



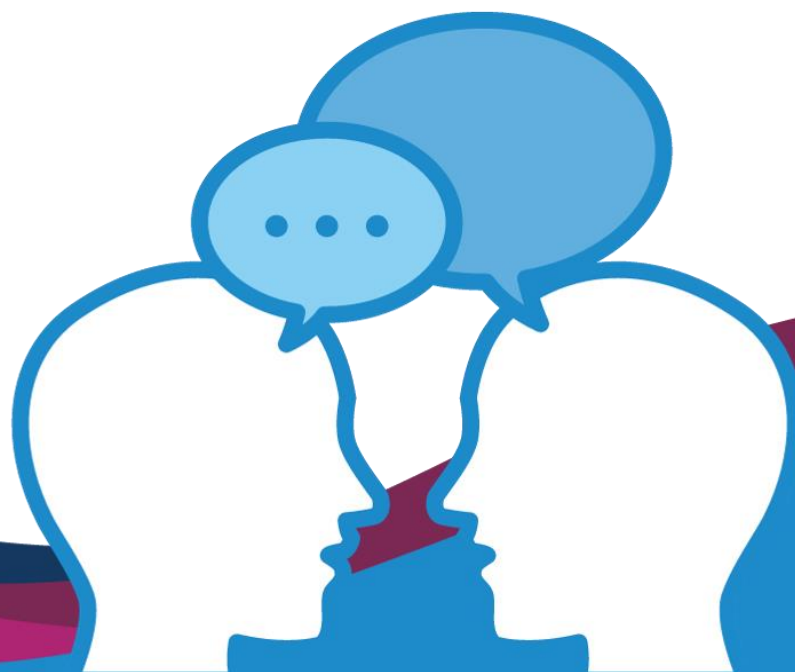
**Lancashire and  
South Cumbria**  
Integrated Care Board

# Head and neck cancer service transformation

## Listening to communities report

October 2023

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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 Swallows group.

## Introduction

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

The Lancashire and South Cumbria Head and Neck Network Programme is working on a model of care that:

- Provides timely and equitable access to head and neck services across Lancashire and South Cumbria.
- Provides world class surgical outcomes supported by diagnostic, day case, outpatient and AHP services provided close to home.
- Ensures that there is involvement of service users and carers in service development and review.
- Retains and attracts a high calibre workforce that provides excellent care pathways.
- Fosters learning and growth through collaborative working and create a service which is stimulating and dynamic to attract a high calibre workforce.

To achieve this the Head and Neck Cancer Network Board is investigating the possibility of 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.

Previous patient engagement with head and neck cancer groups has been reviewed and further engagement sessions have been held to discuss any issues that would affect patients if this model was adopted.

This report outlines the methodology and findings of this.

## Executive summary

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

Focus groups were well attended and although still represent small numbers of people the feedback through lived experience is of high quality.

In general, the people we spoke to were happy to travel for specialist care, especially as a 'centre for excellence' would encourage greater sharing of expertise. There were some concerns around communication between different services.

Participants were keen to emphasise that the nature of their surgery could impact them in such a way that they need further treatments. Dentistry was particularly mentioned since there is a recognised shortage of dentists but many people who have had head and neck complex surgery require greater attention from this service. Lack of access to dentistry

services, and other services that deal with other related conditions, can have an impact on quality of life after surgery.

The main findings can be summarised as the following lessons learned:

1. All services in the network, whether that be in community or in hospital should be connected. Preferably with regular meetings with all staff a patient comes in to contact with but, at very least, with access to each other's notes and shared patient records.
2. Services should have close links and access to other services that patients may need as a result of their surgery.
  - a. Particularly dentistry
3. Hospital services should be aligned to other specialities since head and neck cancer patients may have multiple conditions and there is a need to avoid multiple journeys for multiple appointments.
4. Services should be mindful of the longevity of the condition following complex surgery making a person "a patient for life."
5. Services should be offered to carers to provide support and training.
  - a. Preferably with an emergency contact.

These findings are supported by the insight from the Clinical Strategy Development engagement which NHS Lancashire and South Cumbria ICB began in May 2023. They also reflect the conclusions of the engagement activity carried out in 2019 which looked at improving services.

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?

### We want to make sure local people...



...Are aware and informed about proposals...

... Know how they can get involved...



... Understand why decisions are made...

...Feel enthusiastic about what is possible...



...Have trust in the process.

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 head and neck cancer services (incorporating Ear, Nose and Throat (ENT) and Oral Maxillofacial Surgery (OMFS) specialties) can be improved.

Currently, procedures are carried out at varying levels across our hospitals. Some hospitals only offer some procedures, some offer all procedures, and some hospitals don't offer any. Some also offer support for hospitals operated by other NHS Trusts, with patients travelling between hospitals for some procedures.

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 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.

We have been talking to people with lived experience of head and neck services to gather opinions on what should be considered if such a model were to be developed in Lancashire and South Cumbria.

## Who have we heard from?



### What have we talked about before?

#### Head and neck cancer service review

A patient survey was initially used in 2018 to look at the services offered at East Lancashire Hospitals NHS Trust and Lancashire Teaching Hospitals NHS Foundation Trust.

A breakdown of the results of this survey can be found in [appendix 1](#).

A round of engagement activity took place with patients between December 2018 and March 2019.

A full breakdown of the 2019 survey can be found in [appendix 1](#).

#### 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 2](#).

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

### Deciding who to talk to

The equalities and health inequalities impact risk assessment (EHIIRA) for the head and neck cancer programme 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 head and neck 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 Swallows Head & Neck Cancer Support Group
- Preston Laryngectomy club
- East Lancashire Laryngectomy club
- SOS - Cancer Support group

Five other groups were identified and contacted but had unfortunately ceased operation.

### How many people got involved?

- The Clinical strategy development survey reached 357 people.
- The virtual focus group had nil attendance.
- The Swallows group was attended by 9 people.
- The questionnaire had 12 total responses with five highlighting specifically to being head and neck patients (at time of submitting report).

In total 378 patients were surveyed.

A breakdown of the demographics of the respondents to all of these can be found in [appendix 3](#).





# How did we speak to people?



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

## Focus groups

All of the groups listed above were contacted to invite them to two virtual groups hosted on Microsoft Teams by the ICB communications and engagement team on 13 September and 5 October.

Along with this invite an offer was made to attend their group meetings in person. An invitation was received from the Swallows group in Blackpool who are already involved with the network programme. The group meeting as held on 13 September.

Maire Morton, clinical lead for the programme was in attendance at all groups.

There were three main discussion topics:

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

Along with two other questions 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 head and neck cancer services?
- Are there any considerations that are missing from our list of what patients have told us previously?

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

**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

**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

**Financial sustainability**

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

**Head and neck cancer services**

Head and neck cancer is a general term that covers a group of biologically diverse cancers, such as cancer of the larynx, or voice box (laryngeal cancer) or cancer of the ear (of which there are three distinct structural parts - the ear canal, the middle, and inner ear).

By convention in the UK, it includes cancers that start in the Upper Aerodigestive Tract (UAT). This includes the following:

- Oral cancer (mouth, lip & oral cavity)
- Cancer of the larynx (voice box)
- Cancer of the pharynx (throat)
- Thyroid cancer (which is out of scope for this workstream)
- Other head & neck cancers

**In Lancashire and South Cumbria**

- Head and neck cancer (ENT and Oral Maxillo-Facial) services are provided by all of the Lancashire, South Cumbria and Wigan Hospitals.
- Specialist inpatient and day case head and neck cancer surgery is carried out at LTH and ELHT. LTH supports UHMBT and BTH patients.
- Day cases are carried out at BTH, UHMBT and Wrightington, Wigan and Leigh hospitals, where the ear, nose and throat services are in scope for this review.
- Royal Bolton Hospital has out-of-hours arrangements where ENT emergency patients are supported by LTH, and OMF patients attend ELHT for emergency care.
- Wythenshawe Hospital (Greater Manchester) provides ENT laryngectomy services (that are within the programme scope) and Max/Fax and Thyroid (which are out of scope) surgical support for WWL patients.

## 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 Cancer Alliance also agreed to circulate the survey via the cancer nurse specialists.

The survey can be found here: [www.smartsurvey.co.uk/s/Cancerservicesclinicalreview](http://www.smartsurvey.co.uk/s/Cancerservicesclinicalreview)

This was shared with Trusts to share with patients they may have contact with, through the ICB citizens panel, through the patient groups identified and with hospital Trust cancer nurses to share with their wider contacts.

It was also present on the ICB 'Have your say' web pages.



## 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 head and neck services could be provided in community settings?**

- Dentistry was seen a key service that patients would need to access.
  - Some dentists (if taking new patients) often refuse to take patients with a complex history such as those that have had head and neck cancer surgery.
- Biopsy collection could be better at a local health centre.
- Complex surgery often causes health issues that require ongoing treatment and access to other services.
  - These services should be offered to patients as they are 'patients for life'.
- Some people raised an issue with having lots of multiple layers and locations to services and how this could affect waiting times as referrals are made and delayed.

### **Q: Which head and neck services should be delivered in a hospital?**

Specific services mentioned were:

- Scans
- Oncology
- Only those requiring specialist equipment.

Conversation focussed not on which services would be best in hospital but how they are executed operationally.

- Services need to be joined up;
  - particularly around computer systems with test results and patient information being shared.
  - Others suggested that what was key is to ensure all the specialists involved are accommodated in the same place so they are able to discuss patients quickly and easily. And on demand for consultation with another specialist.
- Carers need to be prepared.
  - Carers often have to support patients but have little training on how to do so.
  - Treatment plans need to be followed and procedures have to be carried out at home that carers have no experience or training on how to do.
  - Carers often notice more about the patient's condition than the patient.
- If a patient has a need for ongoing treatment for conditions caused by head and neck cancer treatment they should all be in the same location and connected.
- There were concerns about hospital services, community services and GPs being connected within the network so that decisions are made as a group and everyone is aware of treatment plans.

- Especially where community teams are required after discharge from hospital to make sure community services are available immediately and fully aware of what is needed.
- Community services are often relied upon in an emergency but are not always available to provide an immediate response. There should be a service that does this.
- Appointments were raised as an area that needed to be improved especially if those appointments were to be held at different locations. There is a worry that people may receive appointments for different locations at similar times making it impossible to attend one or more of them.
- There was reference to digital technologies and the use of virtual appointments for patients who are able to – with people being favourable to this.
- Chemo and radiotherapy were mentioned with a suggestion that these should be done in hospital but in more local hospitals.

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

- There was a concern about visitors being able to travel.
- The key consideration was around post-operative care and support.
  - A patient is a patient for life and should not be forgotten about after complex surgery and services should be in place to support such patients.
  - Patients also prefer to see the same consultant throughout treatment and their ability to do this in a local hospital setting if the majority of the consultant’s time is at a centre was a concern.
- There was again, concern around having another layer and the specialists being in one place and other services in another making it very difficult for those services to be fully joined up.

*“The operation isn’t something we can influence; it has to happen, and we will go wherever and do whatever has to happen. It’s after, where we drop off the radar and that is what needs to change.” [Participant]*

## 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.

1. All services in the network, whether that be in community or in hospital should be connected. Preferably with regular meetings with all staff a patient comes in to contact with but, at very least, with access to each other's notes and shared patient records.
2. Services should have close links and access to other services that patients may need as a result of their surgery.
  - a. Particularly dentistry
3. Hospital services should be aligned to other specialities since head and neck cancer patients may have multiple conditions and there is a need to avoid multiple journeys for multiple appointments.
4. Services should be mindful of the longevity of the condition following complex surgery making a person "a patient for life."
5. Services should be offered to carers to provide support and training.
  - a. Preferably with an emergency contact.

In general, the people we have heard from are in favour of a network model in line with the national recommendations.

The general feeling is that a centre of excellence will benefit patients and improve quality of care.

The main issues raised were around the services that are not part of the centre of excellence provided in the community and at local hospitals. These being around separation of services and joined up care.

The nature of specialised surgery for head and neck cancers brought to light more of the need for services to be established to overcome some of the issues that are faced following surgery. Head and neck cancer patients often require further interventions and access to other services as a result of their surgery and very often these services are not available or are difficult to access. Dentistry was particularly raised.

Another particular issue raised was about post-surgery care and support that is provided for carers. Training and support for the carers is needed.

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 head and neck cancer services in the future.

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

## Appendix 1 – Previous head and neck programme engagement report



Head and neck patient survey 2018.

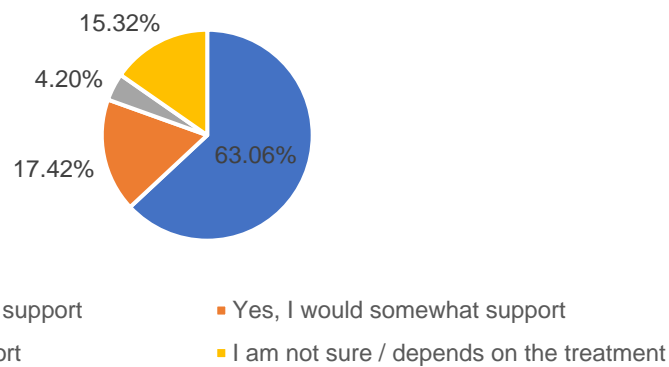


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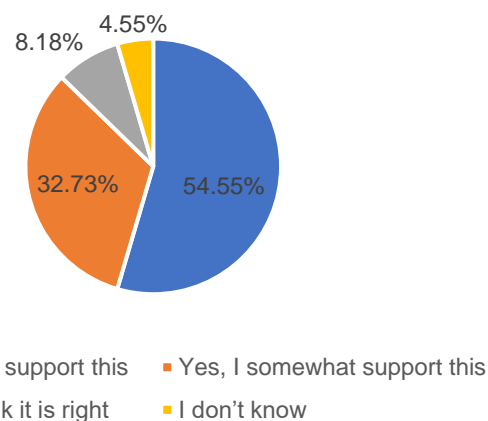
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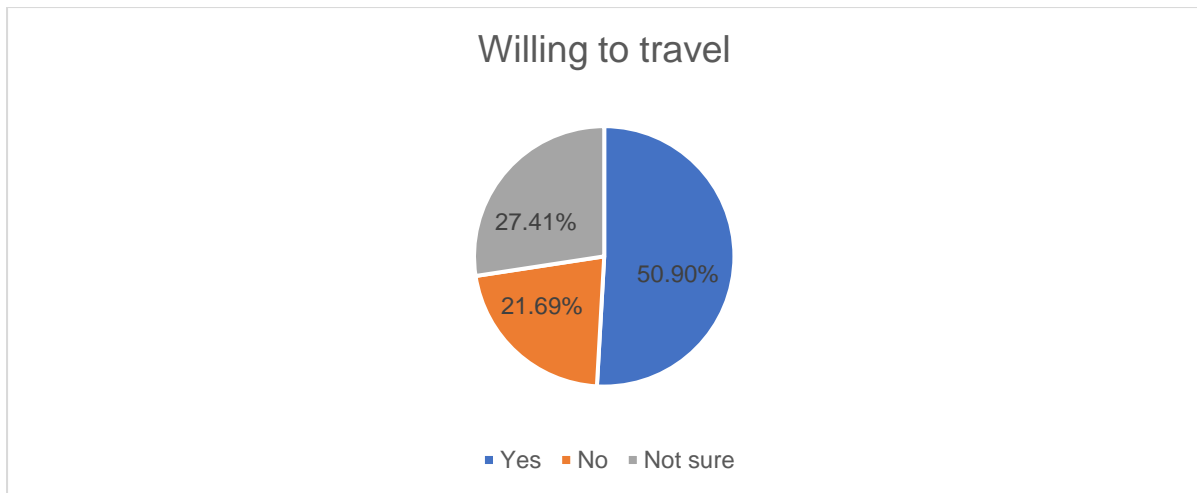
## Appendix 2 – 2023 Clinical strategy survey results (pertinent to this report)

### Treatment in community setting

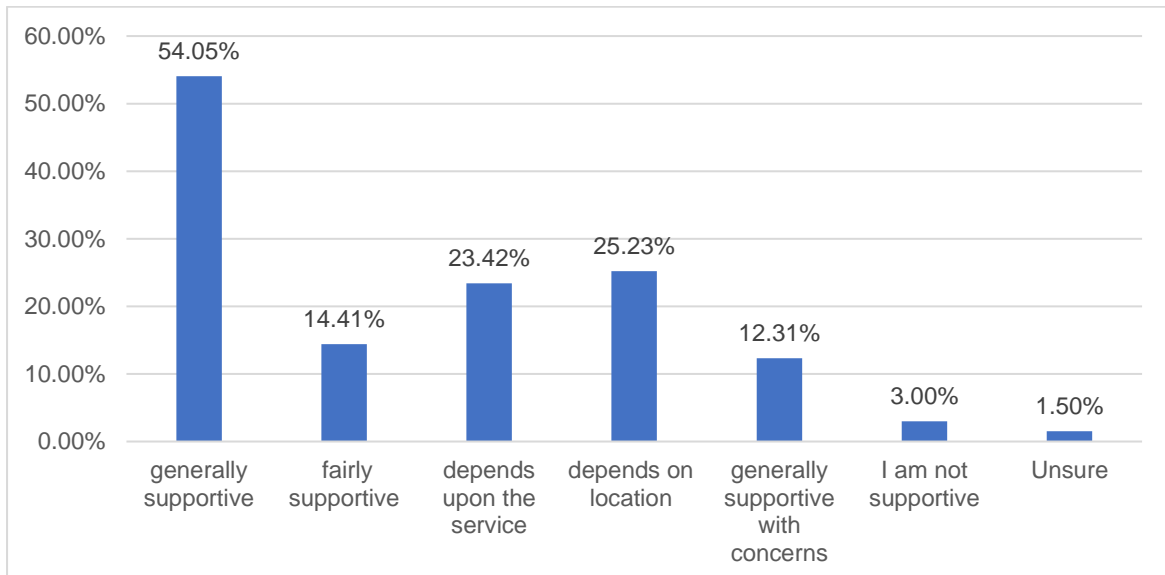


### Services in community setting allowing specialised services in hospitals





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            | • Primary Care/GPs                |
| • Communication                 | • Recruitment/Retention/Workforce |
| • Cleanliness/Hygiene           | • Dental                          |
| • Staff wellbeing/Pay/Morale    | • NHS image                       |
| • Transport/Travel              | • Skills/Training                 |
| • Waiting times                 | • Bureaucracy                     |
| • Access                        | • Leadership/Culture              |
| • Follow up advice.             | • Mental Health/Social care/VCFSE |
| • Estates/Facilities            | • Integration                     |
| • Demand/Increase in population | • Lived experience.               |
| • Digital/IT                    | • Person centred                  |

## Appendix 3 - 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.

