

○ An evaluation of the National
Cancer Survivorship Initiative
test community projects

Report of the baseline patient
experience survey

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PICKER INSTITUTE EUROPE

26 NOVEMBER 2009

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ISBN 1 90594523 and 978 1 9059 45 23 8

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1. Introduction

This report presents the findings of a patient experience survey conducted as part of the evaluation of the National Cancer Survivorship Initiative (NCSI) test community projects. It describes the baseline survey conducted during July – October 2009 and presents the results of analysis of 1284 questionnaires completed by patients receiving care at seventeen test community projects.

It is planned to repeat the survey during July – October 2010 to gather data to measure the impact of the test community projects on patient experience.

To allow aggregation of data, the survey used a standardized methodology with each project using the same questionnaire and approach to mailing. The methodology was developed in collaboration with the test community projects, NHS Improvement – Cancer, the Department of Health and the NCSI work streams.

2. Methods

Feedback was gathered from patients in a postal self-completion questionnaire survey using an approach shown by Picker Institute Europe over the past ten years to generate high quality outputs that lead to a high degree of confidence in the findings. A copy of the questionnaire and the survey guidance are available as separate appendices.

Initial discussions in March 2009 involved all 18 NCSI adult test community projects (TCPs). Two projects withdrew from the evaluation at a later stage (Liverpool and South West London). The University College London Hospital (UCLH) test community was unable to resolve local research and development (R&D) and resourcing issues in time to provide data for inclusion in this report. They are anticipated to have results by January 2010 which will be presented separately. The Three Counties Cancer Network (3CCN) drew separate samples for each of the three projects within the network. Final analysis is therefore presented for 17 projects.

The standard methodology included the use of four survey mailings – a pre-approach letter, a first full questionnaire mailing, a first reminder letter and a second reminder with a full questionnaire pack. Due to difficulties with obtaining local (R&D) governance approvals and/or in drawing their samples, seven test communities were unable to complete the four mailings according to the recommended methodology within the timeframe for the baseline survey. Information about the alternative approaches they adopted is set out below.

Sampling

The test communities were provided with survey guidance setting out the recommended sampling approach. Due to variations between communities, some chose to select sample characteristics that varied from these guidelines.

Each test community was asked to generate a sample of at least 150 patients for the baseline survey, including 75 patients with characteristics similar to the intervention group and 75 other patients who would form a control or comparison group. Projects experienced difficulties identifying a comparison group and it did not prove possible to gather sufficient data to conduct control group analysis.

Between three and twelve months after the end of initial treatment was suggested as an appropriate point to sample patients, however it is clear from the analysis that patients have been included who have been discharged some time before this.

Sites with a number of different projects were advised to generate a sample of 150 for each project. The Three Counties Cancer Network (3CCN) were the only community to do this, generating three samples - one for each of the projects being implemented in each county.

Baseline survey – mailing strategies

Project leads were advised to send a pre-approach letter to all patients in their sample inviting them to take part in the evaluation and giving them the opportunity to opt out before their contact details were given to Picker Institute Europe to be used for the first questionnaire mailing. In this phase the Picker Institute received a number of helpline calls from patients who had received a letter but were unaware that they had a cancer diagnosis. Details were passed to the relevant project leads who were asked to contact the patients directly to explain why they had been included in the sample.

Five communities sent a pre-approach opt out letter as advised, with an overall opt out rate of 10% (range = 3-18%) as shown in the table below.

Test Community	Original Sample Size / Number pre-approach letters sent out	Opt out rate
Clatterbridge	150	3%
Birmingham	150	10%
Mount Vernon	150	5%
Bristol	160	13%
Luton	200	18%

Four communities were required by internal R&D guidance to send a pre-approach opt in letter, with opt in rates of between 22% and 53% as shown below.

Test Community	Original Sample Size / Number pre-approach letters sent out	Opt in rate
South East Wales herceptin project	Opt in - 150	53%
Royal Free and Marie Curie	Opt in - 370	22%
East Kent	Opt in - 150	67%
Bournemouth	Opt in - 300	50%

Six communities were unable to resolve local R&D and/or resourcing issues within the timeframe for the main survey mailing. These projects, shown in the table below, agreed individual mailing schedules.

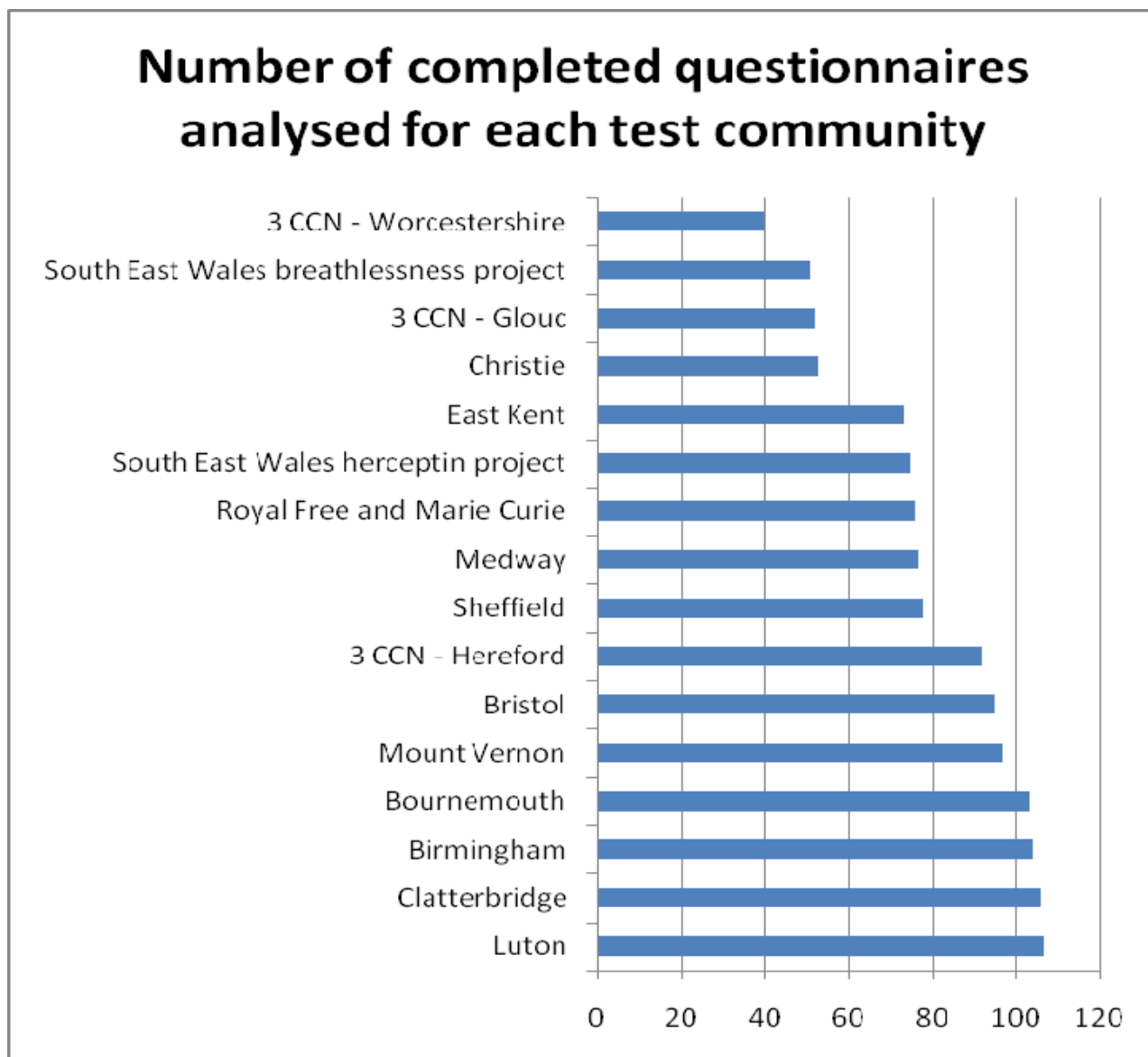
Test Community	Original Sample Size / Mailing approach
Christie	150 / Pre-approach plus 2 questionnaire mailings
South East Wales breathlessness project	150 / No pre-approach; 2 questionnaire mailings
3 CCN: a) Herefordshire b) Worcestershire c) Gloucestershire	No pre-approach letter a) 150 / 3 questionnaire mailings b) 50 / 2 questionnaire mailings c) 86 / 2 questionnaire mailings
Sheffield	133 / No pre-approach; 2 questionnaire mailings
South of Tyne and Wear	7 / handed directly to patients in clinic
Medway	140 / No pre-approach; 1 questionnaire mailing

3. Response rates

The final response rates for each project are shown in the table below.

Test Community	Completed returns	Response rate	Opt outs / blanks	Total returns (including opt outs by phone)	Total mailed	Return rate (including opt outs)
Luton Community Services	107	65%	19	126	164	77%
Clatterbridge Centre for Oncology	105	71%	12	117	147	80%
Pan Birmingham Cancer Network	105	78%	8	113	135	84%
Bournemouth	104	69%	21	125	150	83%
Mount Vernon	97	68%	10	107	142	75%
Bristol	93	68%	13	106	137	77%
3 CCN - Herefordshire	92	61%	10	102	150	68%
Royal Free and Marie Curie Hospice	78	84%	3	81	93	87%
Sheffield	78	59%	11	89	133	67%
Medway	77	55%	6	83	140	59%
South East Wales herceptin project	74	88%	2	76	84	90%
East Kent Hospitals	73	83%	3	76	88	86%
The Christie NHS Foundation Trust	53	71%	2	55	75	73%
3 CCN - Gloucestershire	52	61%	8	60	85	71%
South East Wales breathlessness project	51	34%	6	57	150	38%
3 CCN - Worcestershire	40	80%	5	45	50	90%
South of Tyne and Wear	5	71%	0	5	7	71%
All projects	1284	67%	139	1423	1930	74%
Response rate	67%					
Opt out rate	7%					
Return rate	74%					

A total of 1,284 completed questionnaires were received before the close of fieldwork on 14th October, an overall response rate of 67%. Response rates for projects whose first questionnaire mailings were sent out on 27th July range from 65% to 89%. The overall final response rate is lower than anticipated because six projects did not send their first mailing out until September and were therefore unable to complete the recommended pre-approach plus three questionnaire mailings. The number of returns analysed for each project is shown in the chart below.



4. Results

Results of analysis of the 1,284 completed questionnaires are presented in tables and charts as separate appendices to this report available on request from Picker Institute Europe:

Appendix One: tables and charts of responses to all questions for all 1284 respondents

Appendix Two: tables and charts of responses to key questions for each project

Appendix Three: tables of responses to key questions for different demographic and other sub-groups including by:

- cancer type
- time since end of initial treatment
- age
- sex
- ethnicity
- economic status
- health status
- hearing impairment.

Appendix Four: variations between those with/without an up-to-date care plan

Appendix Five: Content analysis of responses to open ended comments

The following sections of this report provide an overview of respondent characteristics, key findings and variations between the different sub-groups of the sample identified above and a summary of respondent's comments in response to three open ended questions at the end of the questionnaire.

5. Respondent characteristics

- 91% of respondents described their ethnic origin as 'white British'; 52% were female and most were aged over 61; just under a third were aged 60 or under including 3% who were under 41.
- 32% of respondents had a long term condition, including 13% each with either a long term physical condition or a long standing illness and 10% with a severe hearing impairment or deafness; more than half with a long term condition said this caused difficulty with one or more aspect of daily life, most commonly the everyday activities that people of the same age could usually do (41%), access to buildings, streets or vehicles (14%) and communicating or socialising (11%).
- Just over half of respondents completed their education or vocational training before the age of 17.
- Over half of respondents were retired (57%); 31% were working including 3% who were on sick leave; 1% were unemployed but seeking work and 5% described themselves as unable to work because of disability or ill health.
- 94% of patients who completed a questionnaire had been treated for seven main cancer types:
 - breast (32%)
 - colon, rectal or bowel (10%)
 - head and neck (8%)
 - leukaemia or lymphoma (6%)
 - pelvic, womb, cervix, ovary or endometrial (3%)
 - prostate (28%)
 - skin (7%).
- The average time since initial diagnosis was 2.1 years (standard deviation 2.2 years).
- Just under half of the sample had completed their initial treatment in the previous year (ie during 2009 or late 2008) and about a quarter during early 2008 or 2007; 13% had completed initial treatment during 2006 or earlier and 13% did not answer this question. The earliest year given for end of initial treatment was 1979.

6. Key findings

Overall impression of quality of follow up care

- 85% of patients said their follow up care was 'excellent' or 'very good' and just 5% said it was 'poor' or 'fair'.

Knowing who to contact for advice

- 74% of all respondents had a named individual they could contact if concerned but 21% did not; most commonly this key worker was a nurse specialist (70%) or a specialist doctor (27%) at the hospital and for 14% it was the GP.
- 65% of patients definitely knew who to contact in office hours and a further 23% thought they knew; 11% of patients did not know who to contact.
- Patients were less likely to know who to contact out of office hours with 75% saying they did not know who to contact.

Current unmet needs

- 69% of patients said they currently needed no extra help with physical, clinical or medical concerns; just over a quarter (26%) of those who required additional help needed help with four or more different physical aspects of living after cancer.
- Unmet physical needs most frequently mentioned were feeling tired, weak or frail (13%), problems sleeping at night (11%) and bladder or urinary problems (9%). Concerns about physical fitness, weight, sexual function and bowel or digestive problems were also mentioned frequently.
- 73% of patients said they currently needed no extra help with social or emotional concerns; nearly a quarter (24%) of those who required additional help needed help with four or more social or emotional aspects of living after cancer.
- Unmet social or emotional needs most frequently related to fears about a recurrence (16%); smaller number mentioned feeling anxious or depressed (8%), the effect on sexual life (8%), being able to do usual household tasks (6%) and lacking in self confidence (6%).
- 89% of patients said they currently needed no extra help with the economic aspects of living with cancer; most of those who had unmet economic concerns needed help with just one aspect (71%) and few mentioned more than two aspects.
- 3% of patients needed help with their concerns about returning to work and 2% with the costs of attending appointments.

Care provided by health professionals

- Almost all patients reported positive experiences of the care provided by the different health professionals involved and few reported any problems.
- Patients were able to ask the questions they wanted to ask, get answers they could understand and felt the health professionals listened to them; 86% felt they had been

given consistent advice all or most of time and 96% felt they had been treated with dignity and respect by health professionals all (or most of) the time.

- Patients on the whole felt involved in decisions about their care and that their family or friends were as involved as they wanted them to be.
- 67% reported they had been able to access specialist advice when they needed it all (or most of) the time, just 1% felt they had not been able to do this at all and 15% said they had not needed to access specialist advice; almost all patients had confidence in the specialists providing their care all (or most of) the time (91%) or some of the time (7%); confidence in the GP in relation to cancer follow up care was lower but still only 3% said they had no confidence in their GP in this respect.
- 81% felt the different health professionals providing their care had worked well together all (or most of) the time and just 1% felt they had not at any time.

Information and advice

- 80% of patients were given written information; all said the information was easy to understand completely (85%) or 'to some extent' (15%) and just 8% said the information did not cover all they areas they needed. 6% felt they had received too much written information and 5% too little.
- Nearly all reported that they had clear information about scheduling of future appointments and what to expect at these appointments; this is an interesting contrast to responses to a specific question about having a care plan where 64% said they did not have a care plan.
- When asked if they would have liked more information or advice about any aspect of life after cancer, 43% said they would have liked more information about one or more aspect; most frequently identified gaps related to the physical aspects such as side effects or signs of a recurrence (27%), diet and exercise (15%), the psychological or emotional aspects (14%).

Preferences for location and providers of follow up care

- 62% of patients had had most of their follow up care at their local hospital, 16% at another hospital, 10% at their GP surgery and 6% elsewhere; 14% said they had not had any follow up care.
- 6% of patients said they had no preference in terms of who delivered their follow up care; almost all the others preferred to have most of their follow up care at their local hospital – 71% delivered by a specialist doctor and 21% by a specialist nurse; 8% preferred to see their GP; a small number expressed a preference for telephone follow up – 2% with a specialist and 1% with their GP.
- The most frequently cited influences on preference for follow up care was confidence in the knowledge of the healthcare professionals (43%), continuity of care or the relationship with a specific doctor or nurse (36%) and ease of travelling to appointments (29%).

7. Variations

For the purpose of making comparisons between test communities and between demographic and other sub groups, key questions were re-coded to give a score on a 0-100 scale. The most positive response option was scored 100 and the least positive scored as 0. Scores for intermediate response options were allocated evenly between these scale points (for example, for a three response-option question such as Question 12, the middle option was scored 50). Mean scores were then compared to identify statistically significant differences¹. Data for the different groups in the survey are presented for the test communities in Appendix 2 and for demographic groups (including cancer types) in Appendix 3. Variations between those with/without an up-to-date care plan (question 28) are presented in Appendix 4.

The key differences are summarised below.

Variations between different test communities

Comparisons were made across the test communities, and statistically significant differences found in several areas of care. There were too few responses from the South Tyne and Wear community, and these were removed from the analysis. There was no overall trend to the results, but South East Wales projects tended to generate more negative ratings and Christie slightly more positive ratings than other communities. The significant differences were:

- There is a named individual I can contact if I have a concern (p<0.0005: Christie and 3 Counties Worcestershire more -ve)
- I need no extra help with physical concerns at present (p=0.023: SE Wales breathlessness -ve)
- I need no extra help with social or emotional concerns at present (p=0.003: SE Wales herceptin -ve)
- I need no extra help with [financial/occupational] concerns at present (p=0.002: Sheffield -ve)
- I know who to contact in office hours if I have a concern (p=0.003: Mt Vernon -ve)
- I know who to contact out of office hours if I have a concern (p<0.0005: Royal Free/Marie Curie and SE Wales breathlessness +ve, Worcestershire -ve)
- The health professionals listened to me (p=0.007: Clatterbridge +ve, SE Wales breathlessness -ve)
- I have had confidence in my GP in relation to my cancer follow up care (p<0.0005: SE Wales breathlessness and herceptin -ve)
- I have clear information about the scheduling of future appointments (p<0.0005: Christie +ve, SE Wales herceptin -ve)

¹ Mean scores were compared using analysis of variance (ANOVA) with Tukey's wholly significant difference post-hoc test to identify statistically significant differences.

- I have clear information about what to expect at future appointments (p=0.003: Christie +ve)
- I got all the information and advice I wanted (p=0.003: Worcestershire +ve)
- Overall impression of the quality of care and services since end of initial treatment (p<0.0005: Clatterbridge and Christie +ve, E Kent -ve).

Variations between cancer types

Cancer types described by respondents were coded into categories and question scores compared across categories. There were a number of statistically significant differences between categories. There was no overall trend, but Head/neck tended towards more negative views and Leukaemia/lymphoma more positive:

- There is a named individual I can contact if I have a concern (p<0.0005: Leukaemia/lymphoma +ve, Head/neck -ve)
- I know who to contact in office hours if I have a concern (p<0.0005: Head/neck -ve)
- I know who to contact out of office hours if I have a concern (p<0.005: Leukaemia/lymphoma, Other +ve)
- I received the right amount of written or printed information about my condition (p=0.10: Colon/rectal/bowel, Skin/melanoma, Prostate, Leukaemia/lymphoma +ve, Other -ve)
- I have clear information about the scheduling of future appointments (p=0.004: Pelvic/womb/cervix/ovary/endometrial +ve, Colon/rectal/bowel -ve).

Variations between groups based on time since end of initial treatment

Respondents were grouped according to time since completion of initial treatment. There were statistically significant differences between such groups for three questions.

- There is a named individual I can contact if I have a concern (p<0.0005: 2008 (first half) and 2009 +ve, Before 2006 -ve).
- I know who to contact out of office hours if I have a concern (p<0.0005: 2009 +ve, 2006 and before -ve).
- I have clear information about what to expect at future appointments (p=0.012: Before 2006 +ve, 2008 (first half) -ve).

Variations between different socio demographic groups

Between males and females

There are statistically significant variations between male and female respondents on most questions. Men most frequently reported more positive experiences than women. This pattern is similar to that seen in the CQC national NHS inpatient surveys.

The statistically significant differences were:

- There is a named individual I can contact if I have a concern (p=0.002: Females +ve)
- I need no extra help with social or emotional concerns at present (p<0.0005: Males +ve)
- I need no extra help with [financial/occupational] concerns at present (p<0.0005: Males +ve)
- I know who to contact out of office hours if I have a concern (p=0.007: Females +ve)
- I have been able to ask the questions I wanted to ask (p=0.001: Males +ve)
- I got answers I could understand to my questions (p=0.015: Males +ve)
- The health professionals listened to me (p=0.028: Males +ve)
- I have been given consistent advice by the health professionals I have spoken to (p=0.015: Males +ve)
- I have been treated with respect and dignity by the health professionals providing my care (p=0.042: Males +ve)
- I have felt involved in decisions about my care (p=0.047: Males +ve)
- My family or friends have been as involved as I wanted them to be (p=0.010: Males +ve)
- I have been able to access specialist advice when I needed it (p=0.028: Males +ve)
- I have had confidence in the specialists caring for me (p=0.004: Males +ve)
- I have had confidence in my GP in relation to my cancer follow up care (p<0.0005: Males +ve,)
- I have clear information about the scheduling of future appointments (p=0.013: Males +ve)
- I have clear information about what to expect at future appointments (p=0.020: Males +ve)
- I got all the information and advice I wanted (p<0.0005: Males +ve).

Between age groups

Based on the year of birth given by respondents, their age was classified in to the following categories: up to 40; 41-50; 51-60; 61-70; 71-80; 81-90; over 90. There were statistically significant differences in a number of areas of care between age groups. There was no general trend in these differences, but respondents aged 41-50 were often more negative and either under 40s or over 80s often more positive. For the purpose of analysing the differences, all those over 80 were combined into one group. The significant differences were:

- I need no extra help with physical concerns at present (p=0.002: under 40 +ve, 41-60 -ve)
- I need no extra help with social or emotional concerns at present (p<0.0005: over 80 +ve, 41-50 -ve,)
- I need no extra help with [financial/occupational] concerns at present (p<0.0005: over 60 +ve , 41-50 -ve)
- I know who to contact in office hours if I have a concern (p=0.018: under 40 +ve)
- The health professionals listened to me (p=0.007: under 40 +ve, 41-50 -ve)
- I have been given consistent advice by the health professionals I have spoken to (p=0.027: under 40 +ve, 41-50 -ve)
- I have felt involved in decisions about my care (p=0.019: over 80 +ve, 41-50 -ve)
- I have been able to access specialist advice when I needed it (p<0.0005: under 40 and over 80 +ve, 51-60 -ve)
- I have had confidence in my GP in relation to my cancer follow up care (p=0.001: over 80 +ve , 41-50 -ve)
- The written or printed information I was given covered all the areas I needed it to (p=0.003: over 80 +ve, under 40 and 51-60 -ve)
- I have clear information about the scheduling of future appointments (p<0.0005: 71-80 +ve, all under 50 -ve)
- I have clear information about what to expect at future appointments (p=0.001: 61-80 +ve, under 40 -ve)
- I got all the information and advice I wanted (p<0.0005: over 70 +ve, 41-60 -ve)
- Overall impression of the quality of care and services since end of initial treatment (p=0.003: under 40 +ve, 51-60 -ve).

Between educational subsets

There were statistically significant differences in three areas of care between those in different groups in terms of their educational experience (age on completing education or vocational training). For the purpose of analysing these differences, those currently in education were excluded. The significant differences were:

- The written or printed information I was easy to understand (p=0.014: 19 years or over +ve)
- The written or printed information I was given covered all the areas I needed it to (p<0.0005: 16 years or less +ve, 19 years or over -ve)
- I have clear information about the scheduling of future appointments (p=0.001: 16 years or less +ve).

Between employment situations

The statistically significant differences, once those currently in education or training were excluded, were:

- I need no extra help with physical concerns at present (p<0.0005: retired or in part-time employment +ve, unable to work for health reasons -ve)

- I need no extra help with social or emotional concerns at present ($p < 0.0005$: retired or self employed +ve, unable to work for health reasons -ve)
- I need no extra help with [financial/occupational] concerns at present ($p < 0.0005$: on sick leave, unemployed, or unable to work -ve)
- The different health professionals involved in my care have worked well together ($p = 0.002$: unemployed +ve, unable to work -ve).

Between ethnic groups

There were statistically significant differences between ethnic groups across a number of areas of care. However, owing to the very small numbers in most groups, it was not possible to identify reliably where those differences lay. The questions where significant differences were in evidence were:

- I need no extra help with [financial/occupational] concerns at present ($p = 0.014$)
- I know who to contact in office hours if I have a concern ($p = 0.012$)
- I have been able to ask the questions I wanted to ask ($p = 0.007$)
- The health professionals listened to me ($p = 0.003$)
- My family and friends have been as involved as I wanted them to be ($p = 0.007$)
- I have been able to access specialist advice when I needed it ($p = 0.022$)
- The written or printed information I was given covered all the areas I needed it to ($p = 0.013$)
- I received the right amount of written or printed information about my condition ($p = 0.008$)
- Compared with all other respondents together, White British respondents were more likely to say they knew who to contact in office hours ($p = 0.004$), more likely to say they were able to ask all the questions they wanted to ask ($p = 0.030$) and less likely to say they had an up to date care plan ($p = 0.042$).

Between those with/without a chronic health condition

Comparisons were also made between those who declared a long-term health condition and those who declared none. In each case where there was a statistically significant difference, those with a chronic condition were more negative in their ratings. These were:

- I need no extra help with physical concerns at present ($p < 0.0005$)
- I need no extra help with social or emotional concerns at present ($p < 0.0005$)
- I need no extra help with [financial/occupational] concerns at present ($p = 0.001$)
- I know who to contact in office hours if I have a concern ($p = 0.035$)
- I have been given consistent advice by the health professionals I have spoken to ($p = 0.013$)
- The written or printed information I was given was easy to understand ($p = 0.001$).

Between those with/without a hearing impairment

Four questions showed significantly more positive ratings by those with a severe hearing impairment:

- I got answers I could understand to my questions (p=0.018)
- I have felt involved in decisions about my care (p=0.026)
- I have been able to access specialist advice when I needed it (p=0.016)
- I have had confidence in my GP in relation to my cancer follow up care (p=0.002).

Variations between those with/without an up-to-date care plan (question 28)

Almost all the ratings show a difference in favour of those with a care plan:

- There is a named individual I can contact if I have a concern (p<0.0005, No -ve)
- I need no extra help with physical concerns at present (p=0.010, Definitely +ve)
- I need no extra help with social or emotional concerns at present (p=0.008, No -ve Definitely +ve)
- I know who to contact in office hours if I have a concern (p<0.0005, Definitely +ve)
- I know who to contact out of office hours if I have a concern (p<0.0005, Definitely +ve)
- I have been able to ask the questions I wanted to ask (p<0.0005, No -ve Definitely +ve)
- I got answers I could understand to my questions (p=0.016, Definitely +ve)
- The health professionals listened to me (p<0.0005, No -ve Definitely +ve)
- I have been given consistent advice by the health professionals I have spoken to (p<0.0005, No -ve)
- I have felt involved in decisions about my care (p=0.007, No -ve Definitely +ve)
- I have been able to access specialist advice when I needed it (p<0.0005, No -ve)
- I have had confidence in the specialists caring for me (p=0.021, No -ve Definitely +ve)
- The different health professionals involved in my care have worked well together (p<0.0005, No -ve)
- The written or printed information I was given was easy to understand (p=0.001, Definitely +ve)
- The written or printed information I was given covered all the areas I needed it to (p<0.0005, No -ve)
- I received the right amount of written or printed information about my condition (p=0.002, No -ve Definitely +ve)
- I have clear information about the scheduling of future appointments (p<0.0005, No -ve Definitely +ve)
- I have clear information about what to expect at future appointments (p<0.0005, Definitely +ve)

- I got all the information and advice I wanted ($p < 0.0005$, No -ve Definitely +ve)
- Overall impression of the quality of care and services since end of initial treatment ($p < 0.0005$, No -ve Definitely +ve).

Associations

In addition to the above comparisons, associations were investigated between a number of pairs of variables. The findings were:

- Question 4 - Is there a named individual you can contact if you have a concern? - was correlated at a low level with Question 10a - Do you know who to contact in office hours if you have a concern? (Cramer's $V = 0.38$, $p < 0.0005$) and Question 10b - Do you know who to contact out of office hours if you have a concern? (Cramer's $V = 0.21$, $p < 0.0005$), and at a very low level with Question 18 - I have been able to access specialist advice when I needed it (Cramer's $V = 0.18$, $p < 0.0005$).
- Question 6(1) - needing no extra help for physical concerns - was correlated at a very low level with Question 36(3) - having a long-standing physical condition (Cramer's $V = 0.14$, $p < 0.0005$).
- Question 6(2) - needing extra help for feeling tired, weak or frail - was correlated at a low level with Question 7(3) - needing extra help for feeling anxious or depressed (Cramer's $V = 0.36$, $p < 0.0005$) and Question 7(14) - needing extra help for fears about a recurrence (Cramer's $V = 0.25$, $p < 0.0005$).
- Question 9(2) - needing help for financial concerns - was associated with occupational status. Financial concerns were reported by 33% of those on sick leave from work, 25% of those in part-time employment, 25% of those unable to work and 31% of those seeking work, compared to 6% of the sample overall who reported such concerns.
- Those who definitely had clear information about the scheduling of future appointments were more likely to say that they needed no extra help with physical concerns (72% compared with 54% of those who did not have clear information) or social and emotional concerns (77% compared with 46%).
- Whether or not respondents had confidence in their GP in relation to their cancer was unrelated to the length of time since their diagnosis.

8. Responses to open-ended questions

836 patients made comments in response to the open ended questions 40, 41 and 42:

- 708 patients wrote comments in response to question 40: 'things that have been particularly good'
- 459 patients wrote comments in response to question 41: 'things that could be improved'
- 370 patients wrote comments in response to question 42: 'any other comments'

The result of content analysis of responses to each question is presented in Appendix 5. The key findings of this analysis follow.

Question 40: Things that have been particularly good

708 patients made a total of 1157 comments about different aspects of their care in response to this question including:

- 272 about the type of staff (eg doctors, nurses or others)
- 247 about ways the staff behaved towards them (eg kind, friendly, helpful)
- 143 about the information, advice and support provided, including support for patient involvement in decision making
- 143 about access to services and care, including appointments and access to specialists
- 31 about continuity and integration of care
- 229 about effective diagnosis, treatment and outcomes.

Question 41: Things that could be improved

459 patients made a total of 500 comments about different aspects of their care in response to this question including:

- 139 related to the need for additional advice, support or information
- 98 related to difficulties with the process of follow up appointments
- 39 related to a lack of continuity or integration of care
- 43 were about difficulties with physical access or the physical environment
- 114 were suggestions for improvement around diagnosis, treatment and inpatient care.

Question 42: Any other comments

370 patients made a total of 380 comments about different aspects of their care in response to this question including:

- 201 were positive comments about the care they had received relating to the categories covered in responses to question 40
- 132 were suggestions for improvement or descriptions of problems relating to the categories covered in responses to question 41.

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