**Patient Voices; An essential piece in radiotherapy’s data jigsaw**

**Introduction**

Radiotherapy exists in a technology-driven culture. This focus has facilitated earlier diagnosis and advanced treatments, contributing to half of cancer patients now surviving 10 years or more1.The radiotherapy community looks to data to inform improvements. This may be outcome, survival or other conventionally medicalised measures. A wider, holistic appreciation should consider other gauges of success. While more difficult to measure, qualitative outcomes have the potential to add value and quality to increased survival.

**Data Jigsaw**

In July 2021 National Health Service England (NHSE) invited all Radiotherapy providers to participate in an evaluation of ProKnow2 – a cloud based IT solution. ProKnow promises to facilitate cross provider peer review.  A key objective was to “Harness the benefits of big data”3 to enable the impact of treatment plan quality on short and longer-term clinical outcomes to be explored.

There is also a desire from NHSE’s transformation programme to have the capability to link to other cancer data sources to enable measurement of outcomes from treatment, notably linking with RadioTherapy DataSet (RTDS) 4. There are clear synergistic benefits in pairing data sources and there is a desire to do more.

There is a ‘big data’ jigsaw developing with powerful potential in driving strategy, research priorities, policy and ultimately practice. A critical piece of the picture, although still developing, is Patient Reported Data (PRD)

**Patient Reported Data**

PRD is a collective term for Patient Reported Outcome Measures (PROMs) and Patient Reported Experience Measures (PREMs). PROMs refers to information provided by a patient regarding their own health using a self-reporting medium5. PREMs are questionnaires measuring the patients’ perceptions of their experiences of care6. There is growing interest in PRD, as it addresses the 3 areas identified in the NHS Outcomes Framework7: clinical effectiveness, safety and patient experience.

**PROMs**

The Radiotherapy Service Specification8 requires providers to consider routine use of PROMs, although currently, they are only used sporadically outside of a trial setting. A recent UK survey quantified the use of PROMs in standard of care as 11%, due to barriers with professionals and services9. The is certainly value in collecting PROMs and combining with dosimetric evaluation data from ProKnow to fully contextualise what effects radiotherapy treatments are having on patients.

**PREMs**

The National Cancer Patient Experience Survey (NCPES)10 has only two questions relating to radiotherapy, despite 40% of patients receiving radiotherapy as part of their treatment. The National Inpatient survey11 is useful, although the majority of patients receive treatment on an outpatient basis. Local surveys are conducted although this approach does not support national bench marking and sharing of best practice that will support improvements and reduction in variation, an objective of the Radiotherapy Operational Delivery Networks (RODN)12. A National Radiotherapy Patient Experience survey was undertaken in 201213 and despite recommendations to regularly run the survey, it has not been repeated.

As we develop how we define and measure advanced and innovative radiotherapy and it’s outcomes, we need to make space and plans for how we capture and incorporate PRD, complementing existing methods of quantitative evaluation.

A third aspect of PRD, that requires further consideration, is patient voices?

**Patient Voices**

Listening to, understanding and learning from patients’ experiences is essential to ensure that increased survival also equates to preserved quality of life and that we are adequately preparing people for what they can expect post treatment. The technological focus of radiotherapy, according to Merchant14, has often silenced patient voices. Radiotherapy Action Group Exposure (R.A.G.E)15 documents events when as a community we did not listen14 Breast Screening After Radiotherapy Dataset (BARD)16was established acknowledging the latent effects of radiation and taking a more proactive approach to managing risk. It is vital that we listen to groups advocating for raised awareness of the effects of treatment, like the Pelvic Radiation Disease Association (PRDA)17, and that we learn from the mistakes of the past, before we need to respond retrospectively. As the data jigsaw forms, it is essential to promote patient voices to better understand experiences during and after treatment.

Seeking and collating patient narratives provides a powerful means of appreciating experiences in a way which allows the patient to set the agenda, and captures valuable data across cancer trajectories (diagnosis, treatment and post-treatment). It enables patients to tell their full story in their own terms: we can learn what outcomes like ‘loose bowels’ actually means for individuals who experience them, how it affects day to day life, their sense of self and their relationships.

Ashmore *et al18* with the Gynae Cancer Narratives project adopted a narrative correspondence method, as described by Thomas19 to capture patient experiences. This approach facilitated women telling their story, of the impact of treatment on identity, daily life and sexuality. Their stories describe the support needed and strategies to manage ever-increasing expectations of treatment. Existing qualitative research on patient experiences, for example, tell stories of patients who ‘carry on’ despite the physical, practical, emotional and social demands of cancer and treatment20-23. Narrative correspondence allows individuals to describe their experiences in ‘a naturalistic storytelling fashion’ generating ‘insider’ accounts of lived experiences24. This insight allows practitioners to experience a part of a patient’s world, for just a moment and to consider how we may be able to make it better.

**Call to action**

As we engage with patient voices and combine with existing data sources, we must develop paths for consideration of findings. It is not enough to listen; we must be willing and able to implement changes.

So how, in a technologically focused culture, do we ensure that patient voices are heard?

An important start will be to recognise qualitative research as symbiotic to quantitative data, rather than inferior25,26. It will be important to state this in trust research strategies and commit to in practice. Qualitative data taking a more prominent position is timely as we see improved survival. Listening and reacting to patient voices will allow the development of services to ensure patients are best prepared for treatment. It is also fundamental to inform and develop late effects services, for the tens of thousands of patients currently living with effects of radiotherapy.

The Gynae Narratives project is an example, amongst many from health services research, that show how listening to patient voices gives insight into how a system is really working and importantly where it could or needs to improve. There is a compelling case for PRD forming an integral part of audit systems. PRD, captured through multiple and varied methods, illuminates the difference between policy and practice from an experiential perspective.

Now’s the time, for the radiotherapy community to embrace a range of methods to ensure PRD informs thinking, planning and practice. Such an approach could be the difference between patients living with or truly living well with and beyond a cancer diagnosis, treatment and the associated effects.

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