Cancer Research UK Response to NHS England's Consultation on Modernising Radiotherapy Services, January 2018

Cancer Research UK (CRUK) is pleased to have the opportunity to respond to this consultation. Radiotherapy is an important treatment option for many people diagnosed with cancer. We want every person receiving radiotherapy in England to get the best, high-quality treatment for their cancer – and for this to be equitable across the country.

Despite significant improvements in recent years, access to modern radiotherapy such as Intensity-Modulated Radiotherapy (IMRT) remains lower than it should be. The Radiotherapy Board estimates that just over 50% of radically treated patients should receive IMRT[1], but latest figures estimate access to be around 44%. There is also still significant variation in access across England[2].

CRUK and NHS England's 2014 Vision for Radiotherapy[3] set an ambition for how radiotherapy services in England should evolve, to address these issues and ensure that all patients receive advanced and innovative radiotherapy that has been shown to be both clinically and cost effective. A major theme of the Vision is the move towards a networked approach, with radiotherapy centres working in partnership to create an integrated radiotherapy team.

The model proposed by NHS England in this consultation is broadly in line with the Vision for Radiotherapy. We therefore support the principles behind it, including spreading best practice and reducing variation in access to high-quality radiotherapy. As the largest funder of radiotherapy research in the UK, we also welcome the focus on embedding clinical research in radiotherapy services and the ambition to increase clinical trial recruitment. Finally, we also believe that a more coordinated regional approach could help make best use of the radiotherapy workforce and could support the allocation of resources to ensure consistent best practice.

However, achieving these ambitions will require time and resource. We cannot see from the consultation that any additional resource has been allocated to support reconfiguration, networking or the ambition for an increased uptake to clinical trials. If this is the case, this is concerning and services are unlikely to achieve these ambitions.

Furthermore, there is still a need for a sustainable solution for radiotherapy services. NHS England's £130m investment in replacing and upgrading old linear accelerators (LINACs) was welcome, however it is a short-term solution. As recommended in the 2015 Cancer Strategy for England[4], we would like to see NHS England commence a rolling programme of replacements for LINACs. We would also like to see a rolling programme of upgrades to IT infrastructure, which will be a crucial enabler of networking. Finally, there is also a need to review the national tariff for radiotherapy: since payment is currently managed per fraction, there is a disincentive to perform clinical trials exploring hypofractionation. While these issues are outside the scope of this consultation, they should also be important considerations for NHS England over the coming year, as they seek to ensure radiotherapy services are fit for the future.

We ran a survey of people affected by cancer to inform our response to this consultation and commissioned a YouGov survey of the public[1]; results from both surveys will be included throughout this response. Our response has also been informed by our recent report 'Full Team Ahead: understanding the UK non-surgical cancer treatments workforce'[5] and by engagement with the radiotherapy clinical and research community.

[1] 2,054 UK adults, fieldwork November 2017

Key points:

- **We support the principle of a networked approach and hope it will promote consistent, high-quality radiotherapy access. However, there is little detail on how Radiotherapy Networks should be formed. We encourage NHS England to issue guidance to support the establishment of Networks.**
- **Interoperability of IT systems across a Radiotherapy Network will be a significant factor in ensuring they work effectively. These proposals will not be successful unless additional support is given for upgrading IT systems, to promote networking and ensure efficient treatment planning. We urge NHS England to provide additional support for networking; primarily through ensuring the adequate IT infrastructure is in place.**
- **Radiotherapy should be given locally wherever possible; however, we recognise that a small proportion of patients may have to travel to get specialist radiotherapy. Every patient having radiotherapy must get the support they need throughout their treatment, to access the services they need, whether near or far. We have outlined some steps that should be taken in our response.**
- **A networked approach could help with staffing shortages, however this alone will not solve the problem. Health Education England should focus on filling the workforce gaps, as outlined in their cancer workforce plan. Radiotherapy Networks should also focus on developing skills mix approaches.**
- **NHS England should commence a rolling programme of replacements for LINACs and IT upgrades, and should review the national tariff for radiotherapy.**

<u>Further detail is needed on the formation of Radiotherapy Networks</u>

We support the principle of a networked approach; this was also established as an ambition in the Vision for Radiotherapy. We see this as an important step to ensuring consistency in practice across England, and embedding quality assurance. Robust quality assurance is especially important in modern radiotherapy, where it is more targeted and so the quality of treatment planning has a direct impact on the risk of local recurrence.

However, we note that there is little detail about how these Radiotherapy Networks should be formed. Without much direction or defined governance arrangements put in place, the success of the Networks is likely to be a function of existing local relationships. While we agree that forming Radiotherapy Networks should reduce local variation, without a strong steer this could just be replaced with regional variation – with each Network site taking a different approach.

We encourage NHS England to issue further guidance to the emerging Networks, to ensure that they are all given an equal chance of success. We would also value additional information about how the success of Networks will be evaluated and the mechanism by which NHS England will maintain oversight. Furthermore, there are wider changes that must be made to facilitate the successful development of Radiotherapy Networks, including ensuring interoperable IT systems and addressing payment mechanisms, which promote competition, rather than cooperation, between centres.

<u>IT infrastructure will be critical to the success of Radiotherapy Networks</u>

For Radiotherapy Networks to be successful, there must be interoperability across their IT infrastructure. As outlined in the Vision for Radiotherapy, peer review of patient outlining and

treatment plans across a Network could significantly improve outcomes if adopted, by making sure improvements are shared and communicated.

Software also has major implications for the quality and efficiency of treatment, particularly in the treatment planning stage. New technology is increasing the speed and accuracy of planning, which is raising standards and improving efficiency.

However, we have heard several cases where software is not up to date, is incompatible across the proposed Network geography, and that trusts cannot afford to update software to fix this. The proposed model will only be successful if NHS England can ensure that Networks can have the most up-to-date, interoperable software across the Network. This may require providing additional ring-fenced funding; perhaps as part of the second tranche of radiotherapy modernisation funding.

Patient experience must be a priority when designing services

CRUK believes that radiotherapy treatment should be given locally, wherever possible. But for some patients, travelling further will mean being able to access the most appropriate type of radiotherapy for them.

We therefore support the proposed model: for most patients, the proposals will not change where they receive treatment, and they should be able to access high-quality radiotherapy close to home. However, in a small minority of cases, services will be centralised into specialist hospitals. This will make sure radiotherapy is of a consistently high quality across the Network and delivered using the best equipment and technical expertise. We also appreciate that the impact of these changes could decrease over time, as newer hypofractionation approaches will mean fewer treatments are needed – and therefore less travel.

However, clinical benefit must not be the only concern. Maintaining a positive patient experience is critical: because it is the right thing to do, but also to make sure treatment adherence is not affected by changes to travel requirements. Radiotherapy Networks should ensure that services are designed to meet patients' needs by embedding meaningful patient involvement in any service redesign. 87% of people affected by cancer we surveyed believed it is important that patients are involved in the reconfiguration of radiotherapy services.

> *"The system should work for the person with cancer, not the other way round" – a patient*

Good communication is also essential, especially when changes are being made to where patients can have treatment. Networks must make sure the reasons for these decisions are made clear and that those impacted are able to contribute to those decisions.

> *"It seemed to me that the people who came up with the system that required me to travel so far for treatment, when there was a hospital on my doorstep that could have treated me, could never have experienced cancer first hand nor the added effects of cancer treatments. The debilitating effects a long and tiring journey has on someone who's already fatigued from cancer and cancer treatments can only be appreciated by those who have been through it." – a patient*

Patient perspectives on travelling for treatment

Our public survey found that 57% would be willing to travel 'as far as possible' to get the best radiotherapy treatment. Our survey of patients found that 72% would travel further to get the best

quality treatment. However, this is very hypothetical; a patient's response is likely to be very dependent on how well they are, how far they must travel and the support they have available to them. Furthermore, caution must be taken in applying this to a wider population given that the patient survey was a self-selected group. Several people responding to our survey also told us that travelling for treatment was difficult to manage; the impact of this should not be underappreciated.

> *"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? It means that some people, particularly those from poorer backgrounds, will not get the best treatment" – a patient*

Many patients responding to our survey also expressed that the inconvenience would have less of an impact if better support was available.

> *"In order to provide the highest technical standards and have the best people working together it helps to have them in one establishment. It would be lovely if it was on our doorstep but it cannot be on every doorstep. The important thing is that transport is easy to the hospital and things like parking are taken care of, which are often not the case." – a patient*

We also asked whether any steps could be taken to reduce the negative impact of having to travel and received several suggestions:

- 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.

  > *"I think that having all appointments booked in advance at the same time of day allows for a routine to be established. This is important if you have "chemo brain". It also allows for domestic arrangements to be put in place for children etc." – a patient*

- 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)

Radiotherapy Networks could be a positive development for the radiotherapy workforce

We believe the proposed changes to radiotherapy services will have a positive impact on the workforce's ability to manage demand for treatment, provide high quality care and undertake research. 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.

Many of the points raised in this response are also included in our recent report 'Full Team Ahead: understanding the UK non-surgical cancer treatments workforce'[6] and we encourage emerging Radiotherapy Boards to take these findings into account when formulating their strategic workforce plan.

It is important to note that there are significant current shortages of key radiotherapy staffing groups across the board. Current shortages are 3.3% for clinical oncologists, 6.4% for therapeutic radiographers, 9.2% for clinical technologists and 9.0% for clinical scientists (not taking optimum staffing levels into account, which IPEM estimate would result in a 19.6% shortfall). The workload of this last group is likely to increase as advanced radiotherapy techniques become more widely used, which require more time to plan and deliver.

Health Education England should tackle these shortages as part of their cancer workforce plan. The phase 1 plan goes some way to addressing this, however it does not go far enough to make sure the radiotherapy workforce is fit for the future. The phase 2 plan should take a strategic look at the future demands of the radiotherapy workforce, taking into account developments in advanced radiotherapy techniques as well as the current shortages.

Nearly three in four (73%) of respondents to our recent survey of the treatments workforce identified that staff shortages were a barrier to providing efficient treatments and excellent patient experience. This impacts the progress of service improvement initiatives and the sharing of best practice, but also staff morale. This makes it even more vital that Radiotherapy Networks are given sufficient resource to focus on these wider issues across their whole geographies.

Although we recognise that these shortages must be addressed primarily by Health Education England, there is also a role for the emerging Networks: there is also significant regional variation, 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.

Finally, it is important to mention how many people affected by cancer responded to praise the radiotherapy staff treating them. Several also spoke about the importance of good communication.

> *"All staff I encountered were wonderful. Very busy, but always helpful, kind and accommodating" – a patient*
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> *"I will forever be grateful for the treatment I received. Hopefully it will prove to be life-saving. Please radiotherapy services try to be more empathetic to your patients and not take for granted that we know what to expect. Theory is so different to the reality. Talk to us constantly, reassure us, constantly. It is a frightening experience from start to finish of the treatment" – a patient*

<u>Encouraging skills mix approaches</u>

We also encourage a Network-wide approach to skills mix: some members of the workforce could be trained to take on additional responsibilities, revising the traditional allocation of responsibilities within a team to better use the mix of skills within a team. This approach was also recommended in the Vision for Radiotherapy.

A skills mix approach is also welcomed by the workforce: 70% of professionals responding to our recent survey agreed that core skill mix would be a positive development; it was also supported by the people affected by cancer surveyed as part of the research – so long as the approach was properly communicated at the start of their treatment.

For example, Networks should consider expanding non-medical professionals' roles to include:

- Conducting weekly treatment reviews: this can be undertaken by therapeutic radiographers or radiotherapy nurses working as advanced clinical practitioners. This is a standard identified by the Royal College of Radiologists[7].
- Radiotherapy planning: the current dependence upon clinical oncologists to develop plans and check images creates bottlenecks in the system and often results in delays in delivering the treatment to patients. This can be overcome by dosimetrists (trained clinical technologists or therapeutic radiographers) playing a larger role in the imaging-led side of treatment, either outlining target volumes or the organs at risk. In addition, clinical scientists and dosimetrists are already doing more quality assurance of plans.
- Checking of radiotherapy plans: this traditionally involves a clinical oncologist checking and approving after the images are outlined and a further check and approval after the dosimetric plan is signed off. This can be streamlined by shifting the initial image check to the end of the process, to take place alongside the dosimetric plan. However, it should be noted that this is easier to implement in tumour sites that are simpler to plan.

Although highly valuable, these approaches require a Network to have the right staffing numbers and funding for training opportunities. There is also an impact on capacity for those responsible for delivering training. To be successful, such approaches require support from staff and senior leadership.

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.

Research must be a priority for Radiotherapy Networks

A key pillar of the Vision for Radiotherapy was the need to place research at the heart of radiotherapy services. This was later explored in more depth through a workshop we convened in January 2016, establishing principles for supporting radiotherapy research[8]. Radiotherapy Networks ensure equitable access to research across the Network. This must be supported by strong academic leadership at Radiotherapy Network Board level.

We are therefore pleased to see an ambitious target of a 15% increase in clinical trial recruitment in the proposals. However, we are concerned that without additional resource to support clinical trials – primarily in the 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)*

There may be some potential to streamline 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.

The provision of Excess Treatment Costs (ETC)s is also central to the success of research. We were pleased to see the recent commitments from NHS England to reform the approach to ETCs[9] and will be responding to that consultation separately. We would particularly welcome reassurance that ETCs will be covered for trials into new advanced radiotherapy techniques.

Furthermore, there must also be a focus on ensuring equitable access to clinical trials. We would appreciate clarity from NHS England as to whether there will also be minimum volume requirements for centres to host clinical trials. Despite this, 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. In summary, it is important to ensure that services are not reconfigured in such a way that clinical trial recruitment is negatively impacted.

Public Health England must ensure Radiotherapy Networks can access and use high-quality data

High-quality, complete and timely data is a key factor for improving all cancer services. Despite some recent improvements, there is still much to be done to ensure radiotherapy services in England are truly data driven. For example, services should be assessed through robust quality assurance, including examining any variation in practice within and between radiotherapy centres – but this is not currently the case.

There have been difficulties in this area – both in terms of the quality of the data collected through the Radiotherapy Dataset (RTDS) and with centres receiving data back. We have also heard specific issues about the completeness and specificity of coding.

NHS England and Public Health England must prioritise improving the utility of RTDS, so that it can be used to identify and reduce variation in access to high-quality radiotherapy treatment.

There is still much room for improvement in public awareness of modern radiotherapy

There has generally been low public awareness of radiotherapy, especially when compared with other treatment modalities. A recent YouGov survey of the general public confirmed that this is still the case: 52% of people surveys had never heard of any of the types of advanced radiotherapy listed and only 4% had heard of IMRT[10]. The only type of radiotherapy with relatively high awareness was proton beam therapy, at 24%. This contrasts with awareness of chemotherapy; for example, 28% had heard of immunotherapy. This has barely changed over the five years since CRUK first ran this analysis, which is disappointing.

It could also be argued that low public awareness contributes to a lack of public push for better and more equitable radiotherapy services. Since there is low awareness, proactive public and patient engagement by Radiotherapy Networks is important: to make sure services are designed in a way that meets patients' needs and expectation, and to avoid any misunderstandings about the rationale for service redesign.

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References

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