

CANCER RESEARCH UK RESPONSE TO THE APPG ON RADIOTHERAPY'S INQUIRY

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Cancer Research UK (CRUK) is the world's largest independent cancer charity dedicated to saving lives through research. We support research into all aspects of cancer, and fund approximately a third of all radiation oncology research in the UK. CRUK wants to accelerate progress so that 3 in 4 people survive their cancer for 10 years or more by 2034.

We welcome the opportunity to respond to the APPG's inquiry. Radiotherapy is an important treatment option for many people diagnosed with cancer. We want every person receiving radiotherapy in the UK to get the best, high-quality treatment for their cancer – and for this to be equitable across the country. The APPG is playing an important role in acting as a parliamentary voice for radiotherapy, championing the more than 130,000 people each year who receive radiotherapy in the UK each year.

Our responses to specific questions are below. We would be very happy to discuss any of the issues raised below further with the APPG, or to give oral evidence if required. We have focused mostly on England in this response because the pressing issue of the new Specification is within England, however would be happy to provide additional perspectives on radiotherapy services in the devolved nations if needed.

KEY POINTS:

- We are very supportive of NHS England's new radiotherapy service specification, which we see as in line with the Vision for Radiotherapy document published in 2014 by NHS England and Cancer Research UK. We are hopeful that coordinating services across a region could make best use of the radiotherapy workforce, improve the efficiency of machine utilisation, embed research in services and – crucially – tackle unwarranted variation in practice.
- However, the specification alone will not guarantee the progress we would like to see in radiotherapy. Government should provide additional funding for radiotherapy: specifically to replace old machines and update IT infrastructure to insure connectivity between centres. The significant shortages in the radiotherapy workforce must also be addressed.
- We would also like to see progress in the coming years in how innovative radiotherapy techniques are brought into to patients quickly and equitably. We would like to see the Commissioning through Evaluation programme refreshed, as well as earlier engagement between NHS England and the research community.

1. WHAT IS YOUR VIEW ON THE ADEQUACY OF CURRENT AND FUTURE RADIOTHERAPY PROVISION ACROSS THE UK?

We have heard anecdotally that there is variation in access to and quality of radiotherapy provision across the country. However, this is very difficult to assess robustly. Below is an overview of our perspective on the evidence base for radiotherapy provision, mostly in England. We would welcome further published analysis of radiotherapy data, to further our understanding.

The Malthus Programme is a tool for modelling radiotherapy demand in England, originally developed in 2011. This estimates that the proportion of patients who should receive external beam radiotherapy at any point in their treatment is 40.6%^{[1][2]}. This modelling was based on

data from England about cancer incidence and stage of diagnosis from the cancer registry and validated by UK clinicians; it has since been used to inform both national and regional radiotherapy planning. We would prefer to use this figure as a rough benchmark for external beam radiotherapy provision, as it is likely to be more accurate for a UK population than international models. However, it should also be noted that not all radiotherapy given is external beam (for example, brachytherapy) and so the 'true' figure is likely to be slightly higher.

There is a lack of robust and recent data on how provision compares to this figure, apart from the following:

- 2013 analysis of RTDS found that the overall rate of access to radiotherapy in England was 38.6%^[3]. There has not been a directly comparable study since.
- PHE and CRUK analysis has found that 27.6% of tumoursⁱ in England are treated with radiotherapy in the first course of treatment. This is much lower than the 40% overall statistic, but the two cannot be compared directly as the 40% modelled figure includes radiotherapy given later in treatment.
- PHE and CRUK are currently working to understand the percentage of people with cancer who receive radiotherapy at any point of their treatment, which could be more directly compared with the Malthus figure.

Similarly, it is very difficult to judge the extent of regional variation in access with confidence. This is because a large part of variation originates from different areas having a different mix of patients, so each can have very different 'ideal' rates of radiotherapy access. The Malthus programme found that the ideal modelled access rate would also vary significantly, mostly because of differences in cancer incidence, largely due to the age structure of the local population^[1].

RTDS analysis does show significant regional variation in access to radiotherapy, with fewer radiotherapy attendances in deprived areas compared to more affluent areas^[3]. The full reasons for this variation are not well understood, and to what extent this reflects true unwarranted variation. Further investigation into this is needed. Understanding and reducing regional variation in practice must also be a priority for new Radiotherapy Operational Delivery Networks.

Demand for radiotherapy services will increase in the future, as cancer incidence is expected to rise^[4]. According to modelling by the Malthus Programme, the proportion of people diagnosed with cancer who will need radiotherapy at some point in their treatment will not change significantly^{[1][4]}. However, this will depend on how research progresses in that time.

Most radiotherapy activity relates to a small number of cancer sites: breast, prostate, head and neck, and lung cancers together account for 79% of radiotherapy attendances^[4]. Therefore, changes to practice in these sites – and especially significant changes in practice, such as more hypofractionation – could have a major impact on future demand.

Finally, it is also worth noting that beyond overall demand, radiotherapy services – and cancer services more broadly – will have to adapt to treating more older patients, who are likely to have more complex needs. As well as the number of cases increasing overall, the proportion of patients diagnosed who are over 75 will also increase from 36% to 46%^[5]. Cancer services will therefore need to adjust to meet the needs of patients who are more likely to have

ⁱ Malignant tumours, excluding NMSC

complex needs, and require more support to access treatment. Radiotherapy services must be planned with these changes in mind.

2. NHSE PUBLISHED ITS RADIOTHERAPY SPECIFICATION IN JANUARY 2019. WHAT IS YOUR VIEW OF THE PROVISIONS AND PLANS SET OUT IN THAT SPECIFICATION? IS THE SPECIFICATION BEING IMPLEMENTED PROPERLY AND EFFECTIVELY?

The Vision for Radiotherapy, published in 2014 and co-written by NHS England and Cancer Research UK, set a bold ambition for how radiotherapy services in England should evolve^[6]. At the heart of this was the move to a networked approach to delivering radiotherapy. The ambition behind this was to ensure equitable access to high-quality radiotherapy, and to tackle unwarranted variation.

The Radiotherapy Specification published in January 2019 was a major step towards fulfilling the Vision^[7]. We are hopeful that coordinating services across a region could make best use of the radiotherapy workforce, improve the efficiency of machine utilisation, embed research in services and – crucially – tackle unwarranted variation in practice.

However, it is too soon to tell how effective this is being implemented. These Networks became officially operational in April 2019 and will be given several years to adjust into the new model. Different areas will be at different stages of implementation, depending on – for example – how much the centres within the Network already worked together prior to the new Specification being launched, and whether they have the same IT systems. It will therefore take some time before the success of these changes can be evaluated fully.

Underlying this, the potential gains of this model are dependent on networking between radiotherapy centres – which requires the right technology. IT solutions must enable support centres to collaborate on treatment planning and peer review, as well as evaluation of services across and between Radiotherapy Networks.

3. DO YOU HAVE A PERSPECTIVE ON THE LEVEL, FUNDING EFFECTIVENESS OF RADIOTHERAPY SERVICES IN THE UK COMPARED TO OTHER COUNTRIES/ JURISDICTIONS? IF SO, PLEASE EXPAND ON THIS PERSPECTIVE. DO ALL THOSE PATIENTS WHO SHOULD RECEIVE RADIOTHERAPY DO SO?

We would like to see an increase in overall funding for radiotherapy, targeted to specific areas of need, and specific improvement in funding mechanisms such as the national tariff. We would support an increase funding from central Government specifically to ensure equipment and IT infrastructure is kept up to date, to support innovation, and – crucially – to tackle the shortages in the radiotherapy workforce.

However, we would advise against drawing strong conclusions from comparisons in funding for radiotherapy across different countries, especially in the context of a percentage of overall health spend. Different countries will have to spend their money in very different ways, for example based on the type of health system they have, their geography and the health of their population. All of these factors would impact how radiotherapy services are delivered, and how the rest of the budget is spent (which would impact the percentage spent on radiotherapy). We would prefer comparisons to be centred around patient outcomes, as well as detailed comparisons of best practice in radiotherapy delivery.

Replacing linear accelerators is a huge capital investment for providers, and in times of financial strain this results in machines not being replaced in a timely fashion. In October 2016, NHS England invested £130 million to fund machine replacements, which was extremely welcome and very necessary – a third (90 out of 260) of radiotherapy machines in England needed to be replaced by the end of the following year. While welcome, there is still a need for a sustainable solution to replacing machines. The 2015 Cancer Strategy for England called for a centrally-managed replacement programme, for example^[8].

Investment in IT infrastructure will also be crucial for supporting networking, and therefore the success of the new Radiotherapy Specification will be dependent on this. We were very encouraged to see a reference to the importance of networking in the NHS Long Term Plan [9], and to see further commitment from Ministers that NHS England will commit to providing additional investment to support IT connectivity across Networks^[10].

4. ARE THE CURRENT NHS TARIFF SYSTEM AND TARIFF LEVELS FOR RADIO THERAPY FIT FOR PURPOSE?

The NHS tariff for radiotherapy currently involves payments being made per fraction, which has caused issues in the past: there is no incentive for centres to adopt hypofractionation techniques for prostate cancer, as they result in lost income. While this specific case has since largely been rectified, there remains a need to reform the system. Changes to the tariff could also provide stronger incentives for radiotherapy centres to replace radiotherapy machines, which would be a positive outcome. We understand that NHS England are currently working on reforming the tariff for radiotherapy and look forward to seeing the outcome of that work^[10].

5. WHAT IS YOUR VIEW AND/OR EXPERIENCE OF THE LEVEL OF ACCESSIBILITY TO ADVANCED RADIO THERAPY SERVICES SUCH AS SABR?

So far, SABR has only been routinely commissioned for a specific group of people with lung cancer. Anecdotally, we have heard there is significant variation in access to lung SABR, which we are concerned by: there is strong evidence demonstrating the benefit of SABR compared to conventional radiotherapy^[11].

A recent survey of radiotherapy centres in England found that 36 (58% of centres in England) deliver lung SABR^[12]. The reason that SABR is not currently delivered at all centres is largely because commissioning is restricted to centres which will treat over 25 patients a year. Six centres have chosen to deliver SABR despite not being commissioned for it.

While patients should in theory be referred on to centres that do deliver SABR, we have heard anecdotally that this does not always happen and some patients instead receive standard radiotherapy at their local centre. In principle we would support commissioning being extended to more centres, however this must be done carefully and quality maintained: the survey also found wide variation in the approach to delivering image guidance, and to training, which is a possible cause for concern and highlights the need for significant oversight in terms of quality assurance, as the service is rolled out further.

NHS England have identified rollout of SABR as a priority for the new Radiotherapy Operational Delivery Networks^[7], which we support, and hope that this promotes equity in access.

There has also been an NHS England Commissioning through Evaluation (CtE) programme for SABR, exploring its use in oligometastatic disease, re-irradiation of pelvis and spine, and

hepatocellular carcinoma^[13]. Patient recruitment closed in March 2019 and an evaluation report is due shortly. While CtE is in principle a good and pragmatic way of gathering more evidence for promising technologies when randomised controlled trials are not possible or practical, access to innovative technologies has not been fully equitable under CtE programmes, as the techniques are limited to relatively few specialist centres who can meet the minimum patient numbers required. Again, while patients could in theory travel to access SABR, in practice we have heard that this does not happen. We are hopeful that the creation of Radiotherapy Networks could support more equitable access to advanced techniques, through better regional coordination.

There is a broader issue about how to enable earlier access to advanced radiotherapy techniques, and the role of NHS England's Commissioning through Evaluation (CtE) programme. We are supportive of the rationale for the CtE programme, however it could and should be optimised. We would like to see more NHS England having earlier engagement with the research agenda, so that services can quickly adopt new techniques – through either routine or evaluative commissioning. This has been happening well with the new proton beam therapy NHS facilities and we would like to see this approach adopted more broadly.

6. DO YOU HAVE ANY VIEW OF, OR DATA ON, OR EXPERIENCE RELATING TO THE LINK BETWEEN TRAVEL TIMES AND THE UPTAKE OF RADIOTHERAPY TREATMENT, AND ON WHICH, IF ANY, GEOGRAPHIC AREAS SUFFER FROM UNACCEPTABLY HIGH TRAVEL TIMES?

There is a limited amount of robust evidence demonstrating the link between travel times and access to radiotherapy. There has been one robust study by CRUK and PHE which did not find a link between the two, however anecdotally we have heard that this is an issue affecting many patients.

The study undertaken by CRUK and PHE was for prostate cancer and found that the percentage of patients receiving radiotherapy does not decrease with increasing distance to the nearest treatment centre^[14]. The analysis found that 96% of the patients in the dataset lived within 45 minutes' journey of the treatment centre by car; 1.2% lived more than an hour away from their radiotherapy centre. The publication also contains a heat map of travel times in England.

However, this analysis did not examine travel times for patients relying on public transport, and so may be an underestimate of the 'true' travel times for some patients. While this analysis suggests that longer travel times are not a barrier to access for these patients, further research is needed to establish whether this is also true for other types of cancer, (given that prostate is one of the most common types), and for all patient groups.

Furthermore, this does not mean that longer travel times did not have a negative effect in other ways, for example on their experience of care. In a survey of the Cancer Research UK involvement network, several respondents told us how they had found long travel times difficult to manage^[15].

"I already had to travel a 35-mile round trip, and don't think I could have managed a longer one as it's pretty exhausting. It's ok if you have someone available to spend several hours of their day every day to help with transport, but how many people do?"
– a patient

This is likely to be more of an issue for those who are unable to access public transport, as well as patients with more complex needs – such as comorbidities, or who have caring responsibilities. The number of people over 75 diagnosed with cancer will rise in the coming years, so this must be factored into plans and support provided for everyone to access treatment. In past CRUK research into the specific needs of older patients, clinical interviewees based at sites where patients are more likely to have to travel for treatment – such as tertiary centres serving a mostly rural area – expressed concerns that older patients could be excluded from treatment, or from taking part in clinical trials^[5].

However, there are no simple solutions to the travel times issue, as extending radiotherapy services often requires significant investment. Some areas have built satellite centres, but other areas are limited by funds, or not having enough staff to open additional centres. In the absence of this, areas could improve patient experience through other means, such as:

- Planning appointments in advance: many patients reported not being able to do this, which made it very difficult to arrange transport and to get into a routine. It would be preferable for patients to be able to see a full schedule of appointments, which are timed so that if they are travelling long distances this can be done outside of peak travel times.
- Car parking: this is a common issue, with spaces both limited and expensive. Many patients requested free parking.
- If treated away from their local hospital, some said that it would be useful to have a treatment card which detailed their radiotherapy plan so that they could bring this to their local GP or hospital if they had any side-effects.
- Comfortable facilities for waiting and changing (with the latter designed to maintain dignity)

7. HOW DO YOU ASSESS THE CURRENT STATE OF THE RADIOTHERAPY WORKFORCE IN TERMS OF ADEQUACY, MORALE, WELLBEING, TRAINING, SKILL MIX AND RECRUITMENT AND RETENTION?

CRUK published a comprehensive report (“Full Team Ahead”) into the non-surgical oncology workforce in December 2017, which contains detailed analysis of the radiotherapy workforce^[16]. There are significant shortages in the three key radiotherapy staffing groups. For example:

- Clinical oncology: there were 70 vacant posts reported across the UK in 2018, which is double the number five years ago. Half of these posts have been vacant for ten or more years. This is not likely to improve without significant intervention, as the numbers joining the profession aren’t enough to make up the shortfall^[17].
- Therapeutic radiography: the current vacancy rate for the UK is 6.1%. This has remained steady since 2015^[18].
- Medical physics: the vacancy rate in 2015 was 9.2% for clinical technologists and 9.0% for clinical scientists. These figures do not take optimum staffing levels into account; if they did, IPEM estimate this would result in an overall 19.6% shortfall^[16].

For the Full Team Ahead project, we also surveyed the workforce and found that nearly three in four (73%) of respondents to our recent survey of the treatments workforce identified that staff shortages were a barrier to delivering cancer treatments effectively, meaning they did not feel they were able to deliver the treatments to the best of their ability^[16]. This impacts the progress of service improvement initiatives and the sharing of best practice, but also staff morale.

However, the new Radiotherapy Specification could have a positive impact on the English radiotherapy workforce's ability to manage demand for treatment, provide high quality care and undertake research. There is currently significant regional variation in staffing rates, with rural hospitals or those in smaller urban areas having the highest vacancy rates. Ensuring equitable staffing levels across Networks should therefore be an early priority for emerging boards. A Network-wide approach to workforce development could also enable staff to develop more while based in one hospital, without having to move – which would have a positive impact on retention.

However, this is subject to certain caveats and must be considered in the context of significant workforce shortages. Addressing these shortages will be key to realising the ambitions set out in these proposals. Furthermore, for staff to work together across a Radiotherapy Network, there must be interoperable and up-to-date IT infrastructure that supports collaboration.

8. HAVE YOU, OR YOUR MEMBERS IF YOU ARE AN ORGANISATION, EXPERIENCED RADIOTHERAPY FROM A PATIENT PERSPECTIVE? IF SO, WHAT IS YOUR VIEW ON THE QUALITY AND LEVEL OF SERVICE? HOW DO YOU THINK IT COULD AND SHOULD BE IMPROVED?

The UK's Cancer Patient Experience Surveys generally show very positive ratings overall; for example respondents to England's survey rate their overall care as an average score of 8.8 out of 10^[19]. There is limited information about the specific experience of those having radiotherapy, and this is an area for further exploration – however we can see that 87% agreed completely that they had all the information they needed about their RT beforehand. Only 59% agreed completely that once they started their treatment they were given enough information about whether their radiotherapy was working, in a way they could understand. This figure is lower than for chemotherapy (68%), suggesting some improvement could be made in the information given to people having radiotherapy.

In a survey of the Cancer Research UK involvement network to inform our response to NHS England's consultation on the service specification, we asked about what could be done to improve their experience of radiotherapy; please see suggestions above, under question 6^[15].

9. ARE THERE ANY OTHER MATTERS WHICH YOU WOULD LIKE TO RAISE?

We would also like to emphasise the importance of radiotherapy research. Radiotherapy is also a priority area for Cancer Research UK and we have committed to increasing our funding for radiation research. We commissioned an independent panel to determine how we should seek to support radiation research in the future^[20], and as a result have committed to building a national radiation research network – Cancer Research UK RadNet. UK institutions were invited to bid to become one of the Centres of Excellence that will form the network; the outcome of this process will be announced in the coming months^[21].

Radiotherapy research was also a key pillar of the Vision for Radiotherapy and new Radiotherapy Operational Delivery Networks have since been given a target of increasing recruitment to clinical trials by 15%^[7]. This is positive. However, we are concerned that without additional resource to support clinical trials – primarily in terms of the radiotherapy workforce, as previously raised – this increase will not be realised.

“Without time to research and develop treatments, it will feel like the early 90s again, when we were really behind the rest of Europe and our techniques were out of date.

[In those days] our outcomes were right at the bottom of the table” – Head of Radiotherapy Physics (from ‘Full Team Ahead’ report^[16])

There may be some potential for Networks to streamline some of the administrative burden associated with setting up clinical trials, particularly in quality assurance, by pooling resources across radiotherapy centres. But as with many of these proposals, this will only be possible if IT systems are interoperable.

There is also a pressing issue of workforce shortages limiting capacity for research. CRUK is currently exploring this through a funded policy research project. This piece will identify policy solutions to improve this situation, using the existing workforce. Findings from this research are expected by September of 2019 and a report will be published by the end of the year.

Furthermore, there must also be a focus on ensuring equitable access to clinical trials across the country. All centres should offer patients the opportunity to take part in research – if centres cannot run a trial themselves, patients should be given the option to travel to another centre to participate in the trial.

Finally, we would like to reiterate the importance of accurate, accessible data about radiotherapy access, which is vital in examining variation in access. Public Health England have made huge progress with the radiotherapy dataset over recent years and also recently published an excellent and publicly-available online tool for examining the RTDS, which we welcome^[22].

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