1764: Best practice for patient-centred radiotherapy in clinical trials and beyond – a national consensus [Poster discussion]

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Best practice for patient-centred radiotherapy in clinical trials and beyond – a national consensus

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AUTHOR APPROVAL

Yes

ACCURACY OF THE ABSTRACT

Yes

AUTHOR LIST

Yes

ABSTRACT PRESENTATION

Yes

AUTHOR ATTENDANCE

Yes

EMBARGO OF ABSTRACTS

Yes

ABSTRACT VERIFICATION

Yes

CONTACT PERSON

Yes

TOPIC

Interdisciplinary: Other (topic of relevance for radiation oncology, NOT related to any other category)

KEYWORDS

patient-centred, radiotherapy, national

REQUEST FOR DIGITAL POSTER ONLY

No

ABSTRACT TITLE

Best practice for patient-centred radiotherapy in clinical trials and beyond – a national consensus

PURPOSE/OBJECTIVE

Patient-centred radiotherapy refers to an approach where the patient's needs, preferences, and experiences are prioritised. Guidelines for this personalised approach are lacking.

We present an expert-panel national consensus and a set of recommendations for best practise patient-centred radiotherapy, to guide clinical trials and routine practice.

MATERIAL/METHODS

A national multidisciplinary working group was formed, comprising healthcare professionals, academics, and patient advocates, with lived experience of radiotherapy.

Regular qualitative consultations were undertaken to develop a framework to define best practice for patient-centred radiotherapy.

Structured consultation was used to identify themes of patient-centred radiotherapy. For each theme, a scoping review was performed, and further refined through consultation. The following were considered:

- The current situation, and problems
- Possible recommendations

Considerations for national implementation of recommendations, and methods of improving patient and professional engagement, will be formally developed through a consultation workshop with patient advocates and radiotherapy professionals in January 2024. This work is supported by the Science and Technology Facilities Council (Grant number ST/S005382/1).

RESULTS

Three interlinked themes were identified (Figure 1). Recommendations, in response to the issues identified per theme, are summarised in Table 1.

Theme 1: Patient-centred information and communication

Theme 2: Shared decision-making

Theme 3: Outcomes

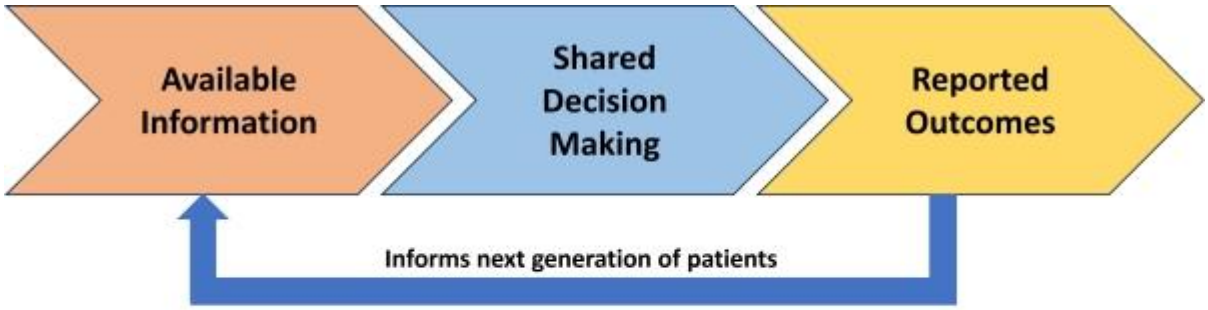

Figure 1: The essential feedback-loop of outcome information required to inform shared decision making (SDM). The available information underpins informed decision making and should be robust and up-to-date. Ensuring outcomes are reported to patients in a meaningful and timely manner means that there can be continuous improvement of available information, and better-informed decision making for the next generation of patients.

Theme 1: Patient-centred information

Patients' baseline understanding of radiotherapy is often limited and some may harbour misconceptions, such as becoming radioactive[1]. The volume and impersonal nature of information provided at consultations can be overwhelming, a feeling potentially magnified for patients with auditory or visual disabilities, learning difficulties or limited English-speaking proficiency. Given average health literacy rates, radiotherapy-related patient-facing written material is often too complex[2,3,4]. Limited time to process information can amplify concerns. Patients may feel left with little information and support following treatment[5].

Theme 2: Shared decision-making (SDM)

There is limited published literature about how patients' opinions are included in radiotherapy-decisions in clinical practice, or patients' preferences in SDM[1]. However, patients who do not perceive themselves to be actively involved in decision-making have a higher risk of decisional-regret and emotional distress[6,7].

Lack of patient understanding, or inadequate time to process information, may hamper engagement in SDM. Furthermore, patient preferences and expectations for SDM may change[8]. Successful implementation of SDM is also dependent on clinician factors, including their experience and knowledge, language and communication style, individual perceptions (e.g., treatment side-effects may "scare" patients), as well as the influence of resource and infrastructure challenges[9].

Validated SDM tools have been designed to help people participate in SDM with healthcare options, but are not widely available, and may not be understood if not matched to a patient's health literacy level[10].

Theme 3: Outcomes

The use of disease and radiotherapy-related treatment outcomes varies widely and can reflect what is easiest or conventional to measure, rather than what is most meaningful for patients. Geographical, socioeconomic, and other inequalities remain, affecting clinical outcomes[11,12].

Use of real-world datasets and novel research methodologies, alongside traditional trials, have the potential to transform understanding of the long-term impacts of radiotherapy[13,14,15]. There are significant challenges to routine implementation. Radiotherapy datasets are heterogenous and composed of multiple complex information formats[16]. Other barriers include concerns regarding data quality, integrity, provenance, completeness, and access.

Patient reported outcome measures (PROMs), including Quality-of-Life (QoL) assessments, are invaluable to understanding patient experience. However, their use varies, interpretation can be challenging, and they are sensitive to response bias[17]. Limited language/translation options exist. Further barriers to effective dissemination of information include maintaining confidentiality whilst supporting accessibility, engaging a broad audience, and supporting different levels of understanding.

Table 1: Key Recommendations

Patient-centred information

- Patient-facing document should be understandable and co-developed with patient advocates.
- Provide sufficient opportunities for patients to discuss their diagnosis and treatment, and their implications.
- Where possible adopt a holistic approach and tailor information formats and delivery to the patient as an individual. Ensure language translation services are available.
- Use a variety of different communication methods (e.g., written information, videos, pictures).
- Consider provision of treatment summary documents for patients, and their community doctor/care teams, to support long-term care.

Shared decision-making

- SDM should be considered a continuous process throughout a patient's pathway. It has the potential to improve treatment satisfaction and reduce emotional distress.
- Adopt approaches that support SDM within the patient-clinician interaction, such as the use of power-questions (e.g., What is important to you?)
- Routine adoption of validated tools to support SDM processes should be considered.

Outcomes

- A collaborative approach with patient advocates should be utilise when designing/setting up trials and routine service.
- Prospective collection of patient experience data is important, including PROMS, QoL, and consideration of equity of care.
- Real world evidence, and new research methodologies, should be optimised and could be used to complement clinical trials
- Where available, validated data outcome measures are recommended, and standardisation across studies would facilitate comparisons.
- There should be a focus on disseminating information quickly to non-experts, as well as healthcare professionals. Participating patients should be informed of study outcomes.

CONCLUSION

Patient empowerment has progressively evolved into a fundamental principle of modern medical practice. We need to elicit, and respond to, what matters to patients, what their values are, and recognise the influence of their current circumstances. Patient information should be developed in collaboration with patient advocates and, wherever possible, the exchange of information should be tailored towards the individuals' needs.

There is not a 'one size fits all' solution to SDM. SDM is an individualised, iterative process that requires supportive systems, trained teams, and prepared patients. Cancer professionals should consider and have time to integrate validated SDM tools and approaches into their everyday practice.

Outcome measures should reflect clinical issues that are meaningful to patients. Optimising the use of PROMS, QoL assessment, and tackling barriers to equity of care is critical in research and daily practice. Novel study designs and data sources represent evolving opportunities to answer challenging questions. Dissemination of robust, up-to-date outcome data in an appropriate format is critical to empower patients and fuel the essential feedback-loop required for patient-centred care.

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CONFLICT OF INTEREST DISCLOSURE

I do not have a Conflict of Interest to disclose.

PERMISSION TO PUBLISH

Yes