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A single centre service evaluation of patients' experiences participating in radiotherapy clinical trials during and post COVID-19 in Northern Ireland, UK

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ABSTRACT

Introduction: Radiotherapy (RT) clinical trials allow patients to access cutting-edge innovative cancer treatments. Clinical Research Therapy Radiographers (CRRs) play an important role in the management and care of RT trial patients. The COVID-19 pandemic caused major disruption to RT trial delivery. Measures to mitigate COVID-19 risk continue to have an effect on patient contact and communication within cancer centres in the United Kingdom (UK). This study aimed to explore patient perspectives regarding their recent RT trial experience in Northern Ireland (NI), UK.

Methods: A single centre service evaluation was conducted in NI. Patients who were recruited into a RT clinical trial from January 2020 to January 2023 were invited to participate. Surveys were posted to 50 participants in April 2023. Quantitative and qualitative data was captured and analysed using descriptive statistics and Braun and Clarke's six-step thematic analysis framework respectively. Ethical approval was obtained through Ulster University and the NHS Trust.

Results: Forty-three of the 50 invited participants responded (86%). Forty-two respondents (79%) had a prostate cancer diagnosis. Forty-one (98%) participants indicated that CRRs were always approachable, polite and courteous and would recommend taking part in a RT trial to friends and family. Identified areas for improvement included aspects regarding consent and participant decision-making.

Conclusion: This study suggests that despite the implemented measures to suspend research and mitigate COVID-19 risk, patients remained highly satisfied with the quality of care that they received through their participation in RT trials.

Implications for practice: The results of this service evaluation will facilitate maintenance and improvement of patient focused delivery of cancer trials within the host centre. This study builds on evidence highlighting the importance of the CRR role and role development for radiographers.

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Introduction

Radiotherapy (RT) is a vital treatment option for people with cancer and has widespread use in both curative and palliative treatment.[1] It is estimated that around 50% of patients receive RT as part of their cancer treatment management.[2]

RT clinical trials are fundamental to the advancement of new technologies and practices within cancer treatment.[3] These trials are complex, requiring specialised skills and understanding of RT treatment for trials to be conducted safely and efficiently.[4] Clinical Research Therapeutic Radiographers (CRRs), who are specialist radiographers, play a vital role in the management and care of radiotherapy clinical trial patients.[5] The overarching aim of RT clinical research is to improve patient outcomes by improving overall survival and local tumour control, and/or reducing associated side effects.[6]

For many patients enrolled within a RT clinical trial, it can be a long process beginning with consent to trial, RT treatment, extra review assessments and extensive follow up which can last up to 10 years.[7] Assessing patient experience within a RT clinical trial can provide invaluable insight into how clinical research has the potential to enhance a cancer patient's journey. Recent satisfaction surveys of cancer patient experience have led to quality improvements in both American and European healthcare settings.[8]

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Improved understanding of the patient experience within a trial has the potential to improve trial recruitment and improve patient satisfaction/retention within the clinical research setting, in line with key NHS objectives.[9] Many research studies have focused on strategies to improve recruitment/retention within clinical trials[7,10] but few have evaluated the experience of those who have already chosen to participate in trials. A recent cancer patient experience survey within Northern Ireland (NI) covered a range of topics within cancer care, but only included a limited number of questions regarding clinical trials.[11] Results of this survey were disheartening as fewer patients reported being asked about taking part in clinical trials in 2018 (15%) compared to 2015 (18%).

Evaluation, with the aim of positively improving patient experiences in a clinical trial, may lead to improvements in treatment compliance, which can inadvertently effect the overall outcome/results of the clinical trial.[12] Furthermore, when patients are not satisfied with their clinical trial experience they may choose to withdraw consent and discontinue follow-up in a trial, which can compromise the study validity.[13]

Since research conducted on this topic is sparse, this service evaluation strived to gain knowledge about patient experience of RT clinical trial participation since the start of the COVID-19 pandemic in March 2020 to present day.

The COVID-19 worldwide pandemic caused major disruption to cancer research delivery with approximately 95% of Cancer Research UK trials being completely paused at the peak of the pandemic in 2020.[14] Measures to mitigate COVID-19 risk still continue to have an effect on patient contact and communication. Nationally, many centres throughout the UK are still conducting post-treatment review within oncology via telephone.[15]

The primary aim of this service evaluation was to establish patients' perspectives regarding their recent RT clinical trial experience. This included how participants became aware of RT trials, satisfaction levels with the RT trial information provided, motivations for taking part in a trial, satisfaction levels with support received from the CRR team, the impact of COVID-19 on their trial experience and overall satisfaction with their RT trial experience.

Methods

Study design

A single centre service evaluation was conducted in the clinical trials department in the Northern Ireland Cancer Centre (NICC) in Belfast, UK. A service evaluation was chosen as this method aims to assess how well a service is achieving its intended aims.[16] This evaluation was approved by Ulster University Nursing and Health Research Ethics Filter Committee in March 2023 (FCNUR-23-021). The Research & Development office within the Trust also issued a letter of support for the study.

Survey design

A structured anonymous postal survey was chosen, comprised of a questionnaire. Questionnaires are a method of gathering both qualitative and quantitative data in a cost-effective manner.[17] In addition, questionnaires also have the advantage of enabling participants to complete them at their own leisure.[18]

The design was informed through a review of relevant literature and adaptation of sections from the National Cancer Patient Experience Survey.[19] An initial draft of the questionnaire was shared with the other six members of the clinical research team in NICC who recommended minor changes to the structure of some of the questions to improve clarity.

Personal and public involvement (PPI) in research provides invaluable feedback so that patient satisfaction surveys are written in a clear, concise and ethical format.[20] Consequently, patient and carer members at the NICC Cancer Research Consumer Forum reviewed the evaluation protocol. Feedback from four forum members was incorporated into the evaluation design. Feedback included a minor addition to the Participant Information Sheet (PIS) to indicate the duration of the questionnaire. Forum members indicated that the length of the questionnaire was apt and not too extensive for potential participants. Feedback related to the questionnaire was very positive and only minor grammatical changes were incorporated as a result of this feedback.

The final questionnaire included questions with Likert scales and multiple choice style questions with additional comments boxes (See Supplementary Information). Variables explored included participant demographics, cancer diagnosis and year of enrolment into the trial as well as how participants became aware of their RT clinical trial. Other variables captured included participant understanding of clinical trial information, their satisfaction with trial information, motivations for participating in a RT clinical trial and their evaluation of the CRR supportive role during treatment. The perceived impact of COVID 19 on clinical trial experience, satisfaction levels regarding RT follow up and overall satisfaction with the RT clinical trial experience, were also recorded.

Sampling strategy

Purposive sampling, a form of non-probability sampling,[21] was the sampling method chosen in this study. This method provides researchers the opportunity to focus their research on a particular group of interest with a very specific purpose in mind.[21] While the sample is not representative of the general population, this is not considered to be a weakness for this type of study.[21] As the researcher was a key member of the RT clinical research team in NICC, this provided them with direct access to clinical trial participant contact details within the study centre.

Eligibility criteria

Participants who had been recruited into a RT clinical trial at the study centre between January 2020 and January 2023, were eligible to participate in this study. Table 1 provides details of the inclusion/exclusion criteria. During this time, 53 patients were recruited into RT clinical trials across a range of disease sites. However, one patient had since died and two patients had withdrawn their consent for further trial follow up; consequently, 50 patients were invited to participate in this evaluation. A pilot study was not deemed optimal due to the small eligible sample (pilot studies recommend including a minimum of 12 participants whose data would not be captured within the study).[22]

Sample size and power

An acceptable margin of error used in survey research is 5–10%, with a confidence level of 95%[23]; therefore, 34–45 participants needed to be recruited in order to achieve statistically significant results.[24]

Participant recruitment

Patients were invited to take part in the service evaluation anonymously by post in April 2023. A cover letter, PIS and stamped addressed return envelope were enclosed with the questionnaire.

In the PIS, participants were informed that, by completing the questionnaire, they were giving their consent for the information

Table 1
Participant inclusion/exclusion criteria for service evaluation.

Inclusion	Exclusion
- Enrolled into a RT clinical trial in NICC between January 2020 and January 2023	- Enrolled into a RT clinical trial in NICC outside of January 2020 to January 2023
- Currently being reviewed as part of an RT clinical trial	- No longer being followed up by the clinical trials team
- Outpatients	- In-patients
- ≥ 18 years old	- <18 years old (Paediatrics were excluded as they are followed up at a different hospital)

they provided to be used for the purpose of this evaluation. The CRRs sent a reminder letter one week after postage to encourage participant response.[25]

Numbers from 1 to 50 were added to each questionnaire when they were returned in sequential order and there were no records linking patient information to numbers on the questionnaires.

Data analysis

SPSS 29 statistical software was used to generate descriptive statistics. Descriptive statistics were used to analyse data for single categorical variables and included frequencies and percentages. Qualitative data, in the form of patient comments, were analysed using Braun and Clarke's six step thematic analysis framework.[26] This analysis enables identification of and interpretation of the data through a strategic reproducible process. The two researchers completed steps one to three of the analysis process independently to ensure rigor and high-quality analysis.[26] This involved multiple readings of the patient comments and individual coding of each comment. Codes were then grouped into themes. During step four, the researchers discussed their themes and any discrepancies between the coding and themes were resolved. Given that the data was limited in comparison to analysing focus groups or interviews, this process was relatively straight-forward. The researchers jointly agreed and presented the themes in the results section (step five and six).

Results

Of the 50 participants who were sent a feedback survey, 43 participants returned their survey (86% response rate). However, one participant was withdrawn from the study as their disease had progressed and therefore they were no longer being followed up as part of a RT clinical trial. Consequently, 42 questionnaires were evaluated.

Demographic information

Participants most frequently reported being aged between 61 and 70 years old (n = 19; 45.2%) with 17 participants (40.5%) indicating that they were 71–80 years old. Forty (95.2%) of the participants identified as male with only two participants (4.8%) identifying as female.

Participants most frequently indicated that their cancer diagnosis was prostate cancer (n = 33; 78.6%). Other cancer sites included oesophagus (n = 3; 7.1%), base of tongue (n = 1; 2.4%) and unknown disease site (n = 5; 11.9%). The most frequent year of enrolment of participants into a clinical trial was 2022 (n = 14; 33.3%) followed by 2021 (n = 13; 30.9%).

Thirty-three (78.6%) participants confirmed that they had heard about their clinical trial from their Consultant Oncologist. Five participants (11.9%) had heard about the trial from the CRR. Other sources of information included their General Practitioner (n = 1; 2.4%), the host website (n = 1; 2.4%) and other methods (n = 2; 4.8%). See Table 2 for full demographic information.

Radiotherapy clinical trial information

Thirty-nine participants (92.9%) confirmed that they were provided with verbal information in relation to their RT clinical trial and treatment. Forty-one (97.6%) participants confirmed that the verbal information provided to them was written in language/words that they could understand. Forty participants (95.2%) confirmed that they were provided with written information in relation to their RT clinical trial and treatment. See Table 3 for further details.

Forty participants (95.2%) indicated that it was easy or very easy to read the written radiotherapy clinical trial information. Thirty-four participants (81%) indicated that it was easy or very easy to understand radiotherapy clinical trial information. See Table 4 for more information.

Thirty-nine participants (92.9%) indicated that they were satisfied or very satisfied with the information provided regarding ongoing care. Thirty-nine (92.9%) participants were satisfied or very satisfied regarding information provided to them about their RT treatment. Thirty-seven participants (88.1%) were satisfied or very satisfied regarding the information provided about the potential side effects of treatment. See Table 5 for further details.

Twelve participants (28.6%) commented on their satisfaction levels regarding the quality of RT trial information they received. Coding of these comments resulted in the formation of two themes;

1) Positive aspects
2) Negative aspects.

Table 2
Demographics of participants.

Variable	n	(%)
Age range		
51–60	5	11.9
61–70	19	45.2
71–80	17	40.5
81+	1	2.4
Gender		
Female	2	4.8
Male	40	95.2
Cancer diagnosis		
Prostate cancer	33	78.6
Oesophagus	3	7.1
Unknown	5	11.9
Base of tongue	1	2.4
Year of enrolment into RT clinical trial		
2020	7	16.7
2021	13	30.9
2022	14	33.3
2023	4	9.5
Unknown	4	9.5
Radiotherapy clinical trial awareness		
Oncologist	33	78.6
Clinical Research Radiographer	5	11.9
General Practitioner	1	2.4
Host website	1	2.4
Other	2	4.8

Table 3
Participants' perspectives regarding the quality of verbal and written radiotherapy trial information provided.

	Yes n (%)	No n (%)	No response n (%)	Total n (%)
Were you provided with verbal information in relation to your radiotherapy clinical trial care/treatment?	39 (92.9)	0 (0)	3 (7.1)	42 (100)
Was the verbal information provided to you in language/words you could clearly understand?	41 (97.8)	0 (0)	1 (2.4)	42 (100)
Were you provided with written information in relation to your radiotherapy clinical trial care/treatment?	40 (95.2)	0 (0)	2 (4.8)	42 (100)

Table 4
Participant perspective on how easy the RT clinical trial information was to read and understand.

	Very easy n (%)	Easy n (%)	Not easy n (%)	No response n (%)	Total n (%)
Read	27 (64.3)	13 (31.0)	0 (0)	2 (4.8)	42 (100)
Understand	20 (47.6)	14 (33.3)	0 (0)	8 (19.0)	42 (100)

Table 5
Satisfaction levels of participants with various aspects of care.

	Very dissatisfied n (%)	Dissatisfied n (%)	Neutral n (%)	Satisfied n (%)	Very Satisfied n (%)
Information provided regarding your ongoing care	0 (0)	1 (2.4%)	2 (4.8)	2 (4.8%)	37 (88.1)
Information provided regarding your radiotherapy treatment	0 (0)	1 (2.4)	2 (4.8)	3 (7.1)	36 (85.7)
Information provided regarding the potential side effects of treatment.	0 (0)	1 (2.4)	4 (9.5)	4 (9.5)	33 (78.6)

Eight of the 12 participants (66.7%) commented on positive aspects, feeling that the information provided met or exceeded their needs and expectations. One participant commented;

"The information provided met all my needs" (Participant 3)

Four of the 12 (33.3%) participants commented on negative aspects; all four of these participants indicated that they would have preferred more information regarding the potential side-effects of treatment. Participants commented;

"More information on possible side effects, but to be fair my treatment was during COVID' (Participant 20)

'There was more minor double incontinence than outlined' (Participant 24)

Motivations for participating in a RT clinical trial

The highest-ranking motivation for taking part in a clinical trial was to contribute important information to medical science (n = 39; 92.9%). Thirty-eight participants (90.5%) also selected that the benefit from additional medical attention and testing that the study provided was a driving motivating factor. Thirty-seven participants (88.1%) also selected that a desire to help people with similar conditions was a motivating factor. Thirty-one participants (73.8%) hoped that the research study would improve their condition and 26 participants (61.9%) were motivated to gain insights into their own health. See Table 6 for more details.

Five participants (11.9%) commented regarding their motivation for taking part in a RT clinical trial. Two themes emerged from the coding of these comments;

1) Personal benefit
2) Benefit to others.

All five participants suggested that the trial was the best option for their cancer and two participants indicated that they hoped that it would help others. Participants commented;

'Doctor explained trial and seemed like the best option for treatment and to be able to help medicine/ others was a bonus.' (Participant 10)

'Really also hoped for speedier treatment if selected and less radiotherapy treatment options.' (Participant 15)

CRR communication, attitude and behaviour

Forty-one (97.6%) participants agreed that the CRR team always spoke to them in a way that they could easily understand during their appointments. Thirty-nine (92.9%) participants agreed that the CRR always listened and checked to see if a patient understood what they were telling them. Thirty-eight (90.5%) participants agreed that the CRR always explained what was happening to them in relation to their treatment and care. Thirty-six (85.7%) participants agreed that the CRR always involved them in decisions that needed to be made regarding their treatment.

Forty-one (97.6%) participants agreed that the CRRs were always approachable, polite and courteous. Thirty-eight (90.5%) participants agreed that the CRRs were always caring and compassionate. Forty (95.2%) participants agreed that the CRRs were always willing to take time to listen to their questions or concerns making them feel safe and supported.

Thirty-eight (90.5%) participants agreed that the CRR team always called them by their preferred name. Thirty-seven (88.1%) participants agreed that the CRR team always asked them for consent/permission before carrying out any treatment or care. See Table 7 for further details.

Twelve participants (28.6%) commented regarding CRR communication, attitude and behaviours, with all participants commenting very positively regarding these aspects of the CRR

Table 6
Motivations for participating in a RT clinical trial.

Motivation	Yes n (%)	No n (%)	Did not answer n (%)
To contribute important information to medical science	39 (92.9%)	3 (7.1%)	0 (0)
To benefit from the additional medical attention and testing that the study provided	38 (90.5%)	4 (9.5%)	0 (0)
To potentially help people with similar conditions	37 (88.1%)	5 (11.9%)	0 (0)
I hoped that the research study would improve my medical condition	31 (73.8%)	11 (26.2%)	0 (0)
To gain insights into my own health	26 (61.9%)	16 (38.1%)	0 (0)

team. Comments were coded and grouped into four themes regarding the characteristics of the CRRs;

- Committed
- Supportive
- Caring
- Approachable and friendly

All twelve participants indicated that the CRR team treated them very well with seven of these participants (58.3%) commenting on their commitment and dedication, indicating that CRRs went above and beyond what was required of them to help the participants. Five of these participants (41.7%) indicated that CRRs were supportive and reassuring, always providing time to listen to participants' concerns. Four participants (33.3%) indicated that CRRs were very kind and caring. Five participants (41.7%) indicated that CRRs were very friendly and approachable. Participants commented;

'The CRR went the "extra mile" to ensure that I was informed and was always willing to spend time and offer support.'(Participant 9)

' … the CRRs … were kind and went out of their way to explain about the treatment I was undergoing. Always kind and supportive.' (Participant 13)

'The CRRs were more than helpful, considerate and caring during and after my treatment. (Participant 23)

'First class treatment at all time by CRR team and all staff members even when under extreme pressure.' (Participant 36)

The impact of COVID 19 measures

Forty-one (97.6%) participants felt safe during their hospital visits for radiotherapy clinical trial appointments during the COVID-19 pandemic. Thirty-two (76.2%) patients felt that staff wearing masks/gloves had a positive impact on their satisfaction with care and communication. Forty (95.2%) participants confirmed that they had a telephone/video consultation as part of their care whilst on a radiotherapy clinical trial during COVID-19. Twenty (47.6%) participants indicated that they would prefer telephone/video consultation for review, while 14 (33.3%) participants indicated that they would prefer face-to-face review consultation. Eight (19%) participants indicated that they would prefer a mixture of telephone and face-to-face review. See Table 8 for further details.

Eight participants (19%) commented on the impact of staff COVID-19 precautions. Comments were coded and divided into three themes;

- Accepted normal practice
- High standard precautions
- Individual participant needs

All eight participants accepted and expected this practice, understanding that the purpose of these precautions was to aid infection control. Five of the eight participants (62.5%) commented that everything possible had been done to ensure their safety during the clinical trial. Two of these eight participants (25%) had individual needs that were impacted by the implementation of these precautions. Participants commented;

"Hard to hear through the masks." (Participant 18)

'With a low immune system it was comforting to see that staff were taking all precautions to keep patients as safe as possible." (Participant 23)

Seven participants (16.7%) commented regarding their preference for their mode of review as part of a radiotherapy clinical trial. Two themes were created from the coding these comments;

1) Benefits of telephone reviews
2) Neutral opinions regarding review format.

Five of these seven participants (71.4%) commented solely on the benefit of having a telephone review as it meant less travel i.e.

Table 7
Communication, behaviour and attitude of CRR team.

Attribute	Variable	Always n (%)	Sometimes n (%)	Rarely n (%)	Did not complete
Communication -During your visits to the hospital as part of your radiotherapy clinical trial treatment did the Clinical Research Radiographer;	Speak to you in a way which you could easily understand	41 (97.6)	1 (2.4)	0 (0)	0 (0)
	Listen to you and check if you understood what they were telling you	39 (92.9)	2 (4.8)	0 (0)	1 (2.4)
	Explain what was happening in relation to your treatment and care	38 (90.5)	3 (7.1)	0 (0)	1 (2.4)
	Involve you in decisions which needed to be made	36 (85.7)	4 (9.5)	1 (2.4)	1 (2.4)
ATTITUDE -During your visits to the hospital as part of your radiotherapy clinical trial treatment was the Clinical Research Radiographer:	Approachable/polite and courteous	41 (97.6)	1 (2.4)	0 (0)	0 (0)
	Caring and compassionate	38 (90.5)	2 (4.8)	0 (0)	2 (4.8)
	Willing to take time to listen to your questions or concerns making you feel safe and support.	40 (95.2)	0 (0)	0 (0)	2 (4.8)
BEHAVIOUR -During your visits to the hospital did the Clinical Research Radiographer	Call you by your preferred name	38 (90.5)	4 (9.5)	0 (0)	0 (0)
	Ask for your consent/permission before carrying out any treatment/care	37 (88.1)	3 (7.1)	0 (0)	2 (4.8)

Table 8
The impact of COVID 19 measures.

	Yes n (%)	No n (%)	Don't know n (%)
During hospital visits for radiotherapy clinical trial related appointments, did you feel safe?	41 (97.6)	1 (2.4)	0 (0)
Did you have a telephone or video consultation/assessment as part of your care whilst on a radiotherapy clinical trial?	40 (95.2)	2 (4.8)	0 (0)
Impact of staff wearing masks/gloves	Yes; positively n (%)	Yes but negatively n (%)	No; there was no impact n (%)
Did staff wearing masks/gloves impact on your satisfaction with care and communication?	32 (76.2)	1 (2.4)	9 (21.4)
Preference for review	Telephone/video consultation n (%)	Face to face consultation n (%)	Mixture of telephone/video and face to face n (%)
What would be your preference for review as part of a radiotherapy clinical trial? (Select one option)	20 (47.6)	14 (33.3)	8 (19)

more convenience, with one patient commenting that this mode of review was preferential due to work commitments. Two participants (28.6%) expressed satisfaction with either format. Participants commented;

'Much time was saved by not having to travel to the hospital. Other family members could be present more easily.' (Participant 28)

'Telephone apps good for me due to work commitments.' (Participant 33)

Clinical Research radiographer's contacts, satisfaction with advice and overall satisfaction with trial experience

Thirty-nine (92.9%) participants confirmed that they were provided with CRR contact details. Twenty-four (57.1%) participants confirmed that they made contact with the CRR team for advice. All of these respondents were satisfied or very satisfied with the CRR advice received because of this contact.

Forty (95.2%) participants indicated that they were satisfied or very satisfied with their radiotherapy trial follow-up arrangements.

Thirty-eight (90.5%) participants were very satisfied with their overall experience of the trials service and four (9.5%) participants were satisfied. See Table 9 for full details.

Satisfaction with experience of the cancer clinical trials service

Forty-one (97.6%) participants would recommend taking part in a radiotherapy trial to friends and family.

Thirty nine participants (92.9%) commented regarding the most positive aspects of participation in a radiotherapy clinical trial. Coding of these comments resulted in five themes;

- CRR support
- Positive culture
- Careful monitoring
- Access to new treatment and technologies
- Hope to help other patients in the future

Seven of the 39 participants (17.9%) valued CRR support, five participants (12.8%) valued careful monitoring during radiotherapy and post treatment, 13 participants (33.3%) valued access to new treatment and technology, six participants (15.38%) valued helping other patients in the future by taking part in a trial and eight patients (20.5%) felt that it was overall a very positive culture to be enrolled in a clinical trial. See Table 10 for related patient comments.

Twenty-three (54.8%) participants commented on how to improve the research service provided. Coding of the comments resulted in two themes;

- Feedback to improve the service
- Feedback that no improvements were necessary

Thirteen of the 23 participants (56.5%) commented that no improvements were necessary, as the service is excellent. The remaining 10 participants (43.4%) provided feedback on how to improve the service. Comments were coded into three themes;

Table 9
Clinical Research radiographer's contacts/satisfaction with advice and overall satisfaction with trial experience.

	Yes n (%)	No n (%)	No response	N/A	Total n (%)
Were you provided with details should you need to contact the Clinical Research Radiographer for advice?	39 (92.9)	3 (7.1)	0 (0)	0 (0)	42 (100)
Did you ever contact the Clinical Research Radiographer for advice?	24 (57.1)	16 (38.1)	2 (4.8)	0 (0)	42 (100)

	Very Dissatisfied n (%)	Dissatisfied n (%)	Neutral n (%)	Satisfied n (%)	Very satisfied n (%)	Did not complete n (%)
Satisfaction with CRR advice given	0 (0)	0 (0)	0 (0)	3 (12.5)	21 (87.5)	24 (100)
Satisfaction re follow arrangements as part of an RT trial	0 (0)	0 (0)	1 (2.4)	7 (16.7)	33 (78.6)	1 (2.4)
Overall satisfaction with experience of Cancer Clinical Trials Service	0 (0)	0 (0)	0 (0)	4 (9.5)	38 (90.5)	0 (0)

Table 10
Sample of participant comments re positive aspects of being enrolled in a RT clinical trial.

CRR support	*'Very satisfied everyone was kind caring and polite; made me feel very comfortable.' (Participant 1)*
	'Professional care, communication and sincerity of the complete team' (Participant 34)
Positive culture	*'Overall positive culture' (Participant 2)*
	'Very good' (Participant 12)
Careful monitoring	*'Careful monitoring within the trial protocol '(Participant 3)*
	'In depth follow up service and sharing information such as this' (Participant 14)
	'I got extra care and attention. Able to talk to one of the CRRs on the phone if there was a problem.' (Participant 18)
Access to new treatment and technologies	*'Treatment appointments were reduced- the effectiveness of the new approach- and the personal care' (Participant 8)*
	'The advantage of having additional medical personal involved in my care and their collaboration with my primary oncologist. The potential of targeted radiotherapy to reduce metastatic spread.' (Participant 40)
Hope to help other patients in the future	*'I was treated brilliantly throughout, always put me at my ease and it was good to know that my participation in trials would help others.' (Participant 9)*
	'Knowing that I can possibly help with others coming behind me in the future to defeat cancer.' (Participant 17)

- Financial aid
- Communication of clinical trial success
- Information provision

Six of the 10 (60%) participants indicated that increased financial aid would help to improve the service further through offering increased testing, treatment and clinical trial options. Participants commented;

'If only more funding was allocated for these type of trials more sick people like myself could be treated.' (Participant 19)

'I am sure it is very hard to improve the service on the budgets given.' (Participant 20)

Three of the 10 (30%) participants commented that the information could be provided in more visual formats and that increased detail regarding side-effects was needed. Participants commented;

'Give as much details of potential side effects- even with percentage or duration of effects.' (Participant 8)

'Maybe a greater use of diagrams that explain various procedures (I think I am more of a visual learner' (Participant 28)

Two of the ten (20%) participants indicated that more communication of the success of trials was needed, both with trial participants and also within the media. Participants commented;

'Continual communication. Positive news stories to media outlets- Obtain a "sponsor" who would "fund" good news via media outlet' (Participant 34)

'Perhaps increased feedback on the success and effectiveness of the treatment' (Participant 40)

Discussion

This single centre post COVID-19 service evaluation reported high levels of satisfaction with the RT clinical trial process as well as very positive feedback regarding participation in a clinical trial. Positive aspects of trial participation included CRR support, a positive trial culture, careful monitoring and access to new treatments/technologies, as well as potentially helping patients in the future. This research aligns with previous findings by Planner et al. (2019)[27] who reported relatively high levels of global satisfaction with trial processes as well as similar positive outcomes. Planner et al.[27] reported that measuring patient trial experience was uncommon and concluded that standardised assessment of patient experience of trial participation has the potential to provide opportunities to improve trial design and delivery.

Results from this service evaluation demonstrated that the majority of patients (78.6%) had heard about their RT clinical trial from their Consultant Oncologist. This finding aligns to previous research, which reported that patients are more likely to have first learned about clinical trials through a doctor.[28] Therefore, there is potential scope for CRRs to raise the profile of RT clinical trials locally as per the National Institute of Heath 2016.[28] The focus of any CRR-led awareness campaign should be to advocate for patients to consider entering a trial through providing information/advice rather than encouraging participation.[29]

Patient decisions regarding trial participation may be influenced by the information that they receive.[30] Clinical trial information sheets should be accurate, adequate and provided in a format and language that participants understand.[31] The majority of participants in this survey confirmed that they were provided with verbal and written information in relation to their RT clinical trial with most agreeing that the information provided was easy to understand. This is an important finding as patient understanding plays an essential role in clinical trials as it directly affects how ethical principles are applied in practice.[32]

At present, within this single centre, all patients are provided with trial information sheets, which outline detailed side effects of RT, supporting patients to make decisions regarding participation in a study by outlining the benefits, harms and scientific uncertainty of the study proposed.[33] Evidence suggests that written information is fundamental as cancer patients only remember one tenth of what they are told during a review.[34] Results of this service evaluation indicated that the majority of participants were satisfied or very satisfied with the information provided regarding ongoing care (88.1%) and RT treatment (85.7%). A small percentage of patients (11.9%) indicated that they may have benefitted from more information regarding the potential side effects of RT. Bergenmar et al. (2010)[35] highlighted the importance of time allocation for information provision to improve understanding of clinical research, indicating that there was a greater perceived level of understanding regarding "risks" among patients who reported time for information provision to have lasted >30mins. This service evaluation highlights the need for a renewed focus on educating patients regarding the potential side effects of radiotherapy; RT side effects should be discussed at consent as well as during and post treatment to ensure that patients are fully informed at all stages care pathway.

In agreement with other studies,[30] this study found that patients' decisions to participate in research were influenced by multiple factors including altruism. Previous research by Locock and Smith (2010)[36] concluded that the reasoning for taking part in a clinical trial can be complex with a wide variety of personal considerations being evident. Their study found that personal benefit emerged as an important primary motivation, whereas altruistic considerations appeared to be a secondary motivation.

Differences in trial populations may explain the differences in trial motivations between their study and this service evaluation.

CRRs provide a vital support from a patient's diagnosis to follow up.[5] During the height of the COVID-19 pandemic, temporary measures were implemented to mitigate COVID-19 risk, significantly affecting patient contact and communication, which are fundamental dimensions of the CRR supportive role. Results from this evaluation demonstrate that the majority of patients were overwhelmingly positive regarding communication that they had received from the CRR team as well as the behaviour and attitude of the CRR team. Participants described feeling supported by their CRR team throughout their RT clinical trial experience. This supports previous studies which highlight the benefits of radiographer-led support.[37]

At present the national UK Clinical trials Specialist interest group and Society and College of Radiographers are currently developing strategies to support radiographers working within clinical trials emphasising the rising profile of the CRR role.[4] A large proportion of respondents in this service evaluation confirmed that they had made contact with the CRR team for advice with all participants confirming that they were very satisfied with the information provided by the CRRs. This evaluation supports previous research that therapeutic radiographers are best placed to provide support and advice to patients receiving radiotherapy,[38] regardless of being in an RT trial or not.

At present, measures to mitigate COVID-19 risk still continue to have an effect on patient contact, with the majority of patient post-RT reviews being conducted via telephone.[15] Reassuringly, a large proportion of respondents in this survey indicated that they still felt safe during their hospital visits for RT treatment during the height of the pandemic. Results also indicated a mix of opinions regarding the preferred mode of patient review. Some participants indicated that they would prefer a mixture of telephone and face-to-face review, while other participants preferred telephone review or solely face-to-face review. These findings were similar to a previous UK survey of prostate cancer patient experience and preferences for review, which found that most patients preferred in person consultations when receiving diagnosis, results and treatment options. However, fewer patients felt that review appointments (40.9%) or side effect consultations (47.7%) should be in person.[39] It is clear that a patient-centred individualised approach should be adapted when deciding what form of review should take place at different stages of the patient pathway.

Whilst, the service evaluation findings were mainly positive, some areas for improvement were identified. A small percentage of participants (11.9%) indicated that they were not always asked for consent/permission before treatment/care was carried out and similarly, some participants (14.3%) indicated that they were not always involved in decision-making. The process of consent should be on-going and not a single event as it requires that patients weigh up the related risks and benefits of a trial and then voluntarily give consent.[40] Meaningful informed consent is vital within the clinical research setting. Whilst, written consent is mandatory/stringent within the RT clinical trial process it is clear that a renewed verbal focus is required to ensure that patients feel involved in all aspects of their care.

Strengths and limitations of the study

Given that the average response rates of satisfaction surveys are commonly below 50%,[41] the response rate (86%) of this service evaluation demonstrates very high levels of participant engagement.

While the aims of the study were aptly addressed through the questionnaire, the questionnaire is not a validated tool i.e. the psychometric properties have not been confirmed.[41] This leads to uncertainty in terms of content validity as it has not been established whether the questionnaire covers the full range of dimensions related to participants' clinical trial experience.[42] It is important to highlight that there is potential for non-response bias within this service evaluation. Some questions within the survey were not answered by a small number of patients. It is possible that those who did not respond to certain questions did not want to offend the CRR team with their dissatisfaction, although there is no way of knowing the real reasoning behind their lack of response.

Age ranges of this service evaluation were also limited to participants who were 51 years old or older. The National Institute for Health and Care Research (2022)[43] suggests that age extremes should be covered within clinical research to include participants under 18 and over 75 year of age so that a wide range of opinions are captured from different age groups.

The majority of participants (78.6%) within this study had a diagnosis of prostate cancer and identified as male (95.2%). Given the lack of variation of gender/age and cancer disease sites, generalisation of results from this service evaluation are limited.

Conclusion

The COVID-19 worldwide pandemic caused major disruption to cancer research delivery.[14] Recruitment to RT clinical trials was significantly impacted during this time period with many adaptations being speedily introduced within the patient pathway in order to sustain research activity whilst maintaining patient safety. This small single centre survey suggests that despite these measures, patients remained highly satisfied with the quality of care that they received through their participation in RT clinical trials.

Patient perspective is an important tool in ensuring that clinical trials design and delivery are patient-centred. Flexibility in clinical trials, where it does not impact safety and quality research, should be maximised to promote clinical trial access and patient convenience. The care of the CRR within this survey was evaluated positively and patients valued participation within a RT clinical trial. Overall findings of this study suggest that, despite the COVID 19 pandemic, participant satisfaction was very high within all aspects of the radiotherapy clinical trials service. Results of this service evaluation will be used to ensure effective patient-focused delivery of cancer trials.

Conflict of interest statement

The authors have no conflicts of interest to declare.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.radi.2024.06.014.

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