NHS
Lancashire and
South Cumbria
Integrated Care Board

Urology services transformation

Listening to communities report

November 2023

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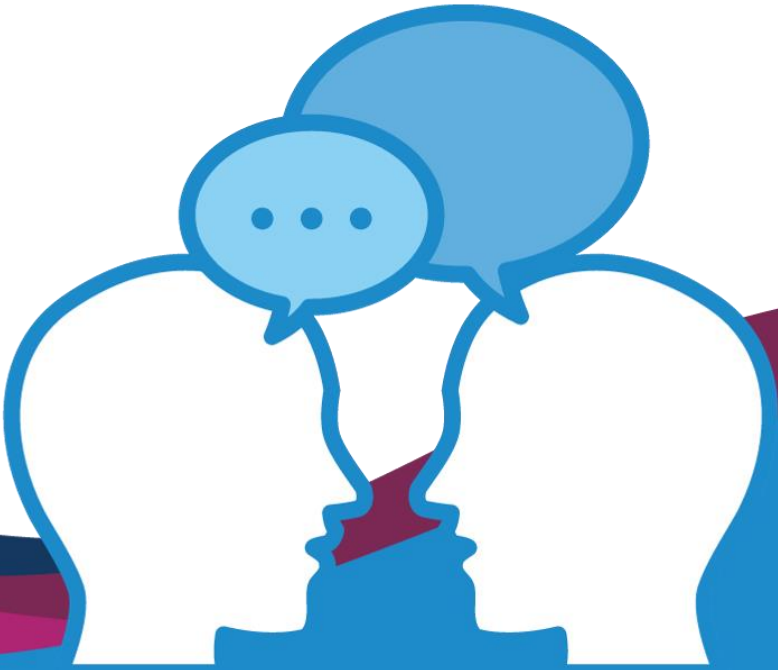

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Acknowledgements

Many thanks to all the participants of this engagement, many of whom have agreed to be contacted for further engagement at later stages. Special thanks to The Bay Prostate Cancer Group.

Introduction

The NHS Lancashire and South Cumbria Integrated Care Board (ICB) along with the NHS Trusts in Lancashire and South Cumbria have a joint vision to improve our clinical services through collaboration.

The Lancashire and South Cumbria Urology Clinical Network (UCN) is working towards a robust and sustainable future operating model for both cancer and benign services that will be:

- A resilient high-quality service that adheres to the required specification/standards and incorporates recognised best practice from NICE, Getting it Right First Time (GIRFT) and British Association of Urological Surgeons (BAUS).
- A service that ensures equity of access to a standardised level of care for our whole population.
- A service that utilises the strength of our network to allow further development of sub- specialty services that are accessible to all
- Efficient and financially sustainable.
- A service that is good to work in and allows for workforce progression and development.

To achieve this the Urology Clinical Network is investigating a move to a network model with the provider NHS Trusts working collaboratively as a connected network of service providers. This is being undertaken with the support of senior clinicians and departmental leads.

To support this work engagement with patients has taken place to discuss any issues that would affect patients if urology cancer services adopted a networked model.

This report outlines the method and findings of this engagement.

Executive summary

Engagement was carried out between September and October 2023. Patient groups were identified and engaged with through focus groups and a questionnaire.

The majority of patient groups identified were for prostate cancer patients resulting in limited responses from patients of kidney or bladder cancer specialties. Efforts were made to contact other patients through cancer nurses and the cancer alliance networks. This work will need to be built upon for future engagement activities.

In general, the people we spoke to were favourable of networking services as communication between specialties was an area they felt needed improvement. Communication still remains a high priority at all levels especially between primary care, urology and oncology.

Travel was raised as an issue both in terms of distance travelled but also due to the nature of treatment the frequency of travel and the requirement to often visit multiple settings. We heard about the frequency of appointments being an issue where radiology can often require a patient to visit a hospital daily for several weeks; that hospital being further away from home caused a problem for both the patient and anyone who transports them.

The main findings can be summarised as:

1. Communication between all specialties is a key priority and wherever services are delivered those providing them should be aware of all aspects of the patient's diagnosis and treatment.
2. Networking of services needs to include primary care.
3. Services should be set up so that hospital appointments should be at the same hospital so that journeys to multiple hospitals is limited.
4. Where possible treatments with high frequency visits such as radiology should be as local as possible.
5. Any changes should not cause delays for treatment due to capacity at a single site.

These findings are supported by the insight from the Clinical Strategy Development engagement which NHS Lancashire and South Cumbria ICB began in May 2023.

At every stage of engagement so far patients have been supportive of the services in general citing only minor issues around communication between different services.

The findings of this report will be published on the ICB website and shared with the groups that took part.

What have we been talking to people about and why?

The NHS Trusts that manage our hospitals in Lancashire and South Cumbria have been working together with the Integrated Care Board (ICB) to look at how Urology cancer services, including bladder, prostate and kidney, can be improved.

Urology Clinical Network has been discussing the proposed models of care under two specialties; cancer and benign services. At this stage the emphasis is on the wider impact to cancer services.

Currently, procedures for these types of cancer are carried out at varying levels across our hospitals. This means:

- Waiting lists are very different depending on which hospital you go to.
- Our hospitals see different numbers of patients, meaning they are not collectively meeting nationally recommended targets such as number of surgeries carried out and number of patients seen.
- Smaller teams in some hospitals makes recruitment and sharing of expertise difficult.

We want to make sure everyone receives the highest quality of care and can access a full range of services no matter where they live.

National guidance recommends moving to a network model for services, which other areas of the country already have in place.

A network model would mean hospital teams working more closely together to share expertise and workload. Outpatient clinics and some same-day surgeries would still take place at a hospital nearest to patients, but more complex and specialist surgical procedures would require patients to go to a centralised centre of excellence.

What have we talked about before?

The majority of previous engagement has been with clinical staff as part of the network. A workshop took place in May 2023 led by the programme leads. This discussed the ways in which a network model could operate and resulted in a number of options that are still being discussed amongst the network.

No previous public engagement has taken place specifically looking at this work.

Clinical strategy development

In May 2023, an engagement programme commenced to capture insight from local people and staff regarding the principles of networked clinical services This concluded in August 2023.

The engagement asked questions about travel, use of community settings and local hospitals, and having specialised services centralised in specialist centres. It was conducted through online questionnaires and face to face meetings with various groups at place.

The findings of the clinical strategy development validate the findings of this report. They can be found in appendix 1.

The survey findings supported a network model with complex surgeries in specialist centres. Key themes for concerns that are pertinent to this report included:

- Travel. People not accessing treatments as too difficult.
- Accessibility especially for the disadvantaged
- Increase need for Patient Transport Services
- Transferring patients to centres of excellence affects timely care.
- Accountability - patients won’t know who is responsible for care.
- Premises investment and community spaces
- Staff wellbeing/Pay/Morale
- Demand/Increase in population
- Digital/IT
- Bureaucracy

How did we speak to people?

To ensure feedback opportunities were as accessible as possible a range of engagement techniques were adopted.

Focus groups

Two virtual groups were hosted on Microsoft Teams by the ICB communications and engagement team on 2 and 9 October.

An invitation was also received from the Bay Prostate Cancer Group who are already involved with the network programme. The meeting was attended on 14 November.

There were three main discussion topics:

- Which urology cancer services could be provided in community settings?
    - What would make you feel confident about accessing services in the community?
- Which urology cancer services should be delivered in a hospital?
- If highly specialised/complex urology surgeries were delivered in a ‘centre of excellence’ what should we make sure is taken into consideration?

Along with another question to be asked directly or pulled out of discussions if they were apparent.

- What is most important to you/your family when receiving care and treatment from urology cancer services?

For the focus groups a presentation was created:

Why we are working together collaboratively as a system

To deliver the best health and wellbeing for our population

- Poor health affects many of our communities
- Health inequalities are neither acceptable nor fair

High-quality services

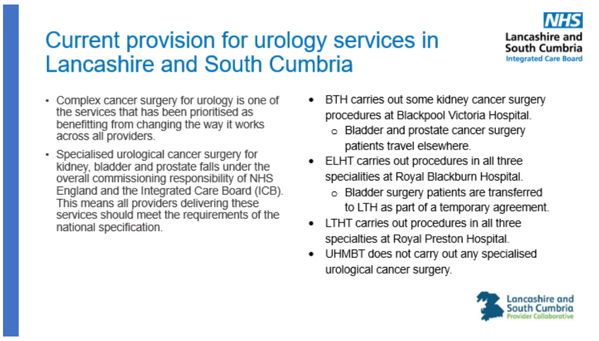
- Our services are under unprecedented pressure, which risks quality and safety
- Some of our services are currently unsustainable
- With system working we can improve together to all deliver high quality care to our patients

A happy and resilient workforce

- Our colleagues are our biggest asset, but are under tremendous pressure
- Ensuring their wellbeing is paramount, as is attracting the best talent

Financial sustainability

- We are facing significant financial challenges
- We need to make every penny count



Current provision for urology services in Lancashire and South Cumbria

- Complex cancer surgery for urology is one of the services that has been prioritised as benefitting from changing the way it works across all providers.
- Specialised urological cancer surgery for kidney, bladder and prostate falls under the overall commissioning responsibility of NHS England and the Integrated Care Board (ICB). This means all providers delivering these services should meet the requirements of the national specification.

- BTH carries out some kidney cancer surgery procedures at Blackpool Victoria Hospital.
    - Bladder and prostate cancer surgery patients travel elsewhere.
- ELHT carries out procedures in all three specialities at Royal Blackburn Hospital.
    - Bladder surgery patients are transferred to LTH as part of a temporary agreement.
- LTHT carries out procedures in all three specialties at Royal Preston Hospital.
- UHMBT does not carry out any specialised urological cancer surgery.

Questionnaire

Since not all patients attend support groups it was decided to try to capture these by generating an online questionnaire which could be shared with patients either through the third sector groups or through the various service clinics.

Working with the Cancer Alliance it was decided to merge the questions from this programme and those of a very similar programme looking at urology services together into one ‘cancer clinical services review’ questionnaire. This allows the findings of that survey to be shared with the Lancashire and South Cumbria Cancer Alliance for their work.

The survey can be found here: www.smartsurvey.co.uk/s/Cancerservicesclinicalreview

The survey was shared with Trusts to share with patients they may have contact with, through the ICB citizens panel and through the patient groups identified. It was also present on the ICB 'Have your say' web pages.

To address the issue of most third sector groups being for prostate cancer patients the Cancer Alliance also agreed to circulate the survey via the cancer nurse specialists.

Who have we heard from?

Deciding who to talk to

The equalities and health inequalities impact risk assessment (EHIIRA) for the Urology Clinical Network identified a set of people who may be affected by the programme.

These groups were represented in the clinical strategy development survey described above. The objectives of this report required a focus specifically on urology cancer patients.

A review of known groups was conducted which identified the following third sector existing patient groups. It was more effective to engage with members of these groups rather than setting up additional meetings.

The groups identified and contacted about the project were:

- East Lancashire Patient Voices Group
- The Urology foundation (national)
- The Bay Prostate Cancer Group
- Blackpool and Fylde Prostate Cancer Support Group
- East Lancashire Prostate Cancer Support Group
- South Lakes Prostate Cancer Support Group
- Southport and West Lancs Prostate Cancer Support Group
- Millom prostate cancer support group

The majority of the groups that are listed on various websites are mostly prostate cancer groups. Each group was contacted with either no response or some responding to say they were no longer operating or had only two or three members. Where possible conversations were had to introduce this engagement opportunity and views were shared during those conversations as well as details circulated to invite people to the virtual focus group sessions.

How many people got involved?

- The Clinical strategy development survey reached 357 people.
- The virtual focus groups had six attendees.
- The Bay Prostate Cancer Group was attended by four people.
- The questionnaire had 20 total responses with five highlighting specifically to being urology patients (at time of submitting report).

In total 387 patients were surveyed 30 of which were urology cancer patients.

Although this is not a fair representation of the total population of Lancashire and South Cumbria we must note that approximately 502 procedures are carried out per year. Having spoken specifically to 30 patients that have been through the services this equates to a six per cent representation.

The survey population represents a similar age profile to what we would expect in terms of prevalence of service use; ie; more people over 45.

A breakdown of the demographics of the respondents to all of these can be found in appendix 2.

What did we hear?

Since the questionnaire and the focus groups asked identical questions, the responses have been included together. Full notes from each of the focus groups is available; comments have not been included verbatim and summarised for purposes of this report.

The participants were, in general, favourable of the network model being pursued. They had some concerns and areas they felt should be considered as part of any planning.

Q: Which urology services could be provided in community settings?

Any diagnosis tests were raised as an option for procedures that could be done closer to home.

Outpatient appointments before and after surgery were discussed as being a key service that would benefit patients if it could be done locally. However, participants did understand this would be better in a hospital setting in terms of clinician’s time. A solution to this would be having more appointments via telephone or video call when appropriate.

Likewise, participants debated whether or not radiology could be carried out in a local setting. Those that had experience of treatment said that it was ok if they could come by themselves as they were able to take time off for treatment. The issue comes with the frequency of treatment (daily in some cases) where patient rely on other people to take them to and from appointments; it is difficult for carers to take the time off work frequently. Therefore, keeping radiology treatment as local as possible and reducing travel would be best.

Talking about networking services participants advocated for this not just being about secondary care services but working more closely with GP practices for diagnosis and treatment. There was also a call for GPs to routinely do prostate specific antigen tests.

Respondents also shared their opinion that if a service were to be delivered in local areas, they should be able to expect a more personal service seeing the same team of health care professionals each time who know them as people not just a patient number.

Q: Which urology services should be delivered in a hospital?

Some participants described how they had appointments at different hospitals which was frustrating. They felt that going to hospital appointments at their nearest hospital and not travelling further than necessary would be best. This seemed more apparent when hearing from patients in the South Cumbria area; some patients saying that traveling from Kendal to Lancaster for radiology was frustrating when they have a hospital in Kendal.

If, for some reason, a patient does have to travel to multiple hospitals the overwhelming opinion was that they would expect the clinicians they were seeing to know they had been elsewhere and what happened there.

Wherever appointments are held if there is a need to travel to them then services should be coordinated so that appointments don’t clash or can be arranged on the same day to reduce journeys.

Q: If highly specialised/complex urology surgeries were delivered in a ‘centre of excellence’ what should we make sure is taken into consideration?

Travel was raised a number of times. The majority said they were happy to travel for better treatment. One participant said they were already traveling out of Lancashire in order to be seen more quickly. However, like others, they said a single site would only work if it had capacity to manage waiting lists and there was worry that people could be waiting longer.

Another consideration discussed was around the length of time someone was in hospital after surgery. Participants said that the longer they were in hospital the less favourable it was for that hospital to be far away from home. Repatriation to a nearer hospital for recovery was important.

The networking of services was praised by most participants who saw the benefit of clinicians sharing experience and expertise and learning from others. Respondents had hope this would remove many of the communication issues they had encountered where referral notes or blood test results had been ‘lost’ between different specialties and hospitals.

One particular point was around the specialisms working together, especially urology and oncology. Some participants suggested that they felt there was often a disagreement about how some conditions are treated between the two departments. One example was around a patient being referred to oncology who then started treatment without notifying the urology team that made the referral and not discussing the treatment. The urologists later suggested they wanted to operate but couldn’t because of the oncology treatment having already started.

The only concern that was raised was around capacity for the staff in one location and whether having all patients going to one centre meant they would be waiting longer for the treatment. This may be something that should be considered when reassuring patients of any future changes.

To finish, one patient said: “I believe you think about the patient above all else, but I suspect the number crunchers get in the way when you attempt to provide the very best service for all patients.”

What we have learned

What our patients have told us

The following is a summary of the key themes and issues the feedback suggests need to be addressed in future planning.

6. Communication between all specialties is a key priority and wherever services are delivered those providing them should be aware of all aspects of the patient’s diagnosis and treatment.
7. Networking of services needs to include primary care.
8. Services should be set up so that hospital appointments should be at the same hospital so that journeys to multiple hospitals is limited.
9. Where possible treatments with high frequency visits such as radiology should be as local as possible.
10. Any changes should not cause delays for treatment due to capacity at a single site.

In general, the patients and public are in favour of a network model in line with the national recommendations.

It is also clear that the patients we have heard from are happy to travel to a central location for higher quality specialist procedures with shared expertise. Although the issue of length of stay and communication between all services were concerns.

Those we heard from were also keen that as many services as possible be held in their local area in the community where possible. However, they were pragmatic to what could realistically be done in the community and what would be best in a hospital setting.

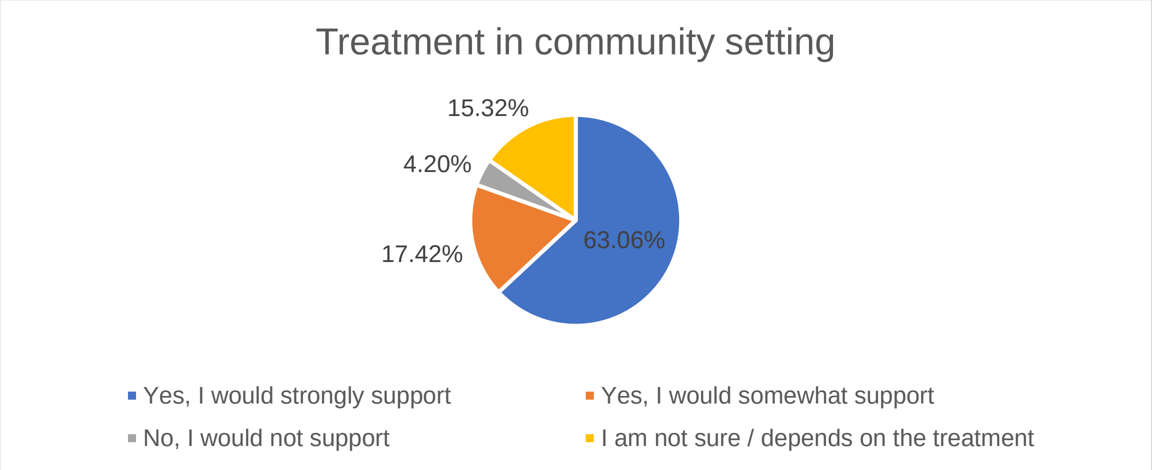
With urological cancer treatments often requiring multiple specialties and multiple hospital visits the main concern was around ensuring services are joined up and coordinated. Communication needs to be paramount so that every specialty knows where a patient is up to with their diagnosis and treatment. They should be coordinated so that treatment is not delayed.

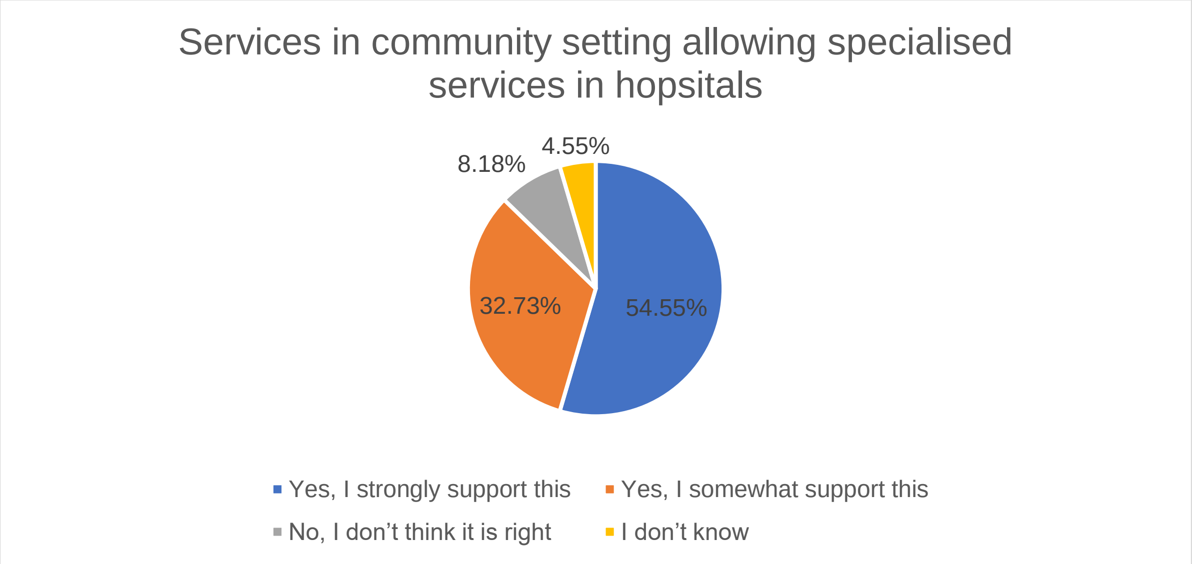
Any future engagement will need to expand the population size to include at risk groups which will include members of the public that may not be patients but have conditions or demographics that put them at higher risk of becoming a patient of urology cancer services in the future.

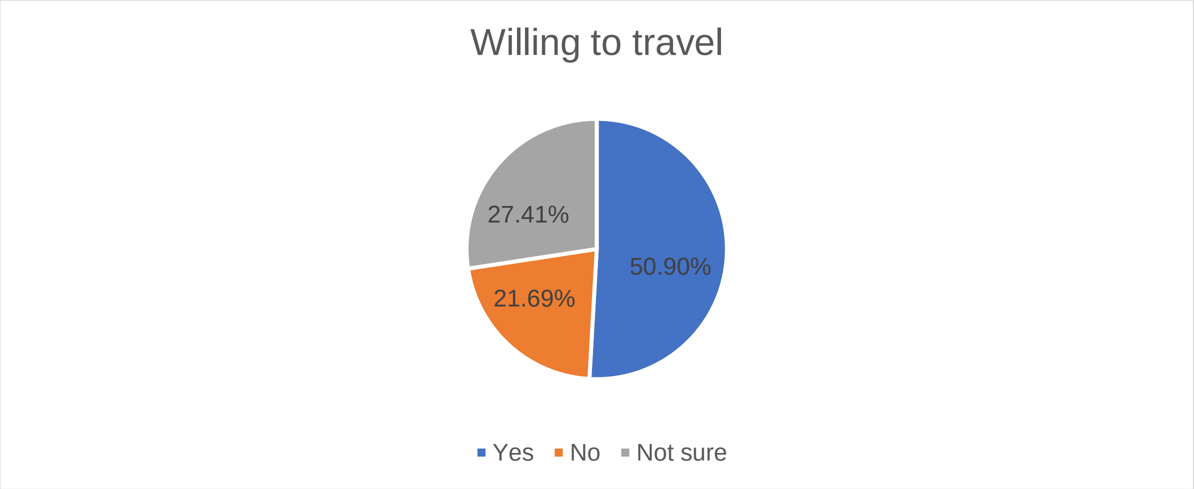
Attention will also need to be paid to address the benign services element of the network programme.

The findings of this report will be published on the ICB website and shared with the groups that took part.

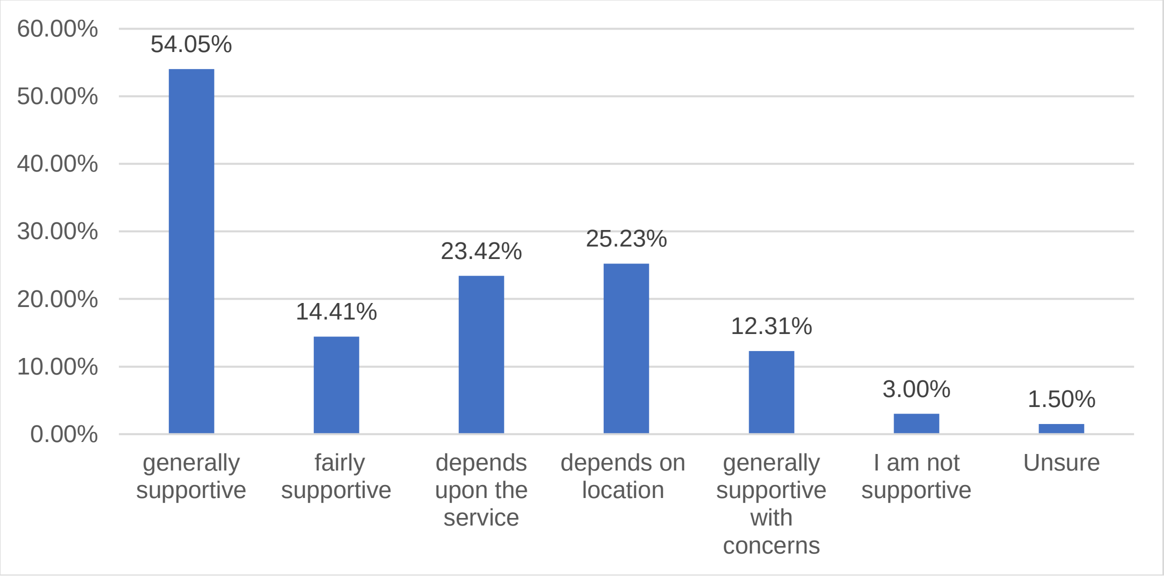
Appendix 1 – 2023 Clinical strategy survey results (pertinent to this report)







The survey asked participants specifically: “Thinking about highly specialised care, it is quite often safer and provides better results for patients if this is provided from specialist centres rather than from every hospital. How do you feel about more services being delivered in this way if it means better results for you and your family?”



Those who said they were supportive but had concerns cited their concerns as:

- Travel. People not accessing treatments as too difficult.
- Potential for multiple different locations for patient care.
- Long term conditions patients build relationship with their teams this could be lost. Reduces opportunity for holistic approach to patient care. Accountability and patients won’t know who is responsible for care.
- Transferring patients to centres of excellence affects timely care – safety. Disparity between speed at which you get seen for specialist treatment if you live near a city.
- Mental health impact of being away from family during illness – isolation and recovery impact.

Other comments that were received within the survey were themed into key points. These were:

- Depends what services
- Dilute care so specialists only become complex care
- Premises investment and community spaces
- Accessibility especially for disadvantaged
- People with LTCs and multiple issues may have to visit several ‘centres of excellence’ for their care rather than one location
- Increase need for Patient Transport Services

Participants were also asked what challenges (beyond access, staffing, waiting times, quality and finance) they felt should not be overlooked. Responses included:

- Inefficiency/Waste
- Communication
- Cleanliness/Hygiene
- Staff wellbeing/Pay/Morale
- Transport/Travel
- Waiting times
- Access

- Follow up advice.
- Estates/Facilities
- Demand/Increase in population
- Digital/IT
- Primary Care/GPs
- Recruitment/Retention/Workforce
- Dental
- NHS image
- Skills/Training
- Bureaucracy
- Leadership/Culture
- Mental Health/Social care/VCFSE
- Integration
- Lived experience.
- Person centred

Appendix 2 - Demographic monitoring

Below are a breakdown of the demographics of all respondents. Where demographics are not available from focus groups they have been added to the “prefer not to say” category.