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North Cumbria Radiotherapy Patient and Carer Feedback

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1. Executive Summary

Methodology

- ❖ To reach patients and carers currently using the Cumberland Infirmary Radiotherapy facility, and interact sensitively with this group, an assisted self-completion method was used.
- ❖ A Public Knowledge interviewer was present through the one week fieldwork period to support respondents if required.
- ❖ 82 surveys were completed, with a 2:1 patient to carer ratio.

Services and Facilities

- ❖ Information and support leaflets and access to a Macmillan support service were the most important features within the new facility to both patients and carers.
- ❖ There was interest amongst 67% of patients (half of carers) in radiotherapy information sessions, which are currently provided in the Northern Centre for Cancer Care in Newcastle.
- ❖ Additional comments focused upon help with transport for those who travel a long distance to receive treatment and upon refreshment/catering facilities.
- ❖ Parking and site accessibility were the facilities most important to patients and carers, and the need for better parking facilities was reiterated in feedback provided in the additional comments box.
- ❖ Aesthetic features of the centre were significantly more important to patients than carers.

Treatment Information and Delivery

- ❖ Receiving information face to face in an appointment with an Oncologist or Radiotherapist was universally valued by patients and was the preferred option for all patients.
- ❖ Diagrams and care plans were a current way 35% of patients received information, and there was demand for this amongst a higher proportion (44%).
- ❖ 41% of patients suggested they would like to receive information about their treatment depending upon which stage of treatment they are at.
- ❖ A "change in circumstance" and "when needed" were common reasons for choosing to receive information in line with stages in treatment plan.
- ❖ 54% of patients want to receive as much information as possible about their treatment, some specifying this would help put them at ease.
- ❖ All patients agreed, the majority of these strongly, that they would like to receive treatment using the latest technology and techniques, and within a radiotherapy dedicated facility.

Future Communication and Additional Comments

- ❖ 61% of those who wanted to receive updates about the new facility would prefer to source the information themselves, either through newsletters in the hospital or using the North Cumbria University Hospital website.
- ❖ Patients also brought attention to the lack of a facility in West Cumbria, contributing to long journeys to Carlisle, and felt there should be facilities at both sites.

2. Background and Methodology

NHS England has a responsibility to the public to ensure users of NHS specialist services receive the highest level of care. In line with this, NHS England is currently running a tendering process to find a new provider of radiotherapy services in North Cumbria ensuring the population have access to the new innovative treatments which are becoming increasingly routine.

The current service is provided by North Cumbria University Hospitals but will change to a new provider as NCUH are not bidding to be re-commissioned. The new service will continue to run from the Cumberland Infirmary hospital site, within a new purpose built facility, and patients and carers will access the service in the same way.

To consult with those who are closest to the service, NHS England commissioned independent market research company, Public Knowledge, to undertake assisted self-completion interviews, within Cumberland Infirmary Radiotherapy Centre to gain feedback from patients and carers visiting the centre. NHS England were keen to understand what is important to both patients and carers when attending a radiotherapy appointment and what is wanted from a new radiotherapy service, to ensure patient needs are met within the new service.

A short 5 minute self-completion, easy to read, questionnaire was designed and developed by Public Knowledge in collaboration with NHS England to gain this feedback. The questionnaire can be found in the Appendices for reference.

170 surveys were delivered to Cumberland Infirmary and an experienced interviewer from the Public Knowledge team was present in the radiotherapy centre between the fieldwork dates of the 8st to the 12th of December. Our interviewer was there to support patients and carers while completing the survey if required, to sensitively encourage participation and disseminate background information to the survey if asked. This methodology was carried out in accordance with the MRS Code of Conduct.

Sample Profile

Overall, 82 radiotherapy centre visitors completed the survey. The ratio of patients to carers who completed the survey was 2:1, 54 patients and 28 carers. No other demographic data was collected.

3. Data Processing and Analysis

Throughout the report the research findings have been illustrated using easy to read colour charts, which provide an immediately accessible graphical overview of the answers given by respondents. The charts are clearly labelled and the corresponding question from the questionnaire included at the bottom of each chart for ease of reference, in addition to the 'base' or sample size for each question.

Within this report any mention of 'significance' refers to statistical significance. Statistical significance is used to refer to a result that is unlikely to have occurred by chance and in this case is tested using Pearson's chi-square. Significance can be calculated to different percentages, with higher percentages representing more noteworthy responses.

Data collected from patients and carers was assessed for statistical significance.

Open responses were collected and due to the relatively small sample size and the variety and richness of the verbatim collected, quotes have been included throughout the report to provide this additional insight.

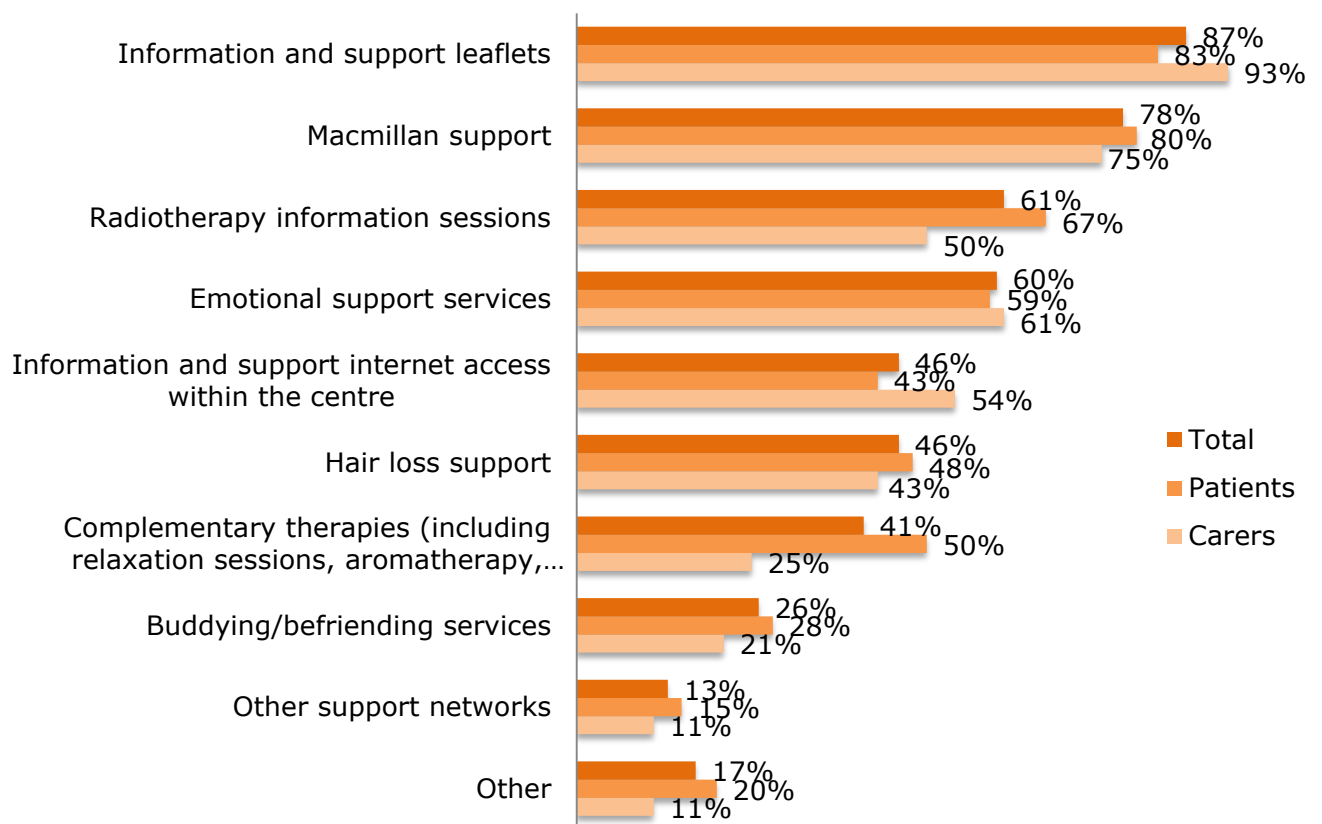
4. Key Findings

4.1. Services and Facilities

To understand which support services patients and carers would like to see within the new service, we compiled a list of current services with the North Cumbria Radiotherapy centre, and included certain services available within other radiotherapy centres in England.

As shown in Figure 1 below, the provision of information and support leaflets, and Macmillan support were the most valued services amongst patients and carers. Information in the form of leaflets was almost a universal requirement amongst carers, with a slightly higher proportion of patients than carers wanting to see Macmillan within the new facility.

Figure 1. Desired Services Within the New Facility



Q1. Which of the following would you like to have access to within the new facility?

Base: Total All Respondents - 82, Patients - 54, Carers - 28

There was also interest in Radiotherapy Information Sessions, a service currently provided within the Northern Centre for Cancer Care based in Newcastle-upon-Tyne. Two thirds of patients stated they would like to see these sessions, and half of carers, which is still a substantial interest.

Unsurprisingly, complementary therapies, another support service offered within the Northern Centre for Cancer Care, appealed to twice the amount of patients than carers, with half of patients wanting to see these relaxation and emotional wellbeing based supporting therapies offered in the new service.

Additional support and services mentioned within the 'other' option focused upon transport and catering facilities demonstrated within the quotes below.

Transport

"Help with transport. I live a long way away." **Patient**

"Information regarding availability of patient transport." **Patient**

"Telephone me for accompanied transport." **Carer**

Catering

"Water machine or hot drink machine." **Patient**

"The current voluntary tea trolley is important and should continue in any facility or be replaced by a cafe run by volunteers and should never be replaced with a profit making and expensive cafe." **Patient**

Other

*"Open choice to have light switched on within the room when getting treatment and also having music on (it is a choice now but to make people aware of this would be nice or for them have control would be good too)." **Patient***

"Anything which makes the situation easier." **Patient**

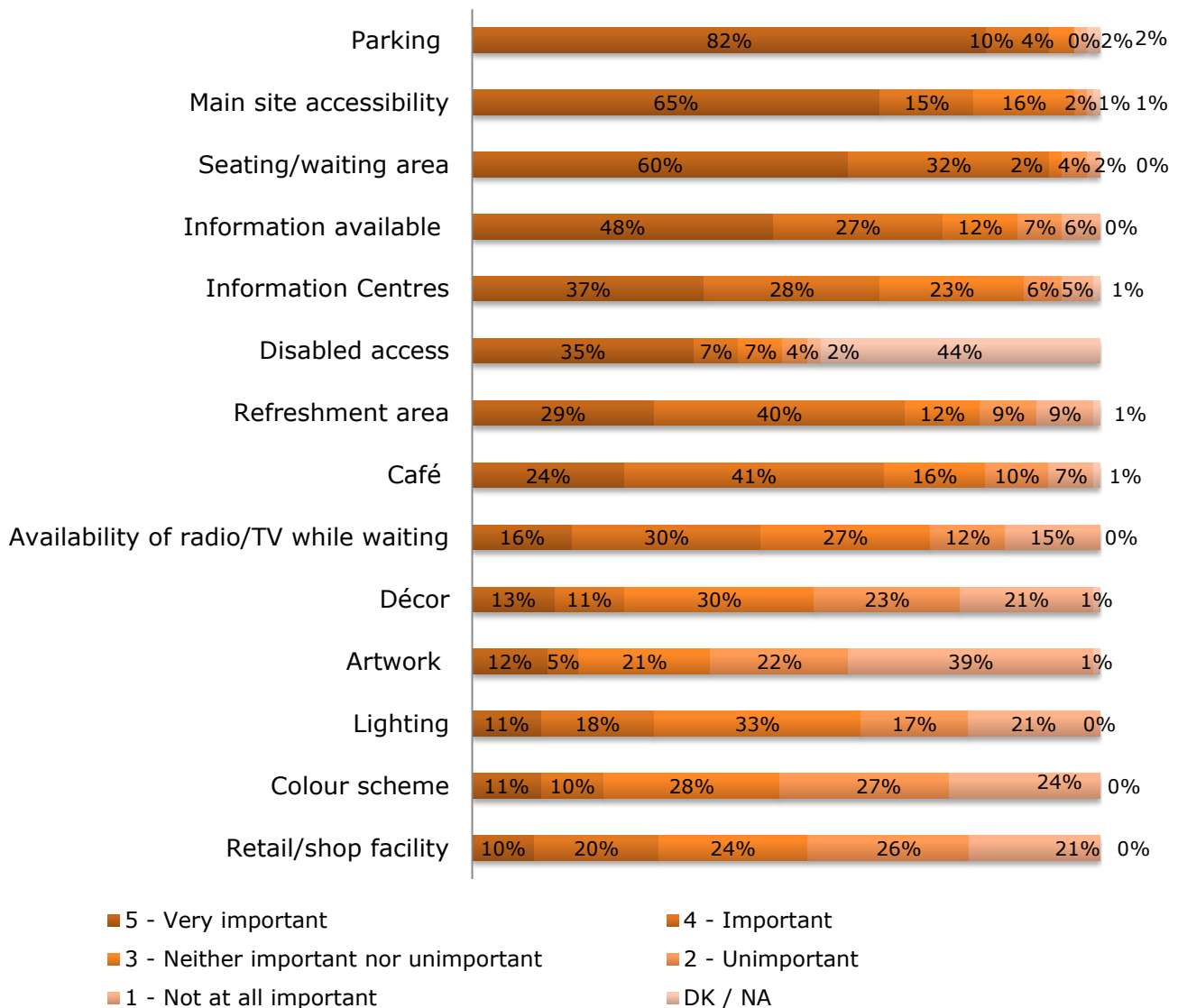
To understand the importance of current facilities within the Cumberland Infirmary Radiotherapy Centre, patients and carers were asked to indicate how important certain features of the service were to them personally.

Convenience in terms of getting to the centre, are paramount amongst both patients and carers, along with parking and site accessibility, 92% and 80% respectively, across the whole sample.

The waiting/seating area is also a large factor in patient/carers experience of the service with the sample almost universally signalling this is important, 93%.

Supporting the feedback from Q1, available information was found to be more important to carers, albeit to a slightly lower percentage from both groups (82% and 70%). This could possibly be attributed to the answer focusing on information specifically, rather than information and support.

Figure 2. Importance of Current Facilities in the New Radiotherapy Centre



Q6. How important are the following facilities in terms of the new radiotherapy centre?

Base: Total All Respondents - 82, Patients - 54, Carers - 28

It was the aesthetic aspects of the new service which were significantly more important to patients than carers, with décor (19% Vs 1%) artwork (17% Vs 1%), colour scheme (15% Vs. 4%) and lighting (15% Vs. 4%) very important to this group. These decorative features can be used to creating a calming environment and to distract, even if for a short amount of time, during the stressful period of radiotherapy treatment.

As lighting during treatment was also mentioned as a free response at Q1, some patients may also have been considering this when weighing up the importance of this centre feature.

The introduction of a retail facility split respondents, with half of patients and 39% of carers finding this unimportant or not importance at all.

4.2. Treatment Information and Delivery

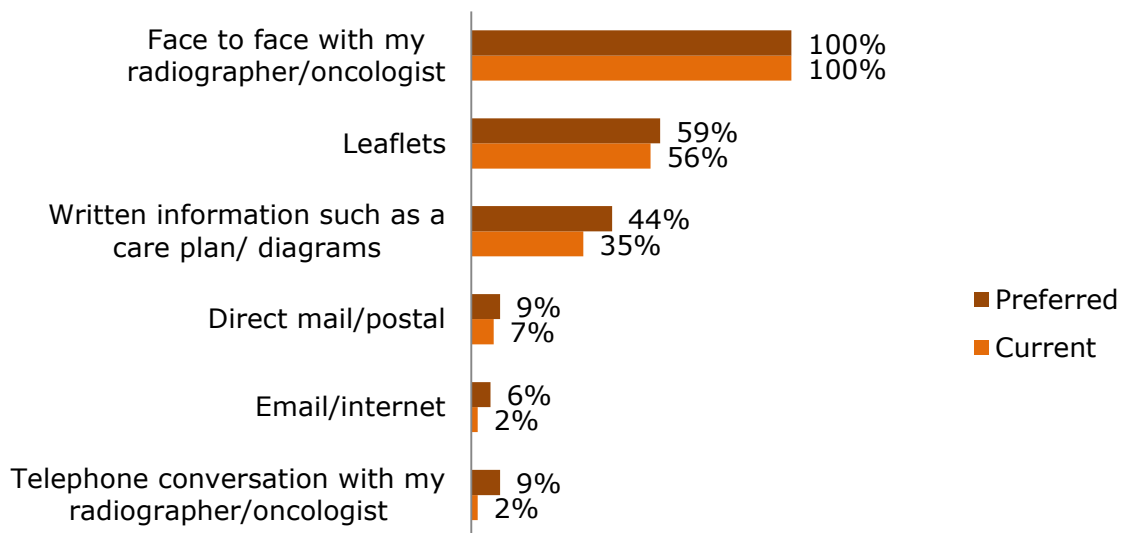
To gain insight specifically into radiotherapy treatment delivery and dissemination of information, patients were asked additional questions.

All patients valued their current face to face appointments to receive information from their Radiographer and/or Oncologist and all felt this was part of their preferred treatment method.

As can be seen from Figure 3, there is a demand for written information in the form of diagrams and care plans, which could be useful in displaying the information visually alongside the face to face meeting. Currently just over a third of the patients sampled received information in this way, with 44% interested in it as a preferred option.

There was a low level of preference in postal, email and telephone methods, which are currently used with a minority of patients.

Figure 3. Current and Preferred Methods to Recieve Information about Treatment



Q2. Please let us know how you currently like to receive information about your radiotherapy treatment and which is your preferred option?

Base: Patients - 54

Patients were then given the opportunity to suggest any other communication routes to receive their treatment information. While 85% of patients didn't suggest any other routes, a sample of individual patients' comments which were relevant to the question are below.

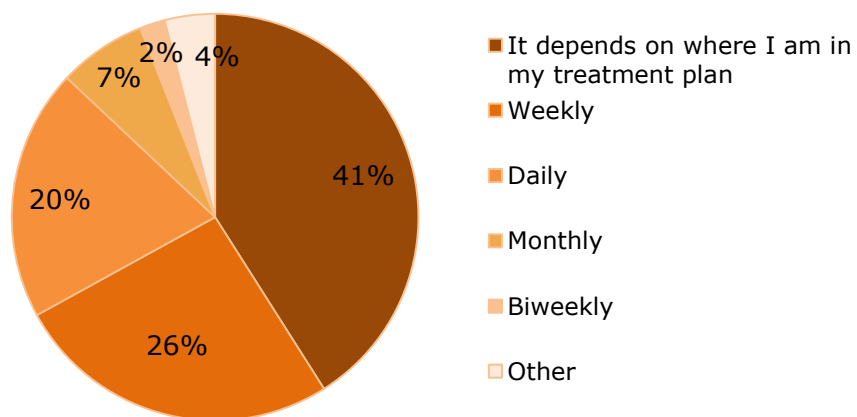
"A follow up. Perhaps with a radiographer/nurse after seeing the consultant to help clarify procedures and treatment. Often you don't think of questions until afterwards." **Patient**

"Links to vetted websites." **Patient**

"What happens- the whole procedure from start to finish." **Patient**

In terms of how often patients hoped to receive their treatment information, 41% felt frequency depended upon the stage within the treatment plan.

Figure 4. Preferred Frequency of Receiving Radiotherapy Treatment Information



Q3. How often would you like to receive information about your Radiotherapy treatment?

Base: Patients - 54

Within the remaining sample, the majority wanted frequent information delivered by the service, one quarter selecting weekly and one fifth wanting to receive information daily.

The 41% of patients who would like to receive information variably depending on the stage of treatment they are in, were asked to elaborate on their answer.

Almost a quarter of this group specified they would like to receive the information when there was a change in treatment/condition and another quarter only wanted to receive information when it was necessary.

Change

"Only if there is a change in circumstances." **Patient**

"When things change." **Patient**

When necessary

"When and if it is needed. I don't really want to know." **Patient**

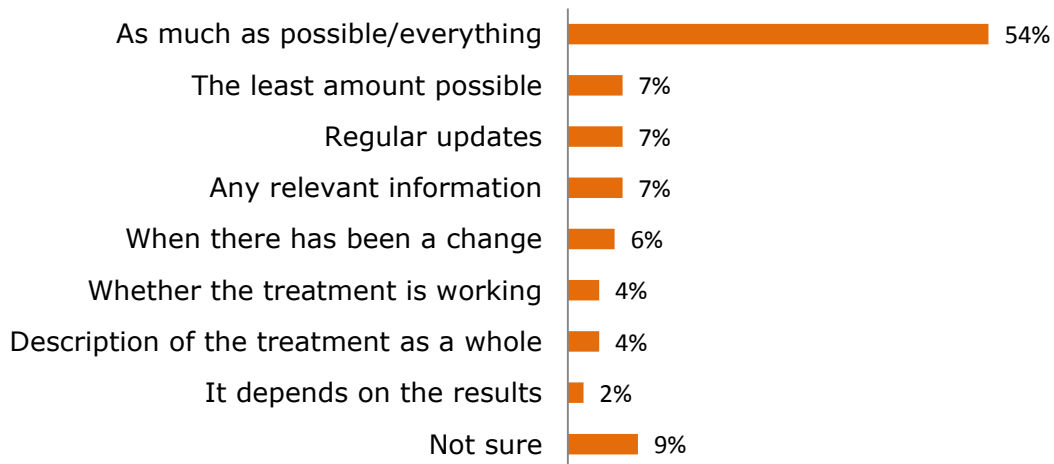
"Weekly updates, more info before treatment." **Patient**

"Whenever I'm here." **Patient**

In terms of the amount of information patients would like to receive, we have coded open responses as the majority of patients focused upon similar themes.

Just over half of patients wanted to receive all information and as much as possible about their treatment. A small proportion of respondents identified they would like the opposite and to be told as little as possible, with others preferring either regular updates, only relevant information and only information when there has been a change.

Figure 5. Desired Quantity of Information Received about Radiotherapy Treatment



Q4. And how much information would you like to receive about your treatment?

Base: Patients - 54

Q4. Verbatim

As much as possible

"Everything - as much as possible." **Patient**

"All of it." **Patient**

"As much as possible, how things are progressing. Side effects. I think receiving as much information as possible will help to put the person going through radiotherapy at ease and help them to relax." **Patient**

"Description of the treatment. Perhaps actually seeing the equipment (or photos), it is a bit scary. Clear concise but detailed description of what will happen during treatment. As well as possible side effects." **Patient**

Least amount possible

"The least possible." **Patient**

Regular updates

"Daily updates." **Patient**

Relevant information

"All I need - good or bad." **Patient**

"Any information that is relevant to me at that time." **Patient**

Change

"Only if the situation has changed." **Patient**

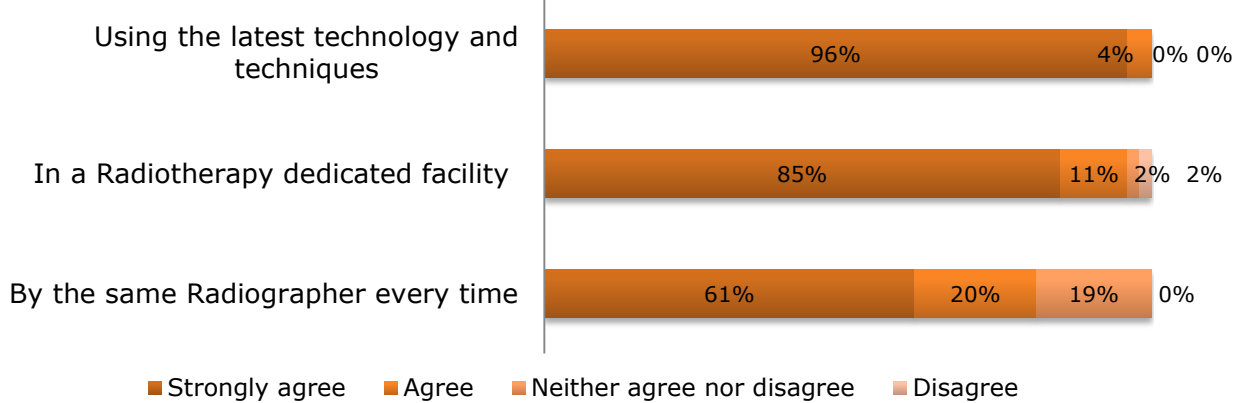
Delivery of Radiotherapy Treatment

Finally, patients were asked to rate statements about the delivery of Radiotherapy treatment to the extent to which they agreed or disagreed with them.

All patients agreed they would like to receive treatment using the latest technologies in Radiotherapy, 96% of these in strong agreement, supporting the decision to procure for the new service to enable this offer.

Access to a dedicated Radiotherapy facility is also important to patients, 96%, and having treatment delivered consistently by the same Radiographer is a desire for 81%.

Figure 6. Delivery of Radiotherapy Treatment

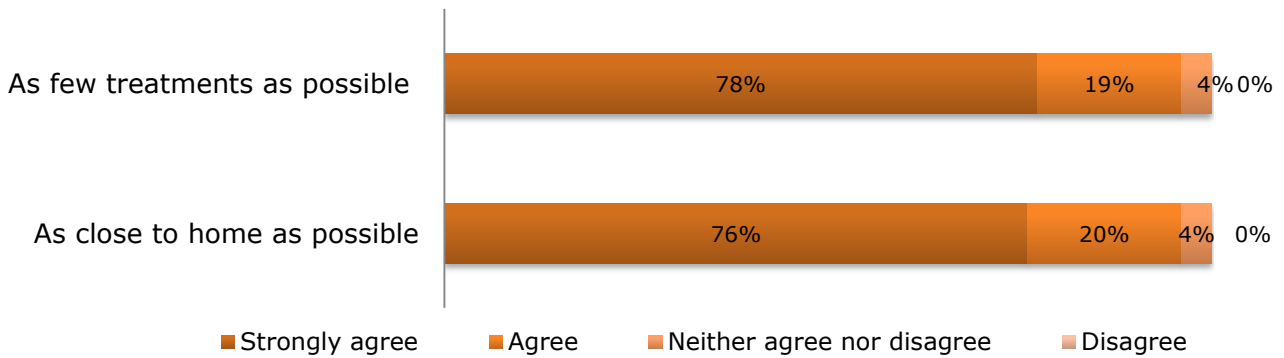


Q5. In terms of delivery, how would you like to receive your radiotherapy treatment?

Base: Patients 54

Convenience is also extremely important to patients, as this will remove any additional stress on top of that which patients are already experiencing. There was almost universal agreement (96%) with wanting to receive as few treatments as possible and having a treatment facility located near their home.

Figure 7. Convenience of Delivery of Radiotherapy Treatment

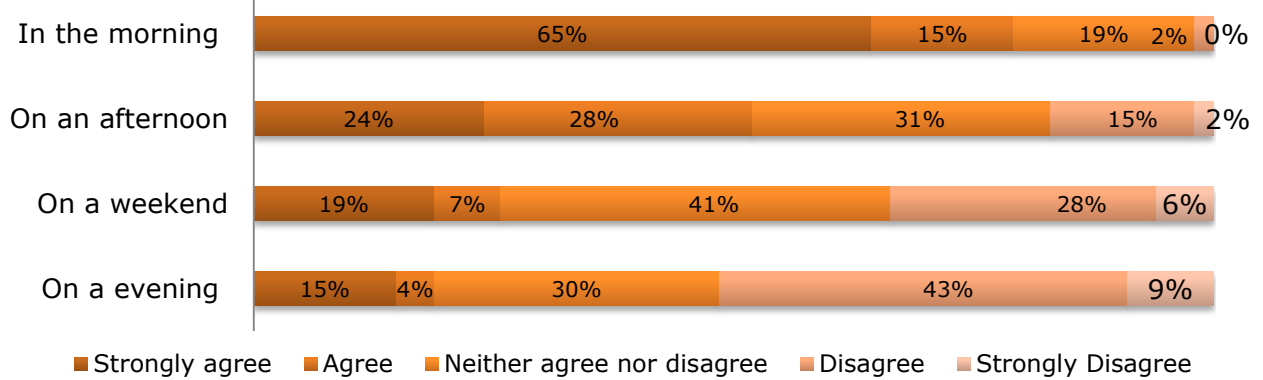


Q5. In terms of delivery, how would you like to receive your radiotherapy treatment?

Base: Patients 54

Overall, timing of receiving Radiotherapy treatment was less important to patients when compared with technology, dedicated facilities and convenience. 80% of patients identified they would like to receive treatment in the morning, the most popular timing for Radiotherapy amongst this group. Evenings and weekends, particularly evenings weren't as popular in terms of delivery of treatment, with just over half of the sample (52%) disagreeing with an evening treatment provision.

Figure 8. Timing of Delivery for Radiotherapy Treatment



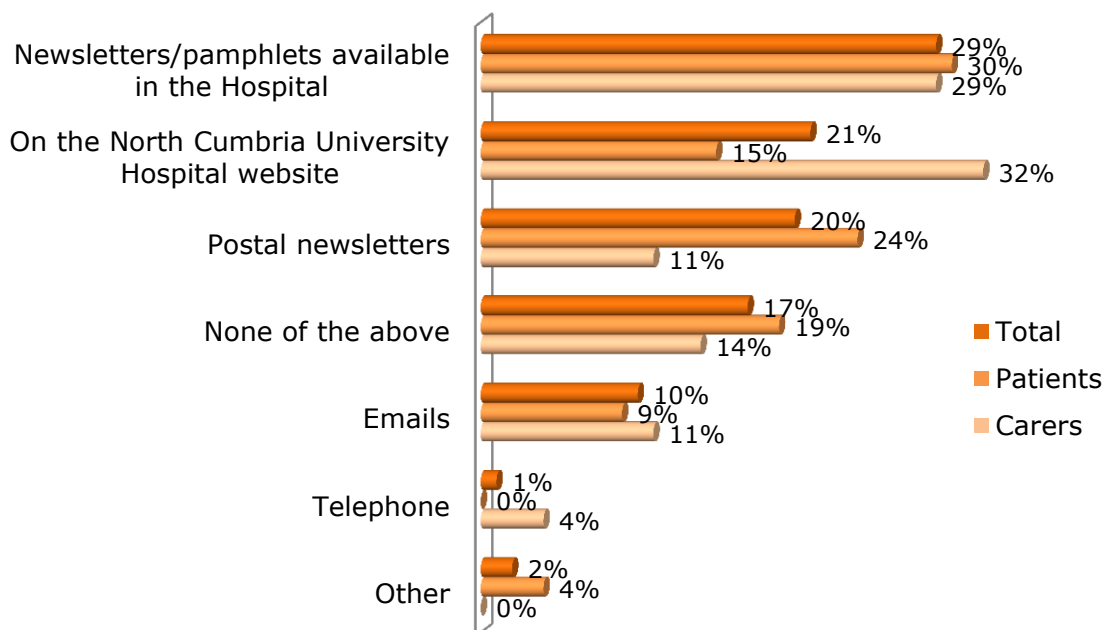
Q5. In terms of delivery, how would you like to receive your radiotherapy treatment?

Base: Patients 54

4.3. Future Communication

As NHS England are keen to provide updates to patients and carers throughout this procurement stage, which can take up to three years, respondents were asked how they would prefer to receive this communication.

Figure 9. Preferred Communication Method



Q7. How would you prefer to receive communications about the development of the new radiotherapy service for North Cumbria? Please choose one option

Base: Total All Respondents - 82, Patients - 54, Carers - 28

Of those who identified they would like to receive updates, 61% selected methods in which they would source the information themselves. Almost a third, 29%, were happy to be

updated within the hospital via newsletters and pamphlets available in the Hospital and another fifth indicated they would like to use the North Cumbria University Hospital website to find out this information, this being the preferred method amongst carers, 32%.

Only 17% selected none of the options indicating they did not want to receive updates.

4.4. Additional comments

Patients and carers were given the opportunity to provide any additional comments before completing the survey. Across both groups, additional parking facilities and the introduction of treatment carried out at West Cumbria Hospital to provide treatment closer to home, across both areas of Cumbria, were the most common responses.

Q8. Verbatim

Parking

"Parking is clearly an issue. Many patients have a long car journey and it is very stressful worrying about parking availability when it is important to relax and concentrate on being well. Dedicated spaces could be allocated as part of the appointment system." **Patient**

"More parking spaces, when getting treatment you don't want to worry about getting parked or not parked as it is usually." **Patient**

Facility in West Cumbria

"Treatment should be available at West Cumbria Hospital for patients from the West Cumbria area." **Patient**

"Would it be possible to have one machine positioned in West Cumbria? We have loads of people with long journeys and they all have to travel before and after treatment. It must be 50-50 from all over Cumbria." **Patient**

"Radiotherapy should be carried out at West Cumbria Hospital. As we are from Cleator Moor we have to travel every day to receive treatment." **Carer**

Providing additional support, to the requirement for the new facility to be aesthetically pleasing, comments focused on the décor both from patients and carers. This will be a welcomed distraction technique for patients while waiting to receive their treatment,

Aesthetics and facilities

"Seating, nice decor, magazines and access to refreshments are important. An aquarium (provided by a sponsor) would also be a relaxing distraction." **Patient**

"Make the facility less depressing and clinical for the patients and carers." **Carer**

"Wi-Fi access please so your work can continue whilst getting treatment." **Patient**

There were also complementary comments given to the current service, with patients hoping the same staff would continue within the new facility, and current satisfaction with the service.

Positive Feedback

"Use the same staff." **Patient**

"I think the service is currently very good." **Patient**

5. Conclusions

As all patients who completed this survey identified they would like to receive their radiotherapy treatment using the latest technology and techniques and within a radiotherapy dedicated facility, this provides support to the procurement decision.

From the feedback received from patients and carers, the priorities for the new centre are parking and accessibility, with parking currently an issue and the majority of patients and carers indicating main site accessibility is important. The provision of a service within West Cumbria was also highlighted, as well as help with transport to the centre, as having only one centre in Carlisle means certain patients and carers have long journeys alongside the stress of undergoing radiotherapy treatment.

As patients wellbeing is paramount, the new facility being as comfortable and calm an environment as possible for each individual should be taken into consideration. Patients, particularly, focused upon the aesthetics of the centre and found aspects such as décor, artwork and lighting more important than carers. Comments also focused on the need for distractions to aid relaxation.

In terms of receiving treatment, information patients would like to proceed with the current method of face to face appointments with Radiographers and/or Oncologists, alongside care plans, diagrams and leaflets, and information and support leaflets were also a requirement of the new facility. This delivery method would provide written information patients can then take away on top of their appointment with their treatment provider. Feedback was more varied in terms of how often and how much treatment information is required, and is likely to some extent to be subjective to the individual, with a large proportion but not all patients wanting as much information as possible.

In terms of interest in new features for the centre, there is interest amongst patients especially, for radiotherapy information sessions, emotional support services and complementary therapies which would all support the overall wellbeing and care provided to patients alongside the delivery of treatment using new, up to date technologies.

6. Appendices

NHS England Patient and Carer Consultation Survey **North Cumbria Radiotherapy Service**

NHS England is responsible for making sure that people receive the highly specialist services that they need, which includes some cancer services.

In line with this responsibility, it is running a procurement exercise for the provision of Radiotherapy services for people living across North Cumbria. This means going out to tender to identify a new provider for this service.

This is happening because, due to the age of the equipment, the current service is unable to provide many of the new innovative treatments in Radiotherapy that will become routinely available over the next few years and we want to make sure that the population of North Cumbria has access to the most up to date services.

The service will replace the existing service provided by North Cumbria University Hospitals and will be provided by a different organisation, as North Cumbria University Hospitals is not applying to run the new service. However, an important message is that patients will access the service in the same way as they do now. It will continue to be provided on the Cumberland Infirmary hospital site in a new purpose built facility.

To support this procurement we are seeking the views of existing patients and carers to understand what is important to you when attending for a Radiotherapy appointment so that we can ensure the new service meets your needs as much as we possibly can. We hope that you will take the time to complete this survey.

This questionnaire should only take around **5 minutes of your time to complete.**

All answers you give are **strictly confidential and anonymous** and will be dealt with in accordance with the Market Research Society Code of Conduct.

If you would like to take part, please let us know if you are visiting the centre today as a patient or carer?

Patient **Carer**

Q1. Which of the following would you like to have access to within the new facility? *Please tick all that apply*

- Complementary therapies (*for example relaxation sessions, aromatherapy, reflexology etc.*)
- Emotional support services
- Buddying/befriending services
- Radiotherapy information sessions
- Macmillan support
- Hair loss support
- Information and support leaflets
- Information and support internet access within the centre
- Other support networks

Other (Please tell us which other facilities you would like in the box below)

If you are filling in the questionnaire as a carer, please go to Q6

Q2. Please let us know how you currently like to receive information about your radiotherapy treatment and how you would prefer to receive information?

Please tick all that apply in each column

	<i>Current</i>	<i>Preferred</i>
Face to face with my Radiographer/Oncologist		
Telephone conversation with my Radiographer/Oncologist		
Direct mail/postal		

Email/internet		
Written information such as a care plan/diagrams		
Leaflets		

Q2b. Are there any other ways you would like to receive information about your treatment?

Q3. How often would you like to receive information about your Radiotherapy treatment? *Please chose one option*

- Daily (**Go to Q4**)
- Weekly (**Go to Q4**)
- Biweekly (**Go to Q4**)
- Monthly (**Go to Q4**)
- It depends on where I am in my treatment plan (**Go to Q3b**)

Other – please specify in the box below:

Q3b. How often would you like to receive information about your treatment in relation to your treatment plan?

Q4. And how much information would you like to receive about your treatment?

Q5. In terms of delivery, how would you like to receive your radiotherapy treatment?

For each statement, please tell us how much you agree or disagree with each

	<i>Strongly Agree</i>	<i>Agree</i>	<i>Neither agree nor disagree</i>	<i>Disagree</i>	<i>Strongly Disagree</i>
As few treatments as appropriate					
As close to home as possible					
In the morning					
In the afternoon					
On an evening					
On a weekend					
In a Radiotherapy dedicated facility					
By the same radiographer every time					
Using latest technology and techniques					

Q6. How important are the following facilities in terms of the new radiotherapy centre?

For each option, please tell us how important each is to you.

	<i>Not at all important</i>	<i>Unimportant</i>	<i>Neither important nor unimportant</i>	<i>Important</i>	<i>Very Important</i>	<i>Don't Know / Not applicable</i>
Parking						
Main site accessibility						
Disabled access						
Seating/waiting area						
Décor						
Colour scheme						
Lighting						
Artwork						
Availability of radio/TV while waiting						
Refreshment area						
Information available						
Information						

Centres						
Café						
Retail/shop facility						

Q7. How would you prefer to receive communications about the development of the new radiotherapy service for North Cumbria? *Please chose one option*

- On the North Cumbria University Hospital website
- Emails
- Postal newsletters
- Newsletters/pamphlets available in the Hospital
- Telephone

Other please specify here:

- I'd prefer not to receive any communication about this

Q8. Are there any other comments you would like to make regarding how the proposed new radiotherapy facility for North Cumbria can improve on the current service?

Thank you very much for your feedback on the future of Radiotherapy services in North Cumbria.

This survey has been conducted by independent Market Research agency Public Knowledge in accordance with the MRS Code of Conduct. All responses you gave are confidential and anonymous.

If you wish to check the validity of this survey, or if you have any further questions, you may call Public Knowledge on the following free phone number 0800 1951842 or you can email info@publicknowledge.eu.