Managing NHS waiting lists

A review of new arrangements

Report supplement: Patient and carer focus groups and interviews

Prepared for the Auditor General for Scotland
March 2010

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Part 1: Summary

Background

1. Audit Scotland published its national report, *Managing NHS waiting lists – A review of new arrangements*, on 4 March 2010. The report is available at www.audit-scotland.gov.uk. As part of our review of these new arrangements, we commissioned George Street Research to carry out focus groups with people who could potentially be disadvantaged by the new system. The aim was to provide qualitative information about the views and experiences of people from potentially disadvantaged groups about the new system of managing waiting lists.

2. This supplement accompanies the national report and summarises the main findings from the focus groups and interviews. It is in a further two parts:
   - Summary of the main findings (**Part 2**).
   - Findings (**Part 3**).

Methods

3. The work was conducted with people (or their carers) who were identified as being potentially disadvantaged by the new system and included:
   - people living in remote and rural areas
   - older people, including people with dementia
   - people with learning disabilities
   - people who have visual impairment
   - people who are illiterate
   - those whose first language is not English
   - people who are homeless.

4. Respondents were aged 16 or older and were either currently on, or had within the past six months been on, an NHS waiting list for a new outpatient appointment (at a consultant-led clinic following referral from their GP or dentist) or for an inpatient or day case appointment.

5. Between 9 and 20 September 2009, George Street Research conducted five focus groups, one paired in-depth interview (where two people are interviewed together) and four single face-to-face in-depth interviews. All groups and interviews were conducted within three of the sample board areas for the study: NHS Lothian, NHS Highland and NHS Western Isles. The topic guide used for this is shown in Appendix 1.

6. Appendix 2 shows the profile of the focus groups and in-depth interviews.

Part 2: Summary of main findings

Initial contact with the hospital

7. For most respondents, initial contact with the hospital was relatively straightforward. Almost all had been referred by their GP. After the referral, respondents had been contacted directly by the hospital, either by letter or by telephone and, in some instances, by a combination of both. Very few respondents had been provided with a leaflet explaining waiting times by their GP and there were some requests for more information to be provided at the point of referral.

8. NHS boards have different ways of agreeing appointments with patients. There was general dislike of implied consent, where the hospital writes to the patient offering them an appointment time and date and the respondent has to contact the hospital if it does not suit them. Most respondents would prefer the hospital to send a letter offering an appointment, with a request for the respondent to then contact the hospital to confirm this is acceptable. There was general agreement that the letter should offer a contact telephone number so that respondents can contact the hospital if necessary. In general, there was a preference for this to be a telephone number where the organisation called is charged for the call.

9. In terms of equity of access, there were some concerns expressed by those respondents for whom English is not their first language that many, and in particular older people, were not able to understand information provided. People who are homeless held a view that hospitals are not prepared to spend time chasing up non-attendees and that few understand their perspective. Remoteness was not an issue. Respondents in remote areas felt that they have a service that is equal to, or better, than that offered elsewhere.

Offers

10. Almost all respondents accepted their first offer of a hospital appointment and most felt that the time between referral and offer of an appointment was acceptable. Overall, respondents felt that appointments should be offered 2-4 weeks in advance for cases which are not urgent. This time period allows for work or family commitments to be taken into account.

11. For most, the service offered seemed to be a good compromise between allowing time to organise schedules around an appointment, without having to wait for an appointment for a lengthy period of time. There was also a general assumption that waiting times were related to the urgency of the appointment.

Accessing services

Could not or did not attend

12. Very few respondents were unable to make an appointment they had accepted. The concept of 'two strikes and you're out' was generally accepted by respondents, although anecdotal evidence suggests that, in some instances, hospitals are offering more than two appointments to meet the needs of patients and this degree of flexibility is welcomed.[1] That said, there was a view from some respondents that unavoidable medical or social reasons should be taken into account and if there is a genuine reason for non-attendance, that a hospital should consider offering more than two appointments before returning a patient to their GP. These respondents queried the time and expense to the NHS of returning to the GP and then starting the process again.

13. On the whole, most respondents felt that hospitals treat patients fairly, although many of their comments were based on hypothesis rather than actual experience.

Reviews

14. Only one respondent had been referred back to their GP and felt this was reasonable given his specific circumstances.

Appointments cancelled by the hospital

15. Only four respondents had an appointment cancelled by the hospital and assumed that this was because of a more urgent need elsewhere. However, one respondent who had an appointment cancelled due to staff sickness and holidays was not happy with this situation.

Equity of access

16. In general, access appears to be fair for most groups who might be considered to be disadvantaged in some way. While some issues such as travel times and travel costs were raised, many of these apply to any hospital user.

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[1] The term 'two strikes and you're out' refers to the principle in the guidance from the Scottish Government that patients should be removed from the list if they cannot attend two offers of an appointment.

Written communication

17. There was a general requirement for any written information to be clear, use simple language, be user-friendly and take into account the needs of all patient groups. There were requests for information to be provided on directions to the hospital, how long the stay in hospital might be and so on. Rather than provide this in the letter, most respondents would prefer this to be provided separately as an enclosure with the appointment letter. Suggestions for changes to a sample letter included use of a larger font size, use of simple wording and consideration of whether all the information was necessary.[2]

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[2] This is based on an example letter from NHS Highland and specific examples may not be applicable to letters produced by other NHS boards.

Part 3: Findings

Initial contact with the hospital

18. For most, initial contact was relatively straightforward. Almost all respondents had been referred by their GP and only two had been referred by their dentist. Nobody could recall having been provided with information about waiting times by their GP or dentist, other than to be told that the hospital would contact them in due course. Only a few of the respondents could recall seeing or being provided with a leaflet explaining hospital appointments and waiting times. After the referral, respondents had been contacted directly by the hospital, either by letter or by telephone and, in some instances, by a combination of both letter and telephone.

19. NHS boards have different ways of agreeing appointments with patients. For example, the experience of respondents in the Highland area was that they use implied consent.[3] In Lothian, respondents said they were sent an initial letter with a request to contact the hospital within three weeks to set up an appointment. Another respondent in Highland thought they had been offered an appointment by letter but they had to telephone the hospital to confirm this was acceptable to them. Two respondents in the Western Isles reported receiving a letter saying they were near the top of the queue, with a request to telephone and make an appointment.

20. In most instances, the preference from respondents was for the hospital to send a letter offering an appointment, with a request for the respondent to then contact the hospital to confirm that this was acceptable, rather than an assumption of implied consent. There were many concerns that implied consent did not take account of those who might be on holiday when the letter arrived or non-delivery by the post office for example. There were also some suggestions that a reminder letter should be sent out a week in advance of the appointment. Homeless respondents also stressed that implied consent could be a problem for them as they may not have received the letter if they have moved on from temporary accommodation since referral.

21. There was general agreement that the letter should offer a contact telephone number so that respondents could contact the hospital to cancel or change an appointment, so that

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[3] Implied consent is where the hospital writes to the patient offering them an appointment time and date and the respondent has to contact the hospital if it does not suit them. If the hospital does not hear from the patient then it assumes the patient will attend.

their appointment could be offered to another patient. Views on the provision of a telephone number where the organisation called is charged for the call to confirm the appointment were mixed. For those who regularly use landlines, and for those on low incomes (including homeless respondents), this would be welcomed. However, some of the younger respondents were using mobile telephones as their main means of telecommunication and pointed out that these numbers can be expensive when using a mobile telephone. Their preference was for a landline number at the hospital.

Equity of access

22. There were concerns expressed by those for whom English was not the first language that many, and in particular older people, were not able to understand information provided in a letter or via telephone contact. One respondent said that he and his brother both had to act as interpreters for his elderly parents who spoke very little English. His concern was that if a family member was not available to help with the appointment process when an initial letter arrived, an important appointment could be missed.

> *"People like me who've been living here for a long time would not have a problem with this. But my parents speak hardly any English and they rely on me or my brother to act as interpreters for them. They won't do anything with a letter like this until one of us next sees them and if that's in two or three weeks time, they might have missed an appointment, through no fault of their own. I think this would be a particular issue with many elderly people like them."*

This view was also expressed by another respondent who noted that she helped out with translation services for various local voluntary groups and that older people were particularly vulnerable.

23. One respondent who needed an interpreter noted that when she received an initial letter from the hospital asking for her to make contact, she had to take this letter to her interpreter who then telephoned the hospital and organised the appointment on her behalf. This respondent noted that if she did not have access to an interpreter, she would not have been able to make the appointment. She would have preferred a letter to be sent with an appointment time already organised as this would have saved her having to use her interpreter on two different occasions (once on receipt of the initial letter and then again when she had a second letter confirming the appointment). However, this second letter confirmed that an interpreter would be available to her on the day of her appointment and this was welcomed. There was also a comment that when the services of an interpreter are required, that they should be the same gender as the person for whom they are interpreting.

24. One respondent noted that the letter offering an appointment should also offer a telephone number for a language support helpline as this would be preferable to offering access to a translator service. He noted, *"language is a failing in the system; unless you*

have fully trained staff at the other end of the phone, you end up feeling let down". He also considered references within leaflets to alternative languages to be "*window dressing*" and felt it would be difficult to actually access a translator.

25. Among homeless respondents, contact was not a particular issue for most since they were residents at the hostel for homeless people and letters could be addressed to them there. They are generally able to stay at the hostel for three months. Even in instances where an appointment letter is sent after they have moved on from the hostel, letters are forwarded because *"it's them that's housed you"* and hostel staff will usually know where they have gone.

26. However, this level of service was not universal and one respondent reported an incident when he was staying at a previous shelter and had then left. An appointment for an important scan was sent to the shelter but they returned this to the hospital marked 'return to sender' as he had moved on and the hostel did not know where he was. He then had to wait another six months for a new appointment.

27. There was a general view from the people who were homeless that hospitals are not prepared to spend time chasing up returned letters or non-attendees. In the case of one particular individual, the hospital was aware of his homeless status and contact could have been made via the outreach project for homeless people or his caseworker at the council. His case worker had his mobile phone number so they would have been able to contact him if they had tried this route. There was some debate about whether the case worker would have been able to pass on his mobile number because of data protection, but one respondent suggested that there should be a box on the housing forms asking if it is acceptable to pass on details to the hospital if necessary.

28. There was a perception that this sort of incident happens more to people who are homeless and drug users than other hospital users. There was a strong perception among people who were homeless that the NHS does not care enough about these types of patient to follow things up.

29. Those in remote areas felt that the service offered by the hospital was equal to what they would have been offered in a more central location. One respondent attending a remote group in the Highland region noted that she had waited longer for an appointment in Glasgow than she had in Highland. There was a general view that, if anything, those in remote areas had a better level of service than those in central areas.

In general, respondents were happy with initial contact, although there were requests for more information from the GP at the point of referral and respondents considered this an appropriate opportunity for GPs to hand out waiting time leaflets.

There was a dislike of implied consent and a preference for an initial letter offering an appointment with a request to contact the hospital to confirm the appointment time.

Offers

30. Almost all respondents accepted their first offer of a hospital appointment and most felt that the time between referral by their GP or dentist and offer of an appointment was acceptable. Also, many respondents felt there has been an improvement in appointment waiting times in recent months, although none were aware of the new system of managing waiting lists specifically to attribute this to.

31. Most respondents felt they were offered an appointment within an acceptable time period, although there were mixed views over how quickly respondents felt they should get their first offer of an appointment. For those with work or family commitments, it was felt that they needed time to make arrangements to be able to attend their appointment, and in these instances, it was generally felt that the appointment should be offered a minimum of 2-4 weeks in advance in non-urgent cases.

32. Respondents who had not been able to accept their initial appointment offer were happy with the service they received and felt that the hospital had been flexible in meeting their needs. Most were offered more than one alternative appointment date and time. For example, one respondent whose first language was not English had to contact the hospital to set up an appointment and was not able to accept a short notice appointment because of holiday commitments. However, the hospital made an alternative offer and the respondent felt the hospital were flexible in offering alternatives and in meeting her needs.

33. One respondent who had been on holiday when the offer letter arrived had missed her appointment, although she was able to telephone and set up an alternative appointment with no difficulties.

34. One respondent in a remote area who had been referred by her dentist and who described her need for an appointment as *"semi-urgent"* due to the pain she was in was happy to accept an offer by the hospital to bring her appointment forward by a week.

35. Another respondent whose first language was not English noted that there were about six weeks between seeing the doctor and having the hospital appointment. She felt that this was too long and was very anxious and worried that it could be a serious problem. While waiting, her condition also got worse which made her even more concerned. She went to her doctor once in this time to query the wait for a hospital appointment and was told she would have to wait. She now has to wait another two months before she gets the test results and treatment can start. These two issues combined have increased her anxiety levels and she would have preferred to have been offered an earlier appointment, such as a short-notice appointment if another patient cancelled.

36. At the group with homeless people, respondents emphasised that they have very little money, it can be difficult to get across town to hospital at short notice and that time is needed to plan or find the money for the journey. There were some requests for financial assistance to pay for the cost of travel to and from a hospital and one respondent suggested the hospital could give out bus tokens. One respondent had applied for a community care grant five times but had been refused every time.

In general, respondents were happy with the notice period they were given, they felt that they were treated fairly and some noted improvements in the appointment service in recent months. For most, the service offered seemed to be a good compromise between allowing time to organise schedules around an appointment, without having to wait for an appointment for a lengthy period of time. There was also a general assumption that waiting times were related to the urgency of the appointment.

Could not or did not attend

37. Very few respondents were unable to attend the appointment they had accepted. Most assumed that patients would make every attempt to make an appointment once offered and that only a very small number of patients would be likely to not attend without cancelling the appointment.

38. However, there were concerns about the need for specific circumstances to be taken into account if a patient could not, or did not, attend an appointment. Many concerns centred around the concept of implied consent.

39. Most respondents felt that failure to attend an appointment would be based on a serious reason such as an unavoidable family problem or issue. Most felt that hospitals providing 2-4 weeks notice of an appointment, with a reminder of this appointment, would cover all but unforeseen emergencies.

40. One respondent for whom English was not their first language commented that hospital staff needed to have specific training to give them an understanding of cultural issues and religious events that might impinge on hospital attendance.

41. There was general agreement that individuals without a genuine reason for not attending should have to return to the GP for a further referral. However, most felt that at a local level hospitals offered greater flexibility than the current system requires. For example, one respondent had been unable to attend two appointments but had been offered a third at the same time and this had been accepted.

42. Some respondents queried the need to be returned to a GP after not attending two appointments in instances where reasons for non-attendance were genuine (eg, medical or social reasons such as child care or holidays that had been booked and paid for in advance). It was assumed that it was easier and cheaper for a hospital to provide more than two options for an appointment, rather than a patient having to return to a GP and re-start the process. This was perceived to be more costly in terms of both money and time. One respondent whose first language was not English noted, *"for most people, two strikes and you're out will be okay. The concept is okay so long as it doesn't disadvantage the already disadvantaged such as shift workers".*

43. While most respondents were broadly in agreement with the 'two strikes and you're out' approach, some homeless individuals commented that they had missed appointments because of their chaotic lifestyle. One commented *"they think you're not bothering with your health but you can't help it".* Others commented that missing appointments can result in being *"bumped down the list"* which they thought was unfair.

44. One respondent cited an instance of having missed two appointments to get on a Hepatitis C combination treatment course. He had been *"second from the top"* [of the list] but had been *"wiped off"* the list. He finds it difficult to attend appointments in the morning before he has been able to find drugs but felt that the NHS "*don't understand*" this.

The concept of ‘two strikes and you’re out’ was generally accepted by respondents, although anecdotal evidence suggests that in some instances hospitals are offering more than two appointments to meet the needs of patients and this degree of flexibility is welcomed. However, there was a view from some respondents that unavoidable medical or social reasons should be taken into account and, if a refusal is genuine, that a hospital should consider offering more than two appointments before returning a patient to their GP.

On the whole, most respondents felt that hospitals treat patients fairly, although many of their comments were based on hypothesis rather than actual experience.

Reviews

45. Only one respondent had been referred back to his GP and this was because he had undertaken an alternative treatment that appeared to negate the need to attend the hospital for an appointment. He is currently waiting for a new appointment date with the hospital. He felt that his GP was not forthcoming with information on the process, and that he had to elicit information rather than being offered this, but did feel that his views had been taken into account.

46. One respondent in the Western Isles had been removed form the waiting list but did not know why. He went back to his GP to enquire about this, to be told that the GP did not know why this had happened.

Appointments cancelled by the hospital

47. Only four respondents had an appointment cancelled by the hospital. One respondent in the Highland region had had his appointment cancelled twice, although he felt his appointment was not urgent and that another patient must have had a more urgent need. A patient in the Western Isles had an appointment cancelled by the hospital because of an urgent case that had come in but again was happy with this situation. Another patient in the Western Isles had a cancellation due to the hospital being short staffed because of sickness or holidays. He was not particularly happy with this situation.

48. The fourth respondent had his appointment cancelled when he attended the hospital and was unhappy about this. The letter provided to him prior to the appointment had referred to driving restrictions as a result of the appointment but had not specified anything further. He had assumed that he might be unable to drive for 1-2 hours but in fact this restriction was for four hours and he could not wait at the hospital for four hours after his appointment.

> *"I couldn't hang around for that long at the hospital. I care for my disabled wife and I just couldn't leave her for that long. If they had given me this information in the original letter, I could have arranged for a volunteer to drive me over and then back again. I was annoyed that they had wasted mine and their time and I then had to make another appointment."*
> *(Older person, Lothian)*

49. Other respondents hypothesised that a hospital would only cancel an appointment because of more urgent need elsewhere.

Written communication

50. As noted above, some spontaneous comments were made in relation to letters received from hospitals about appointments. When respondents were prompted with a copy of an appointment letter from NHS Highland, a similar range of comments were made.

51. Homeless respondents said it would be good to have a telephone number where the NHS would be charged for the call, as money to make a telephone call is often a key issue. In the words of one respondent:

> *"They should assume you **haven't** got the letter, not assume you've accepted the appointment if they don't hear from you. You've no excuse if there's a Freephone number".*

52. Respondents at all groups thought it would be useful for hospitals to send a reminder letter about an appointment. For example, many homeless individuals lead chaotic lives and may simply forget an appointment.

53. There were mixed views on the amount of information that should be included in the letter. Some respondents noted that they wanted the letter to be as brief as possible and simply include information on the date and time of the appointment, with a contact telephone number to confirm or rearrange the appointment. They felt that if further information was to be provided, this should be within an accompanying leaflet.

54. However, others asked for more information such as the length of time they might have to spend in hospital, directions on how to get to the hospital, how long the appointment would take and what to expect at the hospital. Those respondents who had not received an accompanying leaflet about hospital waiting times also felt a leaflet explaining the system would be a useful accompaniment to the letter, if not already provided by the GP surgery.

55. One respondent whose first language was not English who needed translator services noted that she had never been offered any translated materials or documents in her own

language. She thought it would be a good idea for materials to be offered in a variety of languages but had never thought to ask for this and it had never been offered.

56. There were some comments that the letter could be more user friendly, particularly for those with literacy problems or learning difficulties. These suggestions included:

- use of a larger font size
- use of simple wording - examples of words that could be simplified included “assumption” and “require”.
- changes to some of the wording used - for example, the terms “specialist” and “specialty” might be confusing to some patients and some respondents suggested consultant or the name of the doctor would be more user friendly
- consideration of whether all the information was necessary, for example, use of the patient’s reference number since this meant nothing to respondents.[4]

> There was a general requirement for any written information to be clear, use simple language, be user-friendly and take into account the needs of all patient groups.
>
> There were requests for information to be provided on directions to the hospital, how long the stay in hospital might be and so on. Rather than provide this in the letter, most respondents would prefer this to be provided separately but as an enclosure with the appointment letter.

Equity of access

57. Some issues in relation to equity of access have been referred to elsewhere in this report. However, there were a few issues raised by respondents because they were either living in remote or rural areas, they were older, their first language was not English or they were homeless.

Residents of remote or rural areas

58. Mostly, those in remote areas felt that they have a service that is equal to, or better, than that offered elsewhere. They also acknowledged that they sometimes have an option as to which hospital to attend. For example, some people in the Highland region attending groups had an option to attend Raigmore Hospital in Inverness or (although not in all

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[4] This is based on an example letter from NHS Highland and specific examples may not be applicable to letters produced by other NHS boards.

cases) a local hospital in Fort William. Two individuals in the Western Isles opted to use Raigmore Hospital rather than the local hospital in Stornoway.

59. One issue on which there was general agreement was the timing of appointments. For example, individuals based outwith Fort William cannot reach Inverness using public transport before late morning and respondents commented that this does not seem to be taken into account when appointments are offered. Even where an individual has access to their own vehicle, an early morning appointment means a very early start and can impact on other family commitments such as getting children off to school.

60. The one way in which some Stornoway-based respondents felt slightly disadvantaged is because of the reliance on specialists to visit the island. Some cited examples of bad weather preventing attendance by the specialist and one respondent noted an instance of turning up for an appointment to find the specialist was not there. However, in general, most preferred to access services locally wherever possible to fit in with working patterns, family lives and so on. One respondent in the Highland region noted that having to travel to Raigmore in Inverness made the appointment more stressful than if they could attend locally.

61. While most respondents preferred to access services locally wherever possible, one respondent chose to use mainland services because of very negative perceptions of the hospital on the island.

62. Overall, most respondents living in remote and rural areas were very positive about their experiences of the NHS and waiting lists. They felt they are offered a good quality of service and some considered that the services they receive may be faster than in larger urban areas such as Glasgow or Edinburgh. Some of the respondents in remote areas were also older people or had learning disabilities, and these additional factors did not impact on views of the service.

63. One respondent in Stornoway noted a bad experience of being referred to the orthodontist in Inverness, travelling there only to find out the X-rays had not been received from her local dentist, and having to leave and go back to the hospital a few weeks later. However, respondents considered that this was an isolated incident rather than a pattern of disadvantage.

Homeless people

64. Homeless respondents noted a number of issues relating specifically to their homeless status and some of these have already been mentioned elsewhere in the report.

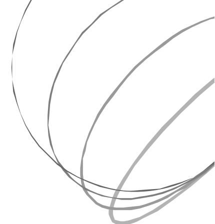
65. One homeless individual noted that when attending an appointment they need something for their withdrawal before they can have treatment for other conditions, but said that often this is refused and they end up signing themselves out without having had the treatment. Other homeless individuals noted that their first priority is getting drugs *("you need to get sorted for heroin first"*) which means they are unlikely to keep a hospital appointment, particularly if it is early in the day. All homeless individuals commented that ex-users should be employed within the health service as others do not understand what they are going through.

Reimbursement of travel costs

66. Respondents in Stornoway noted that there is an option to obtain refunds against travel costs, although respondents in Highland were not aware of this. A respondent in Lothian noted that a nurse at the hospital had suggested he would be able to obtain travel expenses because of a wasted journey to hospital. However, despite letters asking for reimbursement, this has not been forthcoming. He has found this situation annoying primarily because he had not expected to have travel costs reimbursed but as this was prompted by a member of the nursing staff, he felt he was led to expect that his costs would be reimbursed.

67. Whilst age was not an issue for most of the respondents, one older person noted that early morning appointments for those without their own transport are expensive because of having to pay peak fares on the trains. She felt that hospitals should give consideration both to the age of patients and to the distance they would have to travel before offering an appointment.

In general, access appears to be fair for most groups who might be considered to be disadvantaged in some way. While some issues were raised, many of these apply to any hospital user.



Appendix 1

Topic guide

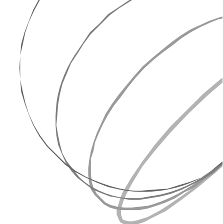
Focus groups with potentially disadvantaged groups

Please make it clear to participants that they are not obliged to tell the group about their personal circumstances.

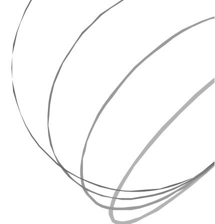
Objective 1: Assess whether boards are complying with the New Ways guidance for managing patients and recording information[5]

Initial contact	PROMPTS/NOTES TO MODERATOR
1 How did hospital initially make contact with you? Did you get a letter with details of your appointment? IF RECEIVED LETTER: 2 Do you remember if there were any problems with the letter or were all the details you needed clear? **For people with dementia, learning difficulties, visual impairment or non-readers, or whose first language was not English:** 3 What help would you have needed at this stage? Was the hospital able help? **Homeless group:** 4 Did you get information about your appointment? What is the best way of contacting you?	**Important details on the letter might include:** Date, time, location. How to contact the hospital, eg to accept or change your appointment time. Who to ask for help and how to contact them. **Notes to moderator** There needs to be a strand of questioning throughout in interviews/groups about how they would know what to do, ie did the info come in a language /format they could access? For homeless people an issue will be how best to contact them.

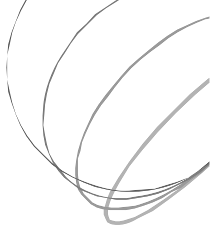
[5] New Ways is the name given to the new system of managing NHS waiting lists in Scotland.



Reasonable offer	
ASK ALL GROUP MEMBERS: 5 When the hospital first offered you an appointment, were you able to accept the first appointment? IF NOT, What did the hospital do next? Did you ask to be seen at a clinic nearer to your home? Were you prepared to wait longer to be seen at a clinic closer to home?	**Note to moderator**: The hospital should make patients up to two offers of appointments (that is, if the patient declines the first they must make a second offer of an appointment). The hospital can make a short notice offer, eg if there has been a cancellation, but if the patient turns it down, this does not affect their right to two offers of an appointment.
6 How did you feel about the amount of notice you were given? 7 How much notice were you given? 8 Did they write or phone Did you feel it was too short notice, or that you did not want to wait that long or was it about right? Why did you feel it was too short notice? Why did you feel it was too long to wait?	**Not enough time:** For example to arrange childcare or if you care for others, to rearrange other appointments, holidays, and so on. **Too long** People might have been worried or in pain. **Note to moderator** We are trying to find out if patients feel they are treated fairly. It is possible that the board could give someone very short notice of an appointment, and if it is a written offer, this reduces the time further. Some boards use what they call 'implied consent', which means that if patients do not reply to a written offer within a week their consent is implied.
9 Did they make you more than one offer of an appointment?	**Note to moderator**: Patients are guaranteed they will wait no more than 15-weeks for a new outpatient appointment or a hospital admission although boards are aiming to see everyone within 12-weeks. If a patient turns down two offers of an appointment which the hospital makes (excluding an offer at very short notice (eg within a week)) the patient can be returned to the start of the 12 to 15-week wait.
Refusals/Declining a reasonable offer	
10 Did anyone turn down all the appointments they offered you? IF SO, what happened next?	
ASK ALL: 11 On the whole, do you think the hospital treated you fairly? Do you think they made you reasonable offers? **For people with dementia, learning difficulties, visual impairment or non-readers, or whose first language was not English and for the homeless:** Do you feel they made it easy for you to attend? **Probe if necessary** How do you think they could improve things to help you?	**PROMPT:** How well did they communicate with you? Did the info come in a language /format they could access? Was a translations service available when they phoned the hospital?

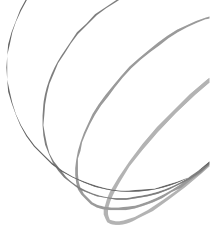


Could not or did not attend	
12 Did anyone find they could not attend after they had accepted an appointment? Did you tell the hospital beforehand? How much notice were you able to give? **Probe** for reasons for not being able to attend. Is there anything the hospital could have done to make it possible for you to attend?	**Note to moderator**: The patient can be returned to the start of the 12 to 15-week wait if they cannot or do not attend an agreed appointment.
13 What did the hospital do? Were you offered another appointment? Do you think you were kept sufficiently well-informed about how long you would have to wait and why? **For people with dementia, learning difficulties, visual impairment, non-readers or whose first language was not English:** How were you told or reminded about the appointment?	**PROMPTS** How did you feel about how long you would have to wait? You might have wanted more time to arrange childcare, rearrange other appointments, and so on or you might have felt you were asked to wait too long? If too long, did you ask for an earlier appointment? Did you realise that if you cannot or do not attend for an appointment, you can be put back to the start of the 12 to 15-week waiting time period, or removed from the list.
14 Thinking about your GP, did they explain to you that you should inform the hospital if you were unable to attend and that you could be put back to the start of the waiting time? 15 Did the GP practice give out a leaflet about New Ways/waiting times – **show leaflet.**	

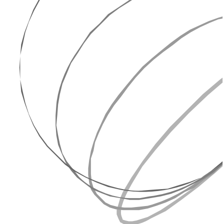


Reviews	
16 Has anyone here been referred back to their GP (or dentist) without being seen or treated? 17 Did anyone have periods of time when you could not attend for any reason? For example you might not have be able to get treatment for medical reasons or because you were busy, or on holiday, or had other commitments or interests. How long did these periods last roughly? A few weeks or months? Did someone review your situation and decide whether or not you could be offered another appointment? 18 Were you involved in a review and asked how you felt about being referred again? 19 Did you feel your views were taken into account? 20 Do you think you received clear information about why these decisions were taken?	**PROMPTS** What did your GP/dentist do then? Were you referred back for the same condition? How was that decision taken?

Contacting the hospital	
21 For those of you who have had to contact the hospital how easy was it to contact them? **For people with dementia, learning difficulties, or whose first language is not English:** 22 And **how** did they make it easy for you to communicate with them? How could they have helped? What more could they have done?	**PROMPTS** Were the instructions on the letter clear about what number to call and when? Were the times you could call convenient for you?

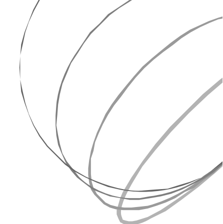


Hospital appointments cancelled	
23 Did the hospital contact you to say they would have to cancel or reschedule your appointment? Did they tell you why they had to change your appointment? And how much notice did they give you? How did you feel about that? **For people with dementia, learning difficulties, non-readers or whose first language is not English:** Did the information come in a way you could easily understand?	**PROMPTS AS APPROPRIATE** What would be the best way of giving you information? Was it in a language you could easily understand? Was it provided in Braille or taped or provided in another format to suit your needs?

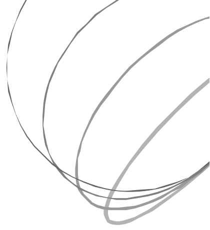


Objective 2: Assess whether any groups are being disadvantaged by the new arrangements, including potentially vulnerable groups and people living in remote and rural areas

Equity of Access	
24 Ho did you feel about the way they communicated with you? Did you feel that hospital staff were understanding about any particular requests you might have had? 25 Has the hospital helped you to arrange and attend your appointment given your particular circumstances? Did staff know how to get additional support if needed? **If requested**, were staff able help? What other support would you like to see the hospital offer to help people accept and attend an appointment? **For people with visual impairment:** How understanding do you think the hospital was of your situation? Is it possible to get all the documents in Braille or taped information or in any other format to suit you? **For people whose first language is not English:** Was it possible to get all documents translated into your preferred language?	**PROMPTS** For example about information on help with travel costs, carer support and overnight costs **Note to moderator** Some languages are largely spoken, not written eg Urdu
26 Were you told what would happen if you could not or did not attend for an appointment? **For people with dementia, learning difficulties, visual impairment, non-readers or whose first language is not English:** 27 How did they do this? 28 Was this the best way of telling you [maybe the carer] about this?	**Note to moderator:** When patients are referred to hospital by a GP or dentist, hospitals must see people within about four months (it is currently 15 weeks). Once an appointment is agreed, if a patient cannot or does not attend, they may be offered another appointment, but the hospital can put the patient back to the start of the 15-week wait or remove them from the list.



Appointments	
For those with dementia, learning difficulties, non-readers or whose first language is not English: 29 Would you find it easier to have a longer appointment? 30 Were you offered a record of what was discussed? 31 Was it in a form you could easily understand?	**PROMPTS** Were you were offered a longer appointment? Did you ask for a longer appointment?
ASK ALL 32 Was the hospital able to offer you an appointment at a time that suited you, taking into account any particular needs you have? IF NOT: Did they offer you an appointment at another hospital with these services?	**Note to moderator:** For remote and rural this could include travelling/transport issues.
For people with dementia, learning difficulties, or people whose first language is not English: 33 Were you offered written summaries of discussions relating to appointments? Were they useful/? ...or do you think they would have been useful?	**PROMPTS** For example, what was discussed or agreed, if you were being removed from the list and why or if you were going to have to start your waiting time again?
For people with dementia, learning difficulties, or people whose first language is not English: 34 If you need someone to help you communicate, to explain your needs and so on, was the hospital able to offer this help and support?	What help would you have liked from the hospital?



<table>
<tr><td colspan="2">Written communication</td></tr>
<tr><td colspan="2">SHOW SAMPLE OF LETTER SENT OUT BY THE NHS BOARD AND ASK ALL:
Notes to group moderator:
When talking to groups of people with dementia, learning difficulties, visual impairment or non-readers, or whose first language was not English:
i. Depending on their abilities, these groups may have problems with written communication. Need to judge whether to show letters and ask the questions relating to it.
ii. Some may have carers there who might deal with these communications and can be asked questions.</td></tr>
<tr><td>35 I would like you to tell me what you think of this letter – is it clear, well-laid out, is the lettering large enough, and what you think could be done to improve on it.
• Date?
• Time?
• Venue?
• If you wanted to contact the hospital, have they made it clear how to do that?
• Is it clear who can help you with any particular needs you might have and how to contact them?
• You should tell the hospital if you are unavailable at any time during the waiting period: is that clear enough in the letter?
• You should tell the hospital if you agree to an appointment but then find out you can't make it – Is that clear?
• Is it clear from the written communication that you could be put back to the start of the four month (15-week) waiting period for various reasons?
• Is it clear how you can get additional support you might need?</td><td>PROMPTS: Do you think the health board has made this letter easy enough to read and understand?
How do you think it could be improved?</td></tr>
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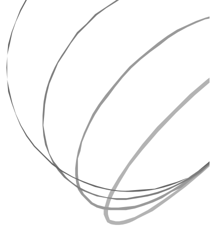
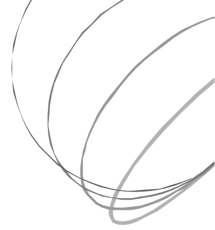


In remote and rural areas:

36 Ordinarily, you should wait no more that about four months – currently 15 weeks is the maximum waiting time, though boards are trying to see everyone within 12 weeks. However, the waiting times rules are different if the clinic you need to attend is infrequent (less than once a month). Do you think this should be stated in the letter?	**Note to moderator:** The letter may well not refer to this so this question can be omitted.
Choice of location	
37 Were you offered the chance of going to a different hospital or clinic to be seen earlier? Or did you ask to be seen at a clinic nearer to your home? 38 How did you feel about going somewhere else? Were you prepared to wait longer to be seen at a clinic closer to home? Did you accept the offer? **Probe** for reasons for accepting/declining. Did you like being given additional choice or did you prefer to wait to be seen closer to where you live even if it means waiting longer?	**PROMPTS:** Where did they offer to see you? ⇒ Could be within the same health board area, at a private hospital, at the Golden Jubilee in Clydebank, at Stracathro in Edzell.
39 If you were offered the chance to travel for a quicker appointment, Were you given information about help with travel costs, overnight accommodation (if required)?	



Appendix 2

Composition of focus groups and in-depth interviews by NHS board

Exhibit A

Composition of focus groups

Focus groups were held in three of the sample areas and included representatives of different groups of people.

Location	Composition of groups	Total number of respondents per group
Highland	**Ages 44+ years**	**8**
	Male and female, including: 1 with visual impairment 1 person who could not read and write	
Highland	**Ages 18 to 25 years**	**7**
	Male and female, including 1 with visual impairment	
Western Isles	**Ages 18 to 39 years**	**6**
	Male and female	
Western Isles	**Ages 18 to 39 years**	**7**
	Male and female, including 2 with visual impairment	
Lothian	**Homeless people, aged 16+**	**8**
	Male and female	

Source: George Street Research

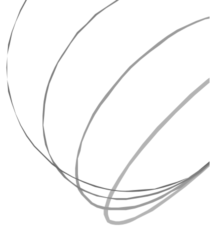


Exhibit B

Composition of in-depth interviews

In-depth interviews were held with people whose first language was not English (FLNE) of different ages and older people with limited mobility.

Location	Respondent profile	Total number of respondents
Lothian	**First language is not English:**	
	Male aged 18-39	1
	Male aged 50+	1
	Female aged 50+	1
	Female aged 18-39	1
	Older people / limited mobility:	
	Female aged 65-75	1
	Male aged 76+	1

Source: George Street Research