

Appendix 3 - Experience map that can be used for further experienced based co-design and clinical redesign projects or for people who want to do training

An experience map is a visualisation of an entire end-to-end experience that an individual goes through.

For each touch point the emotions and experiences that were identified by people who are blind or have low vision are described, followed by comments of hospital staff. It includes some direct quotes from people describing their individual experiences.

This experience map has been provided in a number of different formats to cater for people who are blind or have low vision, including audio recordings, a high contrast image and in words.

Touchpoint 1: Hospital admission and giving consent

Consumers' experiences and emotions

Consumers reported the following emotions about their experiences of hospital admission and consent:

- Frustration
- Imposition
- Intimidation
- Depression
- Feeling sorry for myself

Consumers reported the following experiences about hospital admission and consent:

- Can't read or complete the forms, and there is no digital form available
- No support is offered or provided when completing the forms
- Family had to support them through or complete the admission paperwork
- Need somewhere private to read otherwise disability is on show
- Staff did regularly update my profile
- Help was offered by staff to complete the forms

Some of the quotes by consumers were:

- "They'd help someone if they're in a wheelchair, why not if they are blind?"
- "They focused on my ability to read signature on the consent form instead of whether I understood what I had consented to."

Clinicians' experiences and emotions

Clinicians reported the following emotions about supporting people who are blind or have low vision through the hospital admission process and requesting consent for their treatment:

- Confusion
- Hesitant

They identified the following experiences about the hospital admission process and getting consent:

- Admitted in the same way as sighted people
- They talked to family and friends about preferences of the person who is blind or has low vision
- It's difficult

Clinician quotes included:

- "Paper form? How does that work for people who can't see? The nursing staff are aware, but patient can't read it"
- "We're always hesitant with forms. I can read, but I'm not a doctor and don't want to come across biased. I know the benefits (of drugs) ... but can't be seen to force (by telling them what the information says)."

Touchpoint 2: Communication between people who are blind or have low vision and hospital staff

Consumers experiences and emotions

Consumers reported the following emotions about their experiences of communication with hospital staff:

- Disrespectful
- Expectant
- Panic
- Patronising
- Insulted
- Disempowered
- Bewildered
- Helpless
- Felt forgotten
- Vulnerable
- Comfortable
- Calm
- Vulnerable
- Supported

Consumers reported the following experiences about communication with hospital staff:

- No space on forms to note visual impairment
- Staff should know – duty of care
- Continually having to repeat to different people about your blindness or low vision
- They talked to who was with me, not to me!
- Staff don't believe me about missing medicine
- Didn't communicate who they were
- Some people introduced themselves upon entering room
- Didn't communicate what was happening
- I always have to advocate for myself
- They didn't communicate what was happening
- Visual things were used to explain, e.g. pointing, it's over there
- Some staff were responsive
- Some people received 1:1 care that was great
- Some staff spent extra time explaining things

Some of the quotes were:

- “They told me there is braille information on that. I don't know what people think but just because you go blind you don't automatically read braille or speak French either.”
- “When I did ask who they were they didn't take me seriously. Some people would respond with ‘Guess’.”
- “It's hard to say all the time “Who is it?” You get sick of it, especially in a strange environment and when there's so many people you can't put a name to a voice.”
- “I had to cry to get the help I needed.”
- “Staff should always say who they are and what they are doing. Gosh that a made a difference when they remember to tell me every time.”

Clinicians experiences and emotions

Clinicians reported the following emotions about communication with people who are blind or have low vision:

- Accommodating

Clinicians reported the following experiences about communication:

- Identified people who were blind or had low vision each shift at handover
- The guide on how to support a person who had problems with their vision was very useful
- There were not always instructions shared at handover about how to provide care for a person with problems with their vision
- The problems are not what we observe
- We have a ward culture of alerting each other about what people need

There were no clear quotes about this.

Touchpoint 3: Staff awareness and understanding about the needs of people who are blind or have low vision

Consumers' experiences and emotions

Consumers reported the following emotions about the awareness and understanding of hospital staff about their needs:

- Intimidated
- Disconcerted
- Vulnerable
- Isolated
- Nervous
- Comfortable
- Supported
- Lucky
- Respectful
- Amazed
- Wonderful

Consumers reported the following experiences about the awareness and understanding of hospital staff:

- Lack of staff trust in independence in people who are blind or have low vision
- No understanding of condition
- Staff didn't want to help
- Staff didn't take responsibility to help
- Staff made extra time
- Social work access was provided
- Good staff handovers
- Near nurses' stations
- They had done training on caring with someone with low vision
- Lucky to have (an orthoptist) which hastened the improvement
- I have no doubt that (having an orthoptist) makes a difference
- Popped up the side railing of the bed so that I wouldn't fall out
- Provided direction on what to do and what not to do
- Orthoptist made such a difference

Consumer quotes included:

- “People either are really helpful and go out of their way or didn’t give a rat’s and were too busy to help you.”
- “A bit more stressful for nursing staff as it’s a bit worrying, they can’t see where they are going.”
- “They don’t know how to lead someone who is blind... (didn’t) ask how can I help you or physically know the best way to provide that help when guiding someone who is blind or has low vision.”
- “We’re being treated differently and at a disadvantage because we have a disability when were in hospital.”
- “I had IV pain relief, but I wasn’t given the button, and because I couldn’t see it I effectively had no pain relief for a good hour... that was pretty dramatic. My support person showed up and found me and then advocated on my behalf.”
- “Need to break down assumptions about what people who are blind or have low vision do and don’t need / want.”
- “In hospital I was told I couldn’t take my guide dog in... unbelievable!”
- “The orthoptist was incredibly thorough and caring how they did things... they went out of their way to try and get a resolution as soon as possible.”
- “They are all in it together, and they all understand each other... It was a really nice environment.”

Clinicians’ experiences and emotions

Clinicians reported the following emotions about their awareness and understanding of the needs of people who are blind or have low vision:

- Stressful
- Worrying
- Uncomfortable

Clinicians reported the following experiences about their awareness and understanding:

- Orthoptist gives clear feedback
- Orthoptist gives clear care instructions
- Having a safety alarm on the bed helps
- Information is communicated in handover
- The care guide describing how to support people who are blind or have low vision is placed in the person’s file
- People who can’t see well are placed in beds close to nurses’ station
- There is a lack of funding to support these people
- Sometimes we know they need more help but have too many other patients to also look after
- It is a lot of responsibility to look after someone who is blind or has low vision
- People who are blind or have low vision experience variation in care
- Coach them, help them, know how to help them

- Aware people who are blind or have low vision may be at higher risk of having a fall
- Awareness of how to position a person on the ward when they have visual neglect due to stroke
- Clinical knowledge of stroke

Clinician quotes included:

- “If the orthoptist isn’t at work when new patient comes in then nurses don’t know what to do, it delays their care and... discharge which doesn’t benefit hospital, nurses are not so well informed.”
- “I’d hate to be in that position.”
- “Staff talk about the stress of this – they say its time consuming; more staff need to get involved; it means less time to look after other patients – don’t get special (resources) to look after visual impairment patient.”

Touchpoint 4: Orientation to the ward and hospital environment

Consumers’ experiences and emotions

Consumers reported the following emotions about being oriented to the ward and hospital environment:

- Not feeling comfortable
- Confronting
- Frustrating
- Stressed
- Traumatic
- Anxious
- Frightening
- Rude
- Need to be proactive

Consumers reported the following experiences about orientation to the ward and hospital environment:

- If I’m admitted to the same ward each time, it’s familiar and easier
- No orientation provided
- It was good to be near nurses’ station, can get more help
- Needed more help on the ward as didn’t get an orientation about where things were
- Independence was taken away
- Missing out on tea and coffee when no orientation

Consumer quotes included:

- “I had someone put me in a corner and leave me there.”

- “They took away my personal independence. Staff decided if I needed a wheelchair, but I may prefer to walk.”
- “I got oriented to the toilet but when I went there, I didn’t know there was vomit all over the floor.”
- “I was in an unexpected ward as they didn’t have a bed in the ward, I should have been in. They didn’t tell me, and I woke up to people screaming out for help and it was frightening and quite traumatic.”
- “They should not move your stuff. You want to find something but can’t if they’ve moved it and haven’t told you.”
- “They used to wheel me into the shower room, and then I’d say I’d work this out. They were prepared to help me out... but it was a bit of a process.”

Clinicians’ experiences and emotions

Clinicians reported the following emotions about orienting people who are blind or have low vision to the ward and hospital environment:

- Feeling lost
- Understanding

Clinicians reported the following experiences about orienting people to the ward and hospital environment:

- Place them near the nurses’ station
- Ask them where they want things placed
- Tell them where they’re taking them
- Put things in their hands

Clinician quotes included:

- “They can’t see what you are doing so you need to explain everything.”

Touchpoint 5: Looking after yourself, independence and mobility

Consumers’ experiences and emotions

Consumers reported the following emotions about their ability to be independent, look after themselves and get around:

- Struggle
- Confusion
- Okay

Consumers reported the following experiences about their ability to be independent, look after themselves and get around:

- Hard to find things
- Assumed dependence by staff
- Lose competence

- Lose independence
- Staff don't want to help
- Don't want to ask for help
- Need training about what people who are blind or have low vision need
- No one took responsibility to help
- Don't tell you what's going on or orientate you
- Can't fill in the menu
- Sometimes orientated to the room and meals
- Pushed the wrong button
- Don't know what button are for
- Washing hair is hard
- Don't know where towels or button to flush toilet is
- Don't know where taps are
- Pushed to your limit to do things in rehabilitation, and at the end of the day you notice the difference

Consumer quotes included:

- "At home things are automatic and you're in your comfort zone. I need more support when I'm in hospital. You don't know how much extra help you need until you get there."
- "Meals – if no one told me it was there – it would disappear – or I'd only realise it was there when they can to collect it."
- "No-one told me the meal was there or came to help me eat meals."
- "No-one tells you where the call button is or where the button is to flush the toilet, or where the towels are."
- "I didn't shower for two days (because of the extra help I needed) and I didn't want to trouble them."
- "They tell me where is the sink, shower, toiler, supplied in the bathroom and I was right from there."
- "Staff did not believe me when I told them they had missed an important medicine (I had counted them [the tablets] out)."
- "They do things for you and work out where you're at. If you need help with peeling the top off (a container) they'd help you that."

Clinicians' experiences and emotions

Clinicians reported the following emotions about the ability of people who are blind, have low vision or vision problems to look after themselves and get around:

- Misunderstanding
- Worry

Clinicians reported the following experiences about the ability of people who are blind or have low vision to look after themselves and get around:

- Self-care is big task
- Family needed to be around 24 hours a day
- Confusion with meals
- Cultural barriers with self-care
- Family members don't help
- They wait for the nurses
- Aim to keep IV in the same place
- Experience board on the person's bed
- People who have stroke often have other reasons for needing help (physical, cognitive)

Clinician quotes included:

- "You never see a (guide) dog or white stick."
- "I say to the patient, I want you to do as much as you can, but I'm here to help."
- "I keep talking and ask them what they do at home: if you can't see at home how do you do it, teach me how you do it, then you empower them."
- "You think the family would help... then we find the cold meals."
- "Imagine if 15 people on the ward all needed help to be fed."

Touchpoint 6: Preparing for and being discharged from hospital

Consumers' experiences and emotions

Consumers reported the following emotions about preparing for and being discharged from hospital:

- Daunting
- Upset
- Bad
- Stressful
- Worried

Consumers reported the following experiences about preparing for and being discharged from hospital:

- Organised compact and home services
- Knew importance of understanding discharge
- Not clear or precise
- No digital copy of discharge summary
- Need a friend or carer there
- Too long for e-reader
- Not designed for people who are blind or have low vision

- Need more time to have information explained to absorb
- No follow up

Consumer quotes about the discharge process included:

- “Even when I asked what the discharge information said the doctor told me my sister could read it (but she was several hours away).”
- “I asked someone to read it to me and they said wait for your family member, but I told them she was two hours away... social worker got someone to read it to me (after I was upset).”
- “In the discharge lounge, I... didn’t know who was in the room with me or where the toilet was or tell me my family were there and waiting in another room. No one asked how I was getting home.”
- “After discharge I had to give myself an injection for a blood thinner at home. They told me once... My parent and I had to work it out ourselves at home.”
- “When they said I could go home... I got really worried because I was thinking now what am I going to do because people supporting me all the way... suddenly I’m going home I’m going to have to fend for myself.”

Clinicians’ experiences and emotions

Clinicians reported the following emotions about getting people who are blind or have low vision ready for discharge:

- Feeling lost

Clinicians reported the following experiences about getting people who are blind or have low vision ready for discharge:

- Follow-up people 48 hours after discharge
- Will organise more support and help
- Medical discharge letter is more important
- Multidisciplinary team and family planning essential
- Unsure about accessible resources available
- Early discharge planning is vital

Clinician quotes about the discharge process included:

- “Medical staff talk about all the follow up appointments and interventions... as well as occupational therapy. From nursing perspective, we don’t provide that sort of information.”