NHS Halton, Knowsley, St Helens and Warrington Clinical Commissioning Groups (CCGs)

Pre-Consultation Engagement Findings Report

January 2019

Participate Ltd. 29 Chapel Lane, Rode Heath, Cheshire ST7 3SD
Tel: 0845 094 8191 Email: info@participate.uk.com Web: www.participate.uk.com
Co. Reg. 06313232 VAT Registration No. 933 8827 88

ParticipateUK
@ParticipateUK

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Contents

Introduction

Participate Ltd has been commissioned by NHS Halton, NHS Knowsley, NHS St Helens and NHS Warrington Clinical Commissioning Groups (CCGs) to support a process of pre-consultation engagement in regards to the proposal to transform specialist, non-surgical cancer care services.

The key aim of the engagement process was to ensure a robust and transparent approach that enabled stakeholders to shape options for consultation.

The following report outlines the findings from the engagement with a variety of stakeholders.

Context

Excellent specialist cancer care services are provided across Cheshire and Merseyside. With the Clatterbridge Cancer Centre ranking as one of the best in the country. Local people in the Halton, Knowsley, St Helens and Warrington areas are able to access these specialist services.

Identified challenges and increased demand for cancer care means the CCGs need to look at ways of changing how they deliver some services in the future, to ensure they continue to provide the best possible care for patients. A model of care is being drawn together to make sure cancer care services deliver what is needed for its patients in the best way possible.

The model outlines that inpatient care will be provided from the new Clatterbridge site in Liverpool. However, it is proposed that the majority of outpatient care and other support services will be delivered in a local Hub. The proposed Hub would work with other local hospitals offering improved local access to a range of specialist cancer services without travelling to the main cancer centre.

Challenges identified include:

- The number of people diagnosed with cancer is rising, which means that every year services need to respond to growing demand

- Consultants working alone - providing cancer services in this way can mean that patients sometimes wait too long for treatment and support service appointments
- The range of support services that patients' access can vary depending on where they live and where they go for their first appointment
- Access to clinical trials can vary, meaning that some patients can access new treatments not available to others
- If cancer patients become unwell (out of hospital) they are generally directed to A&E, which is not always the best place for people receiving cancer treatment
- Access to new and more complex therapies currently means travelling to Clatterbridge Cancer Centre on the Wirral.

Engagement Methodology

The engagement approach ensured a range of stakeholders were given the opportunity to be involved in the pre-consultation engagement discussions across the four CCG areas. Following an extensive mapping exercise to identify stakeholders the following engagement activities were undertaken. Overall the engagement aim has been to give targeted opportunities for engagement for those with a stake in cancer care to gather quality insight to shape the options development process.

Method	Number	Output
Stakeholder Panel Events	3	162 representatives from forums, groups and organisations that have a stake in local cancer care were invited to join a Stakeholder Panel. This included Healthwatch's, cancer charities, Trust staff and patient support groups. Around 40 representatives attended each event and participated in discussions. These stakeholders were asked to disseminate insight across their networks and feedback at events. They also reviewed and fed into the evaluation criteria.
Focus Groups	10	69 service users and/or carers across the 4 CCG areas took part in detailed focus group discussions.
In-Depth Interviews	10	5 interviews with front line professionals from STHK. 5 interviews with front line professionals from WHH.
Feedback Form	71 people completed the form. Mix of Professionals and patients/carers	Feedback form put onto CCG websites, promoted through distribution of the Case for Change by CCG leads and by sending the link to the stakeholder panel. Aim was not for quantity, but quality of insight generated.

In addition to the activities outlined, each of the CCGs undertook direct engagement with local authorities, political stakeholders, internal and external media channels, GP commissioning leads, governing bodies, partner organisations etc. A full outline of activities by each CCG can be found in the following tables.

Activity description	Media channels used	Documents distributed	Audiences	Date	Numbers reached
Halton CCG					
Web page on NHS Halton CCG website.	Public website	Case for Change document and info	Public and stakeholders	05-Sep-18	No data, less > than (0.4%)
Eastern sector cancer hub stakeholder panel	Email, personal call and visit	Case for Change document and info	3 sectors	18-Sep-18	30
Eastern sector cancer hub stakeholder panel	Email, personal call and visit	Case for Change document and info	3 sectors	18-Sep-18	12 Halton organisations
Information sent to MPs, councillors and (Overview Scrutiny Committee) Halton health policy and performance board	Letters and links	Case for Change document and info	Political	24-08-18 other dates unknown	2 MP's, all councillors and (OSC) committee
Widnes and Runcorn cancer resource centre	Visit and catch up	Case for Change document and info	Booking to see other users and groups	27-Sep-18	to all their members on line and face to face.
Primary care	Email bulletin	Case for Change document and info		16-Nov-18	

Activity description	Media channels used	Documents distributed	Audiences	Date	Numbers reached
Knowsley CCG					
Knowsley CCG Staff Communication	Chat with the Chief	Verbal	Knowsley CCG staff	30/05/2018, 04/10/2018	30-40 staff (varies depending on staff availability to attend)
Knowsley CCG Staff Communication	Email	Public Facing Case for Change	Knowsley CCG staff	05/10/2018	Approximately 80.
Knowsley Metropolitan Borough Council Communication	Stakeholder Briefing	Public Facing Case for Change & Stakeholder Briefing	Chief Executive (+ Local Councillors / Elected Members)	19/07/2018, 21/12/2018	1 (+ approximately 40 Councillors / Elected Members from LA Chief Executive dissemination)
STHK & WHH Communication	Stakeholder Briefing	Public Facing Case for Change & Stakeholder Briefing	STHK & WHH Chief Executives	19/07/2018, 02/01/2019	2
Healthwatch Knowsley Communication	Meetings	Verbal	Healthwatch Knowsley	26/07/2018, 30/10/2018, 26/11/2018	1
Healthwatch Knowsley Communication	Stakeholder Briefing	Stakeholder Briefing	Healthwatch Knowsley	31/07/2018, 02/01/2019	1
Knowsley CCG Cancer GP Clinical Lead Communication	Stakeholder Briefing	Stakeholder Briefing	Knowsley CCG Cancer GP Clinical Lead	30/07/2018, 02/01/2019	1
Knowsley OSC Chair Communication	Stakeholder Briefing	Public Facing Case for Change & Stakeholder Briefing	Knowsley OSC Chair	01/08/2018, 21/12/2018	1
Warrington Hospital & Whiston Hospital Site Visits / Exec Meetings	Meetings	Proposed ESCT Estates & Infrastructure specification	Knowsley CCG Long Term Conditions GP Clinical Lead	09/08/2018, 22/08/2018	1
Knowsley MPs Communication	Stakeholder Briefing	Public Facing Case for Change & Stakeholder Briefing	MPs	24/08/2018, 21/12/2018	3

Activity description	Media channels used	Documents distributed	Audiences	Date	Numbers reached
Knowsley MPs Communication	Meetings	Presentation	MPs	07/09/2018	3
Local Stakeholder Groups Communication	Email	introductory mailing to stakeholder groups	Public	29/08/2018	25 (+ extended networks for each borough)
Knowsley Elected Members Communication	Meetings	Presentation	Local Councillors	30/08/2018	40
Information Uploaded	CCG Website	Case for Change, survey and information	Public	03/09/2018	
Stakeholder Panel Events	Meetings	Presentation	Local Stakeholders	18/09/2018, 09/10/2018, 04/12/2018	25 (+ extended networks for each borough) stakeholders invited to events
Knowsley CCG Protected Time Event (PTE) Communication	Meetings	Presentation	CCG GPs, Practice Nurses, Practice staff teams, CCG staff	26/09/2018	110
Media Statement	Statement	Statement	Community	28/09/2018	6 media organisations
Knowsley CCG Governing Body Communication	Meetings	Briefing Paper	CCG GPs, staff, stakeholders, public	04/10/2018	20

Activity description	Media channels used	Documents distributed	Audiences	Date	Numbers reached
St Helens CCG					
Information uploaded	CCG Website	Case for Change, Survey and information	Public	03-Sep	
Verbal update	Meetings	signposted to CCG website	Third Sector, Voluntary and Partners	13-Sep	18
MPs	Briefing	Case for Change and briefing	MPs	24-Aug	2
Local Councillors	Briefing	Case for Change and briefing	Local Councillors	24-Aug	48
Overview and Scrutiny Committee Leads	Briefing	Case for Change and briefing	OSC Leads	24-Aug	
Verbal update	Meetings	signposted to CCG website	Patient Experience and involvement Group	19-Sep	12
Media Statement	Statement	Statement	Community	Sent to Star 27/08/2018 and published 03/10/2018	1
Case for Change distribution		Case for Change hard copies	Carers Centre, Healthwatch,	WC 24 September	
GP / Commissioning Bulletin	Bulletin	Case for Change and survey	Member practices	19/09/2018 and 3/10/2018	34 practices and CCG staff
Engagement Newsletter	Newsletter	signposted to website	CCG members	28-Sep	70 +
Healthwatch	Briefing	Case for Change and briefing		24-Aug	
Key Stakeholders for event		Information sent to participate re invitations for stakeholder events			
Equality groups		Information sent to participate for focus groups and telephone conversations			
Governing Body	Paper	Update paper	Governing Body Members and Public	01-Feb	

Activity description	Media channels used	Documents distributed	Audiences	Date	Numbers reached
Warrington CCG					
Documents on website	Website	Case for Change uploaded	Members of the public	11-Sep-18	58 hits
Press Release	Warrington Guardian		Members of the public	01-Oct-18	171,966 readership
Public Newsletter	Email	Case for Change	Interested members of the public, PPGs and third sector organisations	27-Sep-18	130
CCG Health Forum	Email and discussion at meeting	Case for Change	CCG strategic patient/ public feedback	23-Sep-18	69
PPG Network	Email	Case for change	PPG representatives	03-Oct-18	51
Cancer Health and Wellbeing Event	Event	Case for change	Patients and families who have been affected by Cancer	04-Oct-18	Approx. 50
Equality Groups		Information provided to Participate for further focus groups/telephone conversations			
Commissioning bulletin	Email bulletin	Case for Change	CCG staff and primary care staff	16-Nov-18	407
Overview Scrutiny Committee Leads	email	Case for change	Councillors	24-08-18 other dates unknown as Knowsley CCG lead on this	9
MPs				Knowsley CCG lead on this	2
Local Councillors				24-08-18 other dates unknown as Knowsley CCG lead on this	58

Shaping the Options Development Process

Pre-consultation engagement regarding this programme has taken place via the following methods in 2018; 3 Stakeholder Panel events (18th September 2018, 9th October 2018 and 4th December 2018), Cancer Clinician Interviews, Focus Groups with service users and the distribution of a feedback form.

From the first 2 Stakeholder Panel events a number of queries were raised about the Sector Hub, its model, the rationale behind the concept and why it is required. The 3rd Stakeholder Panel event aimed to provide some further clarity in terms of the rationale behind the Sector Hub, why change is required, the current status of the programme and work ongoing to date, and also the regulatory requirements that the programme is subject to and is required to comply with. A key aspect of the 3rd Stakeholder Panel event was to rotate programme staff (including GP Cancer Leads) around the tables to allow participants to ask any questions that they had on the programme.

As requested by the participants at the initial Stakeholder Panel event, the programme commenced some travel mapping work to assess methods of attending hospitals; this included a public transport / bus journeys exercise and a travel audit by The Clatterbridge Cancer Centre NHS Foundation Trust, St Helens & Knowsley Teaching Hospitals NHS Trust and Warrington & Halton Hospitals NHS Foundation Trust to identify the method of transport that patients have used to attend appointments, in additional to identifying current support for cancer patients accessing cancer services in relation to transport costs, car parking and MacMillan support services available.

At the 2nd Stakeholder Panel, participants were asked to review and rank the criteria sections of an estates and infrastructure request sent to local Trusts to understand their ability to deliver a Sector Hub within the Eastern Sector. Clinical quality was selected by the Stakeholder Panel as the most important evaluation criterion. The other criteria were rated quite similarly. Feedback from this exercise will be fed into the programme team to aid the overall evaluation of the each Trusts ability to hosts a Sector Hub.

Clinician interviews have been undertaken with cancer services staff to understand their views on current service provision and whether they feel that the proposed reconfigured

clinical service model will provide benefits to patient care. Feedback from the interviews provided support for the proposed reconfigured clinical service model, and an understanding that political views on the proposed pathways changes should not be an obstruction to the delivery of an improved model for patients diagnosed with cancer.

The Focus Groups undertaken across all 4 boroughs has allowed service users to provide feedback on their experience of cancer services and their views on the proposed reconfigured clinical service model. Patients have broadly supported the changes to clinical pathways; however concerns have centred around whether there will be an impact to some patients who travel on public transport and are required to travel further than at present for their 1st outpatient appointment under the proposed pathway plans.

In addition to the above, in January 2019 senior clinicians from The Clatterbridge Cancer Centre NHS Foundation Trust, St Helens & Knowsley Teaching Hospitals NHS Trust and Warrington & Halton Hospitals NHS Foundation Trust met and agreed on the proposed clinical service model for the programme.

A further stakeholder panel in March 2019 will aim to provide the following:

1) Feedback on the status of the programme;
2) Review of the Pre-Consultation Engagement Report;
3) Draft formal consultation high-level plan.

The insight gained from all of the pre-consultation engagement to date has been invaluable and will be used to shape the formal consultation process (expected to be summer 2019), and provide further clarity of the issues that stakeholders have raised which the programme is required to review and address wherever possible.

Approach to Analysis

The body of this report contains the detailed analysis and feedback from all responses received. Key themes have been extracted by the specific engagement method and stakeholder group, which is followed in the report with the full data collection.

PLEASE NOTE: Some respondents may have taken part in more than one of the engagement activities, therefore there may be some cross over of information collected. A range of engagement methods provides depth to the feedback gathered and will not impact on the overall information collated.

Some of the service user engagement included less service users than intended due to low response rates from participants. Where relevant this is highlighted in the service user write ups.

The feedback forms, although quantitative, must be treated with some caution as they are based on a relatively small sample of 71 respondents. The information is shown in charts and tables to illustrate the findings clearly. Cross tabulations have been undertaken to provide further information where relevant, these should also be treated with caution due to their small sample sizes.

All responses are anonymous, however, it may be possible to identify individuals from their comments in some cases.

In terms of themes, one response may contain multiple themes. Therefore, where quantified the number of mentions of a theme may exceed the total number of responses.

Summary of Findings

The data sections within this report set out the analysis and feedback from each of the following dialogue methods including: feedback forms, stakeholder events, focus groups and in-depth interviews.

- 71 feedback forms
- 3 stakeholder panel events
- 10 focus groups with service users and carers
- 10 in-depth interviews with healthcare professionals

The overall themes, which have emerged throughout these dialogue methods, are outlined within the summary of findings section below.

Need for Change

- Across the board, respondents asked that current services perceived to be working well to be recognised and used as best practice examples
    - This included clinical services and support services outside of the NHS
- A shortage of oncologists, equality in cancer care and patients needing to travel to access the right care were identified as key aspects of the need for change
- Most patients were very satisfied with the care they had received overall. Suggestions for improvement included:
    - Better signposting to support services inside and outside the NHS
    - More thought around the way information and patient choices are provided e.g. just the right amount with help available to digest and understand the information given, along with an opportunity to come back with queries easily
    - Better appointment scheduling to decrease waiting times at appointments
    - Better follow up post treatment or after diagnosis
    - Increased understanding and empathy for patients with disabilities and other conditions
    - Equal access to clinical trials and understanding around the process and outcomes
    - Training for staff around treating people from different protective groups equally

- Feedback on the whole was that A&E is not the right place for cancer patients undergoing treatment in an urgent care situation
- All agreed a multidisciplinary team working environment was the ideal approach to be using without consultants working alone.

Evaluation Criteria

- Panel members attending the events were asked specifically to rate and discuss the evaluation criteria (full detail on page 73). Clinical quality came out as the most important criterion, closely followed by patient access. Strategic fit was rated the least important
- Professionals were asked what they felt were the most important factors to consider when offering the best possible cancer care. The key factors identified were:
    - Accessibility
    - Collaborative working/cross pollination of expertise/team working
    - Timely service
    - Centralised location
    - Culture and flexibility to enable quick decisions.

Patient Access and Pathways

- Trust professionals discussed pathway disruption currently occurring when patients from the Trust have to go to another Trust for their first appointment
- Some professionals also mentioned there can be changes in pathways and that this could be eliminated with collaborative flexible working
- All respondents thought patients should have equal access to cancer care services across the sector and clinical trials
- Some professionals felt there was limited cross pollination across surgical and none surgical care. Patients weren't aware of a gap in communications across the teams, but did wonder why the two were not being looked at in unison during the proposal developments.

Hub Approach

- All professionals stated that the Hub was a good idea and could improve the quality of care by:

  - concentrating resources,
  - creating a centre of excellence,
  - developing a multidisciplinary team across the sector,
  - consolidating and improving services,
  - centralising outpatient services, and
  - opening up opportunities for clinical trials.
- Mixed views were found amongst the stakeholder panel and patients about the proposed Hub:
  - Those who agreed thought it would improve continuity of care, provide easier access to services and enable better signposting to support services
  - Those with reservations about the proposals thought it could create another tier of care and were not convinced as to whether care would improve. Some were also concerned about potential changes to current services.
- Professionals also hoped it would not downgrade any services
- All participants thought the urgent care aspect of the proposed Hub was a good idea, particularly if it offered more hours than the current provision and kept cancer patients out of A&E. However, the term 'ambulatory care' was seen as confusing and should be kept to emergency/urgent care
- The term 'hub' was also seen as confusing. Overall participants asked that the language used be more accessible without the inclusion of NHS 'jargon'.

Service Suggestions

- A variety of service suggestions to include in the Hub were outlined by the participant's, the most commonly mentioned being:
  - Signposting to local support services
  - Holistic needs assessments
  - An information point for advice and guidance
  - Pharmacy on site
  - 24-hour urgent care
  - Therapies
  - Lymphedema services
  - Rehabilitation
  - Counselling for patients and families

- Other suggestions included:
  - Radiotherapy
  - Peer support
  - Pampering
  - Benefits advice
  - Wig specialists
  - Pain advice.

Infrastructure and Development

- Professionals emphasised the need for a collaborative approach to the proposals, ensuring patients are also involved throughout the Hub development
- They also suggested learning from best practice examples within the sector, in terms of working practices and overall care provision
- Ensuring the Hub is patient centred and future proofing it by building in robustness were also factors the professional's thought should be included
- They were keen to point out that any decisions should not be politically focused
- Panel members emphasised the need for good IT support and communications
- The panel members and service users raised concerns about how the Hub would be staffed and wanted to better understand how this would work with current services
- All agreed getting the environment right was essential such as offering quiet spaces and adequate parking
- Other suggestions included:
  - Appropriate seating
  - Good signage to find your way around the building
  - Refreshments
  - Virtual consultations
  - Creche
  - Disabled access
  - Generally avoiding a hospital type feeling.

Location and Travel

- The location of the Hub was discussed in depth across the groups interviewed with the main concern being distance for patients to travel to receive care. Some, however, thought centralising the Hub could make access easier. Professionals were more likely to say patients would be happy to travel for specialist care
- Patients thought up to 30 minutes was long enough to travel for specialist care with cars being considered the main mode of transport
- Public transport was not thought to be ideal for patients undergoing treatment, but should be offered. Volunteer drivers, shuttle buses, designated drivers and support with travel costs were suggested e.g. toll bridges

- Focus group attendees asked for the cost implications of the proposed hub to be taken into consideration
- Service users thought there should also be more consideration around appointment times for patients in relation to distances to travel and condition of the patient before and after treatment
- They also wanted the proposals to consider the impact on low income patients with regards to travel and parking
- Some also highlighted the need to consider disruption to families with young children during treatment and how local services enable them to carry on as 'normal a life as possible'
- All respondents emphasised the need for adequate and appropriate parking with opportunities for support for parking costs.

The following pages contain the detailed feedback from all activity. It is recommended that the full report is reviewed by the CCGs as part of the options development process.

Participant Profiling and Potential Impacts

The focus groups aimed to gather views from a range of service users and carers from across the four CCG areas. Carers and patient groups were the predominant groups accessed. Some individuals within the groups identified as LGBT, disabled and parents of young families. There were some specific findings relevant to these particular groups as follows:

- One person reported experiencing prejudice when trying to access treatment, because of his sexual orientation. The care worker refused to provide treatment to him.
- Some people with disabilities felt their conditions or disabilities were not considered adequately when undergoing treatment, patients wanted their knowledge and experience of their own condition or disability to be taken into account.

  "There is a lack of understanding, respect and empathy regarding disabilities and patients [own] understanding of their other conditions".

- Parents with young families described how local cancer care services enabled them to continue as 'normal a life as possible', whilst receiving treatment and attending appointments. Ease of access to services was important to them and therefore they felt travelling distances to receive care would impact on their everyday life significantly e.g. taking children to school, spending time with families etc.
- Many respondents expressed concern about travel to and from appointments on a low income and how this would impact on accessing treatment and care.

The in-depth interviews with front line professionals working in cancer care did not identify any specific groups of people who might be impacted by the proposals other than cancer patients overall. The distance to travel to access care was the most commonly mentioned to impact on patients in poor health or undergoing treatment.

Discussions during the panel events amongst participants outlined the need to look at vulnerable groups and lifestyles in terms of ensuring they can access services. Others talked about the provision of a creche for families and the need for mental health support across the board. Disability access was also mentioned as a required consideration.

Respondents completing the feedback forms identified some patient groups they thought could be impacted by the Hub proposals, these included: the elderly, disabled, people with learning disabilities, carers, children, families and those seriously ill.

The tables below provide a profile of those people completing the feedback form, which can be summarised as follows:

- Responses were collected from across the four CCG areas, with St Helens (22) having the most feedback via this method and Warrington having the fewest feedback forms completed (6)
- 60% were aged between 35-64
- Over half were female and this was the gender identified at birth
- 70% indicated they were White: Welsh/English/Scottish/Northern Irish/British
- The majority described themselves as Christian
- 3% identified as being gay or lesbian, 22 people preferred not to say
- A small proportion 6% indicated they had a disability.

Profiling Information	Total	Halton	Knowsley	St Helens	Warrington	Other	Prefer not to say
Age							
16 – 18	0	0	0	0	0	0	0
19 – 34	8	1	3	3	0	1	0
35 – 49	18	3	4	7	2	1	1
50 – 64	24	5	3	11	3	1	1
65 – 79	5	3	1	0	1	0	0
80+	1	1	0	0	0	0	0
Prefer not to say	15	0	0	1	0	0	14
Gender							
Female (including trans woman)	37	9	8	16	3	0	1
Male (including trans man)	17	4	2	5	2	3	1
Non-binary	0	0	0	0	0	0	0
In another way	0	0	0	0	0	0	0
Prefer not to say	17	0	1	1	1	0	14
Gender Reassignment							
In gender given at birth	53	13	11	19	5	3	2
Different gender to one	0	0	0	0	0	0	0

Profiling Information	Total	Halton	Knowsley	St Helens	Warrington	Other	Prefer not to say
given at birth							
Prefer not to say	18	0	0	3	1	0	14
Ethnicity							
White: Welsh/English/Scottish/Northern Irish/British	50	12	11	17	5	3	2
White: Irish	0	0	0	0	0	0	0
White: Gypsy or Irish Traveller	0	0	0	0	0	0	0
White: Any other white background	1	0	0	1	0	0	0
Mixed: White and Black Caribbean	0	0	0	0	0	0	0
Mixed: White and Black African	0	0	0	0	0	0	0
Mixed: White and Asian	1	1	0	0	0	0	0
Mixed: Any other mixed background	0	0	0	0	0	0	0
Asian/Asian British: Indian	0	0	0	0	0	0	0
Asian/Asian British: Pakistani	0	0	0	0	0	0	0
Asian/Asian British: Bangladeshi	0	0	0	0	0	0	0
Asian/Asian British: Any other Asian background	0	0	0	0	0	0	0
Black or Black British: Black – Caribbean	0	0	0	0	0	0	0
Black or Black British: Black – African	0	0	0	0	0	0	0
Black or Black British: Black - Any other Black background	0	0	0	0	0	0	0
Other ethnic background – Chinese	0	0	0	0	0	0	0
Other ethnic background - Any other ethnic group	1	0	0	1	0	0	0
Prefer not to say	18	0	0	3	1	0	14

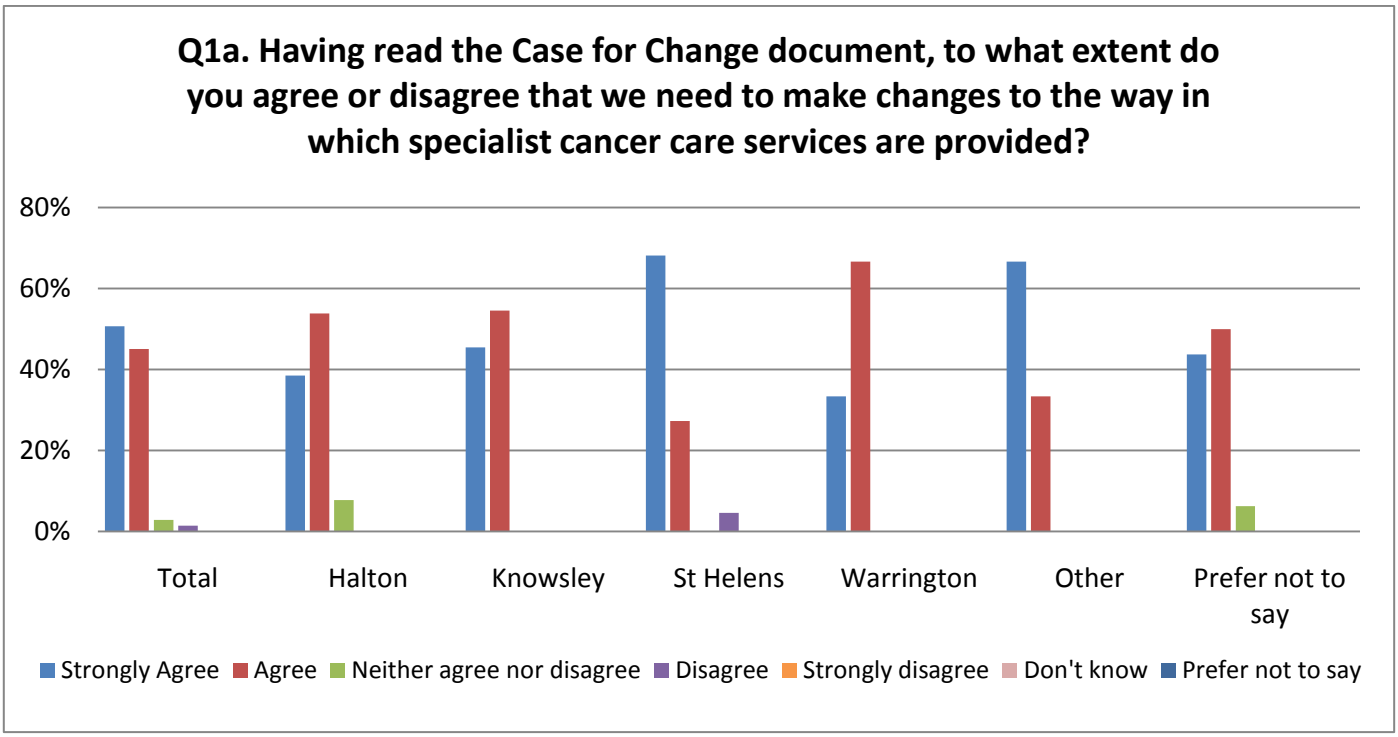
Profiling Information	Total	Halton	Knowsley	St Helens	Warrington	Other	Prefer not to say
Religion							
No religion	10	2	2	4	1	1	0
Buddhist	0	0	0	0	0	0	0
Christian	38	11	7	12	4	2	2
Hindu	0	0	0	0	0	0	0
Jewish	0	0	0	0	0	0	0
Muslim	1	0	0	1	0	0	0
Sikh	0	0	0	0	0	0	0
Atheist	2	0	1	1	0	0	0
Any other religion	0	0	0	0	0	0	0
Prefer not to say	20	0	1	4	1	0	14
Sexual Orientation							
Heterosexual	47	12	9	17	5	2	2
Gay	1	0	0	0	0	1	0
Lesbian	1	0	1	0	0	0	0
Bisexual	0	0	0	0	0	0	0
Prefer not to say	22	1	1	5	1	0	14
Disability							
Yes	4	2	0	1	1	0	0
No	49	11	11	18	4	3	2
Prefer not to say	18	0	0	3	1	0	14
Base	71	13	11	22	6	3	16

Feedback Form Data

The following section sets out the analysis of the data collated from the Transforming Cancer Care feedback form. In total there were 71 feedback forms completed.

Agreement on the Case for Change

The vast majority of respondents (96%) completing the feedback forms agreed or strongly agreed that changes need to be made in the way specialist cancer care services are provided. People living or working in the St Helens area felt the most strongly about the need for changes.

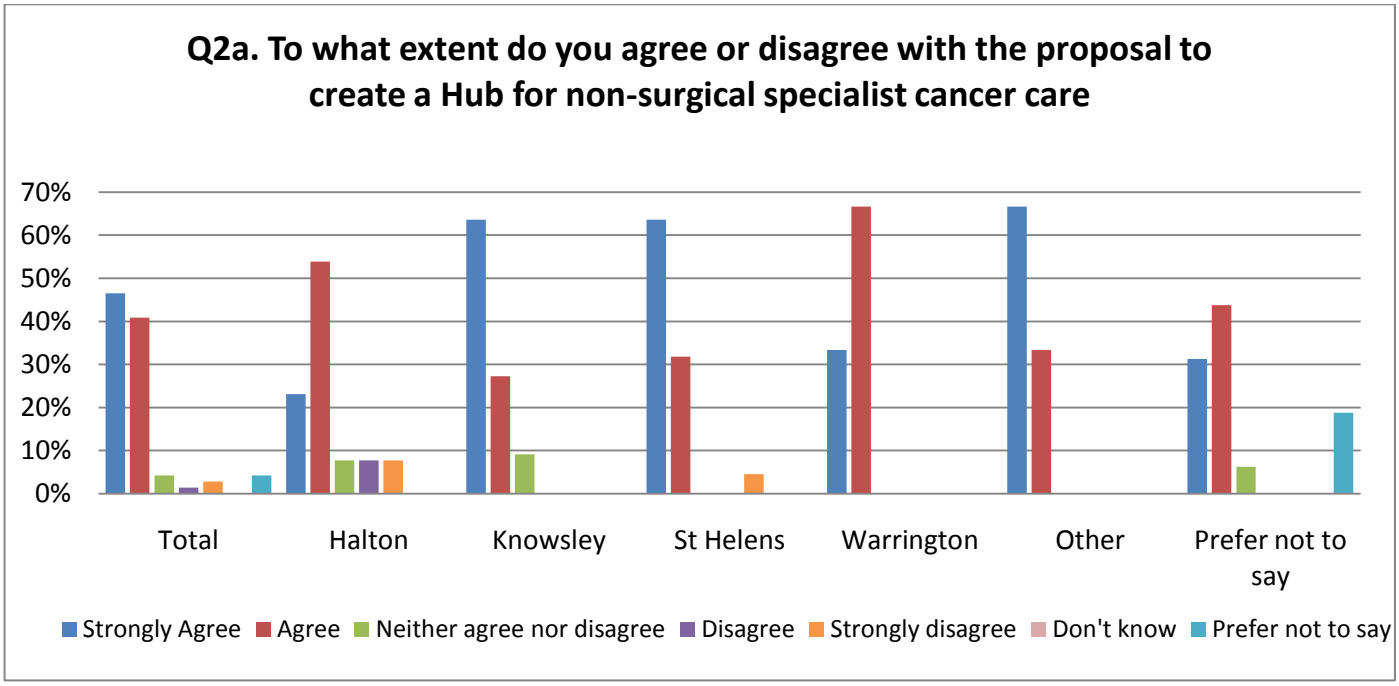


Respondents were asked why they thought changes in specialist cancer care services are needed. Most felt patients currently have to travel too far and they wanted to have access to high quality cancer care and early diagnosis. As indicated in Q2a, many felt a specialised cancer hub would be good, expressing that they felt the current service was not fit for purpose. It was also stated that a team approach was required to provide better services and experience for patients. Please be aware that the table over the page demonstrates the frequency a theme has occurred in a response and as one response can have multiple themes, the frequency may exceed the number of overall responses.

Q1b. Please explain your reasons for the answer given to Q1a.	Total	
	Counts	%
Base	71	100%
Patients currently have to travel too far	32	45%
Access to high quality cancer care	21	30%
Early diagnosis and treatment is important / waiting times	19	27%
A specialised cancer hub would be good	16	23%
A team approach to provide a better service and experience	14	20%
Current service is not fit for purpose	13	18%
To maintain cancer care we have to change things	8	11%
Need better access to oncologists	8	11%
Better use of consultants and concentration of experience	8	11%
Any improvement would be beneficial	7	10%
Better streamlining and co-ordination of patient pathways	6	8%
Demand for cancer care is increasing	6	8%
Access to new therapies important	6	8%
Basic service is poor	5	7%
Having a dedicated cancer service will relieve some pressure on A&E	5	7%
Dedicated cancer hub would avoid infections at hospitals	4	6%
There is a shortage of staff	4	6%
Current service is good	3	4%
Lack of consistency of care from hospital to hospital	3	4%
Disjointed system is timewasting and costly	2	3%
There is a lack of care in the current system	2	3%
First consultation was timely	1	1%
Case for change document is biased towards the positives	1	1%
Consider the impact of public transport which some patients will need to use	1	1%

Agreement on Proposed Hub

When asked about the proposal to create a Hub, 87% were in agreement. Nearly half of which (46%) strongly agreed with the proposal, particularly people living or working in Knowsley and St Helens. A small proportion (4%) disagreed and a further 4% were unsure, stating that they neither agreed nor disagreed.



Overall, the respondents were in agreement with the proposal to create a Hub because they felt it would ensure patients are provided with specialist treatment, continuity and good quality services and care whilst also being easy to access. Many also like the idea of a one stop shop approach.

Q2b. Please explain your reasons for the answer given to Q2a.	Total	
	Counts	%
Base	71	100%
The need to provide specialist treatment	41	58%
Easy to access / local service	41	58%
Needs to be in one place - one stop shop	29	41%
Continuity of care / same doctors or consultants	14	20%
Good quality treatment the most important priority	13	18%
To ensure sustainability of services / room to grow	10	14%
Faster access to services	9	13%
Need good public transport for those that don't drive / transport links	7	10%
Better than having to attend A&E	7	10%
Personalised care - not one size fits all	6	8%

Q2b. Please explain your reasons for the answer given to Q2a.	Total	
	Counts	%
Base	71	100%
Care should be consistent - not better in some areas	6	8%
None	5	7%
For better patient outcomes	5	7%
Reducing stress for patients / carers	5	7%
Easier for staff to be based at one hub	5	7%
Good aftercare / easier testing and results	4	6%
Some patients may not be fit to travel too far	3	4%
Don't know / need more information	2	3%
Need to avoid adding extra (transport) costs for patients	2	3%
Reduces the need to travel to a main cancer centre	2	3%
Need a team that has surgical members and understand surgical issues	1	1%
Improved access to trials for all	1	1%
Case for change document isn't fair and balanced	1	1%
Specialised care difficult to maintain in generic centres	1	1%
Include nutritional advice	1	1%
Involve the voluntary sector	1	1%
There is no improvement or benefit to the cancer patient or their Carers	1	1%
Holistic and support services are well provided by the voluntary sector - this just adds cost	1	1%
Insufficient parking at suggested hub locations	1	1%
Ensures that the main cancer centre can concentrate on the serious cases	1	1%

Services Offered

A wide variety of suggestions were made as to what other services should be offered to cancer patients receiving outpatient care. Therapies, counselling for patients, families and carers were the most commonly suggested. Support and advice from a variety of sources and for a range of reasons were noted e.g. benefits, nutritional, information and cancer support.

Q3. Please list any other services that you feel should be offered to cancer patients when they are receiving non-surgical outpatient care.	Total	
	Counts	%
Base	71	100%
Therapy treatment areas e.g. massage / holistic	26	37%
Personal counselling	23	32%
Family / Carers Counselling	17	24%
None	15	21%
Benefit advice	9	13%
Nutritional advice	9	13%
Local community cancer support / support groups	8	11%
Transport / affordable travel / Parking	7	10%
McMillan Nurses	7	10%
Cancer information support	6	8%
Enhanced supportive care	5	7%
District nurses and clinical nurse specialists	5	7%
Financial advice and support	4	6%
Rapid access to acute care - avoiding unnecessary admissions	4	6%
Rapid access to diagnostic tests	4	6%
Aftercare support	4	6%
Better links and communication across services (hospital, McMillan etc)	4	6%
Access to clinical trials	3	4%
Access to psychological services	3	4%
Palliative support	3	4%
Speech and language therapy	3	4%
Chemotherapy, radiotherapy Support services	3	4%
Face to face appointments	3	4%
Reliable single point of contact	3	4%
Nice waiting room / multi media	2	3%
Café	2	3%
Symptom Management	2	3%
Physiotherapy	2	3%
Up to date information services	2	3%
Confidential advice line for reassurance	2	3%
Advice on side effects of medications	2	3%
Continuity of care - seeing the same specialists / nurses	2	3%
Lymphoedema services	2	3%

Q3. Please list any other services that you feel should be offered to cancer patients when they are receiving non-surgical outpatient care.	Total	
	Counts	%
Base	71	100%
Extravasation treatment and specialist camouflage, aesthetic and reconstructive services	2	3%
Access to the services of the voluntary sector	1	1%
Access to specialist nursing support	1	1%
Good administration of the pathway	1	1%
Social care advice	1	1%
Occupational therapy	1	1%
Access to clinical services	1	1%
A right for patients to have their say on treatments	1	1%
Support for adapting the home	1	1%
Rehabilitation	1	1%
Citizens Advice	1	1%
Child / baby support	1	1%
Support during the first year after diagnosis	1	1%
Cancer help and advice centre	1	1%
Improve existing excellent service	1	1%

Impact on Specific People/Groups

A quarter of respondents didn't feel the proposals would have any impact on specific patient groups. Travel, transport and cost of travel were areas people felt should be considered. Specific patient groups thought to be impacted by the proposals were the elderly, disabled, people with learning difficulties, carers, children, families and those seriously ill.

Q4. Please use the box below to state any impacts on groups or people that you feel we should be considering in our proposals.	Total	
	Counts	%
Base	71	100%
None	18	25%
Patients living further away from the hub	15	21%
Patients and relatives that rely on public transport	12	17%
Elderly Patients	10	14%
Patients and relatives who drive and need access	8	11%
Good public transport links needed	8	11%
Financial impacts including transport costs	8	11%
NHS Staff	8	11%
All cancer sufferers	7	10%
Disabled patients	6	8%
Those with learning difficulties	6	8%
The whole family	5	7%
All residents	5	7%
Emotional impacts / stress	5	7%
Low income / unemployed patients	5	7%
Location of the eastern hub	5	7%
Parking	4	6%
Patients seriously ill and unwell find travel difficult	4	6%
Employer / employment issues	3	4%
Clinical issues should be the most important consideration	3	4%
BME / minority groups	3	4%
Don't know	3	4%
Local charities that provide similar treatments	3	4%
Treatment and side affects	2	3%
Community services	2	3%
Carers who are receiving treatment themselves	2	3%
Patient groups (PPG)	2	3%
Healthwatch	2	3%
Children of patients	2	3%
Positive impact of all services in one centre	2	3%
Head and neck cancer patients	1	1%
Lack of support including McMillan	1	1%
No referrals for the services offered at the Delamere centre	1	1%

Q4. Please use the box below to state any impacts on groups or people that you feel we should be considering in our proposals.	Total	
	Counts	%
Base	71	100%
Include cancer departments at the hospitals	1	1%
Local cancer support centres	1	1%
Health forums	1	1%
Disability groups	1	1%
Transport groups	1	1%
Local council services	1	1%
Facilities and equipment	1	1%
Those outside the catchment area	1	1%
Should be better than the current model	1	1%
GP's who hear patients concerns and needs	1	1%
Former patients now not receiving treatment	1	1%
Patient choice is important	1	1%
Need flexibility of appointments for those working	1	1%
Access to link workers are essential	1	1%
Bereavement support	1	1%

Other Considerations

Most respondents (53%) either had no further comment or said they didn't know. A wide range of other comments were noted by the remaining respondents.

Q5. Please use the box below to state any other comments or concerns you would like us to consider as part of the proposals.	Total	
	Counts	%
Base	71	100%
None	35	49%
Would be good to have services locally	3	4%
Don't know	3	4%
Introduce the new hubs as soon as possible / support new service	3	4%
Follow up with patients and those discharged to see if they are coping	2	3%
New centre should be close to the hospital for clinical services support	2	3%
Patient experience should drive all decision making	2	3%
Wherever the hub is placed patients should expect the highest standards of care	2	3%
Needs to include high quality diagnostic services	2	3%
Warrington Hospital needs huge investment to make it fit for purpose	2	3%
Clear and effective communication about your proposals	1	1%
Availability of clinical trials	1	1%
Needs to address the workforce problems	1	1%
Maintain a presence on the Wirral so it's not disadvantaged	1	1%
Travel costs such as tolls	1	1%
Better use of technology for communication - emails rather than lengthy letters	1	1%
Holistic services are better delivered by 3rd sector (free parking, better location friendly not	1	1%
There is a lack of oncologists in Cheshire and Merseyside	1	1%
Concern that there will be no access to Clatterbridge Cancer Centre	1	1%
New hubs need to offer the same excellent service as Clatterbridge Cancer Centre	1	1%
New hub should be based at STHK as it has up to date facilities	1	1%
Warrington is spread over a large site making access to different departments difficult	1	1%
Warrington is harder to get to in a busy town centre	1	1%
Needs investment in teams to meet standards	1	1%
Needs to be modern and big enough to house the services	1	1%
The links and communication with other sites and services need to be better	1	1%
You need to show the whole model and other hubs to allay fears about location and access	1	1%
Patients want a clear pathway and correct information	1	1%
Provide free shuttle bus travel for patients	1	1%
Hubs must be accessible especially by public transport	1	1%
Consider what is already on the sites for cancer patients	1	1%
The proposed structure has both a local and centric feel	1	1%
With support structures due to be restructured it will help to add clarity	1	1%
The hub needs to be located centrally for the 4 boroughs	1	1%
Needed due to increase in cancer diagnosis	1	1%
Need to keep to appointment times for Chemo	1	1%
Should include the views and knowledge of volunteers	1	1%
Whiston is much more prepared to be a hub and more central to the district	1	1%

Feedback from Stakeholder Panel

Development of the Stakeholder Panel

The comms and engagement lead from each of the four CCGs provided a list of key contacts for Participate to begin to build a stakeholder database for the engagement programme. The stakeholder list is made up of 162 representatives from forums, groups and organisations that have a stake in local cancer care across the eastern sector. Each contact was invited to join the stakeholder panel and were invited to the panel events, of which there were three.

The role of the stakeholder panel was as follows:

- Deliberate the issues around proposals to feed into the development of models of care for future cancer services
- Work with the four CCGs to help formulate solutions for improving cancer care services across the local area
- Meet at stakeholder events to help achieve the objectives of the panel and to subsequently review the event reports as being an accurate reflection of the discussions undertaken.

Panel Events

The panel events took place during September, October and December 2018. Around c40 respondents attended the first two events and c20 to the third.

The aims and objectives of each of the events were as follows:

- 1st event – gather perceptions of the case for change and proposed hub, and to gain insight into the impact of the hub model
- 2nd event – to discuss travel and transport further and to gather feedback and scoring of the evaluation criteria
- 3rd event – to enable panel members to ask questions directly of managers and clinical leads with regards to the scope, case for change, proposed model and travel.

A further stakeholder panel event will be held in 2019, the aim of which will be to provide feedback on the status of the programme, present the stakeholder engagement report, outline the draft formal consultation plan and provide patient case studies.

Summary of Panel Findings

Evaluation Criteria

During the second event participants were asked to rate the evaluation criteria. All criteria were considered important to some extent as they all received a scoring. Clinical quality came out as the most important criteria, whilst strategic fit was rated as the least important.

Need for Change

- Current non-surgical cancer care services were rated highly amongst participants with some room for improvement
- There was initial uncertainty about the benefits of the Hub model, however as the events progressed, panel members gained more understanding of the benefits
- Case studies were suggested to aid understanding around the pathways and proposed Hub
- Concerns were raised about which services would be lost due to the proposed model
- There was a call for more evidence-based information and understanding around the process
- Some thought patients should be given more explanation as to the benefits of clinical trials
- Panel members liked the thought of having access to more specialist clinicians/staff
- Requests were made for more clarification around how less common cancer care and treatment fit with the proposed model.

Patient Access and Pathways

- The panel members expressed confusion about the current and proposed patient pathway. This was made clearer as the events progressed, but panel members continued to feel they needed further understanding
- It was noted that technical terminology and acronyms should not be used
- Overall panel members want to ensure the pathway remains patient centred
- Some felt there should be consideration around the cost impact to patients in relation to new model of care.

Clinical Quality

- Stakeholders wanted reassurance that the quality of care would be maintained or improved with the changes
- Patient choice was considered important
- All wanted to see equality of care across the four CCG areas.

Staff Requirements

- Panel members wanted further information about how the hub will be staffed, concerns were raised about staff being taken from current services
- Questions were raised about how realistic the plans were in relation to staffing.

Infrastructure/Building Requirements

- Getting the environment right was considered important e.g. offering private spaces, friendly greetings etc.
- Sufficient and accessible parking was also considered important to consider.

Location and Travel

- Some felt there should be equality amongst people who do and don't drive
- Many felt patient wellness should be considered more thoroughly in relation to fitness to travel distances for care/treatment
- Some people thought patients would be happy to travel further for specialist care.

Services Offered at the Hub

- Radiotherapy was mentioned by some, but there was an understanding that this may be expensive to provide
- Panel members thought there should be signposting to other support services
- Other suggestions included: advice, rehabilitation, therapies, lymphedema services, wig specialists, counselling
- There was a very positive view of the proposed urgent care provision at the Hub
- Panel members thought there should be: IT support, good communications, virtual consultations, and a creche
- Other suggestions included a request for better support for long term cancer patients.

Main Panel Event Findings

The following pages contain the main findings for each of the three panel events.

1st Stakeholder Panel Event – September 2018

Introduction

The following sets out the findings from the first Stakeholder Panel event which was held on the 18th September 2018 at Halton Stadium. The event structure is outlined below:

- Pre-event questionnaire
- Case for change presentation
- Facilitated group discussion around perceptions on the case for change
- Proposed hub presentation
- Facilitated group discussion to gain insight into hub model and its impact
- Q&A session
- Post event questionnaire.

The insight from the group discussions and individual exercises have been analysed for common themes. The pre and post event questionnaire findings were captured on paper questionnaires during the event.

The role of the Stakeholder Panel is as follows:

- Deliberate the issues around proposals to feed into the development of models of care for future cancer services
- Work with the four CCGs to help formulate solutions for improving cancer care services across the local area
- Meet at stakeholder events to help achieve the objectives of the Panel and to subsequently review the event reports as being an accurate reflection of the discussions undertaken.

Attendance at the Event

There were 45 participants at the event made up of the following representation:

- Cancer support group - 11
- Community and voluntary group - 4
- Healthwatch - 12
- Hospital/hospital rust - 8
- Partner organisation – 3
- Service user - 5
- Health and care other – 2

Executive Summary

There were 45 participants in total at the first Stakeholder Panel event held on the 18th September at Halton Stadium. The following sets out the executive summary from the exercises and group discussions on the day. The full set of detailed findings can be found in section 3 of this report.

Pre-event and post-event questionnaires

The findings from the pre and post event questionnaires infer that:

- The event was successful in enabling participants to learn more about the transforming cancer care programme
- After deliberating the case for change, the majority of participants agreed more strongly that changes to cancer care were needed
- Although most agreed that the Hub would offer benefits for local people, following the discussions there was more uncertainty that the Hub would be beneficial. This finding mirrors the group feedback, which infers that some of the participants were unsure what actual benefits the Hub would provide and how it would result in a smoother patient journey
- Current local non-surgical cancer care services were rated high overall by the participants, with room for improvement
- Finding out more about and discussing the transformation of cancer care services were the main reasons that participants attended the first panel event
- The participants enjoyed attending the event and would like to attend another. They felt involved and able to express their views
- The event was highly rated overall, however, some people wanted to be invited to the event at an earlier date in order to ensure they could attend. This finding is understandable as some invitations were sent out later than preferred due to the time it took to find some of the right contacts. However, all are aware of the next two events and the diary details.

Findings from Exercise 1 – Perceptions of the case for change

- There were some concerns about whether staff will be taken from Clatterbridge and how they will be recruited
- Participants liked the idea of access to more specialist clinicians and staff

- General queries about waiting times and cancellation of appointments
- Much discussion around travel times and types of transportation, although some people were happy to travel for specialist quality care
- People wanted reassurance that the quality of care and treatment/s would be maintained or improved. Choices of where care is received is also important
- Being able to bypass A&E and use dedicated urgent care services was well received
- Some early suggestions were provided as to what treatment and services could be provided in the Hub (see Section 3.2 for details)
- The participants described their experiences as a patient with many having different pathways to care.

Findings from Exercise 2 – Insight into hub model and its impact

- People were confused about the patient pathway to care and whether it would involve another level of triage
- Some thought the Hub model indicated there would be quicker access to appointments and treatment
- Requests that public transport and travel overall is reviewed as part of the proposals
- Facilities suggested for the hub included a variety of holistic services. These included: clinical, supportive, therapeutic, amenities and alternative services e.g. wig specialists.
- Questions about the Hub centred on travel, location, staff and resources.

Recommendations

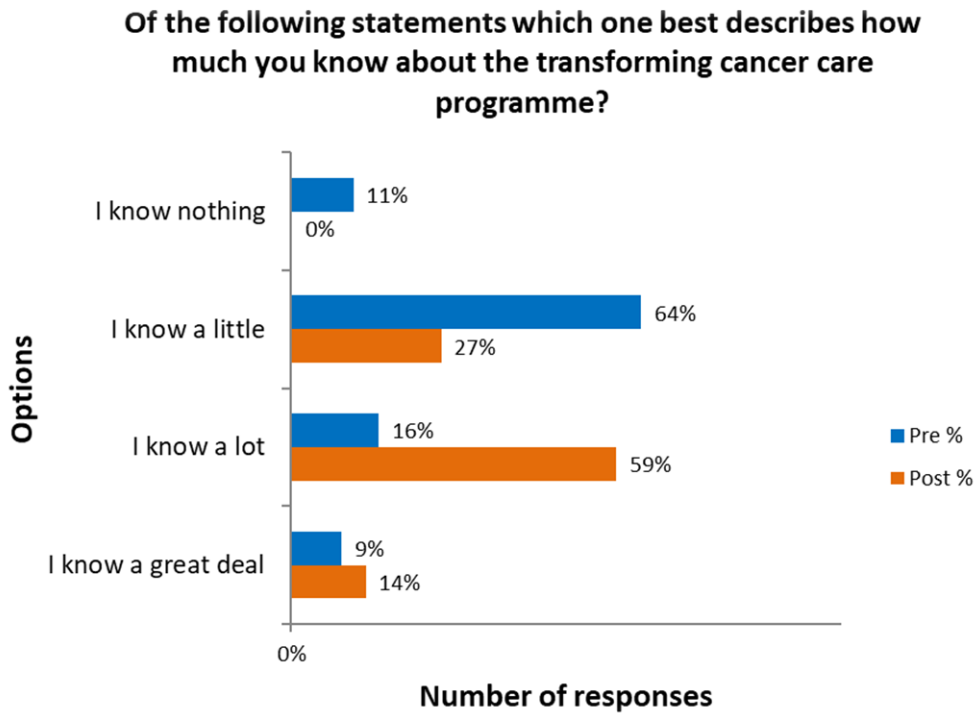
- The detailed feedback within the main findings of this report should be reviewed by the Transforming Cancer Care programme team to feed into the next stage of modelling around the Hub
- The next event in October should give more detail around: the proposed benefits of the Hub; the patient journey with case studies; travel and transport; what it should be called and; the criteria to evaluate any options to take forward.

Main Findings

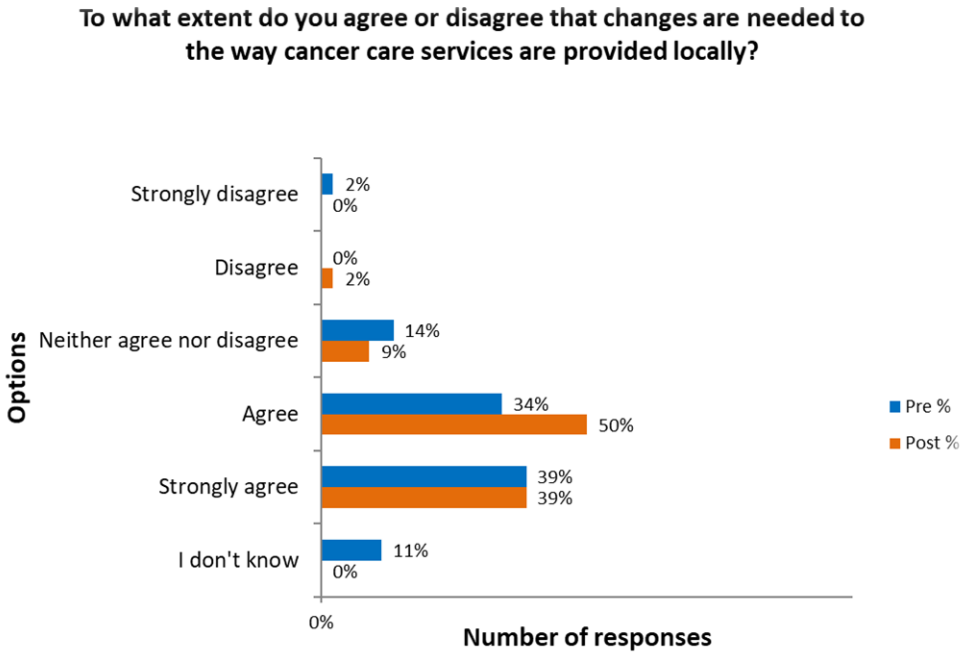
The main findings from each of the activities and discussions at the Stakeholder Panel event on the 18th September 2018 are outlined on the following pages.

Pre and Post Event Questionnaires

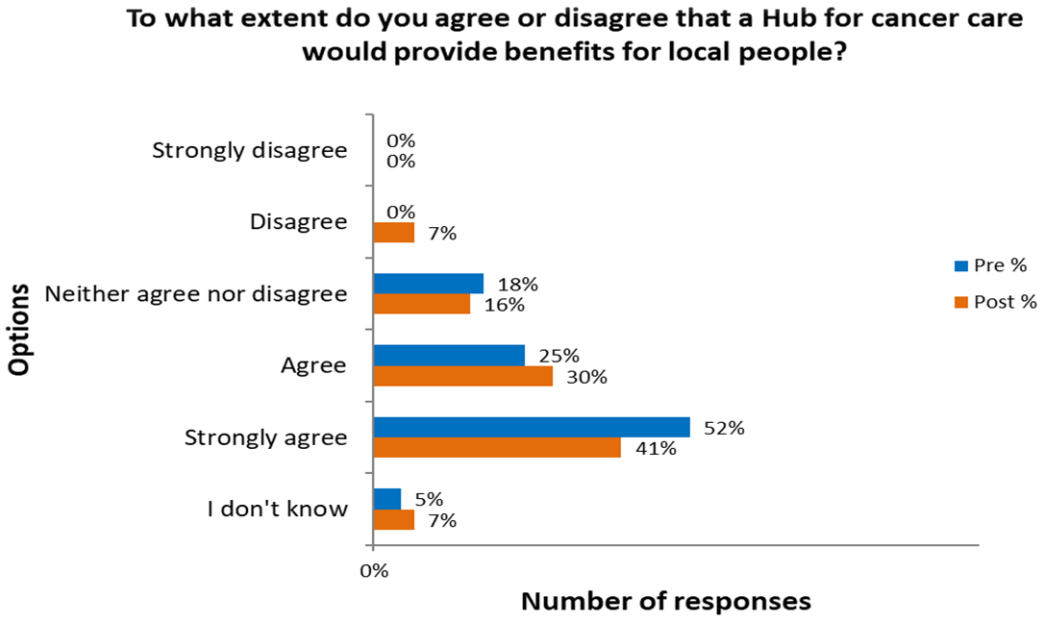
It is clear from the chart below that participants learnt more about the cancer care programme following their participation in the first panel event. With 73% stating they knew a lot or a great deal about the programme after hearing the presentations and discussing it with other participants.



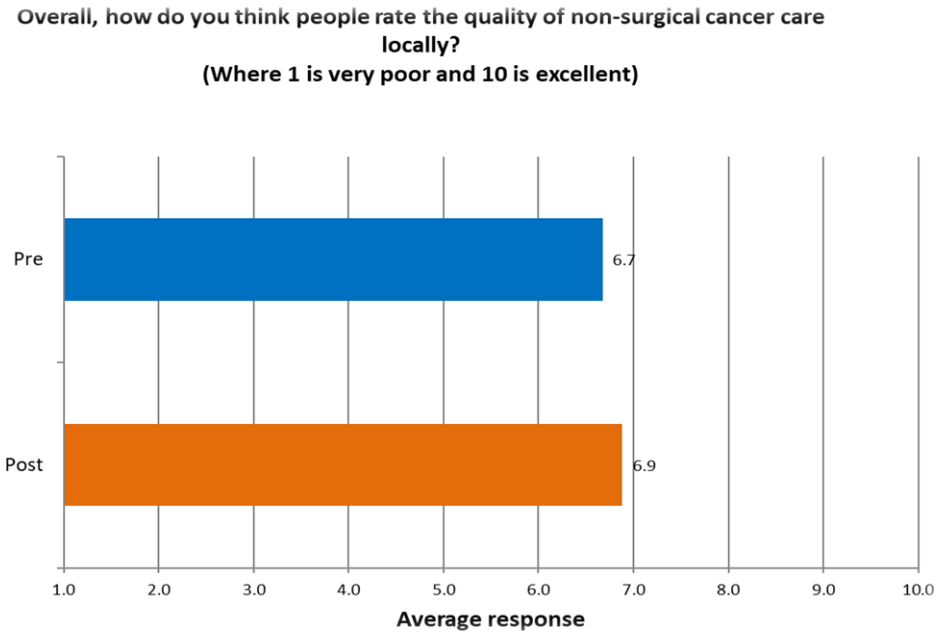
After hearing the case for change, the majority of participants (89%) agreed or strongly agreed that changes were needed to the way cancer care services are provided locally.



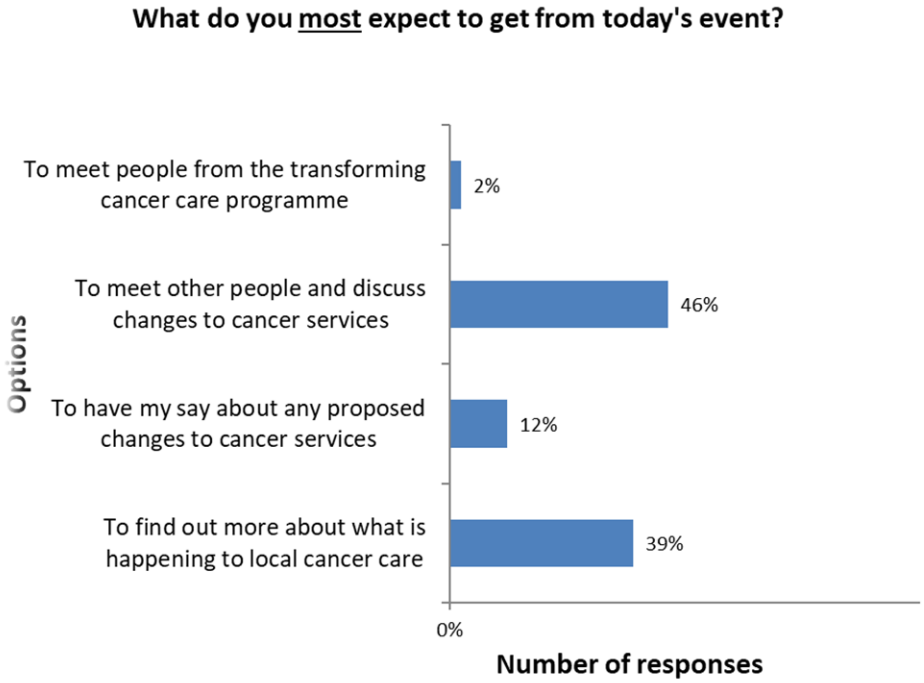
Although most participants agreed (71%) that the Hub would provide benefits for local people, some were less certain or disagreed after the event as they were uncertain of the benefits following discussions.



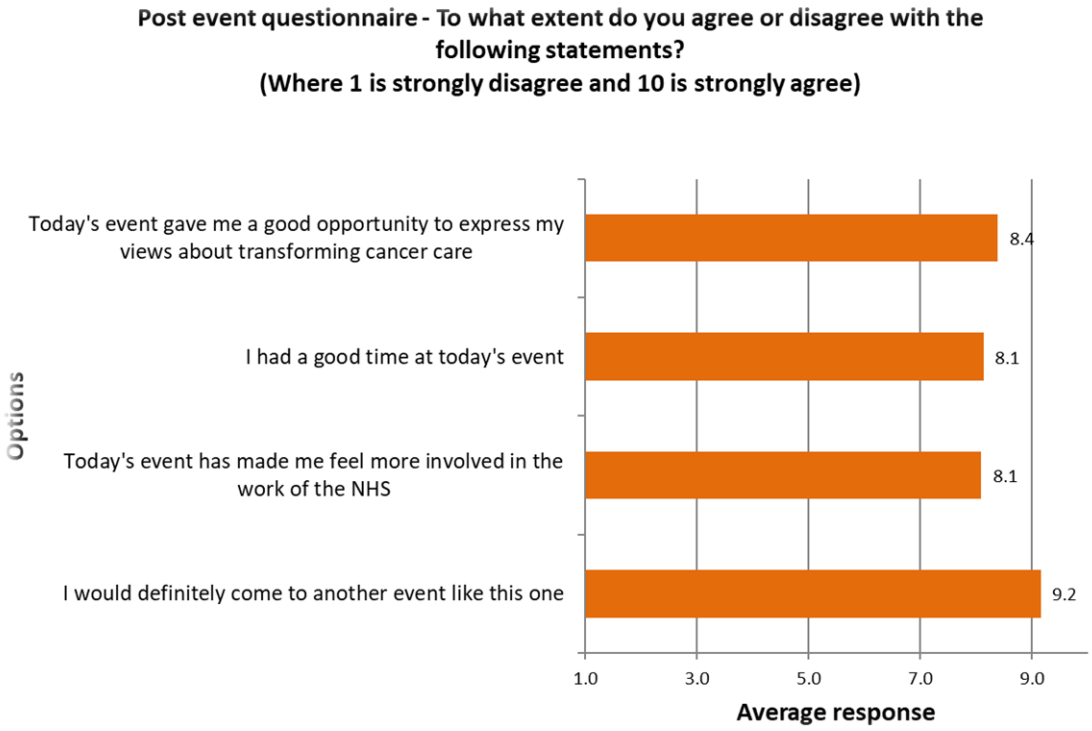
Non-surgical cancer care was rated quite high overall by the participants, but with room for improvement.



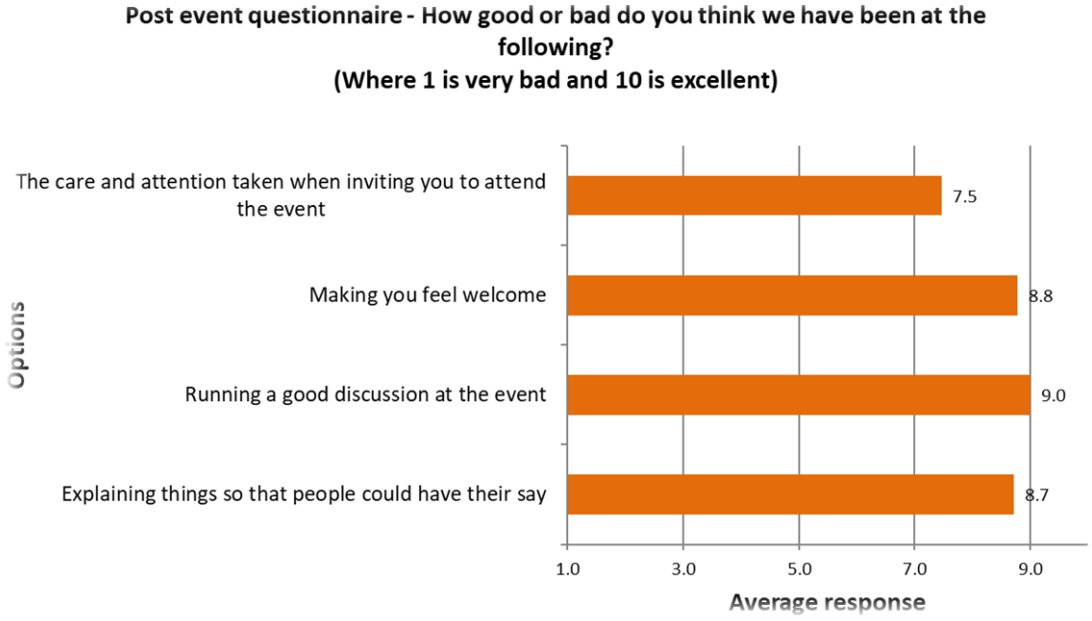
Finding out more and discussing the transformation of cancer care services were the main expectations of participants attending the first panel event.



It is clear from the post event feedback that the participants enjoyed attending the event, would like to attend another and felt involved and able to express their views.



The event was rated highly on all factors, however, some participants invited at short notice impacted on the rating for care and attention with regards to invitations.



Findings from Exercise 1 – Perceptions of the case for change

The following sets out the discussions that emerged after hearing a presentation on the case for change. The comments have been collated by commonly occurring themes.

Thoughts and Experiences

The following comments were collated from the table discussions where participants were asked to share their experiences of cancer care services and give their views on the case for change.

Staff
• Will Clatterbridge staff move to new hubs and there be enough staff • Difficult to recruit staff with specialist skills needed for caseload • How to attract cancer specialist to the North West? • Need to ensure clinicians area aware of benefits etc (non-clinical need) as well as the clinical need for patients • Dementia training for all staff is necessary

Appointments and Waiting Times
• 2 week wait with no information whilst waiting • Clinics delays causes problems with transport • Waiting times between appointments are a long time without knowing results • Experience of appointments being cancelled • Cancellation of follow up appointments leads to negative issues

Transport and Location
• Clatterbridge coming to us • Seamless – Whiston shuttle bus to St Helens • People choose to go to Christie's because of the location • Transported family member to Clatterbridge – too far • Somewhere nearer is better • Closer better especially after treatment • Although they want specialist care and will travel for quality • Accessibility • Some areas of Knowsley e.g. Newton for access to Whiston Hospital • Also, areas of Warrington have cross areas with Manchester • Transport • Think about car drivers, bus/train users. Limited to access. • Travel is a consideration to patients • Reduce travel for local people • Not sure making patients travel further is right • Transport • Clatterbridge is difficult to get to. Same with Aintree. • Mersey tunnel charges for patients can be high and parking • The bridge is an issue when attending an appointment, especially patients with low income and paying multiple journeys • St Helens patients would have to pay for bridge yet Halton residents would not • Patients and staff wouldn't pay over the bridge if it was based on the Widnes side as they would have a free pass or able to avoid the toll • Some issues from transition from Clatterbridge to local hospitals • Already good building spaces in the Warrington and Halton areas to utilise • Increasing patients (W and H) area being seen in different areas – impact on travel etc for patients

Quality of Treatment
• People want to be re-assured of quality of treatment • People want to be given options of where to go • Re-assurance about Clatterbridge centre as quality service

Accident and Emergency
• Like the idea of the emergency hubs • There are complications with A&E such as infections • Sometimes you can go straight to wards not via A&E • Patients with complications and symptoms don't go to clinic or A&E because of waiting • Will be great to bypass A&E for acute illness

Treatment and Services
• More chemotherapy at home/locally • Current SALT support for head and neck cancer in the community • Current availability of radiography • Phone services to help fill treatment gaps • Need to invest in 3rd sector to bring support services closer and bring more equality across all • Not many patients know what other services are on offer • Mental health is important to consider in the hub • Needs to happen, not all services are currently available in Halton • Location of mammogram van • SLT and dietetics joint working St Helens and Halton • Cancer care centre at Halton Hospital provides excellent care the nurses and specialists and volunteers make what is not a nice experience bearable • Allow more treatment options • Chemo in Halton • Radio in Aintree • Consultant in Warrington • Better to have on MDT than stand along consultant

Patient Experience and Pathway
• Postcode lottery • One patient described how the people dealt with were very good but felt there was no flow to the experience of care • Another patient had a different experience, her treatment was in one hospital in Whiston and it flowed very well • Need to clarify why a patient isn't referred to a single consultant in the model but a team of consultants • Cancer patient's pathway is often down to timing i.e. specialists on holiday leads to missing out on treatment • People perhaps need educating as regards to who they are being seen by i.e. specialist nurses know more than patients realise • Important not to feel isolated if there is a positive or negative diagnosis of cancer. • While awaiting results, support is needed • Information for patients when there are complications • Telephone triage isn't working for clinic appointments regarding patient access • Getting referrals sorted in the first place • Need to look at vulnerable groups and lifestyle in terms of being able to access services/get a GP for referral • Ping pong – seeing different services and people • Around the houses • Will patients have a choice of hub • Continuity

Other
• Why is surgery not part of the proposals? • Is this an add on or a reconfiguration? • Information pack is currently given out • Whiston – whole lot • Clatterbridge picture

What does it mean for you and others?

Within their groups, participants were asked to consider what they thought the case for change meant for them and for others who use and provide services.

Staff
• Nurses need less pressure • Change the perception of an NHS career • Opportunity for recruitment – attractive offer for nurses, specialists etc • To have somewhere with specialist staff if unwell is positive • Better support for staff = increased patient safety • Staff with clinical specialisms = staff confident in skills and patients confident in their care

Travel and Location
• The hub reduces travel for support for cancer patients and their support mechanism • Expenses, time and cost of travel and parking   ○ Treatment and travel every day for patients means extra worry for patients • Not having the right information i.e. either free parking or reduced, patient not knowing this • Care closer to home e.g. not needing to travel to the Wirral • The idea of going to hospital and having several treatments in one visit • If all treatments, prescriptions were in one location would be better i.e. not having to go through GP for dressings etc • Keep it local

Treatment and Services
• To streamline the service • Tele-services increased • Could the hub have an outreach system to take services out i.e. mobile chemo units etc for simple chemo treatment • Better inter-department communication • Better IT systems • Non-medical support needs to be detached from an acute site to allow patients not to associate this with their clinical need • No radiotherapy available in the Mid-Mersey area – not equitable • Patients will request a doctor as others will want assurance from a nurse. Will there be access to both and other professionals?

- What is the impact to existing services?
- Ambulatory being localised is a positive
- Patients aren't being signposted to the third sector
- Mental health support needs to be included in the offer
- Hard to know the impact on local services and the handovers yet
- A one stop shop in a hub to see all clinical teams would be a benefit
- Prevention needs to be part of the strategy
- It shouldn't impact on initial diagnostic pathway
- Be able to offer additional support i.e. benefits, therapists, psychological support – need reassurance and support
- More joined up care, better MDT approach
- Need to take third sector organisation/support more seriously, commission third sector more

Patient Experience

- Consider services at the GP
    - There is a lot of variation with GPs
    - They act as gatekeepers to care
    - Need clearer standards at GP level
    - Referrals not considered urgent by GP
- Needs to be what is best for patients and our area
- The offers need to be what's right for the person
- Having a point of contract. Having the right information on services and support services including wills, power of attorney etc
- Getting to know the staff and having the same staff in one location is a positive
- Improved patient journey
    - MDT working – improved outcome

Other

- Consistency across the sectors and within the sectors is important
- Distributing complex work from Clatterbridge to the hubs is good
- Cost incurred attending Clatterbridge

What questions do you have?

Participants were asked to record the questions they had relating to the case for change.

Technology and Patient Records
• Can A.I and telecare be introduced to limit travel? • Has there been any technology thoughts regarding how multiple clinicians could be involved in patients' appointments under current model? • Could an algorithm be used to share data that leads to better visits and making visits as efficient as possible? • Sharing of knowledge/specialisms between staff in different trusts? • The foundation needs to be correct as regards to access to patient, GP and medical records etc.

Accident and Emergency
• Is this moving a pressure off A&E to the hub? • How would it work with A&E? • Will we have to recruit more staff?

Appointments and Waiting Times
• When does 62 days start? • Would hubs cut out need for additional appointments? • Timescales and planned implementation – is there a target or a time in mind? Is building work time in the overall plan and the increase in cancer related activity/numbers. Existing facilities to be more effective?

Patient Journey
• Will it save on multiple places/visits/consultants?   ○ Is the hub adding another step in the system? • Will it be disjointed with extra steps? • What are the current patient experiences at the trusts now? • What if patients choose a different hub on centre of treatment and capacity? E.g. Halton patients choosing to go to The Christie or Knowsley patients in Halewood choosing Liverpool hub?

Transport and Location
• Would patients be happy/accepted that they will have to go to a different place? • Non-drivers versus drivers would be very different. Would other options be available e.g. Ambulances and other transport? • Will patient have to travel more? • Expertise on transport

Hub Queries
• Is the model right for this area? • Not clear on what services the hub will provide? • Why doesn't it stay the same? • What would the hub include? • Feel the model is better for consultants than the patient. • What age does the service take in the hub? • Why are children and young people not part of the sector model discussions? • If successful, what will it look like? • Does the plan have the adequate capacity to meet the demand? • Unclear vision told so far following the presentation • Is it selected patients that go to the hub or specialist centre or do patients have a choice?

Treatments and Services
• Support groups/centres need to be part of the solution • Is there always choice to access clinical trials? • Support centres need to be on the referral route in the pathway • Will radiography planning be at the hub? • Quality of care – will it at least maintain quality or improve care? • Aftercare – how are we going to communicate services and cross border working? • What support is available in the community and local?

Staff
• Would having a site with more specialists be better for a holistic approach? • Working together between NHS Trusts • Gaps in the workforce – how will this mitigate within the hub? • What cohort of patients are being affected? Is it clear what staff work in what location? • Where are the CNS's, is it at the local place where the patient attends?

Other
• The document is clear and easy to understand • Are DWP going to be involved in this?

Findings from Exercise 2 – Insight into hub model and its impact

The following sets out the key themes which emerged from the facilitated discussions following a presentation on the proposed hub.

What are the impacts of the Hub and its benefits?

Participants were asked to consider what impact the hub would have on patients. Some common themes were noted from the discussions.

Patient Journey/Pathway
• What's the pathway? • Good triage required • The model could help patients present earlier at primary care • Personalised plan should be in place for all patients anyway • Huge benefit to offer more patients the choice to take part in clinical trials • Confused on how the pathway for planned care will run • Immediate access to MDT – can better plan for patient focussed care depending on patients' priorities • Will it be another layer of triage? • Feels like a triage that is done already

Appointments and Waiting Times

- Get the first appointment quicker is a real benefit
- If it reduces waiting times then great
- Will be nearer to home/easier access
    - 45 mins seems a long time
    - Quality of care is paramount
- Quicker access to treatment
- Much faster diagnosis

Accident and Emergency

- Not having to go to A&E a benefit but needs to be 24 hours 7 days a week
- Feel it is about prevention therefore getting to diagnosis early – still got to get through GP gateway/referral
- Associated health care relieves pressure on A&E departments
- Getting people out of A&E is positive
- Local urgent care not going to A&E

Travel and Location

- Concern that some patients will be displaced/travel further
- Could Clatterbridge provide some support in local hubs for specialist care?
- More opportunity to deliver closer to home
- Patients reduced travel
- Hub feels more homely as it is local
- During cancer treatment having an urgent care to attend other than A&E due to issues with immune suppressants is very beneficial
- Location – seems a gap in Warrington/Halton
    - Need to look at distance and time (45 mins) for each areas and proposed locations
- Public transport needs to be reviewed as part of this
- Travel for patients is the worse timing. This needs to be a main consideration
- Depending where it is located could determine patient flow e.g. would people from Huyton travel to Halton
- Need equality impact assessment including public transport

Other

- Is linking patients to community services too big a promise? Is it realistic for every patient?
- Family members are often fearful of the discharge, can they cope?
- All the services under one roof

- Change – how people react
- Impact on the place of the hub will affect different patients differently
- Improve cancer care massively – one stop shop
- Money needs to be distributed fairly and this needs to be agreed before agreed hub
- Be seen with better timescales
- Positive aspect re ambulatory assessment. However, this may be dependent on where you live
- This needs to be an increase in capacity not a watering down
- There is trust in the local units and need to be protected
- Bit confused on how it will all be resourced
- Are there duplications of the support services to the surgical offer and the 3rd sector?
- How will the support services be reconfigured to serve the hub as well as the local surgical teams?
- Better outcome
- Specialist care – all questions answered within MDT newly diagnosed clinic
- Already have access to trials so why more access to trials when in a hub?
- Is the service going to be spread too thin?
- Will relieve pressure on staff

<u>What facilities do you think it should offer?</u>

Participants were asked to consider what facilities they thought the Hub should/could offer. The following comments were collected.

- Dietician
- The only thing that's not in the current service offer is the dieticians
- Financial information
    - Disability benefits
    - Family bills
    - Mortgage
- Outreach opportunities – hub staff able to travel to support patients
- Patient transport coordinates
- Easy understanding about travel options and support for travel to access services
- Added travel expense
- Parking cost sensitive
- Parking machines not giving change
- Free parking
- Counselling service for family and patient
- Retail outlets make it feel less like a hospital

- Create a better environment
    - Blackpool Hospital has a Teepee by a company called Camerado, it's a chill out areas in a waiting room used by family, staff and patients
- The right clinical resources in one place
- Minimise department, no battle lines
- Pharmacy – refer to pharmacy policy in Lancs
- Hospital only prescriptions- why?
- Specialist services in one place. Hub must have ambulatory services
- IT services must connect to all HCP's that see the patient, including advanced care plans
- Disabled access
- Patient leaflets for all services with the local area
- Ensure all services are wrapped around the hub
- Refreshment facilities – a lot of choice as taste buds change during/after cancer treatment
- Alternative services e.g. wig specialists
- VCA and CVS – broker with community third sector
- Family support services
- Carers services
- Impact on carers needs to be considered, support for psychological impacts needs to be included
- Radiotherapy services
- Community based and community focused, embedded in the community, bring the community and third sector orgs into the hub
- Are there other venues or land that can be used for the hub?
- All hubs need to offer the same services so no postcode lottery
- Non-clinical environment relaxed and user friendly and comfortable, person centred, build relationships and families are supported
- More links to third sector
    - Family
    - Carers
    - Benefits
    - Peer support
    - Psychological support
- Consider housing support within the model and social support
- Secondary prevention e.g. lifestyle to prevent further complications
- Continue every contact counts for all patients including those diagnosed and those given all clear

- Everything that all patients need to form the care plan and holistic needs
- Standards across the two hospitals need to be brought up consistently
- Support to the children of cancer patients
- The right mindset of the team to treat the person not the tumour
- Social prescribing
- Improved access and facilities for emergency care
- Improve what's already there and get the basics right
- Holistic needs of the patient and family outside for their tumour
- Critical support at the beginning
- Specialist supervision for staff in localities
- Specialist training opportunities for staff in all localities
- Expert patients who are happy to talk to others about their experiences
- Psychological support for patients and families
- As many as possible like those at Aintree plus non NHS services e.g. aromatherapy
- Benefit experts
- Social support e.g. benefits, relationships, housing etc
- Patient support groups
- Macmillan
    - Massages
    - Other services
- Like Lilac centre
- Is this doubling up on what's already available elsewhere?
- Considering what's already available to prevent services closing or link with services already there. Link to lifestyle services, maybe services like in Warrington as they are very good
- Holistic needs assessment
- Not costa coffee – reasonable prices for patients

<u>What questions do you have?</u>

Participants were asked if they had any questions related to the impact and benefits of the hub model following the presentation and subsequent discussions. The following comments were noted, with some common themes emerging.

Transport and Location

- Will it be accessible to public transport, particularly for the less able?
- What plans for transport, how do you influence?
- What will determine if radiotherapy is located at the eastern hub, if it isn't will not be equal to Liverpool and Aintree sites?
- Need another map with other hubs and hospitals
- Is the car park free and availability is good, if no who's responsible to provide the support and who is responsible to communicate that information?
- Need clarification of where the other hubs will be and choice offered for patients?
- Why can the hub not be in the middle of the geographical area?
- City region, Steve Rotherum input?
- What % of patients in eastern who need patient transport – impact, cost, times etc?

Staff and Resources

- What will be the cost?
- If there is money to invest would it be better to improve local services?
- Is it the same number or staff with increasing demand how will waiting times be improved?
- Who is funding the new build at the new cancer site at Liverpool and will this impact on the hub if problematic?
- Do we have the funding for this?
- This is not going to be a cost cutting exercise is it?
- Where is the funding coming from or are services just moving?
- Radiotherapy is expensive, who is going to pay for it?
- Will all hubs offer the same facilities, MDT staff etc, how will this impact on DGH local delivery?
- What's the timescale for this and staff recruitment process?
- Are they relying on volunteers to meet and greet at the hub?
    - Involved in discussions and used within the model
- What assurance can you give on having all the necessary resources when implementing?
- An existing provider but in a new place-based service – will they have the local knowledge to hand?
- Have all clinicians been involved and onboard? E.g. GPs and non-cancer specific professionals?
- What resources will be available for information e.g. resource centre?

Other

- How do we measure the impact going forward?
- Will dynamism be built into the new hub, innovation is key re personalised chemo treatment
- Is this the right model?
- Will patients be given treatment choices?
- Will the hub provide a timely advisor for patient finance issues? What is on offer financially in the hub?
- Have service users and volunteers been involved prior to this event?
- Would the hub communicate with other trusts? e.g. IT interoperability?
- How are we going to access the latest clinical trials?
- Will all the hubs have the urgent access rather A&E?
- How can the 7 day be achieved is this realistic?
- Will there be any impact with the proposed new build of Halton Hospital and the initial discussions of Warrington Hospital?
- Are all the other hubs offer the same services?
- Will this definitely go ahead if NHS England and NHSI merge or if there is a change in government?
- Will it work for people on the lowest incomes re where urgent care base is?
- How can the new development be part of this model?
- Flowchart pathways need to be developed
- What's the evidence for the improved access to treatments?
- Won't the waiting time improve with the new hospital?
- Is the hub development the right options or ambulatory services on existing units better?
- Young people transition
- How has the model been defined taking into consideration The Christie flow and volume?
- What is the timescale for starting the hub?
- Inclusive – signage, papers, services
- Where will hub staff be recruited from? Will this leave gaps in specialist service provision in the 'spoke' areas?
- What is going to hubs from Clatterbridge?
- Were patients consulted at Aintree and findings regarding benefits considered here?
- Will systems (patient notes) link together?

Question and Answer Session

In the final stages of the panel event participants were asked if they had any questions they wanted to ask the presenters. The following questions were recorded.

- How will location be decided?
- Understanding the pathways is difficult, how will it work?
- If patients choose not to use the hub how will it be catered for?
- If you do decide that radiography will be at the hub, where will the money come from?
- Could psychological support be available for patients and family members at the hub?
- The referral process is not clear.
- It is unclear where the hub fits into the process, it feels like you are adding an extra layer.
- Make sure transportation and infrastructure is in place wherever the new centre is placed.
- Transport is a major issue. The 45 minutes is presumably the time by car, public transport would take longer as it is not great.
- Why is surgery being excluded from the pathway? Patients who need surgery may feel they are at a disadvantage.
- Has there been consideration to expand a current hub?
- How is technology going to be used and how is it going to be built in?
- Are you taking on recommendations/feedback now, or is it for when we go to Clatterbridge in 2020?
- Diagnosis means physical, mental and financial implications, will financial implications be considered?

2nd Stakeholder Panel Event – October 2018

Introduction

The following report sets out the findings from the second Stakeholder Panel event which was held on the 9th October 2018 at Halton Stadium. The outline of the agenda was as follows:

- Presentation by Dr Sue Burke, CCG Clinical Lead – The Patient Journey and Proposed Benefits
- Facilitated discussion about the current and proposed patient journey
- Presentation by Mark Lammas, Programme Manager – Travel and Transport Process
- Facilitated discussion about travel and transport
- Presentation by Dr Sheena Khanduri, Medical Director – Hub Requirements and Evaluation
- Facilitated discussion and individual exercise to gather feedback and scoring of the evaluation criteria
- Q&A session

The insight from the group discussions have been collated into common themes and the individual scoring exercise has been inputted and analysed to provide an average score across all evaluation criteria.

Attendance at the Event

There were 40 participants at the event made up of the following representation:

- Cancer support group - 9
- Community and voluntary group - 2
- Healthwatch - 10
- Hospital/hospital trust - 7
- Partner organisation – 3
- Service user - 4
- Health and care other – 5

Executive Summary

There were 40 participants in total at the second Stakeholder Panel event held on the 9th October at Halton Stadium. The following sets out the executive summary from the scoring exercise and group discussions on the day. The full set of findings can be found in section 3 of this report.

Current and Proposed Patient Journey

The key themes from the table discussions about the current and proposed patient journey were as follows:

- In terms of presenting the proposed patient journey to others, the participants suggested ensuring all acronyms are spelt out and terminology is explained fully
- Some other suggestions included: including screening and MDT in the patient journey maps
- There appeared to be some confusion as to how surgery fitted into the proposed journey, or how someone who has had surgery links back into other services at the hub
- Participants wanted to know more about how the staffing and recruitment would work for the hub
- As mentioned during the first event, participants were concerned that delays at the GP referral and diagnosis stage can impact on the time it takes to receive care
- It was noted that there was some confusion as to what ambulatory care is, with participants asking for further explanation
- Many described the positives of ambulatory care within the proposed hub
- Mixed understanding was found about the service offer at the hub
- Participants want to see effective communications and sharing of information in and around the hub
- Some requested that clinical trials should be explained more to ensure people can understand what is involved and what are the benefits
- Ensuring the pathway is patient centred was made very clear within the group discussions
- There was slightly more understanding around the support services that could be offered in the hub, compared to the first event, with participants making further suggestions.

Travel and Transport

The key themes from the table discussions about travel and transport to and from the hub were as follows:

- A number of alternatives to standard public transport and use of a car as a form of transport were suggested including: electric vehicles; shuttle buses; volunteer drivers; park and ride and; NHS taxis
- Other suggestions also included avoiding travel by offering virtual consultancy and treatments at home or more locally
- With regard to bus travel, participants suggested appointments should take into account when bus passes are valid e.g. from 9.30am
- Routes, out of hours travel, the number of buses, timings and costs for patient and carer travel were put forward for consideration
- Parking availability, cost of parking, free passes and permits were also put forward for consideration
- One person described how the parking experience can impact on the overall hospital visit experience
- The cost of travel and multiple visits factored highly amongst the participants with many suggesting help should be provided to pay for travel or free travel
- The toll for local bridges was put forward for consideration
- Participants suggested an audit of travel was required once a location had been identified
- Overall travel times were discussed with many questioning the 45 min travel period
- Some participants highlighted that how a patient feels and the stage at which they are at in their treatment, particularly around immunity levels, could impact on their decisions and choice of transport.

Evaluation Criteria and Scoring

The key themes from the table discussions about the evaluation criteria of the hub and an average score for each criterion are as follows:

- All evaluation criterion was considered important by the participants as they all received a score
- Clinical quality was nominated as the most important evaluation criterion for the participants
- People explained that they felt that standards of care should be the same or better to ensure good patient outcomes and to attract the best workforce
- The other criteria were rated quite similarly, with strategic fit being the least important to participants at the event
- Patient access discussions centred on travel, with some feeling there could be inequality amongst those who do and don't drive. Patient vulnerability should be considered
- A variety of suggestions were discussed with regard to facilities and infrastructure including:
    - getting the environment right i.e. offering private spaces, friendly greeting
    - what services were required i.e. radiotherapy, signposting and advice, rehab, x-rays
    - support services i.e. IT support and virtual consultations
- Support services were discussed further with suggestions including: a crèche; lymphoedema services; therapies; on-going support; safe guarding etc
- The locality of support services was considered important
- Discussions captured, suggest the participants were not clear on what was meant by strategic fit which might have impacted on its low scoring
- Radiotherapy, survivorship, easy of accessing services and looking at technology were considered important aspects of future proofing.

Exploring the Name/Term 'Hub'

- The use of the term 'hub' was not rejected by the participants, however, suggestions included having another name to accompany it
- Some suggested using Clatterbridge as it was considered a Centre of Excellence
- Having a name that means something and is recognisable was an overriding consideration for the participants.

Main Findings

The main findings from each of the activities and discussions at the Stakeholder Panel event on the 9th October 2018 are outlined on the following pages.

Findings from Exercise 1 - Current and Proposed Patient Journey

Following a presentation by Dr Sue Burke about the current and proposed patient journey, participants were provided with a copy of the journeys visual representation and asked to provide feedback during their table discussions.

Some participants provided suggestions as to how the current and proposed patient journeys could be better represented visually. These included:

Current Patient Journey

- Include screening and where this would be situated in the current journey
- Include description of where acute trusts fit in
- Include MDT and an explanation as to what this is
- Give examples of rare cancers

Proposed Patient Journey

- Simplify and/or explain terminology e.g. clinical teams, ambulatory urgent care unit and clinical trials

The following information outlines the main discussion topics and the participants' specific comments about a patient's journey. The findings demonstrate the general discussions about the current and proposed approach.

Surgery
• Surgical patients have access to these services already • Common and rare cancers could have surgery? • How is a surgical procedure linked to the hub services?

Staff/Recruitment

- Staff choosing careers for work/life balance re workloads
- Recruitment throughout the North West
- Issue around recruitment of acute oncology
- Concerns about role of Macmillan nurses in the Hub, poor experiences cited
- Team need to be explicit about what staff will be in the hub and opening times
- Quality of nursing care lets the service down; no comparison, no care, no courtesy, no common sense
- Workforce - will this be new people or relocate existing staff

GP

- Wait time to see GP can be a number of weeks before this process can start
- How can GP receptionist link to care navigators to speed up pathway?
- Continuity of care with GP, review is variable. People tell story over and over, how will this change?
- What about having to wait 3-4 weeks to see a GP before 2-week referral. Will the pathway change this? Can patients be referred to on call GP quicker and may speed up access/referral
- No mentions of information or involvement being passed back to GPs

Ambulatory

- Need to be clearer on ambulatory care model
- What does ambulatory urgent care unit mean?
- Not as part of the hub, could this be on both sites?
- Reduce pressure on A&E
- Keep away from infections
- Need more criteria for the ambulatory timings, open times, what staff will be in there?
- Real positive
- Okay if 24/7
- Hub ambulatory should be first point of contact not via A&E
- Will be a god send
- Urgent care response, how big does it need to be?
- A&E big loop hole at the moment
- Warrington hospital has no 'walk in' centre, the nearest is Leigh or Widnes

Hub Specific Comments

- What is the timescale from now to hub being developed?
- The hub focusses on a tiny part of the patient journey
- What does local and hub mean?
- How is the hub going to utilise the workforce?
- Is it a virtual hub?
- Will services be in local diagnostic and Hub?
- Patients may have to tell stories a few times
- Travel concerns
- Like the idea of a multidisciplinary team at the hub
- May get answers to a lot of questions in one place
- Benefits advice in the hub
- Like the idea of bringing everyone together physically

Communications

- How will the hub improve sharing of patient information to ensure appointments are effective and consultant has all test results – cross hospital communication
- How do you know who your consultant is?
- How will you ensure that all NHS areas are working together?
- Will all up to date information be available at the hub, will computer systems be considered?
- Clatterbridge needs to do better PR to raise brand awareness
- Could have one person recommending service but having all information given to a patient all in one meeting is too much for them to take in
- Key worker to guide through pathway and support with patient, the key worker should be there at the diagnosis stage
- Need one clear message on how to contact

Parking

- Parking is important
- Free parking

Clinical Trials

- More equitable access to clinical trials
- Clarity on what is meant by clinical trials
- Education around what are clinical trials
- Private or NHS trials
- Explain benefits and clinical trials

Pathways

- Patient centred
- Patients should be key in this process
- Inequality with pathways in different areas
- Optimised pathway of care
- Personalised treatment plan
- Already happens
- Better clearer awareness of treatment plan
- Referral process to be clarified, lots is consultant specific

Support Services

- Will it be possible to have GP access to information?
- Will all the support services be on board with the hub?
- Important for all patients to be signposted to that individuals' local services?
- Need benefits advice within the hub
- Welfare rights
- Holistic needs assessment is patchy
- Local facilities for lymphedema
- What will the support services be?
- Tap into the third sector a lot more
- Don't duplicate what is already locally happening
- Directory of services

Wrap Around Services

- How will wrap around service be linked between local and sector hub to ensure seamless care?
- Wouldn't it be better to physically locate all wrap around services together?

Clatterbridge Specific Comments

- Confusion about using Clatterbridge as a site and Clatterbridge services
- Isn't Clatterbridge in Liverpool?
- Be mindful of people not choosing local services and go for brand 'Christies and Clatterbridge'
- No clear model from Clatterbridge on cancers

Other

- Therapeutic environment
- Affordable
- Positive
- Patient attending a routine clinic appointment and NSP
- Complex not delivered at local hospital
- All at local hospital
- No change
- Tests at local hospital
- Location of acute oncology
- Needs to be accessible and easy to access and refer to
- Operational side
- Like Walton MDT
- We need sustainability as by 2030 1 in 2 people will be diagnosed with cancer
- Sustainability, demonstrable improvement with centralised care
- East Warrington do fund raising for Christies so choose Manchester
- Biggest concern with patients going to Christies for treatment
- Concerns that different parts of area are further away i.e. South easier to travel to Manchester
- Need to make patient choice clearer
- Rare cancers
- Rare cancers not just treated at Clatterbirdge Hospital
- Invaluable continuity of care is really important
- Palliative care
- No change
- How do they get back into the system?
- What are the timescales to treatment?

Findings from Exercise 2 – Travel and Transport

The following themes demonstrate the discussions that emerged after hearing a presentation from Mark Lammas, Programme Manager at Knowsley CCG, about the approach to travel and transport for the proposed hub. Participants were asked to take into account free transport, car and public transport options and considerations. The comments have been collated by commonly occurring themes.

Alternatives

• Electric bikes
• Electric cars could be an option
• What about free shuttle busses from the town centre?
• Shuttle busses works well already, think about pick up points
  o Could this be across the 4 sites
  o Increase capacity and timetable
  o Show appointment letter to use
• Volunteer drivers works very well
  o Volunteer drivers – can these be used
  o Build relationships
  o Distance can be limited
  o don't rely on volunteers they are complementary
  o Can be affected by criteria
• Park and ride to be explained
• Explore use of NHS paid taxis to get people to the Hub with not transport
• The possibility of a hopper bus services from local hospital
• Need outreach too
  o Virtual consultation would perhaps negate need for any unnecessary travel but contentious! Complementary not instead of
  o Chemo in your own home or more local

Public Transport
• Bus not always a direct route • Out of borough passes don't work • Time of use of pass, cannot use before 9.30am • Bus passes only give free travel from 9.30am

- Cost is high
- Over 45 mins
- Multiple bus journeys
- NWAD/Midlands PTs charges
- Consultation with local bus providers e.g. stops and routes
- Bus services linked to hub services – helps people with restricted mobility
- Out of hours public transport
- Length of time and any change overs
- Waiting time for buses in non-urban areas
- Some bus routes are less frequent or stop after 6pm
- Extra cost if carer comes
- Merseyside bus pass can only be used in the border
- Possibly patients who are frightened or have mobility issues using the bus
- Need to be clear on public transport and clear on every circumstance
- Often you will need more than one of the two buses to get to your destination

Parking

- Availability, struggle now but even worse
- Cost of parking is usually high
- Speak to private company to have free parking
- Parking fees – vary by site
- Parking permits and clarity of availability
- Designated areas
- Will there be a specific hub car park?
- Is there free parking for cancer patients?
- Passes for visitors
- Maybe free parking overall
- Car park is not sufficient at St Helens and Whiston Hospital, not enough spaces
- Parking needs to be considered and measured i.e. cancer versus COPS patients
- Charge through council re land
- The car park experience can dominate the whole hospital visit experience
- Car parking issues – increased capacity needed
- Patients more stressed by car parking cost/capacity than appointment

Cost

- Free travel and transport including parking for patients who have cancer
- Forget bridge cost due to frame of mind and the general cost of the bridge
- Involvement in volunteer sector i.e. transport and drivers
- All barriers act as a deterrent for attending appointments and follow ups
- Cost of family and friends for multiple visits (information on all travel and transport should be given at the start of their cancer journey)
- How much does it cost?
- Multiple visits e.g. radiography
- Are patients aware of subsides/concessions – needs to be made clear
- Bridges and tolls additional cost
- Could people be allocated an amount of money to organise own transport
    - Means testing does already happen
    - Can be difficult if carer on benefits as this doesn't count
- Tunnel fees and bridge fees need to be considered
- The cost of missed appointment versus cost of a taxi

Car Drivers

- A lot more traffic in Whiston since the new Runcorn Bridge
    - This toll will impact
    - Can this be paid or have a concession?
- Directions
- The bridge needs factoring in
    - Fees
    - Could be given passes
    - Used to able to get Mersey travel passes
    - What about the new bridge and the cost

Data

- Where patients come from
- Sites they visit
- Number by what means
- Could an audit be carried out on patients travelling to hospital, cost, enjoyment etc

Travel Times

- What is the average travel time for all services e.g. radiography?
- Timing
- Traffic needs to be considered
    - It doesn't take into account road works or car parking time
- Will there be a hub out of hours to help with travel and parking?
- Consider rush hour and school traffic
- Need to change metric – 45 mins by bus not 45 mins by car
- 45 mins is not an improvement
- Patient transport whole day due to picking other people up
- Need to make sure as much as possible all treatments/services are on the same day/same appointment
- 45 mins is a long time to travel if your acutely unwell
- If someone struggling for 9am appointment – give them a later appointment
- Rush our car travel would increase time but happy with 45 mins journey via car
- Journey times from the preferential area

Patient Considerations

- Consider how people feel after treatment
- Immunity can affect use of transport due to infections
- How much choice would be involved, if somewhere was nearer could they go there instead?
- The number of journeys required will make a difference
- Might not be too much of an issue if people are only going for one appointment
- Think about the person needs i.e. bus pass after 9.30am
- Personalised transport

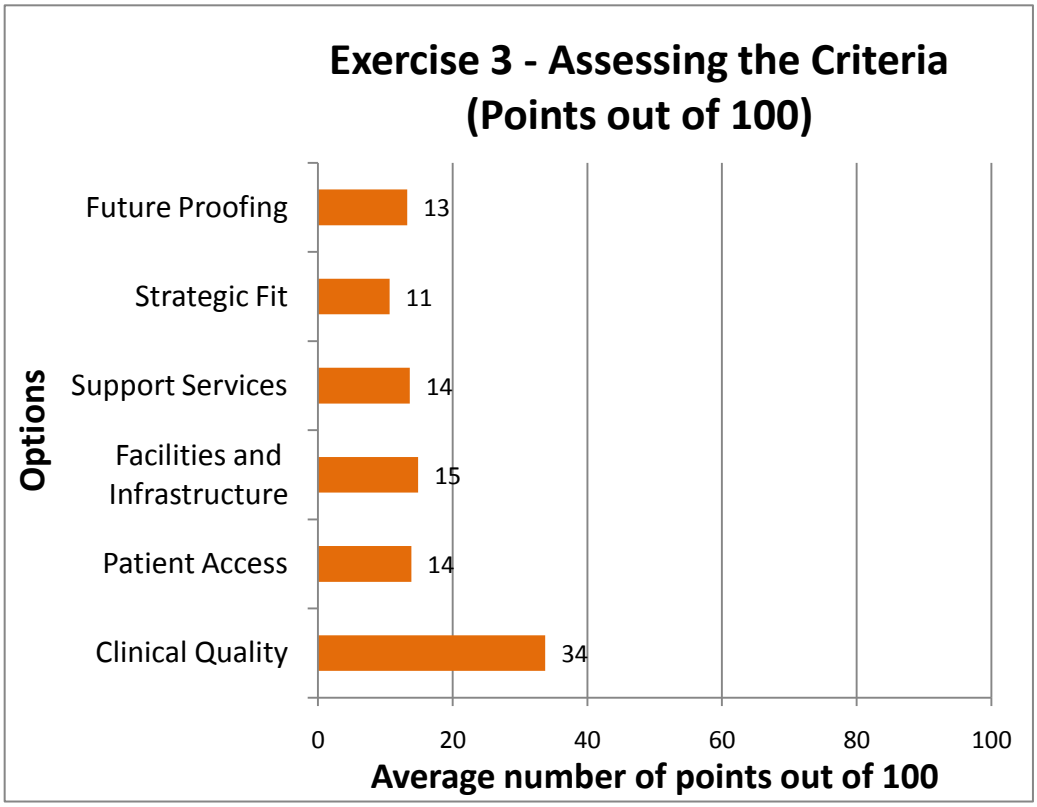
Other

- Some patients get family travel support
- New hub
    - Why does it have to be on existing site?
    - Can it be a new location?
    - Independent of existing sites will be seen as neutral
- Information
    - when appointment is booked
    - Up to date travel information available
- Disabilities – access on the hospital site
- Emergency – will ambulances, PES to the hub and take home or convey to a bedded unit?
- Signage – sign posts on hospital sites for parking and inside for clinic
- Services need centralising
    - Lymphoedema services
- Pot holes on side roads near Whiston
- Technology
- Where in the UK has the travel/transport problem been solved? Need to learn from this
- 2 hot sites Whiston and Warrington have nearby train stations
    - Halton doesn't
- Be mindful of transport services (PTS)
- This needs decision makers to make these journeys themselves
- Impact on service
    - Cancelled appointments

Findings from Exercise 3 – Evaluation Criteria and Scoring

Dr Sheena Khanduri talked at the event about the hub requirements and evaluation criteria. Participants were asked to provide feedback as part of their table discussions. In addition, they were asked to individually score each of the evaluation criteria out of 100 to determine which were considered the most important. The following chart clearly shows that clinical quality was nominated as the most important evaluation criterion for the participants. The other criteria are rated quite similarly, with strategic fit being the least important to participants at the event.

PLEASE NOTE - the total is 101 as there is a rounding error on the averaging of the other scores. If we took each score to two decimal places the total would be 100.



The comments collated provide further insight to participants opinions of the evaluation criteria as follows.

Clinical Quality

- The standards should already be being met
- Communication with treatment units need to be effective
- Same or better
- Keep people out of hospital
- Feedback from clients
- Patient outcomes
- Data can benchmark performance
- Marketing so people know where to go to e.g. journey, hub and urgent care
- 24/7 otherwise people will go to A&E
- Will urgent care be 24/7
- Vital we have the best clinicians available
- Research and innovation can attract more money and academic interest, potential to attract the best workforce
- Clinical quality is the most important as it has the most direct impact on successful treatment
- Improve on 62 days

Patient Access

- Is this a fair target only counting car journeys?
- Are we saying its acceptable for some areas to have worse access?
- Complicated bus journeys, cost of transport and fining a car park space is just as important.
- Delays at clinic can be a lot longer, prompt appointments need to be considered
- Must consider Toll Bridge, Tunnels etc
- Inequality for those who can and can't drive
- How is it different from the current processes, it is not clear?
- Patient vulnerability
    - Effect upon patient mobility and access to transport
    - What facilities and functions would need to be put in place to enable vulnerable individuals to access services given the 45-minute travel time estimate?

- Time of day for appointments versus travel time
    - Will this be taken in to consideration or included in 45-minute travel time?
- How will travel be for a patient who has just been for their treatment
- Free parking – how will this work?
- What will be the opening hours of the hub

Facilities and Infrastructure

- Environment needs to be therapeutic
- Emergency should be separated from planned
- Waiting space
- Human contact
    - Friendly greeting
    - Horrible bar code appointment letters are not welcoming
- Able to get a drink
- Clatterbridge make the best toast
- Information
    - Signposting and advice
- Expect this to be high
- What would a good patient environment look like, how should it be benchmarked?
- Dignity needs to be considered e.g. space and privacy are important
- Without a radiotherapy facility all places in Eastern sector are disadvantaged compared to the other sectors
- Have joined up teams all working together now and in the future
- Virtual consultations and optimising technology
- How may consultants will be involved?
    - Where are they coming from?
    - How will workloads be organised?
- Will there be a receptionist, they are key for information?
- IT requirements
    - Ensure smooth communication
    - Will IT systems be compatible and working with shared care records?
- Are screening services aligned to the hub e.g. breast screening, colonoscopy, cervical, lung x-ray etc?
- Cancer rehab
    - Preventing secondary cancer
    - Smoking cessation

- Weight management/diabetes/physical activity
- Will there be short stay beds?

Support Services

- Links to mainstream therapies
- Most of the support identified is already at the surgical and chemo sites
  - Are these going to be moved to the hub, as I think this would be an extra journey
- If the hub is for the 1st clinic appointment, the support services available should be those appropriate for the appointment
- Macmillan advice services for finance, housing, education etc could be centralised
- Maybe depends on culture of geographical area and patient choice
- Maybe about streamlined access rather than all there
- What happens to external services
- About patient choice and keeping services local
- Having a creche
- Include lymphoedema services
- About people in the hub knowing where to go for extra support at other services
- Already provided in the community, is this repetition of services?
- Consider delivery of services in an environment which is not connected with their clinical treatment
- Duplication of other local services that are not of benefit to the patients who could access more local to themselves
- How to link in with existing services and ensure we don't duplicate
- Back up is vital
- Don't forget after treatment
- Need to be in reach
- Lack of support does impact on psychological wellbeing
- Localised service, social support, living with and beyond cancer
- Need ongoing support
  - Phone numbers for support
  - Right information at the right time
  - Specialist nurses
  - Good signposting
- Lack of understanding about what is already being delivered

    - Shouldn't be duplicated
- Could be a local trust with signposting
- Involvement of family and friends in support services
- Safeguarding involvement in the community
- Patients who need support of family and friends should be taken into consideration e.g. cost, work
- Role of the third sector
    - Faith groups, vulnerable adult safeguarding officers
- Life environmental support around the patient
- Cancer awareness
- Holistic treatment – I want to be treated as a person not a clinical incident
- Not all need to be in the hub if there is good signposting

Strategic Fit

- The chemo treatment sites are currently in different places to A&E and a number of MDT's and surgical sites
- IT integration is a must as well as video conferencing
- Diagnostic model – what diagnostics are needed after the MDT?
    - Is radiotherapy planning going to be part of it?
- Keeping people informed
- Communications with local primary care and services, joining services
- Good IT infrastructure
- Video MDTs are key
- What are the diagnostic needs locally?

Future Proofing

- Radiotherapy has to be part of the long-term plan
- Survivorship
    - Acute cancer patients and who the patient is after treatment
    - Psychological recovery and after treatment
- Able to access services easily
- There is no point realigning services and systems if you are not horizon scanning and future proofing
- Technologies and new hospital sites

Other

- Biggest concern is wrap around services
    - Why duplicate services that are already in place?
    - This wrap around wasn't in the original plan?
- What do they mean by palliative care when it is in place already?
    - In what context do they mean palliative care?
- Shifting place of delivery
- Could there be a better sign posting service?
- Will the walk-in centres have doctor cover?
- Why letters?
    - A digital system that sends physical mail?
    - Where has data come from that informs this need?
- Further away the hub is from your home you are less likely to go back for any complementary services such as massage
- Is the hub just for clinical reconstruction and not for the patient?
- Criteria to be done from a patient perspective
- Consider relatives, carers as these people are all part of life/treatment and recovery or palliative care
- Environment and carbon footprint
- Views of cancer patients current and past
- If staffing wasn't an issue at Clatterbridge what would be best for patients, workforce solution might be the best option.
- Have a patient survey

Exploring the Name/Term 'Hub'

Participants were asked as a whole group about the phrase 'the hub', whether it was the write name/term to be using, whether people would understand what it offers and if it should be connected to a name or location. The group explored this as a whole and were asked to provide feedback. The following responses were collected:

- Hub refers to a centre but it actually isn't
- Centre of something is not the centre of everything
- Call it CLASS – Clatterbridge Local Access Specialist Services
- Cancer Care Centre of Excellence
- Next event put this hub in context with other hubs
- Treated by CCC
    - Name CCC could confuse location
    - Not at where?
    - Should be identified by CCC
    - Local specialist service
- Warrington use term hub for public facilities and NHS
    - Understand the term
- If Aintree, Eastern and others, where is centre of excellence
- Don't use North, South, East and West as it is difficult for people to work out
- Could use something that already exists like 'Lilac Centre'
- Public can expect to be treated by specialists
- CCC at 'name of location'
- If use Clatterbridge in the name people might think they are going to the Clatterbridge area

Question and Answer Session

In the final stages of the panel event participants were asked if they had any questions they wanted to ask the presenters. The following questions were recorded.

- You don't get free transport for all appointments
- At the next event it would be good to know how the hubs fit together and understand how other hubs work and Clatterbridge
- None of the presentations have forwarded information to local GPs, how will communications work with GPs, this should be somewhere in the process?
- Are clinical trials local, regional, national or worldwide?
- Are clinical trials inside or outside NICE guidelines?
- What is the benefit of clinical trials?
    - We need to explain to lay people what the benefit is
- In terms of the location, has it been explored about having it sited independently of the Trusts?
    - Could it be explored?
    - Sometimes we bolt on to what already exists instead of somewhere that might be better e.g. for transport
- Will there be some services that are virtual to the hub, some services are already local, do they have to be all located at the venue?
- Do patients have to go to hospital for all care e.g. Chemo?
- What is Ambulatory care?
    - Most lay people don't understand what ambulatory care is
- What is urgent care?
- Will ambulatory care be 24hr and who will staff it?
- Key is the alignment with A&E services, the ambulatory care services.
- Could we have copies of the flow chart journeys.

3rd Stakeholder Panel Event – December 2018

Introduction

The following report sets out the findings from the third Stakeholder Panel event which was held on the 4th December 2018 at Halton Stadium. The outline of the agenda was as follows:

- Welcome by Dianne Johnson, Senior Responsible Officer for the Transforming Cancer Care Programme / Chief Executive Officer, NHS Knowsley CCG
- Introduction by Louise Bradley, Director, Participate
- Presentation by Dianne Johnson regarding:
    - Process reminder including the national and regional context, the scope of the Eastern Sector Cancer Hub and governance of the programme
    - Overview of the case for change
    - The current and proposed model
    - The benefits of the proposed model
- Facilitated discussions across four tables – experts circulated the groups to discuss the presentation content and answer any queries
- Presentation by Dianne Johnson about the next steps and an update on travel mapping

Insight from the group discussions have been collated into common themes.

Attendance at the Event

There were 23 participants at the event made up of the following representation:

- Cancer support group - 6
- Healthwatch - 4
- Hospital/hospital trust - 4
- Partner organisation – 2
- Service user/Patient Representative - 5
- Other – 2

Executive Summary

There were 23 participants in total at the third Stakeholder Panel event held on the 4th December at Halton Stadium. A summary of the discussions and questions provided by the participants are as follows. A more detailed outline of the discussions and responses from experts can be found in section 3.

- Staff wanted to see a better reflection of current care services and what is happening now within the modelling.
- All wanted to see equal care for all across the four CCG areas.
- People wanted to know whether services will be lost through the new model.
- There was a call for more detail of the evidence base and how the modelling and decisions will be scrutinised.
- Location, transport and travel remain key issues, although there is recognition that quality and equality are important factors.
- Additional suggestions and questions were raised by panel members about the Hub and suggested names of the Hub; see 3.4.
- The participants called for better use of language and terminology within the engagement documents and made suggestions for real case studies.
- People asked for there to be an honest discussion about workforce and whether the plans are aspirational or realistic.
- Many wanted the importance of clinical trials and research to be better explained to patients.
- Participants described how the current treatment of cancer patients attending A&E is fragmented across the localities / boroughs of the Eastern Sector.
- Some people wanted clarification about less common cancers and how they would fit into the Hub model.
- A few people explained how they thought long term cancer patients were not well supported.

- Questions were asked of the experts about the money to support the proposed model and whether they were considering the potential expense for patients' location changes.
- Some people wanted to hear more about the next steps and how patients were being engaged.

Main Findings

Following a presentation by Dianne Johnson, experts visited each table in turn to hear questions and discuss with the participants about the current and proposed model. The experts changed tables after 10 minutes, visiting all four tables during the session. The experts were:

- Dianne Johnson; Senior Responsible Officer for the programme / Chief Executive Officer, Knowsley CCG
- Dr Sue Burke; GP Cancer Clinical Lead, Warrington CCG
- Dr Paul Rose; GP Cancer Clinical Lead, St Helens CCG
- Mark Lammas; Project Manager for the programme / Commissioning Programme Manager, Knowsley CCG

The following sets a summary from the discussions on the day.

<u>Recognising Current Resources</u>

The attendees were keen for current resources and services to be better reflected in the proposed model of care. Across the tables, people felt services and care that are working well were not adequately recognised within the proposed plans. For example, some described how urgent care was already being managed at the Lilac Centre.

"Within the current model and future model some aspects are already covered, like ambulatory care at the Lilac Centre. Is this current model reflective of what is happening now?" Participant

Discussions progressed around equality of care, with many describing how care is not currently equal for all.

"*There is a real inequality for patients that can't use the Lilac Centre for example, we want to make sure everyone has access to a service."* Participant

People also wanted to hear that they were not going to lose services or that care will not be diminished. Others were confused as to whether the Hub would be an extra facility or an add-on to what is already available. The experts explained that care would not be diminished, but that it will actually be boosted.

Evidence Base

A number of people raised the point of wanting to hear what the evidence base is for the proposed Hub model. This included:

- Evidence of best practice elsewhere – other hubs, other areas
- How other Hubs work across the region?
- How can better outcomes be measured and what are they?
- What is the feedback from scrutiny committees?

The experts described how the process is very structured, follows an evidence base, and requires adherence to NHS England regulatory compliance. This evidence base includes the following; National Cancer Strategy, Clatterbridge Cancer Centre Strategic Implementation Plan and an Independent Clinical Senate Review on the proposed model of care. Following this a business case will be reviewed by NHS England before a formal consultation process can commence.

"It is a very rigorous and structured process to set out the model and at the end will be the where [the hub will be located]. It is easy to leap to solutions too early." Expert

Location/Travel/Transport

Quality and equality of care was recognised by the participants as being more important than location on the whole but many described how travel to and from a service, particularly during treatment, could impact negatively on patients.

"It is not distance it is about sitting on a bus for an hour in the condition you are in taking that journey." Participant

Others described that if the location of the hub is further towards Merseyside that it would cause issues for people living in Warrington.

Other discussions centered around knowing whether the Trusts are able to cater for a Hub in their location. People wanted to know if both Trusts could accommodate a Hub currently.

"We have asked the Trusts and their estates can cater for this." Expert

Different types of alternative transport were suggested and the experts explained that investigations were ongoing into travel and transport to and from a variety of locations. They also acknowledged that a range of different methods of transport would need to be considered.

Proposed Hub Model

A range of topics were discussed at the event in relation to the proposed hub, with questions and suggestions provided as follows. These questions will be provided with a response and demonstrated in future FAQ's.

- What will be the major gains to having the hub?
- How would you get a holistic needs assessment?
- Will there be virtual clinics?
- Can Macmillan and Marie Curie support the hub model?
- Could children use the hub?
- Could CVS provide signposting?
- Include additional services e.g. Macmillan benefits advice
- What will be the radiography offer?
- Monitoring of patients through virtual working, helping to avoid attendance at A&E
- How will dialogue between the Hub and the surgical team work?

During the discussions, some people suggested ways in which the model could be better portrayed during the engagement and consultation to help people understand the plans. These included showing all possible pathways to care including using other cancer services across the regions i.e. The Christie in Greater Manchester. In addition, they called for real life case study examples of patient's journeys.

The name of the proposed Hub was considered at the event amongst some participants. Suggestions included:

"Call it 'centre' rather than Hub"

"Look at calling it Clatterbridge with …….. for the name"

Use of terminology and language was highlighted as needing more consideration. For example, people felt the use of the word 'ambulatory' was unfamiliar to members of the public.

Workforce

People asked for there to be an honest discussion about workforce and whether the plans are aspirational or realistic. Some people asked for a clearer indication of opening times and capacity.

The experts explained that there are limited resources across GPs/consultants and that they need to bring them together to support one another and provide a better all-round service.

Clinical Trials

There were some discussions around clinical trials and how people wanted the importance of clinical trials and research to be explained better to patients. The experts acknowledged that patients are saying they want better access to trials.

Urgent Care

Participants described how the current treatment of cancer patients attending A&E is very fragmented across the CCGs. Discussions centered around the need for cancer patients to avoid waiting in A&E.

"We want to avoid [cancer patients going to] A&E that is the Gold Standard". Expert

"If someone feels unwell, they can be assessed at the Hub instead of going to A&E". Expert

Less Common Cancers

Some of the participants asked the experts about less common cancers, what were intermediate cancers and how will they fit into the Hub model.

"Breast cancer is a common cancer and lung is for people living in St Helens. Gynecologic cancer, Melanoma and Pancreatic cancer are intermediary". Expert

The experts explained that the rarer cancers would still be treated by the Clatterbridge teams and that the Hub, although focused on care for common cancers, could help those with more complex cancers. For example, the urgent care service could assess patients and provide care out of the A&E setting.

Long-term Cancer Care

One table discussed how they felt long term cancer patients were not well supported.

"Someone diagnosed 4-5 years ago need to be just a big a priority as those recently diagnosed". Participant

"More people are living with cancer than die from it". Participant

Finances

People asked the experts if there is money to support the proposed model. The experts explained that financial modelling was taking place to understand if more funding is needed but in essence, they were looking to use the same money but in a different way.

Other discussions outlined the need to consider the cost of using the hub for patients e.g. parking and travel costs.

What Next

Prior to hearing the next steps presentation by Dianne Johnson, some people were asking when patients will be consulted and what the next stages are. The experts explained that patients were already being engaged via focus groups across the four CCGs and that another event will take place with the stakeholder panel in January, when patient case studies will be made available. They also explained this first stage in the process was about "*looking at what good looks like and future proofing services within the Eastern Sector".*

Feedback from Service Users and Carers

Focus Groups Overview

Ten focus groups were conducted with cancer care service users or their carers across the four CCG areas, 69 people took part in the discussions overall. The groups were recruited via the stakeholder panel. Participants were sourced through the various support groups and cancer care organisations outlined below.

Grp	Organisation	Description
1	Widnes & Runcorn Cancer Support Centre	Cancer Support Service
2	Lyndale Knowsley Cancer Support Centre	Cancer Support Service
3	St Helens & Knowsley Teaching Hospitals NHS Trust	Cancer Patients
4	LiveWire (arranged by Warrington & Halton Hospitals NHS Foundation Trust)	Community Support Group
5	Sam's Diamonds Charity	Cancer Support Charity
6	Knowsley Carers Centre	Cancer Support Service
7	St Roccos Hospice	Cancer Patients
8	Warrington Disability Partnership	Cancer Patients/Disability Group
9	Halton Carers Centre	Carers Support Group
10	St Helens Carers Centre	Carers Support Group

A discussion guide was developed with the ESCT communications and engagement group. The discussions sought to gather insight into service users' experiences of using cancer care services and their opinions on the case for change and proposed Hub. The groups were an hour to ninety minutes in duration and consisted of semi structured discussions. The facilitator took notes throughout the sessions, a full write up of the notes can be found in the main focus group findings.

Summary of Focus Group Findings

<u>Experiences of Local Cancer Services</u>

- The majority rated their care and treatment as very good, many particularly mentioning the speed of service, care and attention:
    - Some went as far as to say they *'felt like a treasured possession', 'not processed', '[the staff were like] a 2nd family'*
    - Good service was noted in St Helens, Whiston, Lilac Centre, Clatterbridge, The Royal, St Roccos, Warrington, Halton and the Linda Mcartney Centre

- A small number had good experiences of being signposted to support services by their GP or Macmillan, but most felt the signposting was in need of significant improvement. Many saying they found out about support services through word of mouth and searching around:
    - Many experienced additional support services at the centre they were attending
    - Of those who sourced support services elsewhere they were described as life lines
- A number of people mentioned shortfalls in lymphedema provision and/or signposting
- There were mixed views on the level of information and advice provided:
    - Some felt they didn't have enough information
    - Others felt they were bombarded with information *'blunderbuss approach', 'scattergun'*
    - Many agreed it is difficult to take in information at first due to stress, anxiety and lack of understanding, and that you need support to help with this, not everyone had access to support
- Some experienced delays in results and bloods or waiting at planned appointments:
    - People did explain that they didn't want others to be rushed through but felt a more staggered approach should be introduced
    - An example was given of medications/chemotherapy not being ready at appointments and results not being ready for consultant appointments
- Examples were given of shortfalls in follow ups after treatment or having being diagnosed with terminal cancer with no treatment available
- Patients wanted more opportunities to discuss choices with oncologists
- A number of people mentioned wanting access to counselling for patients and families
- As mentioned previously, people with disabilities gave examples of a lack of understanding and empathy around additional conditions or disabilities.

Need for Change to Cancer Care

Consultants

- Overall, people agreed that consultants should be working in teams. However, many thought they already were:
    - A few gave examples of having to wait for consultants to return from holidays
    - Many wanted to see the same consultant and would be prepared to wait a short while to do this
- All want to see consistency of care overall
- Examples were given of time lapses experienced between consultancy appointments, tests and GPs receiving information
- Some described how the language and terminology used by consultants sometimes needs to be better, as well as ensuring patients understand what they have been told.

Appointment Times

- Most did not have a problem with appointments
- Some gave examples of waiting at appointments for long periods, although they understood that this can happen, they felt better planning and scheduling was needed.

Clinical Trials

- Few had experience of clinical trials but all felt patients should have equal access to them. Those who had been on trials wanted better understanding about how it works, benefits, side effects, how randomisation works etc.

Emergency Care

- A&E was not considered to be the right environment for cancer patients
- Many gave examples of having to wait in A&E main waiting areas either because they didn't know about calling beforehand or because there were no other waiting areas available
- People described the current urgent care centres to be excellent

Hub Approach

- Most were very positive about the proposed Hub, particularly the suggestion of an urgent care centre. Many thought it would enable easier access to cancer care,

provide specialist care locally and shorten waiting times. Others said it would provide continuity of care.

- Some felt the Hub proposal would result in another tier of care, *'another place for patients to get lost'*, another walk in centre. There were concerns as to whether it was needed when many were already accessing good care, with some asking *'how will care be improved'.*
- Quite a few people were confused as to what it would actually entail and others were concerned about how it would be staffed and funded.

Service Suggestions

- Signposting to local support services and/or some available at the Hub
- Holistic needs assessments
- Information point for; benefits, Macmillan, medication advice, general advice, pampering, peer support, pain advice, rehab
- Pharmacy on site
- Counselling
- 24-hour urgent care

Environment Suggestions

- Quiet waiting room
- Appropriate seating
- Good signage to find your way around
- Refreshments
- Not a hospital feel
- Adequate and accessible parking

<u>Location and Travel</u>

- 25 to 30 minutes travel time was considered the ideal time for patients, 45 minutes was thought to be possible if there is access to a car and the patient feels well enough to travel
- Public transport was said to be inadequate and possibly unsuitable for patients who are unwell or a risk of infection
- Concerns were also raised about toll costs and access to adequate parking
- Suggestions for alternative travel included; volunteer drivers, shuttle buses, designated drivers etc. Other suggestions centred around cost assistance.

Main Focus Group Findings

The following pages contain the notes from each of the ten focus groups.

GROUP 1
Conducted: 24th October from 3pm
Held at: Widnes and Runcorn Cancer Support Centre
Attendance: 11 attendees (9 patients and 2 carers)

Use of local cancer services

Positive experiences

Individual experiences of care varied but some positive experiences of care were described:

- Care from own GPs and Macmillan immaculate and fantastic
- Speed of service very good
- No fault with NHS treatment
- Rehab physio nurse fabulous
- Excellent service to assess our home for my son following leukaemia. It worked well and was quickly done for him to come home from hospital

Room for improvement

- "Diagnosed with cancer 17 years ago, there wasn't the same support then and I was just given a leaflet but the consultant support was fantastic. I receive treatment every 5 weeks but the pharmacy doesn't seem to get their act together"
    - Example given of going to a planned appointment for treatment but the prescription not being ready to provide the treatment.
    - "I was asked if I wanted to come back tomorrow as the treatment wasn't ready for my appointment"
    - "I wrote a letter of complaint and the head pharmacist said things had gone wrong and that they will improve but it is still happening."
- "If there is a problem, healthcare professionals can fob you off"
- One lady described how she had been diagnosed with breast cancer and after treatment was prescribed with hormone tablets. She described how she had a lot of side effects and was fobbed off by her GP and consultant. She explained how the

oncologist used scare tactics to get her to continue taking the tablets so she kept taking them but was suffering with a variety of uncomfortable symptoms
    - When she asked for another oncologist, she found the experience very different. They explained the options and that she didn't actually need to be taking the tablets
    - She is now left with an array of after effects from the hormone tablets that area causing long term problems
    - She explained how that she wanted to have more discussions with her oncologist and be given informed choices

Areas that need extra support

- One person described how there is a lack of support for children who are cancer patients outside of hospital in the borough
    - "No one called to support us around education or any other support"
    - "There are no groups for children to meet like-minded children on the same journey"
- One couple described how when the wife was given a diagnosis of terminal cancer at Halton Delemere that she was just discharged and no support was provided, they were just left to manage on their own
    - They did go back to their GP and that's when the GP suggested the Widness and Runcorn Cancer Support Centre and Macmillan

Views on the need to change services

Clinics at the Hospital

- 6 of 11 have had an appointment with a consultant at one of the four hospitals
- The group agreed that they don't feel as if consultants are working alone and that they are part of a team
    - "most have specialist nurse led clinics"
    - "why is it an issue if you only have one consultant?"
- Sometimes there is a long time to wait for results "this can be stressful and cause anxiety"
    - One respondent said years ago results were quick but it might be because there are more patients now

- People described there being little or no care after treatment e.g. OT, physio, psychological support, integrative oncology
    - "Need something in this area that brings holistic services together"
    - "Support for after care is not available"
    - "There are support groups but you need to be proactive to find them"
    - "No good signposting"

<u>The challenges now</u>

- Emergency care
    - A few people described how they are supposed to present to A&E as being immune suppressed and that A&E will put them in a separate waiting area. Many explained that this doesn't happen.
    - "A different route into hospital would be better in an emergency"
- Appointment times
    - People described how they saw a consultant before they had their scan "happens regularly in the wrong order"
    - People think the IT systems don't speak to each other
    - "I have been to an appointment and been asked why I am here"
- People explained that they often have to repeat their story
    - "We expect notes to be available to everyone, but are they?"
    - "Sometimes there is no knowledge of my medical history"
- One lady described how she felt the child oncology do seem to be on one system
- Some group members explained that if you go out of the area that they wouldn't expect healthcare staff to have their medical history, some thought they should be able to however

Views on the proposed 'Hub'

<u>The 'Hub' model</u>

- The group described what they thought the hub will provide:
    - Lots of services
    - Everything under one umbrella
    - Short waiting times
    - Good opportunity to get signposting stronger, signposting to approved services, making links

- Ten of 11 people were very positive about the hub, seeing a number of benefits
- One person thought it felt like another walk-in centre and yet another place where patients could be lost in the care system
- In terms of facilities, the group thought it should signpost to services not necessarily have all services under one roof
- They described how there should be a holistic needs assessment
    - "hub would be ideal for this"
    - "I work in psychotherapy and all patients are given a care plan and family assessment but this doesn't happen with cancer"
- One respondent thought clinics should all be nurse led and that this would speed up support
- Concerns centred around accessibility
    - "Would it be 365 days of the year, because it should be?"
    - "Urgent care will be a better idea"
    - "They need adequate parking"
    - "Urgent care needs to be specialised"

Patient Access

- Eight of eleven people would use a car to access treatment and appointments
- All agreed they would avoid public transport due to infections "not feasible for cancer patients"
    - "if no care you are reliant on cabs or friends and it can be difficult and/or expensive"
- Alternatives were discussed such as ambulance drivers, ring fenced transport but some thought that this sometimes takes longer to go from A to B due to numerous drop offs
- All agreed 45 minutes seems a long time for people to travel
    - It was agreed that 25 minutes maximum was enough
- Other considerations described were: the bridge
    - "If you are not well you might forget to pay the toll"
    - "Could they get help with a pass?"
- Concerns were raised about parking and that there seems to be few places to park already on hospital sites
- Some thought parking should be free for patients receiving cancer treatment

Anything else…?

- Some thought there should be an in-house pharmacy at the hubs and that the availability of prescriptions and treatment should be on time, people should not have to wait for meds
- One person suggested the hub should have a quiet waiting room with ambient surroundings “no TV or mobile phones”
- Another person thought there should be appropriate seating and separate rooms or cancer patients
- Another suggestion was to have a contact number for the hub and an educational centre

GROUP 2
Conducted: 25th October from 1.30pm
Held at: Lyndale Knowsley Cancer Support Centre
Attendance: 15 attendees

Use of Local Cancer Services

Positive Experiences

The afternoon's discussion started with positive experiences of using cancer services. The feeling from the group was that they were happy with the fact that they were alive and although there were some positives it was hard to get recent experiences. Comments captured the following types of experiences:

- Some individuals said that the staff and the service they received from Whiston Hospital was really good.
- Many felt that where there was joined up communication things happened fairly quickly.
- Most individuals felt that the services received had improved over the years.
- The group felt that hospital staff were great and good with patients and families on the whole.
- All agreed that the Lyndale Centre was a life line and really helped everyone with a whole range of issues and concerns.
- Many felt that if they had the same GP/Consultant then the treatment process seemed to be smoother.

Room for improvement

- Some individuals said that the diagnosis was not always fully understood by the individual, and one occasion when staff had left a leaflet on palliative care with the individual to read rather than explain in detail.
- The group agreed that staff and consultants listening skills could be improved. On occasion service users have told the consultant something about their condition but it has not been followed through.
- Some participants said that the time frame between information being sent to the GP from the Consultant could be improved.

- Appointment timings and cancellations could be improved, some individuals had appointments cancelled at the last minute and several times.
- Individuals said that signage was not always clear at the hospitals and when you are in a state of stress it can compound the issues.
- Some individuals said that sometimes the language was a barrier to understanding diagnosis or treatment.
- One participant had an experience of wrong advice which meant that her condition worsened, and the consultant laughed when she tried to explain what had happened.
- Many participants said that where there is a choice of hospital that is great, but if they receive treatment from a private hospital, very often there is no transport to take them home and there does not seem to be any follow up.
- Some individuals said that when you call for an appointment, cancer does not seem to be flagged up.
- Some of the group discussed that District Nurses are not all trained in call out services, this causes concern. There was an initiative where so called "Angels" would come to check that everything was okay, but funding is no longer available, some said that this would be a good scheme to reinstate.

<u>Areas that need extra support</u>

- Participants discussed that they thought staff shortages and in particular, secretarial staff, seemed to be the reason for delays to correspondence being received. (However, no exact examples were given).
- Some participants mentioned that they never saw the same nurses and they may have been to the hospital a number of times but still felt they had to go over all of their details and explain their condition, which felt like they were going for the first time again, this was a worry as there were concerns that things could be missed.
- The group all mentioned that phones were an issue as staff never seem to answer the phone in a timely manner and the call goes into a queue, which seems to suggest that there are not enough staff to answer the calls.

Views on the need to change services

Clinics at Hospitals

- Most attendees had only experience of Whiston hospital and Broadgreen so difficult to comment on the other hospitals.
- The group felt that specialist consultants working alone would affect the care and service they received ultimately.

The Challenges Now

- Only one person had taken part in clinical trials and she had not had a positive experience, with nothing followed up properly, she had to see her GP. She would not go through the process again.
- Delayed appointments are covered in the other questions/answers.

Views on the Proposed Hub

The Hub Model

- The group were united in their view that if it meant that they could get their appointments on time then they would welcome a hub.
- Many said that they hoped it would mean that there would be continuity in the service they received.
- The group asked if it would be possible to have an information point at the hub to help with things like benefit information, Macmillan Nurses, medication and also to speak to if they had not had a great experience with their appointment and the information provided. It would be much better to speak to someone at the time they are in the centre.
- Some of the group had negative experiences when a paramedic is called out, they have to wait with the patient to hand over to an A&E doctor before they can leave and this causes a back log with patients in ambulances and hospital corridors, the question was asked if this would still be the case with a Hub?
- The group would like to see more facilities at the Hub, Refreshments, volunteers to help signpost to where patients could access further services.
- The group hoped that the Hub would have teams that could provide a service from start to finish and a Pharmacy.

- They also said that they would like to see counselling services provided at the Hub.
- They would like the Hub to provide shuttle buses.

Patient Access

- Most attendees had either driven to the Focus group or had a lift, not many had used public transport and only one person was collected by organised transport.
- There was concern about the parking and the cost to travel to a Hub.
- The fee for the toll bridge was also of concern.
- Some individuals had been sent home in their nightwear in a Taxi after treatment and hoped that would not be the case at the Hub, as it was undignified.
- The time for an ambulance to arrive caused stress to some attendees, on one occasion the ambulance had been called at 10am but did not arrive until 11pm.
- Some participant had said that they had used the shuttle bus to and from St Helens and it was an excellent service
- Advice was not always clear on long term cancer sufferers and that hospital parking was free.
- There needs to be plenty of disabled spaces in the Hub car park.

Anything Else?

- The Focus Group was a good way to collect information
- Some of the group has experience with DWP not believing that they could not work. There needs to be a better understanding from DWP about cancer and maybe the GP's/Consultants could assist with written confirmation.
- If there is lack of funding will the Hub proceed?

GROUP 3
Conducted: 30th October from 11am
Held at: Whiston Hospital
Attendance: 9 attendees (8 patients and 1 carer)

Use of local cancer services

Positive experiences

- Overall, the group were very positive about St Helens and Whiston Hospitals, particularly about the Lilac Centre.
- "The Lilac Centre and Clatterbridge are very good, if I have any problems I ring the Lilac Centre"
- "Halfway through Chemo I wasn't feeling well and I rang the Lilac Centre, they said come in right away. I felt hugely safe at the Lilac Centre and felt everything was going to be okay. They kept me in for 5-6 hours until I was stable. They also noticed I was in a bad mental place and they suggested how they could help me with that."
- "St Helens is very good, the way they plan your care takes the fear out of it."
- "At the Lilac Centre I felt like a treasured possession."
- The group explained that if they have problems and need to go to A&E that they can phone Clatterbridge and they will make sure your notes are ready on arrival at A&E and you are fast tracked through
- "The process is hugely efficient."
- "It is important that you don't feel that there are gaps you can fall through."
- "The appointments are never rushed you don't feel processed."
- One lady explained how staff start to reassure you as soon as you are walking down the corridor to your appointment."

Room for improvement

- A couple of people explained how you can have a wait to see your consultant if they are holiday or off sick. Although they would have preferred not to wait, they were happy to see the consultant they had been dealing with along the journey.
- Some explained that there can be a wait nowadays for checking of bloods, many explaining that it didn't used to be like that

Areas that need extra support

- One person thought there were some staff shortages and that staff seem to move on a lot

Views on the need to change services

Clinics at the Hospital

- All 9 participants have had an appointment at one of the 4 hospitals mentioned.
- Some people mentioned that on occasions if their consultant is on holiday it can mean them waiting for appointments however, most felt they wanted to wait and see that consultant.
- Others felt there were consultant nurses on hand if you needed any help whilst the consultant oncologist was away
- Some would be happy to see another consultant if they felt reassured that they were up to date on their history and the right message was put across to patients, also that there was consistency
- "I worry about doctors taking calls on holiday and burn out."
- Some agreed that they did need a team working with them

The challenges now

Emergency Care

- Some explained that they wouldn't go to A&E they would go to the Lilac Centre or if they did need to go to A&E they would show their 'chemo alert card' and would be taken straight through or would call Clatterbridge beforehand.
- Most explained that there is a risk of infection at A&E

Appointments

- "I had an instance where my appointment for scans and check-ups with the consultant came through on the days I was on holiday, I called to change but the waiting time was 3 months. I am not sure why."

Views on the proposed 'Hub'

The 'Hub' model

- The group felt their St Helens and Whiston experience of care should be a best practice model and that the environment was also very good in that it did not have a hospital feel
- Not having to go to A&E is good
- Not sure what it is?
- Sounds like a tiered system
- One couple explained that the holistic support as it is now is quite basic and the types of support offered at the hub would be better
- Most felt the Hub would not be of great benefit to them as they have a good experience of services at St Helens and Whiston Hospitals
- Some of the benefits of the hub included holistic support, access to clinical trials, not waiting any longer than 7 days for an appointment and bringing consistency to clinical pathways
- Some thought the emotional support would be good
- Most felt they needed more information on the hub to give an informed opinion and asked to see patient journeys
- Some thought it sounded like actual treatment would not be at the hub but remain local
- One person was worried about how the hub will help the staff and regional teams
- One lady wanted to see support provided for children whose parents were going through cancer treatment as this was not currently available

Patient Access

- All participants would drive or be given a lift to their appointments
- "The last thing you want to do when going through treatment is to get on a bus."
- "You want a painless journey that is well located and spaces to park."
- Some explained that Warrington was terrible to park and get to
- People said they wouldn't go to Warrington due to the parking and traffic issues
- "You are already worked up so you don't want parking hassle."
- Some explained that parking and access at St Helens was a good example for access

- 45 minutes was considered by most to be too long a journey, 30 minutes maximum was thought to be long enough. However, one lady said she would travel longer if necessary.
- "You also need to think about the person who is bringing you, how long is it for them."
- Most thought free or assistance to pay for parking would be good and were not aware of any sort of help for this at the moment

Anything else…?

- "At the moment the clinical pathways are very good, I don't want to see this change."
- Most explained how they felt St Helens and Whiston should be benchmarks for care

GROUP 4
Conducted: 1st November from 1.30pm
Held at: Cancer Survival Support Group at Livewire
Attendance: 10 attendees (8 patients and 2 carers)

Use of local cancer services

Positive experiences

- All agreed that the rehabilitation at Livewire was very good but only a 6-8-week course
- Following the rehab at Livewire, most formed the Cancer Survival Support Group. All agreed this was a very positive experience
- Most agreed that the treatment they received at Halton and Warrington Hospitals was very good "can't fault it"

Room for improvement

- All of the group felt the support following their initial treatment was lacking, most saying other than the rehab that they were not offered any other type of support
- All agreed that they needed something else and hence the formation of the support group
- "There isn't enough aftercare, you are left in limbo." "There are times when you need to speak to someone outside of the family".
- There was no help from the group from Macmillan "couldn't get hold of them".
- One person explained how there were a lot of administrative and communication problems with his treatment. The hospital got his name and address wrong and failed to tell him he couldn't have treatment if he was on Aspirin.
- Poor aftercare was noted by all
- One person explained how they had tried to call Clatterbridge but had no response

Areas that need extra support

- Aftercare
- "They need to signpost to Livewire more"

- One person explained that she felt she needed counselling for herself and her family but none was offered

Views on the need to change services

Clinics at the Hospital

- All 8 had attended Halton or Warrington Hospitals
- All agreed that having one consultant was not good but that they needed consistency
- An example was given of a consultant going on holiday and other consultants left in the lurch
- One person felt the GP should be more cancer specialist trained to help with diagnosis]
- Some described how many years ago there used to be Macmillan nurses at the GPs

The challenges now

- Most said they had never really heard of clinical trials although a few described how they were told after the fact that they had been on a clinical trial
- One person described how they were not told about the after effects of radiotherapy, all felt this should be explained better to patients
- Many described having appointments cancelled

Views on the proposed 'Hub'

The 'Hub' model

- Most were unclear as to what the hub entailed
- One lady thought it was yet another service that would not be around for very long
- One person described it as extended help, somewhere to hear about rehabilitation, availability of local doctors and/or trainee doctors on hand
- Some confusion about Livewire being called a Hub and the proposed Hub
- Suggestions as to what the Hub should provide included a helpline/call centre where patients or carers could call for advice and signposting/delivery of support services
- Some mentioned concerns about travel times
- One person suggested all the leisure facilities like Livewire could have a cancer care hub

Patient Access

- All patients accessed cancer care services by car, most being driven by a family member. One person would get a taxi.
- There were mixed messages regarding the availability of free parking and when it was valid or available
- One lady suggested that you should be able to flag the shuttle bus down when it passes by your home
- Most thought 30 minutes was about the maximum time a patient should travel to services. 45 minutes was not completely out of the question so long as the journey was by car
- The participants want to see treatment all in one place ideally

Anything else…?

- No further comments

GROUP 5
Conducted: 7th November from 7pm
Held at: Sam's Diamonds Charity
Attendance: 4 patients

Use of local cancer services

Positive experiences

- Everything on my doorstop, St Helens down the road. Easy to get back and forth and to have people looking after children but not for long.
- Can't fault St Helens at all
- Treated at Lilac Centre, the nurses were amazing. Less than 10 mins down the road, my husband could drop me off and go back to the children. It enabled us to carry on as normal as you possibly can and demonstrate to the children that everything is normal. Having it on the doorstep took the stress out of it.
- You crave normality for your family and for you. You are trying to protect your family from the stress of it.
- I saw my consultant the same person for 10 years and that continuity was great. I go to the Delemere centre that is local for my complimentary therapies, treatment etc. I don't have any family locally so it really helps. The fact that I can go into hospital, get my bloods done and then go shopping and come back for treatment, means I can keep normality. I do have to go to Clatterbridge for radiotherapy and that is further but that's okay.
- Diagnosis and treatment all good and now have injections at the Lilac Centre which I was worried about but I can't fault it.
- Nurses were brilliant.
- For my second diagnosis I had the same team of people treating me and it felt very comfortable as I knew them already.
- Had reflexology and that was really nice through the Lilac Centre.
- There is a lot more support this time going through cancer then there was 7 years ago and more consideration about living with cancer.

Room for improvement

- Downside, waiting times. You can have an hour waiting.
- For half yearly check-up I never see the same person, the consultant. You get the relationship but you never see them after the surgery.
- This time around the breast care nurse does not how to deal with someone with secondaries. A specialised secondary breast care nurse would be better.

Areas that need extra support

- Need more information and a councillor to help with the emotional side of it. Needed someone to help understand the information to make different choices for treatment.
- Some people however don't want to make decisions and want decisions made for them.
- Continuity of care for everyone – a range of examples of different experiences of good and poor service.
- Depends on the patient as to what support you require.
- How do you find out about lymphedema nurse through the hospital?
- Lack of knowledge about what is out there but actually the Delemere does a range of courses and therapies.
- Secondary cancers don't get as much support as they should.

Views on the need to change services

Clinics at the Hospital

- My consultant had to go on hospital but when I knew I was going to see two other ladies I was okay because I knew they knew my situation. I got the sense that they all knew me and I didn't need the consultant.
- Some feel they have already received the team approach from services they have had.
- It is much nicer seeing the same person because you get to know them, you feel less like a number.

The challenges now

- Clinical trials have been offered but I didn't take it up as I saw it as being test on me
- Mixed thoughts on trials and when they were offered
- You should be offered trials if it is appropriate
- Everybody's journey and circumstances are different. I have the trust in the team to offer me the right options for me.
- There has always been a waiting time. But you can't expect someone to hurry up when they are possibly having a breakdown. You actually don't mind waiting, you kind of expect it.
- Appointment times come through very quickly. Once you are on the treadmill you are off.
- Mixed reviews about visits to A&E and people who are immune suppressed. Whiston A&E facilities for cancer patients was not great, they had been phoned by Clatterbridge and were expecting me but they didn't have a free room for me.
- Others have used the specialist line and sent to the right environment.

Views on the proposed 'Hub'

The 'Hub' model

- If it is the same staff with skills and experience then why can't they deliver it where they are. It is specialist equipment then I would go where the machine is.
- First thoughts are that you will have to travel to Liverpool to get treatment.
- How would the hubs sit in the current system? What will happen to the Lilac Centre?
- I feel like I already have a hub.
- Will the Urgent Care be 24 hours?
- Lack of understanding around what will be in the hub and how it will work.
- Are they taking the services from the Delemere Centre – I can't see them keeping them open.
- I don't think I am missing out on anything now.
- The urgent care sounds good.
- Just need an urgent care 24 hours, independent sign posting services and routine appointment to be better, these are the only things that we would benefit from.

Patient Access/Location

- You should have a choice as to where you travel
- Happy to travel for a specialism and to see different people.
- Location is important to patients.
- It is a big area and the transport system is not great
- It is a worry as to where the hub will be.
- Whatever it is that keeps your life normal you can't do if you have to travel too far.

Anything else…?

- Feel like decisions have already been made and the hub will be happening
- Concerns that not talking to members of the public

GROUP 6
Conducted: 8th November from 10.30am
Held at: Knowsley Carers Centre
Attendance: 2 attendees (carers for patients with cancer)

Use of local cancer services

Positive experiences

- Mum had prostate cancer, nursing care was exceptional and dealt with me as well. They looked after my mum every step of the way
- My friend had a good experience at the Linda McCartney Centre
    - She had a trial which gave her extra time
    - Macmillan were very good and helping her out at home
    - People spoke to her and kept her informed

Room for improvement

- Very poor experience – cancer not picked up early enough even though there were lots of scans and in and out of hospital
    - Finally, she had a PET scan at Liverpool Royal
    - The nurse was very nice and explained more and gave pain relief but then no one else came to see her for 7 days
    - Even social services didn't come when they said they would
    - No follow up after it happened
    - Palliative nurse was very nice
- With my mum the hospital kept saying she was okay but the doctor was saying she is not
    - They put her in rehab for 9 months and she had lots of tests
    - Consultant at Clatterbridge said if she had been brought from Aintree earlier they would have given her treatment not rehab.
    - I was told an old-fashioned examination and not just tests would have shown the cancer

Areas that need extra support

- If there was a hub and someone to turn to or talk to it would have been much better
- No one from Macmillan came to me and the support was needed
- A place to go to find out information
- You need someone to take control, it shouldn't be something you have to look for, it should be offered
- We are looking in to developing a carers passport at Knowsley Carers and we are working with the Trusts. Whereby someone caring carries it with them and it says you are involved in discussions and support for the individual
- It shouldn't be hit and miss when support is offered

Views on the need to change services

Clinics at the Hospital

No appointment with a consultant at one of the four hospitals

- Don't think it matters that consultants are working alone there still seems to be delays
- Local is better
- Depends on the distance to travel

The challenges now

- Waiting is a problem when someone is really not well
- Regarding emergency care – your stress levels are high and A&E is not the right environment
- My friend was not left in A&E, she rang through beforehand and they were waiting when went in, it saved going through everything when at the desk

Views on the proposed 'Hub'

The 'Hub' model

- Good that there will be access to clinical trials
- New therapies should be as near as possible
- Waiting times would be cut down
- Quick appointments when diagnosed

- More information to hand
- More specialist care locally
- Less travel
- Urgent care more specific rather than A&E
- Services it will offer:
    - support services for information to tell you what will happen
    - specialist team for dietary
    - Macmillan's where someone can go and talk to someone – not just physical it is social wellbeing
    - Benefits
    - Voluntary groups
    - Pampering days that you can walk in to make people feel better
    - Designated parking – otherwise it ups the stress levels
- Feels positive
- Feels concentrating on cancer
- More local, won't wait, treatment in 24 days – every day counts

Concerns:

- That they have staff to run it and long-term accessibility of it
- parking

Patient Access

- use a car
- time is a main consideration – mini buses go to Clatterbridge but if last one you can't wait a long time and also big journeys are not conducive to chemo.
- No more than 45 mins travel time
- Maybe there should be a taxi contract
- Have designated drivers who are volunteers

Anything else…?

- Making sure they have teams and money before they build anything
- Good that bringing things more local, having everything in one place
- Carers centre here is very positive
    - Having someone not in the family that you can talk to

- Would expect a link to the hub with the carers centre

GROUP 7
Conducted: 15th November from 1.30
Held at: St Roccos Hospice
Attendance: 4 attendees (patients)

Use of local cancer services

Positive experiences

- Clatterbridge is marvellous
  - They gave me a hospital bed that fits in my bedroom
  - Helped me get equipment from Macmillan
- St Roccos also benefits a lot of people
  - It has been a godsend
  - I have had treatment for 9 years, my oncologists have said a positive mindset has helped
- St Roccos have been able to check on me every week and signpost me to other services
- There is an excellent service at the Royal
  - You have to wait but I have no problem with that
- At St Roccos you can speak to someone other than a family member such as another patient
- There is no Maggie's centre in our area

Room for improvement

- Distance is difficult
- Warrington needs a lymphedema nurse
- I would like to have heard about St Roccos earlier

Areas that need extra support

Views on the need to change services

Clinics at the Hospital

2 people have had an appointment at one of the four hospitals

- Not really aware of consultants working alone
- Aware of MDT teams
- They do work together?

The challenges now

- I wanted to talk to people about clinical trials
- There seems to be lots of trials available
- Mixed views on using A&E
    - Poor experiences at Warrington with pain control and feeling they could be more compassionate

Views on the proposed 'Hub'

The 'Hub' model

- Expect it to provide - Benefits advice, pain control, help with repeat prescriptions
- Minimising stress with cancer
- Sounds like mini Clatterbridge
- One to one, seems more personal
- As I am immune suppressed, I'd rather call in 1st and speak to someone before going into hospital
- Sounds really good – like the idea of going to hub and not A&E, at A&E you are so at risk of infection

Concerns

- Is there money to staff?
- Are they going to able to replicate Clatterbridge on a smaller scale?
- See it as taking a while to set up

Patient Access

- 30 – 45 mins max time to travel
- If you are feeling bad you don't want to travel to far

- Make sure transport is provided

Anything else…?

- St Roccos has a positive feel

GROUP 8
Conducted: 7h January from 1.30pm
Held at: Warrington Disability Partnership
Attendance: 10 attendees (9 patients, 1 carer)

Use of local cancer services

Positive experiences

- Speed of treatment dealt with quickly at Warrington
- Consultation at Liverpool – speed of treatment good
- 90% satisfaction overall
- Excellent service – not kept waiting, no appointments cancelled, pathway fine

Room for improvement

- Have to go outside Warrington for chemo – travelling when feeling unwell is not ideal
- Information provided is not good
    - You can't take it all in at your 1st appointment
    - A Macmillan nurse was present but it is difficult to get hold of them afterwards
    - I wasn't told about practical aspects like parking
- Sometimes there is too much information given in paperwork form
    - Blunderbuss approach to giving out leaflets
        - Lots of duplication
        - Why not given in a digital form?
- Pure chance that I came across a lymphedema nurse, it was not on my pathway as such
- You have to rely on the power of good conversation to find a way through it all
- Whilst having treatment you get seen every day and you don't know what you don't know. Once that stops you are just left – there is no one to check in with you
- Terms used and language used by consultants can be clumsy and inappropriate
- Comms are not very good and technology is not linked up - examples given of the number of letters received. The efficiency and customer services aspect is not good.
- Timings for chemo treatment are not very good, you can be waiting around. Not sure why they don't stagger appointments

Areas that need extra support

- You should be given information at each stage in your pathway
- Power of patient conversation should be tapped into, embraced somehow, perhaps through social media forums
- Should be a check in after treatment e.g. 10 min conversation maybe with peer support
- There is no perception in oncology to treat someone with a disability
    - Example given at maxifacial unit in Fazakerley of the wrong language used, asking about resus and not listening to the patient who has knowledge of their disability and what they can and can't do
    - I was asked if I'd like resuscitating. Is my life worth less than an able-bodied person?
    - There is a lack of understanding and respect and empathy regarding disabilities and patients understanding of their other conditions
- Do feel we have to fight for care sometimes e.g. aftercare and psychological support
    - Some examples given from attendees of receiving psychological support but others hadn't
- We need to know where cancer charities are

Views on the need to change services

Clinics at the Hospital

- They need to work more as a team
- There is a problem with basic record keeping and patient history
    - Referring to a consultant going on holiday and others should know where everything is up to

The challenges now

- No major challenges outlined regarding having one consultant

Views on the proposed 'Hub'

The 'Hub' model

- Seems like a good idea

- Great idea
- Got to be of benefit
- Done elsewhere and didn't work e.g. Charing Cross – would be good to find out why
- What is the evidence base that it would be better?
    - Feel like we are reinventing the wheel
- Doesn't sound any different
- How will the care I receive now be greatly improved?
- Hub should offer psychological support
- Who is employed?
- What is the hierarchy of staff?
- Is the model sound?
- It needs to offer peer support and social connections
- The group like the idea that the hub could signpost to cancer charities and other support
- We should have access to a specialist nurse at the point of need

Patient Access

- As patients we understand that we need specialist units and that we may need to travel
- Very individual – a disability can have an impact on access
- If on the South side of Warrington, you have to travel through town and use toll bridges
    - There is a cost to this and a time factor
- 45 minimum depends on the mode of transport, if a bus there are many stops
- No one was told about any other form of transport other than a car
- The time of appointment is important
    - Seems to be no consideration for travel distances and personal circumstances

Anything else…?

14th July is disability awareness day – good day to promote consultation with the centre etc.

GROUP 9
Conducted: 11th January from 10am
Held at: Halton Carers
Attendance: 3 attendees (all patients, 2 staff members)

Use of local cancer services

Positive experiences

- Overall the group thought the service was very good
  - No query with any of them
  - No cancelled appointments
  - St Helens and Whiston very good
  - Care once there fantastic, staff amazing went above and beyond
  - Staff like a 2nd family
- Macmillan very good, helped with benefits, insurance, support at home, constantly in touch
- Lots taken out of your hands and helped (which is what I needed)
- Done hope course and course at the Royal 'look good feel better'
- Royal Liverpool amazing
- Now seen straight away if I call up at Whiston
- Very quick service/care from diagnosis to operation and treatment
- Given number by the hospital for Checkamlads, they were brilliant

Room for improvement

- Some problems with A&E. I had a routine blood test but I then felt unwell. Called Clatterbridge and they rang through to A&E so they were expecting me and they knew I had potential leukaemia and my immune system was low. Had to wait in A&E for a long period of time and not in private room. Felt very stressed.
- I had canular problems and I went to Delemere. One lady was very rude and dismissive of my problems.
- Someone doing ultrasound refused to have me in the room – I felt this was because I was gay and with my partner and they were Asian.
- Heard a lot about Macmillan in Halton but never heard from them

- Have bloods done in Halton but I find we don't get the results quickly so I prefer to go to Liverpool

Areas that need extra support

- They should prioritise A&E visits as I was sat in the main room with 100s of others and my immune system was low
- Wanted better from Delemere Centre in Whiston, better follow up
- When I went to the Lilac cancer centre but I felt overwhelmed, I think that is just me as they were brilliant
- Halton Carers referred me to Mind - having someone different to speak to is good
- After having regular reviews for 3-5 years it is scary as to what happens next

Views on the need to change services

Clinics at the Hospital

- Most always felt like there consultant was working within a team
    - There were regular MDTs
    - 4 consultants working together
- One did notice there was no one to get a 2nd opinion
- All prefer team approach

The challenges now

- Trails were considered good but one lady described how they can be randomised
    - This is scary because it can cause more stress as to whether you get on it or not
    - Someone described going on a trial and them losing the biopsy results and that it was a painful procedure

Views on the proposed 'Hub'

The 'Hub' model

- Easier access
- Less waiting times
- Would like people to have the same support and care that I have had
- Would like the hub to offer every cancer service under one roof

Concerns:

- Concerns about scale and whether they would receive care at a personal level
- Never going to please everyone
- Depends on location
- Are we talking about changing inpatients and making all inpatients at Liverpool?
- Where is the funding coming from?

Patient Access

- All used cars
- Depends on cancer treatment as to how long is okay to travel
- 30 mins max – any longer and it causes stress and anxiety
- Concerns that if in a city centre the travel time and cost would be more
- Appointment times can be an issue if need to travel a distance
- Some experience of carers using taxis and it costing a lot of money
- Can be long wait for pick-ups and drop offs
- Cost of transport, parking results in extra pressure

Anything else…?

- Is cannabis oil being considered for treatment?
- How is it going to be funded?

GROUP 10
Conducted: 5th February from 11.30am
Held at: St Helens Carers Centre
Attendance: 1 attendee (despite re-arranging and lots of advertising by the carers centre, only one carer with experience of cancer care services attended the tea and toast carers meeting on the 5th February)

Use of local cancer services

- Used cancer care services 5 years ago
- Experience of delays in diagnosis
- Attendance at A&E at Whiston Hospital
- Consultant seen at St Helens Hospital
- Operation took place at Whiston
- No awareness found of treatment or appointments being connected to Clatterbridge
- Long waiting time for first appointment, this then resulted in a speedy referral for a scan and consultation
- The initial appointment where cancer was diagnosed was described as confusing and difficult to get past the word 'cancer' and listen to anything else
- Check ups now take place every 6 months following an extension from every 3 months
- The nurse specialist was described as *"brilliant, very approachable, you felt you could ring her at any time for advice, no problem getting hold of her"*

<u>Room for improvement</u>

- The respondent described feeling like she wanted a 'time out space' 'somewhere comfortable to go' out of the consultancy room to take in what was said over a cup of tea and then to go back into the room to ask questions or hear more
- When asked about whether the patients' other conditions were taken into account, the respondent said they just seemed to focus on the cancer and could have been more considerate about the other conditions

Views on the need to change services and Hub

- The respondent felt like there consultant was working as a team
- Urgent care was described as much more preferable to attending A&E

Feedback from Professionals

In-depth Interview Overview

Ten in-depth interviews were conducted with front line professionals working in cancer care. Five were from St Helens and Knowsley Teaching Hospital NHS Trust (STHK) and five from Warrington and Halton Hospital NHS Foundation Trust (WHH). The interviewees were recruited via contacts provided by the CCGs communications and engagement leads.

A discussion guide was developed with the ESCT communications and engagement group. The interviews sought to gather insight into:

- Current working practices and their views on what is working well and where there is need for improvement,
- Opinions on the proposed hub,
- Identification of any current blockages,
- Which services they considered to be the most important
- What they thought was the best approach to setting up a cancer hub.

The interviews were approximately 30 minutes in duration and consisted of semi structured discussions. The facilitator took notes throughout the sessions, a full write up of the notes can be found in the main in-depth interview findings.

Summary of In-depth Interview Findings

<u>Overview of the Current Cancer Care Services</u>

- All those interviewed gave a variety of examples of where their Trusts cancer care services were working well
- Professionals working in STHK described the care provided in their geographical area as high quality, with strong pathways and excellent team working
    - The Lilac Centre was particularly highlighted as being a centre of excellence which could be used as best practice examples of cancer care
    - The professionals explained that the ethos and culture of the team working across the trust was very good
- Professionals from WHH also provided a breakdown of services they felt were working well and described the communications across the team as good

  - Areas mentioned as working well included: radiology, Halton Cancer Centre, and a dedicated team of nurse specialists
  - The respondents felt Halton was a vanguard for prevention
  - Many of the WHH professionals spoken to felt having local services for chemotherapy was important to prevent poorly patients from travelling to far for treatment
- The majority of professionals across the two Trusts felt oncology was stretched and described examples of difficulties having lone oncologists and getting them to have a physical presence at MDTs
- Professionals working in WHH described how it was not ideal that patients would go to Whiston for a first appointment. They felt this affected the patient experience and, in some cases, due to the nature of the conditions e.g. difficulties breathing, that travelling further for the first appointment was not suitable for the patient
- The WHH professionals felt there could be more opportunities for clinical trials and better IT systems linking with Clatterbridge.

<u>Opinions on the Proposed Hub</u>

- All professionals interviewed felt the Hub was a good idea and could improve the quality of care. Many described it as follows:
  - Concentrated resources
  - Centre of excellence
  - Streamlining services
  - Multi-disciplinary team across the sector
  - Consolidate and improve
  - Centralising outpatient services
  - Open up more opportunities for clinical trial.
- Many thought it would provide better lines of communications for oncology and some thought it would enable better timing of interventions
- STHK professionals were concerned as to whether the ethos and culture they had developed could be replicated
- Others hoped the Hub would not result in a downgrade of services and more workload but would actually build on current plans and provide a better continuity of care for patients
- A few also noted it could keep more patients out of A&E
- Professionals across the Trusts highlighted distance for patients to travel as a potential issue, with some feeling patients would not be phased by this

- WHH professionals were keen to ensure that the Hub should service patients equally across the sector in relation to travel and care.

Most Important Factor

- Interviewees were asked what they thought was the most important factor in offering the best possible cancer care. The following were the most mentioned:
    - Accessibility
    - Collaborative working/cross pollination of expertise/team working
    - Timely service *"right thing for the patient at the right time"*
    - Centralised location with the least travel
    - The culture and flexibility meaning quick decisions can be made
- Other important factors mentioned by individuals were:
    - Quality of care *"patients should not get worse care due to changes"*
    - Patient centred care
    - Staff resilience
    - Good communications
    - MDT set up
    - Reducing A&E admissions
    - Less cost implications for patients

Potential Blockages

- Many professionals spoken to didn't feel there were any blockages that they could foresee
- Some felt there could be opposition across the Trusts and described the need for collaborative, equal working
- Availability of oncologists, location of the Hub and no cross pollination across surgical and none surgical were mentioned as likely blockages
- Some professionals from WHH also thought the first appointment in St Helens for their patients and no clinical nurse specialist cover could create problems

Best Approach to Setting up a Hub

- The interviewees were asked what they felt was the best approach to setting up a cancer Hub that would work for patients and staff. The most common suggestions were:
    - Collaborative working to develop the Hub including patient involvement
    - Patient centred
    - Learning from best practice as to what is currently working in the sector
    - Avoiding political influence

  - Future proofing/forward thinking – building in robustness

- Other suggestions by individuals included:
  - well trained staff
  - responding to the demands of the local population
  - joined up care with other services
  - flexible oncology
  - financially viable
  - Chemotherapy in one place
- In terms of location, all professionals were keen to see the Hub within their location and at their current Trust site.

Main In-depth Interview Findings
The following pages contain the notes from each of the ten in-depth interviews.

Professional In-Depth Interview 1

Q1. **I'd like an overview feel from you about local non-surgical cancer care services in your area. What do you feel is provided particularly well and where do you feel there is room for improvement?**

In terms of what is provided well, there is high quality care in terms of standards. In order to deliver that there are issues in terms of pressure of services, demand and limited workforce and things are undoubtedly stretched.

I work in St Helens and Knowsley, are pathways are strong, we are regularly compliant with 62 days. Everyone tracking that pathway and making sure the timeline is appropriate, the feedback we get and external monitoring testifies that they are good at that.

Capacity and access and better use of resources and shared use of diagnostics. Working in a bigger environment you to have that protection of a stronger and MDT environment rather than danger of working in isolation.

Q2. **What are your thoughts about the Hub approach and how do you feel it will affect patients?**

As a clinician it makes a huge amount of common sense about the patient group and huge amount of potential improvement for patient pathways. Streamlining pathways and potential to bringing closer to home will have a huge benefit for the patient population. More centralised hub making available for trials and MDT bring things into the future.

Q3. **How do you feel the Hub model could potentially affect you and how you work?**

The way we work will have better lines of communication for oncology. The current model they fly in and fly out and they are stretched particularly due to travel time. A point of access in one location makes it more stable and has huge benefits.

What do you think patients will think? Working in a region where patients travel for care, I don't think patients are phased by travel if they know what they are getting at the end is quality care. They just want to make sure it is the very best. I can't see how it particularly causes a huge problem for them. Advantage potential for a lot more, radiotherapy could be

closer to home, quality of care and likely insurance of consultant continuity of care and better trials where previously trials were poor – will ultimately lead to better cancer survival.

Q4. **From your experience, what are the potential or current blockages to enabling you and your colleagues working closer together to deliver non-surgical cancer services?**

An issue that we currently face is availability of resources, the oncologists being stretched across sites, trying to juggle in different places. A centralised location will help that and streamline services, especially acute oncology.

Q5. **What do you think is the most important factor in offering the best possible cancer care in your area?**

Ensuring quality of care.

Accessibility is critically important and we need to make sure it is a managed pathway but we also need a model that delivers both quality and accessibility.

Q6. **What do you feel is the best approach to setting up a cancer Hub that will work for patients and staff?**

- It needs professionally well-trained able staff
- Patient centred
- Respond to demands of local pop
- Well located

Is there anything else you would like say?

It can't be in isolation, the whole delivery across the whole region in primary secondary and other care needs to be joined up to everything else going on.

That is where it has not gone as well in the past e.g. women's care

Would you like to stay in touch: Yes, would like to stay in touch.

Professional In-Depth Interview 2

Q1. **I'd like an overview feel from you about local non-surgical cancer care services in your area. What do you feel is provided particularly well and where do you feel there is room for improvement?**

We have been extremely fortunate as we have the centre on the same site as the breast cancer centre, I am extremely happy. What we use to have was one oncologist but now we have 3, 1 medical and 2 clinical. We are not in the situation where we only have 1. I can see where this is all coming from as other don't have the same.

In Ormskirk there, breast service is closing and I have seen the other end of the spectrum, I can see the sector wanting to make it more robust.

Q2. **As you are probably aware, the local CCGs are talking to people about developing a Hub for non-surgical cancer care. What are your thoughts about the Hub approach and how do you feel it will affect patients?**

It is probably a good idea because it would concentrate resources in one area. Need to make it in an area where people can access it as people may not be in a state to travel. We were one of the first spokes from Clatterbridge giving chemo on site and that was the reason for it because people can't travel. I wonder if we could have Chemo in one place in the eastern sector but you still have the ability to have a flexible location for oncologist. Oncologist could still do clinics in one place.

I would feel very disappointed if my patients got a worse service, if they get good or better then great but if compromising on standards then that wouldn't be right or fair.

Q3. **How do you feel the Hub model could potentially affect you and how you work?**

Depends where it is. If on a St Helens and Knowsley site then it wouldn't affect me greatly. If elsewhere my concerns would be not just facility and buildings but the ethos of doctors and nurses e.g. at the Lilac centre consultant oncologists can just bob in if there is something we need to check, that flexible approach and will is an ethos, a culture that we have built up in the trust over the years. That is difficult to replicate in a new place.

I only hope that this is not a tick box exercise, people really need to see what goes on in the different sites and what the patient will exactly receive in the service and environment.

I would hope that if this type of service is not provided elsewhere that we could develop the kind of best practice we have here, elsewhere. I would like to think that we could provide this type of service to everyone.

Q4. **From your experience, what are the potential or current blockages to enabling you and your colleagues working closer together to deliver non-surgical cancer services?**

For us none whatsoever, we also have a self-supported follow up programme. Having oncologist on site we can do a virtual MDT, it is an excellent integrated system. We also have the ability to fund raise for our patients. I have a quote from another doctor that says we don't know of any other service that pulls funds together for patients. This is the type of commitment that staff have to patient care.

There are a lot of other things that commissioners don't have to provide that our patients are getting through our other funding e.g. free bra

I can't speak for other places but the feedback I get from patients and doctors from Clatterbridge about our service, they say this is something they don't get elsewhere.

Q5. **What do you think is the most important factor in offering the best possible cancer care in your area?**

- Expertise
- Commitment to the job
- Proximity for patients – not be all and end all
- Making sure the patient is in the centre of this not about ease of service for Clatterbridge and oncologist. What is best from the patient and work from there.

Q6. **What do you feel is the best approach to setting up a cancer Hub that will work for patients and staff?**

Obviously take into account numbers, the site and where you feel it is a feasible option. We have to understand that this day and age finance has to come in, it has to be affordable. Look at what we have got and what is financially viable and make a decision.

I suppose that those who came up with it already know that it is required and having a hub is a better option. I take that as a given.

Needs to be on clinical, medical and not political grounds

Is there anything else you would like say?

- Trials – I hope they take that into consideration
- Forward thinking, following patients up
- Patients are used to their local hospital and if they go somewhere else and don't know the doctor and hospital, they need to see someone they know, even if they travel to the hub, they need someone that is a common factor e.g. their nurse. Someone who is known to them locally at the hub site
- Culture and flexibility and ability to provide above and beyond.
- Interested in hearing back about the work individually.

Professional In-Depth Interview 3

Q1. **I'd like an overview feel from you about local non-surgical cancer care services in your area. What do you feel is provided particularly well and where do you feel there is room for improvement?**

Haematology is slightly different, not much involvement with the cancer centre but some via the Royal. We do liaise closely with oncologist and cancer services and important pathway. The Lilac Centre is a unique centre and shared with haematology and oncology, we feel it is good practice, as it allows shared care and we focus expertise rather than plurality and we feel it is a useful thing and have been praised for this. We liaise about patients on a repeated basis.

Symptoms pathway and origin pathway very good here. We liaise with oncology on this and its closely linked with acute oncology nurses.

Team working is really good across the whole of the Trust. For example, I am not in a clinic at the moment but they know that they can call me and I will go if required. Everyone pulls in the same direction. Team working and doing what is right for the patient and getting things done in a timely fashion.

We do link in with Clatterbridge but it is almost as if we are part of the team.

The Lilac Centre is superb with speciality CNS, extra support and care,

It is almost as if we are working in a hub model already.

Improvements – access to clinical oncology and oncologists is an issue in the region and it is a recurring theme. We have had fantastic support from doctors but you do sense that they are short of numbers and struggle to cover what ideally would be covered. So, we have never had clinical oncology at MDT, though they can dial in or video.

Patients having to travel to the Royal to see clinical oncology or to Clatterbridge raises geography issues for patients.

We don't feed into medical oncology quite so much as we do our own but they do have problems with cross cover of holidays.

Q2. **As you are probably aware, the local CCGs are talking to people about developing a Hub for non-surgical cancer care. What are your thoughts about the Hub approach and how do you feel it will affect patients?**

I think it will be of benefit. Two competing issues, centralisation versus treatment closer to home, both desirable but competing factors. With a hub we can drive up the level of patient care to what we see we are doing here. If you have co-location of nurse specialists, diagnostics etc, all co-located, it is much easier to provide and breed excellence.

We have clinical trials here so access that way as well.

A hub would breed excellence of clinical care. We feel we provide an excellence of care but we feel this could be done elsewhere.

Our trust is looking at how we might work more closely with follow up of patients or distance modelling of chronic diseases – we are being used as an exemplar. We find any patients we do help in Warrington want to have follow up here.

A hub would improve quality of care.

Downside is, will it impact patients having to travel and possibly downgrade other services.

Q3. **How do you feel the Hub model could potentially affect you and how you work?**

My part as haematologist, I don't think that will be impacted. Don't think this will be fully centralised. If we had the hub here the lilac might do more none haematological chemo, will that impact on my patients to get them in? I hope not. Will it involve us to see more Warrington patients, therefore increase workload?

Other part of my role is helping other specialities with diagnosing lymph nodes etc, I don't think it will be affected.

Acute oncology, advanced nurse practice who manages complications of chemo. If we can make that unit bigger and provide more of that and expand, getting more people out of emergency will be better for patients.

Q4. **From your experience, what are the potential or current blockages to enabling you and your colleagues working closer together to deliver non-surgical cancer services?**

Other than whether there is a delay on getting clinical oncology. I don't think we have particular blockages in diagnostics. In my role no major blockages.

You can always have more staff and everywhere is pushed for staff. We have a turnover of temporary nurse specialists. Length of time it takes to train is a challenge.

A bigger centre and therefore more staff and a junior team is a challenge at times. Need to build in robustness and cross experience is beneficial.

Q5. **What do you think is the most important factor in offering the best possible cancer care in your area?**

Offer a timely service that does the right thing for the right patient at the right time.

Getting them on the right pathway. Minimising swapping of pathways.

Teams that work too rigidly on MDT can be a problem, we want decisions made promptly.

For example, we found there were a lot of breeches of patients diagnosed with lymphoma, we found they were changing pathways. We set up a situation whereby when an imaging report identifies lymphoma as a possible diagnosis, we contact those processing the imaging and we give advice of where they can present patients for diagnosis to ensure they get on the best pathway. Saving any breeches. Speeds the whole pathway up. This is the one thing that gets key decision makers to get patients on the right pathway and get them through that pathway as quickly as possible. That is what I think excellence looks like.

Q6. **What do you feel is the best approach to setting up a cancer Hub that will work for patients and staff?**

- Consensus.
- No political fudges.
- There is now a mention of a shared site which makes it look like a political decision to keep both hospitals happy.
- The hub has to be a hub, one thing.

Is there anything else you would like say?

- You want people to be bold and future proof it, and be ambitious e.g. looking at extended number of patients and new treatments etc.
- Thinking about 10/15 years' time not just now, look forward.
- Clinical trials are massive part of looking towards the future, we are well served but not enough trials overall.

Professional In-Depth Interview 4

Q1. **I'd like an overview feel from you about local non-surgical cancer care services in your area. What do you feel is provided particularly well and where do you feel there is room for improvement?**

What really stands out about the services we provide is our chemo unit at the Lilac centre. It is staffed by our own staff and has a really good reputation and won lots of awards. It has continuity with staff, good retention of staff and lots of staff go on to senior roles from it. Continuity with patients very good, we have our own triage line.

We have support service, complimentary therapies, counselling. Patients do a lot for the unit themselves to raise money and get involved. There way of contributing to a service they find is really good.

Our oncologist has been instrumental in the development of oncology services and the lead is very innovative and encourages other too.

Good team of nurse specialists. Instrumental in this.

We have our own hub already, fabulous comms and links. Own links with others to help keep patients out of hospital.

What we provide is excellent.

Improvements - things are getting busier, more patients for chemo, space is a premium. But we have plans in place to increase the space we have. Plans for an acute oncology assessment space and more chemo areas.

Q2. **As you are probably aware, the local CCGs are talking to people about developing a Hub for non-surgical cancer care. What are your thoughts about the Hub approach and how do you feel it will affect patients?**

Having everything under one roof, multiple disciplinary team with a model of a one stop service at diagnosis would enhance the journey for the patients. They have a plan in place and know who their key worker is going to be. To have this across the sector it would improve quality of care and equal care for all.

We see patients who sit on the border geographically, we see great differences in support that patients are getting and what we provide hear is really good and everyone has access to that.

The location of the hub maybe a negative thing, patients may have to travel further, but if they know the care will be there, they will travel. Ends justify the means and if they know the reason they will understand.

Q3. **How do you feel the Hub model could potentially affect you and how you work?**

Just going to build on our plans anyway, certainly for ambulatory model.

As an acute oncology team, we are looking to keep people out of hospital.

Having the hub status, there is a lot financially it will help us as a team to do what we wanted to do anyway.

Q4. **From your experience, what are the potential or current blockages to enabling you and your colleagues working closer together to deliver non-surgical cancer services?**

Not sure there are. Within cancer services we have a really good team and with other teams in the trust we work closely with acute medicine, diagnostics, radiotherapy and we get patients through very quickly.

Q5. **What do you think is the most important factor in offering the best possible cancer care in your area?**

Provide an equitable service for all patients.

That patients have a say in how the services are delivered.

Q6. **What do you feel is the best approach to setting up a cancer Hub that will work for patients and staff?**

Asking patients what they want.

Looking at the service you have already, looking at problems along that way also from patient feedback, performance figs and how you can build on that.

What services, how many clinics, how much chemo for the number of patients coming through.

Is there anything else you would like say?

We work like a hub already, relationships really good, comms good, CNS brilliant, we all put the patients first and work innovatively. Strong oncology team. Very visible on chemo unit and keep patients out of hospital. Have our own ambulatory care unit within chemo unit and on acute unit working in collaboration to stop putting pressures on A&E site.

Professional In-Depth Interview 5

Q1. **I'd like an overview feel from you about local non-surgical cancer care services in your area. What do you feel is provided particularly well and where do you feel there is room for improvement?**

Good things – improvement made in lung cancer diagnostic pathway. Over 3-4 years introduction of pre-MDT meeting which has halved the number of people we discuss in an 1hr meeting with full disciplinary team, therefore each patient gets more time especially complex ones.

- Radiology department is excellent, they have worked hard to shorten the investigations and improved from before. More recruitment too.
- National audits have shown consistent improvement in initial KPIs in cancer patients and significant improvement in surgical section and therefore marker of overall cancer care. Warrington was previously behind but now above national average.
- Halton cancer centre where there is the chemo services and benefits team, councillors etc – a lot of support services required for cancer patients there and very good environment – very good thing there locally
- We have a dedicated team of cancer nurse specialists and always have good feedback

Room for improvement – over last few years there has been struggles with oncological clinical and medical cover and rates of treatment received by our patients. There have been vacancies at Clatterbridge and some plans for cover but that has not always been perfect. MDT coordination has been affected.

There is a low oncology treatment rated in Warrington and Halton and there does seem to be some effect on impact on oncology cover that might be causing that.

Compared to surgical rate the oncology treatment rate is not as good and lower than national average.

We have looked into reasons with Clatterbridge but there are multiple reasons. But in my view, there is low oncology cover which impacts on this. Lack of oncology does adversely affect decision making because of other work gone into MDT so now we are discussing

most complex. During this discussion if there is not an oncologist present it does adversely affect care.

Access to oncology appointment – the patients are not getting a good experience. The plan from Clatterbridge is that the first new patient appointment would be at Whiston but that means longer travel as they used to be at Warrington and Halton for oncology. They are going to a hospital that they don't know. Parking is a problem etc. lot of patients are frail or have poor respiratory – it is not a good patient experience for them. Going all the way to Whiston is adversely affecting patient experience for oncology patients.

As we cover a lot of Cheshire – for them to go to Whiston is a long way.

Q2. **As you are probably aware, the local CCGs are talking to people about developing a Hub for non-surgical cancer care. What are your thoughts about the Hub approach and how do you feel it will affect patients?**

I understand where the requirement comes from but I think the requirement is that there needs to be some front admission of care and recognition of workforce shortage.

I think there is a genuine workforce shortage and therefore the solution would be to concentrate resources. That is where it has come from. If this improves things then it is of benefit. But it needs to serve the population equally.

Right now, it is not equal because of travel and patient experience is poorer.

If there was a hub then the policies and pathways associated with the way of working has to be equal across the patch. If serving the whole of eastern sector. Has the potential to be beneficial.

Q3. **How do you feel the Hub model could potentially affect you and how you work?**

I think it will involve travel for MDT purposes but if its benefits patients and better than getting now and improve outcomes and waiting times, then I wouldn't have a problem.

Q4. **From your experience, what are the potential or current blockages to enabling you and your colleagues working closer together to deliver non-surgical cancer services?**

Before hub model was officially thought about. We had thought about a process. We found barriers that it seemed unequal. It didn't feel collaborative and an unequal movement of services. Any collaborative working has to be exactly that, we felt it wasn't equal.

Q5. **What do you think is the most important factor in offering the best possible cancer care in your area?**

- High prevalence of cancer we should all be addressing that, smoking and deprivation
- Early diagnosis leading to better outcomes
- Prevention strategies
- Halton – is a vanguard for prevention for better living and healthier living
- Accessibility of services by patients
- Wherever a hub is sited it will be far away from someone but it needs to be somewhere where it provides equality in terms of service and accessibility.
- Current hubs in Merseyside and that does impact patients and therefore important to have a hub in the eastern sector.
- Accessibility to oncology services and patient experience toward oncology services

Q6. **What do you feel is the best approach to setting up a cancer Hub that will work for patients and staff?**

- Geography
- Future proofing effectively, able to be working for patients 5-10 years down the line. Right now, for radiotherapy we don't have for anywhere in the Cheshire area.

Is there anything else you would like say?

From my perspective I work for Warrington and Halton and I would like to see the hub sited in Cheshire for accessibility and improving what poor experience our patients are getting and to improve radiotherapy etc.

We do already have a good service at Halton. They should be able to provide additional services at Halton. The unit is under the badge of Clatterbridge already. As a brand it would be expansion of Clatterbridge's own centre and could mould to benefit patients.

I would like eastern centre site based at Halton, I think it would improve the experience of our patients.

Professional In-Depth Interview 6

Q1. **I'd like an overview feel from you about local non-surgical cancer care services in your area. What do you feel is provided particularly well and where do you feel there is room for improvement?**

Really motivated and highly engaged group of people who are keen to develop the services and embrace the national initiatives e.g. timeliness pathways. The clinicians are highly supported by the cancer department, all have good relationships with the team, CCGs and clinicians.

We have a fantastic radiography department in terms of scans and report. Despite recruitment problems.

Pathology is very good and turnaround time is very fast.

Done a lot of work across the departments to ensure it works well.

For molecular tests we have done a lot of work to smooth the pathways with Liverpool and our pathways and have seen much improved turnaround times for our patients.

Plenty of staff here, all of main tumour groups supported with a broad range of clinicians. We have resilience, not staffed by locums. We have cross cover built into job plans.

We have good numbers of nurse specialists to support patients and clinical support workers.

Where we are doing virtual pathways, we have good navigators.

Good staff for MDT prep and structures to enable the team to function efficiently and we have oncology presence with MDTs.

Improvements

Like most places we need much more resilient cross cover when oncologists are away. We need 2 oncologist and 1 medical oncologist – we think the hub will bring us this. Enable us to deliver standards to deliver by peer review.

We are all on a cycle of continued improvement all the time. We are in the middle of modernising the lung cancer pathway across the network. Our service has improved dramatically as a result of that being changed.

Q2. **As you are probably aware, the local CCGs are talking to people about developing a Hub for non-surgical cancer care. What are your thoughts about the Hub approach and how do you feel it will affect patients?**

The hub will help us consolidate and improve on e.g. oncology care that we have started doing already.

We have acute oncology embedded in this Trust for several years. As a result, the Lilac centre functions as an ambulatory care. The opportunity is that the hub would enable us to extend that e.g. 7 days a week.

Also enable us to enhance relationship with acute oncology teams and on call teams.

Consolidate the oncology with patients.

Some patients will come to the Lilac centre but there are some that may come through GP into A&E. There are opportunities for capturing those patients as well more reliably through oncology pathways, if we extended some of the working through the front door. Which enables people to stay out of hospital.

I think it will impact on surgical cancer care in certain circumstances. I think the surgeons will help use it to configure their own services. They are keen to have clarity on this.

It will mean that some patients will travel further from their homes but do they want to receive high quality care within a team where there is fantastic resource and cover or would they prefer care closer to home where outcomes may be different.

Q3. **How do you feel the Hub model could potentially affect you and how you work?**

Things have already changed in a sense that oncology care has already moved from Warrington to Whiston. They now teleconference into MDT. That has had a knock-on effect in terms of lung service it has forced us to look at the nurse support the patient gets. We have had to work out clear pathways and comms strategies between the nursing teams across the two Trusts.

By doing this – we have established that we can accommodate these patients re staff and space. We can't give feedback on patients however as they are not our actual patients. It seems to have worked well**.**

Q4. **From your experience, what are the potential or current blockages to enabling you and your colleagues working closer together to deliver non-surgical cancer services?**

Main blockage – Warrington have been depleted re chest and we have been willing to go over and help them. But the opposition has come completely from Warrington. WHH initially engaged but they may have felt their service was threatened but in practice we would have driven things much earlier and driven innovation across the sites.

Q5. **What do you think is the most important factor in offering the best possible cancer care in your area?**

- Medical staffing levels – need resilience to run services effectively and high quality
- Culture of an organisation – we are a really signed up bunch of lead commissioners and that translates into good outcomes to patients. The interface with other departments is good. Therefore, easy to lead change and innovation
- Physical environment – space e.g. we could have radiotherapy unit on either site and expand building as not land locked

Q6. **What do you feel is the best approach to setting up a cancer Hub that will work for patients and staff?**

Critical decision – lack of decisiveness at the moment is impeding progress. Once a decision is made it will help with a change in attitude and enable people to work collaboratively and help people get on with it.

Is there anything else you would like say?

It may be worth speaking with thoracic surgeons because there plans to reconfigure are happening in parallel. (e.g. Julius Assante-Siaw)

Professional In-Depth Interview 7

Q1. **I'd like an overview feel from you about local non-surgical cancer care services in your area. What do you feel is provided particularly well and where do you feel there is room for improvement?**

When I first came, I thought it was very good and much more personal than I had seen before in Manchester. Very good for the patient. It then got taken off us and having to go to St Helens for first appointment and then to Halton with no consultant cover initially. I thought it really disadvantaged patients. It has helped now a bit with a nurse consultant which has made a difference but could be improved better.

It is brilliant that people can receive chemo care locally.

Better that they can be reviewed while having chemo but not great that they are having to go to St Helens to be seen. They feel that they are under Clatterbridge but never go to Clatterbridge. They are confused that they have to go to St Helens first.

What doesn't work with 1st appointment at St Helens – they don't have CNS, which plays a huge part in patient care. I think they need them at that appointment as the patient often has questions. We are kept informed but it is better to be in there.

Q2. **As you are probably aware, the local CCGs are talking to people about developing a Hub for non-surgical cancer care. What are your thoughts about the Hub approach and how do you feel it will affect patients?**

It is difficult because each area has the same views that our patients are at the front and wherever some patients are going to have to travel and will affect them.

I think it would be beneficial to have a set centre like the Delemere centre but it is not centralised for some patients as Warrington borough is bigger. If in the right area it would be very advantages for staff and patients and cut down on DNA's, improve patient treatments.

Needs to be a lot less wishy washy than it is at the moment.

Q3. **How do you feel the Hub model could potentially affect you and how you work?**

If in the right place it could be very beneficial and streamline our work. If not, it causes a lot more work, causing it harder to keep on top of patients.

We could have more involvement with Clatterbridge staff, more networking, knowing what is available.

Q4. **From your experience, what are the potential or current blockages to enabling you and your colleagues working closer together to deliver non-surgical cancer services?**

First appointments being at St Helens. No actual CNS cover.

Q5. **What do you think is the most important factor in offering the best possible cancer care in your area?**

- Centralised hospital or hub where staff from referring hospitals can link in and go across for appointments.
- Less travelling for patients.
- Less cost implications for patients – unless palliative care they get very little help on this front.
- Cut down on A&E admissions which would be a huge impact.

Q6. **What do you feel is the best approach to setting up a cancer Hub that will work for patients and staff?**

- Patient involvement
- Frontline staff involvement in cancer care
- A&E staff – they can reflect on number of attendances from cancer patients

Is there anything else you would like say?

It is hard because wherever it is impacts on others, they need to look at what they already have in place and plan from there.

Professional In-Depth Interview 8

Q1. **I'd like an overview feel from you about local non-surgical cancer care services in your area. What do you feel is provided particularly well and where do you feel there is room for improvement?**

What works well:

- The oncology treatment is in the Delemere Centre, alongside therapists that do reiki, counselling etc. We see them when they meet oncology at their first appointment.
- There are good communications.
- Good parking here so it is not stressful for the patient.
- Volunteers go around each week, patients get to know them and builds up a rapport.
- Cohesive set up.

Improvement:

Not that I can think of. It runs really well and smoothly, each aspect runs well, have close relationship with oncology.

The surroundings recently updated, all bright and airy.

Q2. **As you are probably aware, the local CCGs are talking to people about developing a Hub for non-surgical cancer care. What are your thoughts about the Hub approach and how do you feel it will affect patients?**

At the moment they have to travel for radiotherapy which can be stressful and tiring. Chemo patients can sometimes end up in A&E. An urgent care/ambulatory care in the hub would be good and nicer for patients. They could nip in and have bloods and urine tests and would streamline the service for them in an environment they know.

Q3. **How do you feel the Hub model could potentially affect you and how you work?**

As a team we work between Warrington and Halton, from my point of view it would be fantastic to have access to patients and for everything to be on site with radiotherapy too. Oncology is a major part of our service. There is loads of space to develop the services that we need.

Q4. **From your experience, what are the potential or current blockages to enabling you and your colleagues working closer together to deliver non-surgical cancer services?**

No blockages.

If the hub was based on a Warrington and Halton site that would be improve things greatly. The first appointment with oncology is very important. If it was on another site it could be a problem. It is nice for them to see a face that they know. If we missed that first oncology appointment it could be a big blow. As a Trust we rate that as a major part and it does really help patients

Q5. **What do you think is the most important factor in offering the best possible cancer care in your area?**

- Accessibility for patients – the less travel the better
- Cohesiveness and good communications between the team – if all on one site we would find that we can speak to people face to face, on the site that would be fantastic (she means if they had radiography on site too)
- Wound problems can be a problem – one of us could see them straight away if radiography was on site
- Radiotherapy not on site but would be good if it was re wound treatments and being able to see them on site.

Q6. **What do you feel is the best approach to setting up a cancer Hub that will work for patients and staff?**

Is there anything else you would like say?

I have seen oncology for a long time. The amount of experience is expanding and we communicate closely, our team is working really well and would be gutted to see that change. Having therapies on site enables us to introduce to patients on site.

Professional In-Depth Interview 9

Q1. **I'd like an overview feel from you about local non-surgical cancer care services in your area. What do you feel is provided particularly well and where do you feel there is room for improvement?**

Works well – nice unit available at Halton, with Macmillan funding, waiting environment for patients, holistic need support and volunteers supporting the patient's journey. A new enthusiastic breast oncologist and those doing radiotherapy. Can treat centre flows very nicely from the patient's perspective it works well. Lots of positive feedback

Improvements:

Having a lone medical oncologist does have an impact on appointment times and then if she is on leave there is no one else to pick up work load. Far from ideal with significant increase demand. Would be ideal if we had increased availability of medical oncologist so working collaboratively would work.

Also, trials – we are keen on these but short on recruiting for trials particularly breast cancer trials locally, we have to send them off to other areas. We need personnel to support.

Q2. **As you are probably aware, the local CCGs are talking to people about developing a Hub for non-surgical cancer care. What are your thoughts about the Hub approach and how do you feel it will affect patients?**

- Working more closely with personnel
- On-site support
- Increased accessibility of services for patients
- Centralise outpatient services, once done the patients see an improvement

Concerns: where sited, would champion own trust but if at St Helens and Knowsley rather than Halton it would have implications on our patients and we would lose them to Christie. Travel would be issue for our patients. Merseyside would be very well served.

Q3. **How do you feel the Hub model could potentially affect you and how you work?**

Having things geographically closer would help with discussions with patients and about patients, open path of communications with other staff. More oncologists to speak to patients. Better Timing of interventions and MDT. At Chester they have joint oncology, and they are present at MDT. To bring that model of care would be great. At times it would be good to talk to them at a pre-MDT with the oncologist. Makes the MDT more efficient.

Q4. **From your experience, what are the potential or current blockages to enabling you and your colleagues working closer together to deliver non-surgical cancer services?**

Availability of single medical oncologist

Limitations of geographical sites of 2 sites, the time lag between we see the patient for results and oncologist sees them. I would love it to tie together, morning oncology clinic and then patient is seen straight away. Reducing appointments for patients and parking etc. would allow breast care nurses to flow and provide patient support for the journey.

Q5. **What do you think is the most important factor in offering the best possible cancer care in your area?**

Centralised location for the service

Planning scans adapted from our side for CT, now available at both radiotherapy units in region but still that is an extra point of travel for the patient. Could that be utilised for our existing scanning facilities.

Multidisciplinary approach – at moment very stretched, we need another breast care nurse.

Metastatic support – we are weak on this and have a significant amount of patients with this disease and don't have specialist support for this

Q6. **What do you feel is the best approach to setting up a cancer Hub that will work for patients and staff?**

See what the patient wants from it, what they think provides a good service for them i.e. parking, journey times, transport support, length of time at hospital, parking certificates, allocated spaces, catering facilities, environment, clinical room, counselling rooms, dressing rooms (at the moment they dress in the consultant room, better to be in clinical environment).

IT infrastructure – systems not efficient and our systems don't link with Clatterbridge. We need to look at this as a whole region. We have big delays if they see a Clatterbridge colleague, it can be 2-3 weeks before we get a paper letter. Clatterbridge have blackberry phones that they dictate on but there must be issues somewhere. This could have significant impact if there are more consultants.

Is there anything else you would like say?

At the moment there are plans to re-build on the Halton site with multi support on the site. We already have a dedicated space with our oncologists in mind that exists, that has a fit to purpose. When I have worked at other trusts I can't see where they are going to put this on their existing land.

Professional In-Depth Interview 10

Q1. **What do you feel is provided particularly well and where do you feel there is room for improvement?**

Positives:

- MDT works well. Oncologists come to MDTs, radiologists dial in, they are not always present but part of MDT.
- Patients are then seen as outpatients for a review
- Treatment takes place at Clatterbridge
- Clinicians and nurse specialists are very approachable, the team work works well.

Negatives:

- Patients can be travelling a long way which patients don't like, if there was one nearer it would be better regarding travel.
- Having staff based locally would be better and streamline MDT
- Oncologists spread across a wide path is difficult and holidays can be a problem.

Q2. **As you are probably aware, the local CCGs are talking to people about developing a Hub for non-surgical cancer care. What are your thoughts about the Hub approach and how do you feel it will affect patients?**

- Great idea
- The river crossing and travel is difficult
- Clatterbridge is inaccessible geographically regarding travel
- Having an Eastern Hub is a good idea

Q3. **How do you feel the Hub model could potentially affect you and how you work?**

- Have support
- Not much cross pollination across surgical and none surgical

- Having oncology nearer would be better and enables back up would be more useful

Q4. **From your experience, what are the potential or current blockages to enabling you and your colleagues working closer together to deliver non-surgical cancer services?**

- Distance and travel
- We went through a stage of difficulty with accessing oncologists and some recruitment issues but we are now on an even keel
- Still would like x2 oncologists each week – job planning has been an issue

Q5. **What do you think is the most important factor in offering the best possible cancer care in your area?**

- MDT set up
- We are lucky in Merseyside re our colorectal and Christie is nearby too
- Local MDT – we have regular input and specialists
- You need the right people in the room at the right time for the discussions
- Need cross pollination of team
- Good supportive team at local hospital
    - Everyone needs to pull in the same direction

Q6. **What do you feel is the best approach to setting up a cancer Hub that will work for patients and staff?**

- Collaborative working and approach – got to go the same way as others and Trusts working closer together
- Joint MDTs
- People specialising in certain things
- Better service overall
- Best service you can for patients and Trusts working together and Clatterbridge providing local support

Is there anything else you would like say?

From a geographical view Halton is probably in the middle – for location of the hub.

Glossary

ESCT	Eastern Sector Cancer Transformation
CCG	Clinical Commissioning Group
STHK	St Helens and Knowsley Teaching Hospital NHS Trust
WHH	Warrington and Halton Hospital NHS Foundation Trust
A&E	Accident and Emergency
LGBT	Lesbian, Gay, Bisexual and Transgender
CNS	Clinical Nurse Specialist
MDT	Multi-Disciplinary Team