

# **EFRS Statement on Patient Engagement and Inclusion in Radiotherapy**

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Engagement is a function of people's ability, willingness and gradual choice to take a proactive role in managing their own health, combining individual, relational, socio-economic and organizational factors.

In the last decade, the World Health Organization (WHO) has emphasized the need for patient engagement and involvement in healthcare and published a number of documents to facilitate the development of strategic plans for an improved quality and safer care [1][2][3][4]. The WHO Patients for Patient safety programme, launched in 2004, has patients and community engagement as a core priority. It aims to integrate the involvement of patients and families in their care journey and to establish patient, family and community partnerships with health professionals [5].

The 'EFRS Statement on the Importance of Patient Engagement and the Patient Voice within Radiographic Practice' was published in January 2021 [6]. It emphasizes the importance of patient engagement within radiographic practice.

This document aims to translate the umbrella statement into clear actions for radiotherapy (RT) departments to invest in or further develop the engagement and inclusion of their patients. It will cover four main topics for patient engagement and inclusion: patient involvement in process design, patient involvement in decision making (including clinical research), patient involvement in safety management, and patient involvement in education. For each topic, suggested methods to engage patients are described. Moreover, the key role of radiotherapy radiographers (RTTs) in patient engagement procedures is being discussed. Radiotherapy radiographers are experts in radiotherapy and are specially trained in providing care and support across the radiotherapy treatment pathway. Their daily interaction with patients enables them to understand patients' needs and expectations. Their role is also to act as "patient advocate" and maintain this throughout their radiotherapy journey [7].

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Patient engagement can take place at different levels across the healthcare system and at multiple ways. Three main levels of patient and family engagement include direct care settings, organizational design and governance, and policy making. Direct care concerns individuals and activities that range from receiving or seeking for information to being partners with their health providers as for example in decision making for their treatments. At organisational design and policy making, patients or patient organisations contribute to healthcare improvements at departmental, organisational or healthcare system level. The spectrum and degree of patient involvement varies from surveys, to having advisory role or to co-lead interventions participating in committees with policy makers. [8][9] Whatever the level and degree of patient engagement might be, needs careful planning to be meaningful and lead to improved healthcare services.

## **TOPIC 1: PATIENT INVOLVEMENT IN PROCESS (RE)DESIGN**

The radiotherapy process includes different steps and the involvement of multiple professions [7]. Inclusion of patients in the designing or redesigning of these processes has become a very powerful tool for radiotherapy organisations. Patient experience [10] and, to lesser extent patient satisfaction, [11] have been the main concepts used to assess and improve the radiotherapy pathway [12].

Three aspects of the RT process for discussion include:

- improving the infrastructure and the radiotherapy departmental environment;
- improving patient information and education in radiotherapy;
- involvement of carers.

### **Patient involvement in infrastructure and improvement of the departmental environment**

Resources dedicated to improvement of efficacy in radiotherapy by improving the infrastructure and processes can be used in the initial design process of a new radiotherapy service. Advice from patients and their carers can improve the patient journey through the radiotherapy service and improve cost effectiveness. Representatives of patient organisations should be involved as committee members in the decision-making process for initial design to promote the role of the patient's voice from the beginning.

Recently, during the pandemic new treatment options, such as hypo-fractionation, have made changes in the typical paradigm of radiotherapy, and such changes require processes to be redesigned. Patients undergoing new treatments should be involved by giving feedback about their experience to support implementation and continuous improvement of newer treatment regimes. Patient experience could also inform on potential toxicities related to

hypo-fractionation for future patients. This approach could include a role of patient advisor where patients who have already experienced similar treatment pathways, could offer new perspectives. This could be invaluable for the development of new strategies to optimize pathways, environments, and processes [13].

Furthermore, there are various approaches such as patient-oriented apps (choice of music playlist), telemedicine and the improvement of the treatment environment (corridors with images, and scents) chosen by the patient through questionnaires and advisory patient councils to create a pleasant environment to improve patients' perception of care. These approaches promote a patient centred focus when improving environments within radiotherapy departments. There is evidence to support that patients compliance can be improved and that anxiety levels associated with the disease can be reduced [14] which is an important consideration during radiotherapy treatment.

### **Patient involvement in patient information and patient education**

The internet is a powerful tool to access information and patients often turn to it to find out more about their condition. However, online educational materials for patients from academic radiation oncology websites are quite complex, and are often confusing. Educational material from national societies aimed at patients is scarcely available. Educational material can become a source of fear for patients who cannot understand the information provided. To improve patients' understanding of radiotherapy and its role in their treatment it is suggested [15] that the language used in online information should be simplified to communicate the information at a more appropriate level. Cancer charities, in some countries are often a good source of information and provide support for patients, and have been developed with input from patients [16].

Recently during the pandemic, efforts have been made to meet the needs of patients through technology. Many initiatives are emerging to make patient-driven research practically feasible [17]. These initiatives should be guided by the networks of patients who use technological platforms to share data about their disease and treatment.

A study by Jimenez et al (2018) [18] demonstrated that improved access to technology for the education of radiotherapy patients led to opportunities for innovative methods of patients' education. This study examined the impact of an educational tool using the Virtual Environment for Radiotherapy Training (VERT) system on knowledge of therapeutic processes. Artificial intelligence tools have also been used in recent studies to identify the patient needs and results have highlighted how people with chronic conditions complain of numerous unmet needs in the course of their illness [19]. Of these "unmet needs" the majority relate to the emotional sphere rather than the medical one, where patients attempt to understand how to live with their disease, how to cope with negative developments and how to share doubts and uncertainties generated by the disease with other people.

In fact, technologies are being used to redesign how patients access health information. Many examples can be found supporting the use of digital health technologies to improve patient education and the integration of medical and lifestyle skills or behaviours. These include mobile health, wearable devices, telemedicine and personalized medicine. The tools for patient education can be delivered in standard formats, with pamphlet's or written information, or through a wide range of multimedia (video, audio, interactive games), depending on the topic and different learning styles of patients [20].

### **Involvement of the carer**

The concept of "engagement" can be expanded to include models where carers are involved directly in the care process (Caregiver Engagement) with the intent of creating an effective, equitable and sustainable healthcare system. Caregiver engagement (Caregiver Health Engagement Model) can improve the process of emotional change and proactive management of care needs [21].

For healthcare professionals, it is essential to immediately identify the patient carer, because they are the key person with whom healthcare professionals need to engage with during the course of treatment and who will be able to describe the patient's experiences. The carers are an indispensable support for patients, not only for the management of daily life but also to help define an individual care plan that meets patients' needs and desires.

### **Patient involvement and healthcare interventions assessment**

Patient empowerment and engagement can be measured using appropriate scales and studies have explored the effectiveness of new models of care based on empowerment [22]. Evaluation models for health care interventions defined by the UK National Institute for Health and Care Excellence (NICE) use information provided by patients and caregivers for its evaluations and decisions in relation to [23]:

1. Patient outcomes;
2. Impact of treatment on outcomes, symptoms, physical and social functioning, quality of life, impact on family, friends, and work activity;
3. Ease of models for health care interventions, side effects;
4. Patients preferences;
5. Subgroups such as older patients or patients with specific treatments who may have differing perspectives to health care professionals or researchers;
6. Areas that need further research.

### **Recommendation**

Patient engagement is a powerful tool for improving patient experience within the radiotherapy process. It is recommended that radiotherapy departments involve patients and carers throughout the radiotherapy (re)design stages, and take infrastructure, use of online materials and technological applications into consideration for the benefit of patients. Professional societies should also develop information materials on RT, in collaboration with patients, families and advocacy organizations, thus providing valuable and meaningful information on the radiotherapy process and the professions involved.

## TOPIC 2: PATIENT INVOLVEMENT IN DECISION MAKING

### Patient involvement in decision making prior to and during RT

Shared Decision Making (SDM) in a healthcare setting is a process whereby patients and healthcare professionals work together to understand and decide what management, treatments, or support packages are appropriate bearing in mind an individual's own circumstances. It combines the patients' expertise about themselves and what is considered important to them with the clinical knowledge regarding the benefits and risks of the options. As such the expertise of the patients is regarded in equal value as the clinical expertise of the healthcare team. The principles of SDM can therefore be applied in a radiotherapy setting across the patient journey, specifically prior to and during a course of radiotherapy treatment. To be effective patients and healthcare professionals take on the two roles as experts:

Table 1. Clinician and patient roles in shared decision making

Healthcare Professional	Patient
<p><b>Expert:</b> <b>Clinical knowledge</b></p> <ul style="list-style-type: none"> <li>• Effectiveness</li> <li>• Benefits</li> <li>• Risks</li> </ul>	<p><b>Expert:</b> <b>Self knowledge</b></p> <ul style="list-style-type: none"> <li>• Social surroundings</li> <li>• Attitudes to illness / health</li> <li>• Risks</li> <li>• Preferences</li> <li>• Choice</li> <li>• Experience</li> </ul>

### Guiding principles for shared decision making in RT prior to or during treatment

The following guiding principles can be applied to ensure SDM:

- Support and empower individuals
- Patients are "partners"
- Making a shared decision is mutually beneficial
- Patient centered care and shared decision making are tightly intertwined

### Organisational policy for shared decision making in RT

To ensure patient inclusion within their RT treatment, it needs to be embedded within an organisation's strategic policy. A culture of collaboration between healthcare professionals and patients is required within radiotherapy departments to develop and promote a shared responsibility for decision making. An increase in engagement amongst healthcare staff can be found where shared decision making is seen as an organisational priority for service improvement [24]. While policy is evident at national level the translation of such policies into organisational strategy can be challenging [25]. Radiotherapy departments should review current practice to determine barriers and develop quality improvement initiatives [26]. SDM process should be documented in patients' medical record to justify the treatment approach and assist in future shared decisions in care management.

For shared decision making to be a central theme within radiotherapy it is important to involve all stakeholders. Some steps could include:

- Partnership with national patient forums or patient advisory groups to collaborate in policy development, implementation, and evaluation of radiotherapy services in the context of SDM.
- Translation of national and organisational policies at departmental level, with patient involvement as a central theme in governing charters.
- Include the concept of patient experience in mission statements to promote a culture which encourages patient and public involvement in all operational initiatives.

Policies should promote:

- Patient representation as key stakeholders in quality improvement committees
- Patient representation in research and development, and clinical initiatives
- Patient advocacy by radiographers and self-advocacy by the patient themselves.
- Patient feedback on experience and satisfaction usually provided by surveys or complaints' forms

## RT radiographers' role development in the clinical setting to lead patient involvement in SDM

All Radiotherapy radiographers have a professional responsibility to support patient engagement and involvement within their practice [27]. In addition role development for radiographers provides an opportunity to further support patients and enhance SMD [28]. Examples include:

- Information & Support Radiographers<sup>1</sup>
- Advanced Practitioners<sup>2</sup>
- Consultant Radiographers<sup>3</sup>

These roles are engaged in providing relevant information and support to patients, relatives and carers on all aspects of radiotherapy treatment, side-effects and care during and after treatment. They also educate and discuss any concerns or questions regarding treatment matters. In addition, they may refer to other appropriate professionals or services that may be of assistance to the patient and they engage patients as partners in making sure information is accessible and appropriate to their diverse needs. Through these roles and communication channels, patients are encouraged and empowered in SDM processes throughout their radiotherapy pathway.

## Shared decision making in RT research and clinical trials

The EFRS statement on patient engagement within radiographic practice has highlighted the importance of patient and public involvement (PPI) in healthcare research [6]. The recommendations within these guidelines can be used to inform clinical practice within radiotherapy departments and clinical trials. Patient involvement should be a central theme in clinical research planning, delivery and evaluation [29]. It is recommended that patient inclusion in decision making within research is mandated within organisational policy in line with national recommendations. National patient groups are a valuable resource to support clinical practice, ensuring a gained value to the research being undertaken and optimal use of the resources.

- Departments should identify the barriers to introducing clinical trial options for patients.
- Information shared with patients should be clear and concise, with options delivered in an unbiased manner.

- Eligibility checking is essential prior to patient engagement so that the relevant options can be considered by patients throughout their care pathway [30].
- The use of an evaluation framework for clinical trials could enable patients to consider options according to their individual values and preferences [31][32].
- Decision aids can positively impact conversations around clinical trial consent [33].

There is potential for shared decision making to be successfully adopted in the clinical research setting by:

- Encouraging sponsors at early stages to engage with patient representatives.
- Developing training and CPD opportunities for radiographers on shared decision-making with patients in relation to research.
- Adequate preparation for patients, such as providing clinical trial information in advance, and promoting self-advocacy for patients.
- Development of decision aids which are relevant to clinical trials. Patient input and feedback should be used to inform future practices.
- Adequate time and opportunity for shared decision making, through longer consultation times, and use of digital and written information to support conversations.

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<sup>1</sup>The Information & Support Radiographers are here to: (1) Provide relevant information and support to patients, patient's relatives and carers on all aspects of their radiotherapy treatment, side-effects and how best to look after themselves during treatment; (2) Explain and clarify medical terms to patients; (3) Provide a confidential setting to discuss any concerns or questions patients may have regarding the treatment; (4) Refer patients to other appropriate professionals or services that may be of assistance to them. [34]

<sup>2</sup>Advance Practitioners: Advanced Clinical Practice is delivered by experienced registered healthcare practitioners. It is a level of practice characterized by a high level of autonomy and complex decision-making. This is underpinned by a Master's level award or equivalent that encompasses the four pillars of clinical practice, management and leadership, education and research, with demonstration of core and area specific clinical competence. [35]

<sup>3</sup>Consultant Practitioners: Providing clinical leadership within a specialism, bringing strategic direction, innovation and influence through practice, research and education. [35]

## Recommendation

Relevant policies on SDM are recommended at organisational level in order to support development of a culture of patient inclusion. Radiotherapy radiographers should play a key role in supporting shared decision making with patients throughout the radiotherapy journey. Through radiographers working in partnership with patients and carers, the patient's experience and cancer journey can be optimized, while making it mutually beneficial. Role development for radiographers is recommended to maximize the potential for radiographers to include patients in SDM prior to, during and after their treatment. Finally, patient involvement in clinical trials is another important aspect of the cancer journey where SDM can benefit clinical practice.

## TOPIC 3: PATIENT INVOLVEMENT IN SAFETY MANAGEMENT

Radiotherapy is a complex healthcare process due to the complexity of pathways, the use of ionizing radiation, the use of continuously evolving technology and the coordinated interaction of the multidisciplinary team. Like any complex human activity, RT is not devoid of the risk of incidents and accidents. Furthermore, patients unknowingly introduce complexity and uncertainty into RT processes and can contribute to occurring incidents or accidents.

RT is a sequential process in which the quality and safety of each phase depends on the previous one. The complexity underlines the need for excellent quality and risk management systems in radiotherapy, in which patients should be active partners [36]. This results in patients being a part of the radiotherapy team, aiming to prevent adverse events and contributing to the safety of their own treatment.

Practical examples of patient involvement in safety management can be found in other settings from around Europe [37][38][39]. In radiotherapy the importance of patient involvement in safety is evidenced [40] and experiences specific to radiotherapy can be found in literature [41][42][43]. Furthermore, considering the patients psychophysical conditions, radiographers have a key role in facilitating proactive patient involvement in safety.

### Best practices of patient involvement in safety management

#### *Patient involvement in identification*

Accurate patient identification checks are an important safety issue due to the personalization of each RT treatment. Patient involvement in self-identification can be done through use of technology or by using conventional approaches. Technological approaches include patients identifying themselves using biometrical data, such as facial or fingerprint recognition. Conventional methods include patients being identified using a facial photo and by confirming their name and date of birth against written records. While technological methods force the process to pass through a physical barrier, the amount of involvement in conventional methods is often determined within the process design (e.g. does the departmental protocol allow patients to confirm their iden-



tity against their photo in the treatment screen or file, or are patients asked to proactively identify themselves every time a new healthcare professional will take charge of him?)

Radiographers have a crucial role in ensuring accurate processes for patient identification are in place during treatment preparation thus their contribution in developing a departmental policy about identification is imperative. Moreover, radiographers should seek patients' compliance with the use of biometric technology, which, according to most national legislations, requires prior authorization from them for the acquisition of biometrical data.

### *Patient and staff communication*

In order to facilitate patient involvement in safety, a specific information booklet is helpful about the radiotherapy process. This should be developed with and provided for patients. Furthermore, family members or carers could be involved particularly for patients who, psychologically and/or physically, cannot be engaged. The services of a translator should be provided if needed where language barriers exist. To facilitate patient involvement and communication, a 'consultation radiographer' could be a good investment for RT departments.

For patients to be active partners in the radiotherapy team, it is important they can freely communicate with staff and feel comfortable to ask questions. Open communication and the willingness of radiographers to answer questions can provide a great opportunity for patients to discuss their doubts and concerns about unusual events, side effects and their treatment.

Open communication will enable staff to obtain a complete account about patient wellbeing, medical history, and the use of medications, (complementary or alternative). The personal situation of patients can also be discussed and any specific requirements relating to treatment can be considered (e.g. the desire to become pregnant).

A fundamental benefit of open communication would include risk reduction (e.g. the detection of major errors such as the treatment site laterality being planned incorrectly). Moreover, patients may also become more willing to participate in patient reported outcome or experience programs. Benefits for the patient include

feeling empowered to communicate about fears, doubts and concerns and feeling confident to report key points during treatment or follow-up consultations.

Radiotherapy radiographers seeing patients on a daily basis for treatment are importantly the frontline staff caring and listening to patients during their radiotherapy treatment and time must be allowed within departmental schedules to support timely support and discussions with patients.

### *Patient and staff collaboration during treatment*

Effective collaboration between radiographers and patients during treatment can result in a better experience for both parties. When patients feel they contribute to their treatment, they better understand their position within the treatment delivery process. This results in patients being open to discuss anything unusual and feeling more confident to comply with the radiographer's instruction (e.g. lying still during treatment until confirmation of the end of the treatment is given). It could also help in error detection, such as the use of an incorrect immobilisation device or treatment accessory (bolus, shielding, etc.).

### *Patient involvement in schedule management*

The overall departmental workflow should be considered when reviewing treatment schedules to ensure that delays can be avoided for all patients where possible. Cooperation between patients and scheduling staff can improve both the patients and radiographers understanding of scheduling requirements. Treatment delays can increase anxiety in patients and put pressure on radiographers to keep on time for their patients. These factors may have an impact on patient safety. Open communication about scheduling considerations can encourage patients to comply with scheduled treatment times and to make themselves available during the entire course of treatment. Patients become more aware of the negative consequences for other patients and the overall service if they are not aware of the importance of complying with the schedule.

Being open about scheduling considerations also provides the patient the opportunity to discuss preferences and scheduling conflicts, thus dealing with their treatment burden.<sup>4</sup> Since cancer patients have a large group of health workers involved with their treatment, it is likely that RT appointments and patients' appointments elsewhere have to be scheduled around each other. By giving patients the opportunity to communicate about issues with their schedule, radiographers have the opportunity to adapt the schedule so that both patients and departments benefit.

### *Patient involvement in risk management*

Patients have the potential to provide a valuable source of information for both organisational aspects of safety and patient safety incidents [44]. Some feasibility studies have demonstrated good results when examining patient feedback for safety improvement [45] [46][47]. Within radiotherapy, dedicated reporting tools could be provided to patients in order to allow them to report any issues and to communicate any suggested improvements for the organization.

Furthermore, the patients' engagement definition includes the inherent right of patients to be informed in case of an adverse event. This value became a requirement at the European Council Directive 2013/59/EURATOM [48] regarding radiation protection. At an organizational level, strategies should support the development of disclosure policies and procedures [4] involving patients, carers and frontline staff [49] and should provide to all parties involved in an incident (patients, carers, and healthcare professionals) psychological and general support in the aftermath of an adverse event [3][5]. Cancer patients and/or their carers who have experienced a radiotherapy incident could provide invaluable input and insight into the development of disclosure processes for radiotherapy departments.

Patient involvement in proactive risk assessment has been a controversial issue [50] due to the impact that the investigation of potential failures may have on patients [51]. However, with careful recruitment and training of former patients in proactive risk assessment, their involvement in such activities can be beneficial [50]. Patients can identify different modes of failure to healthcare professionals [52] since they have experienced the incident from a patient's perspective [53]. Such an initiative has been developed by the Dutch safety program VMSzorg. Patients are involved in different steps of the proactive risk assessment process in different ways and at different times [53].

### **Recommendation**

Patients involvement in their own treatment can improve patient safety. It is recommended that a culture of a patient centered care is developed in RT departments where patients feel free to raise their concerns. Radiographers should promote patients' active participation in their treatment in terms of patient identification and in the reporting of any unusual event. Patient involvement can be beneficial in developing strategies for incident disclosure and in proactive risk management when it is carefully planned.

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<sup>4</sup>Treatment burden can be defined as treatment work, delegated by health care systems to patients and its impact on their functioning and well-being; there are growing demands on patients to organize their own care and self-manage to comply with complex regimens [54].

## **TOPIC 4: PATIENT INVOLVEMENT IN RADIOGRAPHER EDUCATION**

The EFRS statements on "Radiographer Education" (2019) [55] and "Statement on the Importance of Patient Engagement and the Patient Voice within Radiographic Practice" (2021) [6] outline the current status of patient engagement (patients, representatives, and carers) in European radiographic education and discuss key components of patients partnership in education. This section further highlights the importance of cancer patient engagement in radiographer education in the context of radiotherapy.

Cancer patients belong to a group of patients with chronic disease who are regular users of the healthcare system. Radiotherapy, which is usually delivered daily over multiple sessions, affects patients' lives in various domains, including physical, psychological, and socio-economical. Their special and sometimes unmet needs have been extensively demonstrated in the literature [56][57][58][59][60]. As previously mentioned, radiotherapy radiographers play a central role in the treatment of patients which goes beyond cancer management enabling them to embrace patient-centred care [61][62].

### **Patient involvement in the educational curriculum**

The education and training of radiography students should incorporate the patient perspective in the educational curriculum, to develop the necessary skills required to meet the needs and expectation of radiotherapy patients. Cancer patients, are considered experts in their conditions and they can effectively teach communication skills while they can contribute to co-authoring educational material. Furthermore, patients can inform students on the psychological and socio-economic implications of treatment [63]. Yet, patient engagement in education has to be thoroughly planned so as not to have a negative impact on cancer patients involved. Strategies for patient engagement in education have been stated in the aforementioned EFRS statements [6][55] and more broadly within work by National Societies [64].

## **Patient involvement in continuous professional development**

Continuing professional development (CPD) programmes should also include patient involvement. Until recently, qualified radiographers were guided by their educational experience with programmes focussing on mainly technical and technologically-based competence. Clinical practice also had a similar focus on technical competence. Patient engagement in CPD can promote a continuing focus on patient centred care. As radiotherapy is rapidly evolving, patient engagement in continuing education is now recognized as a valuable source of feedback for RT radiographers regarding the side effects or concerns that patients may have in relation to new technologies. CPD programmes can facilitate bidirectional learning between RT radiographers and cancer patients and further enhance this partnership.

Patient's involvement in webinars and scientific conferences as presenters and panellist should be promoted while radiographers should also participate in similar patients' organisations activities. Patients' should also be encouraged to publish their experiences, in scientific journals providing direct knowledge and wide dissemination of their expectations and recommendations in a way that promote quality improvements. Partnership between editors and patient organisation could assist in such interventions developing continuing educational material valuable in promoting patient's voice.

### **Recommendation**

As patient engagement in health care services becomes a universal imperative [1] and in some countries a recommended requirement, it is recommended that European educational institutions and professional societies include cancer patients and advocacy organizations in their education, training and CPD. Curricula should be regularly reviewed and updated, and CPD programmes should be designed in partnership with patients to promote a culture enabling radiographers in Europe to develop skills and competencies that lean towards patient-centred radiotherapy.

## SUMMARY

Radiotherapy is a complex process where multiple steps have to be followed [7] in order to achieve the best treatment outcome for patients. Radiotherapy patients and their carers have special needs and expectations as they often experience the burden of treatment for a prolonged time. Patient engagement during radiotherapy process design and in shared decision making can provide valuable input to the RT process enhancing their overall care. Patients' education and engagement in their treatment can also improve patient safety. RT radiographers are radiotherapy experts who are professionally accountable to the patients' physical and psychosocial wellbeing, prior to, during and following examinations and radiotherapy [7] and are required to support cancer patients in their radiotherapy journey. Involving patients in radiography education is the first step towards patient-centred care. The EFRS recommends that radiotherapy radiographers embrace the patient voice into their practice and foster patient engagement throughout the radiotherapy process. The EFRS will continue to promote a culture of patient engagement through its activities.

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