. It was noted by one group that specialist staff in general were very good at communicating with older people and understood the need for appropriate address, inclusion and use of language.
- 3.2.9 In other areas, a frequent experience among staff was to translate an explanation given to older people about care or treatment into more straightforward language, sometimes after a doctor's round. However, this was seen as a universal problem and was felt often to be due to time constraints and heavy workloads. From a community perspective,

not providing enough information about medication on discharge was highlighted as an issue. It was felt that some staff were reluctant to give information for fear that an older person may become confused and not able to cope at home.

3.2.10 Labelling people as ‘daft’ or ‘demented’ was seen by most groups as happening infrequently, and the perception was that education was improving the situation. However, it was noted in one group that the use of inappropriate labelling by some clinicians, such as “*mildly demented*” (3:p.3) was still in use. There were concerns that this would have serious implications in accessing some services, such as Community Assessment and Rehabilitation Teams, who are unable to accept a client if there are mental health problems indicated. Another group noted that the term “*mildly confused*” (4:p.3) was often mentioned in clinical letters about a patient when it wasn’t felt to be based on sound clinical judgement. This was perceived to have a ‘Chinese whispers’ effect among health and social care agencies and could have repercussions on the long-term diagnosis and treatment of the older person.

3.3 Treatment and care

Table 4: Percentage of overall responses to treatment and care statements (n=38)

Figures in bold indicate a majority response to ‘often’ or ‘sometimes’ witnessed.

Statement	Often %	Some-times %	Rarely %	Never %	N/A %
1. Giving an older person an incontinence pad when they don’t need one	10.5	13.2	21.1	44.7	10.5
2. Not giving an older person enough privacy when helping them with activities such as toileting, washing or dressing	7.9	42.1	23.7	10.5	15.8
3. Letting older people have a limited choice in things like when and what they eat, when they go to bed or have a bath	18.4	34.2	18.4	15.8	13.2
4. Giving older people inappropriate clothing	13.2	26.3	23.7	18.4	18.4
5. When undertaking assessments, missing out questions about sexuality	42.1	34.2	5.3	5.3	13.2
6. Having some expensive treatments refused because of age, such as beta-interferon for MS sufferers and drugs for Alzheimer’s disease	13.2	15.8	26.3	21.1	23.7
7. Giving older people inappropriate aides/equipment, such as beakers, or tip-back chairs	2.6	26.3	34.2	26.3	10.5
8. Giving older people too many tablets and not reviewing them often enough	26.3	36.8	15.8	10.5	10.5
9. Catheterising older people unnecessarily (2.6% no answer)	13.2	23.7	26.3	23.7	10.5
10. Assuming that people over 80 do not want to be resuscitated	10.5	18.4	13.2	39.5	18.4

- 3.3.1 Table 4 shows that issues of privacy in care (2), limited choice (3), medication and reviews (8) were seen as occurring more frequently than the other statements. The lack of assessment of sexuality was particularly encountered by the participants who completed the questionnaire.
- 3.3.2 With respect to assessment of sexuality, it was felt that this was an issue that affected all age groups, but again was observed to be more pronounced for older people as there was an assumption that older people are not sexually active. In some groups, it was felt quite strongly that older people do not always feel comfortable with questions about their sex lives and do not want to be asked. Other groups questioned whether it was the older person or the member of staff who was most embarrassed. However, others had had experiences of older people being relieved to be able to discuss these issues, such as a couple who were admitted to a residential home, and an older gentleman in the wake of a recent illness. Other participants had observed in-patients talking about sex between themselves, but had problems talking to professionals about certain issues. Reasons for this were seen as generational, in the way that people had been brought up; gender, in that some professionals appear insensitive to the feelings of an older gentleman being assessed by a young female nurse; and professional inexperience and, as some suggested, maturity, in how to broach and assess the subject. It was acknowledged that this type of questioning was not suitable in an initial assessment, but should be deferred to an appropriate time.
- 3.3.3 Statement 5 also stimulated general discussions about assessment. The way older people are jointly assessed was also a topic of concern, particularly among groups with mental health participants. The view was that joint assessments include opinions from all involved in the care except for the views of the older patient, and questions arose as to how valid the ultimate decisions about care and treatment were in the absence of these views. Some were concerned that decisions could be made based possibly on financial gain, particularly when a status change could result in greater payment to the home for the person's care. An example of the status of elderly mentally infirm was given.
- 3.3.4 Over-medication and the need for reviews were perceived as an important issue, and this provoked a wider discussion about drug therapy and older people. The perception that insufficient time and attention was paid to the problem because of the age of clients was expressed by most groups, although it was noted that this could happen in other age groups. There were some revealing examples in relation to older people. Some participants noted that patients discharged from hospital on a new treatment regime were sometimes readmitted still on the old treatment. From a community perspective, with the advent of the Primary Care Visitor to review medicines in the over 75's, it was felt that a large percentage of clients visited needed

medication reviews, emphasising the lack of monitoring in this field. Others felt that, on discharge, instructions for a new set of medication were quickly forgotten due to the lack of understandable written instructions. On some occasions community staff observed that this had led to clients taking both old and new drug regimes with serious results. This was seen to be compounded by the fact that there is a delay between discharge and information to the GP received by the hospital consultant. Aside from this, there was a consensus view that instructions for medication are confusing and inappropriate for older people, who may be unable to synthesise the information for a variety of reasons. Linking to section 2 about communication, questions were raised during these debates as to how much older people really understand about their treatment.

- 3.3.5 While the giving of inappropriate aids was not often witnessed, there were several examples of this occurring through discussion. Giving beakers to patients inappropriately was encountered by the groups, through the dispensing of drinks by unqualified staff. Giving an older person an incontinence pad when not needed was not viewed as a problem by most, but the use of large pads when smaller more discreet ones would suffice, was witnessed and considered inappropriate by one group. Others mentioned the unsuitability of hospital clothes, especially underwear, often worn by older people due to difficulties with laundering. This was also felt to inhibit physical rehabilitation.
- 3.3.6 As with access to services (3.1.8/9), the issue of resources was keenly expressed in this section. Lack of choice in when older people go to bed or have a bath was seen to be the result of insufficient staff in both acute and community settings, and recruiting staff to work twilight hours. This was not necessarily only affecting older people, but this age group were seen to be the biggest users of the service. Choice of meal times was also thought to be restricted by the organisation of hospital and community services rather than unfair treatment due to age. One group remarked that schemes such as Meals on Wheels were not able to offer client choice due to the large distribution difficulties.
- 3.3.7 One issue concerned the use of evidence based decision-making and its potential for appearing to discriminate against older people in treatments. One group gave the example of the prescribing of Statins for lowering cholesterol levels. It was reported that many older patients had been reading about the reported benefits of this drug and asking for a prescription. However the perception in this group was that there was insufficient evidence of its effectiveness, and treatment was not taken forward. It was acknowledged that this could be a problem not just for older people, however the group was cognisant of the fact that ageism had become a sensitive issue and that questioning practice was a positive step forward.

- 3.3.8 While most people had not encountered unfair treatment regarding resuscitation, the need to have conversations with older people about this was seen universally as difficult. In addition, whether or not such a conversation was desired by older people was largely unknown and was seen as hard to establish. The new resuscitation policy was felt to have engendered a culture of unnecessary resuscitation by one group, whereas in another group participants had witnessed anger from a crash team at being called to resuscitate an 85 year old man.
- 3.3.9 The role that relatives play in treatment decisions was also discussed in one group. There was the view that younger relatives could be quite insistent about treatments, difficult to handle, and were listened to above the wishes of the patient - *"shouting the loudest"* (6:p.3). *"Weekend relative's syndrome"* (6:p.3) was described, where concerned relatives tended to strongly urge for services or treatments at weekends when they were able to visit. The perception was that, as relatives were not able to gain a full picture of care, judgements about the right treatment became confused with feelings of guilt and this was seen to affect the older person adversely.
- 3.3.10 Some general issues about care were highlighted in the group discussions. Much debate about care and the potential for ageist practice centred again around assumptions, this time about what certain standards should be and these were not necessarily based on the client view. For example, showering every day may be a standard of hygiene subscribed to by professionals, but not by older people. The issues of dentures was raised, and some participants noted that soft diets are ordered in a hospital setting because of the assumption that people cannot manage normal food. These were perceived as small but significant examples of insidious ageist practice.
- 3.3.11 All participants were aware of the very difficult problems in making clinical judgements that were in the best interests of the client. Not seeming to permit access to services, treatment or care could appear discriminatory, but there was a view that it is difficult to separate age discrimination from frailty, and making clinical decisions with clients with complex social and multi-pathological conditions can never be straightforward. In addition, many practice issues are challenging to undertake, such as assessments of sexuality, information giving and involving people in discussions about resuscitation. Avoiding these issues was felt to appear insensitive and ageist, but could be due to the lack of knowledge about the right approach to use.

3.4 Summary of Main Points

- 3.4.1 With reference to the questionnaire statements completed at the beginning of each group session, most participants had rarely or never experienced age discrimination in relation to accessing services, but a large percentage had often or sometimes witnessed statements

concerning attitudes to older people and how they are communicated with. Approximately half of the treatment and care statements were experienced more often than not. The issue of assessing sexuality was seen as the most problematic statement overall, witnessed by 76.3% of participants.

- 3.4.2 Discussion of access to services highlighted perceptions regarding difficulties of access to specialist units, investigations or treatments being denied or delayed because of age. The care of older people on the wards was also felt to be compromised by the perception that some staff gave it a low priority.
- 3.4.3 Perceptions of ageist practice in relation to communicating with older people and attitudes towards them highlighted the use of inappropriate address through poor assessment; frequent exclusion of older people from conversations but discussing care in their presence; the complexities involved in information giving and adopting a non-ageist approach; and, though improving, some instances of labelling from the mental health perspective. Where this latter issue did occur, it was seen however to have detrimental effects on diagnosis and treatment. On the ward situation, it was felt that communication issues were more common among 'visiting' staff, such as agency nurses and some doctors.
- 3.4.4 With treatment and care, issues relating to the assessment of sexuality were widely debated, highlighting assumptions about sexual activity among older people, and the discomfort and embarrassment experienced from both staff and the older person. This theme was also reflected in debates about resuscitation, where it was acknowledged that client involvement was difficult and selecting the right approach was universally agreed to be unclear. Other areas discussed included the lack of client input at joint assessments in mental health, and insufficient time and attention devoted to safe medication of older people because of their age. In the community, this was felt to be improving with the role of the Primary Care Visitor in referring for medication review. While some treatment and care decisions could be viewed as ageist, the difficulties making clinical judgements in the face of complex needs was recognised as challenging.
- 3.4.5 Not only had insensitive treatment from staff been perceived, but all groups felt that relatives were also instrumental in adopting an ageist attitude. This was manifest as relatives requesting, demanding or questioning access to services, treatment and care without consulting or taking into consideration the wishes of the older person. There was a perception that this may be due to not seeing the full picture of care, fear of the burden of caring, and feelings of guilt.
- 3.4.6 The issue of discrimination in relation to resources appeared across all areas, felt to promote ageist practice and be disproportionate to need. This occurred with the funding of Rapid Response; discrimination

regarding bed availability for mental health patients over 65 years; and non-provision of the Social Services community support team for the over 65s. Lack of staff was felt to be responsible for reduced quality of care such as the limited choices older people had in when they go to bed. While this problem was not felt to be confined to older people, they were seen as the biggest users which enlarged the potential for ageist practice.

- 3.4.7 Although there appeared to be several examples of age discrimination in a variety of areas and setting, there was agreement that care received in specialist wards was of a good standard and that improvements had been made in combating unfair or insensitive treatment.

4 Discussion

This study has provided a range of perceptions around insensitive treatment because of age, and has appeared to reveal a complex and multi-faceted picture of the more discrete and less visible aspects of discrimination through the experiences of the participants. The discussions have shown that ageist practice is far from straightforward, and there are a number of issues that are worth briefly elaborating on here.

There are clear links between ageist practice and quality of care. From a practice perspective, the debates that centred around insensitive treatment and the right approach to a feature of care seemed to indicate that predominant problems lay with the following main areas. These were a lack of client-centred care, especially assessment, unfair decision-making around clinical priorities, and the absence of agreed clinical standards, with communication problems ranging across all areas. In addition, the role of relatives emerged as an added variable. These issues will now be discussed further.

4.1 Client centred care

A factor that could be instrumental in contributing towards discrimination in this area could be the difficulties inherent in engaging older people in their care. Explanations for this vary, but a fact remains that patients who do not participate in decision-making about their care are more frequently older people, despite the fact that they have a desire to take part (Hamalainen et al 2002). Different care choices are not always discussed with older patients, and even those who are highly educated are not always heard (Tinker 1995). As a result, older people may over time become resigned to acceding to doctors' decisions, and be modest and inactive in the consultation (Hamalainen et al 2002).

The resulting detachment could result in professionals taking over and older people becoming reliant on workers to do their decision-making for them. This in turn results in a less than client-centred outcome. For example, one study demonstrated that most older people did not agree with a nursing assessment of their abilities (Harkness et al 2002). Clues that workers in East Kent were making decisions on behalf of older people in this study were evident in the perception that 'assumptions' were being made about care and treatment needs. While this can be confused with the caring role, there were many instances where judgements based on an assumption of what was right, were in fact inappropriate and insensitive. This occurred for example when addressing older people, giving them beakers to drink from, deciding what information to give them, or assuming they are deaf, or will not understand.

From a policy perspective, the resultant disempowerment is further compounded by the enduring perception that 'doctor knows best' (Irvine 2002). Ham and Alberti (2002) suggest that this particular perception is predominant with older people due to an implicit 'compact' between doctors and patients that was fostered at the inception of the NHS. This agreement stems from the government granting the medical profession a large measure of autonomy and control over its work, culminating in the power inequity between doctors and patients (Klein 1983). Ham and Alberti argue that new policy that attempts to shift the balance of power through imposing patient involvement criteria has not accounted for the different generational expectations of how the NHS should work, and the subsequent difficulties of its implementation in this age group.

The issue of empowerment and its relationship to discriminatory practice was evident again in this study with the lack of choice in all care settings, but this time more subtly. Both in the acute and community settings, resources and rigid organisational frameworks were squarely blamed for poor flexibility around going to bed, having a bath or mealtimes. While it was recognised that all service recipients are vulnerable to this lack of choice, older people are the largest users (DoH 2001). With the potential for disempowerment and the associated lack of assertiveness in this population group (Bytheway 1995), this situation does raise questions as to whether services would be more flexible were the largest recipient to be younger and more vocal.

4.2 Clinical priorities

It was of concern that that discrimination in relation to admission or access policies were clearly evident, affecting the most critical and vulnerable people. That some situations were seen to be linked to resources highlights how the issue of discrimination can be intertwined with rationing debates (Grimley Evans 1997). In addition, older people waiting for surgery appeared to be 'bypassed'. This finding runs counter to client-centredness, and how willing older people are to give up their place in the surgery 'queue'. Bowling et al (2002) conducted a large national survey targeted at people over 65 on the cardiac surgery waiting list, asking if they would be prepared to give up their place for a younger person. Most did not wish to cede priority, although willingness to give up one's place increased with age. This could be interpreted as older people valuing themselves less and being less assertive. The authors warn however that ageing 'baby boomers' may be even less willing to give up their place or tolerate an unequal position, and will be more outspoken about their rights to health care provision.

4.3 Clinical standards

As identified in the study, it was evident that all participants were in agreement about the very difficult problems in making clinical judgements that were in the best interests of the client. Key to some of

these practice issues seemed to be the difficulties in developing and operationalising clear clinical standards to assist in making decisions, as evidenced by the intricate and often circular debates in the groups. Even when systems or standards are in place to ensure quality of care, resource implications seemed to impede best practice. This was seen in relation to access to Rapid Response and the use of dosset boxes for safe medication. While some standardisation in trauma management was being tested in the acute setting, it appeared to be absent with some of the more challenging areas such as assessment of sexuality, communication and resuscitation.

Guidance is confusing. Taking resuscitation as an example, the implementation of the human rights Act has led to updated guidelines from professional bodies. These are likely to need careful interpretation in light of local circumstances before they can become a practical tool for decision-making (Stewart et al 2003). Guidance on how to achieve “openness and transparency, whilst maintaining sensitivity and inclusiveness” (BMA 2001) is not evident. Further to this, a survey of nearly 500 members of the British Geriatric Society revealed that distress to patients and relatives, lack of time, resources and patient knowledge were all barriers to ‘Do Not Attempt Resuscitation’ discussions with users (Durrant et al 2002). This illustration serves to highlight the importance of seeking greater clarity in how policy can be implemented.

4.4 The role of relatives

A further dimension highlighted by the study findings relates to the role of relatives. On the face of it, ageist practice would appear to be connected to staff’s behaviour with older people (Tinker 1996; DoH 2001). It was of interest therefore that the groups implicated relatives as being instrumental in engendering the potential for discrimination to take place. Strong feelings were expressed about the conduct of relatives and the conflicts inherent in managing care decisions that were non-ageist and in the best interests of the older person. From the relative’s perspective however it could be argued that being presented with a situation which may result in having to take on caring responsibilities of any nature is highly emotionally charged and conversely not always in the best interests of the carer (Henwood 1998). Given the economic and physical cost of caring (Carer’s UK 2002), such a reaction is hardly surprising. This no doubt accounts for the pressure exerted to defer this responsibility by insisting that the older person goes into institutional care, rather than back home which may seem to be a less secure option.

It is also possible that feelings of guilt in the amount of contact relatives do have with an older relative may provoke a sense of concern in relatives when interacting with professionals that could be interpreted as overly demanding. Reasons for this could stem from poor interaction between nurses and patients’ relatives, where relatives have difficulty

initiating dialogue and receiving information (Laitinen and Isola 1996). Also, relatives can be typically avoided or ignored by many professionals (Henwood 1998). In addition, health and social care workers do not fully recognise the competence and knowledgeability that relatives have of the older person, which results in aggravation (May et al 2001). When this is coupled with the lack of health and social care resources, heavy workloads and resultant frustration felt by workers, it is not surprising that conflict can arise. Such a situation highlights the clear need for careful, appropriate and inclusive dialogue with relatives throughout the care cycle in order for clinical decisions to be mutually understood and agreed upon and for conflict to be avoided.

4.5 Implications for practice

Given all these forces at play therefore, it is evident that a paradox arises. If there is a fundamental lack of engagement with older people caused by power imbalance, health belief systems, poor communication and lack of appropriate clinical guidance, it could be argued that older people are unable to be sufficiently aware of what the appropriate choice is for them. As a consequence, it becomes hard for older people to engage in client-centred care, and safeguard their own interests by assisting in the often complicated decision-making processes. Further conflict ensues when relatives and professionals assume this function, as there are still barriers to implementing best care. It can be seen that such a situation of heightened susceptibility provides a fertile ground for ageist practice to take place.

Ways to tackle these problems have been suggested; a few examples are listed here:

- Walker (1999) examines methods of overcoming barriers to the inclusion of older people in decision-making by identifying eight principles of empowerment. These allow older and frail people an active voice in determining their own health and social care.
- Eastman (1998) argues that the problem lies in institutional ageism and urges managers to address local policy and practice at an organisational level for change to be effective.
- Biggs (1990) outlines education and training to combat ageism using experiential methods to examine attitudes to old age through group work.
- Tinker (1994) identifies practice solutions through interprofessional work, highlighting the need for common understandings and joint practice standards.

Despite these examples, there is little evidence in the literature of successful implementation, stressing the need for specific action plans at a local level tailored to meet local requirements.

4.6 Limitations of the study

This was a qualitative study based on perceptions and as such can never be representative of the sample population. Qualitative research of this nature however does not seek representativeness but gains credibility through the collection of rich data, and diversity of experiences, and the study certainly made some headway in this respect.

The study focused on staff and does not capture any views of users and carers which in itself could be criticised as being discriminatory. This is however a central feature of suggestions for further work emanating from the findings.

To some extent, the quantitative data accumulated through the use of the questionnaire underestimated the global response to the problems, as discussions 'jogged' memories and provoked wider debate. They should therefore be treated as an adjunct to the main qualitative data.

It is important to note that the identification and articulation of what was seen to constitute ageist practice was of a subjective nature, although consensus was reached within and between groups on a range of issues. Clinical incidents deemed as discriminatory often hinged on individual understanding of terminology. For example, groups often used the term 'inappropriate' which by its nature is a clinical judgement and can vary between professionals. Many of the views expressed by participants will differ from those reading the report, true consensus in this area and therefore practice guidelines may be difficult to reach because of this. It is therefore important that further work is conducted with professionals.

5 Conclusion

The day to day experiences of frontline staff provide an insightful perspective and represent a helpful lens through which to view patients' experience of services. These reveal a wide diversity of issues that lead potentially to the ageist label being attached to particular circumstances.

Underlying these circumstances are complex and inter-related factors. There is no simple manifestation and therefore no straightforward intervention to address ageism in the provision or delivery of services. Additionally, running through many of the findings are hints of wider societal attitudes that will need a longer term approach than merely providing staff training or patient leaflets.

However a number of influencing themes emerge that will help to direct future work and focus the attention of commissioners and service providers.

These revolve around:

- 5.1 The expectations and perceptions of older people themselves either as users or carers, and what influences these, for example generational factors.
- 5.2 The impact of healthcare staff attitudes (including 'professionals' and support staff). This includes assumptions about the needs and capabilities of older people and **revolves** around assessment processes but **centres** on individual behaviours such as communication.
- 5.3 The influence of organisational systems (as opposed to reviewing age related clinical policies) – policies, operational practices, allocation of resources, training, recruitment – leading to suggestions of 'institutional ageism', for example prioritisation, phlebotomy rounds, numbers of staff, impact of financial constraint.
- 5.4 The circumstances, expectations and perceptions of relatives and carers – for example their knowledge, life pressures and guilt.

6 Recommendations

On the basis of the focus group work, the key words that need to flow through all future work in this area are **choice** and **control**. Whilst a factor influencing the environment in which services are delivered to current users of older people's services is the level of assertiveness and knowledge of the client group itself, there are signs already of a shift in this situation.

The awareness and understanding of users of health services are set to increase substantially over the coming decade. It is important therefore to be framing service provision now with the perspective of a knowledgeable and assertive clientele. This will ensure services in the future meet the demands required of it, but importantly it will shift the expectations and current users and providers of care.

6.1 Role of commissioners

Crucial to this process is the role of commissioners. To address the underlying factors highlighted above this should include:

- 6.1.1 Setting the agenda, making its position on ageism clear and setting clear standards for providers – the 'zero tolerance' agenda
- 6.1.2 Influencing the environment in which services are delivered – such as planning and the allocation of resources
- 6.1.3 Demonstrating openness and communicating clear, explicit values to help shape the expectations and perceptions of service users, relatives and frontline staff

6.2 Programme development

Rather than take a piecemeal approach to this, one way might be to initiate a programme ("Positive About Older People") aimed at targeting each of the areas noted in the conclusions:

- 6.2.1 A programme of initiatives needs to draw on models of good practice in the local area and national arena and could include:
 - Communications programme developed with and aimed at users around the general standards of service that can be expected – in particular values and standards – this could include targeted material on the 'difficult' issues identified by focus groups
 - Training and education of staff around issues such as behaviour and communication that uses models of practice that are effective;
 - Review of organisational systems impacting on older people's services from the client perspective;

- Review and development of workable models that will facilitate the engagement of older people and their carers, working towards enhancing client-centred service provision;
- Review of lessons from parallel situation – such as learning of Metropolitan Police from MacPherson (Stephen Lawrence) Inquiry;
- Assessment of resource allocation processes and provision of facilities (including assistive technology) from the client/carer perspective;
- Developing a local accreditation scheme for wards or departments to participate in;
- Communications programme aimed at relatives and carers about expectations and aspirations of services for older people;
- Piloting and evaluating new developments to ensure effectiveness before wider dissemination.

7 References

- Bauer A (2000) Unjustified exclusion of elderly people from studies submitted to research ethics committee for approval: descriptive study. *British Medical Journal* 321:992-993.
- Biggs S (1990) Ageism and confronting ageing: experiential groupwork to examine attitudes to older people. *Journal of Social Work Practice* 4 (2) 49-65.
- Bowling A (1996) Health care rationing the public's debate. *British Medical Journal* 312: 670-4
- Bowling A (1999) Ageism in cardiology. *British Medical Journal* 19:1353-1355.
- Bowling A, Mariotto A & Evans O (2002) Are older people willing to give up their place in the queue for cardiac surgery to a younger person? *Age and Ageing* 31:187-192.
- British Medical Association (2001) Decisions relating to cardiopulmonary resuscitation. A joint statement from the British Medical Association, The Resuscitation Council UK and the Royal College of Nursing. London: BMA
- Buswell K (2001) Waiting for ages. *Nursing Standard* 15:52.
- Bytheway B (1995) *Ageism*. Buckingham: Open University Press.
- Department of Health (2001) *Older People: The National Service Framework for Older People*. London: The Stationery Office.
- Department of Health (2002) *National Service Framework for Older People: Interim Report on Age Discrimination*. London: Department of Health.
- Durrant J, Morris R & Masud T (2002) Attitudes towards 'Do not Resuscitate' policies and decisions: a questionnaire survey of UK Geriatricians. *Age and Ageing* 31: supplement 2 (July) p.40
- Eastman M (1998) Why and when institutions do not work: Sans everything revisited. In *Residential versus Community Care* Jack R (ed) chap.11 pp.202-212 Hampshire: Macmillan Press.
- Ellis J (2002) Bad old days. *Nursing Standard* 16 (25) 23-4
- Flick U (1998) *An Introduction to Qualitative Methods*. London: Sage Publications
- Grimley Evans J (1997) Rationing healthcare by age: the case against. *British Medical Journal* 314: 822-825.
- Ham C & Alberti KG (2002) The medical profession, the public and the government. *British Medical Journal* 324: 838-842.
- Hamalainen PM, Perala ML, Poussa T & Pelkonen M (2002) Patient participation in decision-making on the introduction of home respiratory care: who does not participate? *Health Expectations* 6:118-127.
- Harkness MK, Feltbower R, Yates D, Kemp H & Stanners AJ (2003) Do older hospital in-patients have in-sight into their functional abilities? *Age and Ageing* 32: supplement 1 (May) p.6.
- Henwood M (1998) *Ignored and Invisible? Carers' experiences of the NHS*. London: National Carer's Association

Irvine D (2001) *Patients and doctors: all change?* Newcastle upon Tyne: University of Northumbria.

Kitzinger (2000) Focus groups with users and providers of healthcare. In Pope C & May N (2000) (eds) *Qualitative Research in Health Care* chap. 3 pp.20-29. London: BMJ Books

Klein R (1983) *The Politics of the National Health Service*. London:Longman.

Laitinen P & Isola A (1996) Promoting participation of informal caregiving in the hospital care of the elderly patient: informal caregivers perceptions. *Journal of Advanced Nursing* 23, 932-947

May J, Ellis-Hill C & Payne S (2001) Gatekeeping and legitimisation: how informal carer's relationship with health care workers is revealed in their everyday interaction. *Journal of Advanced Nursing* 36 (3) 364-369.

Morgan DL (1997) *Focus Groups as Qualitative Research*. Thousand Oaks: Sage Publications

Pope C & May N (2000) (eds) *Qualitative Research in Health Care*. London: BMJ Books.

Rivlin MM (1995) Protecting elderly people: flaws in ageist arguments. *British Medical Journal* 310:1179-82.

Rosenfeld KE, Wenger NS, Boyd K & Teres D (1997) Do-not-resuscitate orders in the elderly: Age discrimination or patient preference? *Archives of Internal Medicine* 157 (9) 1041-1043.

Scott H (2000) Age discrimination should be outlawed in the NHS. *British Journal of Nursing* 9 (1) 4.

Stewart K, Spice C & Rai GS (2003) Where now with Do Not Attempt Resuscitation issues? *Age and Ageing* 32: 143-148.

Sutton GC (1997) Will you still need me, will you still screen me, when I'm past 64? *British Medical Journal* 315: 1032-3.

Tinker A (1995) Elderly people, discrimination and some implications for interprofessional work. *Journal of Interprofessional Care* 8 (2) 193-207.

Tinker A (1996) *Older People in Modern Society* 4th edition. London: Addison Longman.Wesley

Walker A (1999) Older people and health services. In *Health and Exclusion Policy and Practice in Health Provision* Purdy M & Banks D (eds) chap.9 pp.158-178.

Williams A (1997) The rationing debate: Rationing healthcare by age: the case for. *British Medical Journal* 314:820-822.

**National Service Framework – Standard 1 ‘Rooting out Age
Discrimination’**

**Audit of Health Care Providers
Focus Group Schedule**

1 Access to services

- Hospital beds
- Access to treatment in A&E
- Access to specialist services
- Access to investigations
- Access to therapy/rehab, chiropody any other service
- Access to being a research subject
- The way people are assessed
- Other issues?
- Could there be other reasons for any ‘ageist’ practice witnessed?

2 Communication

- How people are called to their face or referred to between workers
- Sensitivity to hearing problems (shouting, tone of voice, adjusting body posture, addressing need for correction)
- How information is given – verbal and written (sensitivity to visual problems, how people are spoken to), do people understand what is said?
- Fully informing about care
- Other issues?

3 Attitude

- Degree of respect, friendliness, politeness
- Caring attitude, approachability
- Awareness of and response to needs
- All staff
- Attitude to carers
- Other issues?

4 Privacy and Dignity

- When discussing personal issues
- When being examined
- When receiving personal care
- With visitors
- Other issues?

- Could there be other reasons for any 'ageist' practice witnessed?

5 Personal Care

- Attention to hygiene, washing and bathing needs
- Attention to hair and nails, general appearance needs
- Access to toilets when needed
- Dietary needs
- Getting up and going to bed – according to personal wishes?
- General issue of timing of care – to suit organisation or person?
- Other issues?
- Could there be other reasons for any 'ageist' practice witnessed?

6 Treatment

- Medicines – access to most effective, able to understand directions, help in taking pills etc, too many
- How treatments are decided – surgery vs medical treatment – what types of surgery may be difficult to access?
- Resuscitation
- Gender and race issues?
- Exclusion from latest treatment or beneficial interventions?
- Understand treatments?
- Other issues?
- Could there be other reasons for any 'ageist' practice witnessed?

**National Service Framework – Standard 1 ‘Rooting out Age
Discrimination’**

Audit of Health Care Providers

Participant Reference Sheet

Age discrimination happens when someone makes or sees a distinction because of another person’s age and uses this as a basis for prejudice against, or unfair treatment of that person.

In this discussion group today, we are going to focus on the following areas:

- **Access to Services**
- **Communication**
- **Attitude**
- **Privacy and Dignity**
- **Personal Care**
- **Treatment**

These will be discussed in relation to experiences that you have:

- **seen or heard for yourself in the care setting**
- **heard via an older service user or their carer**
- **or read about in medical notes.**

Thank you for your help.

**‘Rooting Out Discrimination’ Questionnaire
Staff Perceptions of Age Discrimination in the Workplace**

The questionnaire is divided into four sections. The first three sections look at different areas of care and give statements about discrimination that may happen to older people *because of their age*. After reading each statement, you will be asked to tick a box that best describes how often you have come across this through:

- seeing or hearing it for yourself in the care setting
- hearing it via an older service user or their carer
- or reading about it in medical notes.

Not all the statements will apply to your working situation, so please use the box ‘N/A (not applicable) to me’. The last section asks a few details about yourself. All information in this questionnaire will remain completely anonymous and confidential, and you will not be identifiable. Thank you for your help.

Section 1: Access to Services

Please tick one box per statement.

Statement	Often	Some-times	Rarely	Never	N/A to me
1. Not being referred to specialist services locally or outside the area, when this is needed					
2. Not having surgery despite being fit enough					
3. Not being referred for investigations such as blood tests, x-rays or scans					
4. Being excluded from respite care because you are over 65, even if you had it before					
5. Having difficulties getting some services to see a person who is over 65					
6. Having problems getting a recuperative care bed if you are over 65					
7. Relatives urging for an older person to go to a nursing home when it is not appropriate					
8. Older people having a low priority with respect to medical attention, referrals, surgery or investigations					
9. Not having cardiac investigations or treatments such as pacemakers because of age					
10. Not being offered the chance to take part in research, such as entering a clinical trial					
11. Having difficulties getting onto a GP list					

Please use the space below to add any further comments about access to services not captured by the statements

.....

.....

.....

Section 2: Communication and Attitudes

Please tick one box per statement

Statement	Often	Some-times	Rarely	Never	N/A to me
1. Staff speaking to friends or relatives about the older person in his or her presence, but excluding them from the conversation.					
2. Shouting at an older person even if they are not deaf					
3. Not fully informing an older person about their condition, treatment and/or care, assuming they wouldn't understand or don't want to be bothered about it.					
4. Calling an older person 'lovey' or 'duckie' instead of their preferred name					
5. Discussing sensitive issues within earshot of the older person but not with them					
6. Speaking 'on behalf' of an older person about a matter without making sure of their opinions					
7. Discussing personal and sensitive issues with an older person loudly within hearing of other people					
8. Not giving enough or appropriate information about medicines – 'just take them'					
9. Labelling older people as 'daft' or 'demented' if they have a problem understanding					
10. Talking to or about older people in a patronising way – treating them like children					

Please use the space below to add any further comments about communicating with and attitudes towards older people not captured by the statements

.....

Section 3: Treatment and Care

Please tick one box per statement

Statement	Often	Some-times	Rarely	Never	N/A to me
1. Giving an older person an incontinence pad when they don't need one					
2. Not giving an older person enough privacy when helping them with activities such as toileting, washing or dressing					
3. Letting older people have a limited choice in things like when and what they eat, when they go to bed or have a bath					
4. Giving older people inappropriate clothing					
5. When undertaking assessments, missing out questions about sexuality					
6. Having some expensive treatments refused because of age, such as beta-interferon for MS sufferers and drugs for Alzheimer's disease					
7. Giving older people inappropriate aides/equipment, such as beakers, or tip-back chairs					
8. Giving older people too many tablets and not reviewing them often enough					
9. Catheterising older people unnecessarily					
10. Assuming that people over 80 do not want to be resuscitated					

Please use the space below to add any further comments about treatment and care not captured by the statements

.....
.....
.....

Section 4: Now some questions about you.....

1. Which setting do you work in?
(please tick one)
- Community – general
 - Community – mental health
 - General Practice
 - Hospital – general
 - Hospital – mental health
 - Hospice
 - Recuperative care
 - Social Services
 - Other (please specify)

2. Which of these areas best describes the job you do? (please tick one)

- | | |
|-------------------|-----------------|
| Medical | Portering staff |
| Nursing | Office work |
| Therapy | Clerical |
| HCA | Research |
| Teaching/training | Social work |
| Domestic staff | |

Other (please specify).....

Thanks you for completing this questionnaire.