

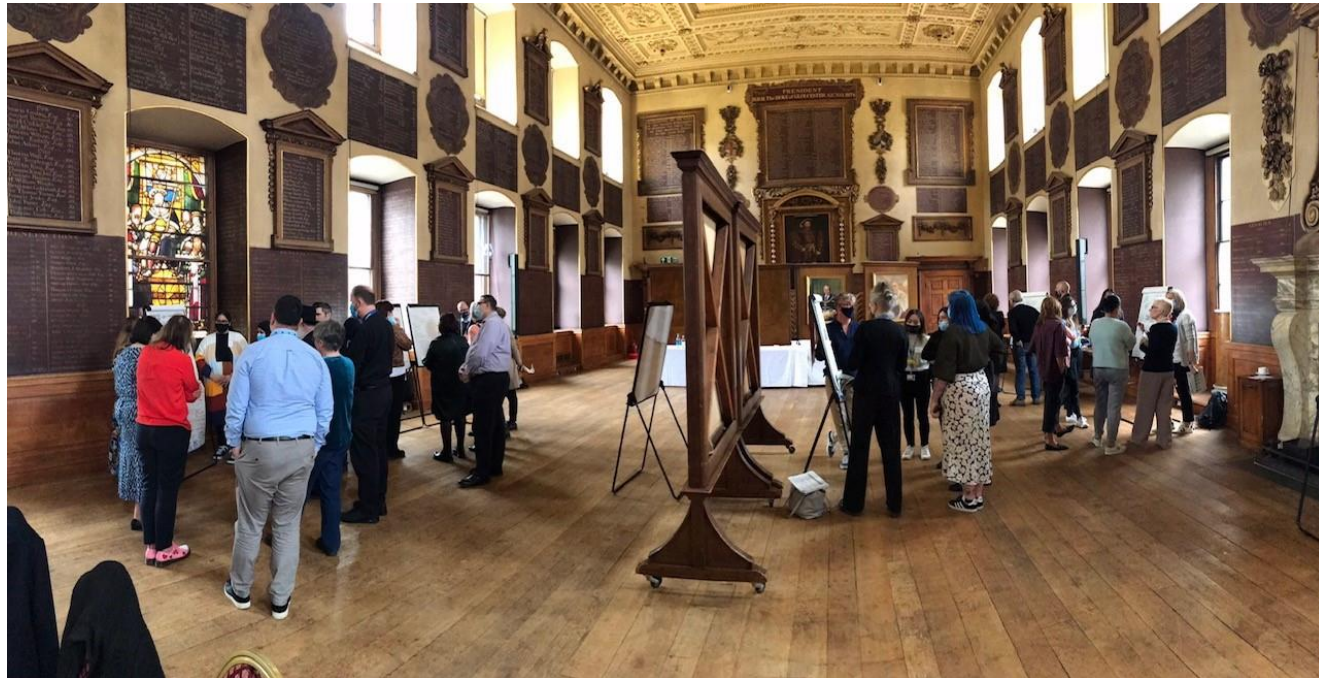


Valuing patient and community voices

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① I am listened to and what I say is acted on



② I make decisions that are respected, and I have rights that are protected



③ I am given information that is relevant to me, in a way I understand



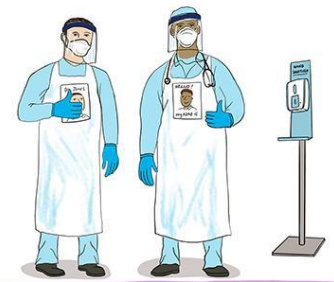
④ I am supported to understand risks and uncertainties in my life

I-Statements

National
Voices



⑤ I know how to talk to the person or team in charge of my care when I need to



⑥ I know what to expect and that I am safe when I have treatment and care



⑦ I am supported and kept informed while I wait for treatment and care



⑧ I am not forgotten



Valuing patient and community voices



I am listened to and what I say is acted on

I make decisions that are respected, and I have rights that are protected



We will respect your decisions about your care and protect your individual rights



I know what to expect and that I am safe when I have treatment and care



We will listen to your feedback and act on it



I am supported and kept informed while I wait for treatment and care



I know how to talk to the person or team in charge of my care when I need to



We will provide support so that you know what to expect and feel safe during your care



We will provide information to support you while you wait for treatment and care



We will make it simpler for you to contact us and get the information you need, in a way you understand



Experiences of Care week April 24th – 28th





Barts Health
NHS Trust



Patient persona research



Background & objectives

The Trust wanted to create a range of personae to highlight some of the unseen challenges that patients face when accessing services provided by the trust and to get staff thinking about how the way they provide their service impacts on the patient. The personae will be used in both staff and service development.

This hopefully become a growing library of personae that teams can use to develop additional patient segments specific to their area of work.

The Barts Health team conducted a programme of patient segmentation research using qualitative research in order to achieve the following key aims:

1. Understand patient needs and how these vary for different types (or segments) of patient, taking into account the diversity of patients and a desire to ensure that seldom-heard groups are understood.
2. Develop patient personae that help with detailed understanding of patient needs across a range of segments.
3. Provide a range of patient personae and present them in a way that is useful and relatable.

The personae are all based on real life stories, events and feedback gained from patients through qualitative research.

As well as covering a diverse mix of patients the personae cover a range of service types including; A&E as well as both surgical, inpatient and outpatient services.



Patient depths: sample overview

In order to ensure some representation of response from key groups of interest and to ensure we heard from a diverse a range of patients as possible we set some quotas to aim for.

We looked to speak to a variety of patients in different circumstances across the following categories:

- Patients with a range of disabilities (physical, neurodivergent/learning, neurological, mental health etc.)
- Those who speak English as a second language
- Full time carers
- Patients with a range of condition types (life limiting, chronic/long term, minor illness/injury, surgical patients)
- In-patients & outpatients
- Patients across a range of age groups from babies, young children, young adults and teens to older patients
- Patients from a range of socio-economic backgrounds
- Patients with communication barriers
- Patients from a variety of ethnic groups/backgrounds





My name is
Sahiba

- I am aged 64
- Indian Sikh
- Limited English
- Chronic illness (Diabetes, Hypothyroidism)
- Health anxiety & IBS
- Planned appointment

"I get very anxious these days when leaving the house and I need to prepare both mentally and physically in many ways. Anything related to my health gets me especially anxious. I am very reliant on my family to help support me with appointments, including translation."

Overweight

Poor diet management

Embarrassed

Anxious

Multiple concerns

Reliant on family

Who I am?

Sahiba lives in Essex with her older husband. As Sahiba has never worked in the UK and talks in Punjabi at home, her English is limited. Since retiring, her husband has also become less confident in his English skills. They have three adult children, with their eldest son, Ranveer, choosing to live closer by in order to help assist his parents. Neither Sahiba or her husband drive since her husband's vision has deteriorated, so Ranveer takes on the responsibility for transporting his parents. Ranveer works full time but spends much of his time helping assist his parents with appointments, admin and translation needs. Sahiba has anxiety and as a result of this rarely leaves the house, as it induces IBS. Sahiba often becomes very concerned over perceived symptoms and worries frequently about her health.

Why I needed care

Sahiba has hypothyroidism and has become **increasingly overweight in recent years**, particularly since reducing her activity outside of the home. Although Sahiba has been given nutrition advice to try and better control her diabetes she **struggles to follow the advice**. Sahiba has an appointment to check her bloods, urine and discuss her symptoms. Sahiba gets very anxious ahead of appointments and **needs a lot of time to mentally prepare**. When Sahiba's appointment **letter only arrived 3 days before her appointment this caused Sahiba some increased anxiety**, particularly when she saw her consultant would also be different to her usual one.

How I accessed care

Sahiba's appointment is in the afternoon, she would prefer appointments in the morning to avoid the build-up of worry on the day. Sahiba wants her husband to also attend the appointment with her, as he is a calming influence for her. After spending many hours helping his mother with her anxiety, Ranveer drives his parents to the hospital. When they arrive Ranveer struggles to find a parking space and has to park at a different side of the hospital to where they need. The long **walk to the department is difficult** for Ranveer to manage as his **mother struggles with her fitness levels and he also needs to help assist his father with his poor vision**. The **surface in the car park is uneven** and presents a trip hazard.

My wait to be seen

The family arrive early for their appointment and are disappointed to learn that there is likely to be a delay. This causes Sahiba some increased anxiety which makes her IBS symptoms worse. Sahiba needs to visit the toilet a number of times during her wait but as the **closest toilet is out of order** she requires her son to help her find the closest one as there are **no clear signs directing to the next one**. Sahiba **finds the toilet to be messy and unclean**. This **increases her anxiety levels** as she has some concerns around infection control. These concerns have become exacerbated since Covid.



Sahiba

How I was treated

Sahiba was relieved to see that the nurses performing her tests were the same nurses she had seen previously and appreciated it when they **remembered her and asked how she was getting on**, this **made her feel more at ease**. When Sahiba saw the consultant she was surprised to see that her new consultant was much younger than her previous consultant. This concerned Sahiba as she **assumed that the younger consultant may be less experienced or less qualified**. When the consultant introduced himself he **did not explain why he was seeing her instead or what his experience was**, which Sahiba would have preferred. Sahiba needs to rely on her son much of the time for translation support, particularly with medical terms. The new consultant **spoke very quickly and used slightly different terminology** to what the previous consultant used, which made translating trickier for Ranveer. As Sahiba was having to rely on her son for translation she **felt less able to raise some of the health concerns she had** regarding some itching and discomfort around her urinary tract, so she did not mention these.

After I was discharged

Sahiba was given some information to take away by the consultant telling her about diet and nutrition to help better control her blood sugar levels. However, Sahiba **did not find this information particularly relevant or useful as much of the dietary information gave examples of more western food choices** and Sahiba assumed that so long as her food was home cooked that it would be better for her, despite being high in carbohydrates. Sahiba also struggles to make good food choices as **she finds the comfort of eating the foods she enjoys helps her with her anxiety** levels. Sahiba **continued to struggle with some of the symptoms she felt she could not raise in her appointment** and as a result of this found that her anxiety and IBS had worsened.

My physical needs...

- I appreciate that parking spaces are limited. Providing clearly signposted drop-off points so my son can drop my at the entrance while he finds parking might help, particularly if some seating is provided while I wait.
- Please ensure that toilet facilities are well signposted and well maintained. Particularly in post-pandemic times it is all the more important to reassure me that am in a clean and safe environment.

My information needs...

- I would appreciate you telling me a bit about you and your experience, it may help me to feel that I am in safe hands and to open up to you more.
- Adapt dietary advice to be more appropriate to my cultural cuisine. I would be more likely to take this advice on board.
- I may not feel comfortable discussing all of my concerns with you, particularly if they are of an intimate nature. Some information to take home covering the more personal symptoms of my condition may be better, particularly if they are already translated.

My emotional needs...

- Please give me plenty of notice ahead of appointments. Leaving the house is a big deal for me and I need plenty of time to prepare and for my son to get time off work.
- On the day of my appointment I can get very worked up, an option of an earlier appointment would be better for me to avoid my stress levels building up.
- As I am anxious about my health I may get upset when discussing my symptoms or assume the worst case. I may need some reassurance to calm me down and some empathy to help me feel listened to.

My communication needs...

- I get very anxious when waiting, so regular updates on how long it is likely to be will help to reassure me that I am moving along in the queue.
- While my son may do some interpreting and translation for me, I would still like to fully understand and participate in conversations if I can, so please talk slowly and leave gaps for translation if needed.
- While I may prefer to have a family member attend appointments with me, it is still important for me to be offered the opportunity to have an interpreter as there may be some things I would rather not discuss in front of family or they may not always be available.





My name is
Jordan

- I am aged 8
- White British
- Chronic condition (bowel disorder)
- Autism & special educational needs
- Planned appointment

"I spend a lot of my life in and out of hospitals and it's not much fun. My autism makes these visits hard for my mum to manage, particularly as my little brother is often with us too. My mum struggles to get me to my many appointments and fit these between school pick up and drop off times."

Complex care needs

Transport barriers

Visits hospital frequently

Cross service needs

Childcare barriers

Incontinent

Who I am?

Jordan lives at home with his mother, Leanne and his two younger siblings aged 5 and 2 in Hertfordshire. Leanne is a single mother and the family rely on income through benefits. Jordan has a number of communication and learning barriers, including Autism and Global Development Delay. Jordan has a suspected but undiagnosed metabolic disorder. Leanne has had to fight hard to get all the support she needs to be able to care for Jordan and has required some assistance with organising benefits, therapies, equipment and applying for an educational health care plan. Leanne has found the systems for receiving support hard to navigate.

Why I needed care

Jordan has been previously diagnosed with a bowel disorder which results in him being incontinent. Jordan attends periodic appointments to help monitor and manage his symptoms. Jordan **has to be seen at the hospital frequently** and the **journey is quite far** for his mum Leanne to make with him into London from where they live. Leanne has to rely on lifts from Jordan's grandfather as she finds **travelling by public transport too difficult** with Jordan's needs. **Managing Jordan's appointments around his 5 year old sister's school pick-up times can be very tricky** for Leanne and any appointment she attends with Jordan also often requires her to bring along her youngest son as his nursery hours are limited.

How I accessed care

Leanne has requested if Jordan's appointments can happen in the middle of the day to fit around school.

However, Jordan's appointments often still come through during these times and **Leanne often has to cancel appointments**. Visiting the hospital with Jordan and her younger son can be difficult for Leanne to co-ordinate. In order to avoid paying parking charges, Jordan's grandad drops the family outside of the hospital and picks them up later. Leanne therefore **has to manage guiding Jordan while pushing the pram with her toddler in by herself**. As the consultant Jordan sees is not permanently based at the hospital his appointments can take place in different areas. The **inconsistency can be difficult for Jordan to cope with**. On the day of Jordan's appointment, Staff were not informed about the consultant being in the department that day which resulted in confusion and delay with checking Jordan in.

My wait to be seen

Waiting for appointments can be difficult for Leanne to manage, particularly if they are in **an area where there are no play areas to engage her sons as Jordan can become restless**. Sometimes Jordan will **repeatedly ask how much longer it will be** and it can be difficult at times for Leanne to give Jordan a clear answer. With Jordan's autism he can **struggle with crowding and lots of activity around him**. Leanne finds that **waiting areas in quieter parts of the hospital can help** and can find it particularly hard when waiting areas are in busy thoroughfares. Because of Jordan's condition and his younger brother's age, Leanne will often have to take both of her sons to the toilet in order to be changed. Leanne can sometimes **find it hard to bring in the pushchair and fit herself and both boys into the baby changing facilities** at the same time.



Jordan

How I was treated

Due to issues with finding a suitable room to conduct his appointments in **Jordan's consultant appeared stressed and flustered**. He **voiced his frustrations about a lack of equipment and resources** to Leanne.

While Leanne appreciates the barriers he is facing it **causes Leanne some concerns about her son's care**. Having seen Jordan previously, the consultant has **built up a good understanding of how best to interact with Jordan** and tries to **bring some of his explanations to life by showing pictures and using models**. Leanne used to struggle to understand her son's condition which caused her frustrations at time. However, **by seeing the same consultant over time and building an understanding with each other**, she has **been better able to make her consultant aware of when she doesn't understand** and he will take the time to try and re-explain things.

After I was discharged

A few weeks after Jordan's appointment Leanne received a phone call from her consultant who advised Leanne that after reviewing his progress with colleagues they now think Jordan would benefit from having a Stoma. The **brief description the consultant gave over the phone about Stomas left Leanne feeling confused and concerned**.

As Leanne did not feel fully consulted in this conversation and because of the lack of explanation around how the consultant came to this conclusion, Leanne's reaction was to feel that this was not the right decision for Jordan. Leanne **wished that this conversation had taken place face to face as she find it easier to communicate her concerns and queries in this way**.

My information needs...

My mum may benefit from being signposted to other support services or organisations to help support her with my care and get everything she needs to best support me.

My physical needs...

- My mum needs a clean, safe and generous enough space to help change me and my brother. My mum may also need to use the toilet too so including a toilet within changing facilities helps.
- My mum can sometimes struggle pushing my brother's push chair through doors while holding my hand too. Doors that are lightweight, automatic or have press to open buttons can help.

My emotional needs...

- I can struggle with dealing with unfamiliar environments. Try to keep my appointments in areas I am more familiar with.
- Busy environments can make me anxious or distracted. A designated waiting area away from people passing through can help.
- I can struggle with waiting, play areas can help entertain me and my brother and take my mind off the environment I am in.

My communication needs...

- Remember barriers I have made you aware of when setting my appointment times.
- Using visuals and things that I can hold and interact with can help me to better engage with you.
- While it is important to engage with me, it's also important that you engage my mum as well as she may also struggle to understand my condition.
- For difficult or more complicated conversations, it may be better to have these in person or even via an online call. Where these need to be held over the phone, set aside more time to fully explain the situation.

