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A review of the results from the National Radiotherapy Patient Experience Survey in England

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ABSTRACT

Aim: The goal of the survey was to obtain a meaningful picture about patients' experiences across all radiotherapy centres within provider NHS trusts within England.
Methods: A survey questionnaire was constructed to assess patients' views about their care, information and support at all stages of their radiotherapy pathway. The questionnaire was posted to patients who attended for radiotherapy within NHS trusts in England from April until December 2012.
Key results: Many of the results were positive, for example 99% of patients had either complete confidence or confidence to some extent in the health care professional undertaking their consent. 97% of patients said that the amount of information given to them before their radiotherapy was either excellent or satisfactory. However there were 10% of patients who were not invited to an information session before radiotherapy, 14% of patients who were not told how to communicate with their radiographers whilst their treatment was delivered and 13% of patients who were not given a contact number to ring if they had any problems relating to their radiotherapy after finishing.
Conclusions and recommendations: The results indicate that the majority of patients have experienced high quality care in many aspects of their radiotherapy pathway. However there are some areas where improvements could be made. It is recommended that all Radiotherapy Service Managers (RTSMs) review their local results and implement improvements where required and they re-audit on an annual basis. It is also recommended that the national survey is repeated at regular intervals to monitor progress.

Introduction

The National Radiotherapy Implementation Group[1] (NRIG) commissioned a comprehensive Radiotherapy Patient Experience Survey[2] to allow services and commissioners to understand the patients experience during the radiotherapy process and from this enable NHS Trusts to review and implement changes to make improvements. The survey was undertaken by Quality Health,[3] who lead the National Cancer Patient Experience Survey,[4] and as part of the comprehensive Radiotherapy Programme,[5] it was funded by the NHS National Cancer Action Team. As funding was limited, it was agreed as a one-off survey during 2012.

The goal of the survey was to obtain a meaningful picture about patient experience across the 50 radiotherapy centres within NHS trusts within England, and to understand patients' views about this experience, at every step from referral to follow up across the radiotherapy pathway. The National Radiotherapy Patient Experience Survey Report[2] published the overall findings and each provider trust was sent a copy of their individual data, to enable comparison against the overall findings.

Background

Patients have the right to receive high quality care during their course of radiotherapy. National policy is focused upon the delivery of high quality care and the principle that the patient must be fully involved in all decision making "No decision about me without me" is at the heart of policy and practice.[6] Patients have the right to be treated with compassion, dignity and equity and to receive information to help their decision making at every step of their cancer journey.[7,8] Policies demand that the information given at each stage should be given in a way that is relevant, understandable and delivered in an appropriate way to meet their own specific need, and therefore the national drive is to provide tailored information, specific to meet individuals' needs.[9,10]

To measure success the government has conducted surveys of patient experience across the NHS[11] and in relation to cancer the

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National Cancer Patient Experience Survey[4] has focused upon the overall cancer pathway from referral to follow up. In this survey there was only one question which was specific to the radiotherapy experience, and whilst local surveys are undertaken by providers to understand patients' views of radiotherapy services it was recognized that there would be value in understanding the national picture for each radiotherapy provider as part of the National Radiotherapy Programme.[5]

The aim of the National Cancer Action Team Radiotherapy Programme,[5] was to drive the development of quality services and as patient experience is central to the delivery of a quality service, the National Radiotherapy Improvement Group[1] (NRIG) agreed that the survey would be helpful as:

1. Patient experience is central to a quality service but we do not know objectively what that is.
2. The National Cancer Patient Experience Survey[4] is not sufficiently discriminating for radiotherapy this survey would provide more detail about the radiotherapy services and the steps of this pathway.
3. A National Radiotherapy Patient Experience Survey[2] would support the work of the National Radiotherapy Programme[5] and help to identify any further work streams required to support developments.
4. Whilst only funded as a one-off survey it would provide a baseline opportunity for development of an action plan and opportunity to develop and improve services.

Methodology

A quantitative methodology was adopted using a questionnaire survey.[2] A questionnaire was devised which consisted of 60 questions in 11 sections (see Table 1). It included questions requiring yes/no responses, questions with multiple choice options and one free text question with three sections, which asked respondents to provide comments about anything particularly good, anything that could be improved and any other comments on their radiotherapy experience.

Approval from the Ethics and Confidentiality Committee of the National Information Governance Board[12] under Section 251 of the 2006 Act was acquired to run the survey and Quality Health[3] was contracted to facilitate the survey.

The questionnaire was designed by a working group of the National Radiotherapy Implementation Group[1] (NRIG), Service Delivery Sub Group. Its membership comprised the Associate Director – Radiotherapy National Cancer Action Team, a Radiotherapy Service Manager, Society and College of Radiographers (SCoR) Professional Officers and lay representative from the Society and College of Radiographers Public and Patient Liaison Group, a lay representative from the Royal College of Radiologists together with Quality Health.[3] The lay representatives were also members of NRIG. A pilot questionnaire was tested, by Quality Health, with a group of patients to check the validity and appropriateness of the questions. As a consequence of this pilot Quality Health made a small number of adjustments.

All NHS Trusts in England with radiotherapy services were requested to take part. It was agreed that the questionnaire would be circulated directly to patients by post from Quality Health, to all eligible adult radiotherapy patients who attended for radiotherapy at the radiotherapy centres from 1st April 2012. As the radiotherapy provider sites vary in size across England, it was agreed to aim for 500 returns from patients who had attended each centre and therefore the chosen survey period would need to take this into account. To collect sufficient data it was agreed that the survey would run for four months and would be distributed at the end of August 2012 with data collection closing at the end of December 2012. Postal distribution was agreed to encourage an honest response, as this would enable patients to feel comfortable to criticize a centre as their response would not be attributable to their radiotherapy centre.

Table 1
National Radiotherapy Patient Experience Survey categories.

Section	Number of questions
Consent	7
Written information before your radiotherapy	5
Information from websites	6
Going to hospital	4
About your radiotherapy	10
Daily treatment visits	10
Information about support	2
Further visits to clinic	3
Your overall radiotherapy care	5
About you	5
Other comments	3

The results in the Quality Health report[2] were published in absolute numbers and percentages and have been reproduced in this paper with kind permission from Quality Health.[3] A positive scoring methodology was used on each question other than "indicator" questions, to allow a clear understanding to be developed on the level of agreement with positive statements about treatment and care. Therefore, on most questions, percentages were recalculated to exclude responses when the question was not applicable to the patient, to remove neutral responses such as 'don't know' or 'can't remember', but to include in the denominator those response options which were negative to some degree. The scores reported in this paper therefore agree with this positive scoring methodology used in the national report.

Results and discussion

Response rate

With 49 of the 50 radiotherapy providers in England taking part and only one NHS radiotherapy centre in England failing to provide data, this survey provides good representation across the country and suggests the results give a clear indication of radiotherapy patients' experiences in England. The centre which failed to provide data was approached by telephone and encouraged to participate however there was no agreement made to make this possible. 24,101 (70%) patients returned their questionnaire; with an average of 492 patients per trust. The response rate was high, with a higher overall percentage response rate being experienced for this survey than the 64% achieved for the 2013 National Cancer Patient Experience Survey.[4]

Profile of the respondents

The majority of respondents (89%) were aged over 50 years with 33% of respondents being between 51 and 65 years of age as indicated in Fig. 1. 56% of respondents were female and 44% were male. The vast majority of respondents (96%) were heterosexual with only 1% being gay or lesbian and 4% preferring not to respond. The majority of respondents (60%) had no other long standing condition as indicated in Fig. 2. The vast majority of respondents (96%) were white British with the remaining 4% being from other ethic backgrounds. Two thirds of respondents (70%) had received over 10 radiotherapy treatments as indicated in Fig. 3.

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