

Public Engagement Report: proposal to establish a single centre for liver metastases resection

25th November 2013

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The full results of both surveys are available from the Healthwatch Suffolk office on request.

EXECUTIVE SUMMARY

Background

A joint Cambridgeshire, Norfolk and Suffolk Health Scrutiny Committee has been set up to consider the proposal from NHS England to reconfigure the liver metastases resection service. To inform the discussion of the Joint Committee regarding the impact on service users, Healthwatch Suffolk, Healthwatch Cambridgeshire and Healthwatch Norfolk worked together to carry out a public engagement exercise.

The engagement exercise consisted of two components:

- Questionnaire surveys for hospital inpatients at CUHFT and NNUHFT, and the general public
- Telephone interviews

A total of 159 people responded to the two surveys and six people were interviewed.

Findings

Inpatient Survey

Majority of the 43 respondents attended NNUHFT had their surgery at NNUHFT.

Patients are generally positive about the care that they have received from both CUHFT and NNUHFT:

- All respondents said they had confidence in their doctors
- Most people said they also had confidence in their nurses
- All respondents received a good post-operative surveillance by scans
- All respondents considered the information provided was sufficient
- Majority of people felt they had been treated with dignity and respect
- All respondents said the information they received regarding their treatment was sufficient
- Majority of the respondents had been allocated a key worker

When asked about the potential impact of the proposal to develop a single surgical centre for liver metastases resection service, several themes were identified by the respondents:

- Anxieties pertaining to friend/relative visits
- Anxieties about travel
- Anxieties about unfamiliar environment

General Public Survey

A total of 116 people had taken part in this survey.

There is no clear majority in favour of either CUHFT or NNUHFT to be the single regional centre for liver metastases resection. Indeed nearly one quarter of the people said that they had no preference at all.

‘Specialist centre for your illness’ had been rated as the most important characteristic when choosing a hospital for treatment. Whilst ‘good access by public transport’ was ranked as least important. Analysis of open-ended data had identified a number of themes that are of clear importance to our participants:

- Informed choices
- Accessibility
- Environment

Telephone Interviews

Six people were interviewed, and the following themes were emerged from the discussions:

- Professional centralisation - both for surgeons and for patients
- A sense of loss
- Transport
- Image and choice
- Regional hubs vs national excellence
- Cost effectiveness
- Gains of a centralised service

The responses to the telephone interview were clear and concise in broad support for the centralisation of services as a requirement. However, there was a desire for further considerations being made on the policy responses to the issues / problems stated.

Conclusion

Overall, there was little difference between the patient experience in CUHFT and NNUHFT, although more positive comments were associated with CUHFT.

The public had not expressed a preference in either CUHFT or NNUHFT to be the single regional centre for liver metastases resection.

There was a general acceptance and broad support for service centralisation and development of specialist centres as a requirement. However when asked about the potential impacts, a number of themes were emerged from both the surveys and the telephone interviews.

It will be important for both service commissioners and providers to note the anxieties and potential issues identified by the service users in relation to service centralisation, and respond accordingly. In particular, the findings of this public engagement should be used by NHS England East Anglia Area Team to underpin the development of the engagement and service implementation plans for liver metastases resection service.

1.0 INTRODUCTION

- 1.1 A joint Cambridgeshire, Norfolk and Suffolk Health Scrutiny Committee has been set up to consider the proposal from NHS England to reconfigure the liver metastases resection service.
- 1.2 The Joint Committee had its first meeting on the 25th September 2013 to review clinical evidence. The second meeting on the 29th of November will be focusing on the impact of the proposal on patient and carer experience.
- 1.3 As the independent champions for health and social care, Healthwatch Cambridgeshire, Healthwatch Norfolk and Healthwatch Suffolk have worked collaboratively to collect and analyse the experiences and views of the public in the three counties on the proposed service changes.
- 1.4 This report summarises the findings of the engagement exercise, and aims to inform the discussion of the Joint Scrutiny Committee regarding the impact on service users.

2.0 BACKGROUND

- 2.1 The Improving Outcomes series of guidance (IOG) are produced by the National Institute for Health & Clinical Excellence (NICE). They are a key component of the Cancer Reform Strategy, aiming to improve the outcomes for cancer patients along the whole care pathway from diagnosis to treatment. IOG makes recommendations about how health services should be delivered.
- 2.2 There are 10 published cancer service guidance and they set out how health services should be delivered. The Colorectal IOG was issued in June 2004, and the key recommendations are:
 - People who may have colorectal cancer should be offered rapid referral for endoscopy
 - Endoscopy should be available for diagnosis
 - People should be treated by a multidisciplinary team
 - Colorectal teams treating people with rectal cancer should have special training
 - People who need emergency treatment should be treated by a colorectal cancer team
 - Information and support should be improved
- 2.3 In 2011, the former Anglia Cancer Network and the former Midlands and East Specialised Commissioning Group worked together to take forward the establishment of a single specialist surgical centre for liver metastases. A project steering group was set up to co-ordinate and oversee the implementation of an IOG compliant liver metastases service in the Anglia Cancer Network region.
- 2.4 A service specification for the reconfiguration of surgical services for treatment of colorectal cancer liver metastases was produced by the Anglia

Cancer Network. This was shared with service providers at an Information Event in July 2011.

- 2.5 An external review was commissioned by the National Cancer Action Team to consider the possible models of service provision in the region, particularly the number of surgical centres. The report was published in August 2012 and recommended a single site for colorectal liver metastases resection in East Anglia.
- 2.6 A modified service specification was reissued by the project steering group. Two hospital trusts within the network had expressed an interest in becoming the single centre. They are:
 - Cambridge University Hospitals NHS Foundation Trust (CUHFT)
 - Norfolk and Norwich University Hospitals NHS Foundation Trust (NNUHFT)
- 2.7 An external review panel was set up to assess the proposals received from CUHFT and NNUHFT. A recommendation was made in May 2013 to develop the single surgical site at CUHFT.
- 2.8 As part of the new commissioning infrastructure created by the Health and Social Care Act 2012, NHS England East Anglia Team has the responsibility to commission specialised health services for people in the region including cancer. The recommendation to establish a single centre at CUHFT for liver metastases resection surgery was supported by its executive team in June 2013.
- 2.9 No formal public consultation had been carried out as part of the decision making process. However, there were patient representatives on both the project steering group and the external review panel. Working with Healthwatch Cambridgeshire, Healthwatch Norfolk and Healthwatch Suffolk, NHS England is currently developing an engagement plan, and this will be implemented once a final decision has been made.

3.0 PUBLIC ENGAGEMENT

- 3.1 Healthwatch Cambridgeshire, Healthwatch Norfolk and Healthwatch Suffolk carried out a public engagement exercise on the proposed development of a single liver metastases resection surgical centre in East Anglia. The engagement exercise consisted of two components:
 - Questionnaire surveys
 - Telephone interviews
- 3.2 The objectives were to:
 - Compare the patient experience of those who had liver metastases resection surgery at CUHFT and NNUHFT
 - Assess the impact of establishing one centre for liver metastases resection surgery on patient experience

- 3.3 The engagement exercise took place from 21st October 2013 to 23rd November 2013.
- 3.4 The results of the public engagement exercise will form part of the evidence to be reviewed by the Joint Health Scrutiny Committee on the 29th November 2013.

Surveys

- 3.5 Two different surveys were designed for two groups of participants:
 - Hospital inpatients at CUHFT and NNUHFT
 - General public
- 3.6 The surveys sought to obtain both qualitative (comments on the service proposal) and quantitative data. Participants were asked several types of question including 'rating', 'multiple choice' and 'open response'.
- 3.7 Both surveys were created and uploaded to www.surveymonkey.com, which is an online survey creation service. It allowed Healthwatch Suffolk (lead organisation to analyse the results) to gather responses with one URL by including a link on emails, websites, Twitter and Facebook.
- 3.8 A FREEPOST address was provided. Hard copies of the questionnaire were also made available on request from Healthwatch Suffolk.

Survey 1

- 3.9 There were 15 questions in the first survey, and the purpose was to compare the experience of patients who had liver metastases resection surgery at CUHFT and NNUHFT.
- 3.10 The two hospitals were asked to identify patients under the HRG code C787 (liver secondary with surgery) between the period of April 2012 to June 2013. Due to an oversight, NNUHFT had used a different timeframe (April 2010 to August 2013) to select the participants.
- 3.11 To ensure patient confidentiality, the surveys were sent out directly by CUHFT and NNUHFT with an invitation letter from the three Healthwatch organisations. Please see appendix 1 for details. As a result of the different timeframe, 26 and 61 surveys were sent out by CUHFT and NNUHFT respectively.
- 3.12 The hospitals had also included a cover letter to explain the context. Please see appendix 2 for a copy of the letter from CUHFT.
- 3.13 To encourage participation, a FREEPOST envelope was provided.

Survey 2

- 3.14 This survey was designed to gather the views of the general public on the proposed service reconfiguration by NHS England. It also attempted to find

out what people would consider when choosing a hospital for surgical treatment.

- 3.15 The survey had eight questions. An invitation letter was also developed to accompany the questionnaire. Please see appendix 3 for details.
- 3.16 A range of methods were used by the three Healthwatch organisations to promote and circulate the survey in their respective counties. They included:
 - Emails to Healthwatch members
 - Information in the newsletter
 - Distribution through the voluntary community sector network
 - Collection of public feedback at Healthwatch events and meetings
 - Twitter and Facebook
 - Healthwatch websites

It is estimated that in excess of 4,000 individuals and stakeholder organisations had been reached and given the opportunity to have their say.

Telephone Interviews

- 3.17 Respondents of both surveys were asked if they were available to have a more detailed discussion about the proposed service change. A total of 90 respondents had indicated a willingness to give further opinions.
- 3.18 From the above sample, a sub-sample of 21 was chosen that represented the gender breakdown of the original sample based on a ratio of 2:1 Female:Male respondents. The sample was drawn from across all postcodes given, roughly representing the numerical occurrences of 'Ipswich', 'Cambridge', 'Norwich and others present - such as Colchester, Peterborough and Stevenage.
- 3.19 Due to time constraint, six interviews were arranged and took place on the 23rd November 2013.
- 3.20 All the interviews were of duration ranging from roughly fifteen to twenty minutes in length. There was a standardised topic guide in use, asking questions about:
 - experiences of the service;
 - Opinions on the strengths of the system as it is experienced and understood now
 - opinions on value that could be lost should a shift to a single location be realised
 - What the respondents feel could be the major gains from merging into one centre of care
 - For the general public (and how the general public may view such change)
 - On an individual basis (as experienced by an individual)
 - Any additional points or comments that the respondent would like to add towards the inquiry

4.0 SURVEY FINDINGS - HOSPITAL INPATIENTS

4.1 All percentages reported are proportional to the total number of people that chose to answer each question.

Participants (Question 2 - 4)

4.2 The survey was completed by patients of the NNUHFT (32) and CUHFT (11). As described in section 3.11, 62 and 26 people were invited to take part from NNUHFT and CUHFT respectively. 100% of our participants categorised themselves as a patient. No participants identified themselves as a carer.

4.3 A total of 43 people responded.

4.4 As figure 1 shows, with regard to the age profile of our sample, the largest proportion of our sample belonged to the 60 - 69 (41.86%) age grouping, followed by those who are aged 70+ (39.53%), 50 - 59 (16.28%) and 40 - 49 (2.33%). There were no respondents under the age of 39.

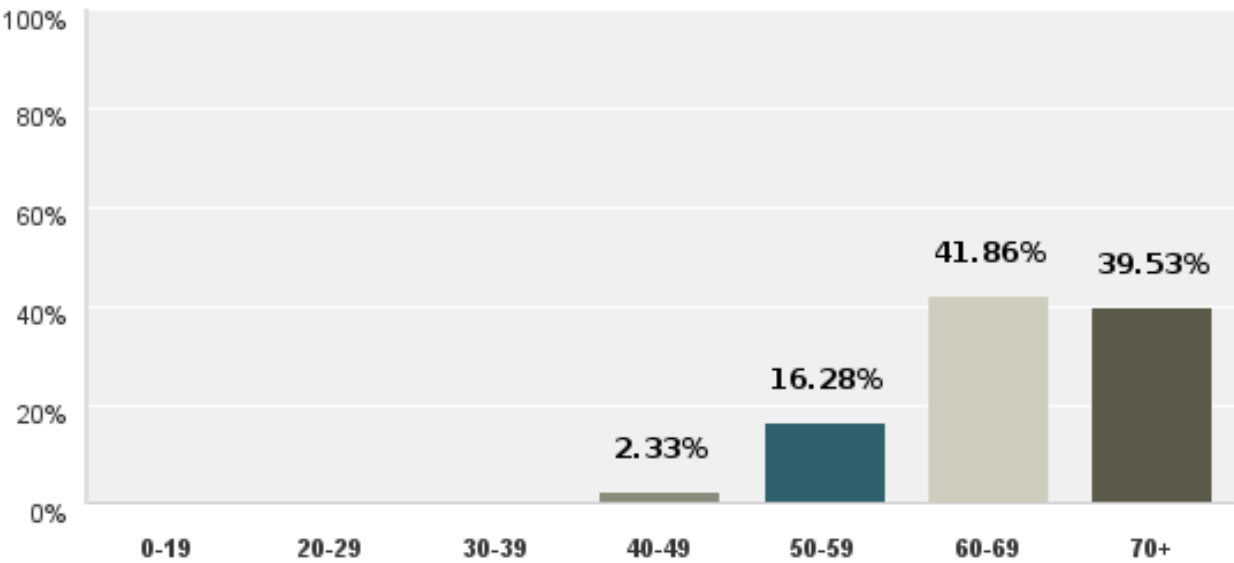


Figure 1: Age profile of our sample.

4.5 There was a roughly even gender ratio with 55.81% of participants attributed to the male category and 44.19% attributed to the female category. As with the survey circulated to the general public, no participants selected the transgender category.

Treatment (Questions 5 - 16)

4.6 As figure 2 shows, a clear majority of participants received their surgery at the NNUHFT (74.42%) with 25.58% attending CUHFT. This is also the case for follow-up care with 73.81% of respondents attending NNUHFT and 26.19% attending CUHFT. This is important as it will mean that the responses to subsequent questions are weighted in favour of the NNUHFT.

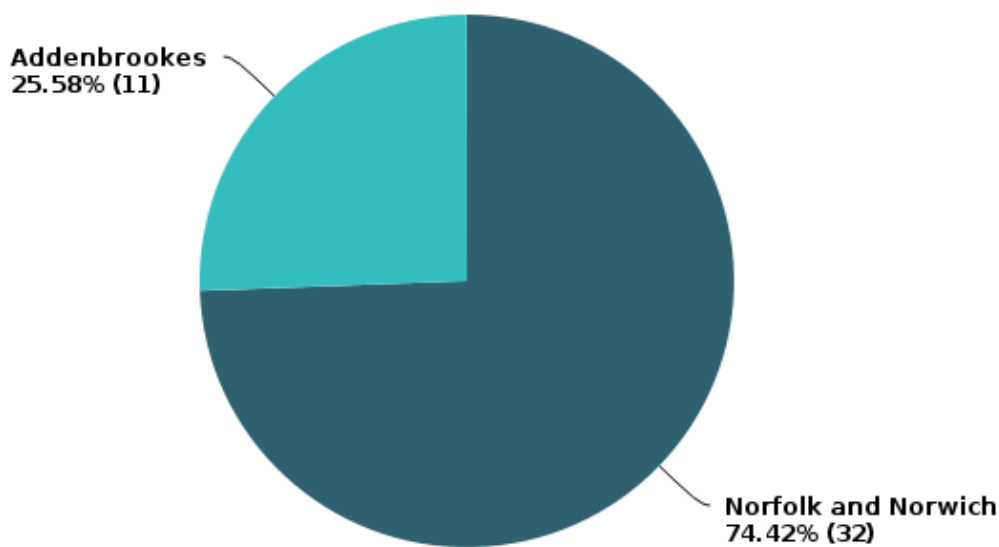


Figure 2: Hospital at which participants were treated for their cancer.

- 4.7 Figure 3 below shows that, when asked about GP referral to treatment, a significant majority of patients said that they were seen by a hospital clinician within ten weeks. 79.31% were seen within five weeks. There were two patients that reported not being seen by a clinician for over 20 weeks although no justification was provided as to why that was the case.
- 4.8 Similar responses were given when asked how long it was before the patients were referred to a specialist centre with 81.25% of respondents seen within five weeks, 12.50% seen between six and ten weeks and two individuals seen after more than 20 weeks.

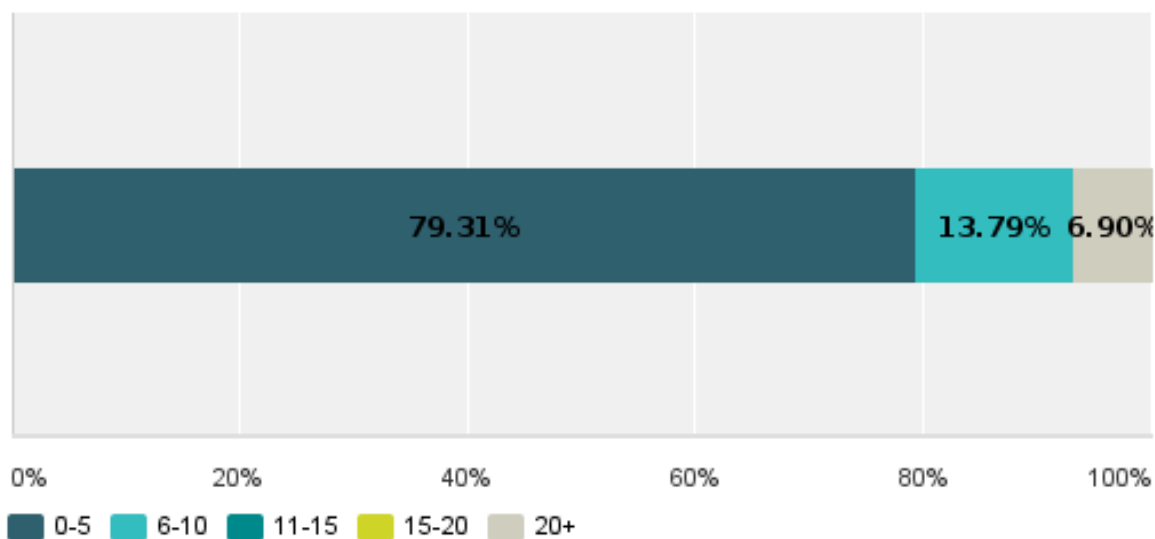


Figure 3: Referral to treatment.

- 4.9 No respondents that had their surgery at CUHFT told us that they had to wait more than ten weeks.
- 4.10 43.09% of 41 respondents told us that they had undergone treatment for their liver cancer prior to their surgery.
- 4.11 We asked if, after the removal of bowel cancer, the patient received a good post-operative surveillance by scans. Of those that responded (32), 100% of respondents said that they did. Interestingly, just 8 out of 41 respondents said that they were offered a choice of hospital for their surgery.

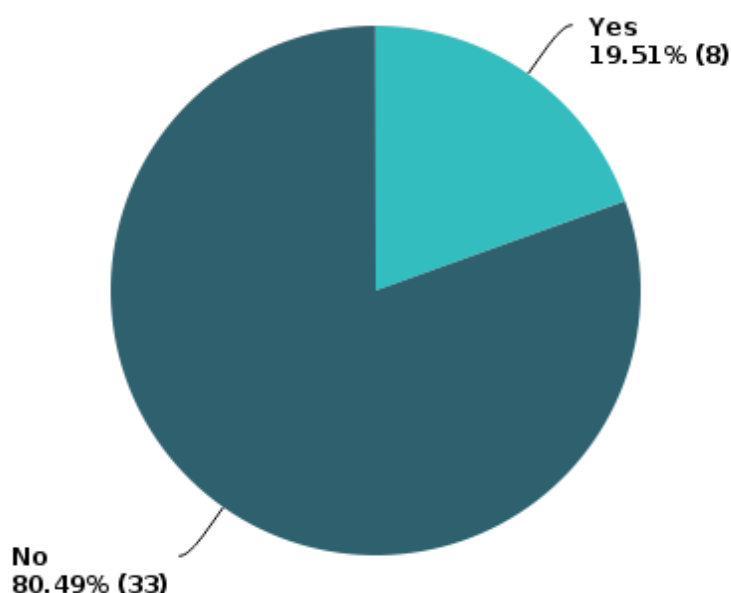


Figure 4: Participants indication of whether they were offered a choice of hospital for their treatment.

- 4.12 97.67% of 43 respondents told us that they were treated with dignity and respect in their treatment. All respondents that received their care at CUHFT told us that they were treated with dignity and respect.
- 4.13 One person, who attended the NNUHFT for treatment answered with no. They summarise several reasons for this choice including apparent lapses in care such as the mismanagement of pain relief, staff bedside manner, nutrition and failures to respond to the requests of patients.
- 4.14 These are all evident within the participant's commentary as follows:
- “...the standard of care dropped dramatically. I arrived on Gissing about 4pm, and just before the evening food arrived. I had not ordered anything, but had been told I could have a soft diet... No-one returned, so I got nothing. This lackadaisical approach to duty proved to be typical.”

“The table over my bed had a faulty catch, and the table kept slipping down onto me. I reported this to the staff for the next two days; nothing was done and on the third day it collapsed heavily onto my operation wound. In considerable pain I pushed it aside and the contents ended up on the floor. Fortunately a junior doctor was passing, and he cleared everything up and got a new table.”

“Later that evening, one of the machines in the ward was bleeping loudly and, as they were trying to sleep, several patients pressed their buzzers. It was over an hour before anyone came to investigate, and (still upset from the earlier incident with the table) I said “about time” -the nurse immediately became rude and aggressive, saying “don’t you talk to me like that”.”

“While I was in HDU, it was found I had become allergic to morphine... oral painkiller was prescribed, but was not effective... one morning at 0730, in desperation I telephoned my husband at home in King’s Lynn. He contacted surgeon in King’s Lynn, and he took the unusual step of contacting the N & N team to sort it out. Eventually, a senior anaesthetist attended and prescribed something stronger- indeed he was with me when my husband arrived at 2pm. During that night however, I again had problems with pain. Because the drug prescribed was a controlled drug, it required 2 nurses on hand to administer, and during the night it seemed to be difficult to get 2 nurses available at the same time. Eventually the pain levels were reduced.”

“A few days later, it was decided I had a leaking bile duct, and that a stent would have to be inserted. The ward staff told me they were preparing me to go to the theatre, but no-one had explained why. I rang my husband who managed to contact one of (name removed) team, and found that someone had belatedly briefed me. By the time I went to the theatre my husband was at the hospital and was able to help comfort me. The procedure caused a lot of pain - no anaesthetic or sedative was used. On return to the ward I was desperate for some pain relief. A nurse immediately set about this, but it took 1 hour to locate my drug chart, so pain relief was delayed yet again.”

- 4.15 100% of 43 participants were in agreement that the information they received regarding their treatment was sufficient.
- 4.16 We asked participants if they were allocated a key worker. 42 people answered the question and 36 (85.71%) of them stated that they were. 33 of 28 respondents answered yes when subsequently asked if they had sufficient access to their key worker. Just one respondent out of 11 respondents from CUHFT told us that they were not allocated a key worker.
- 4.17 When prompted to indicate if the patient had their surgery changed by the hospital, four people out of 42 respondents stated that they had. All four of

the positive respondents were attending NNUHFT for both their surgery and aftercare. One of the participants chose to give further explanation as to the reasoning for their particular change and this is summarised in the below comment.

“The only reason the liver resection was cancelled (or postponed) was because a bed in the HDU did not become available as expected. The resection was carried out a week later. Bowel, liver and oncology departments have been magnificent.”

Clinical staff (Questions 17 - 21)

- 4.18 We asked participants if they had confidence in the doctors treating them and 100% of respondents stated that they did. This positivity was also evident when asked if they had confidence in the nurses that were treating them with 36 (90%) of the respondents stating that they did. Four people answered no, all of which had their treatment at NNUHFT.

- 4.19 Some of the respondents offered further comment by means of explanation:

“...My surgery took place at NNUH as Private patient. However my recuperation experience in Cringleford ward was horrific in terms of nursing care. The nurses themselves were great but under far too much pressure to attend to my needs. "Others are in a far more critical state than you!" Whilst I'm under an NHS oncologist I've NEVER been allocated a clinical nurse specialist”

“I had confidence in most of the nurses that cared for me - but some were not up to standard”

- 4.20 41 out of a total of 42 respondents told us that they received consistent information from the clinical staff involved with their treatment.
- 4.21 We asked respondents to indicate if their privacy was always maintained when their treatment was being discussed. Three people told us that their privacy was not maintained and 38 (92.68%) told us that it was.

Access (Question 21 - 22)

- 4.22 We asked respondents if they had experienced any difficulties when travelling to the hospital for their surgery. Five people skipped the question. Of the 38 that responded in total, 35 (92.11%) people told us that they had not experienced difficulties with travel. Three people answered with yes.
- 4.23 Their reasons are summarised by their comments below.

“Taxi to great Yarmouth rail station (no bus service) train to Norwich station, then bus to NNUHFT. This journey took time and effort.”

“My husband does not drive and I had to be at Norwich hospital by 7am. Thankfully weather was not icy as quite a distance. A member of the family drove me to hospital and another brought me home. If I had to attend further afield I would find this very difficult attending CUHFT.”

Impact on patients (Question 23)

- 4.24 Participants were asked to indicate how the changes might have impacted on them should Liver resection services be moved to a hospital at which they were not being treated. Several themes were immediately evident and these are as follows:

Theme 1: Prohibitive for family/friend visits

- 4.25 There is significant consideration made to how the proposed changes are likely to impact on friends and family members who are seen as an integral part of the patient’s recovery in hospital.

- 4.26 This theme is evidenced in the following example comments:

“This would have made the whole experience extremely difficult. My wife does not drive and reaching CUHFT would not have been easy...”

“I would be concerned that having visitors would be difficult due to the distance involved. Having visitor’s helps in the recovery from the surgery and for the patient’s wellbeing...”

“It would have been a disaster and would have caused additional stress and trauma to me the patient and also my family... Also making visiting more difficult for relatives has an impact on them and causes stress. This would also have a negative impact on the patient”

“Visiting by my husband and family would have been very difficult and therefore infrequent. This would have been bad for my morale...”

Theme 2: Anxieties about travel

- 4.27 There is a particular emphasis on concerns that centralising the services will lead to problems for patients when considering travel arrangements. We are able to group comments into several sub themes as follows:

- Travel: Distance
- Travel: Cost
- Travel: Transport
- Travel: Time

- 4.28 The above themes are evidenced by comments summarised below.

Distance

“Long way to travel and for family to visit”

“...Travelling long distance to hospital when you are seriously ill and would have a huge impact on the patient...”

“Much further to travel as I live in Suffolk”

Cost

“It would have been difficult for travel and also expensive.”

“I am retired on a small pension, the cost of travel and the time involved would be prohibitive...”

Transportation

“If the hospital had been further away from my home it may have been more difficult to attend appointments, as hospital transport has now been suspended in Suffolk to other counties. Criteria has been changed for eligibility...”

“Would have been very difficult (almost impossible) for my husband and 2 young children to visit me. Transport issues.”

Time

“I travel by public transport. A typical journey time between my home and NNUHFT is 1h30. CUHFT is expected to be 3h 20. This increase in travel time would have been very awkward for me when attending appointments, especially when early am or late pm or involving long investigations.”

“...It would have been far more difficult for more to attend appointments etc. As I would have needed much more time off work than was necessary.”

Theme 3: Anxieties about unfamiliar environments

- 4.29 This is a theme that attracted less of a response. However, there were a couple of concerns evident within the rhetoric of our respondent's comments about attending an unfamiliar place or environment for treatment.

“...Would cause anxiety to have to go to another hospital.”

“Longer/more different journey. More stressful as unknown area.”

“...Being in an unfamiliar location would have an adverse effect on patients.”

- 4.30 Participants were asked if there were any other comments that they wished to make about the proposals. Overall, with the exception of some specific cases, respondents appear positive about their care and treatment as summarised by participants in their comments below.

“Exceptional care throughout”

“Since being transferred to the care of the N/N from James Paget - I have been extremely well treated and have found nothing whatsoever to complain about. As far as I am concerned, the team whole care I am under, have been nothing less than exemplary.”

“...The treatment and the aftercare that I received at Norwich hospital was outstanding and couldn't wish for anything better that I was given by all the staff. I also had bowel cancer surgery at the QE hospital in Kings Lynn in July 2010 and also received the same outstanding treatment.”

“Only that CUHFT have a fantastic team dedicated to your survival and care”

- 4.31 Finally, we asked respondents to tell us the likelihood that they would recommend their hospital to a friend or family member.
- 4.32 Most people responded positively to this question with a rating of either “1” (most likely), “2” or “3” (neither likely nor unlikely). Three participants responded with a rating of “6” (the maximum negative rating allowed). Two of the patients belonged to NNUHFT and one belonged to CUHFT.

Summary

- 4.33 The proportion of responses equates to roughly 50% of the total numbers of people invited by each hospital to take part. About twice as many respondents had their treatment at the NNUHFT and the results should be considered in this context. With this in mind, a number of differences were identified.
- 4.34 When asked about GP referral to treatment, a significant majority of patients said that they were seen by a hospital clinician within ten weeks. Further analysis reveals that no patients at CUHFT reported waits of greater than this period however at least two respondents told us that they had to wait 20 weeks or more for treatment at NNUHFT.
- 4.35 It is positive to find out 100% of respondents said they received a post-operative surveillance by scans after the removal of bowel cancer.

- 4.36 One person told us that they were not treated with dignity and respect at NNUHFT. 100% of CUHFT patients answered positively to this question.
- 4.37 A patient of the NNUHFT highlighted a number of issues related to lapses in care that may require some attention. No patients of CUHFT shared these views.
- 4.38 With regard to clinical staff, a total of four participants told us that they did not have confidence in the nurses at NNUHFT with one particular individual summarising a number of reasons for their negative selection.
- 4.39 It is important to note however that patients are generally positive about the care that they have received from both hospitals.
- 4.40 Analysis of open-ended data related to the potential impact of the proposed changes for patients and their families reveals the following themes:
- **Anxieties pertaining to friend/relative visits:** It is evident that respondents considered the potential for distance to be prohibitive to family and friend visits an issue that requires consideration. Such visits are seen as integral to reducing stress during the recovery phase and the absence of such support may have a detrimental effect on patient wellbeing.
 - **Anxieties about travel: A second concern relates to travel demands and can be broken down as follows:**
 - Increased distance from home may cause difficulties for patients in travelling to have treatment.
 - Financial pressures resulting from an increased expenditure required to travel to and from the hospital for treatment may enhance stress levels for patients and their carers.
 - Time management concerns. For example, the need to take a greater amount of time off from work to undergo treatment because more time is needed for travel to appointments.
 - **Anxieties about unfamiliar environments:** There were some indications from patients that being in an unfamiliar place or environment may cause additional stress.
- 4.41 When asked about whether or not they would recommend the hospital at which they have been treated to a friend or family member, most people said that they would with the exception of three participants who respond with a rating of “6” (the maximum negative rating allowed). Two of the patients belonged to NNUHFT and one belonged to CUHFT.

5.0 SURVEY FINDINGS - GENERAL PUBLIC

5.1 All percentages reported are proportional to the total number of people that chose to answer each question.

Participants (Questions 2 - 3)

5.2 The survey for the general public was completed by a variety of respondents that featured, amongst their number, patients of the acute trusts, carers (13.86%), family members and members of the general public. A total of 116 people responded.

5.3 As figure 5 shows, the largest proportion of our sample belonged to the 60 - 69 (33.33%) age grouping, followed by those who are aged 50 - 59 (23.42%), 40 - 49 (17.12%), 70+ (12.61%), 20 - 29 (8.11%) and 30 - 39 (5.41%). No persons aged 0 - 19 took part in the survey.

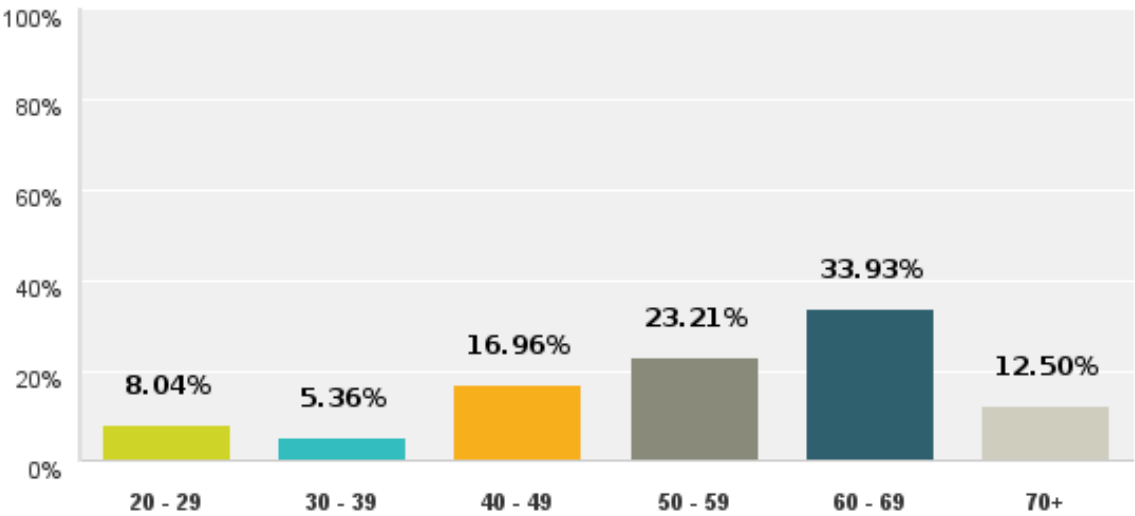


Figure 5: Age profile of our sample.

5.4 With regard to gender, 109 individuals responded to identify themselves as either male or female. No participants selected the transgender category. The samples demographic is predominantly weighted in favour of female (72.48%) participants with just 27.52% of participants attributed to the male gender.

5.5 Participants were invited to respond to our survey by Local Healthwatch in Norfolk, Cambridgeshire and Suffolk. It is therefore important to consider the location of our respondents.

5.6 Figure 6 below shows the locations of our participants on a county level as identified by their reported postcode.

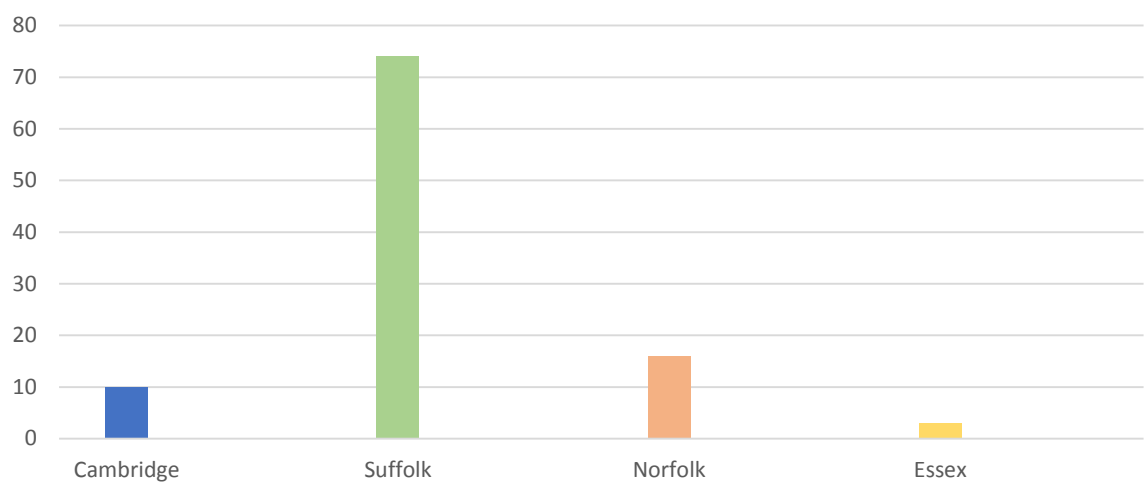


Figure 6: Respondents county location.

Choosing a specialist centre (Question 4 - 6)

- 5.7
- Figure 7 shows that overall, when offered a single choice of a specialist regional centre for liver cancer surgery, there is no clear majority in favour of either CUHFT (37.96%) or NNUHFT (37.96%) hospitals. Indeed 24.07% of the sample said that they had no preference at all.
- 5.8
- It is important to note that, due to the self selected nature of our sample, we cannot generalise this result to the entire population of Suffolk.

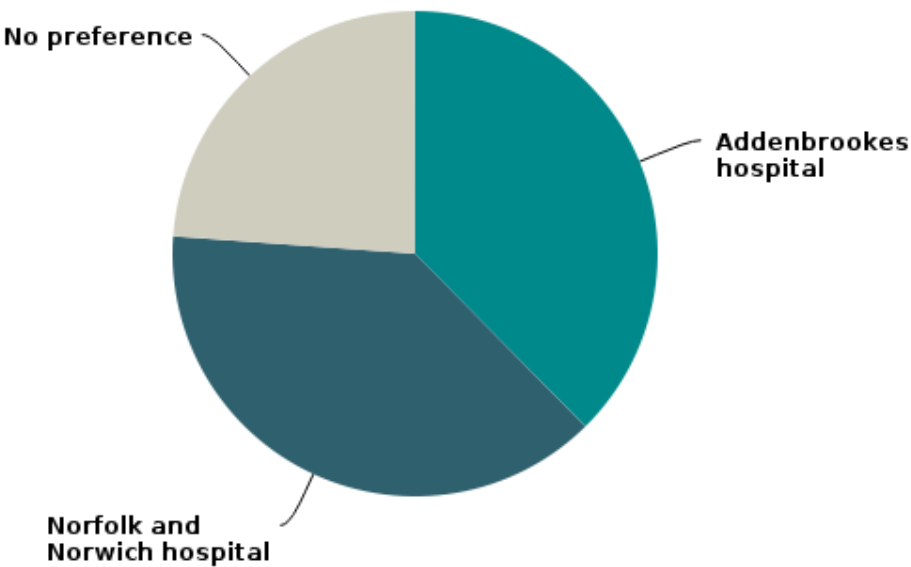


Figure 7: Choice of hospital.

5.9 Figure 8 shows our respondents preferences of hospital for treatment against their reported locality. It appears from this analysis of our particular sample that individuals who live in Cambridgeshire are perhaps more likely to choose CUHFT as their choice of surgical centre however it is noteworthy that this result cannot be reported as representative of the view of every person that lives within the county. There was no majority of participants that indicated a preference for either hospital within our sample of Suffolk, Norfolk and Essex respondents.

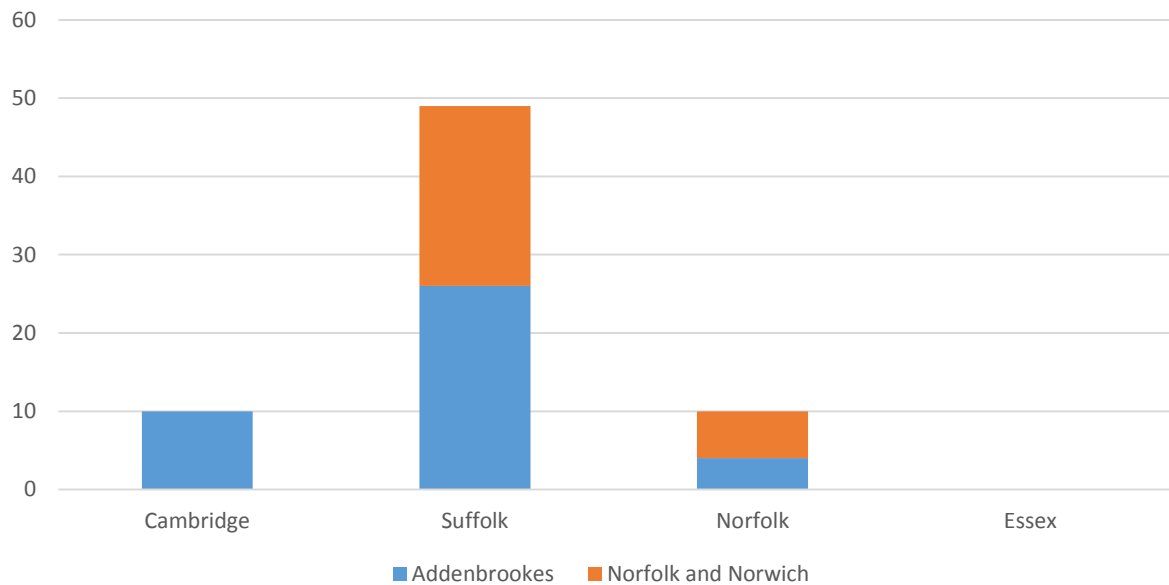


Figure 8: Respondents preference of hospital against reported locality.

- 5.10 We asked people to rate the characteristics that are most important to them when choosing a hospital at which to have treatment. Participants ranked their answers from “1” (most important) to “8” (least important). Their answers are summarised in figure 3 below.
- 5.11 For the purpose of reporting, a higher “average ranking” is indicative of characteristics that have a high importance for our sample.
- 5.12 “Specialist centre for your illness”, with an average ranking of 6.86, is the most important characteristic for people when choosing a hospital for treatment. This is followed by “Recommended by your local hospital doctor” (5.48 average ranking), “Distance from home” (5.44 average ranking) and “Recommendation from your GP” (4.76 average ranking).
- 5.13 The characteristics that were least important to people are those with a lower average ranking.
- 5.14 “Good access by public transport” was ranked as least important with an average ranking of 2.17. This was followed by “Good access by road” (3.51 average ranking) as the second least important and “Recommendation from a friend or family member” (3.52 average ranking) as the third.

- 5.15 When prompted to share characteristics that would influence a decision as to which hospital to choose for the surgery element of treatment, respondents gave a varied response. 60 persons offered comment and analysis of their responses has identified a number of themes as follows.

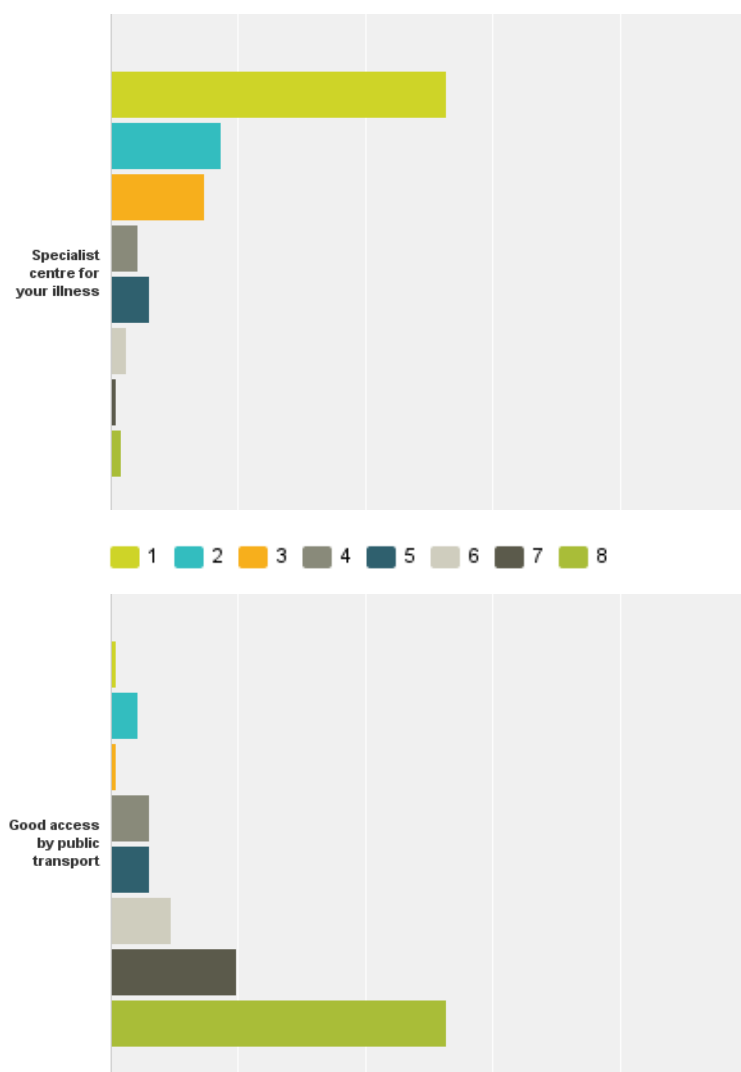


Figure 9: Responses show that the most important characteristic for people in choosing a hospital is “Specialist centre for your illness” and the least important characteristic is “Good access by public transport”

Theme 1: Informed choices

- 5.16 There is a strong discourse evident related to the need for patients to have clarity as to where they can find information to help them to make informed choices about their care.
- 5.17 There are three sub-themes evident within the comments and these are as follows:
- Ratings
 - Reputation

- Availability of information

- 5.18 Respondents indicated that ratings and outcomes are of significant importance when choosing a hospital for treatment.
- 5.19 This might involve surgical outcomes and mortality rates as well as performance data related to the surgeon in charge of their treatment.
- 5.20 Some respondents made particular reference to specific sources of data including the Care Quality Commission, outcome ratings, hospital mortality rates, national cancer patient experience surveys and Healthwatch.
- 5.21 See below for a list of the comments that are listed within the overall theme of informed choices.

Performance data and Ratings

“Success rates and waiting times”

“Good ratings compared with other similar hospitals with same speciality”

“Mortality rates and survival outcomes would be my number 1”

“Good published statistics on success and recovery”

“Rating in the National Cancer Patient Experience Survey, and Peer review reports”

Reputation

“Reputation for delivering the specialty Reputation for quality and safety Cost of parking for visitors”

Availability of information

“To make an informed choice you need accurate professional information about where to get the best treatment. Which specialist, which hospital and statistical evidence e.g. tables showing success rates, mortality rates etc.”

“Available information about quality of care at the hospital”

“Initial contact. Information on the internet attitude of staff”

Theme 2: Accessibility

- 5.22 The theme of accessibility transcends several different elements of the patient journey including transport, locality, facilities and access for family,

friends and carers visits. This theme is evident within the comments listed below.

- 5.23 Some sub-themes are also evident. One of these relates to financial worries and the other to considerations for visitors, deemed important to assist with wellbeing when in the acute hospital setting.

Accessibility for family and other visitors

“I would choose firstly on the basis of the expertise in dealing with my condition, and secondly on the basis of accessibility. The best option could be for actual surgery in an expert unit followed by recovery and rehabilitation near home...”

“...Does nobody ever think of the effect of all this travelling has on relatives and friends. The patient has to cope with facing the fact that they may not receive any/few visitors at a time when they are very vulnerable.”

“In my opinion, whilst one would want the best available treatment for oneself or a relative, it would be wrong to underestimate the influence and value of having one's support network within easy reach. Having to travel considerable distances would either reduce the number of visits a patient would receive and/or put increased strain on the supporting family to make those visits...”

Facilities

“Blue badge access and facilities”

“Good disabled parking and access to all departments”

Financial barriers

“Any help with travel costs”

“...Cost of parking for visitors”

“Cost”

Theme 3: Environment

- 5.24 Although not a concern for the majority of our participants, several considered that a reputation for cleanliness and modern facilities is important when choosing a hospital for surgical treatment.
- 5.25 See below for a list of comments that are listed within this theme.

“Friendliness and cleanliness”

“I would research on the internet for modern facilities Cleanliness”

Summary

- 5.26 Most of the respondents of the public surveys were from Suffolk.
- 5.27 When offered a choice of centre for liver metastases resection surgery, there is no majority of our sample that have expressed a particular preference in either attending NNUHFT or CUHFT for treatment.
- 5.28 Our sample generally favoured clinical opinion and service characteristics over other characteristics such as family recommendations and road access when thinking about making a choice as to where they would like to be treated.
- 5.29 Whilst this is the case, analysis of open-ended data has identified a number of themes that are of clear importance to our sample. These are as follows:
 - **Informed choices:** People want information available to them to help them make decisions about their care including hospital/surgeon performance data and service user opinion of the services.
 - **Accessibility:** People want services that are accessible in terms of facilities and visitor access.
 - **Environment:** A reputation for cleanliness and modern facilities is important.

6.0 SURVEY FINDINGS - TELEPHONE INTERVIEWS

Method and Sample

- 6.1 Six telephone interviews were undertaken from initial sample of ninety survey respondents who had indicated a willingness to give further opinions on the proposals.
- 6.2 While the final sample of six is low, the opinions stated are useful in our wider understanding of issues that arise as part of the proposed move towards a single location of care.
- 6.3 There was a standardised topic guide in use. Please refer to section 3.20 for more details of the questions.
- 6.4 The following analysis identifies the respondents solely as Non-Patients (NP's) and Patients (P's) with direct experience of the services being considered here. PJM are the initials of the Healthwatch researcher.

Themes

- 6.5 The following section deals with themes that have emerged from the interviews. They follow - roughly - the form and flow of the topic guide (as mentioned in section 3.2). Feeding directly from the broad feedback received in the survey data, patients were invited to discuss matters relating to impact; convenience; barriers to effectiveness; and personal affirmations on the ideas to centralise. The outcomes were clustered around the following themes.

Theme 1: Professional centralisation - both for surgeons and for patients

- 6.6 There is a real belief that centralisation and expertise somehow 'go together' and should, perhaps, be seen to be together. This lies in a notable zone of discomfort with many, though there is a tacit understanding of the value of such connectivity. Some respondents understood centralisation as being the logical connection between professional reputation and development and the delivery of a sound, comprehensive service on liver care. Others understood such connectivity, augmented by the attraction of funding for development:

NP1: For decent [...] care you need to be near a teaching hospital [...] the more well thought of teaching hospitals, the more money's going to be there for research and for specialisation [...] CUHFT is a hospital which is attractive to young, up and coming medics. It is a damn sight better to put CUHFT on your CV than it is Kings Lynn [...] [and] it attracts research money.'

- 6.7 With a teaching hospital there appears to come a (occasionally resigned) sense of inevitable linkage with the argument for centralisation of care on matters requiring such focused expertise. However, there is also a tangible sense of optimism regarding a potential spread of expertise in care - a kind of 'sharing' of such expertise across the region, *rather than* centralisation. It is an alternative notion, based largely on a lack of resistance to centralisation but an agreement to share the resources that may well be *centralised*. P1 states that there is a hope that a specified 'day of care' each week can be arranged for the Yarmouth Paget Hospital, where a designated day each week sees experts attend the hospital to care for sub-regional patients, negating the requirement of the patient to travel (in this case) to Norwich or Cambridge.
- 6.8 Therefore, there appears to be a tension between bespoke provision and the idea of centralisation - namely, that there is greater scope for bespoke provision in a centralised facility but people consider centralisation as somehow taking this bespoke dynamic away. This is where a sense of loss is clearly evident.

Theme 2: A Sense of Loss

- 6.9 The sense of loss is perhaps the most clear and striking, emotive reason why people sense that centralisation of a service might both be perceived as

negative and, perhaps, be *experienced* as negative also. While not grievous in its impact, there is a clear belief amongst those who were consulted here that the notion of converging expertise in one location might weaken the provision that is available locally. It might seem like something of a plausibly groundless, but nevertheless *common sense* reaction to the potential for withdrawal of valued localised care, but there is a real fear that something sacrosanct, symbolically local and reflexive in function is being eroded permanently. For example, NP3 suggests that local health provision is held in as high regard as a truly sacrosanct pillar of local community:

NP3: If you close down a service close to somebody's home then people are going to be in uproar about it

PJM: Do people react against centralisation [...] subconsciously because it appears the local hospital might be weakened by things being taken away from it?

NP3: Yeah, I think the frightening thing about hospital closure [...] is that people see their local hospital as something like a church really [...] It's not just about taking that service away [...] it's a better use of NHS resource.

- 6.10 The reaction of the public is likely to be negative when authorities talk about shifting service away from a localised service provider and towards a centralised hub, but the argument can be won when a simple logic is applied to the overall discussion at hand. What appears to be taken away can often be reapplied when discussed in the context of urgency, kin and the vagaries of practicality:

NP2: I understand when you start talking to the general public and you say 'are you happy about taking a service away from West Suffolk Hospital and putting it at Cambridge?' immediately people think 'Oh, you're going to close our local hospital down!' and it gets very emotive. But, if you say to a person, 'if your husband, your wife, your daughter had this condition, [...] and it was life threatening, where would you rather have her treated?' I'm sure they would say that they would rather put up with the inconvenience of going to Cambridge or Norwich.

- 6.11 There is, according to some, a very real fear that the process of centralisation is becoming a model that shall be applied to virtually everything - signalling, yet again, the fear of closure of local facilities. Closing such facilities also has a logistical effect on access. As we have seen, there is worry about the loss of facilities as a 'thin end of the wedge' in the overall discourse but there is also a pervasive sense of dislocation and inconvenience.

NP4: If you've got children to transport it is difficult; if you're both working and they've got to get to one of these big hospitals, getting there to visit would be very difficult; I think that's the main worry - getting there as a visitor or as an outpatient.

- 6.12 There is also articulated a sense that, with centralisation comes the chance for socio-demographic foci to be addressed in health care - looking after, in

other words, the needs of the population on a more bespoke, non-critical level and being able, as a result, to be reflexive to such need from month-to-month and year-to-year without having to concentrate on 'bigger issues' that can be referred to the central hub.

- 6.13 In addition to the 'structural' impact - and associative concerns - of the move towards centralisation, there is also a very real human impact too. As P1 states, 'I personally feel that you might become more of a number and less of a person.' In addition, surgeons get to know the patient over time and via multiple liaisons and there is a fear that the 'personal touch' will be lost. This has a very real impact on the self-efficacy and self-esteem of the patient - with loss of such contact with familiarity can lead, it is strongly inferred, to potential mental health problems such as depression. The impact and effectiveness of regular contact and familiarity may well be under-researched. The power of recovery (self-efficacy in many ways) could well be attached to the confidence of familiarity. P1 concludes that those who care for him in Lowestoft and Yarmouth 'make sure I don't get in the doldrums; they really get on to us; you are as good as you feel [...] don't switch yourself off.'
- 6.14 Finally, a sense of loss is also experienced when discussing where the members of staff actually *go to*. This is pertinent because it segues with the points made above on familiarity. There is a prevailing sense that loss is equated to losing familiar faces and losing the relationship that patients have built up with them. This misses a point that the staff-patient relationship might not be *lost*, just the location of interaction *changed* - but the overriding sense is that the geographical/physical move will equate to an *end* of such a relationship.

P2: It depends where the staff went. I mean, I've got a very good specialist nurse in the liver department in Norwich; she's superb. She's the one I see every time I go for a check-up. I mean, I suspect they're all nice but, you know, you get used to dealing with certain people, don't you? [...] There's less worry about going to see someone because you know they're going to tell you what's what.

NP4: Personal contact: could you soon get to know the doctors and the nurses on the ward that you go to if you go there [new Hub] frequently, yes, I suppose you would lose that if you were travelling there just for an operation.

Theme 3: Transport

- 6.15 Getting to and from a new centralised service hub appears to be a persistently cited problem in both terms of potential and actuality via experiences. Should the Hub be situated in Cambridge, for example, the state of the A14 causes much concern, largely due to the ubiquitous combination of heavy goods vehicles and the propensity for gridlock as well as the effect on drivers in poor weather and the hours of darkness. Driving, as many respondents say, is problematic due to a combination of the illness/condition and the treatment that they have - often resulting in the

inability to actually drive themselves to and from hospital treatments. The distance - along with the problems of distance and road conditions, weather and darkness - are extremely important. These factors are coupled with the proposed rise in patient numbers and the potential for congestion of both a vehicular and human form. As P1 states, 'there will be more patients [in Cambridge] and less access'. It's a pertinent observation. Potential solutions and compromises are offered up though. As NP4 states, 'there could be a hospital transport put on, like they do outpatients one day a week at outlying hospitals, that sort of thing.'

- 6.16 There also remains a problem regarding visiting too. This is often an 'unintended consequence' of reorganisation; the overarching aims are often focussed on the effectiveness of the service provision, but those who wish to visit significant others are potentially relegated down the list of priorities. Despite the primacies spoken of clearly having a correct focus on care and recovery, the requirements of visitors (and the affirmative effect they have on recovering patients) are still very much of importance. As P2 points out, Cambridge instead of Norwich for her could have meant a lonely existence or, alternatively, a stressful one for her husband:

P2: it depends where you live a lot; obviously it's nice to have somewhere a bit closer [...]. If I'd have to go to Cambridge, I don't think I'd have any visitors and my husband would probably have struggled to get there in-between working and visiting [...] it would have been horrendous for him.

- 6.17 And there remains issues relating to visiting the most needy when one is geographically distanced from the central hub. As NP4 points out, some patients need visitors more than others maybe do - especially when very young or very old:

NP4: If you had a child in and you had to go every day, or an elderly relative and you had to go every day, then I could see it would be very difficult. However, despite repeated concerns there is also a dose of realism thrown in for good measure. There remains the essential understanding that transport diminishes as a central problem if the condition is critical enough: getting to and from a hospital, however distant, is immaterial when faced with a critical condition and, in effect, expertise is primary and transport, therefore, is a secondary:

NP1: At the end of the day, we are talking about life and death situations and [...] if it's going to offer you the best possible chance then you are going to travel for it.

NP2: [...] if you're in a life threatening condition - and cancer *is* a life-threatening condition - then you want to go to the best place and transport becomes secondary.

Theme 4: Image and Choice

- 6.18 There remains the consumer approach to choice that permeates the use of hospital services. Choices are made on public image, hearsay, media

coverage and intuition. As NP2 states, the choice of radiotherapy treatment that his wife chose lead to some initially disappointing waiting time *on-site* but:

NP2: we chose CUHFT [for radiotherapy] at that particular point because we hadn't had any experience of CUHFT at all and it had the *halo effect*. [emphasis added]

- 6.19 When considering the switch from sub-regional service provision towards a centralised hub, it is therefore an observable dynamic that suggests the reputation of a potential site for the hub is stronger when the hospital - in this case CUHFT - has a high regard amongst those who may come into contact with its services. In effect, relocating to CUHFT may 'take the edge off' the more unpopular aspects of the relocation simply because CUHFT is held in such high regard by people all across the region. They are, in short, prepared to accept CUHFT as something of a centre of excellence already and, with this perception, comes a certain confidence that relocated service simply *must* be exceptional - a 'halo effect' indeed.

Theme 5: Regional Hubs versus National Excellence

- 6.20 Despite regional excellence being celebrated via the 'halo effect' of CUHFT, there is also a tacit recognition that CUHFT may be excellent, but it is not completely *specialist* in its own right. There have been occasional inferences that, despite the potential creation of regional centres being an affirmative step forwards in both the collectivity of expertise and the confidence in care, there remains a sense that CUHFT (in most cases) still remains a *regional* hub rather than somewhere where a patient would want to go if a *national* option existed. In this case, the Royal Marsden is cited regularly as being the beacon institution for care in the field of cancer care and, as NP2 states, there remains a distinction between a perceived centre of excellence and something of an *authentic* one:

NP2: If we had a serious problem with cancer then we might say 'oh we don't even want to go to CUHFT, we want to go to the Royal Marsden, a *real* centre of excellence' [emphasis in original quotation]

- 6.21 And, with such a national image, then the *model* of the Marsden might well be the way forwards in developing a public perception of a central hub for cancer care in the East. NP3 suggested that the expertise, recognised on a national stage, might well be utilised like a brand - being treated by an expert connected to the brand might well be as good as being treated at the *home* of the brand:

NP3: I want to see more innovative thinking about services. It doesn't just have to be taking from one hospital and putting it into another. [it must be about seeing] Cambridge grow and grow and grow with that service so they almost brand it, much like, say, the Marsden [...] when anybody talks about the Marsden they know it's about cancer.

- 6.22 The Marsden person is the expert who might well come to you, wherever you are based, and perform your operation. It is, indeed, about feeling the confidence in the expertise and understanding and appreciating the quality associated. Follow-up care can be done by the local hospitals; the central hub of expertise must still *provide the expert*.

Theme 6: Cost-Effectiveness

- 6.23 The issue of cost to the public purse arose many times in conversations - not least due to it being perceived as a substantial dynamic in the moves towards creating the Hub. When asked about the gains that a central hub might bring, it was commonplace for respondents to acknowledge the benefits of cost effectiveness. In most cases it was connected to the idea that a place with a busy rota tended to be a place where expertise could flourish, as well as being a place where the best equipment and associative resources could be stored as well as utilised:

NP2: it has got to be more cost-effective for one centre to be doing one hundred operations a year than two centres doing fifty.

NP3: having lots of centres all over the place doing lots of stuff is a good idea if it's general stuff, but if it's specialist stuff, you can't have specialist centres and consultants doing relatively small numbers of patients all dispersed around the area because [...] for sustainability of the service, it's not efficient

NP4: It would be cost effective [...] for the hospital to have all its gear and all its equipment and all its top staff in one unit rather than scattered around the country (sic) but would that mean closing another unit in the local hospital?

- 6.24 Overall, while opinions on the virtues of centralisation remained mixed, it is clear from the responses above that cost-effectiveness is important, logical and progressive - but issues relating to creeping closures of facilities elsewhere remain vibrant and clear.

Theme 7: Gains of a Centralised Service

- 6.25 Finally, what gains might be made from centralisation? Overall, respondents were largely receptive to the idea that centralisation would be progressive if not altogether convenient on a personal level. As we have seen, travel and familiarity have been cited as perhaps the strongest emotive issues relating to a resistance to change, but the sense is that centralisation remains the most effective way of *getting things done* to a high standard in future. Change may be necessary in many ways, but public and localised discourse remains based on protectionism and a sense of an assault on services. As NP3 states, the media see the transferral of service provision from local to sub-regional as a broad negative, never really concentrating on the plausible affirmative outcomes that a brave decision might have:

NP3: It takes one gutsy person to close down a service: the local media love it - they never see it as a person doing something really innovative or doing something for the good of the people or the population.

NP4: All the latest knowledge, all the latest research would be in one place - it would be a big plus on that score [...] I can see that it would be very good to have one big unit for the area, I can see why, but just on a practical side it would be hard to get there.

- 6.26 There is a coherent sense that centralisation can bring about some significant improvements in care but, as we have seen, there are sincere reservations about the unseen and, indeed, unintended consequences of such a move on patients, their families and local communities. As NP4 points out,

NP4: I think you've got to consider, first of all, that you are more likely to get better in a big, modern hospital than if you're in a little, local one.

PJM: Is it a price worth paying to lose locality but gain greater security from more experts?

NP4: Well I think it is [...] if you really *needed* it.

PJM: Need overrides...

NP4: Convenience.

Perhaps, in conclusion, this is the fundamental dynamic present across all responses - *need* and the *perception* of need.

Summary

- 6.27 The responses to the telephone interview were clear and concise in broad support for the centralisation of services as a requirement rather than as a desired shift in policy. People were mindful of the logistic issues relating to travel and visiting; the loss of something of the 'personalised' aspects of localised provision; and, finally, were accepting of value for money considerations while mournful of the loss of continuity that a move towards a centralised provision might bring. In conclusion, there is broad support coupled with a desire for further considerations being made on the policy responses to the problems stated.

7.0 CONCLUSION

- 7.1 While the number of patients to be affected by the proposal service change will be small, it is important to ensure people are given the opportunity to have their say and their views are listened to and acted on.
- 7.2 It is interesting to compare responses to our two separate surveys because it gives us the perspective of patients that have used, or are currently using, the services and those that have never used the service.

- 7.3 Overall, there was little difference between the patient experience in CUHFT and NNUHFT, although more positive comments were associated with CUHFT. Respondents were generally positive about the care and treatment that they had received at both hospitals. Some concerns were raised by patients of the NNUHFT with regard to nursing care.
- 7.4 When asked about the potential impact of the proposal to develop a single surgical centre for liver metastases resection service, several themes were identified by the respondents:
- Anxieties pertaining to friend/relative visits
 - Anxieties about travel
 - Anxieties about unfamiliar environment
- 7.5 People generally identified clinical opinion and service characteristics as more important than other characteristics such as family recommendations and road access when thinking about making a choice as to where they would like to be treated.
- 7.6 Overall, respondents have not expressed a particular preference in either CUHFT or NNUHFT to be the single regional centre for liver metastases resection. Subsequent telephone interviews with respondents to both surveys have established however that there was a general acceptance and broad support for service centralisation and development of specialist centres as a requirement.
- 7.7 Whilst the above might be the case, it is clear that patients and the public do have concerns about the impact that the proposed changes might have on other aspects of their wellbeing such as the stress of being located in an unknown environment or the potential for difficulties in seeing significant others when they need them most. This theme is evident across both of our samples and also from our telephone interviews indicating that it is a matter that requires careful consideration.
- 7.8 It is clear that the survey participants value the need for a service where they are able to obtain high quality care with sufficient information to help them to understand their treatment and make choices where appropriate. Consideration should be given however as to how this can be achieved within the context of the concerns highlighted by patients and the public above.
- 7.9 It might be determined from our combined data that people want to have the best care available, close to their home and from clinical staff with the right skills and with the right information available to help them to understand their treatment choices.
- 7.10 Some of the findings in this public engagement exercise have wider implications. In particular, it will be important for both service commissioners and providers to recognise the anxieties and potential issues identified by the service users in relation to service centralisation in general.

- 7.11 NHS England East Anglia Area Team is asked to use the contents of this document to underpin the development of the engagement and service implementation plans for liver metastases resection service.
- 7.12 Finally, Healthwatch Suffolk, Healthwatch Cambridgeshire and Healthwatch Norfolk would like to thank the co-operation and support of CUHFT and NNUHFT teams in carrying out the inpatient survey.

APPENDICES

1 - Invitation Letter: Inpatient Survey	 Appendix 1 Liver Metastatic Question
2 - Covering Letter from CUHFT: Patient Experience Survey	 Appendix 2 Liver resection cover letter
3 - Invitation Letter: General Public Survey	 Appendix 3 General Public Survey.pub