PFPI Report

Patient Focus
Public Involvement
Providing
More Personal Information to the NHS
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Contents

Foreword .........................................................................................................................3
Executive Summary ........................................................................................................5
1. Chinese Consultation (Edinburgh) ...........................................................................13
2. Chinese Consultation (Dumfries) ..........................................................................22
3. Background to Black and Ethnic Minority Consultations ..................................31
4. Black and Minority Ethnic Young People’s Consultation, Glasgow ..........33
5. Arab Community Consultation .............................................................................43
6. Multi-ethnic Consultation (Aberdeen) .................................................................52
7. Jewish Community Consultation .........................................................................61
8. MelMilaap Day Care Centre Consultation .........................................................73
9. Elderly Muslim Community Consultation .........................................................81
10. ORAN Street Day Centre Consultation ..............................................................88
11. South Lanarkshire Citizen’s Panel Consultations: Background ..................94
12. Hamilton Consultation Meeting .........................................................................96
13. Rutherglen Consultation Meeting ....................................................................103
14. Lanark Consultation Meeting ............................................................................111
15. East Kilbride Consultation Meeting ..................................................................118
Appendix 1 .....................................................................................................................125
Appendix 2 .....................................................................................................................133
Appendix 3 .....................................................................................................................136
Appendix 4 .....................................................................................................................137
Appendix 5 .....................................................................................................................140
Appendix 6 .....................................................................................................................141
Appendix 7 .....................................................................................................................150
**Foreword**

We are now into the second year of the Equality and Diversity Information Development Programme. We have devoted most our attention so far to ethnicity, and the results are now showing - we now have agreed ways of recording and describing patient ethnicity. However it is equally important to make sure that people in Scotland understand why this information is needed.

For this reason a major emphasis in our work during 2006 has been to raise awareness of the need to record ethnicity and diversity information. These reasons include supporting better health care, ensuring we comply with legislation and maintaining good clinical governance standards. During the year we have hosted consultation meetings across Scotland, across all diversity groups and all clinical settings.

Providing more Personal Information to the NHS presents the findings of these consultation meetings. The meetings were arranged in collaboration with BEMIS (Black and Ethnic Minorities Infrastructure in Scotland) and South Lanarkshire Citizens Panel.

The Report is a collection of the individual consultation meetings and is divided into fifteen chapters. Nine of the chapters describe the meetings held with Black and Ethnic Minority community populations and the four describe the meetings with representatives from the majority ethnic (ie white) population.

Most people attending the meetings were willing to provide more information to the NHS in Scotland if the main purpose was to improve their health care. Obviously there are some issues and concerns and respondents wanted to see clear safeguards in place to support them in giving this information.

We have seen the Disability Equality Duty (DED) published and the NHS has also accepted the wider challenge to put an end to all forms of discrimination, whether based on age, disability, gender, race, religion or belief or sexual orientation. Collecting appropriate information from all people in Scotland in a safe and secure environment is essential to support quality health care. The ultimate aim is to see and describe improvements in the health and well being of those who are currently disadvantaged or face discrimination in our health services.
I am pleased to contribute the foreword to this report. I hope that it encourages NHS Boards to engage with their diverse local communities in order to support the distinctive needs of the population they serve.

Dr Andrew Fraser

Chair of the Equality and Diversity Information Development Programme Steering Group
Director of Health and Care
Scottish Prison Service Headquarters
March 2007
Executive Summary

The National Health Service (NHS) in Scotland is committed to ensuring that people are treated fairly and equally. This should apply to everyone, whatever their ethnic group, religion, age, gender, sexual orientation or disability. To demonstrate that the NHS is treating people fairly and to monitor progress it is essential to collect better information about the range of diversity among users of the NHS. The Information Services Division (ISD) of NHS National Services Scotland is the agency responsible for collecting, analysing and interpreting routine national statistics on health in Scotland. ISD has set up an Equality and Diversity Information Programme (EDIP) to improve the collection, analysis and interpretation of information on diversity, with the ultimate aim of improving care for patients and ensuring that everyone is treated fairly.

If the quality of diversity data collection is to be improved, it is important to understand people’s views about providing personal information. Public consultation is part of Patient Focus Public Involvement (PFPI) work undertaken by EDIP. During 2006 EDIP held a series of consultation meetings across Scotland in order to hear and understand what people have to say about providing more personal information to support their healthcare. This work was carried out in partnership with NHS and other statutory organisations, voluntary and community groups, including BEMIS (Black and Ethnic Minority Infrastructure In Scotland), the Chinese South East Cancer Support Group, the Fife Arabic Society, MelMilaap Day Centre For The Elderly, MECOPP (Minority Ethnic Carers of Older People) MECC (the Multicultural Elderly Care Centre) MeAL (Multi Ethnic Aberdeen Limited), Oran Street Day Centre For the Elderly, the Scottish Council of Jewish Communities and YCSA (the Youth Counselling Services Agency).

A total of 160 people attended nine consultation groups held across Scotland. There was an average of 18 attendees per meeting and 132 people completed a questionnaire. The groups included a wide range of ages and first languages included Arabic, Bengali, Cantonese, Chinese, English, Punjabi, Spanish and Urdu. Most of the attendees spoke English to some extent but several required assistance - translation and interpretation services were available as required.
The meetings were based on an oral presentation, which was modified and/or translated as required, and the attendees were encouraged to comment and participate. The attendees’ comments were noted and either summarised or noted in italics in the full reports for each meeting. In addition attendees were asked to complete a short questionnaire.

**Results**

**Respondents raised a number of issues of concern related to their use of NHS services, including:**

- Language barriers
- Problems reading or understanding hospital information letters and appointments
- Medication worries
- Concerns about lack of time with their GP
- Perception of a general lack of knowledge among NHS staff about other languages, cultures and religions
- Dietary issues, including the suitability of hospital food
- Transport and mobility problems
- Unsuitable hospital appointment times (especially when dependent on their family to take them or to provide informal interpreting services)
- Problems describing pain/symptoms
- Lack of questioning about socio-cultural information, such as communication support or dietary requirements
- Concerns about the ethnic categories used in the 2001 Census
- Issues around circumcision
- Issues around translation and interpretation services
- Concerns about being asked the same questions over and over again.
- Lack of communication training for NHS staff.
- Concern about why NHS staff want to know a patient’s religion, culture or language
- Concern about information about health being exclusive rather than inclusive – for example the description of NHS 24 on the internet as a ‘distinctly Scottish service’.
Attitudes to giving more personal information

Overall, attendees reported that they would be willing to provide a wide range of socio-cultural information, but only if they knew what it was to be used for and how it would help them. Several of the groups stated the importance of sharing this information with other relevant agencies and organisations, to avoid being asked these questions repeatedly. Other issues were raised in relation to specific areas:

Ethnicity
- Young people said that they had no problem grasping the concept of ‘ethnicity’ but this phrase led to considerable discussion and required further explanation with other groups.
- The group from the Arab community felt that they were overlooked as they were absent from national statistics due to the Census classification.
- One of the groups felt that further detailed demographics would be unlikely to benefit either patients or the NHS.

Religion/Faith/Spiritual Needs
- Young people did not seem to place the same importance on this question as older people, but agreed that they would provide this information.
- One of the groups from the Chinese community thought this question was irrelevant.
- One of the Chinese groups suggested that ‘faith’ was an unsuitable term and that the question be changed to something like ‘How willing are you to tell us about your religious belief and would you like to talk to someone about coping with your illness?’
- There was an expectation among the groups that information supplied with regard to religion or dietary preference would lead directly to action by NHS staff.

Language preference, interpreters and format of information
- All the groups agreed about the need for qualified interpreters rather than having to rely on family members, although one group was unsure if the NHS could provide access to the interpreters required.
- The groups agreed that alternative formats for information would be of benefit.
- One of the groups mentioned a general lack of information about how to complain and the fear that complaining might influence treatment or staff opinion.
• Both Chinese groups thought it was important for information to be provided in Chinese.
• One group raised the issue of providing information for carers so they could receive the support they need.

**Dietary preference**
• Most of the groups considered dietary issues important but doubts were raised as to whether the NHS would be able to meet individual dietary demands.
• One of the attendees highlighted the difference between the British and Chinese traditions around childbirth and explained how she had found it nearly impossible to follow her culture’s tradition with regard to food and bathing after having her baby.

**Mobility and Access**
• The groups wanted further explanation about terms in this section, but agreed that they would be willing to provide this information. One of the groups suggested the NHS might not be able to use this information to provide better services.

**Gender Preference in relation to Health Care Staff**
• This was highly relevant to some groups, who wanted female patients to be seen by female doctors and interpretation for female patients to be provided by female interpreters.

**Response to Questionnaire**

Most of the attendees completed the questionnaire, though many needed support to do this, especially among the groups with a high number of elderly attendees or those groups where there were already communication difficulties. The term ‘disabled’ appeared to cause confusion and proved difficult to interpret and the term ‘ethnic group’ also posed problems. In the two Chinese groups, 65% and 86% of the questionnaires were completed in Chinese. Elderly people appeared to need more support to complete questionnaires. The questionnaire is shown in Appendix 2.
Barriers to providing more personal information

Although willing to provide more personal information, the groups mentioned a number of requirements necessary to make this possible:

- Forms and questionnaires should be easy to understand and complete.
- There should be a clear explanation of the reasons why the data is being collected.
- Appropriate people should be involved in the development of forms and questionnaires.
- Staff asking questions or distributing questionnaires should receive appropriate training.
- Interpreters should be available to help complete questionnaires.
- There should be a clear explanation and reassurance in relation to the confidentiality of data collected.
- There should be assurance that information would be used by staff to support culturally appropriate care and to improve services.
- Sharing of information was acceptable but patients should be asked first with clear information around confidentiality and security.
- Information should be provided about how to access or change personal information held by the NHS.
- There should be consideration about who asks for this information, where and when.
- Information should be available for next of kin or carers when required.
- There should be further consultation on the religion and sexual orientation questions.
South Lanarkshire Citizens Panel

Through partnership work with the South Lanarkshire Citizens' Panel (SLCP), the EDIP held Consultation Meetings in Hamilton, Rutherglen, East Kilbride and Lanark.

The presentation encouraged the attendees at the meeting to share their experiences both of providing information to the NHS and of obtaining information from the NHS. During the discussions that followed, various concerns were raised, which are covered in detail in the accounts of the individual meetings, but included:

- The considerable amount of time currently spent at appointments, both GP and hospital, providing information that has already been provided.
- Communication problems between patients and GPs.
- Overall lack of awareness about issues such as the Carers Rights to Assessment and the Emergency Care Summary Leaflet.
- Information not being shared within the NHS or between statutory organisations, for example, between Health and Social Work.
- The possible – and current - uses of Information Technology to support healthcare.
- The importance of personal information being collected by staff trained in this.
- The benefits to patients and staff as a result of the provision of more personal information.
- Inequity between how GP surgeries across Lanarkshire informing patients of services, health checks, vaccinations etc.
- The problems some people face when accessing NHS services – from a lack of wheelchairs, to print being too small in medicine leaflets, to not knowing how to request an interpreter at an appointment.
- The fact that ethnicity is often assumed rather than enquired about.

Willingness to provide more personal information

This exercise highlighted a few issues around the questionnaire, including:
- Layout needs to be considered further.
- Clarification required about assistance in completing the questionnaire.
- Questions must be in plain English.
- Further consideration required around the question on ‘spirituality’.
- Consideration must be given as to where and when this questionnaire would be completed.
Recommendations

- Careful thought is required with regard to the design, format and content of data sheets and questionnaires requesting more personal information.
- Plain English must be used.
- Meaningful definitions are required for the terms ‘disabled’ and ‘disability’ and, possibly, ‘ethnic group’.
- Respondents should be given clear explanations about why more personal information is required.
- In return for providing this information, feedback must be provided to the people of Scotland about how the information is used locally and nationally, along with examples of the difference it is making to patients and carers.
- Information should be collected once and shared appropriately.
- NHS staff from all ethnic groups require good interpersonal communication training.
- All staff should undergo appropriate training in equality, diversity and inclusion.
- Requirements for interpreting services must be identified and collected.
- Emergency Care Summaries should consider ‘interpreter requirements’ and ‘ethnic group’ as necessary data items.
- Any national guidelines on using interpreters and translation services should include a section for patients, explaining how to access an interpreter, how to receive translated information, what to expect from the service and any local differences in the service provided.
- Effective, relevant information about illnesses, medication and appointments should be available in appropriate formats.
- The possibility of publishing a ‘Welcome to the NHS’ document, in various formats, should be explored.
- The NHS complaints process should be simplified and wider action taken by the NHS to ensure that services users know how to complain. NHS organisations currently introducing Ethnic Monitoring should provide service users with clarity about the Scottish Census 2001 categories.
Conclusion

The groups were all extremely positive about the EDIP and had few concerns about providing more personal information to the NHS, although some of the attendees acknowledged that this might be a problem to some people. Also, although most of the attendees were well and agreed that the questions were not highly relevant to them, they stressed that they would be happy to provide this information as they could envisage the benefits there would be for some people and communities.

Overall, the groups all agreed that they would support the NHS in terms of collecting more personal information to provide and inform services, resulting in more culturally sensitive care. However, the groups stressed the importance of users understanding why this information is being requested and how it will be used. The questionnaire is shown in Appendix 7.

Consultation

All consultation work was carried out by Joan Jamieson, EDIP Programme Manager (joan.jamieson@isd.csa.scot.nhs.uk) and Vijay Khanna, EDIP PFPI Support Worker. We want to express our thanks to the members of the consultation groups and to the organisations who supported this consultation. We recognise that the opinions of these groups do not necessarily reflect the views of all members of their communities across Scotland.
1. Chinese Consultation (Edinburgh)

How the consultation group was engaged

As part of a consultation process on the collection of personal information EDIP held a meeting with members of the Minority Ethnic Carers of Older People (MECOPP) programme.¹ MECOPP provides support and information for carers from black and minority ethnic communities within Edinburgh and Lothian. MECOPP, with support from the National Resource Centre for Ethnic Minority Health (NRCEMH)², has secured MacMillan funding to employ a Chinese Cancer Link Worker. The link worker provides advocacy, information, counselling, home visits, training to health and social staff and outreach services, with the aim of encouraging the uptake of cancer services by the members of the Chinese community.

The consultation group consisted of members of the Chinese South East Cancer Support Group, which is facilitated by the link worker. This group meets monthly at the Rainbow Arch Restaurant in Edinburgh.

Consultation preparation

Three planning groups were held with the link worker before the meeting and as a result, the invitation letter (Appendix 3), the PowerPoint presentation (Appendix 4) and the Questionnaire (Appendix 5) were translated into Chinese by the link worker.

1 MECOPP: http://www.MECOPP.org.uk

2 NRCEMH: http://www.nrcemh.nhsscotland.com
Summary of characteristics of the group attending

- 23 attended the group (higher than the normal average of 18).
  - 7 men, 16 women
  - Ages ranged from 18 years – 81 years
- Attendees travelled from Fife and Lothian.
- Half of the people in the group had cancer, while the others were there in their capacity as carer or to provide support.
- Six of the attendees were unable to read or write in any language (information provided by the link worker).
- Nine of the respondents were over the age of 60 and one was between 45-50.
- 23 were registered with a doctor and had attended at some point.
- 19 had experienced hospital referrals.
- 23 expressed difficulty in describing symptoms to the doctor.
- 23 said they did not get enough time with the doctor.
- Two said they understood what was being said in English.
- 21 relied on the interpreter for this group meeting.
- 22 of the attendees had either resided in or been born in Hong Kong.

Format of the meeting

An oral presentation (Appendices 1 and 4) formed the basis for the meeting, which was held during the normal monthly meeting of the South East Cancer Support Group. The Chinese link worker provided interpreting throughout the meeting and the attendees’ comments were noted and are either summarised or included (in italics), although these are not necessarily verbatim.
Results

Response to being asked about giving specific personal information

Table 1

<table>
<thead>
<tr>
<th>Question : How willing are you to give the following….</th>
<th>First time</th>
<th>After more explanation</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Ethnicity</td>
<td>13</td>
<td>1</td>
</tr>
<tr>
<td>Faith/Spirituality</td>
<td>13</td>
<td>0</td>
</tr>
<tr>
<td>Language preference</td>
<td>23</td>
<td>0</td>
</tr>
<tr>
<td>Require interpreter</td>
<td>23</td>
<td>0</td>
</tr>
<tr>
<td>Information Format</td>
<td>23</td>
<td>0</td>
</tr>
<tr>
<td>Dietary preference</td>
<td>23</td>
<td>0</td>
</tr>
<tr>
<td>Mobility access</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Gender preference Health Care practitioner</td>
<td>23</td>
<td>0</td>
</tr>
</tbody>
</table>

The questions above centred on how willing the attendees would be to provide the NHS with more personal information to support their health care.

The results in table 1 demonstrate that what had appeared to be straightforward questions were initially difficult for the group to understand.

The word ‘ethnicity’ did not appear to be commonly understood and required explanation. The concept of ethnicity as being somewhat multi-dimensional, referring to a common group identity, based on language, culture, religion, arts, customs and practices seemed to be helpful. As a result, 19 (91%) of the attendees said that they would give their ethnicity.
The question on ‘faith/spirituality’ initially received a similar response but clarity of definition and using different words for ‘faith’ (including ‘religion’, ‘beliefs’, ‘set of principles’) seemed to be more appropriate. Similarly, ‘spirituality’ required the explanation that this does not necessarily mean religious but that, in a time of crisis, such as a life-threatening illness, many people look for help and would like to speak to someone on a one-to-one basis. When the question was changed to ‘How willing are you to tell us about your religious belief and would you like to talk to someone about coping with your illness?’, 19 (83%) attendees responded positively.

There were no difficulties understanding the questions about language, requirement of an interpreter, diet preference and gender preference of health care practitioner. When asked about the importance of these, one man explained, via the link worker, the difficulties he has in communicating with doctors, both in terms of explaining his problems and his difficulties in understanding what is being said to him.

The first time it was asked, the question around mobility seemed to convey very little. However, when explained further - with words like, ‘able to walk easily’, ‘move arms, hands and legs’, ‘need help with washing/dressing/walking’ - 20 (87%) of the attendees responded positively.

When asked, “Do you think the NHS can provide health care to suit your particular needs?”, 23 (100%) of the attendees responded that this was ‘unlikely’.

This was the first time the EDIP programme manager had personally worked with an interpreter for the purpose of explaining the Equality and Diversity Information Programme (EDIP) and, when trying to develop further discussion around the issues raised, the lack of freedom to interact with the group was limiting.

It also very quickly became apparent the importance of language, terminology and the way questions are designed and asked. In a group of 23, the amount of interaction and participation was quite limiting.

When the attendees were asked the question: “Has Carrie [the link worker] made a difference in helping you?”, there was unanimous positive agreement.
Response to Questionnaire

The link worker provided the attendees with assistance in completing the questionnaire, which they were encouraged to complete so they could experience what it might feel like to be given this type of form by the NHS.

The questionnaires were distributed at the end of the meeting, just before lunch, which may have helped to get 23 (100%) returns but the environment was very supportive - the group knew one another, they were completing individually but as a group, and the link worker provided language support where required. There were five (22%) blank fields, all for the religion/spiritual belief question.

The first observation was that the responses were completed in Chinese on 15 (65%) questionnaires, which has significant resource implications if NHS organisations are considering asking patients this type of information in various languages, especially where free text space is provided, as it was in this instance. Fortunately, the link worker was able to write the English translation on each form.

The question, ‘Do you consider yourself disabled?’ yielded 22 (96%) negative responses. Considering that half the group have cancer, this shows that this question at least requires clarity of definition and explanation and possibly a redesign. From observation, three of the group required mobility support, two with a walking stick and one requiring carer/support.

The questions on ‘preferred speaking language’ and ‘requirement of an interpreter’ revealed that 19 (83%) of the attendees would like to request a Cantonese interpreter.

The group, which was larger than average, consisted of a high number of Cantonese speakers, which resulted in a more closed, question/answer type of meeting, with no real time to develop themes and/or pick up individual issues. On reflection, if attendees are to be encouraged to participate fully in a consultation meeting, the organiser should assess the optimum size of the group and the number of health care persons and interpreters required, both at the meeting and in the preparation and planning stages. However, via the link worker, the group expressed their thanks for the opportunity to hear about the EDIP programme and to participate in this type of meeting.
What is your current religion or spiritual belief?

Only five (22%) of the attendees left this question blank and three (13%) replied ‘none’.

This is an example of the kind of response that can be obtained when free text is available.

However, the responses do not reveal very much and demonstrate the need to explore various issues further with the respondent, for example, “What does ritual practice mean to you and how can we help?”

What best describes your ethnic group or background?

All the attendees chose an option from the Scottish Census 2001 Classification but ten (43%) opted to tick ‘Other British’ and ‘Chinese’.

The positive response of this group to the Ethnic Group question possibly reflects the group’s initial questions about ethnicity as the link worker had provided a lengthy explanation of this term at the beginning of the meeting.

Ten attendees opted to tick two boxes, which may reflect that the older Chinese attendees originally came either from Hong Kong when it was under British rule or had accepted the opportunity to come and work in the UK during the 1950s/1960s (nine opted for ‘Other British’ and ‘Chinese’).

In general, all the attendees are willing to give more personal information, especially in relation to communication, interpreting, diet and gender of healthcare practitioner.

Confidentiality did not appear to be a major issue with this group. This may partly be because, as half the group have provided so much information to the NHS as part of their cancer care, they can see the benefits in giving information and understand that, to ensure continuity of care, information must be shared. On the other hand, it could be that the attendees did not grasp or understand that there might be issues around providing more personal information or perhaps they did not fully understand the question.
The size of the group and the language barrier did not lend to equality of participation and few people were really able to participate. For example, time constraints did not allow for much exploration of when, who, where and by whom this information should be collected. However, in the light of the time required to explain and interpret the questions, it may be that primary care, where patients are known to the staff, would be appropriate.

**Reflections on this consultation**

The purpose of the meeting was set in the context of the legal and policy drivers that are challenging the NHS to collect more personal information. It is anticipated that, by the collection and use of specific cultural and social information, the NHS can demonstrate that racial equality is being achieved, cultural competence is being promoted and patient-centred care is being supported, ensuring that everyone benefits from health improvement.

The meeting could have been improved by:

- Devoting more time to the design of the questions, with explanations of the terms used.
- Hosting several smaller groups rather than one large group.
- Recognising that, when ill, clients are possibly not able to concentrate for too long when using an interpreter.

Although language is but one means of communication, to really empathise with clients who have little or no English, the meeting has to involve a more personal relationship. This group, in particular, are very positive about having the link worker supporting them, both in terms of her link work and her empathy and interpreting skills.

Simply translating information/health material is not an answer in itself. Testing is required with a small group of the target audience, both in the design and piloting of any information, and, in this case, within the context of a group meeting approach.
Providing background material and translating everything into Chinese was appropriate for this group and was appreciated. The preparation and planning meetings with the link worker allowed plenty of time to check the translations and the emphasis of points to be made.

Meeting in a venue that was familiar to the group was ideal.

**Recommendations**

- NHS organisations considering obtaining more personal information should meet and plan with relevant target groups and stakeholders to ensure the target group fully understand why they are being asked these questions and what is being asked of them.
- When redesigning/modifying the way personal information is provided, it is important to listen to and be informed by the personal experiences of those for whom the NHS wants information from.
- For this particular group, identifying and collecting information about interpreter requirements, and using the information to provide an interpreter in a timely way, is essential.
- Emergency Care Summaries should consider ‘interpreter requirements’ and ‘ethnic group’ as essential data items for out of hours care.
- Technology should be in place to allow this information to be collected once and shared appropriately.
- Every patient has a right to the relevant information about their illness, which should be supplied in a relevant format.

There is a need to explore with a sub group of this group in more detail their experiences, their issues regarding confidentiality and where, when and by whom this information should be collected.
**Conclusion**

Overall, this group is willing to give more personal information - if providing this information is seen as relevant and beneficial.

The NHS will be more successful in obtaining more personal information from patients/carers if clear communication is provided in a relevant format about why this information is required and how it will be used.

**Note**

This consultation was carried out by Joan Jamieson, EDIP Programme Manager, Vijay Khanna, EDIP PFPI Support Worker and Carrie Ho, MacMillan Cancer Link Worker. We would like to thank all the participants. We are particularly grateful to Carrie Ho for her support. EDIP recognises that this particular Chinese Cancer Support Group do not necessarily reflect the views of all the members of the Chinese community in Scotland. The results will primarily used to aid the Communications and Actions required by NHS organisations in their collection of more personal information from NHS service users.
2. Chinese Consultation (Dumfries)

How the consultation group was engaged

This was the sixth group meeting with Chinese residents of Dumfries which has been facilitated by Carrie Ho of Minority Ethnic Carers of Older People (MECOPP)\(^4\).

MECOPP provides support and information for carers from black and minority ethnic communities within Edinburgh and Lothian. MECOPP, with support from the National Resource Centre for Ethnic Minority Health (NRCEMH)\(^5\), has secured MacMillan funding to employ a Chinese Cancer Link Worker. The link worker provides advocacy, information, counselling, home visits, training to health and social staff and outreach services, with the aim of encouraging the uptake of cancer services by members of the Chinese community.

This group was established through the link worker’s outreach work and, to date, the group has attended both cancer information events and events involving joint working with the local NHS Health Improvement Team.

Initial findings from the group are that, among the Chinese community, there is a lack of knowledge of health services and provisions, a lack of general health information, various issues around accessing appropriate interpreters and a reticence about complaining.

\(^4\) MECOPP: http://www.mecopp.org.uk

\(^5\) NRCEMH: http://www.nrcemh.nhsscotland.com
**Summary of characteristics of the group attending**

- 22 people attended, including one child, who was there with their parent.
- One person had cancer.
- Two people were caring for a relative with cancer.
- Several of the attendees had literacy problems.
- All the attendees were associated with the catering business.
- All the attendees were registered with a GP and had attended at some point.
- 13 of the attendees had been onward referred to hospital (seven for maternity services).

**Format of the meeting**

As a result of the previous Chinese Cancer Support Group Meeting, the presentation (Appendices 1 and 4) which formed the basis for the meeting and the format of the meeting were modified. The link worker provided interpreting services and the attendees’ comments were noted and are either summarised or included (in italics), although these are not necessarily verbatim.
Results/Discussion

11 females and 10 males recorded ‘Gender’. This data item was left blank on one form.

One child is not recorded, making the total 22.

Response to being asked about giving specific personal information

Table 2

<table>
<thead>
<tr>
<th>Question: How willing are you to give the following….</th>
<th>Yes</th>
<th>No</th>
<th>D/K</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ethnicity (your culture, background, group you belong to)</td>
<td>22</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Faith/Spirituality/Religion/Talk to someone about your illness</td>
<td>0</td>
<td>22</td>
<td>0</td>
</tr>
<tr>
<td>Language preference</td>
<td>22</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Require interpreter</td>
<td>22</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Information Format (written, verbal, Audio, link person)</td>
<td>22</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Dietary preference</td>
<td>22</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Mobility access (help with transport, wheelchair access, dressing)</td>
<td>22</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Gender preference Health Care practitioner</td>
<td>22</td>
<td>0</td>
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</tbody>
</table>

The questions above centred on asking how willing the attendees would be to provide the NHS with more personal information to support their health care.

The group interacted well during this first, warm-up session and attendees were more than willing to interrupt and ask for clarity about any of the questions they were asked.
The question regarding Faith/Spirituality/Religion did not seem to be relevant to the group, who responded quite differently to the Chinese Cancer Support Group, who initially struggled to understand the question. When more explanation was provided, 83% of this group said they would give this information. In part, this may reflect the fact that, when the attendees were asked to state their religion on the questionnaire, 73% recorded ‘not applicable’. Also, the majority of this group were well - the BME Young People's Group also struggled to see the significance of this question and provided a similar response.

There was much discussion around language preference, the requirement of an interpreter and the format of information.

It was stressed by the group that information (such as referral letters, information about illness/conditions) is required in Chinese. Apart from the child, the attendees all said that they read and write in Chinese and that their preferred format of communication would be in Chinese. However, having evidence in their hand of, for example, an appointment, even in English, was seen as important as they would be able to find someone to help with translation. It was also stressed that a phone call in Cantonese would be of benefit.

The group also stressed that having the link worker speaking Cantonese and providing information about cancer, general health information and support has made a big difference to them.

The attendees were eager to provide examples of their experiences of the health service.

“I was at my doctor. Language line was used. The doctor seemed to be getting frustrated. There was one telephone, the doctor spoke to the interpreter, the phone was given to me and the interpreter asked the question. I passed the phone back to the doctor and the interpreter told him what I had said. At the end of the meeting, the doctor told me next time to bring a friend/family to interpret for me, as the language line takes too long.”

‘My husband was sick and I was very worried. I pleaded with him to go to the doctor. I even had my family come round to try and persuade him to go but he said no, it is too difficult for me as I can’t be understood and I don’t know what the doctor is saying.’
“I haven’t been able to get an appropriate interpreter, I don’t want my Scottish friend to have to come with me to explain my problem to the doctor.”

“I have past experience where the interpreter was not reliable and was unprofessional”.

Asked if anyone had complained about their concerns regarding interpreters, one person replied:

“How and who do you complain to?”

When asked if anyone had received information from their GP or heard of Health Rights Information Scotland⁶, there was a negative response. When asked if they would like to complain, heads were seen going down. One respondent said:

“I don’t know how to complain, and if I did complain, what would happen to me?”

When asked if they thought that complaining might be seen as a negative thing to do, there was a general response of not knowing what would happen.

Diet preference, mobility and access to preferred health care practitioner did not generate any strong feelings, although, overall, the group would like to have appropriate Chinese food but didn’t think the NHS could provide this. As they all come for the catering business, it is possible that the attendees may have low expectations of the NHS being able to provide for their catering needs. Gender was important to the women in terms of gynaecology and breast screening, while some men suggested that female health staff were more caring.

There was not sufficient time to explore the various issues further with this large group or to discuss how their concerns could be resolved. However, when asked what their priorities would be with regard to providing more personal information, the group unanimously agreed that language preference, interpreter and format of information were priorities, although the attendees doubted if the NHS could meet these requests.

Response to Questionnaire

The attendees were encouraged to complete the questionnaire so they could experience what it might feel like for them to be given this type of form by the NHS. All completed the questionnaires to a certain extent and were encouraged to ask for help if required. The questionnaire was self-completed in Chinese by 86% of the group, with only three respondents completing it in English. This is a higher finding than with the Chinese Cancer Support Group, where 65% completed the questionnaire in Chinese.

One respondent left the ‘gender’ and ‘disabled’ questions blank but it is possible that, as considerable discussion was going on around the completion of the ‘ethnic group’ section, this was an oversight rather than deliberately left blank.

Response from questionnaire ‘What is your current religion or spiritual belief?’

All responded to this question, although 16 (73%) recorded ‘not applicable’ (n/a).

This is quite a different response from that of the Chinese Cancer Support Group, where 35% either left this blank or recorded ‘no religion’. In this group, 73% recorded ‘not applicable’. Unfortunately, as the questionnaires were self-completed at the end of the session, there was no opportunity to ask the attendees about this. However, during the discussion about providing information, it was apparent that this group could not see how it would be helpful for the NHS to know this.

It should also be noted that, on the day of consultation, this was a well group. However, it does perhaps pose a challenge for the NHS in how it asks questions on religion and spiritual matters as the response of this group to this question is similar to the response from the Black and Minority Ethnic Young People’s Group.

The group required clarity as to what to complete and there was confusion, especially around the ‘Ethnic Group’ question that, at the beginning of the session, had not appeared to pose a problem. It became apparent that the format of the form was confusing the attendees as they thought they had to tick one item from each box (Appendix 2/5), which resulted in some of the group writing ‘Chinese’ repeatedly. As a result, this section of the form proved difficult to interpret meaningfully, even with Carrie’s support.
All attendees chose an option from the Scottish Census 2001 Classification, with 18 (82%) choosing ‘Scottish’ and ‘Chinese’. 3 of the respondents chose ‘Other’ (Hong Kong) and 1 chose Scottish/Chinese/Portuguese. The respondent who wrote down ‘Scottish/Chinese/Portuguese’ explained that he was from Macau and saw himself as all three. The respondents who recorded ‘Hong Kong’ most likely came from Hong Kong to Scotland from 1950 onwards. However, this section of the questionnaire seems to require better design and explanation of the ethnic categories (currently Census 2001 ethnic categories for Scotland).

The General Register Office of Scotland (GROS), as part of their preparation and planning for 2011 Census, tested a number of new and reviewed ethnicity questions in April 2006.

The questionnaire was provided in both Chinese and English and all the attendees reported being able to read and write in Chinese. This demonstrates that one consultation meeting with one community does not necessarily mean the results are homogenous.

**Reflections on this consultation**

- The use of an interpreter worked better with this Chinese group than at the previous consultation meeting, which was held in Edinburgh. This, in part, can be contributed to the modification of the ‘warm up’ session, which focused on Table 2 and the fact that this group were more comfortable working through an interpreter.
- Although there are similar themes coming from the Chinese groups in Edinburgh and Dumfries, there are also striking differences.
- Any questionnaire requires particular attention to the design and format of the questionnaire, the context of questions should be clearly apparent and there should be clarity about how responses are to be made.
- The benefits of a wide pilot exercise for a questionnaire should be considered.
- The experience of working with an interpreter helps one realise the complexity of language.

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• Adequate time is required for questions and answers to be translated, therefore the number of questions should be minimised by honing in on key issues or organising more than one meeting.
• There is an enthusiasm within this group to get involved and they are eager to learn more about NHS health care.
• Questions or issues raised by the group that cannot be answered have been forwarded to the appropriate local contact, demonstrating that we are acting on their issues.
• Referring patients to the Internet or even to attend the library to seek information is not always appropriate.

Recommendations

• The possibility of developing an NHS Scotland welcome-type resource in various formats, explaining what the NHS is, what it does, how to access services, what you can expect etc, should be explored.
• Local NHS organisations should ensure that there is clarity regarding what reasonable provisions are in place for those for whom English is a second language or who require communications support.
• Including a socio-cultural data capture at GP registration would help inform local NHS providers of the size and type of communication support required.
• To help improve the patient journey (e.g. referral to hospital that includes the need for an interpreter, wheelchair access etc), information technology systems must be able to store, retrieve and transfer key socio-cultural information about patients as part of their general health data.
• The NHS complaints process should be clarified, available in appropriate formats and easily located, both at local and national level.
• The non-detrimental effect of complaining on the complainant should be stressed.
Conclusion

This group, like other groups, would be prepared to provide the NHS with more personal information, especially as they felt access to interpreters and appropriate formats of information would increase their access to health promotion activities. The group did not report any problems around the sharing of this type of information with other agencies or organisations if it would make a difference to their health.

However, significant improvements are required to assist this group in providing the information required.

Note

The consultation was carried out by Joan Jamieson, EDIP Programme Manager (joan.jamieson@isd.csa.scot.nhs.uk) and Carrie Ho, MacMillan Cancer Link Worker. We would like to express our thanks to Carrie Ho and to the Chinese group in Dumfries for making this consultation possible. EDIP recognises that the opinions of this particular group do not necessarily reflect the views of all the members of the Chinese community resident in Scotland. The results will primarily be used to aid the Communications and Actions required by NHS organisations in their collection of more personal information from NHS service users.
3. Background to Black and Ethnic Minority Consultations

As part of EDIP’s Patient Focus Public Involvement (PFPI) work a system of partnership working was established with the Black and Ethnic Minority Infrastructure In Scotland (BEMIS)\(^8\).

EDIP was concerned to ensure that consultation group meetings should be held in the context of a supportive environment for those who participate. BEMIS is an umbrella organisation for black and minority community groups which reaches out to local groups and communities across Scotland, ensuring diverse representation and the inclusion of all groups. A great deal of the work of BEMIS is aimed at promoting and supporting issues of concern for black and ethnic minority communities at various levels, including local authorities and public bodies, funders, the Scottish Executive, the Scottish Parliament and training bodies.

A series of meetings were held between BEMIS (Rami Ousta, CEO and Tanveer Parnez, National Development Officer) and EDIP to agree a partnership approach to the consultation meetings. Following the presentation of an overview of EDIP to BEMIS, it was agreed that BEMIS would contact their participation community organisations to request that they host a consultation group meeting.

Following further discussion, it was agreed that:

- The Arab Community Consultation Meeting would be run in Kirkcaldy in partnership with the Arab Society
- The Jewish Community Consultation Meeting would be run in Glasgow in partnership with the Scottish Council of the Jewish Community in Scotland.
- The Rural BEM Communities Consultation Meeting would be run in Inverness in partnership with local BEM groups in the Highlands and Islands.
- The African/Caribbean Community Consultation Meeting would be run in Aberdeen in partnership with the local African/Caribbean community.
- The BME Youth Representatives Consultation Meeting would be run in Glasgow in partnership with the Youth Counselling Service Agency

\(^8\) http://www.bemis.org.uk/ Centrum Building 38 Queen street, Glasgow G1 3DX
BEMIS organised and managed all arrangements with regard to developing local partnerships, securing the relevant candidates, organising venues and all associated issues (i.e. keeping records of attendees, invitations, etc.), while EDIP organised the content and format of the group meetings.
4. Black and Minority Ethnic Young People’s Consultation, Glasgow

Youth Counselling Services Agency (YCSA), 

The main aim of the YCSA is to provide counselling and support services specific to the needs of young people from black and minority ethnic communities. Services include, for example, counselling, family mediation, drug and alcohol advice, literacy and numeracy tutoring, training and development and a free phone help line.

Summary of characteristics of the consultation group attending

- The group traveled from across Glasgow.
- Ten attended (university students, upper school pupils, employed youth worker).
- Six male, four female.
- All reported to be well.
- All fluent in English and bilingual in one or more of the following: Punjabi, Urdu, Arabic, Spanish.
- All registered with a doctor (six with a South Asian GP) and all had attended their doctor at some point.
- Three could remember being referred to hospital.
- All were born and educated in Glasgow.
- All prefer to speak in English, especially if describing a health issue.
- They did not all know one another.

9 Contact: YCSA, 11 Forth Street, Glasgow G41 2SP. Tel 0141 420 6600, www.ycsa.org.uk. Email : info@ycsa.org.uk
Format of the meeting

A presentation (Appendix 1) formed the basis for the evening, with the attendees encouraged to participate freely. The attendees’ comments were noted and are either summarised or included (in italics), although these are not necessarily verbatim.

Results/Discussion

Response to being asked about giving more personal information

Table 3

<table>
<thead>
<tr>
<th>Question : How willing are you to give the following….</th>
<th>Yes</th>
<th>No</th>
<th>D/K</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ethnicity</td>
<td>10</td>
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<td>0</td>
</tr>
<tr>
<td>Religion/Faith/Spirituality needs *</td>
<td>1*</td>
<td>9*</td>
<td>0</td>
</tr>
<tr>
<td>Language preference</td>
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<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Require interpreter</td>
<td>10</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Format to receive information (written/oral)</td>
<td>10</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Dietary preference</td>
<td>10</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Mobility access (walking/dressing/transport)</td>
<td>10</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Gender preference Health Care staff</td>
<td>10</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

The questions above centered on the willingness of the attendees to provide more personal information to support their health care.

*It should be noted that the attendees said they would give their religion if asked, but didn’t think they would need to talk to anyone about their religion or illness whilst in hospital.
Ethnicity

This group had no difficulty grasping ‘ethnicity’ as seven of them had experience of completing equality opportunity forms. All attendees reported that they would be willing to give this information.

Religion/Faith/ Spirituality Needs

This generated a fair amount of discussion among the group. The attendees could understand the rationale of providing information about their religion in terms of monitoring/informing staff about potential cultural sensitivity but failed to grasp that it might be to their advantage to talk to someone about spiritual needs, despite an attempt to explain further what spiritual needs might include (e.g. that this is not necessarily a religious matter but when you are ill going into hospital/anxious about your health, you might like to talk to someone on a one-to-one basis).

As one attendee said: “Even if I have pain or I am ill, I would take it as pain and get on with it.” It may be that, as these young people see themselves as fit, healthy and embracing life, at this stage in their life, they do not feel any need for self-reflection or for considering the impact illness might have on them.

After the discussion, all the attendees agreed that they would provide their religion but only one felt that they might need to talk to someone.

This question appears to require to be broken into at least three components:

- Question on religion
- Question on talking to a faith leader
- Question on talking to someone about illness

Further investigation is required.
Language Preference, Interpreter, Format of information

Whilst this question seemed irrelevant to all of the attendees, when encouraged to talk about their family members, all agreed that they have relatives whose preferred language would not be English. One attendee gave an account of his elderly grandparent being admitted to hospital and how his parents had to act as interpreters. There were nods of agreement when it was suggested that this was a relevant question to ask and it was widely agreed that ‘proper’ interpreters should be available, rather than relying on family members.

Whilst the attendees were not asked to comment on the literacy level of their friends and family, they agreed that alternate formats would be helpful to those people who did not read or write in any language.

Dietary Preference

The attendees agreed that they would provide this type of information as diet is an important part of their faith. However, there was some concern about whether the NHS could actually meet individual dietary demands.

Mobility Access

This question required to be broken down, explained and examples provided of what ‘mobility access’ might include, such as transport requirements, support with walking, support with dressing, personal hygiene. Again, although this question seemed irrelevant to the fit young people in the group, they could see the importance of their frail elders providing this information.
Gender Preference Health Care Staff

The attendees agreed that it would be good, especially for the Muslim community, if requests with regard to gender preference could be met and agreed that they would provide this information.

However, why the NHS would need this type of personal information required much more explanation than expected. As stated earlier, these are fit young people who have been born and brought up in the Glasgow area, they are all English speakers and they all self-classified as Scottish Pakistani/Arab Scottish. To them, it was very important to know why it would be of benefit for the NHS to know this information.

It was also brought to our attention that their willingness to provide information is directly related to how questions are phrased and how easily understood the definitions/options are.

Response to Questionnaire

The attendees were encouraged to complete the questionnaire to give them a ‘feel’ of what it might be like to respond to a questionnaire along these lines. As there had been considerable discussion in response to the question in Table 3, the attendees had little problem filling in the form.

To the attendees, the ‘disability’ question seemed to be irrelevant and the question was raised of how the NHS could use this information. The group suggested that a further breakdown of the question was required to enable someone to declare any disability they might have.

The design of the questionnaire (Appendix2) proved difficult. They commented that they did not know which ‘ONE ethnic group from the list below’ to choose as the boxed effect gave the impression that they were to choose from each section. This resulted in four of the attendees asking for clarity and there was a discussion among the group about which box they were each selecting, during which the comment “I never know what to put down” was overheard.
Form filling was interrupted by a discussion about what it means to self classify and what best describes our ethnic background or culture. A more focussed discussion on this would possibly help to explore the tension that these young people might face if asked to complete this type of question in terms of seeming to being loyal to their family roots/origin/home life (some confusion remained with ethnic origin) and their roots in Glasgow. The preference which seemed to emerge was that the attendees would like to be able to specify both ‘Scottish’ and ‘Pakistani/Arab/Indian’ as they operate within one or more cultures.

They felt the current Scottish Census 2001 Classifications met their needs but said that the ethnic group question on its own was not helpful as wrong assumptions could be made.

**Experiences of the health service**

A general discussion question was introduced to encourage the attendees to provide an account of their experiences when attending any health setting.

One attendee gave their account of attending A &E. “My knee was giving me pain. I went to the casualty with a friend, gave my particulars to the receptionist and took a seat. I waited for four hours. People seemed to be getting attended. Eventually, I was seen – I didn’t require any follow up.”

To clarify this account, several questions were asked.

Q. Were you advised by the receptionist what would happen next?
“No. I don’t think so.”

Q. Did you feel any discrimination as other people went before you?
“Not really, I am young, male and black but did not associate that with waiting to be seen.”

Q. What, if anything, would have made the visit better?
“I suppose knowing how the casualty system worked.”
Another young person provided their account of a visit to their GP. “I had a headache, it didn’t go away. I went to see my doctor and was told to take paracetamol. It didn’t get better so I phoned NHS 24 and was asked to attend one of the centres. The doctor was very good, he asked me questions. I had final exams, I was anxious and he (the doctor) talked to me about stress and reassured me. The NHS 24 doctor seemed take more of an interest in my problem and took time to explain and to reassure me.”

This led to the question: Where would you go for health advice?

This question had to be broken into the particular reasons a young person might need health advice and the examples provided were travel injections, sexual health advice and when the GP surgery is closed.

All of the attendees said they would start by talking to friends. Three of the attendees were very aware of the services of Community Pharmacies, possibly because they have family members who are pharmacists. All knew about the Sandyford Initiative. Apart from the attendee who had attended NHS 24, none of the attendees knew what it was for, what the telephone number was or when it was available, even though this meeting was being held on the Thursday before the Easter Weekend break, when NHS 24 adverts had been TV, promoting the NHS 24 helpline number.

10 http://www.sandyford.org 2-6 Sandyford Place, Glasgow G3 7NB. Tel no: 01412118130

Issues and barriers to the provision of personal information

- Language. There is a barrier in terms of appropriateness of having an interpreter and because the meaning of everything cannot always be appropriately interpreted.
- Uncertainty. If people are unsure why certain personal information is required (especially ethnic group/religion), it will not be provided.
- Demanding. There is a concern that, if a patient makes a definite request in the diet/gender preference options, they will be seen as being “too picky.”
- Assumptions. By providing information, there is a concern that potentially wrong judgements could be made.
- Sharing. If they don’t know who is going to see the information provided, people are reluctant to provide too much information.
- Procedures. There are benefits around the sharing of information if it speeds up procedures.
- Confidentiality. There should be some form of disclaimer on any forms requesting personal information about how this information will be treated.
- Access. Many people do not know how to access their own personal/health information.

Reflections on this consultation

- Meeting with any group requires clarity of aims and objectives and knowing the characteristics of the group in advance (in this case school pupils, first year university students, youth worker and graduates) helps to inform the approach and content of the meeting.
- Having had past experience with young people, the approach to the meeting was set in the context of ‘Credit Cards and Mobile Phones’ in terms of the amount of personal information that we are required to give. Reading Consultation On Advice Note On Engaging Children And Young People In Community Planning and a response from Glasgow Council Voluntary Sector was useful.

The day of the meeting was also when the Delivering a Health Future: An Action Framework for Children & Young People’s Health in Scotland\(^\text{14}\), A Draft Consultation was published and it was good to use excerpts of this when setting the scene and to leave a copy for the YSCA to respond to.

For only one in ten to know about NHS 24 is quite concerning as many young people are carers and/or provide the language support for their families.

With this group, concentrating on why the NHS is asking for more personal information, exploring in detail the issues and potential actions which would improve the communication side of the EDIP project, as well as discussing the content, design and format of any questionnaires, could have been quite an informative exercise.

It would be interesting to explore with a sub group in more detail the group’s concern that providing too much personal information might be considered being ‘too picky’ and might have an adverse affect on how they are treated.

**Recommendations**

- NHS organisations introducing ethnic monitoring should remember to include young people as stakeholders.
- Listening to young people, their insights, their ideas and their opinions is not only the right thing to do but offers the opportunity for the NHS to present itself as children and young people focussed.
- Questionnaires and forms - written, electronic, filled in by staff or self-completed - should be designed in collaboration with the stakeholders who are expected to respond.
- Questions such as ‘Do you consider yourself disabled?’ with only a Yes/No response are meaningless. Providing either free text for a full response or a selection of ‘How can we help?’ options seems more appropriate.
- Questions on religion/faith/spirituality need further exploration and clarity of presentation to enable respondents to be able to respond. They need to know exactly why the question is being asked, how the information will be used and how the appropriate person can be accessed with regard to any concerns they have about their illness.
- Effective communication in appropriate formats is essential for all health information.

Conclusion

Overall, if they knew why it was being requested and how it would be used, the young people in this group would be willing to provide more personal information. In many cases, they struggled to see the relevance of this information for themselves but they could all relate to family/friends who would potentially benefit from having a culturally-appropriate health service.

Note

This consultation was carried out by Joan Jamieson, EDIP Programme Manager (joan.jamieson@isd.csa.scot.nhs.uk) and Vijay Khanna, EDIP PFPI Support Worker. EDIP recognises that the opinions of this group do not necessarily reflect the views of young people across Scotland. The results will primarily be used to aid the Communications and Actions required by NHS organisations in their collection of more personal information from NHS service users. We would like to thank YCSA and all the young people who took the time to come along and participate with such enthusiasm.
5. Arab Community Consultation

Fife Arabic Society

The Society was established in 2000 with the following objectives:

• To provide a platform for promoting friendship, understanding and support for all the members
• To promote the understanding of the Arabic culture, language and society within the Fife community
• To provide speakers and facilities for education, schools, societies and professional meetings to provide better understanding of the Arabic culture
• To provide training to members to increase their chance of employment
• To provide advocacy and advice to members and liaising with various agencies and service providers on their behalf.

The Fife Arabic Society is a member of Frae Fife, a Race Equality Partnership which has links with service providers and is one of the ways the Arab community in Fife influences local services, including health.

Summary of characteristics of the consultation group attending

• Nine people attended the group, although two women had to leave early for child care.
• One could not really speak or understand English and a group member acted as interpreter.
• The group consisted of a postgraduate student, unemployed, employed, housewives.
• All were registered with a GP.

15 Fife Arabic Society “FAS” C/o FRAE Fife 1 Victoria Road Kirkcaldy, Fife. Tel no 01592 204005.
Email: fifearabic@yahoo.co.uk
Web: http://www.fifearabicsociety.org.uk/

16 http://www.fraefife.co.uk/
Six had had an onward referral to a hospital.

Seven identified communication problems in explaining their symptoms when visiting their doctor.

All were associated with Fife Arabic Society.

Format of the meeting

A presentation (Appendix 1) formed the basis for the meeting, with attendees encouraged to participate freely. The attendees’ comments were noted and are either summarised or included (in italics), although these are not necessarily verbatim.

Experiences of the health service

To begin with, a general discussion question encouraged the attendees to provide an account of an experience when attending any health setting. This generated questions rather than a discussion.

One man immediately raised the issue of where the NHS stands with regard to cultural sensitivity. “What about our religious and faith belief that our boys have access to circumcision? The Muslim community and Jewish community are having difficulty accessing this service. The waiting time in Kirkcaldy is seven years, in Dundee it is two months and in Edinburgh, it is six years. One GP said there were not enough resources. Where does this sit in NHS Policy?”

A brief discussion followed, centering around whether or not this was a health/cultural issue and, if so, how the NHS should prioritise this type of procedure. No decision was reached, other than that this group would like to see this service provided.

The presentation contained some Census 2001 results that were not broken down by Arab ethnic group. The comment was made: “What is this Census? The Arab community is the third largest group in Scotland - how can our needs be met if we are missing?” There was a general nod of agreement to this from the entire group.

Another attendee recounted the experience of being referred by the doctor to a hospital consultant. “When I got the appointment, it was not the doctor that I had expected. What I expect is to see that doctor, every time I go it is another doctor.”
The referral process was explained, along with the team approach to health care and the movement of staff as part of doctor/registrar training. When the attendee who had raised this issue was asked if the doctor had access to their records and had been able to provide treatment, he answered: “Yes – but why is not explained that you may not see that doctor? In our culture, we see the named doctor and these other doctors may not be experienced enough.”

An attendee asked if it was possible to demand to see the consultant and was assured that this could be done.

Another attendee mentioned that there was no Halal diet. “For me, this is not an issue but for some this is an issue as part of religious observance and could be seen as discrimination by the hospital for not providing appropriate diet.”

One of the female attendees highlighted her experience of maternity care. “My husband did the interpreting for me but the questions and answers were addressed to me. I was not asked if I would like an interpreter.”

Another woman described how she often supports Arab women in Fife area: “I can recall an occasion when I attended an appointment where, on the first two occasions the interpreter was provided, and this just stopped.”

The group was asked about the length of time their GP spent with them at appointments. All agreed that this was not long enough, which led to questions being asked about whether GPs are required to have equality and diversity training and if GPS all know about accessing interpreters for their patients.

The group was asked how attendance at NHS services could be improved and the following suggestions were provided:

- Clarity about the position on access to circumcision.
- Referral to the consultant in person if a condition is serious.
- An explanation as to what doctor you may or may not see.
- Clear signage regarding access to interpreters.
- Provision of Halal diet.
- Recognition for the Arab community, with their needs assessed and addressed.
Results

Responses to being asked about giving more personal information

Table 4

<table>
<thead>
<tr>
<th>Question: How willing are you to give the following….</th>
<th>Yes</th>
<th>No</th>
<th>D/K</th>
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<td>Religion/Faith/Spirituality needs</td>
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<td>Language preference</td>
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<tr>
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<td>8</td>
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<td>Mobility access (walking/dressing/transport)</td>
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<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Gender preference Health Care staff</td>
<td>8</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

The questions above were centered on the willingness of the attendees to provide more personal information to support their health care.

Ethnicity

There appeared to be no problem with providing this information. However, the group’s main concerns were that, as a community, Arabs are absent from national statistics and, therefore, overlooked, despite the fact that the Arab community is not a small community and is making a contribution to Scotland. The group stressed that they are hopeful that the review of the Census Classifications17 and the testing of the ‘Ethnicity’ question will ensure that they are recognised and their needs are considered.

Religion/Faith/Spirituality Needs/Dietary Preference

For many, the Muslim faith is the principal to how they live and, within that, there is a dietary preference for Halal food. However, the group also made it clear that not all Muslims eat Halal food and that the NHS should not use this information as evidence that every Arab is the same. This point was also raised at other group meetings - meeting with one group from a community does not necessarily mean that their thoughts can be assumed for all members of that community.

The group expressed no problem in providing this information as they felt that it would enable them to receive appropriate care and understanding from NHS staff.

Language Preference, Interpreter, Format of information

Seven of the group mentioned that they would prefer to communicate in Arabic. Therefore, if they provided this information, they would expect the NHS to ensure there was always an interpreter and that the interpreter would be appropriate for the person (e.g. gender). The entire group want written, appropriate communication, preferably in Arabic but English would be acceptable, as they all felt they would be able to find someone to translate for them if required. The group also mentioned that they would like to be able to talk to someone in Arabic if they required clarity about communication/health information.

Mobility access

This generated very little discussion but this was a relatively young group and none had declared that they were disabled.

Gender preference of health care staff

This was seen as a highly relevant question, especially among the men, who wanted to know if women could demand a female doctor. This led to a short discussion on the element of choice and the ability of the NHS to meet such individual needs, which resulted in the recognition that it was not likely to be possible to provide female NHS staff in all health settings across Scotland. NHS Glasgow’s Colposcopy
Clinic was used as an example of where, as a result of reviewing the service, identifying women’s needs and making reasonable adjustments, an all female staff has been made possible.

**Response to Questionnaire**

Two of the group had to leave before the questionnaire was circulated but the remaining seven attendees completed and returned the questionnaire with minimum assistance. Census 2001 classifications were used and all wrote the word ‘Arabic’ in the space marked ‘any other…..please write in below’, one chose from Section C, two from section D and four from section E.

The questionnaire was changed following comments made by the previous groups. None of the attendees expressed any difficulties in completing or understanding the questions asked.

All of the attendees completed the questionnaire in English, with support given to one respondent. Only one blank field (around Dietary Advice) was identified and none of the respondents declared disability - with this group, it was difficult to assess if the redesign to actually declare ‘if yes, how we can help you?’ was of value.

One respondent gave a full answer to the question about requiring an interpreter for support: “To explain or interpret the pain which I feel.”

The group had earlier expressed the need for interpreters of appropriate gender. Some NHS organisations have their own Interpreting and Translation Guidelines but I explained that I was unaware if the level of detail to meet specific individual needs is possible. Interpreting services are often employed on a sessional or on-demand basis and it is not necessarily best practice or, in many instances, possible, to provide continuity of interpreter.
There is a requirement for NHS Boards to follow their policy/guidelines about the role of the interpreter who is there for the patient and staff, rather than to provide advocacy services. However, it should be recognised that, as well as the interpreter, an advocate may also be required. Currently, The Scottish Translation, Interpreting and Communication Forum Guidelines, Section 4\textsuperscript{18} are widely used across the public sector in Scotland while the report on a recent Lost in Translation Workshop, which was hosted by Health Scotland, National Resource Centre for Ethnic Minority Health and Health Rights Information Scotland, is currently awaited and will hopefully inform policy development.

None of the respondents expressed any difficulty with providing religion/denomination/body of faith/dietary preference. They had already stated that, by giving this information to the NHS, it would be expected that the NHS would act on it, for the benefit of both patients and staff.

Ethnic group had been discussed earlier and the group were unanimous that the current Census outputs were unacceptable, not just for themselves but for other minority community groups.

The fact that respondents chose from three of the Census groupings yet all wrote 'Arabic' would suggest that confusion arises when respondents do not have a clear list of categories which reflect their ethnicity. However, there is an expectation within the group that the GROS Test Questions, which were issued in April 2006\textsuperscript{19}, will bring about significant improvements with regard to the ‘Ethnic Group’ question.

### Issues and barriers to the provision of more personal information

- The reasons for the data collection should be made explicit and understandable to the patients – ‘What's in it for me?’.
- Targeting of the appropriate people, who need to be involved.
- Training of staff involved in the asking of questions.

\textsuperscript{18} http://www.scotland.gov.uk/Resource/Doc/47210/0025542.pdf

- Provision of timely circumcision.
- Use of the information by the NHS.
- Desirable that female NHS staff/interpreters available.
- Availability of Halal food across the NHS.

**Reflections**

- Be more prepared when meeting groups who appear to be missing from national statistics, by obtaining information either from local or grey literature.
- Check at the beginning of the session how much time attendees can devote to the meeting.
- Although no interpreter had been requested for this meeting, check at the beginning of the meeting if communication support is required so the presentation can be modified if required.
- Better capture of discussion can be made by taping the session (but only if this is acceptable to the group).

**Recommendations**

- NHS organisations currently introducing Ethnic Monitoring should provide patients with clarity about how to fill in the Scottish Census 2001 categories, especially where Arabic is not an option.
- Clear explanation should be given to patients as to why Scottish Census 2001 classification are being used.
- Any National Guidelines on using interpreters and translation services should include a section for patients, explaining how to access an interpreter/translated information, what to expect from the service and any local differences in the service provided.
- Training focusing on the value of obtaining more personal information from patients should be provided for staff.
- Training should be provided for the staff who will collect this information
**Conclusion**

This group supports the NHS in terms of collecting more personal information which will be used to provide and inform health service delivery. Their expectations are that they will be recognised and valued as NHS service users and will experience more culturally sensitive care from NHS staff.

**Note**

This consultation was carried out by Joan Jamieson, EDIP Programme Manager (joan.jamieson@isd.csa.scot.nhs.uk) and Vijay Khanna, EDIP PFPI Support Worker. EDIP recognises that the opinions of this group do not necessarily reflect the views of the Arab community across Scotland. The results will primarily be used to aid the Communications and Actions required by NHS organisations in their collection of more personal information from NHS service users. We would like to thank the members of the Arab community who took the time to come along and participate.
6. Multi-ethnic Consultation (Aberdeen)

MeAL (Multi Ethnic Aberdeen Limited)²⁰

MeAL is committed to promoting and raising the visibility of ethnic individuals, business owners and organisations in the north east of Scotland. MeAL aims to promote and encourage a harmonious, multi-ethnic, multi-racial and multi-faith society and to work towards the social, educational, economic and cultural equality of all cultures in the north east of Scotland. It was hoped that a number of African/Caribbean community members might be recruited for this consultation meeting.

Summary of characteristics of the consultation group attending

- Attendees were recruited by MeAL.
- Six attended.
- Five were registered with a GP.
- Two had attended a doctor.
- Two had experienced onward referrals to hospital.
- One spoke and understood very little English.
- Four were in paid employment, one was a housewife and one was a recent arrival in Aberdeen.
- All volunteer at MeAL.

Format of the meeting

A presentation (Appendix 1) formed the basis for the afternoon, with attendees encouraged to participate freely. The attendees’ comments were noted and are either summarised or included (in italics), although these are not necessarily verbatim.

²⁰ http://soulnspice.freeservers.com/
Results

Response to being asked about giving more personal information

Table 5

<table>
<thead>
<tr>
<th>Question: How willing are you to give the following….</th>
<th>Yes</th>
<th>No</th>
<th>D/K</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ethnicity</td>
<td>6</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Religion/Faith/Spirituality needs</td>
<td>6</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Language preference</td>
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<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Require interpreter</td>
<td>6</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Format to receive information (written/oral)</td>
<td>6</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Dietary preference</td>
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<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Mobility access (walking/dressing/transport)</td>
<td>6</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Gender preference Health Care staff</td>
<td>6</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

The questions above centered on the willingness of the group to provide more personal information to support their health care.

Ethnicity

Although all agreed that they would provide their ethnic group and understood the question, one attendee stated that the NHS asks too many questions and commented: "Too many questions - married, religion, postcode…What has this do with seeing the doctor?"

There seemed to be a lack of understanding among the group of why and how the NHS uses personal information provided by patients. Even when an explanation was provided about how this information helps the NHS to monitor access to services and demonstrate non-discriminatory practice and how the GP, local health boards and national bodies such as ISD use this information, the group seemed unconvinced that further detailed demographics would be of value.
Religion/Faith/Spirituality Needs/Dietary Preference

Although all agreed that they would provide the information required in Table 5 (above), only one attendee declared their religion. Not having a religion may, in part, have contributed to the comments below.

“If I went to the doctor with a headache and he asked my religion, I would think that he might want to pray over me.”

“Again, too many personal questions.”

“I don’t think a lot of people would understand this question. What is ‘body of faith’?”

Willingness to talk to someone about an illness did not generate any discussion but the members of this group appeared to be well. In the BME Young People’s Group and the Chinese Group in Dumfries there were similar findings, with the groups unable to see the need for or relevance of this question.

Language Preference, Interpreter, Format of information

The attendees agreed that they were willing to declare this but they were not convinced that access to interpreters would be available. The group also asked about the rights of carers to access an interpreter and there was concern about who would explain what was happening to a new immigrant to Scotland whose partner had become ill. The group also raised the issue of older people who came to Scotland in the 1940/50s, many of whom had not had access to English lessons - how would they cope if their partner took ill?

To date, the gathering of carer information has not been considered by The Equality and Diversity Information Programme but carers may require access to communication support and this should not be overlooked. In order to capture the appropriate socio-cultural requirements, and to ensure that the NHS can help carers to act as equal partners with regard to health service provision for the person they are caring for, the group felt that the gathering of information about next of kin/carer should be considered.
Mobility access

The attendees agreed that, if they required support in terms of walking/dressing/transport, then they would provide this information. However, the group was less sure whether the NHS, with its limited resources, would be able to provide what was required.

Gender preference of health care staff

The attendees were willing to give this information, and no one expressed any real issues around this.

Response to Questionnaire (Appendix 2)

Following comments from previous groups, the questionnaire had been amended and was distributed just before the end of the meeting, allowing time to hear feedback. All were encouraged to complete the questionnaire and all the questionnaires were completed and returned. One person was given a copy of the questionnaire used at the Chinese Group Meetings (Appendix 5) - dietary preference was not an option on this questionnaire.

One extra choice was added to ‘Gender’ – ‘Transgender’, and one person commented that “Some people might find this hard to accept and it may be difficult for homosexual people.” This suggests that there may be a requirement to provide modified, simple definitions that are easy to read.

For example, ISD Finalised Diversity-related Generic Data Standards for in NHS Scotland, provide the following definitions:

- Gender: A statement by the individual about the gender they currently identify themselves to be (i.e. self-assigned)
- Sexual Orientation: An [individual’s] orientation towards persons of the same sex (this covers gay men and lesbians); the opposite sex (this covers heterosexual men and women); or both sexes (this covers bisexual men and women).
The issue of whether definitions are required was raised again when the group came to the question about being disabled, which led to one person asking: “What does ‘disabled’ mean?”, which was accompanied by a general nodding of heads around the group. Despite having been asked earlier in the meeting about willingness to provide information about mobility issues, a question which appeared to be understood, there seemed to be general uncertainty within the group around the definition of ‘disabled’. This issue had previously been identified by the BME Young People’s Group as requiring clarification, which had led to the addition of the line ‘If ‘yes’ – how can we help you?’ - but this assumes an understanding of the term ‘disability’.

Currently, the legal definition of disability is: ‘A physical or mental impairment which has a substantial and long term adverse effect on ability to carry out normal day-to-day activities’\(^1\). The Disability Rights Commission (DRC) is currently consulting further on this definition and has recently published Guidance on Gathering and Analysing Evidence to Inform Action\(^2\). At the moment, the NHS does not have the definitions or terms to be used to record disability data - The National Clinical Data Set Programme\(^3\) commences this work in summer 2006.

No new issues were raised around language and communication with regard to completing the form.

For the Chinese attendees in the group, the ‘dietary preference’ option raised the issue of hot/cold food. One attendee described how, after childbirth, it is an important part of her culture that the mother should have cold food, wash (but not shower or have a bath) and stay in the house for at least one month. However, after having her baby, this attendee revealed that she did not feel confident enough to refuse the tea, toast and shower she was offered and, when asked how she got round this dilemma, she revealed: “For the shower, I said I was waiting for my husband and pretended to have one when he came”.

\(^1\) Schedule 1, para 1(1) Disability Discrimination Act 1995

\(^2\) www.drc-gb.org

\(^3\) http://www.clinicaldatasets.scot.nhs.uk/
Another attendee asked if NHS staff receive training in cultural and religious sensitive issues, such as childbirth. Equality and Diversity training is being made available in each NHS Board. However, this does raise various possibilities, e.g. if women could be asked their cultural preferences at ante natal booking.

With regard to the ‘ethnic group’ option, the members of the group appeared to have chosen from the appropriate sections.

**Experiences of the health service**

Although only two of the attendees had attended a doctor or had an onward referral to hospital, the attendees were all encouraged within the group to share their experiences with the health service.

One person reported that he had not joined a GP practice. As he is currently well, he explained that he had not found the need to register but, further probing revealed that his previous childhood experience of the doctor in Nigeria appeared to be of a large amount of injections and he had also acquired negative assumptions about taking or giving blood. When asked what he would do if he felt unwell, the attendee admitted he was unsure and that he knew he should join a practice. This was met with encouragement from the other attendees as even the newest person to Scotland, who had only been here for six months, had joined a GP practice.

To encourage further discussion, several questions were asked.

Q. Would you use NHS 24 if you were ill?

At this point there appeared to be quizzical looks from the attendees. The out of hours service and information health line were explained, which led to a degree of recognition from one attendee. However, none of the attendees knew the phone number for NHS 24 or how to contact the service. “*How do you access it – when you don’t know how to?*” asked one of the attendees.

As the meeting was co-located within an Internet Cafe, the non-GP registered attendee was asked to use the internet to find out about NHS 24 and share his findings with the rest of the group before the end of the meeting.
Q. For those who have registered with a doctor, what type of information were you asked to give when you registered?

Responses from four of the attendees indicated that they remembered being asked clinical and demographic details and had visited the practice nurse.

Q. Does the doctor know if you need an interpreter/support with communication?

One of the attendees said: “Oh no. I was never asked about that. It is very difficult for the doctors to arrange an interpreter; they are not keen on doing that. I think it’s easier to get an interpreter at the hospital than with the GP.”

When asked if anyone could explain this statement, it became apparent that none of the attendees knew how to access communication support. The newest person to Scotland had been to the doctor but had taken along a friend to interpret.

Another attendee recounted her experience. “I had just arrived here (Aberdeen) one month, when my partner fell in the house and knocked himself out. Somehow, I manage to dial 999 but the call operator seemed to be more interested in getting the postcode. I come from a country that does not use postcodes, I have travelled in America and Australia, I have good English but I just wanted to know that an ambulance was on the way. When I got to the hospital, they kept asking me medical-type questions that I didn’t understand in English. Not only patients need interpreters but in this case me – how can I get this?”

Other comments included:

“It seems to me that the NHS asks for too much information… Are you married? What is your religion? What’s your postcode? Do you need this to get to see a doctor?”

“Too many questions. Who are you going to share it with? Coming from a different country, I think this is invading your privacy.”
**Issues and barriers to the provision of more personal information**

- Timing of data collection – this should be collected at GP registration rather than when ill or at a time of crisis, which was felt to be inappropriate.
- Your information should be available when it is needed.
- Confidentiality must be explained. Perhaps this could be contained in a welcome pack which could be provided to everyone entering the country and would include key information about the NHS and how to access an interpreter.
- Staff must be trained to be sensitive to patients’ needs.
- Information about health must be clearly inclusive – when NHS 24 was searched on Google, the description found said: ‘NHS 24 is a modern, distinctively Scottish service, which aims to give people across Scotland equal access to health advice, information and help...’ This led to the comment: “I’m not Scottish… This is not for me.”

**Reflections on this consultation**

- Any questionnaire requires particular attention to the design and format of the questionnaire, the context of questions should be clearly apparent and there should be clarity about how responses are to be made.
- The benefits of a wide pilot exercise for a questionnaire to collect more personal information from patients, similar to the GROS Census Test Questionnaire, should be considered.
- When information is required, referring patients to the Internet or even to the library may not always provide appropriate and/or accurate answers.
Recommendations

- Including a socio-cultural data capture at GP registration would inform local NHS providers of the size and type of communication support required and of staff training requirements and would also improve the ability of the NHS to provide effective and sensitive health care.
- If more personal information is to be provided, careful thought is required in the design and format of any data sheet or questionnaire and the collection process.
- If possible, EDIP should include information for carers.
- Meaningful definitions are required for terms such as ‘disability’ and ‘disabled’.
- More consultation is required on the Religion/Sexual Orientation questions.

Conclusion

This group would be willing to provide this equality and diversity information if:

- There was clear explanation of why it was required
- It was asked at an appropriate time and in an appropriate place
- If details were provided regarding the sharing of this information – who would it be shared with, why would it be shared and how would this benefit the person who had provided the information.

Note

This consultation was carried out by Joan Jamieson, EDIP Programme Manager (joan.jamieson@isd.csa.scot.nhs.uk) and Vijay Khanna, EDIP PFPI Support Worker. EDIP recognises that the opinions of this group do not necessarily reflect the views of the wider minority ethnic communities across Scotland. The results will primarily be used to aid the Communications and Actions required by NHS organisations in their collection of more personal information from NHS service users. EDIP would like to thank the MeAL members who took the time to come along and participate.
7. Jewish Community Consultation

Scottish Council Of Jewish Communities

The Scottish Council of Jewish Communities is a representative body for Jewish communities in Scotland.

The Council advances public understanding about the Jewish religion, culture and community, and develops and provides information and assistance to educational, health and welfare organisations. It works in partnership with other organisations and stakeholders to promote good relations and understanding among community groups and to promote equality. The Council represents the Jewish community in Scotland to Government and other statutory and official bodies, monitors the Scottish Parliament and liaises with MSPs and others on matters affecting the Jewish community.

Summary of characteristics of the consultation group attending

- The Glasgow Jewish Council of Jewish Communities recruited the attendees.
- 11 attended – mostly professional.
- All were registered with a GP.
- All had experienced onward referrals to hospital at some point.

Format of the meeting

A presentation (Appendix 1) formed the basis for the evening, with attendees encouraged to participate freely. The attendees’ comments were noted and are either summarised or included (in italics), although these are not necessarily verbatim.
Results

General questions to stimulate discussion

In summary, the responses included:

• People do not always find it easy to describe what is wrong - for example it’s not easy to find the words to describe the type of pain being experienced.
• It may be more difficult for an older person to describe what the problem is.
• Often, a person takes someone with them to act as their advocate, which can take time.
• Older people often use the first few minutes of a consultation to apologise for bothering the doctor, limiting the time available to get to the root of the problem.
• People often do not want to bother the doctor with trivial symptoms – more information is required so people know when they should contact their doctor.
• One attendee said that relatives often call in advance of appointments on behalf of a patient, with the aim of helping the doctor ask leading questions to help reveal the actual problem.

Experience of giving information to the NHS

In summary, the responses included the following points:

• Overall, the attendees found it difficult to recall what information they had provided when they registered with their GP. Following some prompting, ‘demographics’, ‘previous doctor’, and ‘current/past medical conditions’ were put forward as information provided at time of registration.
• None of the attendees had been asked about socio-cultural information, such as communication support or dietary requirements.
• One attendee explained the registration process, which led to a discussion about the new General Medical Services contract and the fact that the equivalent of one point is being offered for the capture of a new patient’s ethnic group.
• It was felt that there was a lack of clarity in the way ethnic group is currently held for local and national statistics
• It was felt that there was confusion between religion, ethnicity, identity and other socio-cultural data
- It was felt that the current Scottish Census 2001 categories did not meet the descriptive needs of the Jewish community and, indeed, many other communities.

Some attendees provided examples of their experiences with regard to providing information to the NHS.

“My daughter has joined a University. As part of the studentship she was required to join a local GP practice but we were not told that, by doing this, her registration with the family doctor was terminated. When home on holiday, she went to attend the GP – only to be informed she was not registered.”

“My cousin’s daughter, likewise, had this problem. She was at university away from home, joined a practice at the university location, took unwell and felt it would be better to be at home, only to discover that her medical notes were not available at home as they had been transferred. This led to wasted time and problems around gaining access to treatment.”

“When you phone up as a relative to get information, you are told you can’t get it.”

“My sister was asked her religion when she was admitted to hospital. As she doesn’t particularly identify herself as a practicing Jew, and the question was not set in context in terms of what was happening to the information, she didn’t see the relevance of the question so she declined to answer. She had ovarian cancer and didn’t know she was at higher risk of developing breast cancer due to an identifiable gene sometimes found in Ashkenazi Jewish women. Therefore, she wasn’t offered screening and, several years later, went on to develop breast cancer. It was only because I attended her breast cancer appointments with her and was aware of the link that the issue was raised, which has led to me and my cousins being offered screening.”

“As we are Jewish, it seems the main question they (NHS staff) hone in is - our diet. For many, Kosher food is important but not for all.”

“When a Jewish person dies in hospital there seems to be lack of knowledge about what to do, both by staff on the ward and mortuary staff.”
“There may be ward guidelines but are they always available and are they quality assured by the Jewish Community? One ward publication (referring to managing the death of a Jewish child) read – ‘don’t handle with bare hands’. On checking with the Rabbi, all he could he think of was that this was a wrong interpretation of ‘handle with kid gloves’. There should be a member of hospital staff available to support situations like this and staff should know who to turn to.”

“When my son was circumcised, the hospital doctor was not happy. My son had been jaundiced and he objected to carrying out a further bilirubin test to ascertain if he was sufficiently clear of the jaundice for the circumcision to be carried out safely. The situation was made worse as the doctor was an old school classmate, who probably had no idea I was Jewish - very embarrassing.”

“A few weeks ago a Jewish friend was in hospital. It was close to the start of the Sabbath, and my friend was anxious as to what might happen in the ward. A nurse approached who acknowledged that she was Jewish, explained that she had worked in a Jewish Community Home and my friend immediately felt at ease. This nurse knew all about the Sabbath, Kosher food and respecting individual needs.”

What information is known

When asked where the Jewish community was placed in national figures, the following comments were made:

“We are in ‘all people’”
“We are in ‘other’”
“Seven Pakistanis in Orkney - that’s small.”
“If it is Fair for All – where are we?”

The new GP General Medical Services contract awards one point for recording the ethnicity of people registering with practices. One attendee informed the group that this was equal to £120 per year for the whole practice. This led to a very lively discussion.

24 http://www.nhsemployers.org/primary/primary-902.cfm
Another attendee mentioned the recent Census Classification Review\textsuperscript{25} that has informed the test questions for the preparation of the 2011 Census. The Test Census is currently being implemented in targeted areas across Scotland\textsuperscript{26} and new questions have been introduced, including:

- Experience of discrimination
- Current religion
- National identity
- Ethnic group (with the ability to record 'Jewish').

There was recognition from the group that making radical changes to current ethnicity questions is not easy as there are valid reasons for being able to compare or at least match current ethnicity classification with any new categories. Examples such as research and national statistics were given.

Another attendee stated:

“If we are giving information (in relation to ethnicity), it should be asked in the same way across public sector organisations. Should this programme (referring to EDIP) not be linked to Social Care?”

**Benefits of giving more information**

An attendee stated.... .

“It’s not to do with ethnicity. This is a dead end. We have more concerns, like: Why is it when you phone up to speak to your consultant you are asked if you are a private patient? Are we second class citizens? Have we not right of access as NHS patients? All we have heard tonight is about us giving the NHS information - getting information back is virtually impossible. This is all about data, it’s meaningless for the patient.”

\textsuperscript{25} http://www.scotland.gov.uk/Resource/Doc/54357/0013557.pdf

\textsuperscript{26} http://www.gro-scotland.gov.uk/files/2006-census-test-form.pdf
“Communication - they (the NHS) get no information because of a lack of good communication between doctor and patient. It is bad enough when you can speak English but it must be really bad if you need an interpreter. The NHS is not providing a basic feedback to the patient. What kind of training to doctors get?”

“…If (giving more information) benefits us, we need clarity about why we are being asked this? How it will benefit us? What information will we get before we are asked?”

“…What training will be given to staff?”

“I have had experience working with interpreters and they are not qualified. What is the guidance policy for interpreters? It may be okay for the communities who have been established for many years but finding interpreters for new immigrants, asylum seekers and refugees - they are just not there.”

“It depends if you can get the appropriate interpreter.”

“Would you like to speak to someone about your religion, faith….’ Who is that someone - it, needs to be more specific than that.”

“…Dietary preferences fine but can we eat it? My father-in-law was in hospital, the Kosher meal arrived sealed and he was unable to open it due to his condition. We blame him for not asking but could the staff not have asked ‘What can we do help you with this?’”

“…Gender preference of health care staff - may be okay to ask this in big cities but this is not a practical question to ask, in small towns or rural areas.”

Questions for discussion

Some prompts were given, including confidentiality, sharing information, the effect the availability of information may have on health. As a result, attendees responded with:

“Sharing information between organisations should happen. If you are looking to collect this information, so are social work - can this not be collective together?”

“How many times are these questions going to be asked?”
“Clarity about the collection. Is it for a survey? How will it be used?”

“An explanation, in plain language, describing what is in it for me.”

“Ensure that doctors are properly equipped with communication skills.”

“Staff fully trained in equality and diversity.”

“Staff who know where to go to get support if there are areas of culture they do not understand. They could also ask the patient.”

“Any NHS Guidance requires to be quality-assured by appropriate, Jewish, informed people.”

Response to Questionnaire (Appendix 2)

Completing and returning the questionnaire was voluntary but the eleven attendees were encouraged to complete the form. Nine questionnaires were returned, with all but one field completed.

Comments about the form included:

- “Design and format needs addressing.”
- “Plain English. What does ‘disabled’ mean? How do you know what to write?”
- “Information is required to be distributed regarding this type of data collection and written in such away that can be easily understood.”
- “We wouldn’t give information like this without knowing who we were dealing with.”
- “Ethnic group not relevant.”

Discussion

Communication and information were themes which ran throughout the meeting, from the perspective of patients, NHS staff and, in particular, doctors. It was explained that, on average, 10 minutes are allocated to patients attending for a GP consultation, 15-20 minutes for new hospital attendees and 10–15 minutes for subsequent visits.
Interpersonal relationships are important in any relationship, especially between the health care team and the patient. How patients perceive a GP practice or hospital, whether they trust the health team and what level of treatment they accept depends on good communication. This group expressed particular concern about the communication training that NHS staff receive as they felt their experiences demonstrated a lack of sensitivity by health care staff. Panesar and Sheikh\(^\text{27}\) report that most UK trained health staff will have received little or no training in transcultural medicine and there still exists: “The erroneous belief that providing similar care to all members of a multicultural society is sufficient to overcome discrimination.”

NHS Boards across Scotland are providing various basic training/awareness raising programmes to their staff on equality and diversity matters, while professional codes of conduct require all health professionals to keep up-to-date with the necessary skills and knowledge to ensure that they continue to provide high quality care. The Royal College of Nursing\(^\text{28}\) and the General Medical Council\(^\text{29}\) are two examples of where health professionals can access training and information. A recent publication - ‘Caring for Jewish Patients’\(^\text{30}\) - examines attitudes and responses of Jewish patients to life, family, disease and death and includes the history of Judaism.

Personal health records act as one way of ensuring communication between patients and their various healthcare providers, as well as serving as a repository of their health history. When patients are repeatedly asked the same questions, their health records are not available or staff fail to manage effectively the information provided, seeds of doubt can be planted in patients’ minds as to both the trust they can place in staff and the efficiency of the NHS to deliver personalised care.

For this group, the provision of information explaining why the NHS needs further personal information from patients was seen as imperative.

\(^{27}\) Panesar S S, Sheikh A, *How to talk with people from other backgrounds*, Practice Nursing 2006, Vol 17, No 2

\(^{28}\) http://www.rcn.org.uk/resources/transcultural/adulthealth/sectionone.php

\(^{29}\) http://www.gmc-uk.org/publications/valuing_diversity/introduction.asp

Issues around the need for the NHS to produce clear, concise, basic NHS access information in collaboration with their users (e.g. ‘What everyone needs to know about the NHS’) were raised in this and other group meetings. The NHS needs to identify what we all need to know and then involve patients and users of NHS services in the design of the format this information is provided in.

Health Right Information Scotland (HRIS)\(^{31}\) has already produced ‘Confidentiality – it is your right’ and ‘How to see your records’ in alternate formats, with the aim of ensuring that the information is accessible to as many people as possible. HRIS are in the midst of revising their policy on the production of NHS information in alternative formats which, hopefully, will have wider learning outcomes for the NHS as a whole.

The particular information issues for this group focused on:

- The effects of changing GP practice.
- The context of being asked for personal information e.g. religion.
- The opportunity to change information previously withheld or provided e.g. religion.
- The assurance that information that staff use to support cultural care is quality assured by appropriate, qualified persons.
- The right of access to a hospital consultant.
- The need to ask and record that patients are/are not willing for their next of kin to ask and receive information about or on behalf of them.

Training NHS staff in effective communication, equality and diversity and, in particular, to the practice and beliefs of individuals is integral to the NHS Fair for All NHS Health Department Letter\(^{32}\) and the theme of Our National Health: A plan for action, a plan for change\(^{33}\), which states: "NHS staff are professionally and culturally equipped to meet the distinctive needs of people and family groups from ethnic minority communities.“Building a Health Service Fit for the Future\(^{34}\) further builds on this vision for NHS Scotland: “Care designed for each individual, ensuring the patient is at the heart of what we do” and “Equity of access, based on clinical need, to services of the right quality.”

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All NHS Boards are committed to ensuring that all staff is trained in equality and diversity relevant to the Knowledge Skills Framework\textsuperscript{35} that individuals need to apply in their post. This group highlighted the need for reassurance that ward and mortuary staff have access to knowledge and training regarding what to do when a Jewish person dies in hospital and know where to access additional support.

The Spirituality (2002)\textsuperscript{36} requires all NHS Boards, in consultation with their local faith communities, patient representatives and planning partners, to develop and implement a spiritual care policy for the provision of chaplaincy, religious and spiritual care services. Integral to developing their spiritual care policies, Boards have to: “Promote a close working partnership between their service providers and local faith communities on the provision of spiritual care services and the appointment and employment of spiritual care staff.” This should ensure that local faith communities are recognised and that information is available regarding how to contact them.

The choice of self classification for ‘your ethnic group’ from the Scottish Census 2001 categories was not seen as providing any meaningful information for the NHS, mainly as there is no suitable category that encompasses Jewish culture, religion, language and origin. From the completed questionnaires it can be seen that there was no consensus in responses. Indeed, all attendees wrote supporting information on the form.

Little is known in Scotland about the health of the Jewish Community. There are potential social factors such as gender and religion of health care practitioner that either create barriers or facilitate use of NHS services. What decision aids, such as leaflets and videos, would enable people from the Jewish community to understand their options, consider the personal importance of possible benefits and harms, and participate in decision making?

On a more positive note, Jewish parents who wish their child to be circumcised do not have the same issues around location or waiting times that were raised by the Arab community in Kirkcaldy.

\textsuperscript{35} http://www.paymodernisation.scot.nhs.uk/afc/ksf/index.htm
\textsuperscript{36} http://www.show.scot.nhs.uk/sehd/mels/HDL2002_76.pdf
Overall, sharing information, as long as the context and reasons are explained, was seen as a positive step for the NHS. There were concerns among this group about the lack of information sharing in terms of involving carers and of health records not being available when required.

There was also concern that, if communication support was required (e.g. interpretation, advocacy, sign language), the person was not only appropriate but had also been adequately trained. This, in part, is related to the new immigrant and asylum seeker communities who probably have less confidence that an interpreter has all the necessary qualifications. Although the members of this group had no need of communication support, they had an affinity for those who might.

**Recommendations**

- Information should be collected once and made available appropriately.
- Any presentation on the provision of more personal information needs to be plain and simple.
- NHS Scotland needs to interact widely with all of the Scottish population about this programme.
- People need to know ‘What is in it for me?’.
- Information and feedback are required from the NHS.
- Plain, easy-to-understand definitions are required.
- Doctors from all ethnic groups require good interpersonal communication training.
- Questions should be asked about next of kin/carer.
- All staff should undergo appropriate training in equality, diversity and inclusion.
**Conclusion**

The group have some reservations about providing more personal information as described in the presentation unless there is a clear explanation of why this is required, supported by a robust communication plan and guidance which considers the recommendations listed above.

**Note**

This consultation was carried out by Joan Jamieson, EDIP Programme Manager (joan.jamieson@isd.csa.scot.nhs.uk) and Vijay Khanna, EDIP PFPI Support Worker. EDIP recognises that the opinions of this group do not necessarily reflect the opinions of all of the Jewish community in Scotland. The results will primarily used to aid the Communications and Actions required by NHS organisations in their collection of more personal information from NHS service users. We would like to thank all those who participated in this consultation.
8. MelMilaap Day Care Centre Consultation

As part of a process of consultation on the collection of diversity data, two meetings were held with the manager of the MelMilaap Day Centre For the Elderly and both the EDIP Manager and Support Worker met with the elderly attendees informally over lunch to provide a brief of the intended Consultation Meeting.

MeMilaap Day Centre For The Elderly

The MeMilaap Day Centre For The Elderly is for elderly male and female people over the age of 60, mainly from Sikh community. It is a well-known, established and recognised community centre which is run under the auspices of Glasgow Social Work. The Centre is managed by a manager and staff, all of whom speak, as a minimum, Punjabi and English.

Summary of characteristics of the group attending

- 21 elderly clients attended plus 3 staff.
- They were all looking forward to attending and participating in this meeting.
- All were registered with a GP and had experienced further referrals to hospital at some point.
- Six were registered with a South Asian GP.
- The ages of attendees ranged from 65 – 85.
- Three members of staff were also present and supported the elderly attendees.
- 63% of the attendees were women, while 37% were men.

Format of meeting

The meeting was conducted in Punjabi and was facilitated by Vijay Khanna, Support Worker for the Equality and Diversity Information Programme (EDIP) within the Information Services Division (ISD) of National Services Scotland.

An oral presentation, based on a presentation that is being used across Scotland (Appendix1), formed the basis of the meeting, which also included an overview
of the EDIP Programme. Attendees were encouraged to participate freely, which many of them did, and their comments were noted and are either summarised or included (in italics), although these are not necessarily verbatim.

Results

General questions to stimulate discussion.

- The attendees explained that it is not always easy to describe what is wrong as a result of the language barrier e.g. challenges around describing pain.
- The attendees mentioned that not being able to speak directly to the doctor makes it very difficult to describe illness and several added that they often have to take a family member to act as an interpreter, which takes extra time.
- The attendees were all happy with the amount of time the doctor gave them and didn’t feel that the doctor rushed them.
- A couple of attendees mentioned that patients should get to the root of their illness straight away, rather then wasting the doctor’s time by talking about personal problems.
- None of the attendees knew about the existence of interpreting services. They were quite happy to take someone with them, such as a friend, relative or somebody from the Day Centre and were unaware that these people were going out of their way to help them.
- One of the attendees described what had happened to his wife, an elderly lady whose illness wasn’t understood properly: “My wife suffered with real bad pain in her right leg and she was treated for that but she was not getting any better. After three weeks of treatment, she was admitted to the hospital. The doctor there was an Asian doctor. She could now speak direct to the doctor and was understood properly. The doctor gave her the right treatment and she is back on her feet now.”

Experience of giving information to the NHS

- None of the attendees remembered what information they had provided at the time of registering with their doctor but they mentioned that, wherever they go for treatment, the same information is requested, again and again.
- Some of the attendees were uncomfortable about answering questions on topics such as religion and language as they were unsure what this had to do
with their illness. An attendee mentioned that they sometimes feel as if they are being racially discriminated against which may explain why they felt that providing this information might not be to their advantage.

- The attendees agreed that, if they knew why they were being asked about topics such as their religion or language, they would willingly provide this information.
- All of the attendees were happy with the time they were given when they were with the doctor but none of them knew how much time they were able to spend with the doctor during an appointment. In fact, most of the attendees said they could spend as long with the doctor as it takes to discuss their illness.
- When asked about providing personal information, most of the attendees were quite happy to provide the required information. However, one female attendee insisted that there was no need to provide personal information as “The computer does it all for you”. The facilitator tried to explain that the information first has to be collated and then entered into the computer.
- All the attendees were in favour of chaplaincy, especially if they did not have any friends or family to speak to when they were in hospital. They were also of the opinion that future generations (their children and grandchildren) would benefit from chaplaincy. However, it was mentioned that it would be more helpful if the chaplain was from the same faith group.
- All the attendees were in favour of using interpreters. Even if a friend or relative accompanied them, they felt that there were many occasions when the terminology was misunderstood. It was also agreed that, if they knew in advance that an interpreter would be at an appointment, they would feel more comfortable and less stressed, confident they would be understood better by the doctor.
- All of the attendees were concerned about the food available in hospital. The attendees explained they had found that most of staff in the NHS did not recognise the difference between Sikh and Muslim and kept insisting that it was all Halal meat. As a result, when in hospital, most of the attendees either opted for vegetarian food or arranged to be provided with food from home.
- The attendees agreed that providing staff with training about different religions and main socio-cultural needs would be very helpful.
- One attendee said: “I was in hospital for two months and staff knew that I couldn’t walk or stretch to reach the food tray, but every time they would leave my tea or milk on the table where I was unable to reach it. Staff then assumed that I didn’t like my tea and stopped giving me tea. One day, there was an Asian nurse on the ward and I was able to explain to her what was happening. A message was left for the staff but still the need wasn’t met.”
• One attendee who finds it difficult to get out of her bath described how she goes to her daughter’s home once a week so she can be helped in and out of bath. This attendee had no idea that she could talk to her doctor about her personal bathing needs or that she could request help with this from Social Services.
• All the attendees complained about waiting times for appointments. One male attendee reported that he had been waiting 18 months for a bowel appointment.

What information is known

• When asked where the Sikh or Hindu communities were placed in national figures, the attendees didn’t have a clue what was being talked about and had never heard about the National Census. One of the attendees said: “Our family members deal with it or they throw away any forms like that because they don’t know why they want to have the information.”
• When asked about their ethnicity, the attendees had no idea what was meant but when the question was simplified they replied either ‘Sikh’ or ‘Indian’.

Benefits of giving more information

• The attendees were all very keen to provide their personal information when they realised it would benefit their care.
• The main problem facing the attendees is language and they reiterated that it would be much appreciated if interpreters could be arranged in advance, as they would feel more comfortable.
• The attendees said that it would be much easier if information regarding appointments and access to interpreters was provided in a format they understood, which would also make it much easier for them to know what to expect when they went for their appointment.

Questions for discussion

• Language issues were the group’s dominating concern.
• The question about disability was not very clear and the attendees had difficulty understanding what was meant by ‘disability’.
• The attendees agreed that all staff involved in care of patients should have some form of equality and diversity training to ensure they could be culturally sensitive to patients’ personal needs.
• The attendees felt that information should be shared between different organisations so that needs are met quicker and a better service is provided.
• The attendees highlighted the frustration of being asked for the same information repeatedly, especially when they have already provided this information.
• The group felt that every member of staff should be given training that covers communication and treating everyone fairly and that staff should be more sensitive towards age, disability, gender, race and culture.
• The group did not know anything about the Census therefore they did not enter into any kind of discussion about it.
• 21 (88%) of the elderly attendees required support to complete the questionnaire.
• 20 (83%) of the attendees requested interpreter communication, including the staff.
• Although only one field was left blank, ten (42%) of the attendees ticked ‘prefer not to give this information’.
• The ethnic group section was not only completed under Section C but also each section was marked as “NO”, “this is not right” or “N/A”.

**Discussion**

The key barriers for these attendees are communication and the provision of health information in formats that are not easily understood, reducing their ability to engage as equal partners in their healthcare. Their over-dependence on family to act as interpreters and advocates and provide them with information about their illness demonstrates that the NHS still has some way to go in providing a patient-focussed health care service.

If EDIP is fully implemented and the appropriate information is collected and used by staff to provide appropriate communication support, to inform local and national planning for the use of interpreters, advocacy and formats of information, then the NHS will be demonstrating their commitment to promoting equality of opportunity for patients to participate in their healthcare and equity in access to information.
Through talking to the group, it became apparent that this group could be disadvantaged for access to some NHS services. For example, in terms of the new Community Pharmacy Minor Ailment Service\(^{37}\) - what equality impact assessment has been carried out to ensure that the information about this service is reaching this group of elderly people who match the criteria for registering with a local pharmacy? Are this group aware of their rights as health service consumers? Do they know that Health Rights Information Scotland\(^{38}\) produces patient rights information in alternate formats and languages?

However, it is interesting to note that all 21 attendees were so positive about their GP giving them sufficient time, although they agreed that there should be an interpreter every time they went to the surgery.

Although there had been discussions about this issues raised by the questionnaire and the attendees had accepted the benefits of providing more personal information about topics such as ethnicity, language and dietary preference, they all found the questionnaire (Appendix 2) extremely difficult to complete. The fact that the questionnaire was in English meant that the form had to be orally translated into Punjabi/Hindi before the majority of attendees could respond. Also, it is not known why ten of the attendees (42%) said they would prefer not to give this information when, in actual fact, they all did. It may be because answering all these questions was such an arduous task - it certainly was for the workers who were supporting the 21 attendees to complete their questionnaires.

From this process, it is clear that the question of where this personal socio-cultural information is requested and who requests it needs consideration – the setting should certainly not be a ‘mass-gathering’ such as this meeting. Many people need time to listen, understand and reflect on questions before providing the information required.

As NHS organisations implement EDIP, any implementation plan will require close attention as to how we communicate. We must ensure that all NHS staff likely to be involved in this type of data collection have an opportunity to experience providing this socio-cultural information themselves.

\(^{37}\) http://www.scotland.gov.uk/Publications/2006/06/26102829/1
Recommendations

- Information should be collected once and made available to different organisations, if appropriate, when required.
- The language barrier must be addressed.
- People who do not read, write or speak English need others to provide them with the information they need - every attempt should be made by the NHS that there is equal access to key health information.
- Most of the attendees did not know that they could ask for an interpreter and that this service is free. When asked if an interpreter is required most of them will say “No” but this group explained that this is because people tend to believe they can’t afford to pay for this service.
- All staff should receive appropriate training in equality, diversity and inclusion.

Conclusion

The elderly attendees were very interested in hearing about EDIP, which is very encouraging as, when the Age Equality Duty is introduced, the NHS will have to ensure there is equal participation in health care for people of every age, based on respect, dignity and value of each individual. There were visible signs of engagement, both in terms of non-verbal body language and through a considerable amount of interruption and story telling.

This Elderly Day Centre Group are looking forward to information being collected at one place and at one time and would also be grateful if their needs regarding language are met in a way that would helps them to understand more about their illnesses.

39 http://www.ageconcern.org.uk/AgeConcern/AAED1882B5404199A5BAEC22F58A9BB0.asp
Note

The consultation was carried out by Joan Jamieson, EDIP Programme Manager, and Vijay Khanna, EDIP PFPI Support Worker and interpreter. EDIP recognises that this particular group do not necessarily reflect the views of the Asian Indian/Pakistani communities in Scotland. The results will primarily be used to aid the Communications and Actions required by NHS organisations in their collection of more personal information from NHS service users. We would like to thank all the Elderly Day Care Attendees and Staff for their enthusiastic welcome and participation in the Consultation Meeting.
9. Elderly Muslim Community Consultation

To ensure continuity of support for participants, EDIP is working in partnership with existing groups. Therefore, two pre-meetings were held with the manager and management team of the Multicultural Elderly Care Centre (MECC), setting out the context of EDIP and explaining the expected outcomes of the consultation meeting with members of the elderly Muslim community. The meeting also aimed to provide an overview of the EDIP programme and the members of the management team were pleased to know that their clients were being asked to get involved by engaging with them about EDIP.

The Multicultural Elderly Care Centre\(^40\) (MECC)

The MECC promotes welfare of the elderly by working with statutory and voluntary organisations to provide holistic day care services with cultural and religious sensitivity.

Frail and elderly individuals who are eligible for these services undergo a social needs assessment in order to obtain information on how their individual needs are to be met in order to enhance quality of life. A care plan is then devised for each individual, which is then implemented in full consultation with both the individual concerned and their carers.

Summary of characteristics of the consultation group attending

Respecting the cultural needs and dignity of the attendees, the Consultation Meeting was delivered in two sessions, with males and females separate.

- 33 elderly Day Centre clients attended (8 female, 25 male).
- Two female workers were present with the female group (to provide support with completing the questionnaires).

\(^40\) http://www.scdc.org.uk/scarf/past-projects/health-social-care/multicultural-elderly-care-centre/?sess_scdc=9c19b4f5aee8836123d0184027251f1e
• Three male workers were present with the male group (to provide support with completing the questionnaires).
• All attendees were registered with a GP and had experienced further referrals to hospital.
• Ages ranged for 57 – 89.
• The attendees’ languages were Urdu, Punjabi and Bengali.

**Format of the meeting**

The meeting, which was held at the Taleem Centre in Glasgow, was conducted in Urdu and Punjabi. It was facilitated by Vijay Khanna, Support Worker for the Equality and Diversity Information Programme (EDIP) within the Information Services Division (ISD) of National Services Scotland.

An oral presentation, which was a modified version of a presentation that is being used by EDIP at patient/public engagement events across Scotland (Appendix1), formed the basis of the evening. The attendees were encouraged to participate freely and their comments were noted and are either summarised or included (in italics), although these are not necessarily verbatim.

**Summary of personal issues raised by attendees**

**Language (this was the biggest barrier for most of the attendees).**

• “It is very difficult to make suitable appointments because we are always relying on others and, once we get to the surgery, we hardly get the chance to talk to the doctor because there is always somebody with us who translates for them.”

• One of the female attendees reported: “We find it very difficult to talk about our illness if a male (such as son/husband) accompanies us and the doctor is a male as well.”

• Some of the attendees were aware of the interpreting services: “But sometimes interpreters are not there or it is difficult to book an interpreter and it’s not always very easy to talk to someone you don’t know.”
Information Format
- “It is always very difficult to read the hospital appointment letters because of the language barrier. You always have to ask somebody to read it for you and sometimes you don’t want everyone to know about your illness. If you can’t read or write then it is even more difficult to remember your appointments. So there are always loads of people involved in your health problems.”

Medication
- “When the doctor prescribes different medicines for different illnesses, it is very difficult to remember which one is which and it is always a fright in your mind whether the right medicine and right dosage is taken.”
  “Always fear in mind if we have been understood properly for right medication to be prescribed.”

Time
- “It is very difficult to explain your illness and pain and I always feel I am taking too much of doctor’s time. I keep thinking whether the doctor understood me properly because I have to ask somebody to explain for me.”

Providing personal information to NHS staff
- Most of the attendees experienced difficulty in remembering what information had been provided when they registered with their GP.
- “Whatever information was provided at that time was done by family members.”
- None of the attendees had been asked about their cultural or dietary needs at GP surgery.
- “Medical staff don’t have enough knowledge about our language, religion or cultural needs.”

Interpretation Services
- Many of the attendees believed that interpreting services should be tailored to individual needs.
- Several of the attendees felt that NHS staff do not make themselves clear: “I live on my own. When I receive a letter from the GP or hospital, I have to wait till somebody can translate for me and, when I get to appropriate place, I don’t understand which floor or which clinic to go to. There is no-one at the reception who can be understood properly.”
• “Last time I went to the Health Centre for my physiotherapy. When I got there, I was told it was in the next building which, according to the way the receptionist was pointing, I thought was the next room but actually it was a clinic five minutes walk from there. I saw an Asian woman and she directed me to the right place. When I got there I was told to go upstairs. I was unable to operate the lift as it was a different lift where you have to push the doors to operate the lifts. I couldn’t go up the stairs because of my sore knee. I was half an hour late already. I was tired and started getting very emotional. I went back home.”

• “When I went to doctor’s regarding my knee pain, he told me off in front of the interpreter, saying I had missed my appointment at the physio and the interpreter was waiting as well. I explained my situation and difficulty in understanding where to go.”

• “I had to spend hours in hospital, as on day of discharge from hospital, I did not know how to get home. I was admitted in one hospital but transferred to another and my family had no idea where I was. I had no money with me.”

• “It would be much easier to speak to the same doctor with the same interpreter because I do not want everyone to know about my illness.”

• All the attendees were in favour of talking to a priest appropriate to their faith while they were in hospital.

Other issues included:

• Transport and mobility – lack of ease of access to GP surgery, hospital appointments and as a general barrier to socialisation.

• Unsuitable hospital appointment - especially when dependent on family members, who work, to get them to their appointments.

• Dietary issues – culturally-appropriate food should be available for those of Muslim faith who wish to honour and obey their religious observances should be available for hospital patients.

• Staff training - staff must understand cultural and religious needs, especially the significance of Ramadam.
Response to Questionnaire (Appendix 2)

Although 33 attended the meeting, only 13 questionnaires were completed. In part, this was due to the groups being late in getting started and the men leaving early to go to their exercise class.

Of those completed, five (38%) ticked ‘disabled’. There was confusion about this term and it was difficult to interpret meaningfully to this group the concept of disability. However, once they understood, those attendees who had ticked ‘disabled’ were able to describe what help they required, including:

- Transport and interpreting
- Walking aids
- “A trained person”
- "Stroke – speech problem"

Of those who completed and returned their questionnaires, all the women (three, 100%) and three (30%) of the men indicated they would require an interpreter, two (15%) of Muslim attendees did not have dietary preference and all but one completed the ‘ethnic group’ question.

Discussion

In general, with regard to participating and taking control of their health/illness, communication remains the biggest barrier for this group, which is in keeping with the findings from the consultation meeting held at the MelMilap Elderly Day Centre.

However, this group highlighted their concerns around medication.

The attendees explained that, while they appreciated having a family member or interpreter with them at an appointment to interpret what they were saying and what the doctor was saying, they were always anxious that they were being translated correctly so the doctor could assess their problem correctly and prescribe the right medication. Then, if prescribed any medication, the instructions and accompanying supporting material would be in English, so they would have to rely on their family to tell them how often to take the medication and how much they should take.
Understanding diabetes and complying with their medication was a concern for at least one of the attendees. The Scottish Diabetes Annual Survey 2004\textsuperscript{41} reported that: “Data about the ethnicity of people with diabetes is only available for around one third of patients” while the report on Diabetes in Minority Ethnic Groups in Scotland\textsuperscript{42} identified that:

- The prevalence of registered Type 2 diabetes in patients over 70 years is nearly 14 times higher than among those under 50 years.
- The risk of being registered with Type 2 diabetes after adjusting for sex and age is eight, four and three times higher in Pakistani, Indian and Chinese ethnic groups respectively, when compared with the majority White population.

Included in the new Diabetes Action Plan\textsuperscript{43} is the aim to: “Enhance patient self-care and self-management by ensuring that all people with diabetes in Scotland have access to appropriate information and education.” The implementation of this will be gratefully received by those with diabetes who have communication issues, such as literacy and communication challenges, especially where English is not their preferred language.

In the earlier discussion, all the attendees agreed that interpreters and information in alternate formats should be available. Within this group, all of the men had worked in the UK and had a fair grasp of English, both oral and written. On the other hand, the women had little exposure to English as their role had been to support and care for their family.

The completed and returned questionnaires (Appendix 2) showed that half of the attendees had not only ticked one option from Section C but had also marked ‘British’ or ‘Pakistani’ in every section. As demonstrated in earlier consultation meetings (MeMilap, Chinese, Arabic, White majority Elderly Day Centre), where English is not the preferred language, the quality of responses varies depending on the attendee’s ability to read and understand the questions.

\textsuperscript{41} http://www.diabetesinscotland.org/diabetes/maintainPages/pdfFiles/SDS2004summary.pdf
\textsuperscript{42} http://www.show.scot.nhs.uk/misc/Diabetesinminorityethnicgroupsinscotland_mainreport.pdf
\textsuperscript{43} http://www.scotland.gov.uk/Resource/Doc/129328/0030795.pdf
As completing the questionnaire was optional and self-completed (unless help was requested), there is a key issue around validating the responses as accurate as it was not always easy to know if the questions had been understood. On this occasion, explanations were provided in Urdu and Punjabi but, as there was quite a bit of movement with staff and attendees, this was not really the appropriate time for completing a questionnaire requesting this type of personal information.

**Conclusion**

This group had many other issues which we were unable to cover due to lack of time. Overall, a good discussion took place and the MECC elders reported that they are likely to provide this information - if the context and format of the questions are modified to suit their needs. For this group, the benefits of having an interpreter available seemed to outweigh other concerns regarding the questions.

**Note**

This consultation was carried out by Vijay Khanna, EDIP PFPI Support Worker and interpreter. EDIP recognises that this group do not necessarily reflect the views of all the members of the Muslim population resident in Scotland. The results will primarily be used to aid the Communications and Actions required by NHS organisations in their collection of more personal information from NHS service users. We would like to thank all Elderly Day Care Attendees and Staff for their welcome and participation in the Consultation Meeting.
10. ORAN Street Day Centre Consultation

As part of consultation on the collection of personal information on diversity EDIP worked with the Oran Street Day Centre for the Elderly.

Oran Street Day Centre For Elderly

Oran Street Day Centre for the Elderly is for elderly male and female people over the age of 60 from the mainly white Scottish population of north west Glasgow. It is a well-known, established and recognised community centre which provides a meeting place for the elderly. The Centre is run with the help of a manager and staff and provides day care provision for people who need support to remain in the community, as well as providing various activities to maintain and improve the quality of life of the elderly people who attend.

Summary of characteristics of the group attending

- 25 elderly people attended.
- All were registered with a GP and had experienced further referrals to hospital at some point.
- Ages ranged from 60-96.
- Some were hard of hearing.
- Some could not sit for too long.

Format of the meeting

The meeting was very informal, with everyone sitting in a circle. An oral presentation, based on a presentation that is being used across Scotland (Appendix 1), was the basis for the meeting, which also included an overview of the EDIP Programme.

The presentation and discussion had been modified to ensure ease of understanding and to promote participation from the attendees. The attendees’ comments were noted and are either summarised or included (in italics), although these are not necessarily verbatim.

Oran Street Day Centre, 5 Oran Street, Maryhill Glasgow G20 8LY
Results

General questions to stimulate discussion

Time
• The group agreed that they sometimes did not have enough time with the doctor at the surgery. “It is bit difficult to explain to the doctor what is wrong with you if you think you are taking up too much of the doctor’s time.”
• Some of the attendees mentioned that it takes a lot of courage to make an appointment to see the doctor. “The doctor might think it is because of old age but we have concerns.”

Transport
The attendees comments tended to focus on being unable to attend the doctor’s surgery or hospital appointments because of mobility problems/poor health/lack of transport.

• All the attendees reported that they are unable to travel by bus due to mobility problems – one attendee commented that, if public transport was to be used, they would be unable to walk from the bus stop to the clinic.
• 15 of the attendees said that, when an appointment came through, often after many months of waiting, there had been occasions when they could not make it to the hospital due to lack of transport and a lack of arrangements in place to support their mobility problems.
• The attendees said that, if they attend with relatives, they find it difficult to walk to the clinics as there are no walking aids available or parking places available close to the clinic.
• It was agreed that staff sometimes don’t show any sympathy: “They think, being old, you are over-reacting and seeking attention.”
• Many of the attendees had experienced waiting too long in hospital while waiting to be seen by a doctor.
• Two of the attendees who were hard of hearing said: “We are always under a lot of stress when we are in the waiting area in case we can’t hear when we are called for our appointment and whether we can hear everything when we are with the consultant.”
Experience of giving information to the NHS

- Most of the attendees did not remember the information they had been asked to provide when they registered with their GP surgery.
- Most of the attendees said that their medical conditions are recorded.
- One attendee said: “I don’t think they record any information because when you are at the doctor’s surgery or the nurse or the consultant, they seem to ask the same question again and again.”
- When the attendees were asked if they had ever been asked about their social needs, such as communication support, diet or mobility requirements, the answer was “No.”

Examples of personal experiences.

“I was without my doctor for five months. Nobody, till now, has given us any information about why and what happened to him. The new doctor did not know anything about my medical condition and I had to tell him about my medical history because he did not get time to read my history. This made me very angry.”

“The thing that really annoys me is that, whenever I go to my surgery, there is always a different doctor.”

One attendee mentioned that the NHS is not the same as it used to be. “We are always two years behind all the promises that are made. Look at the state of hospitals. Now we have to start paying for car parks. Where are we going to get extra money?”

“We should have one databank where all our records can be accessed from. I was in England and was taken ill but my treatment was delayed because they didn’t have access to my medical notes.”

A 92-year-old attendee said that, after waiting for 18 months for the surgery when he was in the hospital nobody could find his records. “The staff were not compassionate at all.”
**Benefits of giving more information**

- The group was very happy to share information.
- Some of the attendees had concerns about the way appointments with opticians and dentists are arranged and felt they had a very limited choice of services provided: “But, if you go private it is very expensive for dentistry.”
- Some of the attendees were quite happy with NHS services and thought we should be all grateful with services provided.
- Some suggestions were made, including:
  - Collecting all personal information once and sharing it with appropriate agencies involved.
  - Adopting a more personal approach to filling in forms.
  - Information being held in one place so less time is wasted looking for records.
  - Treating elderly people with respect and taking their needs into consideration when attending the doctor.
  - Involving the elderly in how the NHS provides services.

Completion of the questionnaire (Appendix 2) was voluntary and 18 (72%) responded.

The questionnaires returned by this group demonstrated that, even although the attendees could read, write and understand English, most of them needed assistance to fill in the form. There also were a high number of ‘Blank’ non-responses that, in part, might be reflected by the comments below.

Some of the reasons that the elderly gave for their need of support when completing the questionnaires included:

- “Sight not so good.”
- “Shaky hands.”
- The wording of some of the questions (e.g. ‘disability’, ‘language’) not being understood and requiring further explanation.
- Some of the attendees expressed concern about the faith and religion question as they failed to see the relevance of this question in relation to their illness.
**Conclusion**

As with previous consultation meetings, the questionnaire in the current format proved too difficult. Key challenges that are emerging include:

- The requirement for plain and clear communication explaining the reasons such personal information is being asked.
- A self-completion, paper document is not an accessible format for all.
- Most people require support with completing the questionnaire in its present format and request further clarity with regard to the questions.
- Despite having just agreed orally to give the information required, some people completed the questionnaire but ticked the box stating that they would ‘prefer not to give this information’.
- There is a strong sense that this information should be requested much earlier and in the primary care setting.

There was good participation from this group, with attendees discussing and sharing good and bad stories about their NHS experiences. The attendees were very interested to hear about EDIP and stressed that they would value more engagement with the NHS.

The Employment Equality (AGE) Regulations come into force 1st October 2006. Although this legal requirement centres on employment and education, Age Concern has produced information for older people who feel that they have been treated badly in health and social care on the basis of their age.

The NHS is committed to ensuring there is equal participation in the health care of people of all age based on respect, dignity and value of each individual and this is being supported with a Fair For All Age Officer, who will be in post from end of July 2006 and will be based in Fast Forward.

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45 http://www.ageconcern.org.uk/AgeConcern/0E4DC476ED22451BB66ABDF52C0B2B54.asp
46 http://www.ageconcern.org.uk/AgeConcern/Documents/AnAgeEqualityDuty.pdf
47 http://www.fastforward.org.uk/
Note

This consultation was carried out by Vijay Khanna, EDIP PFPI Support Worker. EDIP recognises that this particular group does not reflect the views of the older Scottish population. The results will primarily be used to aid Communications and Actions required by NHS organisations in their collection of their personal information for the NHS users. We would like to thank all Oran Street Day Centre attendees and staff for their welcome and participation in the consultation meeting.
11. South Lanarkshire Citizen’s Panel Consultations: Background

How the consultation groups were engaged

The Equality and Diversity Information Programme (EDIP), established a system of partnership working with South Lanarkshire Citizens' Panel (SLCP).

The SLCP was established in 1998 by South Lanarkshire Council, Scottish Homes (now Communities Scotland), Lanarkshire Development Agency (now Scottish Enterprise Lanarkshire), Lanarkshire Health Board and Greater Glasgow Health Board. The SLCP underwent a review in 2006.48

A Citizens' Panel is meant to be representative of the electorate and is weighted for gender, age, ethnic group and other relevant background factors. Panels are often established though the electoral register or through local advertisements, with membership changing over time. Citizens' Panels usually provide their views on options or proposals for local services through questionnaires, and are often used as a means of recruiting people to take part in discussion groups or other local consultation events.

Following discussions with the SLCP, it was decided that meetings would take place in Hamilton, Rutherglen, East Kilbride and Lanark. A series of emails and telephone calls with Kathryn Tierney49 led to a partnership approach to these Consultation Meetings, with a meeting planned for each of the council buildings within the four selected areas.

The SLCP provided the EDIP with contact details for those members of the Citizens' Panel in Hamilton, Rutherglen, Lanark and East Kilbride who had declared a willingness to participate in discussion forums. Attendees were selected randomly using Mini Tab, an easy-to-use statistical package that allows individuals to be chosen entirely by chance, with each member of the population having a known, but possibly non-equal, chance of being included in the sample. This led to 50 letters being sent out for each meeting, inviting people to accept or decline attendance, along with a stamped addressed envelope and return letter.

48 http://www.laria.gov.uk/content/features/70/feat3.htm
49 Kathryn Tinney, Policy officer, South Lanarkshire Council. Email: kathryn.tinney@southlanakshire.gsx.gov.uk
It was also decided that 15 would be the optimum number of attendees at each meeting as this would encourage discussion and participation. Where more than 15 returns accepted the invite to a particular Consultation Meeting, a further random selection was used to decide on the members of the final group (respondents who had recorded ‘special needs’ were given a weighting of one to ensure their place).

Format of the meetings

Consultation Meetings were held from 7pm – 8.30pm in Lanarkshire Council premises. A payment of £15 was provided to attendees to assist with transport, child-minding expenses etc.

A presentation (Appendix 6) formed the basis for the meetings, with the groups invited to comment on the slides, which were designed to encourage the attendees to discuss the provision, availability and use of information within the NHS and how they felt about providing more personal information. The attendees’ comments were noted and are either summarised or included (in italics), although these are not necessarily verbatim.

Characteristics of Consultation Group Attendees

Through partnership work with the South Lanarkshire Citizens’ Panel (SLCP), EDIP held Consultation Meetings in Hamilton, Rutherglen, East Kilbride and Lanark. A total of 41 people attended the four meetings - an average of 10 attendees per meeting. The attendees were aged between 38-80 years. Other characteristics included:

- Religious background: One Brethren, One Buddhist, One Christian, Two Church of England, 13 Church of Scotland, Nine no religion, Five Protestant and Eight Roman Catholic.
- Ethnic Group: 29 White Scottish, 1 White Irish, 10 White Other British, One White other British (Wales)

Two declared disability. All the attendees were registered with a GP. All the attendees had experienced onward referrals to hospital. Five of the attendees were first time attendees to a Citizen’s Panel.
12. Hamilton Consultation Meeting

Characteristics of Consultation Group Attendees

- 15 people were invited to attend.
- Two cancelled, four did not attend.
- Nine attended:
  - Four women
  - Five men.
- The attendees were aged between 50 – 68 years (mean 53 years).
- Religion:
  - One Buddhist
  - One Church of England
  - Two Church of Scotland
  - One none
  - One Protestant
  - Three Roman Catholic.
- Two declared disability.
- All the attendees were registered with a GP.
- All the attendees had experienced onward referrals to hospital.

Results

The presentation began with an outline of the evening and a brief overview of the Information Services Division (ISD) and the Equality and Diversity Information Programme (EDIP). This was followed by a series of slides designed to stimulate comment, debate and provide an insight into how people feel about providing information to the NHS.

General questions to stimulate discussion

This group had no issues around being able to describe their symptoms of illness. However, the attendees were divided on whether they were able to spend enough time with their GP/hospital consultant.
Comments included:

“The time factor depends on how much time the doctor has. Three quarters of the time with the consultant is spent going over information to explain the condition and the treatment.”

“I don’t mind if time is taken up in repetitions – just glad to ensure that the correct, timely information is given as you can wait a while from visiting your GP to getting your hospital appointment.”

“My condition took a long time to diagnose, there was continual testing before diagnosis and then the treatment began.” (This attendee felt this was a positive outcome.)

When asked if the relevant personal information was available at an appointment, one attendee felt that the information had been collected but not shared between clinicians and commented: “I have two case records but none of the information kept in those records seems to be able to ‘speak to each other’.”

Another attendee commented positively on the electronic transmission of x-rays, adding: “This makes a big difference in reducing time and getting results.”

What would make it easier to give information?

This question led to a variety of comments, including:

“It’s a good idea to take a note of the questions that you’d like to ask your GP with you on a note pad. It’s so often the case that the GP greets you with a ‘Hello - how are you?’ and you respond ‘fine’ and then forget why you made the appointment.”

“The best way to collect information is by talking and by staff asking the right questions of us…”

“…So 10 minutes isn’t really enough!”

The group then discussed the drive towards e-health and personal electronic records, with one of the attendees commenting on the importance of the information contained within these systems being accurate. The attendees were all aware of the use of information technology and systems to support healthcare but
not the detail of how their local surgery uses this technology or what information is stored about them on computer systems and/or paper records.

What information is known

Information collated from various information-gathering exercises, including the NHS Lanarkshire Sample Health Survey 2003 and the 2001 National Census were used to stimulate discussion.

None of the attendees could remember being involved in the NHS Lanarkshire Sample Health Survey and were surprised by the level of undiagnosed, untreated high blood pressure (18% men, 16% women). This provided an opportunity to talk about the attendees’ knowledge of health checks provided by their GPs, which confirmed that most of the attendees were aware of their local services.

Further discussion revealed that the majority of attendees were not too sure about the increasing prevalence of diabetes in the general population and/or the difference in prevalence between ethnic groups in relation to diabetes. To develop this discussion further, the attendees were asked why it would be helpful to the NHS to know if people from the Pakistani population had diabetes and how this might be connected to Ramadan, a time of fasting. The attendees were unsure but, following a brief overview of Ramadan, agreed that knowing a person’s religious beliefs/faith could help to ensure that they remain well through the provision of good dietary and medication advice during special religious festivals.

The attendees were then asked to suggest reasonable adjustments within the NHS that could be made to change the care provided to them. This led to various suggestions, including:

“When someone with a disability is admitted, some questions may not be asked and this can cause problems regarding catheters or hoists. Information about our needs should be collated on the first encounter but no one seems to ask these questions.”

http://www.nhsggcquality.co.uk/equality/healthpro/research/reports/pdf/ramadanAndDiabetes.pdf
“I work in the NHS and knowing in advance that patients need information in other languages and/or an interpreter and their beliefs would make a big difference for staff and patients.”

“To provide better care, information has to be collected by fully-trained staff (meaning ‘staff who know what to do’). For example, to organise a wheelchair if a person should need it on arrival at hospital.”

**Willingness to provide more information**

All the attendees agreed they would be willing to provide details about personal information such as ethnic background, faith, dietary preferences and gender preference in relation to healthcare staff.

All chose white Scottish (section A) from the Scottish Census 2001.

Two of the attendees, who were disabled, shared their experiences with the group and raised various issues, including:

- Complexity of medication – reading the small print.
- Lack of availability of wheelchairs.
- Parking difficulties when attending for hospital appointments.
- Lack of appropriate disabled toilets.
- Sitting in a waiting area unable to hear your name being called.

**Concerns around the provision of more personal information**

One attendee commented: “I’m unsure about storing information electronically as ‘other people’ may have access to private records.” However, when asked about who has access to their paper medical records, none of the attendees had considered that their paper records could be picked up and read without their knowledge. Neither had the attendees thought about some of the strengths of technology, which enable a list, or ‘audit trail’ to be made of everyone who has accessed a specific electronic health record.
One attendee felt that: “An audit trail would be a huge bonus and this should be made clear to patients when explaining the benefits of providing more personal information,” while another attendee recommended the Inland Revenue’s online self-assessment website as an example of a good method of storing electronic information.

Next, the Emergency Care Summary Leaflet\textsuperscript{51} was brought to the attention of the group. None of the attendees had received this leaflet or were aware that the following information was being extracted from their GP records:

- Name
- Date of Birth
- Name of GP surgery
- Community Health Index (CHI) - unique identifying number
- Current medication prescribed by GP
- Adverse reactions to any medications

None of the attendees expressed concern about the data being exported from their GP records, as they were aware that, if they became unwell, this basic information would be helpful for NHS 24 and out of hours services. However, there was concern amongst the attendees that they had not received this leaflet and that they did not know who would have access to the information held about them in the Emergency Care Summary.

**What do you suggest the NHS needs to do to encourage people to give more personal information?**

“Each NHS customer should carry a card that will link into the central ‘store’ of information. The customer would therefore be responsible for holding the key and being in control of their information.”

“There is a need for considering resources in order to match ‘fluent’ care.”
(meaning - if you get information quicker then care should be smoother and quicker and also, that information would be required about where the money and people would be coming from to support this.)

“Aking these types of questions would raise expectations – but if you are realistic, you won’t expect it! Need to be sure we will get what we ask for.”

“Communication about these types of questions has to be clear and questions have to be asked in a way to avoid disappointment and unrealistic expectations.”

“This information should be collected before it is needed – GP surgery may be the best place.”

**Discussion**

This was the first Consultation Group where all the attendees self-selected from the ‘White Scottish’ ethnic group and most of the group were well and had required little intervention from the NHS. This may explain why it was quite difficult for the attendees to think of reasons why other people might not be willing to provide information concerning their culture or diversity.

The attendees expressed no concern that, for many of them, giving this information might not be personally relevant to them. Overall, the attendees thought that the NHS should be asking questions along these lines and their main concerns were around clarifying the reasons why the questions were being asked and how they would be stored and used.

The experiences of those attendees with a disability highlighted some of the issues around access, mobility and sensory impairments. In addition, one attendee, who works in the NHS, highlighted the significant issues faced by both patients and staff where English is a second language, which appeared to provide this group with further confirmation that the EDIP was worthwhile.
Conclusion

This group was extremely positive towards the EDIP and had little concern about providing the information discussed at the meeting. It was agreed that communication to the wider Scottish population about this should be considered, with the attendees making the following suggestions:

- Redesign the questions in the questionnaire into plain English
- Identify any unfairness that may exist for a particular group before going to them – it was agreed that the Electronic Care Summary was a good example of everyone not having equal access to health information that affects them.
- Make good use of personal stories to ‘win people over’.
- Ensure communication from the NHS is clear, concise and appropriate.
13. Rutherglen Consultation Meeting

Characteristics of Consultation Group Attendees

- 15 people were invited to attend.
- 13 attended:
  - Eight women
  - Five men.
- Two did not attend.
- The attendees were aged between 41 - 71 years (mean 53 years).
- Religion:
  - Three Church of Scotland
  - Three none
  - Two Protestant
  - Five Roman Catholic.
  - All the attendees were registered with a GP.
  - All the attendees had experienced onward referral to hospital.
  - All the attendees were relatively well.

Results

The presentation began with an outline of the evening and a brief overview of the Information Services Division (ISD) and the Equality and Diversity Information Programme (EDIP). This was followed by a series of slides designed to stimulate comment, debate and provide an insight into how people feel about providing information to the NHS.

General questions to stimulate discussion

It was initially quite difficult to establish discussion with this group. Overall, the group seemed to have encountered little or no difficulty when attending their doctor or when giving information to NHS staff. There also seemed to be a general consensus within the group that the time they spent with their GP had, to date, been adequate.
However, on reflection, one attendee said: “Time enough, yes, as you are usually seeing them for a specific reason”, meaning that, if you were quite clear about what was wrong with you, then it was straightforward. To this, one attendee commented that the time allocated seemed to be dependent on the doctor.

To help pursue this subject, the attendees were asked if they had experienced Patient Focussed Booking52. Only one attendee knew of this service and explained the process to the others. “My GP has access to various waiting lists, allowing me to choose which hospital I visit… Received notice of 26-week wait, time went by, received another letter asking me to confirm that the appointment was still required, I telephoned to confirm, chose a date and was then sent a letter confirming the appointment.”

This attendee was asked if, either at the GP surgery or at hospital, questions had been asked about any special needs with regard to the hospital appointment? The attendee informed the group that she had not been asked about this and, when this question was opened out to all the attendees, it was discovered that none of the attendees could remember being asked if they had any transport or mobility requirements when being referred to hospital.

Next, the group were asked about how they receive, for example, information about what health checks, tests, and vaccinations are available at their GP surgery. Responses included:

“The surgery leaves a message on my answer machine for my routine blood checks.”

“In the surgery with posters, leaflets.”

“Newsletter produced, but only available in the surgery, not sent out.”

“No pro-active work by my GP.”

“GP asked whether I wanted to be held on database, which allows me to be notified should attention be required e.g. flu jag, heart monitoring etc.”

“Our GP targeted all teenagers for their MMR jag, went well, good notification and surgery opened late and at weekends.” (All agreed this was good practice.)

“The Practice Nurse does most of the contacting.”

With so many different responses, the group were asked if this varied form of notification was equitable, which led to the following comments:

“Not really. I need to remember when my regular blood checks are due. No notification from GP. Your health seems to be your own responsibility. No letters sent as reminders.”

“It should be your GP’s responsibility.”

What information is known

Information collated from various information-gathering exercises, including the NHS Lanarkshire Sample Health Survey 2003 and the 2001 National Census were used to stimulate discussion.

None of the attendees had been involved in the NHS Lanarkshire Sample Health Survey and none were familiar with the diverse population of Scotland, current migration trends and changing government policies in relation to equality and discrimination. However, when reminded that the majority of attendees had said they received information about what was available in their GP practice through posters, newsletters and phone calls, the group agreed that assumptions were being made that everyone could:

- Read
- Read English
- See
- Get to the doctor
- Use the phone
- Access a phone
- Hear
- Speak and understand English
This led to agreement from the attendees that, for some people, accessing healthcare is likely to be problematic.

One of the attendees reported that experiencing difficulties due to information on one computer system (Health) not being available on the other computer system (Social Work). She explained that this often means that information that would make a difference, which has already been provided, is not necessarily shared between professionals so is not readily available.

**Willingness to provide more information**

**Response to Questionnaire (Appendix 7)**

All the attendees agreed they would be willing to provide the information requested by the questionnaire, even though they realised that, for most of them, there was unlikely to be any particular benefit to them as individuals.

**Concerns about providing more personal information**

When asked if they had any concerns about providing more personal information, the attendee’s responses included:

“*Data protection – can we be sure? Will we get Junk Mail, Sales calls?*”

“*Where does this information go?*”

“*The questions seem pretty basic - not much personal information given.*”

“*What happens if your beliefs change?*”

“*Would this information mean that funds would be targeted into specific areas e.g. particular ethnic groups?*”

“A lot of the time, people are not given the right treatment as their history is not asked.”
To explore the issues surrounding where our health information goes and what is done with it, the group was shown a copy of the Electronic Care Summary Leaflet\(^53\). Out of the 13 attendees, only one had received a copy of this leaflet, another had heard of it and none were familiar about what information would be extracted from their GP records and made available to NHS24 and out of hours health services.

It was explained to the group that the information obtained from GP records will include:

- Name
- Date of Birth
- Name of GP surgery
- Community Health Index (CHI) - unique identifying number
- Current medication prescribed by GP
- Adverse reactions to any medications

The attendees agreed that this was basic information that did not reveal anything too personal and would be helpful to NHS24 and out of hours services. However, three of the attendees commented:

“My experience of NHS24 was being asked the same information several times, as if they had not listened.”

“My concern is that if they have information, will they pre-conceive what’s wrong with you? Will they make assumptions by looking at your current conditions?”

“I’m fortunate to have a medical background when describing symptoms as NHS24 ask in a rigid way.”

There was a varied response from the attendees as to how the NHS should – and should not - collect more personal information, including:

- By questionnaire
- At the GP surgery
- Not during hospital visits - the comment was made that a nurse asking questions in foyer: “Isn’t comfortable or private”.

As to who should ask these questions, suggestions included:

“Too much for the GP, either nurse or someone trained.”

“Training in asking the questions important.”

“Must be assured of confidentiality.”

“Person must not be judgemental or make assumptions.”

The group’s overall concerns regarding providing more personal information to the NHS were:

- Security: Who would have access to this information? Where would the information be kept? Who would decide who sees this information?
- Assumptions: Whilst this group was less concerned about the potential sensitivity of such information for themselves, most of the attendees felt that wrong, and potentially disadvantageous, assumptions could be made about people as a result of this information.
- Environment: People must feel comfortable and relaxed when answering questions of this nature.
- Privacy: This information needs to be obtained in a setting where other people are unable to overhear.
- Time: People will need time to think about the information requested and, if necessary, ask questions.
- Purpose: Guidance is required regarding how this information will be used.
- Funding: Will this involve redirecting funding?

What do you suggest the NHS needs to do to encourage people to give more personal information like we have discussed?

This led to various comments from the attendees, including:

“Information about this programme needs to be communicated.”

“Make use of national advertising, TV, newspapers.”

“Something branded, so easily recognisable.”

“‘See Me’ campaign very good example.”
“NHS, should treat it (EDIP Programme) more like a business - patients are customers so sell it.”

Discussion

This was a 'well' group and the attendees came across as articulate and competent in terms of negotiating their way around health services, despite the fact that important health information is obviously not reaching them. There seemed to be an acceptance that the NHS is not perfect but the attendees had all found ways of overcoming any current personal stumbling blocks, for example, choosing to see a particular GP even if that involved waiting longer for an appointment.

When prompted, the attendees agreed that the NHS could be quite daunting for some people, even for some of the attendees. It transpired that, if they were really ill, none of the attendees had a clear picture of how information goes between GP and hospital or of their GP’s current arrangements with NHS24.

This group highlights the fact that the majority of the Scottish population is well, makes infrequent contact with their GP and even less with a hospital. As a result, communicating with the majority Scottish Population about why they should provide more personal information to the NHS when this may never be to their benefit requires particular attention.

It is also important to consider how ‘well people’ will be contacted in order to provide more personal information. As they do not routinely visit health services, the ability to collect equality and diversity information such as this in multiple settings and at opportunistic times, perhaps when receiving travel vaccinations, accompanying a ‘sick’ person, or attending a well person clinic, must be considered.

The attendees all found the evening very interesting and mentioned that they would be happy to attend further meetings.
Conclusion

Overall, the group would be willing to provide the information requested – as long as the recommendations coming out of the Consultation Meetings were embedded into any national approach to collecting more personal information.

Important points to be considered:

- Education required of the Scottish population with regard to discrimination in health
- Questions in the questionnaire need to be rephrased, especially around spirituality.
- The NHS must recognise that it may have to collect this information at various times and in various settings.
14. Lanark Consultation Meeting

Characteristics of Consultation Group Attendees

- 14 people were invited to attend.
- Three cancelled, two did not attend.
- Nine attended:
  - Four women
  - Five men.
- The attendees were aged between 38 – 74 years (mean 55 years).
- Religion:
  - One Church of England
  - Six Church of Scotland
  - Two None.
- All the attendees were registered with a GP.
- All the attendees had experienced onward referral to hospital.
- Two of the attendees were first time attendees to a Citizens’ Panel.

Results

The presentation began with an outline of the evening and a brief overview of the Information Services Division (ISD) and the Equality and Diversity Information Programme (EDIP). This was followed by a series of slides designed to stimulate comment, debate and provide an insight into how people feel about providing information to the NHS.

General questions to stimulate discussion

Seven of the nine attendees said that they found it easy to explain their problems to doctors - five of them mentioned that they knew their GP and felt confident about explaining themselves and the other two agreed that, although they rarely attended their GP surgery, there would not be a problem explaining symptoms.
The two attendees who found it difficult commented:

“Insufficient time to really explore what is wrong. This is not helped by a GP who does not communicate with you. You don’t know whether you should start to speak or wait for his lead. Has his face in notes, computer or writing. So you start and leave with a prescription with little dialogue between us.”

“Sometimes you don’t get the same doctor so, as you are talking to him, he is reading your notes and you hope he is listening to your current situation.”

In relation to the approximate time of GP appointments, nine of the attendees thought that ten minutes was adequate. Some of the attendees have long-term medical conditions and attend their GP surgery regularly - they felt that time was adjusted to suit individual needs and that this system appeared to work well.

One of the attendees commented that ten minutes was insufficient and the attendees were asked if they would consider booking a double appointment. Only two of the attendees knew that they could request a longer appointment, although they had not done so.

Time given by hospital staff was considered adequate and, as few had personal experience of hospital, there was no further discussion around this.

Next, the attendees discussed their experiences of providing information to healthcare staff. All of the attendees found it difficult to remember what information they had provided to their GPs. When asked what they were asked by the GP, the attendees’ responses included, “How are you?”, “Why are you here?” and “Tell me your symptoms.”.

Two of the attendees had earlier mentioned that they found it difficult to describe what was wrong to their GP and they were asked if they had ever told their GP, which led to the following responses:

“As the doctor has poor communication skills, there would be no point.”

“The consultation only gets better once the doctor has picked up signs and symptoms that are significant and then the whole attitude changes. Doctors try to assess serious illness or time wasters.”

“When doctors’ accents are difficult to understand, you don’t bother.”
One attendee described her experience of going to the GP with her husband who has Dementia. “The appointment is for my husband but the doctor always addresses me. My husband has communication problems but it is very wrong, he should ask him. The doctor asks me, I answer, and my husband looks at me and is not always too pleased with what I say. The doctor asks my husband the same questions – what is your date of birth, what day of the week is it etc, and then says ‘You’re doing well’, although my husband just remembers the answers from one visit to the next.

“I have asked my doctor about this but he says that when he asks my husband, he says nothing.”

The attendees were asked if they had been asked questions by health staff such as: Do you have communication problems? Do you have difficulties with mobility or access? What is your ethnic background? The attendees all said they had not been asked any questions along these lines and made the following comments:

“Do they know they are supposed to ask about this?”

“Carer - how are you managing? They never ask.”

“They are not aware of how you are feeling. They should ask a bit more.”

“They should ask about carer needs.”

Following discussion, it transpired that none of the attendees knew about the Carers Rights to Assessment54.

**What information is known**

Information collated from various information-gathering exercises, including the NHS Lanarkshire Sample Health Survey 2003 and the 2001 National Census were used to stimulate discussion.

All the attendees knew and understood what ‘ethnic group’ meant. Some of the attendees had been asked this as part of their employment equalities policy but none of the attendees had been asked this within a health setting.

54 [http://www.carerscotland.org/Information/Helpwithcaring/Carersassessmentguide](http://www.carerscotland.org/Information/Helpwithcaring/Carersassessmentguide)
One attendee said that: “They (doctors) make assumptions about your ethnicity,” and when the other attendees were asked if they thought this statement was correct, they all agreed that they should be asked about their ethnicity, rather than it being assumed.

Next, the attendees were asked if they had received information about:

1. Health Checks available at their GP practice
   - Six knew that some health checks were available at their GP practice but were not sure what these were for.
   - The attendees with diabetes were aware of what was available for them and attended their GP surgery for regular check-ups.
   - One attendee had been offered a health check before taking part in a 5–A-Side Football Tournament and thought this was a good idea as the information from this was passed to his GP.
   - One attendee reported that their GP surgery sent letters to those aged 40 and over inviting them to attend for a 10-minute health check.
   - One attendee thought that doctors should be duty bound to invite all patients for health checks.
   - One attendee asked: “Does it depend on the size of the surgery, as I belong to a small practice?”

2. Confidentiality, It’s Your Right and Making A Complaint About The NHS
   - None of the attendees knew that this information was available or where to collect this kind of information.

3. Your Emergency Care Summary – What does it mean to you
   - Five of the attendees have not received a copy of this leaflet.
   - Four had received their copy but only one had read it.

Copies of the above publications were made available to the attendees, who were pleased to receive the ECS leaflet. Some of the attendees mentioned that they were going to investigate what information and health checks were available to them at their local GP surgery.

A short discussion then took place about whether the attendees felt that the way health checks and information availability seemed to vary within the Lanarkshire area was fair and equitable. All the attendees agreed that there was unfairness but that, until then, they had not realised that there were such wide differences in each other’s experiences in giving and receiving health information.

The group was then asked to consider the diverse population of Scotland and how people with, for example, communication/mobility access/visual sensory impairment/literacy challenges would find giving, accessing and receiving NHS information? The attendees agreed that, as they themselves had experienced difficulties, it would not be easy for some people.

**Willingness to provide more information**

**Response to Questionnaire (Appendix 7)**

- All the attendees would be willing to give this information.
- One field was left blank.
- All the attendees said they could see the relevance of asking these questions.
- All of the attendees said that, although some of the questions were irrelevant to them, they would still answer.

**Concerns about providing more personal information**

In summary, the attendees reported the following concerns about further data collection:

- Should be collected once and shared with the appropriate people who are involved in a patient’s health care.
- Hereditary questions should be included and doctors should have access to, for example, patient’s parents’ records. This led to a short discussion around knowing who your parents are, how far back to go back in the hereditary trail, the storage of medical records and confidentiality.
- Confidentiality was not an issue - the attendees felt there would be more benefits than disadvantages regarding issues around security of information.
• There was acknowledgement from the group that, for some people, providing this type of information could be an issue.
• Although sharing information with health care staff is not an issue, it was agreed that any sharing of information with other agencies should first be discussed with the patient.

What do you suggest the NHS needs to do to encourage people to give more personal information like we have discussed?

The attendees’ suggestions included:

• Develop a Scotland-wide education programme setting out the context and benefits of the EDIP.
• Establish non-discriminatory practice and valuing diversity in school.
• Recognise that communication is a two-way process. Staff should have interpersonal skill training and staff employed from abroad should be trained in the Scottish culture. However, there was a realisation amongst the attendees that, for many people resident in the UK, the Scottish accent and local dialects provide difficulties.

Discussion

This was a relatively ‘well’ group, with only three attendees commenting that their experience with the health service could be better.

However, the variation in the availability and distribution of relevant general health information and access to health checks raised concern for all attendees, who felt they were missing out on key information and services. The Emergency Care Summary (ECS) Leaflet generated the most concern, as it was apparent that none of the attendees knew how or what information was being made available by their practice to support out-of-hours services and NHS24. Although all the attendees felt that the sharing of this information was a good thing, and they were unlikely to opt out of it, they felt there were very obvious, and unacceptable, issues around fairness and inequity.
The group was informed of the Scottish Consumer Council’s report Health On Line, Public Attitudes To Sharing In The NHS\textsuperscript{58}, which reports that the majority of people would like to receive personal, addressed information about the ECS as they would be more likely to read it.

As a result of the attendees highlighting their experiences of poor communication within the NHS and, in particular, their experiences with regard to accessing important information, all the attendees were able to consider how this might effect the wider population of Scotland. Within the group, there was an awareness and recognition that, for many people who have communication difficulties, a sensory/visual impairment or English as a second language, negotiating, finding and receiving information from the NHS must be difficult.

The group were shocked to hear that the NHS does not routinely ask patients questions about their communication and mobility needs and wanted to know how quickly the EDIP could be implemented.

The questionnaire (Appendix 7) offered no problems for the attendees to complete, except that, when the form was printed (double sided), some received a duplicate of side one, which possibly contributes to the one blank field. Quality assurance on forms is imperative!

This group highlights that the fact that, when you don’t know what you don’t know about the NHS, and you have infrequent use of the NHS, it is relatively easy to be oblivious to the fact that you are missing out on opportunities to attend health checks, receive information or make the most of NHS services.

The attendees in this group appreciated the opportunity to hear about the EDIP and felt that the wider population needs to know about this programme, too.

**Conclusion**

The attendees in this group would all be willing to see the introduction of the routine collection of relevant data to support health care. They acknowledged that this might not be the same for all people and that the questionnaire requires to be refined to ensure appropriate responses are given by patients, so that the information given can be acted upon to help improve health care.

\textsuperscript{58} http://www.scotconsumer.org.uk/publications/reports/documents/rp11online.pdf
15. East Kilbride Consultation Meeting

Characteristics of Consultation Group Attendees

- 16 people were invited to attend.
- Four cancelled, two did not attend.
- 10 attended:
  - Five women
  - Five men.
- The attendees were aged between 39 – 80 years (mean 61 years).
- Religion:
  - One Brethren
  - One Christian
  - Three Church of Scotland
  - Three None
  - Two Protestant.
- All the attendees were registered with a GP.
- All the attendees had experienced onward referral to hospital
- Three of the attendees were first time attendees at a Citizens’ Panel.

Results

The presentation began with an outline of the evening and a brief overview of the Information Services Division (ISD) and the Equality and Diversity Information Programme (EDIP). This was followed by a series of slides designed to stimulate comment, debate and provide an insight into how people feel about providing information to the NHS.

General questions to stimulate discussion

Seven attendees reported that they find it easy to explain their problems to doctors, with one of the attendees explaining: “When you know your doctor it is easy to explain yourself.” Three attendees expressed difficulty with explaining problems and/or symptoms to doctors, commenting:
“I’m frightened and as soon as I go into the doctor I start to cry, even although I have known the doctor for years. Hasn’t put me off attending my doctor as he understands and helps me get to the root of my visit.”

“I tend to feel I shouldn’t be there. You look around the waiting room and can see that there are more people worse than you. Usually say ‘sorry to trouble you doctor…’ but he assures me that I am here to prevent me getting any worse.”

In relation to the amount of time allocated to their GP appointment, almost all of the attendees felt that ten minutes was adequate, although several attendees qualified this by saying:

“Doctor spends too much of the time at the computer – I don’t think he is very good at it.” (Meaning using the computer)

“The doctor advises that I write down what I want to discuss.”

“I don’t go that often and when I do, I tend to have a list and try and start with the most important and, no, I don’t always tell everything if I think I’m taking too much time.”

“At hospital – as much time as required. It can take a whole morning – see the doctor/nurse, blood tests, wait while it goes to the lab and then get results. It can’t be helped - these things take time. It can be difficult getting from one place to another but a nurse usually points me in the right direction and I have seen them wheel people in wheelchairs from room to room.”

The attendees were then asked if they could envisage any problems if someone couldn’t see very well, speak or understand English or had mobility problems. The attendees accepted that some people might have problems, with one attendee adding: “Overall, people seem to get around. If they come by ambulance, there are wheel chairs – if they are available. There never seems to be enough.”

The suggestion that it might be good for the NHS to know in advance if people required a wheelchair or wheelchair access, received approval from the attendees, although this was quickly followed by the comment: “Only if the information would ensure a wheelchair was available!”
Next, the attendees were asked to give examples of the information they are asked to provide when attending their GP practice. The general consensus was that the receptionist usually asks for name, address, date of birth. The attendees were then asked if, during the course of an appointment, they had ever been asked if they needed help with areas such as transport, hearing etc. This led to various comments, including:

“I received a letter to attend outpatients and was asked to phone a number if they required transport.”

“My brother has been deaf for years. His GP knows but every time he goes he has say to the doctor ‘speak up and look at me’ as he can lip read. The doctor knows this but doesn’t seem to have written this fact down or is definitely not using the information.”

“The senior doctors know you okay but if you phone up on the day for an appointment it is usually a junior doctor you see who don’t know.”

“The doctors have information that they don’t use… Have you any allergies – so you tell them penicillin yet one of the times I was there, I looked at the prescription before I left the consulting room – penicillin! I got it changed!”

“My husband takes about 20 tablets three times a day. I said to my husband have you ever had a check to see that all these medicines are working properly and not causing adverse effects so he went to the doctor and told the doctor that his wife was worried about all his medication. Nine tablets were withdrawn!”

This led to a short discussion about whether the attendees were aware of medicine reviews. One attendee described how impressed he’d been by the Australian experience where a full medication review was carried out. The other attendees pointed out that this also happens in Scotland.

When the attendees were asked about medicine leaflets, one attendee commented that the print is too small. The other attendees agreed that it was possible that not everyone who was receiving a particular medication would be able to read the enclosed patient information. The attendees felt this was not right and the comment was made: “Someone could be taking something that is in conflict with other medication – surely it is the doctor’s job to make sure we get the right medication and not rely on us to read the instruction leaflet. Is it?”
Definitions

Definitions of the terms ‘ethnic group’ and ‘disability’ were offered. Following discussion, it became apparent that these definitions were not known to all the attendees nor did all the attendees realise that ‘disability’ included so many conditions. It was also discovered that none of the attendees had recently been asked his or her ethnic group in a health situation.

What information is known?

Information collated from various information-gathering exercises, including the NHS Lanarkshire Sample Health Survey 2003 and the 2001 National Census were used to stimulate discussion.

Similar to the other Citizens’ Panel groups, none of the attendees really knew about the NHS Lanarkshire Sample Health Survey 200359.

The attendees showed concern about the level of alcohol consumption findings (men 30% over 21 units and women 21% over 14 units) revealed by this survey. The group felt that alcohol consumption was an issue for young people in East Kilbride and there was a feeling that there was a lack of facilities for young people. When asked about the information available regarding alcohol in East Kilbride, none of the attendees knew, although lack of knowledge about alcohol information may, in part, be due to the attendees not having a need for such information.

Willingness to provide more information

Response to Questionnaire (Appendix 7)

All the attendees were willing to provide this information. Only one person required help in completing the questionnaire.

In summary, comments made by the attendees about the questionnaire included:

- The layout needs to be improved.
- The font size and the space to write down response need to be bigger.
- Clarification required about where to go for help in completing the questionnaire.
- Reassurance required that this information will not be used to make assumptions.

All the attendees were willing to provide the NHS with more information but one attendee asked about the term 'appropriate person' in relation to the question about talking to an appropriate person about their faith/illness/life circumstances.

Another attendee added: “You are asked religion when you go to hospital, do you all agree?”, which the other attendees were unable to answer. The attendee who had posed the question was asked to share their experiences with the rest of the group and said: “I was in the Golden Jubilee Hospital six weeks ago for a hip replacement and, at the side of my bed was a booklet giving me good information about different religions and asking if I required a special diet.”

The attendees were pleased to hear about this good example of providing meaningful information. Another attendee reported: “In hospital you have different ministers and chaplains that come around and talk to you.” Referring back to the slide revealing the census results on religion, the attendees were asked if they could remember seeing Imans or Rabbis at any time during their hospital stay, which none of them did.

Another attendee made a comment regarding the question about choice of gender of health care professional: “The NHS is not always going to be able to provide your preferred health care professional and, anyway, your choice is likely to be dependent on the type of appointment you are attending.”
What do you suggest the NHS needs to do to encourage people to provide more personal information?

The responses from the attendees can be summarised as:

- **Access**: Clarification required regarding who will have access to the information and how it will be used to make a difference to health care.
- **Confidentiality**: What steps will be taken to protect information, where will this information be asked and who will be asking the questions?
- **Context**: Explanation required regarding why this information is required in relation to health care services.
- **Changing Information**: How easy will it be to change personal information?
- **Reassurance**: How will this information benefit ‘me’? Assurance required that the information will not be used to make assumptions.
- **Training**: Whilst the group were not too concerned who might be asking the questions, there was general agreement that staff training would be required on issues such as how to ask questions and how to answer concerns about the collection, access, storing and sharing of this information.

**Conclusion**

There was overall agreement within this group that there was a need for patients to be asked these questions as, for some groups of people, the benefits are likely to be immense. Despite the fact that, for many of the members of this group, there would not necessarily be great benefits, they all agreed that they would be likely to provide the information required.

This group was the first to recognise, without prompting, that there was the potential to distort the information given by using it to stereotype groups of people.
Overall Conclusion

The groups were all extremely positive about the EDIP and had few concerns about providing more personal information to the NHS, although some of the attendees acknowledged that this might be a problem to some people. Also, although most of the attendees were well and agreed that the questions were not highly relevant to them, they stressed that they would be happy to provide this information as they could envisage the benefits there would be for some people and communities.

Overall, the groups agreed that they would support the NHS in terms of collecting more personal information which would then be used to provide and inform services, resulting in more culturally sensitive care. However, the groups also stressed the importance of knowing why this information is being requested and how it will be used – and that the information is seen to be used to the advantage and benefit of patients and carers.

Note

The consultations in Lanarkshire were carried out by Joan Jamieson, EDIP Programme Manager (joan.jamieson@isd.csa.scot.nhs.uk) and Vijay Khanna, EDIP PFPI Support Worker. EDIP recognises that the opinions of these groups do not necessarily reflect the views of communities across Scotland. The results will primarily be used to aid the Communications and Actions required by NHS organisations in their collection of more personal information from NHS service users. We would like to thank the members of the South Lanarkshire Citizens’ Panel who took time to come along and participate.
Appendix 1

Joan Jamieson
Equality & Information Programme Development

Vijay Khanna
Programme Support

“Making sure everyone shares in health improvement”

Outline of Today’s Programme

• Introductions
• What is Information Services Division (ISD)?
• Basic Questions from you
• Overview of Equality & Diversity information Programme
• Discussion
• Opportunity to complete a personal Data Form
**Information Services Division (ISD)**

A national organisation
Part of NHSScotland

Supporting the collection of health information - pre-craddle to the grave

Providing health statistics, information technology & related services for NHSScotland

---

**Some Questions**

How many registered with a Doctor?
How many attended your Doctor at some point?
How many had a referral to hospital?
How many find describing symptoms easy to a doctor?

How long does a Doctor get to assess what is wrong with you?
Questions for Discussion

General

What has been your experience of giving information to healthcare staff?

What would make giving information to health care staff better?

Aim of Group Meeting

To hear what you have to say about giving more personal information to support your healthcare.

Objectives for today

• Have an overview of the Equality and Diversity Information programme across NHSScotland
• Understand why you are being asked to provide more personal information
Definitions

Ethnic Group

Refers to a common group identity based on language, culture, religion or other social characteristics. This means that people define their own ethnicity, that everyone (and not just those in minorities) has ethnicity and that a person’s ethnic identity may change over time.

Equality in health – making sure everyone has appropriate access to healthcare

Diversity in healthcare – creating culture and practices that recognise, respect, value difference of patients and staff.

What is this Information Programme about?

• using collecting & personal social/cultural information from patients/carers to improve services - patient centred

• the NHS in Scotland treating people fairly (legal/policy)

• everyone benefiting from NHS services irrespective of
  • age
  • gender
  • race
  • religion/faith belief
  • sexual orientation
  • disability or sensory impairment
What do we know - Religion (Census 2001)

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<th>Religion</th>
<th>Number in population</th>
<th>% of population</th>
</tr>
</thead>
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<td>47.30%</td>
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<td>859,503</td>
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<td>Hindu</td>
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</tr>
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<td>Muslim</td>
<td>42,264</td>
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<tr>
<td>All persons</td>
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Ethnic Minority Population 2001

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<th>ALL PEOPLE</th>
<th>White</th>
<th>Indian</th>
<th>Pakistani and other South Asian</th>
<th>Chinese</th>
<th>Other</th>
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<td>14</td>
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<td>0.64%</td>
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Patient Focus Public Involvement
Providing More Personal Information to the NHS

Age and Ethnicity (Census 2001)

- 56.05% of all ethnic minority communities are aged under 30 compared with 36.3% of the White community
- 6.75% of all ethnic minority communities are aged over 60 compared with 21.3% of the White community
- The "youngest" communities are Bangladeshi, Pakistani and other South Asians where 31.2% are aged 15 or younger

Heart of the Problem

Overall huge GAPS in the routine data collection on equality and diversity within the NHS

- Equality & Diversity information not generally collected in GP systems (Diabetes maybe)
- Scottish Morbidity Data is a hospital data form (SMR01) ethnic group recorded is 9.2%

Without meaningful information ....................

We fail to recognise equality, diversity and cultural issues - patients, services and staff are all disadvantaged & powerless
Important points about collecting information

- Based on self-definition - something you decide
- Collected with informed consent - appropriate information in appropriate formats
- Agreed information that can be compared with e.g. with Census 2001 and subsequent classification recommendations (GROS Test/2011 Census)
- Collected once (probably in primary care) and appropriately shared across the NHS - confidential
- Collected by fully trained staff
- All information needed for appropriate care

How willing are you to answer these questions?

- How would you describe your ethnic group/culture/background?
- Would you like to speak to someone about your religion/faith/spiritual needs/illness and how it is affecting you?
- What is your preferred speaking language?
- Do you require support with communication? e.g. interpreter
- What format would you like to receive information e.g. written/oral/audio?
- What are your cultural dietary preferences?
- Is there mobility access we can help with e.g. wheelchair/support with dressing/personal care?
- What gender preference of health care practitioner?
Questions for Discussion

Specific

What are the concerns you have in giving more personal information like - ethnic group, religion/belief?

What would NHSScotland need to put in place that would encourage you to give this information?

Getting Involved?

• Want to hear more?
• Would your group like to be kept informed of the progress of this information programme?

Main Contact for Health Information:
Joan Jamieson
Equality and Diversity Information Programme Manager
Information Services Division (ISD)
Cirrus, Marchburn Drive
Glasgow Airport Business Park
Abbotsinch, Paisley
PA3 2SJ
Tel no: 0141 282 2250
Tel mobile: 07917086987

Email: joan.jamieson@isd.csa.scot.nhs.uk
Web Link to Programme: www.isdscotland.org/equalityanddiversity
Appendix 2

Equality and Diversity Information – Consultation Meeting Exercise

What is your age? ......................

What is your Gender?

Female
Male
Transgender
Other – please specify ..............................................

Do you consider yourself Disabled? – Yes / No

If Yes – how can we help you? ...............................

What is your preferred speaking language? ............................

Do you require an interpreter/support with communication? Yes / No

If Yes what support? ............................

What is your current religion / denomination / body of faith?
...........................................................................

Do you have a cultural dietary preference? Yes / No

If Yes please specify ..............................................
What is your Ethnic Group? (Recommendations for 2011 Census will be changed accordingly)

Choose ONE section from A to E, and then tick the appropriate box to indicate your cultural Background

A  White

Scottish
Other British
Irish

B  Mixed

Any mixed background, please write in below

………………………………………………………………………

C  Asian, Asian Scottish or Asian British

Indian
Pakistani
Bangladeshi
Chinese

Any other Asian background, please write in below

………………………………………………………………………

D  Black, Black Scottish or Black British

Caribbean

African

Any other black background, please write in below

………………………………………………………………

E  Other ethnic Background

Any other background, please write in below

………………………………………………………………

If you do not want to give any of this information, please tick this box

This is a sample form of the type of information SOME NHS organisations are beginning to ask of patients.
Appendix 3

Chinese Cancer Support Group

Date: 27/02/2006 Monday

Time: 11:15 am Lunch at Rainbow Arch after the meeting

Venue: Rainbow Arch Restaurant 14 Morrison Street

Theme: Introduce Information Service Division NHS Scotland and Focus Group

The Chinese Cancer Support Group welcomes all Chinese cancer patients and their families and carers.

If you are interested please contact Carrie (RGN Macmillan Chinese Cancer Link Worker) on 0131 4672996 or 07904 362854 for catering purpose.

There will be no charge and your travelling expense will be reimbursed.
Appendix 4

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**Some Definitions**

**Equality**

Establishing a fairer and more equal society where everyone can participate and be involved. This is the focus of the program.

**Diversity**

Developed to increase the diversity. Create a diverse, equal, and inclusive environment.

**NHS**

National Health Service.

---

**Some Questions**

- How many people have a primary care provider?
- How many people have been referred?
- How many people have seen a specialist?
- How many people think the doctor is easy to understand?
- How much time does it take for a doctor to diagnose?

---

**Think**

Could it be better if...

- Patients have enough information on the choice of care
- Patients are not kept waiting
- Patients are expected to know the need for care
- Patients are expected to have special care and treatment

---

**What are the data items?**

- Use of patient or relatives' personal information for improvement
- Use of personal information in the NHS
- Age
- Gender
- Ethnicity
- Religion/Creed
- Personal information
- Disease or condition
什麼好處？
- 個人：例如能夠提供特別健康服務需要/實行合理的改變給你最好的照顧
- 地區：例如監察服務使用/確保無歧視運作
- 全國：例如描述非洲裔人患糖尿病之通知及影響政策發展

什麼個人資料？
- 種族
- 信仰
- 語言 - 翻譯、手語
- 資訊形式
- 性別 - 性取向
- 活動能力 - 通知
- 性別取向
- 選擇醫療員工性別

收集資料的重要事項
- 你自己衡量和決定
- 要得到同意 - 適當資訊及形式
- 同意資料可與2001戶口統計比較
- 收集一次（多數基層健康服務）及在全 NHS使用 - 保留
- 由受過全面訓練員工收集
- 所有資料用作適合服務

促使成功 - 二個重要
- 介定定義 - 標準
- 收集資料 - 科技
- NHS職員 - 訓練
- 剝奪 - 病人及公眾參與

如何發展這項目？
1. 在NHS機構收集：種族背景、宗教、言語
2. 評核資料系統需要的改變
3. 找出及發展－常規模式收集更多個人資料
4. 苏格蘭行政協會：在九月十五日完成之諮詢
   評價報告
5. 聯系2011戶口統計可接纳問題測試

時限
2009年制定常規收集更多個人資料
你是否愿意回答以下问题？
- 你怎样形容你的种族？
- 你对别人谈论你的宗教或信仰有何感觉？
- 你喜欢哪种语言？
- 你在沟通上需要帮助吗？
- 你喜欢哪种资料形式？
- 你有没有饮食喜好？
- 你在行动上是否需要帮助？
- 你是否对管理人员的性别有特别安排？

討論問題
普通
你给予资料给医疗员工之经验？
怎样能改善给予资料给医疗员工？

討論問題
專門
你对提供更多个人资料有无顾虑？
- 如种族，宗教信仰？

苏格兰NHS需作出什么以鼓励你给予这些资料？

參與？
- 想知多些？
- 你有无兴趣收到这项进度？

联系资讯管理员：
Jean Zeevaart
310 Equality & Diversity Information Programme Manager
City of St.HELEN, Health Scotland
Cliffhouse House
Edinburgh EH3 7JS
Telephone 07937781807
Email jean.zeevaart@asd.gp.scot nhs.net

Web Link to Programme：
www.healthcare.scotland.gov.uk/content/1m339606a_nsp2000.pdf?pagesservicContents exited
### Appendix 5

**Equality and Diversity Information**  
**Group Meetings**  
平等及多樣化資料小組會議

**Working Together To Improve Your Care**  
聯合工作來改善對你的照料

---

<table>
<thead>
<tr>
<th>If you do not want to give any of this information please tick this box</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>如你不願提供任何資料請在此格加記號</td>
<td></td>
</tr>
</tbody>
</table>

---

<table>
<thead>
<tr>
<th>Age</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>年齡</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Gender</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>性別</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Do you consider yourself disabled?</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>你認為你是否殘障？</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Yes/No</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>是/否</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>What is your preferred speaking language?</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>你喜歡說甚麼語言？</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Do you require an interpreter/support with communication?</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>你需要翻譯/溝通上之協助嗎？</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>What is your current religion or spiritual belief?</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>你現時的信仰或靈性上的寄託？</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Please tick ONE ethnic group from the list below that best describes your ethnic background or culture. 從下列表格選出你適當的選項。</th>
<th></th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>White</th>
<th>Asian, Asian Scottish or Asian British</th>
</tr>
</thead>
<tbody>
<tr>
<td>白種人</td>
<td>亞洲、亞洲蘇格蘭或英國亞洲人</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Scottish</th>
<th>Indian</th>
</tr>
</thead>
<tbody>
<tr>
<td>蘇格蘭人</td>
<td>印度</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Other British</th>
<th>Pakistani</th>
</tr>
</thead>
<tbody>
<tr>
<td>其他英籍</td>
<td>巴基斯坦</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Irish</th>
<th>Bangladeshi</th>
</tr>
</thead>
<tbody>
<tr>
<td>爱爾蘭</td>
<td>孟加拉</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Any other White background (please specify)</th>
<th>Mixed Any Mixed background (please specify)</th>
</tr>
</thead>
<tbody>
<tr>
<td>其他白種背景（請註明）</td>
<td>混血或任何其他混血背景（請註明）</td>
</tr>
</tbody>
</table>

---

This is a sample form of the type of information some NHS organisations have already started to collect from their patients.  
此表格是樣本，有些國家健康服務機構已開始使用這表格收集病人資料。
Appendix 6

Joan Jamieson
Equality & Information Programme Development

"Making sure everyone shares in health improvement"

Outline of Tonight's Programme

- Introductions
- What is Information Services Division (ISD)?
- Basic Involvement Questions
- Overview of Equality & Diversity information Programme
- Discussion
- Opportunity to complete an anonymised Equality and Diversity Personal Data Form
Information Services Division (ISD)

A national organisation
Part of NHSScotland
Supporting the collection of health information - pre-cradle to the grave
Providing health statistics, information technology & related services for NHSScotland

Some Questions
How many registered with a Doctor?
How many attended your Doctor at some point?
How many had a referral to hospital?
How many find describing symptoms easy to a doctor?
How much time does a Doctor have to assess what is wrong with you?
Questions for Discussion

General

What has been your experience of giving information to healthcare staff?

What would make giving information to healthcare staff better?

Some Definitions 1

Ethnicity/Ethnic Group

Refers to a common group identity based on language, culture, religion or other social characteristics. This means that people define their own ethnicity, that everyone (and not just those in minorities) has ethnicity and that a person’s ethnic identity may change over time.

Equality in health - making sure everyone has appropriate access to healthcare.

Diversity in healthcare - creating culture and practices that recognise, respect, value difference of patients and staff.
Some Definitions 2

The Disability Discrimination Act (DDA) – a health condition or disability that has lasted, or is expected to last, 12 months or more, which makes it difficult for you to do day-to-day activities?

- Long-term illness (for example, cancer, diabetes, HIV, heart disease)
- Physical disability (for example, you use a wheelchair, or you have difficulty using your arms or hands)
- Sensory disability (for example, you are registered blind or deaf)
- Mental health condition (for example, depression or schizophrenia)
- Learning disability (for example, Down’s syndrome)

What is this Information Programme about?
- The NHS in Scotland treating people fairly (legal/policy)
- Collecting & personal/social/cultural information from patients/carers to improve services - patient centred
- Everyone benefiting from NHS services irrespective of:
  - Age
  - Gender
  - Race
  - Religion/faith belief
  - Sexual orientation
  - Disability or sensory impairment
### NHS Lanarkshire: Health Survey 2003: Summary Example

![Image](http://www.scotland.gov.uk/Resource/Doc/0019737/0019737.pdf)

<table>
<thead>
<tr>
<th></th>
<th>Very good/good</th>
<th>Fair</th>
<th>Bad/very bad</th>
<th>Long-standing illness</th>
<th>Acute sickness</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Men</strong></td>
<td>67%</td>
<td>22%</td>
<td>11%</td>
<td>51%</td>
<td>18%</td>
</tr>
<tr>
<td><strong>Women</strong></td>
<td>65%</td>
<td>23%</td>
<td>12%</td>
<td>49%</td>
<td>20%</td>
</tr>
</tbody>
</table>

- **Weekly drinking**
  - men: 30% (over 21 units)
  - women: 21% (over 14 units)

- **Diagnosed diabetes**
  - men: 4%
  - women: 3.5%

- **Untreated Blood pressure**
  - men: 18.2%
  - women: 16.8%

---

### Ethnic Minority Population 2001

<table>
<thead>
<tr>
<th>Census 2001 Health Board</th>
<th>ALL PEOPLE</th>
<th>White</th>
<th>Indian</th>
<th>Pakistan and other</th>
<th>South Asian</th>
<th>Chinese</th>
<th>Other</th>
<th>Ethnic Minority</th>
</tr>
</thead>
<tbody>
<tr>
<td>Argyll &amp; Bute</td>
<td>153,091</td>
<td>40,249</td>
<td>779</td>
<td>368</td>
<td>329</td>
<td>400</td>
<td>15</td>
<td>0.9%</td>
</tr>
<tr>
<td>Ayrshire &amp; Arran</td>
<td>168,139</td>
<td>39,506</td>
<td>488</td>
<td>405</td>
<td>367</td>
<td>379</td>
<td>98</td>
<td>0.6%</td>
</tr>
<tr>
<td>Borders</td>
<td>104,764</td>
<td>30,819</td>
<td>73</td>
<td>185</td>
<td>134</td>
<td>230</td>
<td>16</td>
<td>1.0%</td>
</tr>
<tr>
<td>Dumfries &amp; Galloway</td>
<td>101,785</td>
<td>28,078</td>
<td>96</td>
<td>143</td>
<td>114</td>
<td>265</td>
<td>12</td>
<td>1.2%</td>
</tr>
<tr>
<td>Fife</td>
<td>158,062</td>
<td>34,905</td>
<td>514</td>
<td>1470</td>
<td>750</td>
<td>193</td>
<td>0</td>
<td>1.2%</td>
</tr>
<tr>
<td>Forth Valley</td>
<td>128,153</td>
<td>30,300</td>
<td>344</td>
<td>1386</td>
<td>455</td>
<td>1095</td>
<td>104</td>
<td>1.1%</td>
</tr>
<tr>
<td>G organisms</td>
<td>152,936</td>
<td>36,790</td>
<td>2217</td>
<td>1851</td>
<td>3607</td>
<td>4395</td>
<td>825</td>
<td>1.6%</td>
</tr>
<tr>
<td>Greater Glasgow</td>
<td>151,150</td>
<td>37,783</td>
<td>5264</td>
<td>2067</td>
<td>4512</td>
<td>7150</td>
<td>994</td>
<td>4.5%</td>
</tr>
<tr>
<td>Highland</td>
<td>169,914</td>
<td>36,024</td>
<td>268</td>
<td>271</td>
<td>674</td>
<td>1900</td>
<td>19</td>
<td>0.8%</td>
</tr>
<tr>
<td>Lanarkshire</td>
<td>150,017</td>
<td>36,600</td>
<td>311</td>
<td>2376</td>
<td>3202</td>
<td>1090</td>
<td>120</td>
<td>1.1%</td>
</tr>
<tr>
<td>Lothian</td>
<td>176,387</td>
<td>43,756</td>
<td>2743</td>
<td>7994</td>
<td>3874</td>
<td>8064</td>
<td>404</td>
<td>2.3%</td>
</tr>
<tr>
<td>Strathclyde</td>
<td>192,195</td>
<td>36,092</td>
<td>17</td>
<td>37</td>
<td>45</td>
<td>96</td>
<td>104</td>
<td>0.4%</td>
</tr>
<tr>
<td>Tayside</td>
<td>255,968</td>
<td>51,796</td>
<td>19</td>
<td>59</td>
<td>37</td>
<td>127</td>
<td>102</td>
<td>1.6%</td>
</tr>
<tr>
<td>Western Isles</td>
<td>265,021</td>
<td>52,301</td>
<td>17</td>
<td>92</td>
<td>39</td>
<td>89</td>
<td>84</td>
<td>0.4%</td>
</tr>
</tbody>
</table>
Patient Focus Public Involvement
Providing More Personal Information to the NHS

Age and Ethnicity (Census 2001)

- 96.02% of all ethnic minority communities are aged under 30 compared with 36.3% of the White community
- 6.75% of all ethnic minority communities are aged over 60 compared with 21.33% of the White community
- The “youngest” communities are Bangladeshi, Pakistani and other South Asians where 31.2% are aged 15 or younger

What do we know - Religion (Census 2001)

<table>
<thead>
<tr>
<th>Religion</th>
<th>Number in population</th>
<th>% of population</th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
<td>887,221</td>
<td>17.56%</td>
</tr>
<tr>
<td>Church of Scotland</td>
<td>2,392,801</td>
<td>47.30%</td>
</tr>
<tr>
<td>Roman Catholic</td>
<td>155,593</td>
<td>17.06%</td>
</tr>
<tr>
<td>Other Christian</td>
<td>424,221</td>
<td>8.40%</td>
</tr>
<tr>
<td>Buddhist</td>
<td>4,704</td>
<td>0.10%</td>
</tr>
<tr>
<td>Hindu</td>
<td>6,921</td>
<td>0.10%</td>
</tr>
<tr>
<td>Jewish</td>
<td>7,448</td>
<td>0.10%</td>
</tr>
<tr>
<td>Muslim</td>
<td>422,764</td>
<td>0.85%</td>
</tr>
<tr>
<td>Sikh</td>
<td>6,921</td>
<td>0.10%</td>
</tr>
<tr>
<td>Another religion</td>
<td>8,447</td>
<td>0.20%</td>
</tr>
<tr>
<td>Not answered</td>
<td>422,862</td>
<td>8.30%</td>
</tr>
<tr>
<td>All persons</td>
<td>5,062,211</td>
<td>99.50%</td>
</tr>
</tbody>
</table>
**Disability**

**Visual Impairment**

number of registered blind and partially sighted people in Scotland now stands at 38,366, according to statistics.

People with learning disabilities and mental health are more likely to have a major illness, develop a serious health condition younger and dies sooner than rest of the population.

"The acid test of a national service is not whether it works for those who are generally health, but whether it benefits those with the greatest risk".

(Bert Massie, DRC)

---

**Heart of the Problem**

Overall huge GAPS in the routine data collection on equality and diversity within the NHS:

- Equality & Diversity information not generally collected in GP systems (Diabetes maybe)
- Scottish Morbidity Data is a hospital data form (SMR01) ethnic group recorded is 9.2%

Without meaningful information ......................

We fail to recognise equality, diversity and cultural issues - patients, services and staff are all disadvantaged & powerless.
What are the benefits?

- Individual e.g. meeting specific health care needs/implementing reasonable adjustments for your best care

- Local e.g. monitoring uptake of services/ ensuring non discriminatory practice/planning local services

- National e.g. describing diabetes by ethnic group and disability to inform & influence policy development, describing the preferred format to receive health information.

Important points about collecting information

- Based on self-definition - something you decide

- Collected with informed consent - appropriate information in appropriate formats

- Agreed information that can be compared with e.g. Census 2001

- Collected once (probably in primary care) and appropriately shared across the NHS - confidential

- Collected by fully trained staff

- All information needed for appropriate care
How willing are you to answer these questions?

- How would you describe your ethnic background?
- Would you like to speak to an appropriate person about your faith/illness/life circumstances?
- What is your preferred speaking language?
- Do you require communication support?
- What format would you like to receive information?
- Have you cultural dietary preferences?
- Are there mobility access/personal care we can help with?
- What gender preference of health care practitioner?

Questions for Discussion

Specific

What are the concerns you have in giving more personal information like - ethnic group, religion/belief?

What would NHSScotland need to put in place that would encourage you to give this information?
Appendix 7

Equality and Diversity Information Programme

It would be helpful if you would self complete this form and place in the “BOX” provided.
If you would like assistance in completing this form, please ask.

What is your age? ............... 

What is your gender?
- Male
- Female
- Other - please specify ............. 

Do you consider yourself disabled?
- Yes
- No

If Yes, is there anything we can help you with? (e.g. wheelchair access, transport)

What is your preferred speaking language? ................................................................. 

Do you require an interpreter/assistance with communication?
- Yes
- No

If Yes what type of assistance? (e.g. induction loop, Braille, information in large print, interpreter, advocacy)

What is your current religion/Denomination/Faith group? ............................................ 

Do you have dietary preference? (Halal, Kosher, Vegan)
- Yes
- No

If Yes, please state preference ................................................................. 

Do you have a preference of the Gender of healthcare staff?
- Yes
- No

If Yes, please state preference ................................................................. 

Please turn page over
What is your ethnic group?

Choose ONE section from A to E and then tick the appropriate box to indicate your cultural background:

A White
- Scottish
- Other British
- Irish
- Any other White background please write below

B Mixed
- Any mixed background, please write below

C Asian, Asian Scottish or Asian British
- Indian
- Pakistani
- Bangladeshi
- Chinese
- Any other Asian background please write in below

D Black, Black Scottish or Black British
- Caribbean
- African
- Any other background, please write in below

E Other ethnic background
- Any other background, please write in below

- If you do not want to give any of this information please tick this box.

Working Together To Improve Your Care
For further information contact:
Joan Jamieson
Equality and Diversity Information Programme Manager
Information Services Division (ISD)
Cirrus House
Marchburn Drive
Glasgow Airport Business Park
Abbotsinch, Paisley PA3 2SJ
Tel no: 0141 282 2250
Web pages: www.isdscotland.org/equalityanddiversity
Ethnic Monitoring Toolkit: www.isdscotland.org/ethnicmonitoringtoolkit