

Managing NHS waiting lists

A review of new arrangements

Report supplement: A survey of patients and carers



Prepared for the Auditor General for Scotland
March 2010



Auditor General for Scotland

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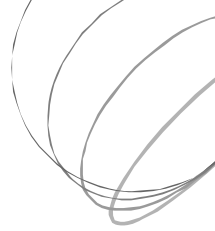
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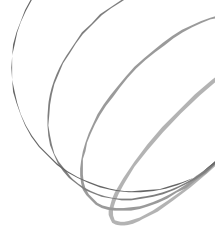
Part 1: Summary

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 this new system, known as New Ways, we commissioned George Street Research to conduct a survey of people who had recent experience of being on an NHS waiting list in Scotland for inpatient or day case treatment or a new outpatient appointment.
2. The aims were to:
 - help gauge the effectiveness of information provided by NHS boards and the communication between boards and patients
 - assess how fair, reasonable and efficient the system appears to be to the target groups.
3. This supplement accompanies the national report and summarises the main findings from the patients and carers survey. It is in a further two parts:
 - Summary of the main findings (**Part 2**).
 - Findings (**Part 3**).

Method

4. The research was conducted with people aged 16 or older who 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 an inpatient or day case appointment.
5. Between 9 and 20 September 2009, George Street Research carried out a telephone survey across the 14 Scottish NHS boards. It conducted 800 semi-structured interviews using the questionnaire shown in Appendix 1. Appendix 2 describes how people were selected for interview, piloting the questionnaire and the profile of respondents.



Part 2: Summary of main findings

Offers

6. Almost all (93 per cent) of respondents had both accepted and attended an appointment; the other seven per cent had either accepted but not attended or had not accepted an offer. Almost all respondents (93 per cent) accepted the first appointment they were offered.

Communication

7. The majority (68 per cent) did not recall receiving any information from their GP or dentist about what might happen if they could not attend an appointment. Respondents' understanding of what would happen if they cancelled an appointment, or failed to attend without cancelling, was not affected by whether or not they remembered being given information by their GP or dentist.
8. Most initial communication from hospitals was written; 86 per cent of respondents reported that the hospital had written to them. Fifteen per cent had needed to contact the hospital about their appointment; nine per cent of these respondents (just over one per cent of the total) experienced difficulties in making contact.

Notice given by the hospital

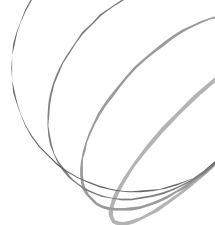
9. The average notice between being told about the appointment and the date of the appointment was four and a half weeks. Those who were given most notice (average 8.6 weeks) were those with a disability or long-standing condition who required a longer appointment. The majority of respondents (83 per cent) felt that the notice given was reasonable. Most (90 per cent) had received an appointment at a time of day that suited them.

Cancellations

10. Five per cent of respondents cancelled an appointment after first accepting it and three respondents (less than 0.5 per cent) said they had not informed the hospital in advance. Eight per cent reported that the hospital had cancelled an appointment and just over three-quarters of these respondents said they had been given enough notice.

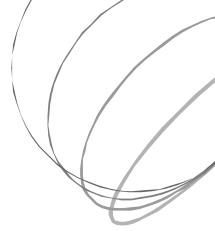
Offers of earlier appointments at different hospitals

11. Seven per cent of respondents said they were offered the choice of an earlier appointment date if they were prepared to travel to a different hospital; 60 per cent of these respondents accepted.



Support for patients

12. Forty-two per cent of respondents said they had a disability or long-standing physical or mental condition. Ninety per cent of these respondents felt staff had handled their needs in a sensitive manner very or fairly well.



Part 3: Findings

Initial contact

13. All respondents (800) were asked if they had received any information from the person who referred them (their GP or dentist) about what might happen if they did not attend an appointment:
 - 28 per cent said yes
 - 67 per cent said no
 - five per cent said they did not know or could not remember.

14. The highest percentages saying yes were recorded for the following NHS board areas:
 - NHS Orkney (46 per cent)
 - NHS Fife (42 per cent)
 - NHS Ayrshire and Arran (34 per cent).

15. The lowest percentage saying yes was recorded for NHS Forth Valley (ten per cent).

16. The majority of respondents (86 per cent) reported that the first contact the hospital made with them to offer them an appointment was in writing (Exhibit 1). Two respondents said that something else had happened: one reported that their GP had contacted the hospital on their behalf, the other had been in hospital for another reason and had been transferred. These two respondents were not asked the following question. Over half (52 per cent) of the remaining 798 respondents asked said that initial contact with the hospital had happened within the previous two months (Exhibit 2). The average was approximately two and a half months ago (10.2 weeks).

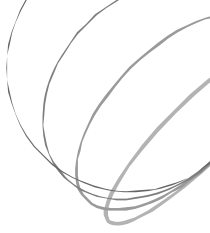
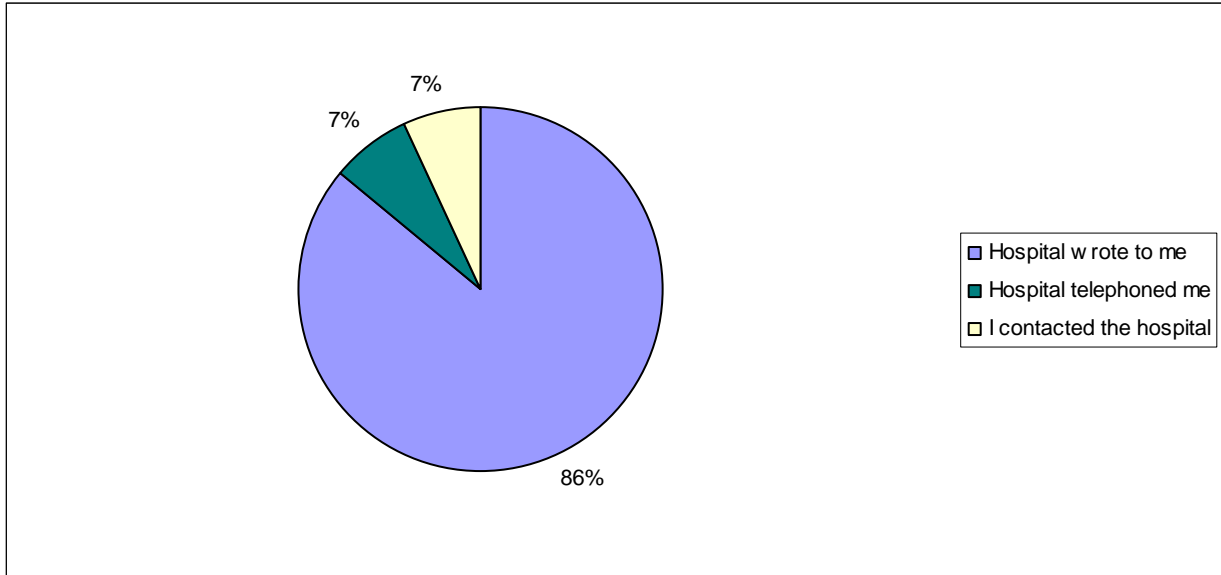


Exhibit 1

Initial contact

The majority of respondents said the hospital had written to them.



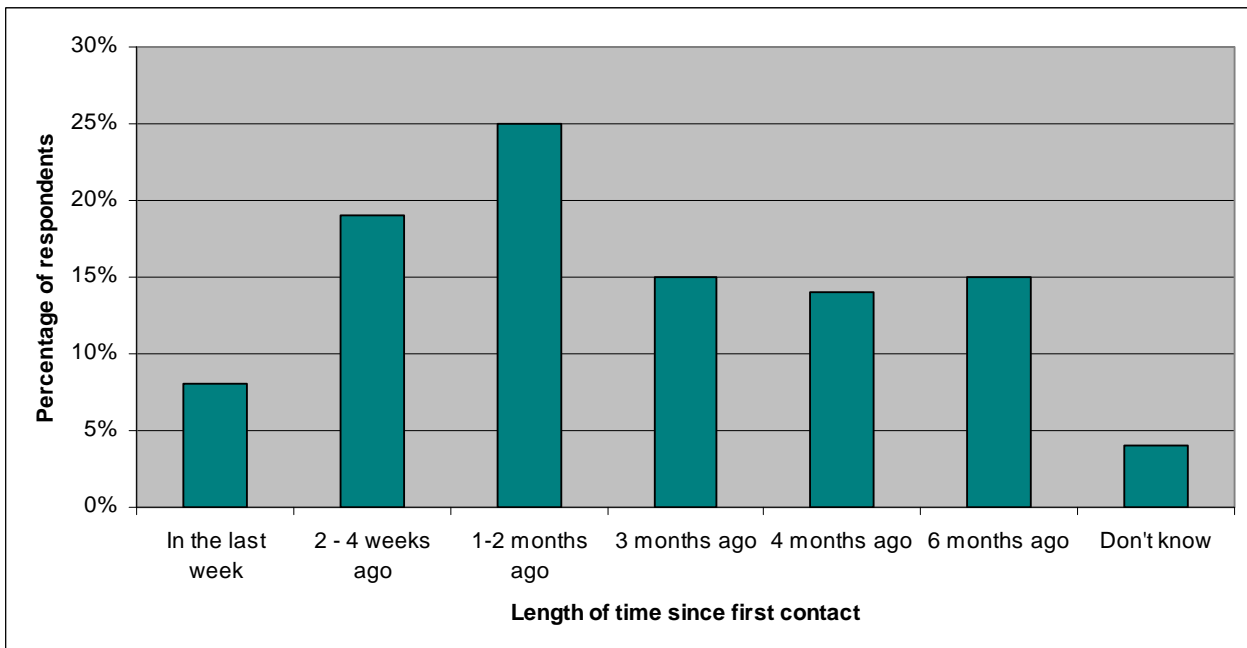
The figures are the percentage of all respondents (800).

Source: Q3

Exhibit 2

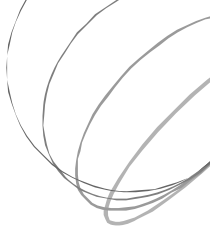
Length of time since first contact

Over half had first been contacted within the previous two months.



The percentages are based on those contacted by, or who contacted, the hospital (798).

Source: Q4a/4b



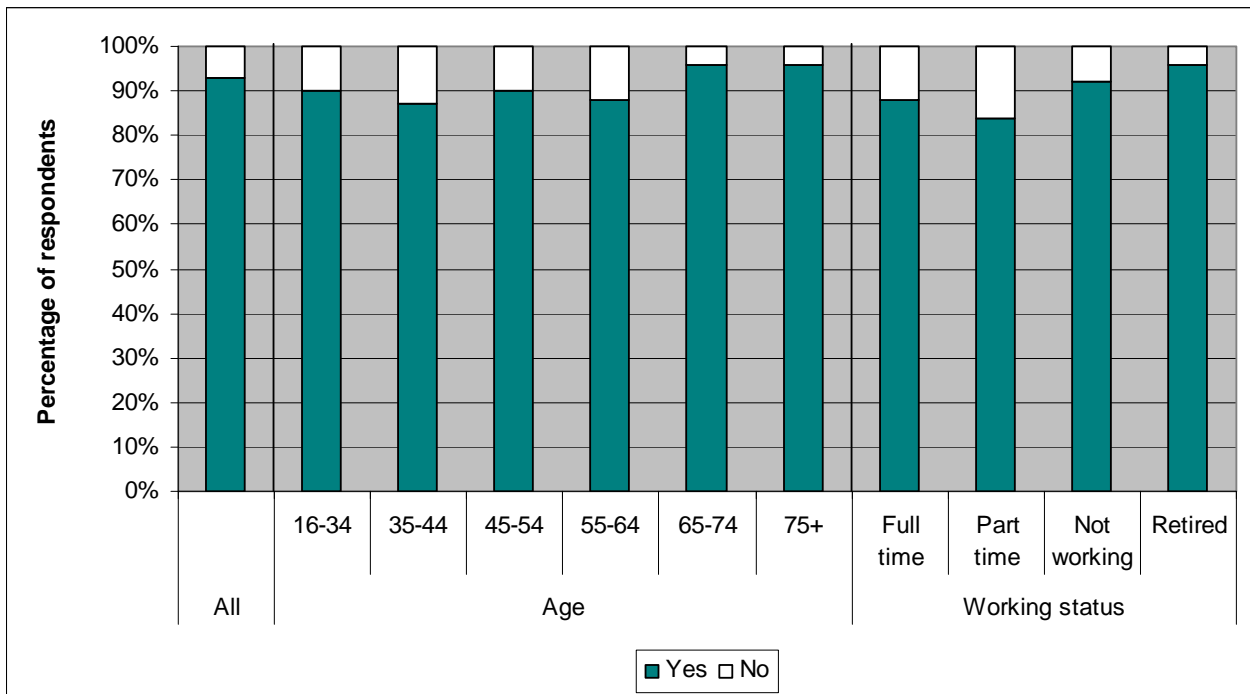
17. All respondents were asked if they had accepted the first appointment offered. Ninety-three per cent said they had (Exhibit 3).

- The oldest age groups (those 65 or over) were most likely and the 35-44 age group the least likely to accept their first offer.
- Those who were retired were the most likely, and those working part-time the least likely, to accept their first offer.

Exhibit 3

Whether or not accepted first appointment by age and working status

Acceptance of the first offer varies according to age and working status.



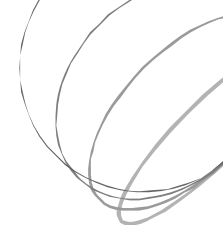
The percentages are based on all respondents (800).

Source: Q5

18. Fifty-nine respondents had not accepted the first appointment, of whom:

- ten respondents (17 per cent) said they had not been made any more offers
- 49 said they were made one or more offers:
 - ♦ 38 respondents (64 per cent) had received one more offer of an appointment
 - ♦ seven respondents (12 per cent) had received two more offers of an appointment
 - ♦ four respondents (seven per cent) had received several more offers of an appointment.

19. Of the 49 who said that they had received one or more offers, 45 said they had accepted one of the appointments and four said they had not.



20. In total, 14 respondents had not received further offers or had not accepted an appointment. These patients said:

- they had not heard back from the hospital (six respondents)
- they had been returned to the end of the waiting list or they had been referred back to their GP (three respondents)
- the hospital had said they would get back to them (one respondent)
- they had a new date but had not accepted it (one respondent)
- the appointment was for a visiting clinic where appointments were difficult to fix (one respondent)
- the process was on hold due to personal circumstances (one respondent)
- they could not remember (one respondent).

Notice and length of wait

21. This series of questions was asked of respondents who had accepted either the first or a subsequent appointment (786 respondents). When asked what notice the hospital gave them of their appointment, the highest number of respondents (38 per cent) reported two or three weeks (Exhibit 4).

Exhibit 4

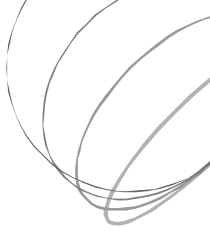
Notice of an appointment

Most patients had up to three weeks notice.

Length of notice given	Percentage of respondents
Less than a week	19
Two or three weeks	38
About a month	17
About two months	13
About three months	6
About four months	1
Over four months	2
Don't know	4
TOTAL	100

The figures are the percentage of those who had accepted an appointment (786).

Source: Q7

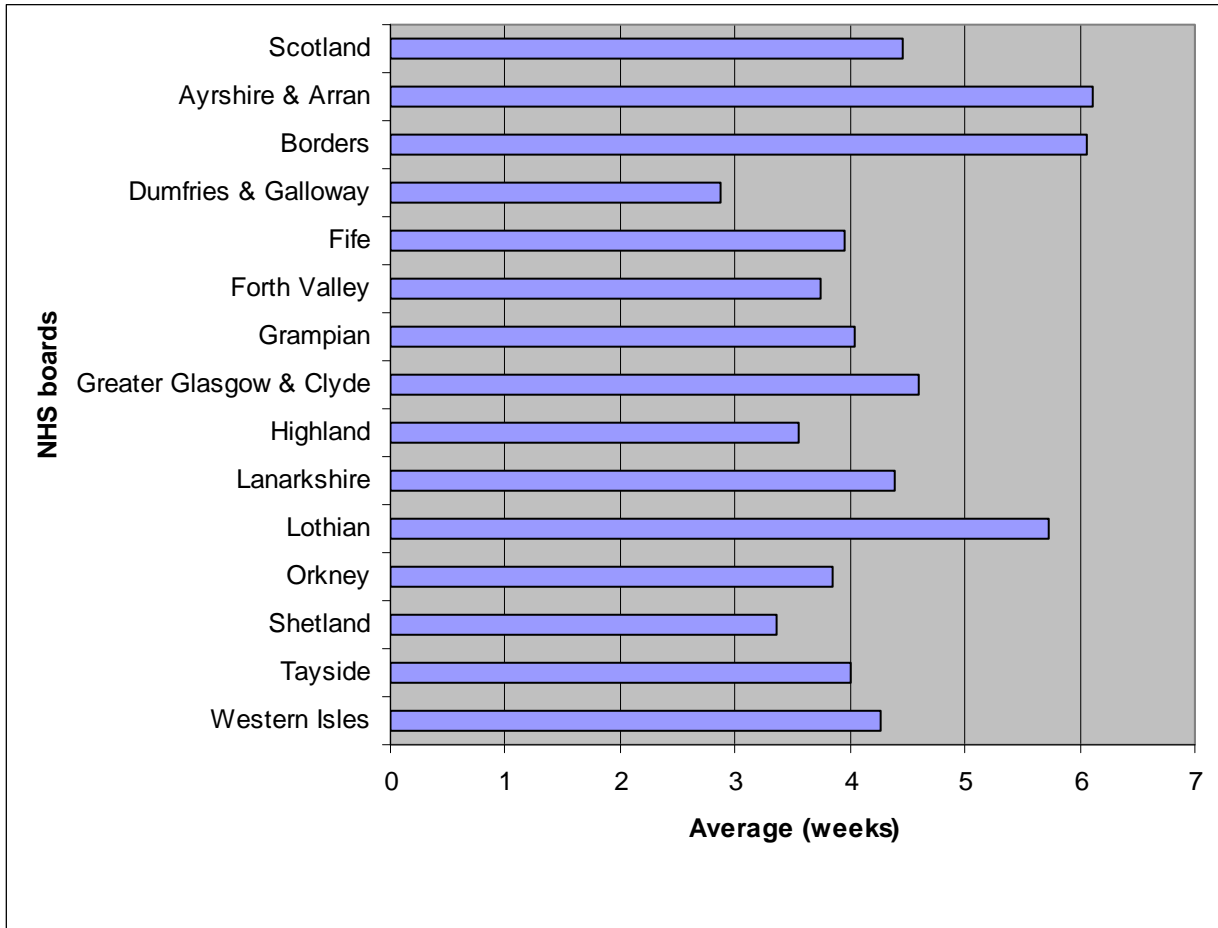


- 22. Respondents with a long-standing condition or disability reported approximately five weeks notice compared with the average of approximately four weeks for all respondents. In addition, respondents whose condition or disability means they require a longer appointment reported, on average, 8.6 weeks notice, while those with a disability who need support to help them arrange or attend an appointment reported, on average, 4.4 weeks notice.
- 23. The average for all respondents across Scotland was 4.5 weeks. NHS Dumfries and Galloway showed the shortest average notice at 2.9 weeks and NHS Ayrshire and Arran the longest at 6.1 weeks (Exhibit 5).

Exhibit 5

Average number of weeks notice recalled by respondents, by NHS board

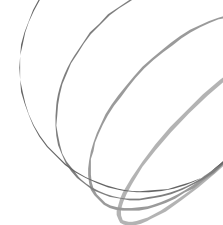
The average notice reported by respondents varied by NHS board.



The figures are based on those who had accepted an appointment (786).

Source: Q7

- 24. When asked how they felt about the notice the hospital gave them of their appointment date:
 - 83 per cent of the 786 respondents felt it was reasonable
 - four per cent said the length of time was too short



- 11 per cent felt it was too long
 - two per cent said they did not know.
25. There were some differences between groups. In the 16 to 34 age group, 65 per cent said the notice they were given was reasonable compared with 87 per cent of the 65 to 74-year-olds and 86 per cent of the over 75-year-olds. Twenty-three per cent of the 16 to 34-year-olds felt the notice they were given was too long, compared to eight per cent of those aged over 75 years. Less than half (43 per cent) of those whose disability means they require a longer appointment felt the notice they received was reasonable.
26. Across Scotland, 92 per cent of all respondents felt that notice of around two or three weeks was reasonable. A week or less was seen as being too short notice. Respondents in Orkney were most likely to say their notice period was reasonable (94 per cent) while respondents in Ayrshire and Arran were least likely to say this (62 per cent).
27. Ninety per cent said that the time of day they were offered suited them; seven per cent said it did not and three per cent said they did not know or could not remember. There was a difference between those respondents answering on their own behalf (91 per cent said the time of day was suitable) and those answering as carers (78 per cent said the time of day was suitable).

Patients who could not or did not attend their appointments

28. The 786 respondents who had accepted an appointment were asked if, after accepting an appointment, they then decided they would not be able to make it. Thirty-nine (five per cent) said this had happened to them. These respondents were asked the remaining questions in this section. For 31 respondents the appointment date had already passed while eight said it was yet to happen. When asked if they had informed, or intended to inform, the hospital that they would not be able to make their appointments:
- 35 said yes
 - three said no
 - one said they did not know.
29. The 35 respondents who said yes were asked if they thought the hospital would return them to the end of the waiting list and if they thought they would have to wait long for an appointment (Exhibit 6).

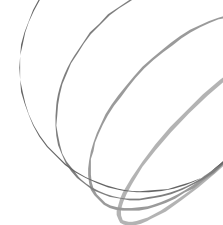


Exhibit 6

How those who cancelled thought they would be treated

Those who cancelled an appointment generally did not think they would be returned to the end of the waiting list or that they would have to wait long for another appointment.

Respondents' expectations	Yes	No	Don't know	Total
Did you think the hospital would return you to the end of the waiting list?	3	25	7	35
Did you think you would have to wait long for an appointment?	9	17	9	35

The figures are the number of respondents who had informed, or intended to inform, the hospital that they could not attend their appointment (35).

Source: Q12c & Q12d

30. These 35 respondents were also asked how much notice they gave, or expected to give, the hospital that they would not be able to attend (Exhibit 7).

Exhibit 7

Notice of cancellation by patients

Most patients gave, or expected to give, the hospital less than a week's notice of having to cancel an appointment.

Notice by patients	Number of respondents
Less than a week	19
About a week	4
Two or three weeks	9
About a month	2
About two months	1
TOTAL	35

The figures are the number of respondents who had informed, or intended to inform, the hospital that they could not attend their appointment (35).

Source: Q13

31. Of the 39 respondents who decided they would not be able to attend an appointment they had accepted, 28 said the hospital had rescheduled their appointment. These respondents were asked the remaining questions in this section.
32. When asked how much notice the hospital had given them of the rescheduled appointment, most said two or three weeks (Exhibit 8).

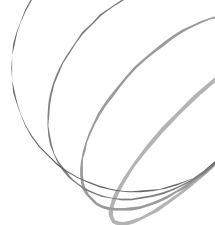


Exhibit 8

Notice of rescheduled appointment

About half of the respondents said they were given two or three weeks notice.

Length of notice for rescheduled appointment	Number of respondents
Less than a week	3
About a week	5
Two or three weeks	15
About a month	1
About two months	2
About three months	1
Don't know	1
TOTAL	28

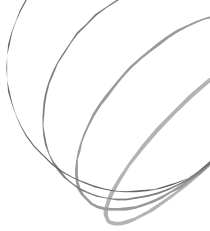
The figures are the number of people with a rescheduled appointment (28).

Source: Q16a

33. When asked how they felt about the length of time they would have to wait for the rescheduled appointment:
- 23 said they felt it was reasonable
 - three said it was too short
 - one said it was too long
 - one said they did not know.

Appointments rescheduled by the hospital

34. The 786 respondents who had accepted an appointment were asked if the hospital contacted them to change or cancel the appointment. Eight per cent (63 respondents) said that this had happened to them and were asked the remaining questions in this section.
35. When asked how the hospital contacted them:
- 39 said the hospital wrote to them
 - 20 said the hospital telephoned them
 - four said that they had found out at the hospital.



36. Respondents were asked how much notice the hospital gave them (Exhibit 9).

Exhibit 9

Notice of hospital rescheduled appointment

About half were given less than two weeks' notice

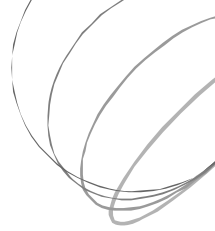
Length of notice given	Number of respondents
None / the same day	5
A day / the day before	7
Two to three days	9
Four to five days	4
About a week	8
Two or three weeks	15
About a month	9
About two months	4
About three months	1
Don't know	1
TOTAL	63

The figures are the number of respondents who had an appointment changed or cancelled by the hospital (63).

Source: Q19a

37. When asked if they felt they were given enough notice:

- 49 of the 63 (78 per cent) said yes
- 12 said no
- two respondents gave other answers:
 - ♦ cancelled due to machinery breakdown but hospital was accommodating
 - ♦ someone was ill so can't object.



Communication with the hospital

38. All respondents were asked what they thought the hospital would do if they could not attend an agreed appointment and told the hospital in advance. They were also asked what they thought the hospital would do if they did not tell the hospital in advance.
39. For each situation, four questions were read out relating to how the hospital might treat the patient:
- Did you think they would contact you?
 - Did you think they would remove you from the waiting list?
 - Did you think they would refer you back to your GP or dentist?
 - Did you think they would offer you another appointment?
40. Respondents could answer yes or no (or don't know) to each question. Respondents had different views on what would happen depending on whether or not the hospital had been notified in advance (Exhibit 10). The biggest difference is seen for the statement 'They would offer you another appointment'. Eighty-three per cent said they thought this would happen if the hospital was notified in advance compared to 40 per cent if the hospital was not notified first.
41. Other comments about what the hospital might do if a patient notified the hospital in advance that they could not attend an appointment included:
- the patient would be put to the end of the waiting list (seven respondents)
 - refusing a second or other offers would result in the patient being removed from the waiting list (three respondents).
42. Other comments about what the hospital might do if a patient did not notify the hospital in advance that they could not attend an appointment included:
- the hospital would be annoyed or "give you a telling off" (seven respondents)
 - the patient would be put to the end of the waiting list (five respondents)
 - the hospital would contact the patient's doctor (three respondents).
43. Expectations of what would happen if patients did not tell the hospital in advance that they would not be able to make an appointment were similar whether the respondent said they had received information from their GP or dentist about this or not.

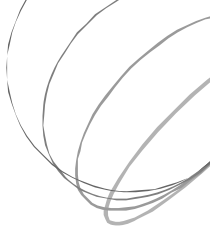
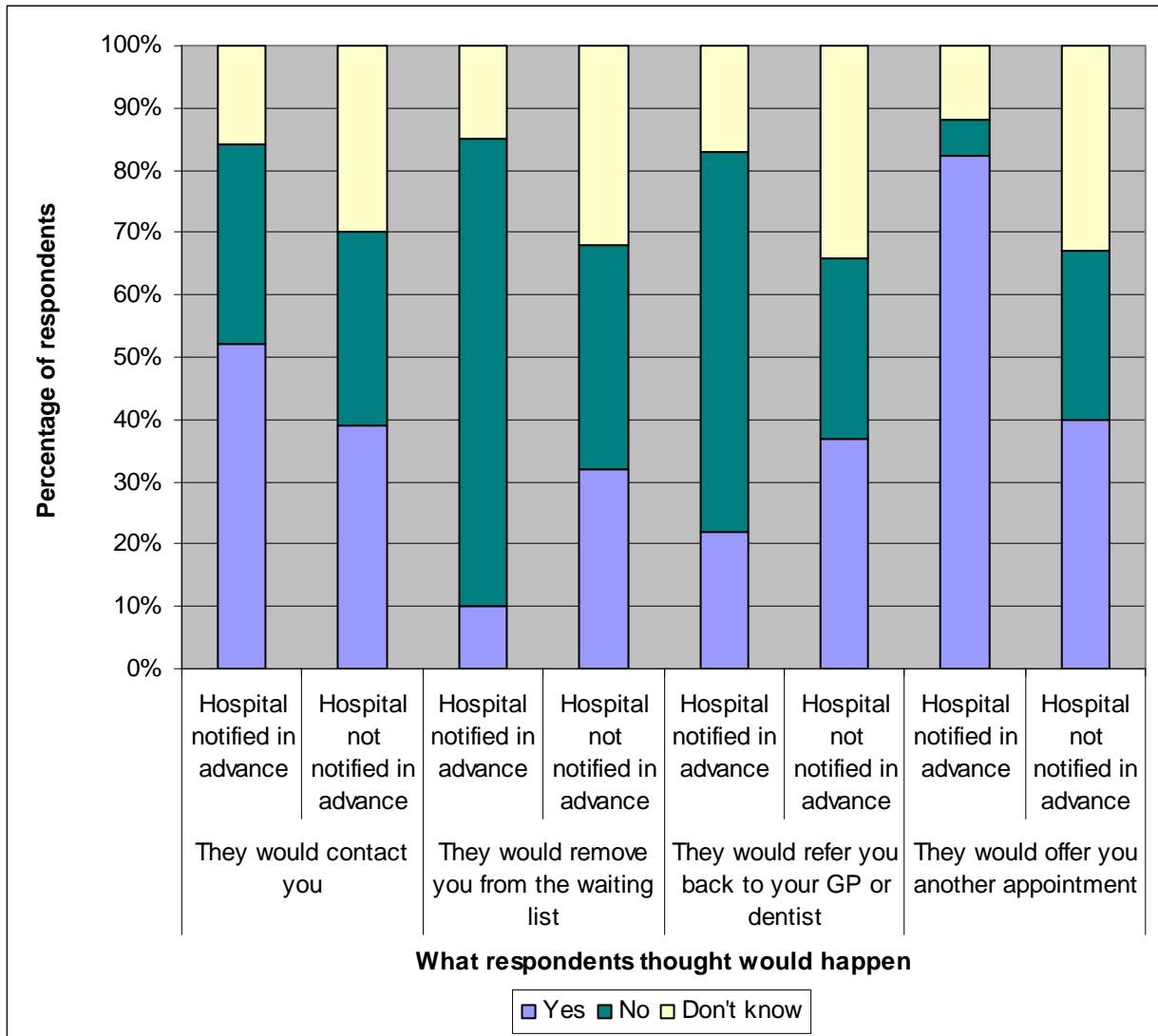


Exhibit 10

What people thought would happen if they could not or did not attend an appointment

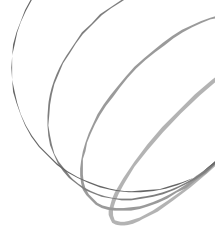
Expectations differed depending on whether or not the hospital was notified in advance.



The figures are the percentage of all respondents (800).

Source: Q20a/b

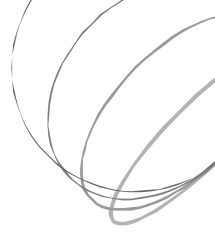
44. Questions then concentrated on communication with the hospital. When asked if they had wanted to contact the hospital at any time about their referral or appointment, 15 per cent (119 respondents) said they had and 85 per cent said they had not. Approximately twice as many people working part-time wanted to contact the hospital (27 per cent) compared to retired people (12 per cent).
45. Those who had wanted to contact the hospital were also asked if they had any problems with this. Nine per cent (11 of the 119) said they had experienced problems including:
 - hospital number was always engaged (two respondents)



- specific contact on holiday / not available (two respondents)
- getting through to the right department / getting transferred (two respondents)
- could not find the telephone number to call (one respondent)
- patient wrote but hospital said they did not receive the paperwork (one respondent)
- didn't know who to contact (one respondent)
- clinic was closed – they had left a message which was not passed on (one respondent)
- letter arrived while patient was on holiday and they were taken off the list before they returned – the hospital had not allowed enough time for them to get in contact (one respondent).

Offers to attend an alternative hospital

46. All respondents were asked if they had been offered the choice of an earlier appointment date if they were prepared to travel to a different hospital to be seen:
- seven per cent (57 respondents) said they were
 - 92 per cent said they were not
 - one per cent said they did not know.
47. The figure was highest in NHS Forth Valley, with 16 per cent reporting that they had been offered this. None of the respondents in Highland said they had been offered this choice.
48. The 57 respondents who had received this offer were then asked if the hospital offered to pay their travel to this different hospital:
- 39 respondents said no
 - 15 respondents said yes, all travel costs
 - two respondents said yes, some travel costs
 - one respondent said they did not know.
49. Of these 57 people, 34 accepted. Reasons for not accepting an earlier appointment at a different hospital included:
- too far away / long travelling time (six respondents)
 - I wasn't bothered (six respondents)
 - time / date wasn't convenient (four respondents)



- it wasn't very urgent (three respondents)
- they only asked if I was prepared to go – they didn't offer an appointment (two respondents)
- on my own so not practical to travel for an operation (one respondent)
- appointment turned out to be later than the local one (one respondent)
- ridiculous for a pensioner to have to travel and then be transported back (one respondent).

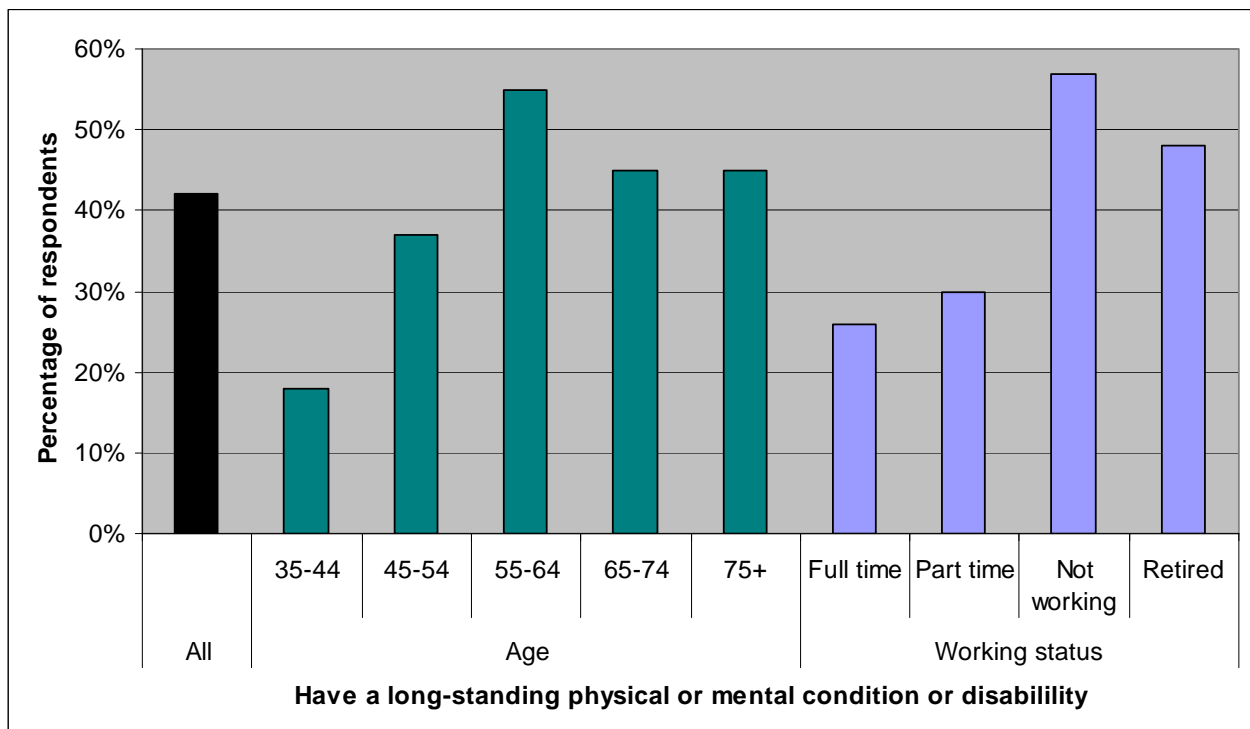
Support for patients

50. All respondents were asked if they had a long-standing physical or mental condition or disability that had troubled them for at least 12 months or that is likely to affect them for at least 12 months. Forty-two per cent said they did and 58 per cent said they did not. Although more common amongst older people, long-standing conditions exist in all age groups. Those with long-standing conditions are less likely to work or to work full-time (Exhibit 11).

Exhibit 11

Long-standing physical or mental condition or disability by age group and working status

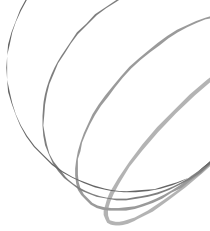
Long-standing conditions vary by age and are highest amongst those who do not work.



The figures are the percentage of all respondents (800).

Source: Q26

51. Respondents with a disability or long-standing condition were then asked how sensitively they thought hospital staff had handled their needs (Exhibit 12). The majority (around 70 per cent) replied very well

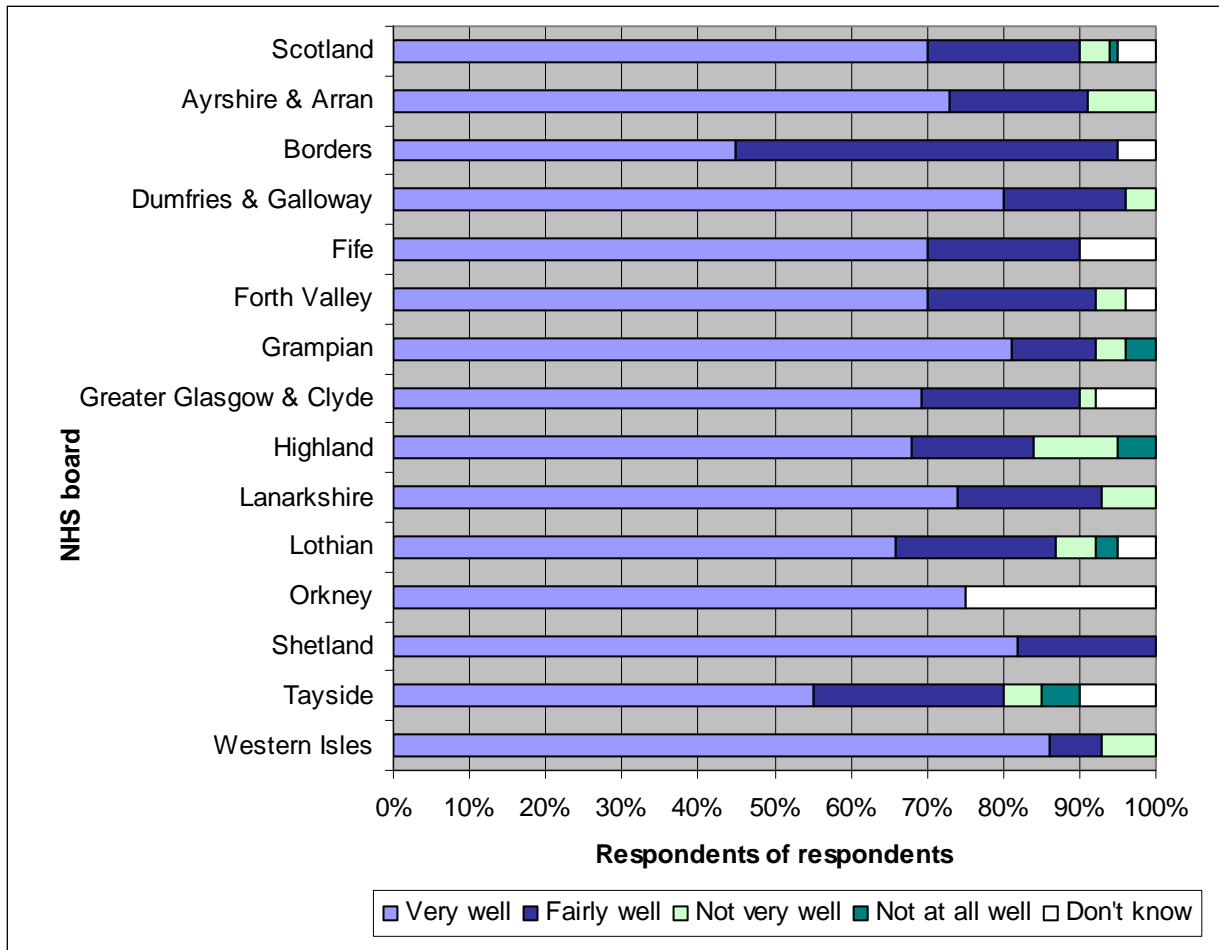


and 20 per cent said fairly well, five per cent thought staff had not handled their needs well and four per cent said they did not know or could not remember.

Exhibit 12

Level of satisfaction with how sensitively needs were handled

Satisfaction varied by board area.

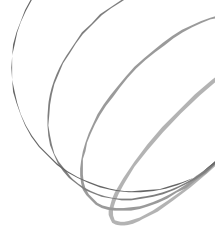


The figures are the percentage of those with a long-standing physical or mental condition or disability (337).

Source: Q27

52. Finally in this section, respondents with a disability or long-standing condition were asked whether they would have liked different types of support and, if so, whether the hospital had offered and provided it. Support offered and provided varied. Of the 337 people, just under half who wanted additional support were offered it and just over a third received it.

- Of the 14 per cent who wanted additional support to arrange or attend an appointment, most (31 out of 47 respondents) were offered this and 22 were provided with it.
- Of the 15 respondents who wanted a longer appointment, one was offered and provided with this.

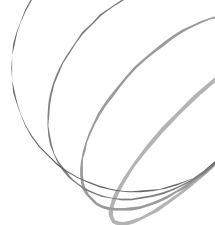


- Of the 35 who wanted written summaries of discussions, ten were offered these and nine were provided with them.
- Of the 15 respondents who wanted help to communicate to explain their needs, four were offered this and three were provided with it.
- Most respondents (74 per cent) said they did not want any of these types of support.

53. Four other types of support were wanted:

- a wheelchair for moving within the hospital (one respondent)
- help with washing and dressing (one respondent)
- quick service (one respondent)
- a post-surgery call to check that all was okay (one respondent).

54. The total is greater than 100 per cent as respondents reported needing more than one type of support.



Appendix 1

Survey questionnaire

New Ways of Managing NHS Waiting Lists: patient experiences

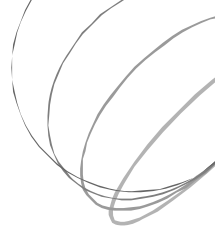
Telephone Questionnaire

ASK ALL RESPONDENTS:

1a Please can you tell me whether you, or someone aged over 16 who you care for, has been referred by your GP or dentist for any of the following **within the last six months**? We are only interested in referrals within the NHS not through any private medical cover.
READ OUT

	Self	Cared for
A new outpatient appointment at a clinic to see a consultant? An outpatient appointment is when a patient is referred to a clinic to see a consultant. As a result of the consultation, the patient may then be referred for treatment or surgery. A new outpatient appointment: this is the first time the patient has attended the clinic: it should not be a follow-up or regular appointment.	1	1
A hospital admission <i>either</i> as an inpatient (with at least one night in hospital) <i>or</i> as a day case patient Patients referred for treatment or surgery will be admitted to hospital either as an inpatient , where they spend one or more nights in hospital, or as a day case - being admitted and discharged on the same day.	2	2
A follow-up or regular appointment at a clinic	3	3
None of these	4	4
Not Applicable (not a Carer)		5

ASK Q1b OF THOSE CODED 1 OR 2 FOR THEMSELVES OR SOMEONE THEY CARE FOR. OTHERS THANK AND CLOSE



1b For which of these, if any, have you / they been referred? READ OUT – MULTI-CODING POSSIBLE

	Self	Cared for
Any form of radiology such as MRI or CT scan or barium enema	1	1
Any homeopathic related treatment	2	2
Any form of endoscopy such as colonoscopy, cystoscopy or sigmoidoscopy	3	3
Any form of oncology / cancer treatment	4	4
Anything to do with pregnancy	5	5
Any mental health issues	6	6
Something different / none of the above	7	7
N/A	8	8

ASK Q1c OF ALL CODED 7 FOR THEMSELVES OR SOMEONE THEY CARE FOR (THEY MAY BE CODED ELSEWHERE AS WELL). OTHERS THANK AND CLOSE

1c Have you/they had any form of contact with the hospital about arrangements for the appointment? This might have involved the hospital making contact by letter or telephone, or it might have involved you contacting the hospital about the appointment.

	Self	Cared For
Yes	1	1
No	2	2

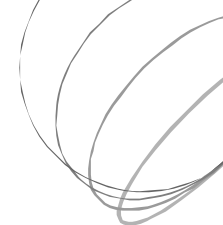
IF CODED 7 AT 1b **AND** 1 AT 1c, EITHER FOR SELF OR FOR PERSON CARED FOR, ELIGIBLE TO BE INTERVIEWED. OTHERS THANK AND CLOSE

IF RESPONDENT HAS BEEN REFERRED FOR MORE THAN ONE CONDITION OR FOR AN OUTPATIENT APPOINTMENT AND AS AN INPATIENT OR DAY CASE IN THE LAST 6 MONTHS, PLEASE REFER IN THE INTERVIEW TO THE MOST RECENT REFERRAL

IF YOU ARE INTERVIEWING A CARER, EXPLAIN THAT THROUGHOUT THE SURVEY WE NEED THEM TO ANSWER FOR THE PATIENT.

IF RESPONDENT NEEDS A TRANSLATOR, PLEASE CODE BELOW, LET OFFICE KNOW AND ASK IF WE CAN CALL BACK AT SOME OTHER TIME TO CONDUCT THE INTERVIEW

Translator needed	1
Not needed	2



SECTION A : INITIAL CONTACT

ASK ALL

2. Did you receive any information from your GP or dentist about what might happen if you could not attend an appointment?

- Yes 1
- No 2
- Don't know, can't remember 3

3. When the hospital contacted you at first to offer you an appointment, did they write to you, did they phone you, did you contact the hospital or did something else happen?

- Hospital wrote to me 1 ASK Q4a
- Hospital telephoned me 2 ASK Q4a
- I contacted the hospital 3 ASK Q4b
- Other (write in) 4

.....

ASK ALL CODED 1 OR 2 AT Q3

4a How long ago did the hospital first contact you? SINGLE CODE BELOW

ASK ALL CODED 3 AT Q3

4b How long ago did you first contact the hospital? SINGLE CODE BELOW

- | | 4a | 4b |
|--------------------------------------|-----------|-----------|
| In the last week | 1 | 1 |
| Two to four weeks ago | 2 | 2 |
| Between about one and two months ago | 3 | 3 |
| About three months ago | 4 | 4 |
| About 4 months ago | 5 | 5 |
| About 6 months ago | 6 | 6 |
| Other (write in) | 7 | 7 |
| Don't know / can't remember | 8 | 8 |

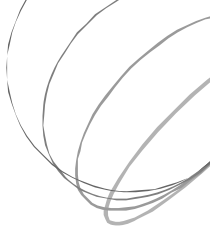
ASK ALL

5. Did you accept the first appointment they offered you?

- Yes 1 – GO TO SECTION B
- No 2 – GO TO Q6a

6a. After refusing their appointment, did they make no more offers, one or two more offers of an appointment or did they make several more offers of an appointment?

- No more offers 1 – GO TO Q6c
- One offer 2 – ASK Q6b
- Two offers 3 – ASK Q6b
- Several more offers 4 – ASK Q6b



ASK ALL CODED 2-4 AT Q6a

6b Did you accept one of these appointments?

- Yes 1 – GO TO SECTION B
- No 2 – ASK Q6c

ASK ALL WHO DID NOT ACCEPT APPT (CODE 1 AT 6a OR 2 AT 6b)

6c What did the hospital do next? READ OUT AND CODE BELOW

- They said they would speak to someone else / the consultant about me 1
- They referred me back to my GP or dentist 2
- I have not heard back from them 3
- They removed me from the waiting list 4
- I was put back to the end of the waiting list 5
- Other (write in)..... 6
- 7
- DK / CR 7

AFTER ANSWERING Q6c GO TO SECTION E

SECTION B : NOTICE / LENGTH OF WAIT

ASK ALL CODED 1 AT Q5 OR 1 AT Q6b.

7a Thinking of the **first** appointment you were offered, approximately how long were you going to have to wait between being told about the appointment and the date of the appointment? SINGLE CODE ONLY

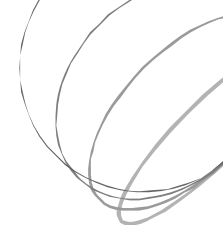
- Less than a week 1
- 2 or 3 weeks 2
- About a month 3
- About 2 months 4
- About 3 months 5
- About 4 months 6
- Over 4 months 7
- CR / DK 8

8 And how did you feel about the length of time you would have to wait between being told about the appointment and the appointment date? Was it reasonable, too short or too long? SINGLE CODE BELOW

- Reasonable 1
- Too short 2
- Too long 3
- DK / CR 4

9 Thinking of the time of day you were offered, was this for a time of day that suited you?

- Yes 1
- No 2
- DK/CR 3



SECTION C : COULD NOT OR DID NOT ATTEND

10 After accepting an appointment, did you **then** decide you would not be able to make it?

Yes	1	ASK Q11
No	2	GO TO SECTION D
DK/CR	3	GO TO SECTION D

ASK ALL CODED 1 AT Q10

11 Can I just check, has the time for that appointment happened already?

Yes	1 – ASK Q12a
No	2 –ASK Q12b

ASK ALL CODED 1 AT Q11

12a Did you let the hospital know before the appointment that you would not be able to attend on that date or time?

ASK ALL CODED 2 AT Q11

12b Have you, or do you intend to let the hospital know that you will not be able to attend on that day or time?

	Q12a	Q12b
Yes	1	1
No	2	2
DK/CR	3	3

ALL CODED 1 AT 12a OR 12b ANSWER Q12c, Q12d AND THEN Q13. THOSE CODED 2 OR 3 AT 12a OR 12b GO TO Q15

12c Did you think they would return you to the end of the waiting list?

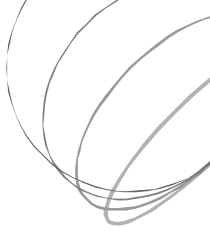
12d Did you think you would have to wait long for an appointment?

	Q12c	Q12d
Yes	1	1
No	2	2
DK/CR	3	3

ASK ALL CODED 1 AT Q12a OR Q12b

13 How far in advance did you let the hospital know that you would not be able to attend?

Less than a week	1
About a week	2
2 or 3 weeks	3
About a month	4
About 2 months	5
About 3 months	6
About 4 months	7
Over 4 months	8
CR / DK	9



NO QUESTION 14

15 Has the hospital rescheduled your appointment?

- Yes 1 – GO TO Q16a
- No 2 – GO TO SECTION D

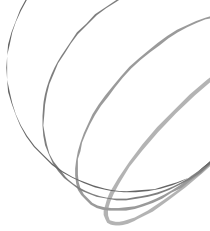
ASK ALL CODED 1 AT Q15

16a And approximately how long is the time between being told about the appointment and the appointment date? SINGLE CODE ONLY

Less than a week	1
About a week	2
2 or 3 weeks	3
About a month	4
About 2 months	5
About 3 months	6
About 4 months	7
Over 4 months	8
CR / DK	9

16b How did you feel about the length of time you would have to wait for this rescheduled appointment? Did you think it was reasonable, too short or too long? SINGLE CODE BELOW

Reasonable	1
Too short	2
Too long	3
DK / CR	4



SECTION D : HOSPITAL RESCHEDULED APPOINTMENTS

17 Did the hospital contact you to say **they** would have to change or cancel your appointment?

- Yes 1 –ASK Q18
- No 2 – GO TO SECTION E

ASK IF CODED 1 AT Q17

18 How did the hospital contact you? Did they write, telephone or contact you in some other way?

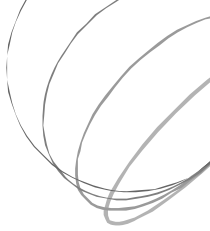
- Hospital wrote to me 1
- Hospital telephoned me 2
- Other (write in) 3
-

19a And how much notice did they give you?

- A day / contacted the day before 1
- Two to three days 2
- Four to five days 3
- About a week 4
- Two to three weeks 5
- About a month 6
- About 2 months 7
- About 3 months 8
- About 4 months 9
- Over 4 months 10
- Other (write in) 11
- DK/CR 12

19b Would you say they gave you enough notice?

- Yes, Gave enough notice 1
- No, Too short notice 2
- Other (write in) 3
-



SECTION E : COMMUNICATION WITH THE HOSPITAL

ASK ALL

- 20a What do you think the hospital would do if you told them you could not attend an agreed appointment? READ OUT – SINGLE CODE EACH ROW
- 20b What do you think the hospital would do if you do not tell them that you will not be attending and then do not turn up for your appointment? READ OUT – SINGLE CODE EACH ROW

	20a			20b		
	Yes	No	DK CR	Yes	No	DK CR
Did you think they would contact you?	1	2	3	1	2	3
Did you think they would remove you from the waiting list?	1	2	3	1	2	3
Did you think they would refer you back to your GP or dentist?	1	2	3	1	2	3
Did you think they would offer you another appointment?	1	2	3	1	2	3

Something else (write in what they thought would happen)

20a.....

Something else (write in what the hospital would do)

20b.....

- 20c Did you want to contact the hospital at any time about your referral or appointment?

Yes 1 – GO TO Q21
 No 2 – GO TO SECTION F

IF CODED 1 AT Q20c

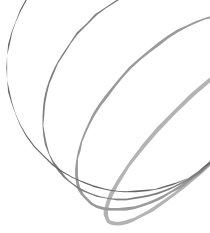
- 21 When you wanted to contact the hospital, did you have any problems in contacting them?

Yes 1 – GO TO Q22
 No 2 – GO TO SECTION F

IF CODED 1 AT Q21

- 22 What problems did you have? DO NOT READ OUT – CODE BELOW. MULTI-CODE POSSIBLE

Could not find telephone number to call	1
Their contact times were inconvenient	2
Their number was always engaged	3
Other (write in)	4
.....	



SECTION F : ALTERNATIVE HOSPITAL

ASK ALL

23 Were you offered the choice of an earlier appointment date if you were prepared to travel to a different hospital to be seen?

Yes	1 – GO TO Q24
No	2 – GO TO SECTION G
DK / CR	3 – GO TO SECTION G

IF CODED 1 AT Q23

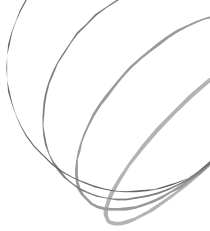
24 Did they offer to pay for your travel to this different hospital?

Yes, all travel costs	1
Yes, some travel costs	2
No	3
DK / CR	4

25a Did you accept this earlier appointment at a different hospital?

Yes	1 – GO TO SECTION G
No	2 – ASK 25b

25b Please can you tell me why you didn't accept the earlier appointment at a different hospital? PROBE FULLY AND WRITE IN



SECTION G: EQUALITIES AND DIVERSITIES

ASK ALL

Finally, it would be helpful to us if we can know a little bit more about you or the person you care for. We need to know this information to make sure that all people in Scotland have their appointments arranged and managed effectively and are not discriminated on grounds of their personal characteristics such as gender, age or ethnic group. This information will remain confidential and anonymous and all the survey findings will be reported in aggregate form only.

26 Do you have a long standing physical or mental condition or disability that has troubled you for at least 12 months, or that is likely to affect you for at least 12 months?

- Yes 1 – ASK Q27
- No 2 – GO TO Q29

ASK ALL CODED 1 AT Q26

27 Thinking of the hospital staff who arranged your appointment, how sensitively do you think they handled your needs?

- Very well 1
- Fairly well 2
- Not very well 3
- Not at all well 4
- DK / CR 5

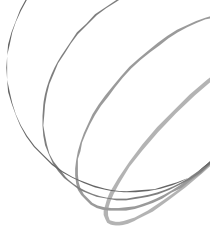
28a Would you have liked READ OUT AND CODE BELOW

ASK FOR EACH CODED 1 AT Q28a

28b Did the hospital offer this to you?

28c Did the hospital provide this to you?

	28a		28b		28c	
	Yes	No	Yes	No	Yes	No
Additional support to help you arrange or attend an appointment (eg, translation service, documents in other languages or in Braille, liaising with carer, reminder of when appointment was, transport to or from the hospital)	1	2	1	2	1	2
A longer appointment (ie, longer than standard appointment)	1	2	1	2	1	2
Written summaries of discussions	1	2	1	2	1	2
Someone to help you communicate, to explain your needs etc	1	2	1	2	1	2
Other (write in) →	



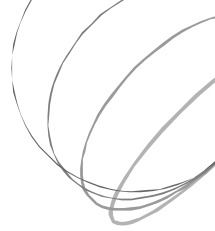
ASK ALL RESPONDENTS

29 Which of the following best describes your ethnic group? READ OUT

White	Scottish	1
	Other British	2
	Irish	3
	Other white	4
Mixed	Any mixed background (please specify)	5
	
Asian, Asian Scottish or Asian British	Indian	6
	Pakistani	7
	Bangladeshi	8
	Chinese	9
	Other Asian (please specify)	10
.....		
Black, Black Scottish, Black British	Caribbean	11
	African	12
	Other	13
	(please specify)	
.....		
Any other background	(please specify)	14
.....		
Any other ethnic background	(please specify)	15
.....		

30 Would you say you are fluent in English or that you are not fluent in English?

Fluent in English	1
Not fluent in English	2
Other (write in)	3
.....	



Appendix 2

Planning the fieldwork

How respondents were selected for interview

There are 14 territorial NHS boards in Scotland. The number of interviews which would have been conducted in each board area was calculated if sampling was done proportionate to the population of each board area (second and third columns in Exhibit A). As this would have resulted in very low numbers of interviews in certain board areas, we agreed quotas to ensure sufficient representation in each board area (fourth column in Exhibit A). A minimum target of 50 interviews was set for mainland boards. Due to the smaller population sizes, a minimum of 35 interviews was set for each island board, ensuring sufficient island representation. The actual sample size reflected the quotas set (final column in Exhibit A).

The profile of eligible respondents was unlikely to reflect the profile of the adult population in each NHS board area, so no fixed quotas on gender, age and other criteria were applied. The margin of error associated with an overall sample size of 800 is +/- 3.5 per cent.

Telephone sample lists were purchased in a ratio of 25:1 per effective interview within each NHS board (based on a minimum 30 per cent effective response, an assumed 15 per cent eligibility and allowing some contingency). Household numbers were called up to five times in order to elicit an effective response, as follows:

- identification of an eligible respondent and an interview, appointment, refusal or
- an effective screening interview that confirmed no eligible respondents in the house or
- a straight refusal at the contact stage.

Interviewers were able to interview not just patients but also, where appropriate, their carers.

Interviewers were instructed to record details for any respondent for whom English was not their first language. In these cases an interpreter would be called on to take the respondent through the survey. None of the contacts required an interpreter. Only one person contacted was not fluent in English and the respondent's carer answered on their behalf.

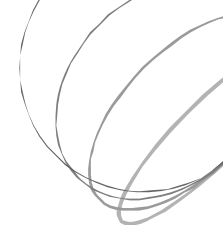


Exhibit A

Profile of quantitative sample

A minimum of 35 interviews was achieved in each NHS board area.

NHS board	Approximate percentage of population	Sample size proportionate to population	Quota set	Sample achieved
Ayrshire & Arran	7	56	50	50
Borders	2	16	50	50
Dumfries & Galloway	3	24	50	50
Fife	7	56	50	50
Forth Valley	6	48	50	50
Grampian	10	80	50	50
Greater Glasgow & Clyde	23	184	130	130
Highland	6	48	50	50
Lanarkshire	11	88	65	65
Lothian	16	128	100	100
Orkney	0.4	3	35	35
Shetland	0.4	3	35	35
Tayside	8	64	50	50
Western Isles	0.5	4	35	35
Total	100	800	800	800

Source: George Street Research

Pilot

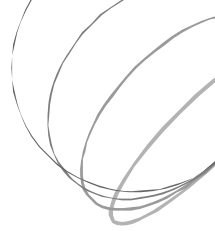
A pilot phase of 50 interviews was conducted across all NHS board areas. Findings from this assisted in:

- refining and validating the format, structure and length of the questionnaire
- checking and validating likely response rates
- establishing the incidence of eligible respondents prior to the main stage fieldwork.

Some very minor changes were made to the questionnaire in light of pilot findings.

Choosing people to interview

In order to achieve 800 interviews, a total of 6,298 calls were made. These resulted in potential interviews; contacts where the telephone was answered and the respondents were willing to complete the survey.



In order to progress onto the full survey respondents had to meet three criteria:

Referral

For the first of these, respondents were asked:

*Please can you tell me whether you, or someone aged over 16 who you care for, has been referred by your GP or dentist for any of the following **within the last six months**? We are only interested in referrals within the NHS not through any private medical cover:*

- a new appointment at a clinic to see a consultant. (Interviewers were instructed to ensure respondents were not referring to a follow-up or regular appointment)
- a hospital admission either as an inpatient (with at least one night in hospital) or as a day case patient
- a follow-up or regular appointment
- none of these / not applicable as not a carer.

Those who answered yes to 'a new outpatient appointment' or 'a hospital admission', carried on to the next criteria question. Respondents who reported that they had a new appointment or hospital admission and also a follow-up or regular appointment were asked to complete the survey in relation to the new appointment or hospital admission.

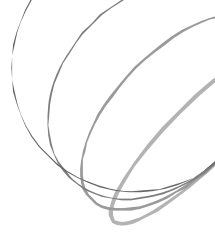
From the 6,298 original contacts, 5,109 (81 per cent) did not answer yes to either of the recruitment criteria and so did not progress.

Reason for referral

Respondents were then given a series of possible treatments or conditions and asked whether they, or the person they care for, had been referred for:

- any form of radiology such as MRI or CT scan or barium enema
- any homeopathic related treatment
- any form of endoscopy such as colonoscopy, cystoscopy or sigmoidoscopy
- any form of oncology / cancer treatment
- anything to do with pregnancy
- any mental health issues
- something different / none of the above.

Only those respondents who had been referred (or who care for someone who had been referred) for *something different / none of the above* (ie, conditions or treatments **not** specified on the list) were eligible to continue.



Respondents could continue with the interview if they had been referred for one of the conditions or treatments on the list providing that they had also been referred for *something else*. These respondents were asked to complete the survey in relation to the referral for the other condition / treatment.

From the 1,189 respondents who had passed the first criteria, 266, or four per cent of the 6,298 original contacts, had not been referred for a different condition or treatment and so did not continue.

Contact with hospital

The third criterion related to contact with a hospital about the appointment and respondents were asked:

Have you/they had any form of contact with the hospital about arrangements for the appointment? This might have involved the hospital making contact by letter or telephone, or it might have involved you contacting the hospital about the appointment.

Only those respondents who answered yes (for themselves or for the person they care for) were eligible to continue with the survey: 123 (two per cent of the original 6,298 contacts) said no at this question and so did not continue. Eight hundred people (13 per cent of the original 6,298 contacts) were eligible. Exhibit B shows the profile of the 800 respondents.

Profile of respondents

Of the 800 interviews conducted across the 14 NHS boards, 744 (93 per cent) were with respondents reporting on their own experiences of NHS waiting lists in the last six months and 56 (seven per cent) were with carers of people who had been placed on waiting lists.

Over half (58 per cent) of respondents were female and 42 per cent male; 33 per cent were working and 67 per cent not working, including people who were retired, unemployed and students (Exhibit B).

The majority (93 per cent) of respondents had typical experiences (ie, they had accepted and attended an appointment) while the remainder (seven per cent) were atypical (ie, they had either accepted but then not attended or had not accepted an offered appointment).

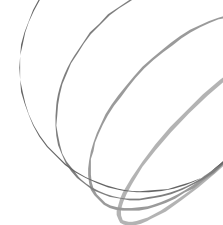


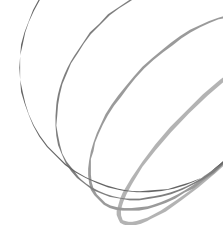
Exhibit B

Profile of respondents

	Percentage		Percentage
Gender		Disability or long-standing condition	
Male	42	Yes	42
Female	58	No	58
Age		Deprivation index	
16-24	3	1 (Most deprived)	8
25-34	4	2	10
35-44	8	3	11
45-54	16	4	13
55-64	18	5	12
65-74	24	6	12
75-84	23	7	11
85+	5	8	10
Refused	1	9	8
Working status		10 (Least deprived)	6
Full time (30+ hrs)	23	Rurality	
Part time (>30 hrs)	10	Large urban	28
Not working	7	Other urban	28
Unemployed	3	Accessible small town	11
Retired	56	Remote small town	11
Student	0*	Accessible rural	11
Refused	0*	Remote rural	12
Respondent type		Ethnicity	
Patient	93	White – Scottish	87
Carer	7	White – Other British	10
Patient type		White – Irish	1
Typical	93	Other white	1
Atypical	7	Asian – Indian (3 respondents)	0*
Fluent in English		Asian – Pakistani (1 respondent)	0*
Yes	799	Asian – Chinese (2 respondents)	0*
No	1**		

0* = less than one per cent. **Interview conducted with the carer.
The figures are the percentage of all respondents (800).

Source: George Street Research



The Scottish Index of Multiple Deprivation (SIMD) data in Exhibit B derive from respondent postcodes.¹ The SIMD was designed with the purpose of identifying area concentrations of multiple deprivation across Scotland. It provides a 'scale' of deprivation.

Rurality figures in Exhibit B were derived from respondent postcodes and relate to the Scottish Government's six-fold Urban Rural Classification system (Exhibit C).

Exhibit C

Urban Rural Classification system

Category	Definition
1 Large Urban Areas	Settlements of over 125,000 people.
2 Other Urban Areas	Settlements of 10,000 to 125,000 people.
3 Accessible Small Towns	Settlements of between 3,000 and 10,000 people and within 30 minutes drive of a settlement of 10,000 or more.
4 Remote Small Towns	Settlements of between 3,000 and 10,000 people and with a drive time of over 30 minutes to a settlement of 10,000 or more.
5 Accessible Rural	Settlements of less than 3,000 people and within 30 minutes drive of a settlement of 10,000 or more.
6 Remote Rural	Settlements of less than 3,000 people and with a drive time of over 30 minutes to a settlement of 10,000 or more.

Source: *The Scottish Government Urban Rural Classification 2007-2008*

¹ *Scottish Index of Multiple Deprivation*, Scottish Government, 2009