Good information for a better service?
A consultation with people with learning disabilities about disclosing personal information

A report by the Scottish Consortium for Learning Disability in collaboration with the Equality and Diversity Information Programme

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- Hear Here
- Speak Up Advocacy
- PAMIS, Glasgow
- South Lanarkshire Carers
- Voice for All

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**Executive Summary**

The Scottish Consortium for Learning Disability (SCLD) and the Equality and Diversity Information Programme (EDIP) of National Services Scotland (NSS) worked in partnership to consult with people with learning disabilities and family carers about their willingness to disclose personal information. People were asked about their present experiences of giving information to, and receiving information from, the NHS. They were also asked about their willingness to disclose further personal information in the future. They were also asked to suggest how, where and when this information should best be collected.

Five groups in different geographical locations across the central belt of Scotland were consulted. Material that was used when consulting with other groups was translated into easy read format. A similar methodology was used which had two main parts to the approach: written material sent out in advance, explaining the purpose of the consultation, and describing the information that was being requested; and secondly the event itself, with two or three facilitators and groups with between four and 15 participants.

After a presentation to explain the work of EDIP and the purpose of the consultation, participants were encouraged to discuss their experiences of the NHS, with particular regard to the sharing of information.

The participants raised a number of other concerns, including:

- The difficulty some medical professionals have in communicating with people with learning disabilities.
- The lack of awareness of many participants about what is available to help e.g. double appointment times.
- Having to give the same information to different people at different times.
- The particular difficulty of being in hospital rather than seeing their GP. This is a new and different environment that can be upsetting, and because they are communicating with doctors and nurses that have not met them before.
- The additional difficulties that people with complex support needs have, particularly if they have no or little speech.
- The attitude of some health professionals towards carers who try to pass on information about the patient when the patient has no speech.

Participants were then asked how willing they would be to disclose more personal information about their:

- Gender preference in relation to health care staff.
- Language preference
- Requirements for an interpreter/help with communication
- Religion/faith/spiritual needs
- Format to receive information
● Cultural dietary preferences
● Mobility access (walking/dressing/transport)
● Sexual orientation
● Ethnicity

Most participants stated that they were happy to disclose the information requested as long as they understood the purpose of gathering it, and saw that it would benefit them and people they knew. They were generally happy to disclose information, provided that it would be used and would help with their care.

Most of the information requested was not problematic. The exceptions were the questions about religion and sexual orientation. There were also some issues with the questions about diet.

After this discussion, participants were asked to complete a questionnaire in easy read format, asking for some of this personal information. Participants provided most of this information. However, some opted not to answer some specific questions. Again, these were most commonly the questions about religion and sexual orientation.

A number of issues arose out of this exercise:

● There was a strong feeling that this information should be collected only once, and in a private place; there was no consensus about who should collect it, although the GP’s surgery seemed acceptable to most.
● There was scepticism about the usefulness of collecting this information. This was based on the experience that some people had had of the way the NHS makes use of the information they already possess. There were a number of examples of people’s information being lost, misplaced or misused.
● Most people needed one to one support to complete the form. This support included explaining some of the terms, and also to write the answers.

The exercise raised questions about the best way of getting information from people with learning disabilities in an ethical and effective manner. Although all the written material used in this consultation was in easy read format, many people still found the process difficult to follow. In a situation where someone does not fully understand the question being asked, it is particularly important to ensure that the answers they give are their own. This highlights the importance of skilled, individual support being available at the point when this information is being collected for use by the NHS.

It also suggests that in future consultations that the NHS holds with people with learning disabilities, where the information being discussed is complex, a different process should be used. Individual interviews should be considered as an alternative to group consultations. Where this is not possible, groups should be kept small and will be more effective if the people in the group already know and feel comfortable with each other.
Recommendations

If the NHS is going to collect information to improve the quality of its service to groups with particular requirements, then the process of collecting the information must itself meet those requirements. To this end we recommend that:

1. Where possible, information should be collected by someone who is known to and trusted by the person concerned. This might be a GP or a nurse, or someone with another role.
2. This person should receive training in communication skills: they must have the skills to communicate with people who have a wide range of communication requirements.
3. In addition, everyone should be free to choose to have individual support from an advocate, friend, carer or support worker to complete information forms.
4. All written information used in the process of information gathering should be available in an easy to understand format.
5. Other formats should be available to people who do not read at all.
6. Translations of easy read formats into community languages should be available on request.
7. A document, in various formats, should be prepared that addresses the reservations people have about this information collection. It should reassure people that the information will be held securely, and explain how it will make a difference.

In the light of concerns raised about certain items of information that are going to be requested, specifically about sexuality and religion, the NHS should:

8. Review whether the benefits to the service will justify the anxiety and concern some people will experience.
9. Produce guidance notes for the information collectors, explaining the direct benefits to patients of disclosing sensitive information.

The NHS already has some measures available to improve communication between doctors and patients e.g. the possibility of providing double appointments. These are not effectively publicised or promoted, and many people remain unaware of their existence. We recommend that:

10. The NHS should promote and publicise the availability of these provisions in a number of ways so that those patients who would benefit most from them, find out about them.

Participants described not being able to read the information that is sent out to people’s homes from the NHS e.g. hospital appointments, and described the difficulties that arose from not being able to understand this information. We recommend that the NHS should:

11. Consult with people with learning disabilities to find out how accessible they find information sent to their homes.
12. Provide alternative ways of sending the same information to people who find letters inaccessible
13. Publicise and promote these alternative forms of information, targeting people who might find these alternative forms most useful.
Introduction

In the project we wanted to discover the willingness of people with learning disabilities and their family carers to disclose information about themselves to the NHS, which would help the NHS ensure that people with learning disabilities have the same access to health services and the same quality of service as other people.

This initiative was part of a larger equalities initiative of the Equality and Diversity Information Programme (EDIP) in which a number of groups from different minority communities were asked about disclosing similar information.

EDIP commissioned the Scottish Consortium for Learning Disability (SCLD) to take this part of the work forward and to provide advice and support on how best to involve people with learning disabilities.

Aims

The aims of the project were:

1. To learn about experiences that people with learning disabilities have in accessing healthcare;
2. To discover how willing people with learning disabilities would be to disclose personal information that could be used to improve health services for them; and,
3. To understand the best conditions under which the information should be collected.

Methodology

Five groups were asked to take part in the project. Two of these groups were self-advocacy groups for people with learning disabilities. These were well-established groups that met regularly and were supported and facilitated by members of staff. Two were carers groups. Of these, one was a group who met regularly and knew each other well.

The other carers’ group consisted of a number of parents of people with complex needs, supported by one organisation that brought these parents together for this event. Most of these parents knew each other but the group itself was not one that met regularly. The fifth group consisted of young people with learning disabilities, their parents and siblings. These individuals and their families were supported by a community organisation that coordinated this event, and invited these people to come together as a group for a single, one-off event.

Two of these groups were based in Glasgow, one in Paisley, one in Falkirk and one in East Kilbride. Some of the groups asked that they should not be identified in the report. Consequently, in the section of this report that discusses each group’s responses, the groups are simply named as “Group 1”, “Group 2” etc.
The methodology for these meetings followed closely that of previous EDIP consultations. Participants were sent information in advance that explained the purpose of this project, the work of EDIP, and the specific questions that people would be asked at the event. SCLD translated pre-existing materials to ensure that these were accessible to people and easy to understand. In addition, SCLD had some of this easy read material translated into two community languages and recorded onto CD.

The meetings were facilitated jointly by EDIP and SCLD. In line with SCLD’s way of working, one of the facilitators was a consultant with a learning disability. The programmes for the meetings were as follows:

1. **Welcome and introductions**, to explain the purpose of the day and some of the key ideas and language used e.g. “equality”, “diversity.”

2. **Presentation**, Describing the Equality and Diversity Information Programme and its work. The presentation described areas of equality work e.g. sexuality equality, which some of the participants might be unfamiliar with, or uncomfortable about. It also described why the NHS wants to gather this information, emphasised that everybody would be asked for the same information (not just people with learning disabilities), and explained how the information could help the NHS deliver a better service for everybody.

3. **Discussion**, about which items of information, if any, people would be happy to disclose. This part of the programme gave participants the opportunity to say what they thought about being asked for this information.

4. **Form filling**, Participants practise completing a form similar to the one the NHS might ask people to fill in. This gives people the opportunity to experience how it feels to commit this information to paper.

5. **Discussion**, of the above exercise, how easy or hard it was to complete the forms, and about what would make it as easy and as comfortable as possible to give this information.

6. **Recording**, As well as note-taking, a graphic artist recorded the main points of the meeting visually. These graphic notes have been included in the report alongside the written notes for each group.

Graphic recording is a useful and strongly visual way of recording a meeting. It gives participants immediate feedback, and can also be used as a reminder later on of what has been said. For further information about graphic recording, please see Appendix 9.

As with the pre-event material, all the material used on the day, including the PowerPoint presentation and the Information Form, were translated into easy read. These materials are all available in Appendices 1 - 9.
Group 1 ~ Summary of meeting

This was a long-standing group that meets regularly. Eight people with learning disabilities attended this meeting.

After an introductory presentation, participants were asked about their experiences of the NHS to date.

How many of you have been to your doctor this year?

All eight participants replied “Yes” to this question.

Have you been in hospital this year?

Seven out of eight participants had been in hospital at some point in the past. For some it had been a long time since they had last been to hospital and for others it was a more recent experience.

Do you find it easy telling your doctor what is wrong with you?

Three answered “Yes”, five answered “No”. Those who answered yes could do so on their own, the others felt that they often or sometimes needed help with this. Help was usually from a supporter or family member.

How much time do you think the doctor has with you?

There was a range of opinion for this question. One person thought 15 minutes, six thought about five minutes. One person thought a doctor would spend “as long as it takes”. This person explained that she had a very good relationship with her doctor and felt that the doctor takes an interest in her personally.
**What sort of things does the doctor ask you about?**

This question evoked various responses: “How are you?” “He asked about my sore stomach.” (This was the complaint the person had gone with rather than an existing condition.) “I go there for the ‘flu injection and I get lots of tablets.”

Some participants (3) had received help from their doctor to stop smoking. One person had joined a smokers’ group via their GP and had also had patches. This had helped them to stop. Others had been given patches and tablets but had not been given the chance to join a group. They said they would have liked to join a group but didn’t know they could. Both said they would have asked if they had known.

Most people felt that their doctor only talks to them about the condition that they are there with. Most people said that their GP rarely or never asks about them and how they are doing more generally.

One person reported having a very good relationship with their GP who has been helping them to sort out a problem at work and had been acting as an advocate on their behalf in the matter.

The main point made by the group was that it is not always easy to talk to the doctor, and the doctor does not often make this easier. As one participant summed it up: “If you have a disability, you need extra time.”

**How many people take a carer with them to the doctor?**

Seven out of eight said that they would take a carer. Of these, most could manage without a carer if they had to, but preferred to go with a carer to make it easier.

Some needed support only to get there whilst others needed support with communication.

**Does the doctor spend more time talking to you than to your carer?**

One person rarely or never takes a carer with them.

Most people felt quite strongly that their doctor or other health professionals often talk directly to their carer and not to them.
What would make going to the doctor better?

The group felt quite strongly that the main problem faced in going to the doctors was how doctors communicated with them. This poor communication included the language the doctors used i.e. hard to understand, and the fact that they usually talked to the carer instead of them. It also included their lack of listening skills, and the lack of time to explain their symptoms. Comments included the following: “[They need to]… change their attitude a wee bit. Some of the doctors are a bit funny with me. They don’t speak to me well.” “Got to listen.”

There followed a discussion about the new information that the NHS was looking to collect. Participants were asked what information they would be prepared to disclose, and gave the following responses:

Would you give the answer to: What is your ethnic group?

Six would answer; two said they would not. Their reasons seemed to be that this was a stigmatising label that could lead to discrimination: “Don’t believe in that. People should see me.”

Would you give the answer to: What is your religion?

Four participants said they would not be happy to give this information. Again, people were quite sensitive about this question and seemed concerned that this information could be used to discriminate against them:

“I don’t mind telling them that (my ethnic group), but when it comes to my religion I don’t like telling folk.”

Would you give the answer to: What is your preferred speaking language?
Do you need help to talk? Do you need help to read?

Everybody said they would be prepared to give this information. There was a lot of discussion about communication support. Everybody was happy to say whether they required help to talk and read. Participants felt that the most important things here were about accessible information, help to read and knowing a person’s preferred language. The group felt that this would help people to understand each other and could see value in this.
Would you give the answer to: Do you need letters from a doctor in a different way?

Everyone replied “yes” to this question. Most people felt that tape would be more useful to them. There was a lot of discussion about people missing appointments because they could not read the letters. The group were aware that the NHS can translate things but thought that doctors and receptionists might not know that people needed this.

Would you give the answer to: Do you have a special diet?

Although no one in the group had special dietary needs they all agreed that this would be helpful for hospitals to know.

Would you give the answer to: Do you need help to get to the doctor/nurse/clinic?

Yes, as everyone thought that they might need some kind of help to get to an appointment.

Would you give the answer to: Do you prefer to see a man or woman doctor?

All eight participants replied “Yes” to this question. For some it didn’t matter for routine appointments whether they saw a man or woman but it would for some types of appointment. Some people said it would depend on the clinic. Where a preference was expressed it was often a preference for a particular doctor rather than a specific gender:

“Yes, I want to see Dr …. all the time.”

“I don’t like Dr …. I have seen him but I don’t like him.”

After this discussion, participants were asked to complete a written questionnaire asking for the same information. There followed a discussion about this activity.
Discussion following the group filling in the forms

What worries you about giving these answers?

“Cause people use it against you.” This person was worried that giving some of the information might lead to them being treated more unfairly.

“I want people to see just me.” There was a concern that the information being asked for was private. This person wanted to be seen as a person first.

Two people made comments that revealed a concern that the information being asked for would not be utilised. There was a cost to giving this information, because it was personal, and that cost would be justified if it led to better services for people, but only if that was indeed the end result: “I would give all information, anything that is needed, but some of it is private.” “I'm not worried but if I have to give it I will give it, but not if I can avoid it.”

Another person was worried that information he gave would not be kept securely: “Someone might steal your name.”

What would make it easier for you to give this information?

The main point that members of the group made here was that they still did not fully understand how this information would lead to better services: “I would tell them if I knew why”.

The group as a whole agreed that it was important to understand why information was being asked for and how it would be used: “What does it matter if you are Catholic or Protestant?”

Who should ask these questions?

The group said it should be a doctor or nurse. They didn’t think that it would ever be appropriate for a receptionist to ask for this information, even in a private room. One person was adamant that it should not be a nurse, as nurses (in this person’s eyes) were not as good now as they used to be: “They don’t seem to care.”

Where should you be asked?

The group very clearly stated that the information must be collected in a private room in the hospital or GP surgery. Privacy was a key issue for the group and none would be happy to give any of the information in a setting that was not private. The group agreed that privacy was more important to them than who was asking.

When should you be asked?

The unanimous view was that this should happen when you first go to hospital or visit your GP. The group didn’t think it would be appropriate for the questions to be asked by a practice nurse, only the GP
Issues about information

A central issue was that of information collection. Only 2 out of 8 participants could fill out the forms on their own. All the others needed some degree of help. This highlights the important question of how this information is to be collected in practice.

At the end of the event there remained general concerns about why the information being asked for was needed and how it would be used. Some people still felt that this would be intrusive, despite being given a full explanation as to why the NHS wanted to collect equality and diversity information. There seemed to be particular sensitivity around: religion, sexual orientation and ethnicity. These questions seemed to be particularly personal. It was also hard for the group to understand how this information in particular could help improve services across the board.

Explanations given to the group in the presentation and in answers to the questions did not convince the group that this information collection might be necessary. There is an issue about how this argument is made to people with a learning disability.

It emerged in the discussion that some people had been told or had thought that they could not see their health records. People were also concerned that getting access did not mean much because they could not understand the jargon in the records. It was explained that doctors are supposed to try and write in plain English as much as possible but concerns remained. Although they knew about disability equality legislation, the group did not seem to know that there was a duty on the NHS to make their records accessible to them when requested. There were questions asked about what type of information might be withheld from a patient and under what circumstances.

Other issues

The group reported that having a learning disability liaison nurse in their area now had made a big difference. They felt it was important to have specialists in their area. The benefit was that this was someone who understood the communication requirements of people with learning disabilities. It was a vital role – there was a problem of information not always being passed on. The liaison nurse had that specific remit.

There were a lot of positive comments about the service people were getting from the NHS. One person said: “I wouldn’t be here today without my doctors and nurses. They have been very good to me.”
Group 2 ~ Summary of meeting

This was a long-standing group that meets regularly. Eight people with learning disabilities attended this meeting.

After an introductory presentation, participants were asked about their experiences of the NHS to date.

**How many of you have attended the doctor in the last year?**

All eight participants had seen their doctor in the last year.

**How many of you have been in hospital?**

Five out of eight had attended hospital.

**Do you find it easy to talk to the doctor?**

After a short discussion, people agreed that it was not always easy to talk to the doctor. One thing that made this difficult was the length of appointments: “Yes and no, you're in and out so fast”

**How much time do you have with the doctor?**

When asked how long they spent with their GP, everyone said less than seven minutes. The common view was that this was not always enough time to have a satisfactory consultation. Nobody knew they could ask for a double appointment.

**What does the doctor ask about?**

There were a variety of answers to this question. Some people described a good relationship with their doctor, and a good approach, which meant treating people warmly: “Some talk about different subjects to get us relaxed”. For others, the doctor only asked about their symptoms: “Have you got any pains?”
How many go with a carer/support worker?

Everyone said they went with a support worker or family member.

Does the doctor talk to you? Does the doctor talk to your carer?

All eight participants answered “Yes” to both these questions. From the discussion it became clear that the doctor talked more to the carer/support worker than to the patient, and that people would prefer that the doctor spoke directly to them more often.

What would make it better for you?

“It’s hard to make an appointment”. People described how difficult it was to get through, and how long they often had to wait before the phone was answered. A different system, that did not take so much time, and was not so stressful, would make it easier. The second thing that people identified was written information coming to them in a more accessible format: “I was sent a letter through the door, but a lot of it wasn’t applicable to me”.

A number of people agreed that it was not easy to read the written information that came to them from their GP or hospital. It was not always the case that there was someone on hand to help them read it, or act on the information.

There followed a presentation on the new information that the NHS would be looking to collect. The group was then asked how willing they would be to answer the following questions:

Would you give the answer to: What is your ethnic group?

A number of people in the group seemed unsure what this term meant, even after an explanation. One understood it in this way: “Your background is different to mine”.

After some discussion, six said they would give this information, one said “No” and one said “Maybe”.

Good information for a better service?

Would you give the answer to: What is your religion?

This was a much more controversial question. Some people thought their religion was a label by which they might be stigmatised and discriminated against:
“I’d be concerned they are prejudiced”.
“I’d want to know the reason why!”
“I wouldn’t tell the doctor that, I’d just tell him I’m ill”.
Some people were happy to give this information as they could see that it would be important for the NHS to know patients’ religion in some situations:
“I’m a Catholic, some like the last rites”.
“Why would they want to know? Maybe if you’re a Jehovah’s Witness”.
But others could not see why the NHS would need to know this information about most people in most circumstances:
“Why do you need to know?”
Only one person said they would be happy to give this information; six said they would not; one said “Maybe”.

Would you give the answer to: What is your preferred speaking language?

This was a hard question for people to understand. However, one of the group used Makaton and this helped the others understand the importance of health professionals knowing how patients preferred to communicate:
“Some people like Makaton. You’d need people to sign”.
“If the doctor couldn’t sign it would leave him confused, and [the respondent] upset”.
All eight participants agreed they would give this information.

Would you give the answer to: Do you need help to talk?

Everyone replied “Yes” to this question.

Would you give the answer to: Do you need help to read?

Five replied “Yes”; three replied “No”.
Would you give the answer to: Do you need letters from the doctor in a different way?

Everybody agreed that they did not find the present communication helpful i.e. standard letters only. Some people preferred the spoken word, some preferred both written and spoken. Six people said they would prefer bigger print. Some people said they would like a phone call, others had a preference for taped version of the letter. A number of people did not want to go without the written information, however: “A letter reminds you what the doctor said”.

Would you give the answer to: Do you have special food?

This was a confusing question for people. A preference for certain foods was understandable, but the idea of certain foods being preferred, or forbidden, because of their culture, was difficult for people to understand. All eight participants replied “No”. However, the understanding of the facilitators was that people were not saying whether they would give this information: rather they were saying that they themselves did not have any cultural dietary preferences.

Would you give the answer to: Do you need help to get to the doctor’s?

Seven replied “Yes” to this question; one replied “No”. Again the facilitators felt that the participants were actually saying whether they needed help to get to the doctor’s, rather than whether they would disclose this information.

Would you give the answer to: Do you prefer to see a male or female doctor?

Four had a preference for a male doctor, three for a female doctor. One person was uncertain. This split over people’s individual preferences did not follow the gender of the participant. For some people, this was the gender of their current doctor whom they liked: “It depends on what’s wrong. I’d prefer a man (i.e. same gender) if it’s personal.”

After this general discussion, participants were asked to complete the form that contained these questions. All eight participants required individual support to read and understand the questions, and to write down the answers. Afterwards, there was a discussion about completing the form.
What worries you about giving these answers?

There were two major worries identified by the group. One concern was that some of these questions were personal, and that they would feel uncomfortable having to answer them:
“I would be embarrassed”.
“Anxious”.
“It’s not anyone’s business”.
The other was that people were not convinced that having this information would help the NHS to deliver a better service:
“I would want to know why they’re asking”.
“Isn’t this information already on file?”

What would help?

“Writing it down”. The person who said this meant that it would help if there was someone who could help write it down.
“Pictures”. This comment referred to the fact that words alone were hard to understand, and pictures could be helpful to aid understanding.

Who should ask the questions?

The group felt that the doctor or nurse should ask these questions. People were aware of the demands on doctors’ time, and there was a discussion about the suitability of the receptionist. Everyone felt it would be all right for the receptionist to ask certain questions such as your age, but not the more personal ones.

Where should this happen?

Everyone agreed that this should take place in private, preferably in the doctor’s room:
“It’s supposed to be in there”.

Good information for a better service?
Issues about information

Lack of clear information was causing people problems and leading to a less satisfactory service from the NHS. Although many of the group reported having a doctor who they got on well with, they did not get clear information from them during appointments because the doctor spoke more to their support worker/carer than to them, and sometimes did not speak in language they could understand. In addition, they had not been given information about double appointments, an option that they felt would improve appointments for them.

Standard written information e.g. letters from the GP practice or hospital was, in many cases, not accessible. People felt disadvantaged by this.

It was not clear to the group how all of this additional information that they were being consulted on would help. The question about religion was felt to be particularly sensitive.

Asking people to complete a written form was problematic. Everyone in this group required individual support to complete it. This form had been translated into easy read format, but this was not sufficient. This raises the issue of how the NHS will collect this information from people, and what support there will be for people to do this.

There was an issue about the methodology of this consultation. All the written material had been translated into easy read format. SCLD were involved in facilitating the events. Yet still the facilitators felt that the group discussions were particularly difficult. Some of the concepts involved in this subject were not easy to explain clearly, and a group discussion was not conducive to helping everyone to understand what they were being asked. In particular, one part of the discussion involved hypothetical questions of the form: “Would you be happy to answer the following question (by an abstract third party at an unspecified point in the future)…” As a result, participants sometimes found themselves answering a different question to the one being asked.
Group 3 ~ Summary of meeting

Six people attended this meeting. Three were parents of people with high and complex support needs. Two were support workers for people with high and complex support needs. One was a paid supporter for family carers. All were female.

After an introductory presentation, participants were asked about their experiences of the NHS to date from a carers perspective. One carer left the meeting early therefore the number for results is five.

How many of you have attended the doctor in the last year?

Five replied that they had.

How many of you have been in hospital?

Four replied that they had.

Do you find it easy to talk to the doctor?

Many participants thought this was not easy, at least it was not easy to have a reciprocal conversation. Carer 6 said: “It is easy to talk but not to feel listened to”.

Some parents felt undervalued or patronised. Carer 5 said: “My GP hasn’t been in the house for 7 years and when he came, he said ‘this is a nice big house’, but my key concern is my son not being well!”

The feeling was expressed that doctors are not good at working with people with high support needs. There was a further feeling that their place as carers was not valued. Carer 3 said: “if you take a 3 year old to the doctor the doctor would listen to what you have to say but when you go with a person with learning disabilities - seems to shut down and all you get is a ‘mmmm’”.

A consistent experience for all was that of their knowledge and experience of the disabled person they cared for being unvalued. They felt that this knowledge should have been highly valued by health professionals, both because the person’s health needs were complex, and because the person in most cases had no speech, and the doctors found it difficult to get accurate information directly from the patient.

One parent had worked out a coping strategy for this response for the doctor. Carer 5 said: “I sit down in front of the computer, write copious notes to give to the doctor & go prepared to doctor/hospital staff. I think it might be easier for doctor to read than listen to me ‘rattle on’. Then the notes can be stored with his record”.

One parent was quite desperate that her knowledge of her son was not being recognised, and the information she has about what treatments work best was being ignored (Carer 5). Her message was simply: “Please listen!”
How much time do you have with the doctor?

Two people in the group were aware that double appointments could be requested, and had taken advantage of this opportunity (Carer 1 and carer 4). Carer 1 felt that how much time you got could vary: “It depends on how acute it is - you possibly get time but if it is to do with ongoing issues you’re in and out”. Carers 4 & 5 had a more positive experience: “... as long as it takes”. Carer 3 said the doctors create a need for longer time by their behaviour. She gave the example of one man who became agitated at the sight of paper, becoming very excited when he sat down beside the doctor’s desk which was covered in paper. Another doctor, in contrast, had prepared for the appointment by moving all the papers away to the far end of the desk, and the result was a shorter, calmer consultation.

What does the GP ask about?

There was a varied response to this. Carer 1 was quite positive: “My GP is quite jocular and talks to my son”. No-one else said their experience was consistently positive: “He doesn’t ask how the person is” (Carer 2) “He talks to the carer ” (Carer 3) “It’s different from the time when you go on your own - it is depersonalized” (Carer 5) “He may ask how is J but not to J” (Carer 4) Carer 4 had a mixed experience of her son’s doctor: “He gives good eye contact, and takes blood easily - this was usually a problem in the past with the previous GP”, as did Carer 5: “it is good when the doctor at least acknowledge them - he doesn’t always do it.” Carer 1 summed up the feelings of the group when she said: “Doctors need help when coping with complex needs”
What would make it better?

This question evoked a wide range of responses. The main point the group wanted to make was that the doctor should see a human being when they see their relatives, and show warmth and empathy. Carer 5 put it like this: “a young doctor more ages with E who is interested in learning disability is what is required”, whereas Carer 6 said: “they should see the person first then the disability”. She referred to this as the Medical Model of care versus the Social Model. Carer 1 described it as: “definite interest and care quality” For Carer 5 what would make it better was a better medical knowledge: “a doctor knowledgeable about the condition (skin condition). He was given cream not once but twice inappropriately.” Carer 3 said that she always felt that meetings went better when she took a note of the meeting or recorded it on tape because she found she always forgot the details afterwards. Carer 2 said that less jargon was a necessity: “…like ‘phlebotomist’ or ‘neurosurgical’” Carer 5 had had a recent experience of her son going into hospital and becoming seriously ill for a number of reasons, many of which were because information about the patient was not managed well. His notes were lost as he was moved from one ward to another, information was not passed from nurses on one shift to nurses on the next, and so on. This person had very little confidence that giving the NHS more information would result in a better service for her son. Although she was quite clear that this bad treatment was not discriminatory, in the sense of not receiving poor treatment, she thought her son was receiving poor treatment because the staff saw him as less deserving of their time or care. She also pointed out that another patient in the ward, who was there because of a condition caused by long-term alcohol abuse, had a far higher level of staff input than her son, particularly when there was any sort of challenging incident. She did not know why this should be the case. What would have made that experience better was more care and respect for the information that the health service already held on her son, and systems of moving that information about that worked.

A discussion followed about what additional information participants would be willing to disclose to the NHS.

Would you give the answer to: What is your ethnic group?

Yes 5
No 0
Good information for a better service?

Would you give the answer to: What is your religion?

| Yes | 4 |
| No  | 1 |

Would you give the answer to: What is your preferred speaking language?

| Yes | 4 |
| No  | 1 |

In relation to the remaining questions shown below, all five participants answered for themselves, with respect to the people they cared for, that they would be willing to provide answers.

- Do you need help to talk?
- Do you need help to read?
- Do you have special food?
- Do you need help to get to the doctor’s?
- Do you need letters from the doctor in a different way?

The group could see why having this extra information could help them and their relatives. They had reservations about whether this information would make a difference in practice because of the way the NHS uses the information it has at present.

When asked where and how this information should be collected, Carer 1 answered: “As long as it’s collected just once!”
Group 4 ~ Summary of meeting

This was a long-standing group of family carers that meets regularly. Thirteen carers attended this meeting. At a certain point, two members of the group had to leave.

After an introductory presentation, participants were asked about their personal experiences of the NHS to date.

**How many people have been to the doctor this year?**

Seven of the group replied “Yes”; four replied “No”

**How many of you have been in hospital?**

Six replied that they had been in hospital; five that they had not.

**Do you find it easy telling the doctor what is wrong with you?**

Three participants said they did find it easy; however, eight replied that they found it difficult.

**How much time do you think the doctor has with you?**

Most people thought seven or eight minutes. Only 5 people knew they could ask for a double appointment.

All thirteen participants had caring responsibilities for a relative, most commonly an adult son or daughter. They were now asked about their relative’s experiences of the NHS, and about their own experiences as carers.

**How many of your relatives go to the doctor on their own?**

All these participants were family carers. That is why this question was phrased the way it was. Ten out of eleven replied that they go with their relative to the doctor’s. Only one person went to the doctor’s on his own.
Does the doctor spend more time talking to your relative (i.e. the patient) or to the carer?

Most thought that their relatives were treated unfairly, in that medical staff did not speak to them directly much but rather to the carer.

The reason for this, they thought was that medical staff were not confident in communicating to people with a learning disability. This was more the case in hospitals than GP surgeries.

Paradoxically, many carers also felt that the medical staff did not listen to them (the carers) either, or value the knowledge they had of their relatives’ medical conditions.

Two carers told of very poor experiences of dentists which had harmful outcomes. In one the dentist did not listen to information from the family about the person’s preferred method of anaesthesia. In another, the dentist did not give the family crucial information about possible after effects of surgery.

Two other carers reported that their dentists were overly-keen to remove their relatives’ teeth, but also reluctant to provide them with false teeth. They felt very strongly that this was discriminatory practice.

After the presentation giving the rationale for requesting this additional information, participants were asked what information they would be happy to give.

The response to the remaining questions are shown in the table below.

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>What is your ethnic group?</td>
<td>10</td>
<td>0</td>
</tr>
<tr>
<td>What is your religion?</td>
<td>9</td>
<td>1</td>
</tr>
<tr>
<td>What is your sexual orientation?</td>
<td>9</td>
<td>1</td>
</tr>
<tr>
<td>What is your preferred speaking language?</td>
<td>10</td>
<td>0</td>
</tr>
<tr>
<td>Do you need assistance with communication?</td>
<td>10</td>
<td>0</td>
</tr>
<tr>
<td>Do you have a health problem/disability?</td>
<td>10</td>
<td>0</td>
</tr>
<tr>
<td>What is your age?</td>
<td>10</td>
<td>0</td>
</tr>
<tr>
<td>What is your gender?</td>
<td>10</td>
<td>0</td>
</tr>
<tr>
<td>Do you have a preference of the gender of healthcare staff?</td>
<td>10</td>
<td>0</td>
</tr>
</tbody>
</table>

In general, this group was willing to disclose most of the information requested in the form. Only one person preferred not to answer the question about their religion, and one other person preferred not to disclose their sexual orientation. However, there was also a lot of questioning of the process.
These were comments made in the discussion following this exercise:
“What are they going to do with this information anyway?”
“There could be a stigma depending on the information given, like mental health problem or sexual orientation.”
“I wouldn’t want more people to know than necessary.”
“Once it’s into the database, who’s going to know about it?”
“People keep promising ‘No-one will know’, but organisations sell information to each other.”
“What benefit is it going to be to us? We’ve given so much in the past – we’d like reciprocity.”

What would make it easier to give this information?

The following factors would make people more willing to give this information:
● Clarity about the process.
● Explanations.
● Guarantees about future confidentiality, “Goalposts must not get moved.”

Who should ask the questions?

The group thought an independent person should be employed to do it. Not an ordinary administrative worker, but someone trained in interviewing skills and experienced in working with people with learning disabilities. The group did not want doctors or nurses to be the ones collecting this information.

Where should you be asked?

The one unanimous point was that this should happen in private, and certainly not in a waiting room.

When should you be asked?

The group thought the best time was before going into hospital.
Who should be asked these questions, the carer or the relative with learning disability?

The predominant view was that the carer should give the information on behalf of their relative. One person said “It’s a waste of time asking our relatives, people will give the answer they think you want.” Another person said “If you ask the relatives you need to prepare them first, you need to put them at their ease.”
Group 5 ~ Summary of meeting

This was an ad hoc group brought together for this consultation. The composition of this group was 11 adults and 4 children. The group was a mix of family members (parents and siblings) and individuals with learning disabilities. The group members were all from South Asian backgrounds. The group had an informal atmosphere. Various participants arrived after the meeting had started, and some had to leave before the end.

The initial discussion at the event was about people’s experiences of the health service to date. Both adults and children answered the first two questions.

**How many people have been to your doctor this year?**

The yes replies were: 8 adults and 1 child. Three people said they had not been. Three did not reply.

**Have you ever been in hospital?**

4 replied “Yes”. 7 replied “No”. Four did not reply to this question.

The remaining questions were answered either by the young people with learning disabilities themselves, or by the parents of the younger children.

**Do you find it easy telling your doctor what is wrong with you?**

5 people answered “Yes”. 5 answered “No”.

Most people reported some difficulty with this. There were two main reasons for this: one was having a doctor who didn’t speak their first language: “Less Asian doctors make it hard.”

Some participants found it difficult to understand doctors who only spoke English. In contrast, people were pleased to have a doctor who could speak their first language: “My doctor speaks Urdu.” This was very helpful for a number of participants who felt that doctors who spoke their first language were able to help them understand better even in English.
**How much time do you think the doctor has with you?**

There were a variety of responses to this. 2 people said they could spend 20 minutes with the doctor. One person said 30 minutes. However, most people said the doctor only gave them 5 minutes.

One person said appointments varied both in length and in quality according to the mood of the doctor:

“Sometimes my doctor is not in a good mood and it’s like he doesn’t listen to me.”

Some people felt that the doctor does not listen to, or believe them, when they say they are ill. Most were not aware they could ask for translation services or longer appointment times.

**What sort of things does the doctor ask you about?**

Some doctors were caring and sensitive. They would start by asking “What is wrong?” or “Can I help?”

“It’s the same questions all the time.” This person felt the doctor only wanted to give them medication and focussed on this.

One person felt that doctors needed support to help patients understand what they were saying. A key issue was around support for different languages.

“You get less information about what is going on there. How can he [the doctor] respond to all the different disabilities…. Things like sign language too….Doctors can’t learn everything, it’s difficult for them [to meet all possible needs].”

**How many people take a carer with them to the doctor?**

Three people said they take someone with them when they go. Two carers said they go with their relative.

**Does the doctor spend more time talking to your carer than to you?**

2 people said this was the case:

“Sometimes he talks to me instead of my son if he doesn’t understand what he [son] is saying. Sometimes it is as if he is not even there. I do try to let him do the talking but if it is not working then the doctor talks to me.”

One parent felt that her doctor sometimes acts as though her son doesn’t have any feelings. She felt that her son was hurt and embarrassed when the doctor talked to her as if her son wasn’t there. She felt that the doctor would never intentionally hurt or embarrass her son but that he was clearly insensitive on this occasion.

“We have three GPs and two make the effort to talk directly.”

“When I go on my own the doctor speaks to me but when I go with my mum he speaks to her.”
“My doctor spoke to my mum more when I was younger…. It depends on which doctor I get.”
“When I go with …. [teenage child] they ask me first and then they ask him the same questions.”
There was a general feeling amongst some that they were treated unfairly by their doctor but they didn’t know why. One parent waited a long time to see the doctor who she felt just asked a lot of questions but did not want to examine her son. This parent felt that the doctor was too quick to write prescriptions for medication without properly examining her son and finding out details. When asked if she questions this, the parent replied: “I asked because he was a Pakistani doctor.” The parent felt comfortable asking because of the shared language and background, but the doctor said that the details didn’t matter and to come back in two months. Another parent had similar experiences with a different doctor. She said the first two times she had taken her son to the doctor he had just given antibiotics but didn’t explain why.

Somebody else talked about his negative experience of seeing his GP:
“I have a fear of doctors. Me and …. we waited 40 minutes to an hour for the doctor. No one was there and we waited another 30 minutes. This was just to give my payslip in for incapacity benefit.”
This man had made an appointment. Another agreed that doctor’s timekeeping was a concern:
“It takes ages and ages.” This person always goes on time to appointments but still routinely has to wait for a long time without explanation.

What would make going to the doctor better?

“Doctors keeping appointment times.”
“If I could get my speech therapy.” This comment came from a young man who had been on the waiting list for 8 months.

One young man had had some speech therapy but needed more, and had been put back on the waiting list for an appointment. He had waited several months without word.
Another person had had a better experience of speech therapy:
“I had speech problems when I was younger but I went to St Thomas Aquinas and the speech unit there helped me to improve and speak clearly.”

Several people felt that locally things are okay. GPs tend to know their needs but when other services e.g. hospitals are involved it becomes difficult. This is usually because the hospital are not informed of language support needs etc.

The discussion moved on to whether people felt okay about giving more information. One person said:
“If the information is used by the NHS and only the NHS then it’s fair enough.”
Good information for a better service?

The response to the remaining questions are shown in the table below.

<table>
<thead>
<tr>
<th>Question</th>
<th>Would you give answers to:</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>What is your ethnic group?</td>
<td></td>
<td>8</td>
<td>3</td>
</tr>
<tr>
<td>What is your religion?</td>
<td></td>
<td>7</td>
<td>4</td>
</tr>
<tr>
<td>What is your preferred speaking language?</td>
<td></td>
<td>11</td>
<td>0</td>
</tr>
<tr>
<td>Do you need help to talk? (Communication needs)</td>
<td></td>
<td>11</td>
<td>0</td>
</tr>
<tr>
<td>Do you need help to read?</td>
<td></td>
<td>11</td>
<td>0</td>
</tr>
<tr>
<td>Do you need letters from the doctor in a different way?</td>
<td></td>
<td>11</td>
<td>0</td>
</tr>
<tr>
<td>Do you have a special diet?</td>
<td></td>
<td>11</td>
<td>0</td>
</tr>
<tr>
<td>Do you prefer to see a man or woman doctor? (same gender)</td>
<td></td>
<td>9</td>
<td>2</td>
</tr>
</tbody>
</table>

Discussion about the information that was requested in the forms

The group expressed a number of concerns about what information they were being asked to disclose.

Some items in the form caused difficulty due to issues with translation. Some individuals struggled with the concept of different sexualities due to their religious beliefs. One young man was very confused by this and kept saying that he had been told in the Mosque that men and women get married. He could not understand that anything else was possible and was quite distressed by this. People asking these questions will have to be very aware of this and be extremely sensitive to religious and cultural sensitivities around sexual orientation. Others understood the concept of different sexual orientations but felt it was an extremely intrusive question because certain answers were morally loaded.

Another area where people had significant difficulty was around the area of cultural and dietary needs and preferences. For most their diet is so integral to their lives that they don’t view it as exceptional. People asking this question will also need to be aware of this and explain using examples or asking direct questions such as: “Do you need halal/kosher food?”
Discussion following the group filling in the forms

“It was difficult because my son doesn’t really fall into any of these categories.” (Type of disability)

The doctor and patient should work together to get the best information. It should be whoever had known the person the longest.

People needed time to think about their answers and sometimes time to talk about it.

People felt that it was probably best to be asked in a GP surgery as most people had a GP

It was suggested that information should be checked annually as some things might change.

A number of people have had problems when information has not been properly updated, e.g. people had missed appointments at hospital due to their records not being updated with change of address details etc. They felt this was bad because they did not get the correct care and support and because it wasted time at hospitals.
Completing the questionnaire

This section deals with the questionnaires that participants were asked to complete at the event. After completing these forms participants were asked what they had felt about doing this activity, and what concerns they would have about being asked by the NHS for this information in the same way.

Forty participants from the five events completed a form. The total response for each question varies and highlights the need for good support for many participants when required to complete forms. The tables below show the collated results.

<table>
<thead>
<tr>
<th>What is your age?</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Under 20</td>
<td>3</td>
</tr>
<tr>
<td>21-34</td>
<td>3</td>
</tr>
<tr>
<td>35-49</td>
<td>12</td>
</tr>
<tr>
<td>50-64</td>
<td>5</td>
</tr>
<tr>
<td>Over 65</td>
<td>11</td>
</tr>
<tr>
<td>Preferred not to answer</td>
<td>3</td>
</tr>
<tr>
<td>Don’t know</td>
<td>2</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>What is your gender?</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>14</td>
</tr>
<tr>
<td>Female</td>
<td>26</td>
</tr>
<tr>
<td>Prefer not to answer</td>
<td>0</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Do you have a preference of the gender of healthcare staff?</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>14</td>
</tr>
<tr>
<td>Female</td>
<td>12</td>
</tr>
<tr>
<td>No</td>
<td>15</td>
</tr>
<tr>
<td>Prefer not to answer</td>
<td>0</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Do you have a health problem 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?</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>28</td>
</tr>
<tr>
<td>No</td>
<td>11</td>
</tr>
</tbody>
</table>
If yes, please tick as many of the following, which apply to you.

<table>
<thead>
<tr>
<th>Condition</th>
<th>Ticks</th>
</tr>
</thead>
<tbody>
<tr>
<td>Long-term illness (for example, cancer, diabetes, HIV, Heart disease)</td>
<td>10</td>
</tr>
<tr>
<td>Physical disability (for example you use a wheelchair or you have difficulty using your arms or hands)</td>
<td>8</td>
</tr>
<tr>
<td>Sensory disability (for example, you are registered blind or deaf)</td>
<td>2</td>
</tr>
<tr>
<td>Mental health condition (for example, depression or schizophrenia)</td>
<td>3</td>
</tr>
<tr>
<td>Learning disability (for example, Down’s syndrome)</td>
<td>18</td>
</tr>
<tr>
<td>Other</td>
<td>6</td>
</tr>
<tr>
<td>Prefer not to answer</td>
<td>0</td>
</tr>
</tbody>
</table>

Is there anything we can help you with?

- “Getting blood taken”
- “Making appointments”
- “Bus/Wheelchair”
- "Yes, need help"
- “Speech therapy”
- “Help to get to the doctor”

What language do you speak?

<table>
<thead>
<tr>
<th>Language</th>
<th>Ticks</th>
</tr>
</thead>
<tbody>
<tr>
<td>English</td>
<td>26</td>
</tr>
<tr>
<td>Scottish</td>
<td>5</td>
</tr>
<tr>
<td>Urdu</td>
<td>1</td>
</tr>
<tr>
<td>Punjabi</td>
<td>1</td>
</tr>
<tr>
<td>Urdu + English</td>
<td>3</td>
</tr>
<tr>
<td>Mirpur</td>
<td>1</td>
</tr>
<tr>
<td>Can’t Remember</td>
<td>1</td>
</tr>
</tbody>
</table>

Do you need an interpreter/assistance with communication?

<table>
<thead>
<tr>
<th>Needs Assistance</th>
<th>Ticks</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>15</td>
</tr>
<tr>
<td>No</td>
<td>24</td>
</tr>
<tr>
<td>Prefer not to answer</td>
<td>1</td>
</tr>
</tbody>
</table>

If yes, what type of assistance (for example, induction loop, Braille, information in large print, interpreter, advocacy)

<table>
<thead>
<tr>
<th>Assistance Type</th>
<th>Ticks</th>
</tr>
</thead>
<tbody>
<tr>
<td>Staff</td>
<td>6</td>
</tr>
<tr>
<td>Pictures</td>
<td>2</td>
</tr>
<tr>
<td>Large Print</td>
<td>1</td>
</tr>
<tr>
<td>Advocacy</td>
<td>3</td>
</tr>
<tr>
<td>Help Writing</td>
<td>2</td>
</tr>
<tr>
<td>Interpreter</td>
<td>1</td>
</tr>
</tbody>
</table>
### What is your current religion?

<table>
<thead>
<tr>
<th>Religion</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Protestant</td>
<td>9</td>
</tr>
<tr>
<td>Roman Catholic</td>
<td>7</td>
</tr>
<tr>
<td>Christian</td>
<td>1</td>
</tr>
<tr>
<td>Muslim</td>
<td>9</td>
</tr>
<tr>
<td>Pakistani</td>
<td>1</td>
</tr>
<tr>
<td>None</td>
<td>8</td>
</tr>
<tr>
<td>Preferred not to answer</td>
<td>4</td>
</tr>
</tbody>
</table>

### Do you have a cultural dietary preference (for example, Halal, Kosher, Vegan)?

<table>
<thead>
<tr>
<th>Preference</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>13</td>
</tr>
<tr>
<td>No</td>
<td>24</td>
</tr>
<tr>
<td>Prefer not to answer</td>
<td>0</td>
</tr>
</tbody>
</table>

**If Yes, please state preference**

<table>
<thead>
<tr>
<th>Preference</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Halal</td>
<td>1</td>
</tr>
<tr>
<td>Vegan</td>
<td>1</td>
</tr>
<tr>
<td>Irn Bru</td>
<td>1</td>
</tr>
</tbody>
</table>

### What is your sexual orientation?

<table>
<thead>
<tr>
<th>Orientation</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bisexual</td>
<td></td>
</tr>
<tr>
<td>Gay man</td>
<td></td>
</tr>
<tr>
<td>Lesbian / Gay woman</td>
<td>1</td>
</tr>
<tr>
<td>Heterosexual (straight)</td>
<td>21</td>
</tr>
<tr>
<td>Not applicable e.g. child</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>4</td>
</tr>
<tr>
<td>Prefer not to answer</td>
<td>9</td>
</tr>
<tr>
<td>Did not understand questions</td>
<td>2</td>
</tr>
</tbody>
</table>

**If other, please tell us:**

- “Be happy”
- “I don’t go out with boys, I go out with girls sometimes” (female)
- “Not interested”

### What is your ethnic group?

<table>
<thead>
<tr>
<th>Ethnic Group</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Scottish</td>
<td>26</td>
</tr>
<tr>
<td>Other British</td>
<td>4</td>
</tr>
<tr>
<td>Irish</td>
<td>1</td>
</tr>
<tr>
<td>Pakistani</td>
<td>9</td>
</tr>
<tr>
<td>Prefer not to answer</td>
<td>2</td>
</tr>
</tbody>
</table>
The following points emerged from this exercise:

1. It is very important to retain the response “Prefer not to answer”. A number of participants used this response at certain questions, in particular the question about religion and the question about sexual orientation. Knowing that they were allowed not to answer particular questions reduced the anxiety of going through this exercise.

2. This form had been translated into an easy to understand format, but there was still a lot of misunderstanding about the information being required of people. For example, two people wrote that they did not understand what Question 9 meant (about sexual orientation), even though there were supporters on hand to explain this individually. Some unexpected answers, for example to Questions 7, 8 and 9 (see appendix 1) suggest that not everybody fully understood the questions they were being asked.

3. The majority of people with learning disabilities needed individual support to complete this form. This took the form of reading and explaining the meaning of questions, helping people to decide on the answer they wished to give, and helping them to write the answers. This opportunity for people to be influenced in how they reply is obvious, and the need for competent and trustworthy support to be available to people is equally clear. Without individual support most people with learning disabilities would not have been able to complete the form at all.

4. Many participants identified for themselves what assistance with communication they would require (Question 6). The range of assistance included staff, advocacy, help with writing, interpreters, bigger print, and pictures to complement the writing. It is important that these requirements should be in place when this information is being collected by the NHS.
Conclusion

Current experience of health services

Many participants reported an unsatisfactory service, which they perceived as being discriminatory on the grounds of their or their relative’s learning disability. One example of this was appointment times: some of the participants reported that the time they had with their GP was not long enough because they took longer to explain what was wrong, or to understand what the GP was saying. But more importantly, many people did not know that they could ask for a double appointment and had never been given that information.

Communication was another area of concern. Some people felt that their doctor did not take the time to listen to them but instead would listen to the carer. Ironically carers themselves also felt that they were not listened to on occasion.

How willing would people be to disclose information?

In general there was a willingness to give personal information to the NHS but there were significant reservations. One was scepticism about the use to which this information would be put. The biggest reason for this scepticism was the way the information that the NHS already possess is ignored, not shared, not acted upon, or lost. In every group there were stories to tell of patients’ files not being to hand, or not being updated, of the wrong medication being prescribed or of some other misuse of patient information. In one group a mother told the story of how her son came to significant harm because his file was lost as he was moved from one ward to another within the hospital, and because of this crucial information was not passed on from one shift of ward nurses to the next. In the face of these stories, the question of whether the NHS would make effective use of more information seems a reasonable one.

A second reservation was a concern that the NHS would not keep this information confidential. There seemed to be an acceptance that information should be appropriately shared between health professionals, but people were worried it would be passed on to other agencies. This concern seems to stem from a general experience of organisations passing on their personal information to others for commercial reasons, and a lack of confidence that the NHS would be able to put the checks in place to make sure that could not happen.

In addition there was some reluctance to answer some specific questions. A number of participants were concerned that they would be stigmatised by their religion, their sexual orientation or their ethnicity. As well as being concerned that they might be stigmatised by this information, people could not easily see the benefits of the NHS having it. This was in contrast to information about dietary preferences, for example, where everyone could see the importance of NHS knowing this, and everyone was happy to disclose it. However not all were confident that information about diet would be acted upon.
Issues in consulting people with learning disabilities

It is clear that the process of collecting personal information from people with learning disabilities would have to be accessible to the people giving the information i.e. they would have to understand what they are being asked for and why, and be able to respond with the right information. The process of facilitating these groups has highlighted some important issues in this regard.

1. It is important that the purpose can be clearly explained to people. Despite the fact that all material had been translated into easy read, many participants still did not understand by the end of the sessions the purpose of collecting this information. Participants stated that it would be easier for them to give the required information if someone explained clearly what it would be used for.

2. It is important that people understand what information they are being asked to give. Some parts of some of the questions such as “cultural dietary preferences” and “transgender” were hard to understand not just because of the language but because they referred to a cultural context far removed from that of the participants. A lot of time and careful explanations were required to bring people to the point where they would answer “Yes” or “No” to some questions. This last point was also true for participants from certain ethnic backgrounds. Even with the support given we cannot be confident that all the responses were valid.

The question of making the information accessible is a key one. It is not always enough to translate information into easy read format for people with learning disabilities. There should also be further support to help people understand.

Where someone with a learning disability does not have English as a first language, there is a particular problem. We realise that there is a growing availability of translators. There is also a growing recognition of the need for easy read formats; however there was no availability of a resource allocation for translating easy read formats into community languages. What this means is that some people who are the most marginalised and isolated are not given the support they need to participate fully in this process.

Thought must also be given to how people supply the information. Many of the participants who had a learning disability required one to one support to complete the information form. It cannot be assumed at the time of collecting this information that people will be able to complete the form independently, even if they can read it.
**What would make it easier to give the information?**

There was broad agreement across the five groups on this question. Knowing why the information was being requested was the most important factor. Being given a guarantee of its safekeeping would also help give people the confidence they need. People were clear that this information should only be asked for once, although they also wanted it to be updated regularly, perhaps annually, in order to ensure its accuracy.

The main disagreement was about who should collect the information, and where. Most thought doctors or nurses should collect it, one group on the other hand explicitly thought it should not be doctors or nurses; but an independent person. All agreed; however that it should be someone who had the skills and experience to work with people with learning disabilities to gather their information. Most people thought that the local GP’s surgery or health centre was the best place for this to happen, not least because most people went there at some point, but one group felt it should happen before someone went into hospital.
Appendices

Appendix Number

1. Invitation letter
2. Pre event information sheet
3. Glossary
4. Consultation event programme
5. Participant information form
6. Presentation (accessible version)
7. Questionnaire
8. Post event information sheet
9. Information on graphic recording
Appendix 1 – Invitation Letter

Dear NAME,

We, (Scottish Consortium for Learning Disability), are doing some work with the NHS (National Health Service). They want to talk to people with learning disabilities. I would like to invite members of your organisation to be involved.

The NHS wants their patients to have good healthcare. They need to know about patients needs to make sure their service meets them. This means they need to ask patients for information about their lives. The NHS knows that some people will not want to answer some of these questions.

A part of the NHS called EDIP (it stands for Equality and Diversity Information Programme) has asked us to work with them. They want to ask some people with learning disabilities what they think about giving information about themselves.

Do you think your group would be interested in talking about these things with us? We can come to where you normally meet, and we are happy to come to one of your regular meetings or have a special meeting just for this discussion. We would like to come and have this meeting sometime in August 2007.

Please let me know if your group is happy to meet with us. My contact details are:

andy.m@scld.co.uk

0141 418 5420
The information we need from you is:

- Where you would like us to meet with you
- How many people will be attending from your organisation
- What date in August and time you would like to meet with us
- Who we should contact with more information
- If there is anything we can do to make taking part easier for your members (for example getting a translator or providing a vegetarian lunch)

I look forward to hearing from you.

Yours sincerely,

Andy Miller
Scottish Consortium for Learning Disability
Appendix 2 – Pre event information sheet

Information Sheet

We have asked you to meet with us to talk about how you feel about the NHS collecting information about people’s lives. At the moment, health information in Scotland does not usually have things about the person’s life. Knowing some information about people’s lives could help the NHS to make sure the services people are receiving are right for them.

In this meeting we will talk about what the Equality and Diversity Information Programme (EDIP) does and how it can help everyone. People who might ask you about your information will be at the meeting too and you will be able to talk to them and ask any questions you have. There are some things we are looking to find out.

We would like to hear about times in the past when you might have given information about yourself to the NHS. Was this a good or a bad experience? How could it have been made better?

We would like to talk about information that might be collected and what you think about this. We are interested in your opinions on these questions; we are not asking you for any personal information.

The information that people could be asked for is:

- How would you describe your ethnic background?
- What language do you speak?
- Do you need help to communicate?
- How would you like to receive information?
- Do you have a special diet?
- Is there access issues that we can help with?
- Do you prefer your health practitioner to be a man or a woman?

We would also like to hear about how you think the NHS should collect this information. We have some questions about this:

- When and where do you think the NHS should collect this kind of information?
- Who should ask you for this kind of information?
- Is there anything that might mean you cannot give the information?
- What does the NHS need to do to help you give the information?
- Who should be able to see this information?

Anything you do tell us will be confidential. This means we are not allowed to tell anyone else unless you say so.
At the end of our research we will be writing a report about what we find out. This report will have all of the information we found out but it will be anonymous. This means that we will not put anyone’s names or personal information into the report. No one will know it is your information or opinions.
Appendix 3 – Glossary

During this piece of work we may have to use some words that are hard to understand. We have tried to explain what many of these words mean. If there are any other words that you are not sure about, please ask us.

**Bisexual** - Someone who is attracted to both men and women.

**Complaints** - The NHS tries hard to look after you but sometimes things go wrong. You can complain to the NHS about things like the care or treatment you get.

**Communication aids** - Some people have problems speaking, hearing, seeing or don’t speak English and might need some help.

The NHS needs to know about special help a person might need so they can make sure that the right help is given.

**Confidentiality** - Is about keeping your information private. Doctors and nurses do need to know things about you that will help them to look after you. A doctor or nurse should not tell people things about you unless they have to so that they can look after you too.

**Consent** - This means that you agree to something happening.

Before a doctor or nurse can examine you, they must ask for your consent. They also need to ask your permission to collect and share information about you.

**Consultation** - Asking for views on policies or services from staff, colleagues, service-users, or the general public. Different circumstances call for different types of consultation. For example, consultation includes meetings, focus groups, reference groups, citizens’ juries, surveys and questionnaires.

**Culture** - When we talk about a person’s culture we mean things like traditions and customs and how they live. Part of this may be about their religion or the country their family originally came from.

**Cultural Diet** - Some people have important traditions or religious beliefs that means they eat special food like all fruit, vegetables or special meat called Halal.

**Diversity** - When we talk about diversity we mean that people are different and have different needs. In health services this means making sure that staff show people respect and value differences in people.

**Disability** - A health condition, illness 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.
Ethnicity/Ethnic Group - Ethnicity is made up of a lot of different things like language, religion and culture. Everyone has an ethnicity and we all have the right to choose how we describe this. An ethnic group is a group of people who share the same features.

Equality - This is about making sure people are treated with the same respect and are valued even though they might have different needs.

Gender - Whether a person is male or female.

Health Records - These are information about your health and any care or treatment you have had. These include things like x-rays or letters your doctor has written about you.

Heterosexual - Someone who is attracted to people of the opposite sex.

Homosexual/Gay - Someone who is attracted to people of the same sex.

Information Technology - Is about computers that are used to store and sometimes share information.

Information Management in the NHS - Is mostly about using information about patients and their services – to make things better, to plan what type of health care is needed and how many staff are needed.

Information Systems - These are used to collect, store, publish different parts of information about health. Your doctor will have one and so do hospitals.

Lesbian/Gay woman - A woman who is attracted to other women.

Monitoring - This is when we collect information to help us to see how well a service is doing.

NHS - The NHS is the National Health Service, this is the organisation that provides health care to people in Scotland.

Sexual Orientation - This is used to describe the different types of sexual attraction. It includes the four most used terms, lesbian, gay, bisexual and heterosexual.

Statistics - These are numbers that will help to tell us about services and what is happening in them.
### Appendix 4 – Consultation event programme

**Equality and Diversity Information Programme (EDIP) Consultation**  
**Venue, DATE**  
10:30 – 2:30

<table>
<thead>
<tr>
<th>Time</th>
<th>Session Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>10:15</td>
<td>Welcome and coffee</td>
</tr>
<tr>
<td>10:30</td>
<td>Introductions</td>
</tr>
<tr>
<td>10:45</td>
<td>Presentation</td>
</tr>
<tr>
<td>11:10</td>
<td>Discussion</td>
</tr>
<tr>
<td>12:15</td>
<td>Lunch</td>
</tr>
</tbody>
</table>

**Introductions**  
We will spend some time introducing ourselves and telling you a bit more about why we have come to talk to you.

**Presentation**  
We will tell you about the Equality and Diversity Information Programme and its work.

**Discussion**  
There are some things that the NHS would like to ask everybody in Scotland so that they can get better care. This is your chance to tell us what you think about these and if you would be happy to tell the NHS this information.
**EDIP Forms**
We will look at the form that the NHS might ask people to fill in. There will be a chance to try filling in the form to see how people feel about this.

**Discussion**
Another chance to talk about the information that the NHS wants to collect and how you feel about it. We will also talk about how easy or hard the forms would be for people.

**Close**
At the end we will tell you about what will happen next. We will give you some information to take away that will remind you about why you came to talk to us.
Appendix 5 - Participant information form

Equality and Diversity Information Programme

Consultation Event

Participant Information Form

Who am I?

I am

☐ a man

☐ a woman

20 years old or younger

☐

between 21 and 34 years old

☐

between 35 and 49 years old

☐

between 50 and 64 years old

☐

65 years or older

☐

Event Information

Event date: _______________________________

Event venue: _______________________________
Appendix 6 – Presentation (accessible version)

Equality & Diversity Information Programme

Joan Jamieson

“Making sure everyone shares in health improvement”

What we will do today

• Say hello
• Tell you about me
• Tell you about my work on Equality & Diversity
• Ask you to talk about some things
• Discussion
• Give you a chance to give some information about yourself
Information Services Division (ISD)

• A national organisation across Scotland
• Part of the National Health Service
• Supports the collection of all our health information from birth and all through our lives

Information Services Division (ISD)

• Provides health information for the Government
• Provides computers and help to the National Health Service
What is this Information Programme about?

- Being more patient centred
- Making sure the NHS in Scotland is treating people fairly
- Everyone benefiting from NHS services no matter their:
  - age
  - gender
  - race
  - religion/faith belief
  - sexual orientation
  - disability or sensory impairment

Heart of the Problem

Information about disability and ethnic groups are generally not collected in GP systems or in hospital systems.

Without meaningful information ……

- we can’t see unfairness
- we can’t see our differences
- we are all disadvantaged & powerless
Important points about collecting information

- Based on something you decide
- Collected with your agreement
- Agreed information that can be compared with e.g. with Census 2001
- Collected once (probably by your GP/Nurse) and shared across the NHS with your agreement
- Confidential
- Collected by fully trained staff
- All information needed for your care - not just medical

What are the benefits?

- **Individual** - meeting specific health care needs and making reasonable changes for your best care
- **Local** – check how many people are using services and make sure no one is being treated unfairly
- **National** - describing diabetes by Pakistani ethnic group to inform and put pressure on policy development
Confidentiality – keeping your information private

The law says that doctors and nurses must keep the things they know about you private.

But they are allowed to tell other doctors or nurses.

For example your GP needs to tell hospital doctors about you if you go into hospital.

Confidentiality – keeping your information private

Sometimes your information is used to help improve the health service.

For example to count the number of cases of diseases or to plan how many staff they need.

Usually things like your name and address would not be passed on when this happens.
Confidentiality – keeping your information private

You have the right to see what they have written about you.

You can say that you do not want other people to be told things about you.

You can complain if you are unhappy with what happens to your personal health information. You can get an advocate or advice service to help you.

---

Ask you to talk about some things

How many of you attended your doctor recently?
Have you been in hospital?

Do you find it easy telling a doctor what is wrong with you?

How much time does a doctor have with you?
**Discussion**

Tell me about the sorts of things your doctor asks about you?

Does the doctor talk to you?

Does the doctor spend more time talking to your carer?

What would make it better for you when going to see the doctor?

---

**Would you give the answer to.......**

How do you describe your ethnic/racial/cultural background?

What is your religion/ what you believe in ?

What is your preferred speaking language?

Do you need help to talk?

Do you need help to read?
Would you give the answer to........

Do you need your letters from the doctors in a different way?

Do you have to have special food?

Do you need help to get to the doctor, nurse, clinic, dentist?

Do you prefer to see a man/woman?

Do you prefer to see someone from a particular ethnic/racial/cultural background?

Talking more

What worries you about giving these answers?

What would make it easier for you to give this information about you?

Who do you think should ask you these questions?

Where do you think you should be asked these questions?

When do you think you should be asked these questions?
Appendix 7 – Questionnaire

Equality and Diversity Information

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.

1. What Focus Group are you attending today?

2. What is your age?

   □ Prefer not to answer

3. What is your gender?

   □ Male
   □ Female
   □ Other
   □ Prefer not to answer

4. Do you have a preference of the gender of healthcare staff?

   □ Male
   □ Female
   □ No
   □ Prefer not to answer
5  Do you have a health problem 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?

☐ Yes

☐ No

If yes, please tick as many of the following, which apply to you.

☐ 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)

☐ Other

☐ Prefer not to answer

Is there anything we can help you with?

__________________________________________

6  What language do you speak?

__________________________________________

Do you need an interpreter/assistance with communication?

☐ Yes

☐ No

☐ Prefer not to answer

If yes, what type of assistance (for example, induction loop, Braille, information in large print, interpreter, advocacy)

__________________________________________
7 What is your current religion?

- - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - -

☐ Prefer not to answer

8 Do you have a cultural dietary preference (for example, Halal, Kosher, Vegan)?

☐ Yes

☐ No

☐ Prefer not to answer

If Yes, please state preference

- - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - -

9 What is your sexual orientation?

☐ Bisexual

☐ Gay man

☐ Lesbian / Gay woman

☐ Heterosexual (straight)

☐ Not applicable e.g. child

☐ Other

☐ Prefer not to answer

If other, please tell us

- - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - -
10  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

______________________________________________________________

☐  Prefer not to answer
Appendix 8 – Post event information sheet

Information Sheet

We asked you to meet with us to talk about how you feel about the NHS collecting information about people’s lives. At the moment, health information in Scotland does not usually have things about the person’s life. Knowing some information about people’s lives could help the NHS to make sure the services people are receiving are right for them.

In this meeting we talked about what the Equality and Diversity Information Programme (EDIP) does and how it can help everyone. People who might ask you about your information were at the meeting too. We hope you were able to talk to them and ask any questions you had.

There were some things we wanted to find out. We asked you to tell us about times in the past when you might have given information about yourself to the NHS.
Was this a good or a bad experience?
How could it have been made better?

We talked about information that might be collected and what you thought about this. We were interested in your opinions on these questions, we were not asking you for any personal information.

The information that people could be asked for is:

- How would you describe your ethnic background?
- What language do you speak?
- Do you need help to communicate?
- How would you like to receive information?
- Do you have a special diet?
- Is there access issues that we can help with?
- Do you prefer your health practitioner to be a man or a woman?

We also asked to hear about how you think the NHS should collect this information. We had some questions about this:

- When and where do you think the NHS should collect this kind of information?
- Who should ask you for this kind of information?
- Is there anything that might mean you cannot give the information?
- What does the NHS need to do to help you give the information?
- Who should be able to see this information?
Everything you told us will be kept confidential. This means we are not allowed to tell anyone else unless you say so.

At the end of our research we will be writing a report about what we find out. This report will have all of the information we found out but it will be anonymous. This means that we will not put anyone's names or personal information into the report. No one will know it is your information or opinions.
Who was at the meeting?

Joan Jamieson who works with the Information Services Division a part of the NHS in Scotland. Joan has a background in nursing and she became interested in ethnicity and health when she worked as a Lead Nurse in Glasgow where there was a large South Asian population with hardly any information about their health.

Idem Lewis who is a Trustee of SCLD representing Key Housing Association on its Board of Trustees. He has lots of experience of speaking up about issues that matter most from the point of view of someone who uses services.

Karen Indoo who is the Data Sharing and Knowledge Manager at SCLD. She has been working with the Consortium since July 2003.

Andy Miller who is the Policy and Practice Development Manager at the Consortium. He has been with SCLD since September 2004.

Vijay Khanna works with the Information Services Division which is a part of the NHS in Scotland. Vijay can speak Punjabi and Urdu and will be at the events to help translate information.
Appendix 9 – Information about Graphic Facilitation

At all of the group meetings graphic facilitation was used to record the key points of the discussion. In graphic facilitation, key ideas and discussion points are drawn to show what is being talked about. This technique allows people to see that they are being listened to and that their input is valued. It is a particularly useful tool where some or all of the group do not read. The graphics can be used during and after the discussion to tell the story of the discussion. Below are some examples of graphics that were drawn during the various events.
For further information contact:

Joan Jamieson
Equality and Diversity Programme Manager
Information Services Division (ISD)
Cirrus House
Marchburn Drive
Glasgow Airport Business Park
Abbotsinch, Paisley PA3 2SJ
0141 282 2250
joan.jamieson@isd.csa.scot.nhs.uk
www.isdscotland.org/equalityanddiversity