

Smart Consult | 26 Cheering Lane, Suite 401, London, E20 1BD Tel/Fax: 020 3900 3009 | Email: <u>mrs-report@smart-consult.co.uk</u> Website: <u>www.smart-consult.co.uk</u>



# Document Control Sheet

Client	NHS England
Document Title	Modernising Radiotherapy Services Public Consultation Report
Status	Final
Version	05
Date	August 2018
Further copies available from	mrs-report@smart-consult.co.uk

# Contents

Section 1: Introduction	3
Section 2: Approach to analysis	6
Section 3: Summary of Key Themes	7
Section 4: Responses from the online survey	20
Section 5: Responses from other formats	33
Section 6: Online Survey – Additional Questions	42
Section 7: Glossary	44

## Section 1: Introduction

Smart Consult has been commissioned by NHS England to independently analyse and report on the data from the Modernising Radiotherapy in England Consultation. The following report summarises the analysed and thematic data from the consultation.

Background



Figure 1: Map of the United Kingdom showing the regions of England<sup>1</sup>

A formal public consultation was implemented between October 2017 and January 2018 at national level across England (Figure 1) to elicit public views on a new clinical model for radiotherapy for rare and less common cancers. The consultation was seeking views on the creation of 11 radiotherapy networks in England responsible for coordinating radiotherapy services for their catchment populations, with the aim of increasing access to dedicated subspecialist teams who would treat

<sup>&</sup>lt;sup>1</sup> Contains OS data © Crown copyright 2018

sufficient numbers of patients to ensure access to more innovative radiotherapy treatments, increase clinical trial recruitment and make sure radiotherapy equipment is fully utilised.

Doctors can give radiotherapy to try and destroy a tumour and cure the cancer. This is called curative treatment. It may be used with other treatments, such as surgery or chemotherapy. If it's not possible to cure the cancer, doctors may give you radiotherapy to help relieve symptoms you have. This is called palliative treatment.<sup>2</sup>

Radiotherapy is central to curative and palliative treatment of cancers; it plays an important role in improving treatment outcomes in England. It is second only to surgery in its effectiveness in treating cancer and around 40% of patients who are cured receive radiotherapy as part of or the whole of their treatment.

### Scope and documentation of the consultation

Under the proposals, it is possible that some rarer and less common cancers could receive radical (curative as opposed to palliative) radiotherapy treatment in a different centre than is currently the case. The proposals did not identify which providers will and will not be able to treat particular rare and less common cancers. In developing the proposals, NHS England conducted a period of engagement with clinicians and provider organisations involved in the delivery of radiotherapy and with patient representative groups to inform the clinical model and service specification. A <u>report</u> of that activity was published on the NHS England website as part of the consultation materials

The new clinical model which NHS England is proposing was detailed in a draft service specification and focuses on the provision of External Beam Radiotherapy for adults (≥18 years of age) and sets clinical, service and quality standards in Radiotherapy Networks. An investment of £130 million is planned by the NHS to improve radiotherapy services in England. This will entail investing in state of the art equipment and reviewing how services are set-up and organised to ensure the maintenance to world class standards. Currently, 52 providers of tertiary radiotherapy services in England are accessed only by referral from a secondary care consultant.

The specification sets out the core purpose, responsibilities and arrangements for the Networks and focuses on developing proactive clinical and provider networks led by Cancer Alliances. Establishing radiotherapy networks would enable staff in neighbouring hospitals to explore joint working arrangements to continue to deliver as many treatments locally as possible.

The public engagement report was published alongside the specification and consultation guide.

<sup>&</sup>lt;sup>2</sup> Macmillan Cancer Support ( <u>https://www.macmillan.org.uk</u> )

### **Consultation Methodology**

The consultation was initially planned to last for 60 days but was extended by one month due to the level of interest. The main vehicle used for the consultation was an online survey. Supporting materials also published were:

- Consultation Guide this document set out the background and context to the consultation, and highlighted proposed changes to the service offer and what that means for people accessing the services;
- Online survey with consultation questions
- Service specification document
- Impact Assessment
- Engagement Report from the discussion period

The consultation was promoted through direct email notification to a wide circulation of stakeholders, particularly targeting cancer charities for onward cascade to their members. In addition, articles were included in NHS England bulletins which are circulated to around 10,000 groups and individuals. All information was published on the website and the consultation was promoted on the NHS England twitter feed. In addition, NHS England held four consultation webinars (online meetings) to talk through the proposals with interested people.

### Section 2: Approach to analysis

This report is the detailed analysis and feedback from all responses received to the consultation which was primarily via the online survey (11,542 responses). However, there was also a significant number received via other formats notably: hard copy (letters - 73), electronic submission (emails – 596) and survey as a word document (2). These responses do not follow the question format set out in the online survey. Those who completed the online survey generally answered all the questions but there are occasions where questions were not completed by respondents.

Some respondents may have answered the online consultation survey and emailed /sent a letter which replicate their response in some way. Thus, we have analysed the emailed documents/letters using the same process but have split the data findings within this report to ensure that responses are not double counted.

The report reviews and summarises the overall responses, quantifies where it can and includes where possible themes which do not respond directly to the questions posed in the consultation.

It should be noted that there was a particularly strong response from the South West region and to a lesser extent the North-West region which led to a significantly bigger response rate than anticipated to the consultation as a whole. However, much of the South West response was in reply to local campaigns related to protecting local services rather than the specific questions raised in the consultation. This will be outlined later in this report within the Summary of Key Themes section and applicable sections when breaking down responses by respondent type. This regional response has been cross tabulated to ensure it does not distort the overall response to the consultation.

Open-ended questions within the online survey and individual comments from letters/emails have been coded into key themes, which have been grouped by frequency enabling the most frequent themes to appear.

For reference, it is noted that comments can be coded several times due to the number of themes it contains, which is why the frequencies add up to more than the number of responses.

This report summarises the themes from the consultation response, and then details each dataset in more details. Cross tabulation of both datasets (online survey and other formats) has enabled us to examine the responses by region. Similarly, themes have been identified by respondent type and referenced throughout the report.

## Section 3: Summary of Key Themes

### Overview

This section summarises themes from both datasets

- Online Dataset The analysis of 11,542 surveys
- Other Formats The coding of 675 emails and letters

The themes revealed from the online survey and other formats (letters and emails) are outlined with this summary section.

Across the consultation the majority of comments were variants of the following themes, with the exceptions of local issues specific to geographical region.

The mains themes are as follows, and are indicated in Figure 2 on page 12:

- 1. Travel
- 2. Patient Experience
- 3. Funding
- 4. Workforce
- 5. Governance/ Implementation
- 6. IT infrastructure

The distinct regional response from the South West was not proportionate to the population or geographic size. However, many of these responses were focused on an understanding that local cancer centres were under threat, which was not a proposal in the NHS England consultation.

The South West response is covered in more detail in the section 4 (Findings from the online survey) 5 (findings from other formats) of the report. However, when you look at responses from regions other than the South West, support was more balanced, whilst still slightly slanted to opposing the proposals. Where there was support this was primarily among NHS organisations or clinicians.

		Support fo	r th	e Proposal		
Response All Regions Online Survey			Response excluding South West Region Online Survey		est Region	
Response	Total %	Number of Responses		Response Total % Number of Response		
Strongly support	6%	709		Strongly support	27%	351
Tend to support	4%	486		Tend to support	19%	243
Neither support nor oppose	2%	274		Neither support nor oppose	6%	78
Tend to oppose	11%	1325		Tend to oppose	18%	232
Strongly oppose	75%	8694		Strongly oppose	29%	375
Not Answered	0%	54		Not Answered	1%	13
Total	100%	11542		Total	100%	1292

The main reasons for supporting the model across the regions related the prospects of better expertise, better patient outcomes and the need for centralized services to foster sustainable use of resources and expertise. There was a consensus among those who supported the model that the prospects of better service delivery with the model was hinged on the NHS addressing the bottlenecks patients may face in accessing care.

Common reasons for opposing the model across the regions related to issues with accommodation, travel logistics and the impact on patient convenience. Lack of family support due to long periods of time away from family during daily treatment, increase in health inequalities among socially disadvantaged populations and the impact on mental wellbeing and morbidity among patients were also considerations. Underpinning the perceptions about the negative impact of the proposed model were reservations about the capacity of the NHS to fully address issues related to the operational practicalities needed to adequately support patients through the treatment process of implementing the model.

In conclusion, those who supported the proposal across most regions believed it would lead to better clinical outcomes and build expertise among staff. Key differences across the regions related to the extent of support or opposition for the model based on geographic location, organisation of local transport and radiotherapy services. However, the common consensus by participants and organisations to both the online survey and response in other formats was mild support for the aims of the consultation but by far larger reservations and requests for clarity over details of the proposal with regards to, implementation, integration with existing services and likely detrimental impact on patient's wellbeing.



Figure 2 Thematic Map of responses to the consultation (All data)

### Themes Detailed

### 1. Travel

Travel was by far the largest theme to emerge from the response to the consultation. It includes the following sub themes which are interlinked:

- o Distance
- Accommodation
- Transport
- Travel Time
- Extra time off work/loss of earnings
- Costs implications
- Parking
- Regional geography

Thematic Response - Travel Comments relating to this theme by percentage				
Travel	All Regions %	Excluding South West Region %		
Distance	16%	11%		
Accommodation	3%	4%		
Transport	14%	9%		
Travel Time	20%	16%		
Extra time off work/loss of earnings	9%	11%		
Costs implications	16%	11%		
Parking	1%	1%		
Regional geography	1%	1%		
Total 81% 64%				

A recurrent observation is the broad consensus that social, economic or educational disadvantage may make people less likely to be able to travel a greater distance for treatment and so inequalities could be introduced in terms of the standard of care. Some respondents suggested that the proposal may discriminate against the poor or low income earners as well as the elderly.

There was an emphasis in responses that the possibility of uneven distribution of accommodation and transport services will reduce access from some regions and create regional inequalities. It was remarked by members of the public, clinicians and NHS organisations that the charity sector cannot be relied upon to provide accommodation or other services to patients - if this is considered to be required (which the document suggest that it is) this must be supported centrally or risk creating significant regional inequalities. The table above shows that when responses from the South West region are removed, the comments related to this theme reduce from 81% to 64%. This indicates that the South West region raised travel as a theme more often than respondents from other regions.

### 2. Patient Experience

Thematic Response - Patient Experience Comments relating to this theme by percentage				
Patient Experience All Regions Region %				
Patient outcomes	2%	7%		
Increased morbidity rates	4%	1%		
Total	6%	8%		

Respondents were quite vocal on the adverse effect that they believed would impact on the patient experience should the proposal proceed as specified in the consultation. Respondents perceived inequalities would affect regions that were more disadvantaged. The elderly and low-income earners were referenced as groups who may encounter greater difficulties in accessing the services of the proposed model. The implication was there would be a negative impact on people living in rural areas, those with rarer cancers, those who are elderly, frail, more unwell, or poor could create health inequalities that may not affect the more affluent. Concluding that patients may decline treatment due to cost, travel, transport or availability of family support if travel times were extended.

Cancer Alliances were clear in their comments that the geography of each region must be considered in detail to ensure that some patient pathways are not destabilised, the impact on existing clinical networks by changing the model to adopt an alternative patient geography/ established pathway could prove adverse and impractical and expensive to align systems to this new model.

### 3. Funding

Thematic Response - Funding Proposal/Services Comments relating to this theme by percentage			
Funding - Proposal/ServicesAll RegionsExcluding South%%			
Funding Proposal/Services5%6%			

Total	5%	6%

Funding was raised as a concern amongst organisations who specified that there was lack of clarity in the in the proposal on funding for the Radiotherapy Network Board and IT required for outcome collection, peer review etc, which was worrying given that the implementation did not appear cost neutral.

### 4. Workforce

Thematic Response - Workforce Comments relating to this theme by percentage				
WorkforceExcluding South%%				
Recruitment/retention	1%	3%		
Deskilling	0%	1%		
Demoralisation	0%	0%		
Training 2% 3%				
Total	4%	8%		

Some respondents reported that deskilling of staff in local centres may occur and this could impact on treatment of more common cancers. Centralising more uncommon treatments will also have an influence on the workforce in terms of recruitment and retention of staff with more advanced centres attracting staff from smaller centres. Even the implementation of the proposal would require considerable planning to ensure that existing staff were not putting under pressure. It was raised recruitment would not be an issue for radiotherapy staff but also support services such as dietitians, physiotherapist, clinical nurse specialist, psychologists, etc.

Some Clinicians who responded stated that although the proposed model offers some answers to the workforce and quality challenges facing the radiotherapy community, it failed to appreciate the subtleties of assessing competence in the staff groups that provide the service. They queried the assumption that centralisation of delivery offered improvements in safety and quality.

There was the recommendation of training and rotation of radiographers through their network departments to facilitate skills improvement.

There were suggestions that concurrent chemo radiotherapy cannot be delivered at a satellite site. The justification for this statement would appear to be the requirement that a clinical oncologist be on site. Chemotherapy is currently delivered by trained nurses without the presence of medical staff and appropriately trained radiographers will be able to supervise the radiotherapy element without the need of medical presence on site but with remote backup.

The table above shows that when responses from the South West region are removed, the comments related to this theme, workforce, increases from 4% to 8%. This indicates that other regions raised workforce as a theme more often than respondents from the South West region.

### 5. Governance/ Implementation

Thematic Response - Governance/ Implementation Comments relating to this theme by percentage					
Governance/ Implementation All Regions West Region %					
Board structure	1%				
Model implementation concerns	cerns 1% 3'				
Total	•				

There was a strong response to governance and implementation of the proposed clinical model which presented an undercurrent throughout all themes. The respondents concurred that there was a need for effective collaborative working but stressed that that consultation documentation did not present in enough details how that would look like, how it would be led, funded, maintained and audited for service delivery.

It was recommended on several occasions clarification on network structure, provider collaboration and commissioner involvement, noting there was no additional funding to cover implementation costs for governance. Some saw the proposal as an administrative burden - putting an additional layer of management and administration in place with a Radiotherapy Network Board across the larger geography.

Furthermore, respondents noted that the documentation, did not specify the evidence base which informed on the proposal. Which was the basis of the assertion that the proposal did not appear to have completed an impact assessment most notably to address regional issues and current clinical networks.

A suggestion was made that virtual teams and remote planning should be part of networked services with treatment delivery closer to home. Patient friendly transport services may also form part of the solution.

The table above shows that when responses from the South West region are removed, the comments related to this theme, governance, increases from 2% to 10%. This indicates that other regions raised governance as a theme more often than respondents from the South West region.

### 6. IT infrastructure

Thematic Response -IT Infrastructure Comments relating to this theme by percentage			
IT Infrastructure All Regions Region % %			
IT Infrastructure	2% 3%		
Total 2% 3%			

Whilst IT Infrastructure as noted above appears a small theme, its significance relies on the fact it was raised by a number of providers within various organisations types: NHS provider and commissioning organisations, Cancer Alliances, Cancer and Radiotherapy Boards as an issue of considerable importance given that the premise of the proposal requires a robust IT system. Additionally, clinicians raised this as a concern highlighting their experience with current systems and often times poor integration between clinical systems.

The need to increase in investment in staffing to support 7 day working across all radiotherapy specialties was highlighted as well as a fully developed and centralized IT infrastructure to support the expansion needed in the implementation of the proposed model. Good efficient IT services between the network hospitals, good communication and referral pathways to ensure patients go through treatment as well as follow up. Improving channels of communication using social media for example a one- stop service for all cancer questions, explanation of services, procedures, and performance statistics.

### Section 4: Responses from the online survey

The following section summarises the analysis of the online survey from the Modernising Radiotherapy survey. In total there were 11,542 responses to the survey.

The tables in this section of the report show who responded to the online survey. Most responses were from members of the public (76%), followed by current or former radiotherapy patients (12%).

Table: In what capacity are you responding?		
Response	Total %	Number of Responses
Member of the public	76%	8753
Current or former patient receiving radiotherapy	12%	1381
Other	5%	527
Clinician – Other	2%	277
Clinician -Therapeutic Radiographer	2%	201
Clinician - Radiotherapy Physicist	1%	85
Voluntary Organisation/Charity	1%	81
NHS Provider Organisation	1%	59
Not Answered	1%	54
Clinician- Clinical Oncologist	0%	50
Other Public Body	0%	42
Industry	0%	13
NHS Commissioner	0%	8
Private provider organisation	0%	11
Total	100%	11542

Question 1. In what capacity are you responding to the consultation?

### Question 2. In which region are you based?

One defining feature of this consultation can be categorised by the high proportional response rate from the South West region which accounted for nearly 90% of the surveys. With the respondents from the North East providing the next highest regional response rate at 5%, followed by the South East at 2%.

As a result of this over representation from the South West, there is an obvious regional viewpoint which is reflected in the themes, which, as observed previously were generally concerned about purported loss of the local cancer centre, which was not a proposal in the NHS England consultation.

However, by cross tabulating the themes by region it has been possible to identify specific differences by area as discussed within Summary of Key Themes section.

In what region are you based?



Question 3. NHS England are proposing a model for radiotherapy services that will see treatment of some rare and uncommon cancers concentrated into fewer centres. Local hospitals will work together within a network which includes (at least) one specialist centre providing the full range of cancer services (including radiotherapy treatment for rare and uncommon cancers) plus local centres that will treat more common cancers. To what extent do you support or oppose this proposal?



Support for the proposal (All responses)

The majority of respondents (75%) to the online survey strongly opposed the proposal for Modernising Radiotherapy service as the chart above illustrates. This percentage increases slightly to 86.8% when 'tend to oppose' is included. Of the 10.3% of respondents who supported the model, only 6.1% did so strongly.

Most of the responses which oppose the proposal are from the South West Region (96% of 8319) responses. This will be discussed further in the regional analysis section.

Regional analysis evidenced that the highest proportion respondents who strongly opposed the model were members of the public (78.7%) and the lowest proportion was among NHS Commissioners (25%).

The highest proportion of those who strongly supported the model were private provider organisations (18.2%) and the lowest was NHS Commissioners (0%).

The chart below shows the response for all respondent types without the South West region data included, which demonstrates a range of support rather than a clear indicator for strongly opposed. What is evident is that there is a similar strength of support for strongly opposed (29%) and strongly support (27%). This percentage difference is minimised when strongly support/tend to support (46%) and strongly opposed/tend to oppose (47%) are merged. Thus, respondents are relatively balanced in whether they in support or opposed to the proposal.



Support for the proposal (Excluding responses from the South West Region)

Members of the public are the largest respondent group irrespective of whether the South West region is included 76% (8753 of 11542) or excluded 56% (721 of 1292 responses) from the online survey dataset.





Less than half of respondents supported the model across the regions, the highest being in the North-West with 46%. Support for the proposed model across the regions was based on the perception that specialist treatment required a high level of expertise concentrated within specific centres. Those who supported the model cut across clinical disciplines, member of the public and clinicians. Clinicians in the North West region support incorporated examples of how the model had worked within the UK or across the world.

There was also the belief that it was expected that service quality and consistency would be improved with the proposed model because of fewer centres providing the opportunity to streamline the protocols regarding the planning and treatment of rare cancers.

Clinicians who supported the model also acknowledged the increasing complexity of radiotherapy treatment and the need to deploy expert knowledge to delivering care along the patient pathway. And concluded if this was the message conveyed to patients, they would understand the rationale behind the proposal.

In general, consideration for the cost and convenience of travel was the most common reason across all regions for opposing the model. Those who opposed the proposed model were mostly concerned about the travel distance patients for treatment. The majority of respondents (across all respondent types) shared the view that the tendency to refuse treatment would increase amongst patients resulting in greater morbidity and poorer treatment outcomes on the long term. The risk of disease progression while waiting was extensively discussed as well as the possibility of increasing the number of people needing palliative treatment because of treatment delays due to logistic issues

### Question 4. Please provide comment in support of your answer.

The variety of responses to this question have been captured in the summary of key themes section. However, NHS organisations and clinician stated the report overestimated the willingness of patients to travel for their radiotherapy and failed to take into account the impact on vulnerable patient groups. Some participants also believed that the level of personalised care received by patients from local centres would reduce.

The East Midlands and the West Midlands were firm in their stance that treatment should be local to patients. The argument was further supported with the issues around transportation for patients attending radiotherapy and particularly those in later stages of treatment due to discomfort. Furthermore, lack of access to transport to meet the schedule of daily treatment requirements could result in poorer access.

Members of the public in the East of England concurred and confirmed their experiences with delays in using patient transport provided by the hospitals because they could not afford taxis or private transportation. Thus, their opposition was based on the premise of as they understood the proposal to provide a scheme of organised transportation.

"Patients will also have to travel a much further distance, and this may mean they will refuse treatment."

### **Radiotherapy Physicist, East Midlands**

"Treatment should be kept local to patients; long distance travel is not possible or practical for everybody. Reducing services and transferring them to a supposedly centralised hospital causes massive variation in the standards of treatment patients receive based on a postcode lottery and excludes those who are too sick, poor or care for others and are unable to be away for such a length of time."

#### Member of the Public, West Midlands

"It is ridiculous to expect cancer sufferers to travel huge distances for their treatment. Do you not realise how ill cancer and its treatments such as chemotherapy and radiotherapy make people feel? For goodness' sake see sense and show some care towards cancer sufferers. Quite apart from the discomfort involved in travelling long distances, there is a large cost element"

Member of the Public, East of England

# Question 5. We have described the potential positive and negative impacts the clinical model proposed in the service specification may have. To what extent do you think our description of the impacts is accurate?

Highly accurate Partially accurate Not at all accurate Don't know Not Answered 30% 90% 100% 0% 10% 20% 40% 50% 60% 70% 80% Not at all Partially Highly Not Answered Don't know accurate accurate accurate All Regions % 3% 23% 44% 24% 6% South West 3% 23% 4% 47% 22% % Other Regions % 36% 18% 18% 24% 4% All Regions % Other Regions % South West %

. Response to accuracy of the positive and negative impacts of the clinical model by region

The graph above denotes that as per the trend in the overall response to the consultation, respondents did not agree with the model and detailed - as previously demonstrated - their concerns and considerations in answers which allowed for free text. The elaboration of this answer is shared in question 6 which provides similar responses to previous answers supplied.

Answers to this question were comparable across regions; despite the over representation of the South West region. The percentage of respondent types who considered the clinical model to be accurate (partially accurate and highly accurate) are very similar for the consultation as a whole: 30% and 28% the South West region excluded. The divergence is seen where 47% of South West respondents indicate that the clinical model is not at all accurate in contrast to 18% of respondents in other regions. There were a greater proportion of responses from other regions who answered

'Don't know' 36% versus 23% in the South West region. Further variance is seen when the data is interrogated by respondent type.

Organisations (excludes responses from individuals) from all regions had a more mixed reception regarding the accuracy of the clinical model but the majority of the regions were generally in favour - only two regions responses were below 50%

- 80% from the West Midlands and International Organisations, Yorkshire and the Humber;
- East of England and North West indicated 70%;
- London and North East 67%;
- East Midlands had 60% support,
- Not applicable/regional/national organisation totalled 54% and Wales noted 50%.
- The responses from the South East at 48% and South West of 29% clearly indicated their stance on the accuracy of the clinical mode.

Clinicians had a definite response and as such only a total of 10 respondents of a cohort of 613 did not supply an answer. 74% of clinicians from all regions considered the clinical model to be accurate (partially accurate and highly accurate). This reduced to 53% once the South West region was excluded from the data.

Members of the public are the largest respondent group within this consultation at 76% for all regions and 56% excluding the South West region, given their previous overwhelming opposition it is notable that the data presents accuracy of the clinical model as almost the same: (partially accurate and highly accurate) was 28% overall and 27% without the South West region.

The response indicating accuracy from Current or former patient receiving radiotherapy was 28% for all regions and increased to 51% when the South West data was excluded. The corresponding percentages for 'Not at all accurate is 45% (all regions) and 13% (excluding South West).

In summary, the data illustrates a fairly balanced response to this question given the greater number of respondents from the South West, overall the answer is overt that over two thirds of respondents do not consider the impacts to be accurate. Yet when the data is reviewed by region and respondent type a more nuanced response is observed.

# Question 6. Please describe any other impacts which you think we should consider, and what more might be done to avoid, reduce or compensate for the impacts we have identified and any others?

The comments provided in this section were for the most part a repeat of the key themes summarised earlier.

Impacts identified include sustainable funding for travel and accommodation and the efficiency in using the charity sector to address these gaps as they may be unable to cope with the demand. Respondents believed the capacity of the proposed specialist sites to handle increased number of patients should be put considered carefully. The need to account for direct and associated costs of treatment which may increase the overall treatment cost over the long term needs to be considered. Variation in transport costs across region implies that the impact of the cost would be more in some regions and patients would be at disadvantage dependent on where they lived. The impact of geographic location on treatment uptake was an additional consideration. Members of the public from all region suggested that patients from regions with difficult terrains may experience more difficulties accessing care.

South West respondents indicated through their comments that they wanted to contribute to the consultation based on their experiences with cancer directly (patients receiving radiotherapy or had received radiotherapy services in the past) or indirectly. All were complimentary about and expressed satisfaction with radiotherapy services from the Sunrise Cancer Treatment Centre at Royal Cornwall Hospital Treliske, Truro. Thus, they were motivated to take part in the consultation if it meant that they could voice their satisfaction and objection to local services being moved.

A proportion of respondents across categories raised the issue of patient choice and local care being a priority.

NHS Commissioners, were keen to articulate the implementation and logistics of the new model, seeking assurances that an impact assessment had been detailed at local level rather than just England as a whole.

Charities and other patient groups were concerned that their organisations would have to assist with the logistics of the proposal and potentially face a cost pressure to which additional funding had not been identified.

"Better experience for patients as a body of expertise will be developed for all professional groups involved in delivering care along the patient pathway" Clinician – Therapeutic Radiographer, North West

"Can the 'one' specialist centre cope with a potential increase in activity? Will this lead to a flow of investment to that centre at the expense of the other centres across the alliance"

### Clinician – Therapeutic Radiographer, East Midlands

"Some areas of the country, particularly rural areas, are isolated in terms of ease of access to main settlements (i.e. where local service provision is based). Geography needs to be considered alongside population statistics or rural areas may not receive equivalent service to populous city locations. Journeying to/from treatment should not impact on decisions regarding treatment options."

Current or former patient receiving radiotherapy, East Midlands

# Question 7. Please describe any equality or health inequality impacts which you think we should consider in relation to the proposed service specification, and what more might be done to avoid, reduce or compensate for the impacts we have identified and any others?

The comments in this section discussed travel and the impact of a longer journey on a cancer patient and their carer/ family support but stressed the health inequality relating to distance and patients potentially declining treatment due to the time taken and length of journey rather than the cost.

Respondents within areas of rurality were concerned that they were already disadvantaged due to their locality and therefore the proposal should have considered regional variation to a greater degree. The broad consensus that social, economic or educational disadvantage may make people less likely to be able to travel a greater distance for treatment and so inequalities could be introduced in terms of the standard of care.

In short, the perception was the inequality of access for patients who must travel long distances, combined with the impact on patients with disabilities who benefited from being treated as near to their home as possible meant patients already faced discrimination, should not be compounded.

The majority of current and former radiotherapy patients including some of those who supported the proposed model, reported that regional or rural-urban differences in access had the potential to create inequalities among patients needing treatment for rare cancers. They highlighted poorer state of health, disease progression and a negative impact on mental and emotional wellbeing as possible impacts. Lack of income for daily earners due to frequent travel could impact negatively on their finances was also raised. "If an elderly patient needs travel across two counties to get their radiotherapy treatment they may refuse treatment altogether, which defeats the object of moving these patients to the more specialised areas."

Clinician – Radiotherapy Physicist, East Midlands

"...Difficulty accessing the service because of disability (mental and physical). It is well known that patients with mental issues do not have as good outcomes compared to a 'well' population."

Current or former patient receiving radiotherapy, West Midlands

"Inequalities will come into play due to the different geographical areas. Some larger cities will accommodate large radiotherapy centres and there patients will be able to access a full range of treatments locally. Those in more rural areas will not be catered for and will have to travel to receive the same treatment. More should be done to ensure that advance treatment for all cancers is available in all centres. The Radiotherapy Networks could be employed to ensure that robust governance is in place at the smaller departments."

Clinician - Therapeutic Radiographer, East of England

# Question 8. Do you have any other comments about the proposals in the service specification?

A recurring theme in this section was how to make it easier for patients to access their treatments. Comments made by current and former patients across the regions include the need to ensure that the process is adequately budgeted for to address upgrades needed for existing centres. The need to put support measures in place to protect the most vulnerable and cater for variations in access due to geographic location was also highlighted.

The need to increase investment in staffing to support seven-day working across all of the radiotherapy specialties was highlighted as well as a fully developed and centralised IT infrastructure to support the expansion needed in the implementation of the proposed model. Good efficient IT services between the network hospitals, good communication and referral pathways to ensure patients go through treatment as well as follow up. Improving channels of communication using social media for example a one- stop service for all cancer questions, explanation of services, procedures, and performance statistics.

"I appreciate that the aim of the proposals in the service specification aim to produce the best treatment/health outcomes for all patients. However, I feel that proper consideration should be given to the needs of different locations and individual patients."

Current or former patient receiving radiotherapy, Yorkshire and the Humber

"One solution does not fit all. Manchester is very different to the East Midlands. London is usually treated as a special case. Also, the definitions of 'rare' need to be clarified. Very few centres would manage 25 external beam thyroid cancers per year but how does radio-iodine fit into this? We need every oncologist in the UK working at their maximum potential."

Clinician – Clinical Oncologist, East Midlands

"There should be explicit models of how IT infrastructure and information governance will work and should be set up across the networks."

"Recruitment and retention amongst the Radiographer staff group is already a challenge for smaller/satellite centres due to the lack of complex patients. Staff don't want to de-skill or have a lack of opportunity."

Clinician – Therapeutic Radiographer, South East

### Section 5: Responses from other formats

### Overview

The following section of the report details the response received to the consultation in Other Formats which was primarily by email but also letter. These responses have been coded for common themes (outlined within the frequency tables in this section). The themes have informed previous sections of the report notably summary of key themes.

Respondents with an organisational title or responsibility e.g. (MP, Councillor, Governor) who confirmed they were writing in a personal capacity or did not specify categorically that they were writing in their professional capacity were classified as an individual, for example member of the public or clinical rather than assigned the applicable organisations categorisation. Respondents who wrote on a collective basis or in a professional capacity were allocated an organisational category.

675 responses were received for the second dataset which came in an alternative format to the online survey. The majority of responses were by email (88%) of which 7% included an attachment.

Table: Format of responses - Dataset Other Formats				
Response Format	Total %	Number of Responses		
•		•		
Email	81%	547		
Email with attachment	7%	50		
Letter	11%	75		
Survey In Word	0%	3		
Total	100%	675		

The respondent categories allocated to other formats do not correspond exactly to the categories for the online format, however it accurately reflects the responses received. Responses have been grouped into similar types of organisations to ensure that broad comparison could be made.

Table: Respondent Categories - Dataset Other Formats		
Response	Total %	Number of
		Responses
Cancer Alliances,	1%	9
Cancer and Radiotherapy Boards		
Clinician	3%	18
Council and Scrutiny Committees	1%	8
Government MPs	1%	7
Members of the Public – Other (All except South West Region)	5%	31
Members of the Public – South West Region	83%	562
Other Public Bodies	0%	2
Patient Groups and Charities 3%		18
STPs Trusts CCGs	3%	21
Total	100%	675

The trend of themes as revealed in the online survey and summarised in the Summary of Key Themes are generally represented in the other format dataset. Travel, workforce and patient experience feature heavily in the commentary. Minor differences between the datasets are noted in responses from organisations with technical and specific queries for instance infrastructure capabilities and workforce implications. The South West region is consistent in its strong opposition to the perception of closure of local cancer care services rather than in response to the proposal identified in the consultation.

All members of the public opposed the proposal to some degree i.e. tend to oppose or strongly oppose, whereas Cancer Alliances, Cancer and Radiotherapy Boards saw the merit of the proposal, although they also identified reservations and/or suggested recommendation.

The support from Cancer Research UK is largely representative of organisations' responses:

"... Support the principles behind it, including spreading best practice and reducing variation in access to high-quality radiotherapy, 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"

### **Cancer Research UK (CRUK)**



• (Other Public Bodies (2)

• Patient Group and Charities (1)

#### Figure 3:Regional Response Dataset Other formats<sup>3</sup>

<sup>&</sup>lt;sup>3</sup> This map excludes the following categories from the other format datasets: Clinicians and Members of the Public.

#### **Cancer Alliances, Cancer and Radiotherapy Boards**

Nine responses were received from Cancer Alliances, Cancer and Radiotherapy Boards across England and all welcomed the prospects of modernizing radiotherapy services.

This group presented a balanced argument about the potential opportunities and challenges of the proposed model. They documented important considerations for implementing the model (collaboration, funding of the infrastructure, ensuring health inequalities were not exacerbated) and the implications for the current/future structure of radiotherapy networks and alliance boards. Recommendations shared which when collated, summarise the requirement for clear guidance and protocols.

Regional issues whilst noted were secondary to the similar organisational concerns, apart from responses from Council and Scrutiny Committees. Cancer Alliances, Cancer and Radiotherapy Boards had a number of queries on the development of the consultation, implementation and governance

In conclusion, Cancer Alliances, Cancer and Radiotherapy Boards were generally supportive of the consultation proposals but also had reservations about operational practicalities. Please summary table below which consolidates responses.

Tab	le: Cancer Alliances, Cancer and Radiotherapy Boards Response (Summarised)
	Identification of the lead cancer alliance for local determination
	Clinical Provision: Providing safe and effective radiotherapy services to patients. Aligning treatment protocols and shared knowledge lead to high quality patient care. Operationalisation of service delivery and utilisation for rarer cancers. Concerns around centralising planning with regards to safety, accuracy and effectiveness if staff not available on the treatment site
	Collaborative working: Success reliant on cooperation from all through effective monitoring, audits
	and collaborative working. To ensure focus on quality of treatment and patient outcome Funding not identified for consultation including additional layer of management, administration.
	staffing, infrastructure, network boards/ clinical leadership
	Health inequality: proposal would disadvantage poorly served communities and individuals such as homeless people and migrants. Daily radiotherapy treatment to have upper limit of travel time
	and distance otherwise could reduce take up of treatment
	Infrastructure:
	Implementation: to clarify the role of the alliance. The overall roles and responsibilities of the
	board (some of these are duplicated with different terminology in different sections of the draft)
	What project management and administrative support is expected and how it will be funded.
	Guidance on governance and accountability across patient, providers pathways and network
Themes	boards. The expected timescales in delivering these requirements.
memes	IT: network funding, organisation, management and reliance on existing NHS network
	Local provision: to be provided locally all stakeholders agree on this (Providers, CCG
	Commissioners, Patient Groups and Local Authorities, County Council and Adult Social Care)
	Services should be delivered locally within current radiotherapy network
	Negative Impact on patient experience/treatment/ wellbeing and social support (family and friends)
	Patient Engagement: Patient experience must be a priority when designing services. Improve public awareness of modern radiotherapy
	Radiotherapy network role: could be a positive development for the radiotherapy workforce,
	however further detail is needed on the formation of Radiotherapy Networks. NHS England is
	encouraged to issue guidance to support the establishment of Networks. Research must be a
	priority for Radiotherapy Networks. Public Health England must ensure Radiotherapy Networks
	can access and use high-quality data
	Stakeholders: Risk to the proposed clinical model - reliance on the voluntary sector
	Workforce: existing issues with recruitment and retention of staff (current staff shortages).
	Clarification on network workforce plans as well as implications of the model for staffing required.
	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.

### Clinicians

Clinician responses represented 3% of the total response to the other formats. The clear focus of clinician's comments were focused on the implications for the network structure, IT infrastructure and patient travel, together with accommodation logistics.

Travel implications and the attendant burden that would impact on patients were a reoccurring theme. They noted the requirements for a clear pathway that would not by it nature create health inequalities.

Clinicians acknowledged that the proposal had potential value in improving quality of care and patient outcomes. They, however, had concerns about the impact on patient access to these services, lack of emotional wellbeing and social support due to long periods away from home, additional layers of bureaucracy on network boards and lost opportunities to harness the existing strategies adopted by local hospitals. These concerns were raised with stronger emphasis from those from the South West

### Council, Health and Scrutiny Committees

There were 8 responses from Councils and Health and Scrutiny Committees. Respondents were in support of NHS England's commitment to providing improved radiotherapy services but strongly opposed the proposed model, they felt the proposal was designed to only meet the needs of urban populations and detrimental to those in rural areas and outer locations like Cornwall. Concerns about the consultation process, costs, distance, transportation, impact gaps, patient outcomes and the capacity of the proposed centres to handle increased influx of patients were raised. The need for a local network consultation with the people on how to mitigate on probable effects on patients was recommended.

### **Government MPs**

Of the seven Government officials that shared their comments around the consultation, six were Members of Parliament (MPs) from the South West region. MPs commended the NHS investment of £130 million in improving radiotherapy services but were in opposition to the proposed model; their decisions were as a result of concerns raised by their constituents after consultations.

Issues raised by MPs were primarily about costs, travel times, the geographical location of some areas, poor public transport system and distance to radiotherapy centres. The remaining

respondent was writing on behalf of the Welsh Government, noted the impact that this consultation could have on Welsh nationals particularly from Powys who received their radiotherapy services mainly NHS Trusts in England. These were primarily around the potential increase in travel time and possible reduction in access to treatment.

### Members of the Public – not from the South West region

This group was the second largest respondent type at 5%. Within the other formats dataset there were (31 individuals, 3 of which are Governors at NHS Trusts).

Respondents reiterated the reoccurring theme of current good local services and the risk that centralisation could potentially cause, for instance the impact of travel on patients' wellbeing during treatment.

Other respondents within this group were former or current patients receiving radiotherapy, carers, and NHS employees. Respondents opposed the consultation for a number of reasons relating to travel: costs implications, travel time, distance, poor public transportation and road networks. As considerations for impacts on patients and their carers/support networks. Other concerns raised reflected that the workforce would be unlike to want to travel further for their job role. It was also stated that there was the inability of NHS to explore other cancer treatment options. One respondent recommended the need to discover, concentrate and increase expertise and skills in other treatment modalities for cancer other than radiotherapy, by far more suggested setting up local centres rather than centralised ones.

### Member of the public from the South West region<sup>4</sup>

83% of all responses in other formats were from members of the public from the South West region. Respondents cut across different demography with the majority of them being patients receiving radiotherapy or had received radiotherapy services in the past.,

The focus of this group's response was on local issues and reflected the same concerns as the online survey respondents to the closure of local cancer services. This concern meant that responses did not address the questions posed in the consultation for modernising radiotherapy services.

<sup>&</sup>lt;sup>4</sup> There is one survey in word which may have been added to the online survey

### **Other Public Bodies**

Two national organisations a national clinical research funder and a profession body submitted correspondence in response to the consultation.

The latter submitted a detailed summary stating that it's response was categorised as 'tend to oppose 'the proposal as there was a lack of clarity in a number of aspects namely concerns raised in the previous engagement exercise not considered for this consultation. Nor did the proposed service model give local provision as an option for treatment, address the feasibility of workforce moving to a networked model and collaboration between stakeholders was key and did not appear to have been evidenced in this consultation.

The Research organisation was gratified that the importance of research and clinical trial participation was recognised in the consultation document, noting 'overall the plans should lead to more equitable access both to the best standard therapy', however it had recommendations around governance, collaboration and integration with clinical networks.

### Patient Groups and Charities

Responses to the consultation from patient groups across the UK were received as detailed in the table below.

Table: Breakdown of Patient groups and Charities responses - Dataset Other Formats		
Respondent Type	Total %	Number of Responses
Charity	39%	7
Healthwatch	17%	3
Patient Group	33%	6
Petition	11%	2
Total	100%	18

Of this total group, 67% of respondents were from the South West Responses were backed with videos, petitions signed by thousands of patients from campaigns organised by patient groups against the proposed model. The majority of respondents opposed the proposal as set out in the consultation. All 3 Healthwatch organisations cited the impact of centralised services in remote populations and patient's ability to travel to further distance for treatment and access to funding including non-emergency patient transport to assist.

### STPs, CCGs, and Trusts (NHS organisations)

Table: Breakdown of STPs, CCGs, and Trusts (NHS organisations) - Dataset Other Formats	
Response	Number of Responses
STPs Trusts CCGs	25
CCG	2
NHS Trust	14
NHSE	1
Total	21

The South West Region has the highest representation; however all raised the following issues to some degree. The group raised the issue of their role within the proposal and viability should their organisation not fit within the proposed model. This led to the impact on staff, relocation and deskilling. Local issues pertinent to that region or organisation were also mentioned, most frequently current clinical pathways and how they would be maintained or changed and fit within the unspecified fully integrated cancer service as proposed in the consultation. Additionally, technical queries for instance on imaging, monitoring treatment outcomes and the practical requirements of delivering a seven-day service.

## Section 6: Online Survey – Additional Questions

The following questions were included in the online survey, not all respondents (11,542) chose to the answer these questions.

### Question 9: Which age group are you in?

Table: Which age group are you in?		
Age	Total %	Number of Responses
18 or under	0%	34
19 – 34	10%	1123
35 – 49	24%	2788
50 - 64	34%	3863
65 - 79	29%	3276
80+	2%	190
Not Answered	0%	3
Prefer not to say	1%	159
Total	100%	11436

Total number of responses is 11,436. 1% (106) of survey respondents did not answer this question

### Question 10: Which of the following options best describes how you think of yourself?

Table: Which of the following options best describes how you think of yourself		
Self-Categorisation	Total %	Number of Responses
Female (including trans woman)	68%	7664
In another way	0%	53
Male (including trans man)	25%	2831
Non-binary	0%	29
Not Answered	0%	3
Prefer not to say	7%	739
Total	100%	11319

Total number of responses is 11,436. 2% (223) of survey respondents did not answer this question

### Question 12: Do you consider yourself to have a disability?

Table: Do you consider yourself to have a disability?		
		Number of Responses
No	80%	9210
Not Answered	2%	203
Prefer not to say	5%	602
Yes	13%	1527
Total	100%	11542

# Question 13: Please select what you consider your ethnic origin to be. Ethnicity is distinct from nationality

Table: Please select what you consider your ethnic origin to be		n to be
Ethnic Origin	Total %	Number of Responses
Asian/Asian British: Any other Asian background	0%	9
Asian/Asian British: Bangladeshi	0%	2
Asian/Asian British: Indian	0%	18
Asian/Asian British: Pakistani	0%	5
Black or Black British: Any other Black background	0%	1
Black or Black British: Black – African	0%	3
Black or Black British: Black – Caribbean	0%	4
Mixed: Any other mixed background	0%	18
Mixed: White and Asian	0%	23
Mixed: White and Black African	0%	3
Mixed: White and Black Caribbean	0%	10
Not Answered	4%	507
Other ethnic background: Any other ethnic group	7%	805
Other ethnic background: Chinese	0%	9
White: Any other White background	4%	417
White: Gypsy or Irish Traveller	0%	5
White: Irish	0%	52
White: Welsh/English/Scottish/Northern Irish/British	84%	9651
Total	100%	11542

# Section 7: Glossary

The following sets out a glossary of acronyms used within this report.

TERM/ACRONYM	DESCRIPTION
• • • •	
Acute trusts	Providers of secondary care
Cancer Alliances	Organisations which plan cancer services for their specific population and design care pathways, particularly when care is required across different providers, and also provide improvement support, measure outcomes (through the CCG Assessment Framework and integrated Cancer Dashboard) and engage with the public on cancer service changes
CCGs	Clinical Commissioning Groups (CCGs) commission most of the hospital and community NHS services in the local areas for which they are responsible
Commissioning	A continuous cycle of activities that contribute to the securing of services, including the specification of services to be delivered, contract negotiations, target setting, monitoring and managing performance
CRUK	Cancer Research UK
Diagnostic Imaging Dataset	A proposed data set containing diagnostic imaging test activity across the NHS, taken from Radiology Information Systems
Elective admission	A planned hospital admission
Health inequality	Differences in health observed between groups due to one group experiencing an advantage over another group, rather than any innate differences between them
Healthwatch	Local organisations which promote the local consumer voice to ensure that the views of patients, service users and the public are fed into improving local health and care services
National Cancer Intelligence Network	A UK-wide initiative, working to drive improvements in standards of cancer care and clinical outcomes by improving and using the information collected about cancer patients for analysis, publication and research
National Cancer Research Institute	The UK wide partnership of organisations that promotes cancer research
NCDR	National Cancer Data Repository
RADIOLOGY	A branch of medicine concerned with the use of radiant energy (such as X-rays) or radioactive material in the diagnosis and treatment of disease
RESPIRATORY	Relating to or affecting respiration (breathing) or the organs of respiration
RTDS	Radiotherapy Data Set - A standard dataset covering every patient treated with radiotherapy in the NHS in the England

Secondary Care	The health care services provided by medical specialists and other health professionals at the second point of contact following referral from primary care E.G. radiology services provided by Radiologists
STP	STP stands for sustainability and transformation partnership. These are 44 areas covering all of England, where local NHS organisations and councils have drawn up proposals to improve health and care in the areas they serve. STP can also stand for 'sustainability and transformation plan', plans drawn up in each of these areas setting out practical ways to improve NHS services and population health in every part of England.