

# East Lincolnshire sleep service engagement report

## 1) Introduction

United Lincolnshire Teaching Hospitals NHS Trust (ULTH) is proposing to undertake a procurement exercise for the sleep service in the East of Lincolnshire.

To ensure we meet our legal duty to involve when changing or developing services, we have carried out a six week patient, staff and public engagement exercise, run from on Friday 23 August 2024 until Friday 4 October 2024.

The feedback received in this engagement exercise will be used to inform the development of a service specification to take out to procurement. Listening to feedback will ensure that we design a service specification that takes into accounts views of current patients of the service, and the wider population of the east of Lincolnshire, on what they would like to see from a sleep service in their areas.

## 2) Engagement activity and response rates

This engagement activity primarily focussed on using two surveys, one for patients and public and one for staff, to gather feedback, with the additional offer to speak to or visit any interested parties or groups to discuss further upon request.

Response rates are as described below:

- Patient and public survey (579 responses)
- Offer of attendance at any patient group meetings to discuss further (none)
- Feedback received on email and social media from patients (7)
- Feedback on email for current service provider (6)
- Staff survey (15 responses)

## 3) Promotion

During the course of the engagement exercise, we have carried out extensive communication with our staff, public, patients and stakeholders about the opportunities to engage. This has included:

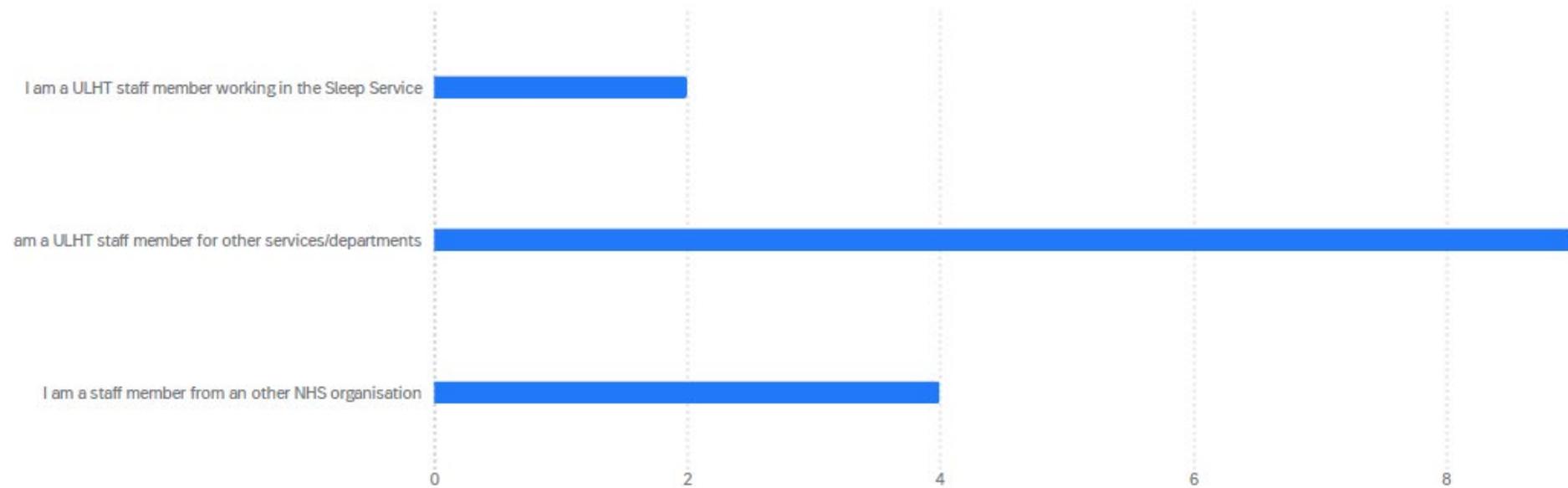
<b>What</b>	<b>Who</b>	<b>When</b>
Social media messaging through ULTH corporate Facebook, Twitter and Instagram accounts	Patients and public	Ongoing from 23/08/24 to 04/10/24
Advertising on ULTH website	Patients and public	Ongoing from 23/08/24 to 04/10/24
Partner messages, asking communications and engagement leads in the Lincolnshire system to share on their social media channels and websites, with staff and with patient groups and databases	Staff, partners, patients and public	23/08/24
Stakeholder message, asking for word to be spread to constituents, staff and on social media channels	Stakeholders, patients and public	02/09/24
Agreement with existing service provider that they would share the survey link with existing patients either electronically or via paper copy, as suitable	Patients and public	12/09/24 to 04/10/24
ULTH staff-facing messaging including in Weekly Round-up, CEO blog, Communications Cascade, staff intranet and on closed staff Facebook group.	Staff	Ongoing from 23/08/24 to 04/10/24
Media message issued to all local media asking for the survey to be shared	Patients and public	12/09/24
Direct contact with local support groups and voluntary sector organisations Hope2Sleep and Lincolnshire CVS asking them to share with members	Patients and public	12/09/24

## 4) Findings

### Staff survey

The survey ran from Monday 2 September 2024 to Friday 4 October 2024 and attracted 15 individual responses.

**Q1 Please confirm which of the following statements most accurately describes you:**



**Q1b Please tell us which organisation you work for:**

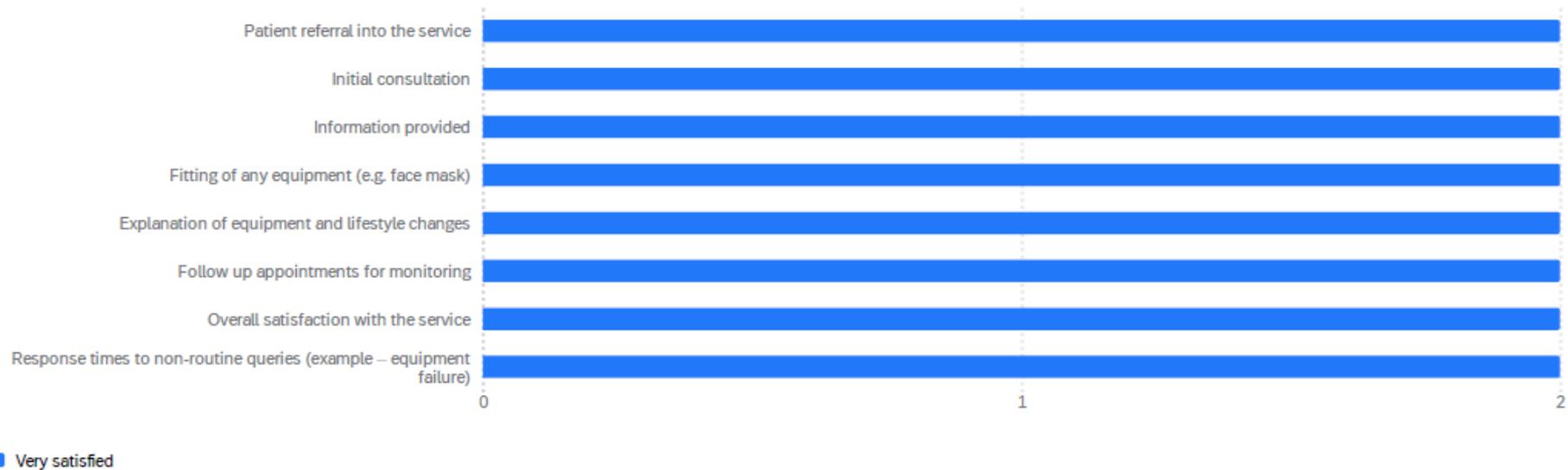
- Most worked for LCHS
- Some provided for a private sector/independent provider

- None worked for ULTH

**Q1c Please tell us how you provide treatment to patients the majority of the time:**

There was an exact split between those providing face virtually or face to face.

**Q1d Thinking about the treatment provided to patients, please tell us to what extent you are satisfied with the following:**



**Q2 Please tell us some that you think currently work really well in the sleep service (summarised):**

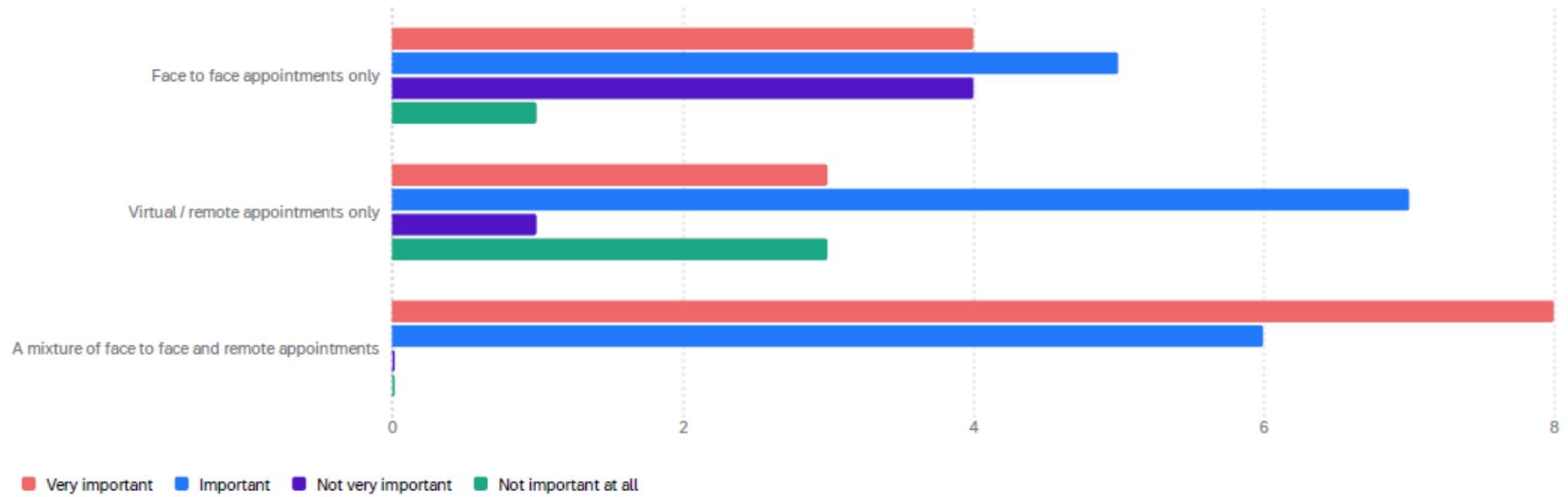
- Excellent MDT working which is documented well.
- The supportive approach with the NIV devices means that respiratory patients can be sent home safely with a reduced possibility of readmission.
- Clinicians with sleeping disorders are very well looked after by Mr Oko which leads to an excellent work ethic and feeling of value.

- Patients are seen in a timely manner and the remote working protects them as already vulnerable patients from hospital acquired illness.
- Home visits are very well received and effective.
- Patients at Lincoln get a good service.
- Telephone appointments
- The pathway involving the Respiratory Physiologists employed by ULTH and based in Grantham and Lincoln is very patient centred and works well.
- Prompt service
- 96 % patient satisfaction 6 week wait time home installation of cpap and masks

**Q3 Please tell us if there is anything you think could be improved in the current service and what support you would need to achieve this:**

- Would have preferred a more local appointment
- Additional administration support
- The service at Boston is disjointed.
- Would like monitoring over longer than 24 hours, say 48 hours.
- Would like one service under one directorate to manage sleep at ULTH
- The virtual service provided by the ENT led semi-private provision is poor- a virtual service cannot replace proper training and mask fitting, and it is expensive for what it is providing
- Received negative feedback from patients seen in the east, including lack of face to face/ lack of explanation / monitoring or treatment delivered rather than shown. a lack of understanding of conditions other than OSA/CPAPNIV
- NIV service provided by ULTH needs to provide home visits to patients who are housebound.
- Phone calls or emails by nurses to ask advice at Lincoln are often not answered by the sleep service.
- Patients also complain they are unable to speak with someone.
- More funding for this service.

#### Q4 How important do you think each of the following are to maintain high standards of quality?



**Q5 Thinking about how we could deliver sleep services in the future please tell us where you feel would be the most appropriate place to deliver each part of the treatment:**



**Patient and public survey**

The survey ran from Friday 23 August 2024 to Friday 4 October 2024 and attracted 579 individual responses.

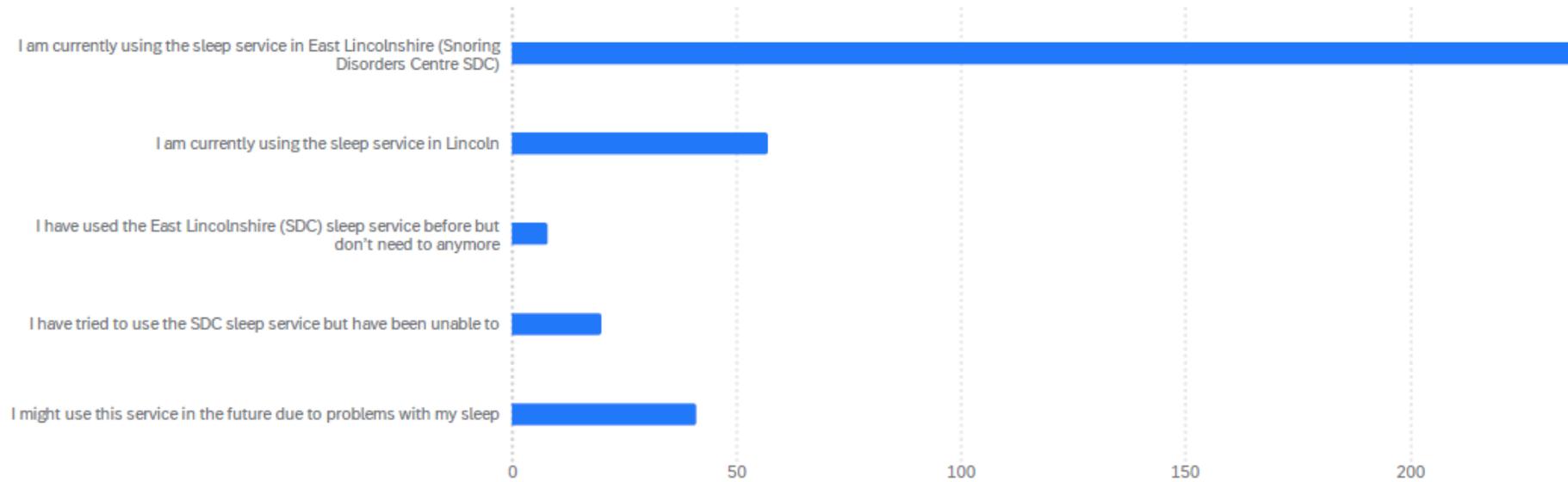
**Q1 Please tell us your full home postcode:**

Responses received showed that the majority of respondents lived in Boston and Skegness area, with others spread across Lincolnshire.

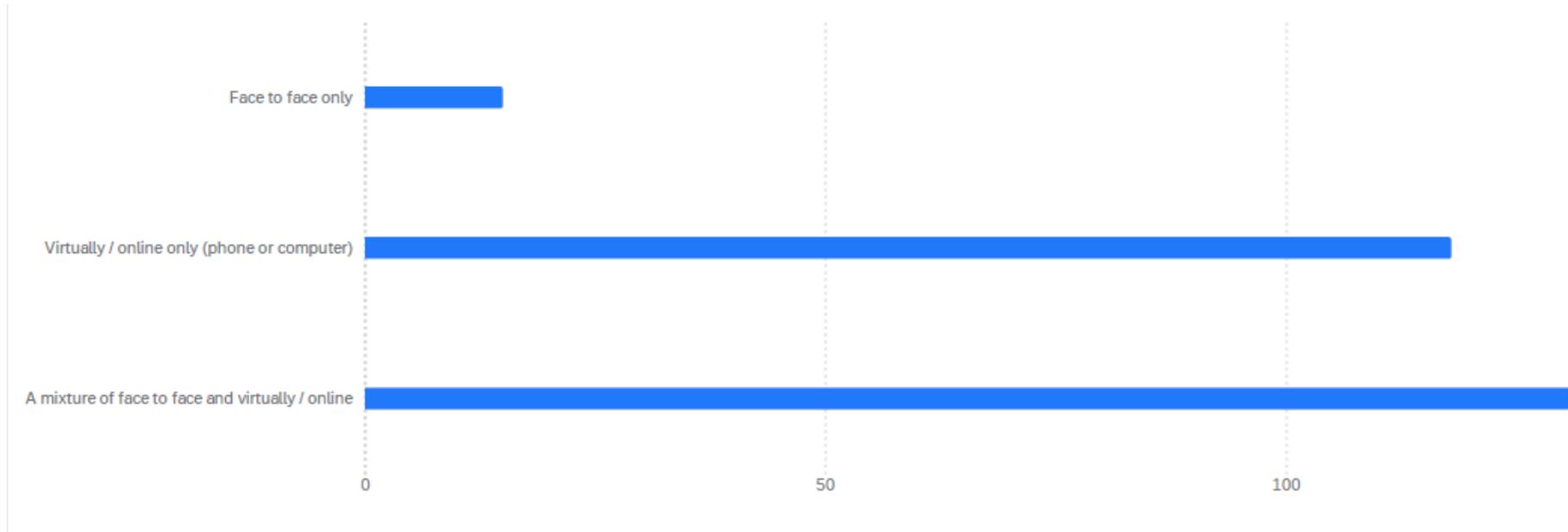
**Q2 Please select the Lincolnshire GP practice you are registered with:**

- The majority were registered with Boston, Skegness and Spalding-area GP practices
- A smaller number came from Lincoln-area practices
- Some patients were registered with practices across the wider Lincolnshire area

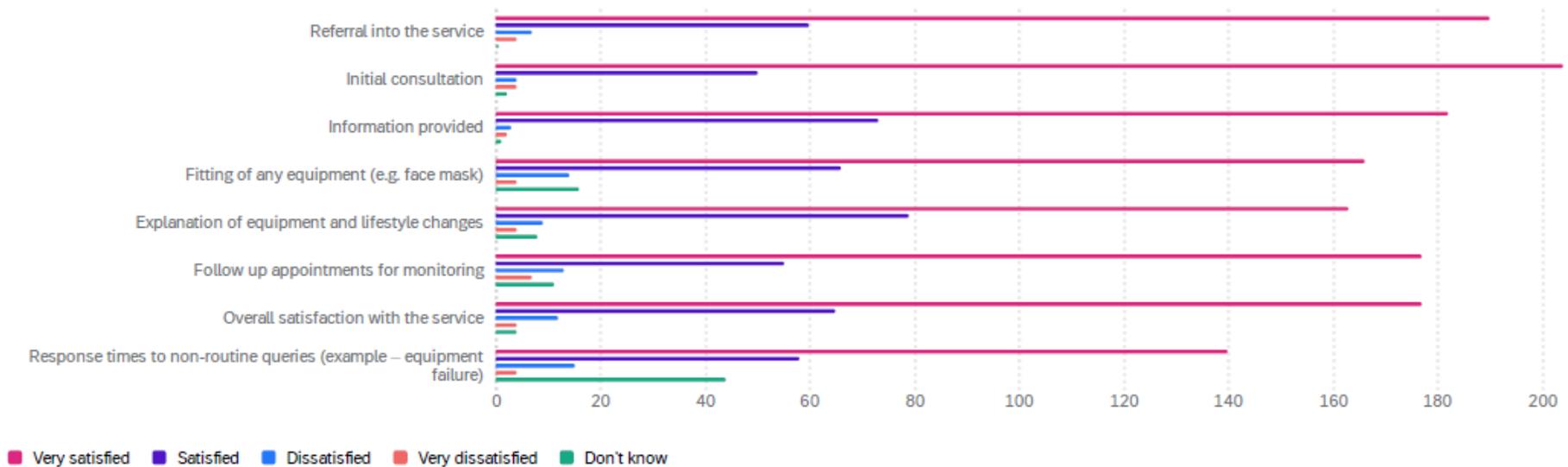
**Q3 Please confirm which of the following statements most accurately describes your experience:**



**Q4 Please tell us if you have received treatment:**



**Q5 If you are currently using or have used this service in the past, please tell us to what extent you are satisfied with the following:**



**Q6 Please tell us anything that you particularly like about the service:**

- It is efficient and everyone is friendly and helpful.
- Once told about any issues with equipment it is very quickly dealt with and fixed
- Appointment always prompt in time any issues and I can get them sorted quickly
- It is easy with phone consultations
- The staff
- They ring close to appointment time.
- Prompt delivery of replacement parts I have needed
- Regular contact check in during the year.
- A point of contact always available.
- Ease of use of the diagnostic equipment.
- Able to speak to someone even if it's not your appointment time

- Personalised care
- I like how informative and encouraging the service is while adapting to use of equipment
- I have never had my appointment cancelled.
- Good communication.
- There is a seamless service between the hospital and the dental surgery providing my mandibular device.
- The referral process via ULTH e-referral system is quick & easy to use by identifying the patients' risk factors for sleep apnoea.
- The service itself is adequate, it is the treatment which I have struggled with.
- No face to face appointment
- Clear helpful instructions
- Continuity of speaking to the same person at each consultation.
- I don't need to visit hospital
- Telephone consultation very convenient and saves lengthy journeys to hospital and saves on parking cost
- Very informative consultations
- The provision of equipment and replacement equipment i.e. masks tubes etc is very good

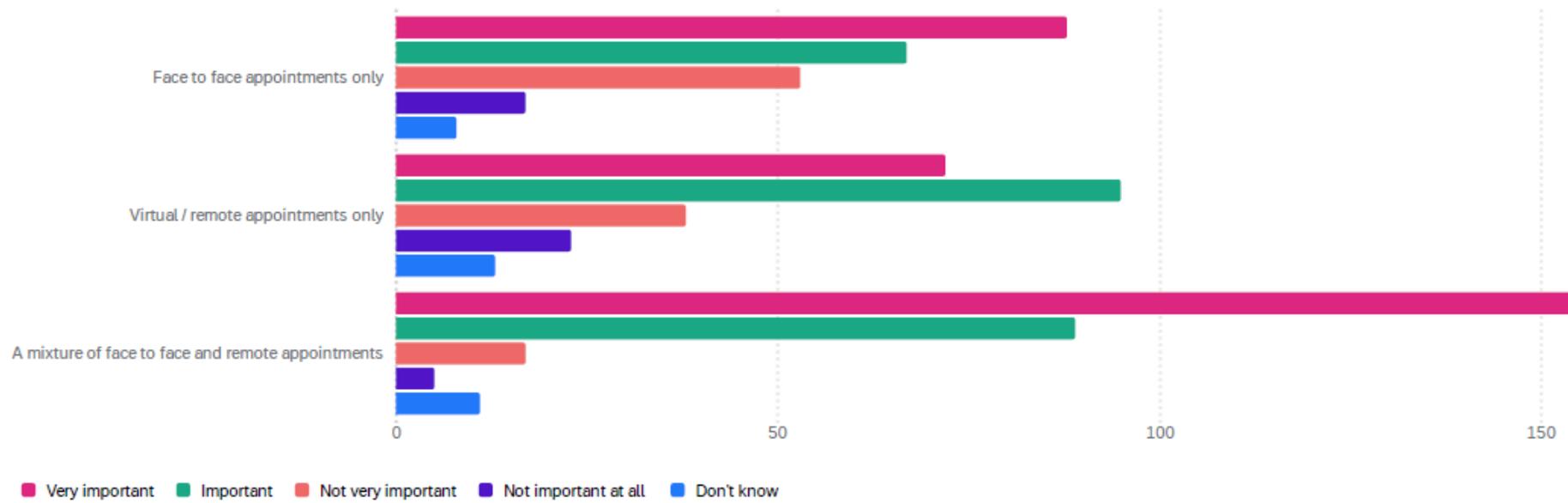
**Q7 Please tell us if there is anything you think could be improved in the current service:**

- I have never had a face to face consultation/ would like a face to face consultation
- Unfortunately replacement equipment has taken up to 3-4 weeks to reach me
- I don't like the machine, it is heavier and more bulky than the previous one.
- Meeting consultant at least 1 time a year.
- I have had no formal diagnosis in writing
- More staff and more space for the CPAP service with dedicated waiting area
- Never been shown how to use the equipment.
- Being diagnosed was scary and had no idea what to do with equipment or explained the risks or prognosis.
- I had to learn about everything online.
- Difficult to get hold of someone as there is no way to leave a message or speak to someone as phone just rings out.
- Improved longevity of the masks.
- Waiting times for assessments.
- Communication via appointments has been poor
- I am a deaf person and struggle with my telephone appointments

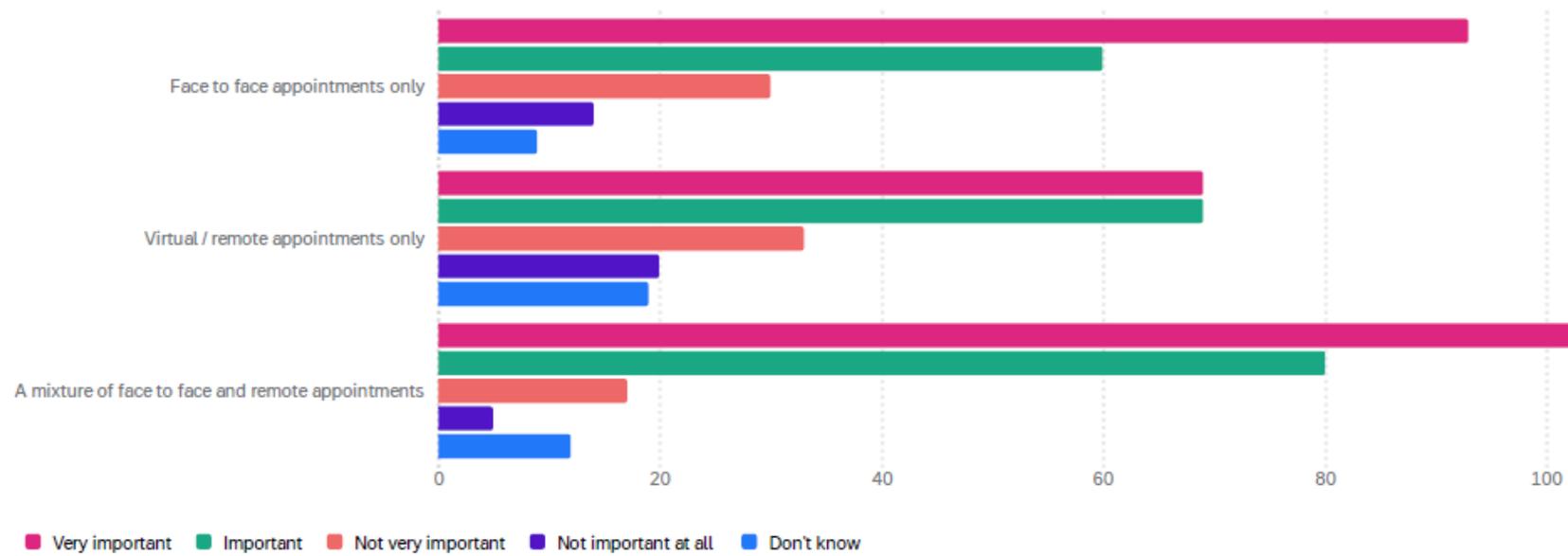
- Telephone appointments outside of working hours, for those who have jobs
- The service needs to be expanded.
- Having the phone lines manned at Pilgrim.
- It is a long time between appointments and results
- A better mask fitting service
- Make the machine smaller to be able pack and travel better.
- I think it may be an idea to periodically be tested to see if the sleep apnoea condition has improved or cured patients so that there's no further requirement for the use of the cpap device.
- Follow up appointments over the telephone sometimes feel a little bit rushed.
- No home visit for disabled and mental health people with social anxiety

**Q8. How important do you think each of the following are to maintain high standards of quality, safety and access for the service?**

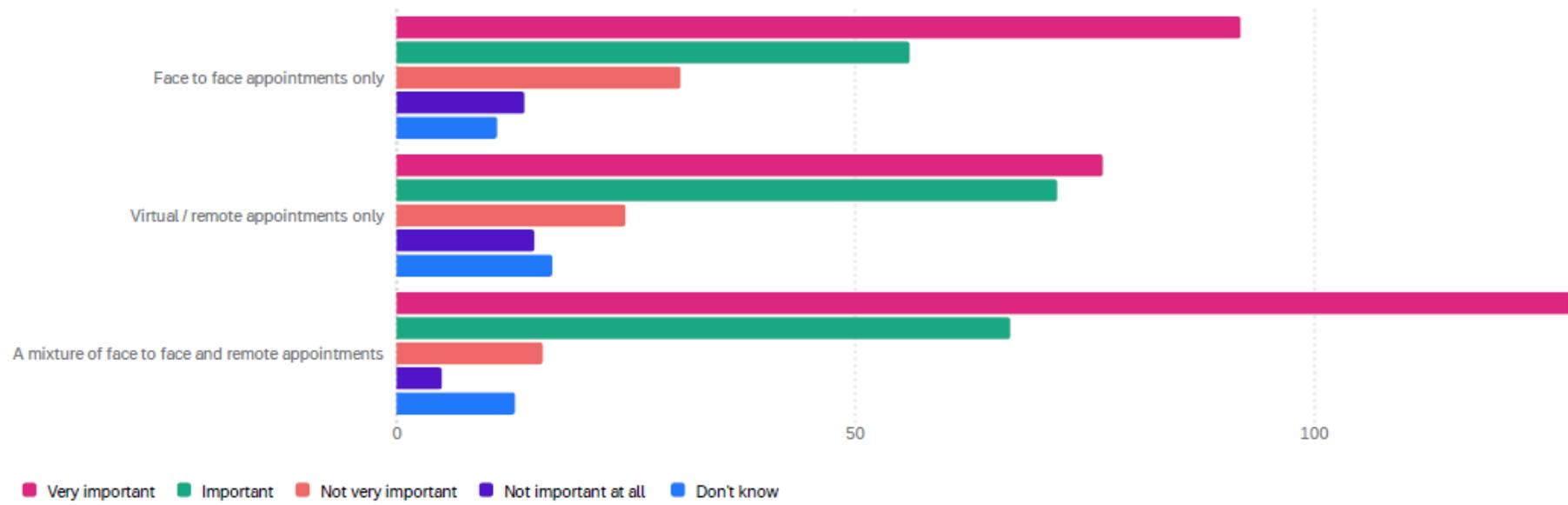
**Quality:**



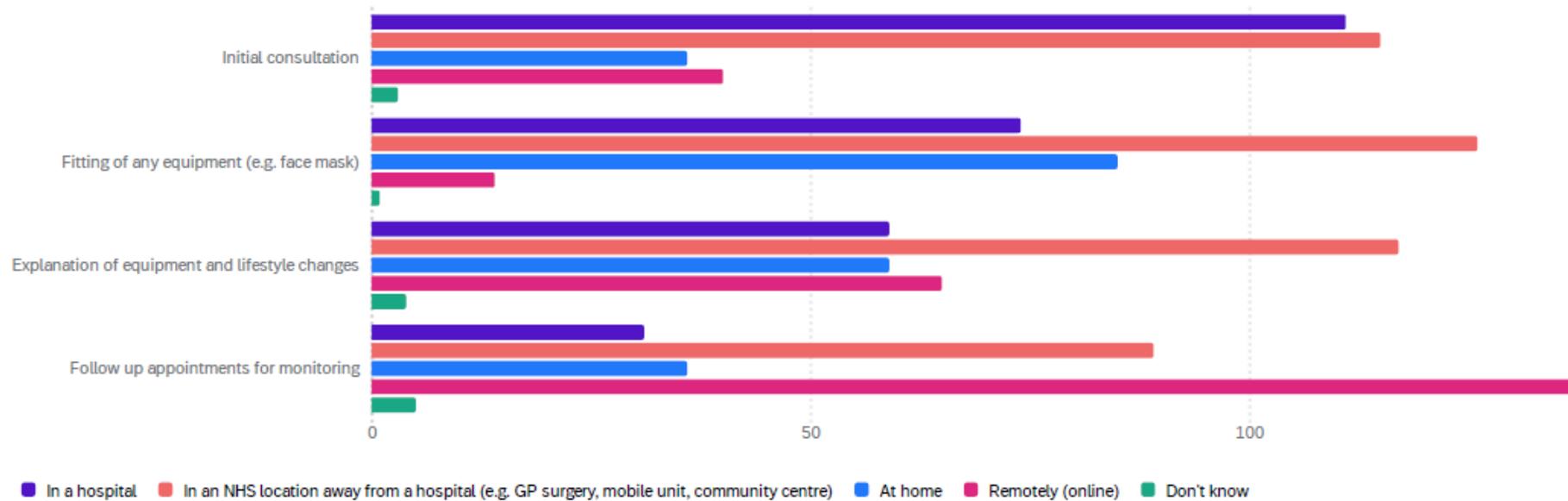
## Safety:



## Access:



**Q9. Thinking about how we could deliver sleep services in the future please tell us where you would prefer to receive each part of the treatment:**



**Other feedback- existing service provider**

The existing service provider offered a large volume of patient feedback and survey results from previous patient satisfaction surveys, evaluating the current service as it stands. It must be noted that this does not constitute first-hand feedback from patients as it has been supplied by the provider themselves. Full details of these patient surveys can be found as an appendix to this report.

It is worth noting that, overall, the feedback shows that current patients of the service are very happy with the service provided, are complimentary about the staff within the service and are keen to see it continue to be delivered as close to peoples' homes as possible.

Constructively, this feedback included information that showed:

- The service is very easy to access
- Good communication is important
- From a 2022 survey of 1,345 current patients, 72% of current patients would like to continue to have consultations online, with 28% not wanting virtual consultations in future.

## **Other feedback- individual feedback by email and social media:**

### **Email**

- One individual emailed with their feedback, saying that they feel there is not sufficient help out there for dyssomnia, parasomnia, and circadian rhythm categories of sleep disorders.

### **Response to social media posts**

- Would like a better service in the South of Lincolnshire
- Have had issues with a delay in getting care from the sleep service following referral
- Training in recognising upper airway resistance syndrome is required
- The current service is fantastic
- Was told none of the services in Lincolnshire deal with insomnia so had to go to Leicester
- Need to find the right staff to be able to communicate with a patient in a way that meets their needs

## **5) Themes**

A summary of themes from this engagement exercise can be found below.

### **Staff**

- Home visits are important and well received
- Pathways involving respiratory physiologists works well
- Excellent MDT working
- Additional administration support needs to be considered
- Desire to see sleep services managed pan-Trust

- Investment needed in the service
- Improvement needed in telephone contacts
- A mixture of face to face and remote appointments were felt to be of most importance
- Overall, it was felt that Initial consultant, fitting of equipment and explanation of equipment should be conducted in a hospital or face to face setting, whilst follow up appointments should be done remotely, where possible

### **Patient and public**

- High level of satisfaction with the existing service
- The only area which evaluated less well was response times to non-routine queries
- Some positive feedback on phone consultations
- Praise for staff
- Some reported they were happy not to have to visit hospital
- Some complaints about delays in receiving replacement equipment
- A high number of responses said patients would like to have more face to face consultations
- Suggest improvement in mask fitting service
- Overall, it was felt that a mixture of face to face and virtual appointments are needed to ensure quality of care, with more of a focus on face to face
- Overall, it was felt that a mixture of face to face and virtual appointments are needed to ensure safety of care, with more of a focus on face to face
- Overall, it was felt that a mixture of face to face and virtual appointments are needed to ensure access to care
- Overall, it was felt that initial consultation, fitting and explanation of equipment should be conducted face to face in a hospital, other NHS or home setting, but that follow up appointments would be preferred either virtually or at another NHS setting.