The Trigger project: the challenge of introducing electronic patient reported outcome measures into a radiotherapy service

Background

Quality of life is a complex concept spanning multiple domains including physical, mental and social well-being. Patient reported outcome measures (PROMS) are tools collected directly from the patient and are a valuable method of collecting data on quality of life without the bias of the physician (1). PROMs, when used in clinical practice, have been shown to improve quality of life for patients and improve overall survival during cancer treatment (1-3). Average life expectancy and the number of patients living with and beyond cancer continue to increase, however, it is estimated that at least 1 in 4 suffer significant long term side effects following their treatment (4, 5). The breadth of choice of treatments are also growing for many patients and the decision between treatments with similar survival rates may be best served with good quality of life data collected by PROMs.

The use and publication of PROMs in clinical trials, where there is often dedicated time and resource, is poor, and often worse in real-life clinical situation (6). The importance of PROMs are starting to be addressed as seen in NHS England's prioritisation of 'living with and beyond cancer' with a commitment to roll out a quality of life metric across the country, including PROMs questionnaires (7). This will evaluate quality of life in multiple different cancers following diagnosis.

There has been a real difficulty in introducing PROMs data collection in an already over stretched NHS service. This is likely to be due to the fact that traditional quality of life questionnaires can be long, not well matched to the side effects of particular treatments and therefore often considered time consuming and irrelevant to the patient and healthcare professional. For successful sustainable uptake of PROMS staff, 'buy in' is imperative and so far this has often been the main barrier to implementation.

Project outline

The Royal College of Radiologists (RCR) and Macmillan Cancer Support were keen to find a solution to this problem, combining a useable treatment-specific PROM for radiotherapy treatment that could be collected electronically. The electronic collection of the PROM was essential to the brief to enable national scale up and reporting. Initially the plan was to scope the addition of a PROM to one of the existing national cancer datasets, namely the radiotherapy dataset (RTDS), to complement the quality of life metric (8). However following discussion with stakeholders this was considered unachievable in this project's time frame, as the process to change a nationally mandated dataset takes 18 months or longer. More importantly, it would also change the fundamental way in which the radiotherapy dataset collated its data which was directly from radiotherapy machines.

The original concept evolved to create an electronic method of collection that would be independent of national registries but could supply the registries with data if the project successfully grew to encompass most of the country. In order to implement this project, the

system had to be independent of any hospital electronic system, which typically vary. For the system to be successfully rolled out it had to be easy to use, set up and relevant to staff (9). It would be patient facing to allow patients to input their own data and to gain appropriate consent for the use of their data.

Most importantly the project needed a short treatment specific questionnaire that would take minimal time to fill out, but highlight those who needed specific help following treatment. ALERT-B is a 4 point questionnaire used to screen for long term bowel toxicity following radiotherapy. It is a set of questions validated against traditional PROMs tools (10). Long term bowel toxicity is improving following modern radiotherapy techniques however still affects quality of life in a significant proportion of people (11, 12). These symptoms are commonly not initially attributed by patients to being related to radiotherapy, and clinicians often have a poor understanding of the complex effect radiation has on bowel function. Many of the symptoms can improve dramatically and rapidly with the correct treatment, but too often these patients do not receive the most appropriate care in a timely manner. A key feature of the ALERT-B questionnaire, is that the patients who are identified as being in need, can more rapidly proceed to being treated according to evidence based treatment protocols that should improve their symptoms and quality of life (13).

The new Radiotherapy Service Specification, which covers the provision of radiotherapy for adults in England, suggests that radiotherapy networks include ALERT-B as a method of collecting long term bowel toxicity data (14). This could be a model for other trigger questionnaires collected electronically for other tumour groups in the future.

Assessment of Late Effects of RadioTherapy-Bowel

ALERT-B Screening Tool

Date:
Your specialist has asked you to complete this screening tool to pick up any bowel or tummy problems you may have developed following radiotherapy treatment.
Please answer Yes or No to the following questions:

1. Do you have difficulty in controlling your bowels (having a poo), such as:

   - Having to get up at night to poo   Yes ☐ No ☐

   - Having accidents, such as soiling or a sensation of wetness ("wet wind")   Yes ☐ No ☐

2. Have you noticed any blood from your bottom recently? (any amount or frequency)   Yes ☐ No ☐

3. Do you have any bowel or tummy problems that affect your mood, social life, relationships or any other aspect of your daily life?   Yes ☐ No ☐
   (e.g., do you avoid any activities or situations- travel, work, social life or hobbies? Do you take continence supplies or spare clothing with you when you go out? Have you made any dietary changes? Do you need to allow for frequency or urgency of needing the toilet?)

If you have any other problems your doctor will be happy to discuss this with you.

Figure 1: ALERT-B screening tool (10)

A challenge to this project was our limited financial resources to demonstrate that this could be achieved at scale as a service evaluation project in multiple centres. Recruitment would have to be integrated into normal practice in radiotherapy departments. The model would be based around on-treat radiographers who would discuss the service with the patient at the time of radiotherapy. The patient would register for the website during radiotherapy and complete the questionnaire to record initial acute toxicity. The system would then invite the participant to redo the questionnaire 6 months later to collect long term bowel side effects. The major benefit to patients of this project is that it picks up early symptoms that may be related to Pelvic Radiation Disease and gives patients a contact to call so that they can be linked to the most appropriate clinicians to deal with their symptoms.

Imperial College Healthcare NHS Trust, Brighton and Sussex University Hospitals NHS Trust and Velindre University NHS Trust were chosen to give a diverse spread of sites, with a lead clinician and radiographer at each department and administration support at Imperial. The aim of this 1-year project was to see how many patients registered and then went on to complete the 6-month questionnaire, against the denominator of those receiving radical pelvic radiotherapy at that particular centre.

The experience so far

At the six- month mark of this year-long feasibility project, approximately 250 patients have registered with the Trigger Project using an electronic platform hosted by My Clinical Outcomes (15). Of those that have answered the initial questionnaires 55% had answered 'yes'

to one or more of the ALERT-B questions which likely represents acute gastrointestinal toxicity. We are now beginning to see the return of the six-month post-radiotherapy questionnaires. This will give us a tangible measure of the burden of long-term side-effects actually experienced by patients receiving pelvic radiotherapy. It may also allow further correlation of tumour type with side-effect burden, as all patients receiving pelvic radiotherapy are eligible.

The 248 patients currently registered with the trigger represent, as of January 2019, 12% of the eligible patients at Brighton & Sussex, 26% at Imperial, and 39% at Velindre. We are hoping to reach the 60% sign up of eligible patients.

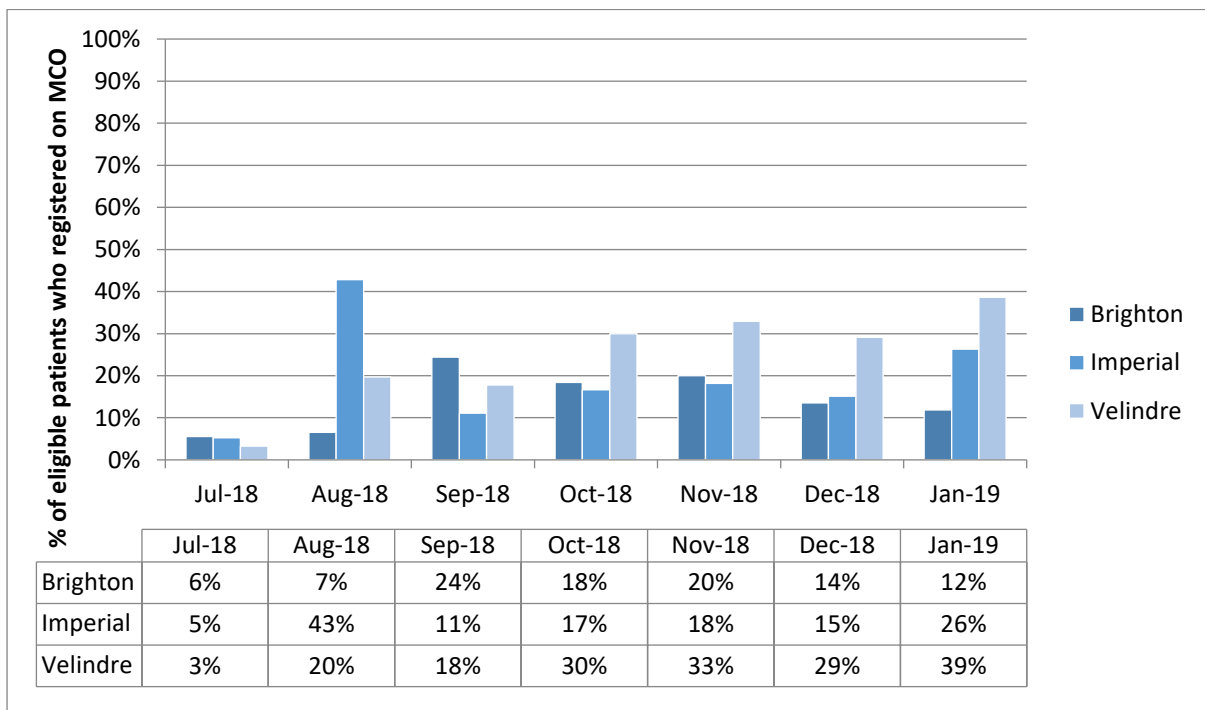|	Jul-18	Aug-18	Sep-18	Oct-18	Nov-18	Dec-18	Jan-19
Brighton	6%	7%	24%	18%	20%	14%	12%
Imperial	5%	43%	11%	17%	18%	15%	26%
Velindre	3%	20%	18%	30%	33%	29%	39%

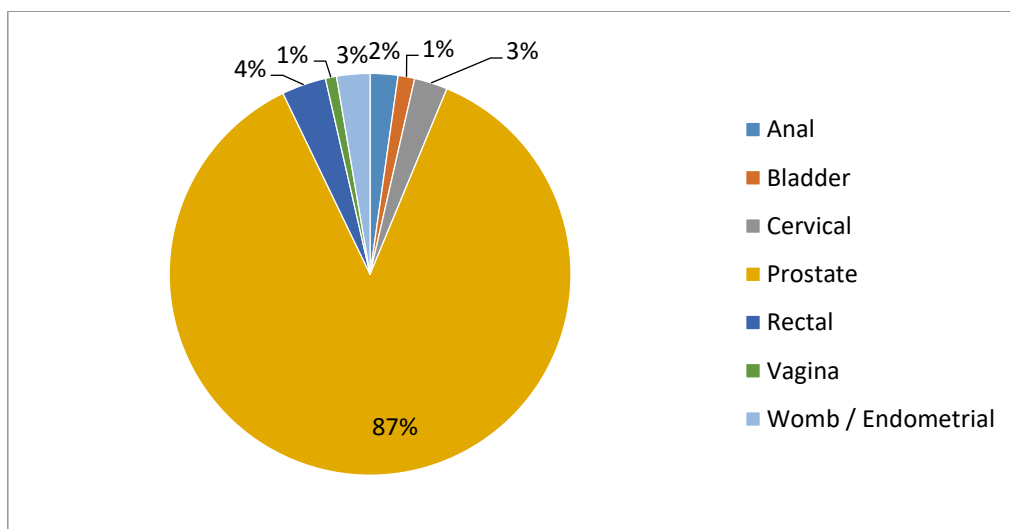Figure 2: Recruitment over time across the three centres

Figure 3: Rates of patients registered on the platform by cancer type

The registration level so far has been low and demonstrates the challenges to implement a project like this without designated resource in the NHS. There is considerable variability between the three sites. This variability has also been found in the NHS England Quality of Life Metric pilot study. We continue to use a learning in practice approach through surveys of staff and by speaking to sites directly. The higher levels within Velindre could be predicted due to their specialist interest in Pelvic Radiation Disease for more than 5 years and thus represents a greater degree of change in the other two sites (16). Staff shortages are seen across the NHS and this means that already over stretched staff do not have time to take on the extra effort required for the TRIGGER project. This may be evident in Brighton and Imperial who have a smaller team of on treat radiographers/ nurses.

This system is designed to help those patients significantly affected by Pelvic Radiation Disease after 6 months and point them to the right help more effectively and quickly. Therefore, patients may not sign up as they do not see the relevance of the project at the time of registration. A lesson to the project is how we can build the system to give more perceived benefits for the patient at registration.

We continue to implement measures to try and combat some of the issues and raise awareness to all staff. Examples of these are a promotional video: filmed at the RCR and at all three radiotherapy centres to promote patient and staff engagement with the project. Also a monthly newsletter: including sign-up rates with a breakdown of cancer type and highlight effective practice, aiming to inform clinicians and promote further engagement.

If these initiatives are effective then this project will have been one of the first of its kind to implement the routine collection of entirely-electronic PROMs, in a scalable fashion, without dedicated funding for sites. This could significantly improve the experience of patients undergoing treatment in the future, as clinical care could support greater self-management and improve follow up of oncology patients by remotely identifying problems so that clinicians review only those with appropriate need.

1495 words

Max word limit 1500

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