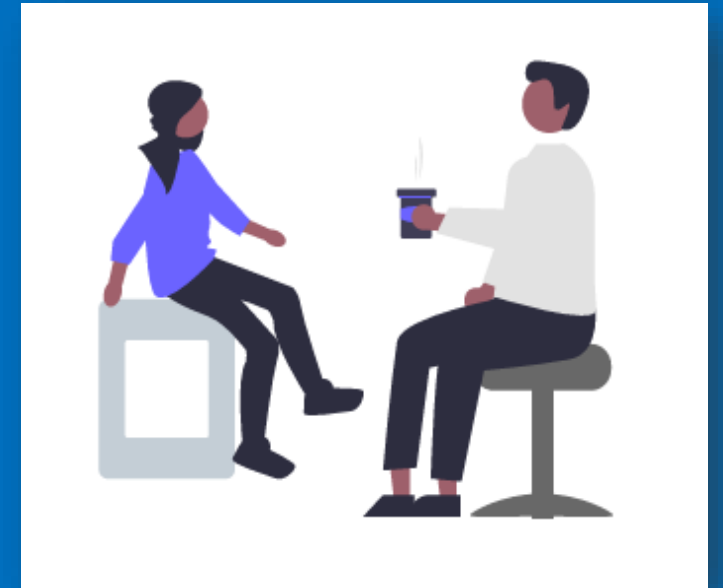


Engaging and championing the public to improve experiences of dying for adult inpatients, and those important to them

Rachel Watson, head of user insights and user experience design



Category: **Engaging and Championing the Public**
Project: **End of life user insights project**
Organisation: **Imperial College Healthcare NHS Trust**

When someone is in their last hours and days of life, we only have one opportunity to provide compassionate and individualised care, and to also support those who are important to them.

Tell us your views to help us improve end of life care at our hospitals



As part of our study, we're looking to speak to people who could give one hour of their time to talk about their experiences of a loved one in end of life care.

Have you experienced someone important to you receiving end-of-life care at one of our hospitals? Would you be happy to tell us what you would like to improve and expect from end-of-life care, for yourself or for a loved one?

Your support will help us to improve the last days and hours of life for people at our hospitals, as well as improve the support we give to their loved ones and those closest to them. Considering the diverse make-up of the communities we serve across North West London, we are particularly interested in understanding more about the needs of people from underrepresented religious and ethnic groups including but not limited to people from Muslim, Jewish, Hindu, Asian, Black, Arab, and/or White European communities. We will provide an interpreter at the interview if requested.

What does taking part involve?

- A conversation of about one hour that can be done over the phone, on a video call, in person in a location of your choice, or by any other method that you would prefer.
- During the conversation, we will ask you questions about what you would expect, need, and value in hospital care during the last weeks days and moments of life, based on your experience.
- We would also like to ask you about the experience of your loved one dying in an Imperial hospital, for yourself and for your loved one, to understand what could be improved and what went well.

You could get involved if:

- You have experience of someone important to you dying in an Imperial College Healthcare NHS Trust hospital (Charing Cross, Hammanmith, Queen Charlotte's and Chelsea, or St Mary's Hospital) longer than three months ago and up to seven years ago.
- You are willing to share your expectations around what you would want care to look like in your last weeks and days of life, based on your experience.

Please note that we are not aiming to speak with anyone who is currently experiencing end-of-life care.

As a thank you for giving up an hour of your time, you will receive a £25 "One4all" voucher valid at a range of stores.

Apply to get involved here

To apply to take part or find out more, please use your preferred contact method:

Phone: 07561 873711
Email: imperial.userinsights@nhs.net
Visit: www.tinyurl.com/EOL-interviews
or scan the QR code
Apply by 11:59pm on 24th August



Please Note: This is a service evaluation project. The people conducting this study are not medical professionals. They are researchers and are not able to answer any questions you might have. If you have any concerns about the medical care that you have experienced, you should contact PALS at imperial.pals@nhs.net or the complaints team at ICHC-Complaints@nhs.net

Our approach

- Focus on what users want and need
- Equity
- Involving staff, and understanding their challenges
- Kindness and compassion
- Collaboration

Project objectives

Overall project objective

Improve end of life (EOL) experience for adult inpatients and those important to them across our organisation.

Discovery (phase 1)

To understand what adult inpatients from underrepresented groups and the people important to them need from the EOL experience in hospital, in the days, hours and moments near end of life and just after death, so that we can understand what improvements are needed

To understand what good looks like for EOL experiences, as a person dying and as an important person from underrepresented groups to help us design future improvement solutions

To understand how the trust can continuously gather and act on insights from people who are receiving or have recently experienced adult inpatient EOL care, to learn from what is and isn't working well and to understand what improvements might need to be made in the future

Co-design (Phase 2) and implementation (phase 3)

To co-design, ideate and test potential solutions with users with lived experience to best ensure we can meet users' needs

To help us support staff and the trust to deliver better experiences for patients/those important to them including developing new ways of working

To develop ways to continually gather feedback and to make effective use of insights. To do this through user-led co-design work, involving patients and those important to them throughout the process

“Taking part in this research is therapeutic. It was a relief for me, I felt some kind of joy giving my experience and opinions. I am happy if I can help someone in the future. I can say my contribution has made the world a better place.”

“Participating in this research has been emotional at times but cathartic, it has provided me with an opportunity to disseminate my experience of being in hospital with my loved one for nearly eight months mostly within intensive care units. I have collated insights most people will never have. I hope that my involvement has and will make a difference for others when EOL takes place, so that they do not have to struggle or cry silent tears of fear and grief .”

Ethnicity breakdown of user insight participants

Demographics of participants:

- Ethnicity: 9 Black, 6 Asian, 3 White, 2 Mixed Race
- Religion: 11 Christian, 7 Muslim, 2 Atheist
- Gender: 11 Female, 9 Male
- Age: 1 18-24, 9 25-34, 3 35-44, 4 45-54, 3 55-64
- Language: 3 who speak multiple languages
- 4 with disabilities, long-term health conditions, or accessibility needs

Black

- 3 Black African
- 2 Black British
- 4 Black

White

- 1 White European
- 1 White British/Irish
- 1 White

Asian

- 4 Bangladeshi/Bangladeshi British
- 1 Persian
- 1 Asian

Mixed race

- 2 Mixed race

Hospital location of loved ones death

- 7 people whose loved ones died at St Marys
- 6 people whose loved ones died at Charing Cross
- 7 people whose loved ones died at Hammersmith

How long ago did their loved one die

- 1 person within the last three years but no sooner than three months ago
- 3 people's loved one had died within 5 months ago
- 2 people's loved one had died within 6 months ago
- 1 person's loved one had died 1 year ago
- 4 people's loved one had died 2 years ago
- 4 people's loved one had died 3 years ago
- 2 people's loved one had died 4 years ago
- 1 person's loved one had died 5 years ago
- 2 people's loved one had died 6 years ago

Expected and unexpected deaths of loved ones

- We had a mix of unexpected and expected deaths

Insights

1. The last days, hours & minutes before death



Key findings:

- **Knowing you have done everything you can as a loved one is really important**
- **People are often unclear what is and isn't possible** and don't really know what to do or ask for
- **It's key to communicate to the patient's loved ones that the best is being done for the patient** and that they are being looked after. A patient being regularly checked on before they die and just after they die is important.



2. Loved ones involved in care



Key findings:

- **Being involved in care during the patient's last moments is important** for the patient and their loved one. In the absence of information, **people do their own research** about what they can do for the person receiving EOL care



3. Experience & communication with hospital staff



Key findings:

- **Loved ones and patients feel that care really differs depending who is on shift.**
- **Loved ones struggle to get an update** and when they do it can be **overwhelming**
- **Sometimes it can be hard to communicate with healthcare staff and understand what they are telling you**, for health literacy reasons or language
- It can cause **distress for both the family and staff**, if staff are unaware that a patient is in their last moments and therefore don't act appropriately - e.g emptying bins
- **Loved ones feel a lack of emotional support in last moments and after death**
- **Some people aren't clear about what part of the service they might need to pay for**



4. Religious & cultural practices



Key findings:

- **Not everyone knows about chaplaincy services** - support to access these services is valuable for loved ones
- **Some families would like to bury their family quickly (within a few hours), to do this they need a death certificate quickly so that they can make arrangements**
- **Religious and cultural needs and end of life preferences should be asked about**, meeting these needs and preferences is really important



5. The environment



Key findings:

- **Most people would prefer to have a side room** but not everyone knows that you can ask for that. They are also not often available and not routinely offered as a result.
- **Having the privacy to have time together with loved ones and to pray and carry out any other wishes is important**
- **Visiting hours can be too limiting** and some nurses are more lenient with this than others



6. Amenities



Key findings:

- **A lack of space, amenities and chairs makes visitors feel unwelcome.**
- **Accessible food and drinks helps makes things a little more comfortable.**



7. Preparing for death



Key findings:

- **Loved ones sometimes need support to have the difficult conversations about preferences at end of life and afterwards**
- **Many loved ones would rather be prepared by the hospital staff**, that the patient had a higher chance of dying even if there is a possibility that they might survive. However that conversation needs to be done with **empathy and sensitivity** and so that they can prepare mentally and emotionally



8. After death



Key findings:

- **Having time after death with your loved one is very important**, sometimes this is rushed
- **Having a staff member check on the patient just before and just after death is important** as it makes families feel like they and the patient are being looked after well
- **Being told what the next steps are and that you will get a phone call is helpful**, not everyone is called though



9. The ideal end of life experience



Key findings:

- **A peaceful environment with family and friends around**
- **Proactive guidance, emotional support, meeting spiritual needs and post-loss support** are key parts of an ideal experience
- **Some felt that a ward or space specifically attuned to end of life needs would be a good idea**



10. Providing feedback about end of life experiences



Key findings:

- **Most people do want to be asked to give feedback**, it helps them feel that the hospital cares, however **some people don't see the point of giving feedback**
- **People want to give feedback throughout the journey and via many channels**
- **Some people feel that there are barriers to giving feedback** and making a complaint could be made easier



Knowing you have done everything you can as a loved one is really important.

“It's not something that everyone is good at thinking about but I think I'm quite good about it. My sibling can't really think about it but I really tried to make it as nice as I could for mum and that really helped me”

Roman Catholic, White, 45-54, Female

“I always thought I was a very rational and quick thinker – but in those moments around his death I was completely blind. I felt completely useless and didn't know what to do and just left everything with the doctors, so when a doctor wasn't able to show up for 10 hours I just accepted that at the time. At the time I didn't feel I could contest this.”

Persian, Muslim, 60, Male

Co-design opportunity area 1

How might we co-design a way for people to know what support is on offer and how they can support and care for their loved one near end of life? How do we empower people to feel like they have been able to do everything they can to give their loved on the best end of life experience possible?



It's key to communicate to the patient's loved ones that the best is being done for the patient and that they are being looked after

“If you take away food, monitors, etc this may have to be explained to different members of the family”

Lived experience representative

“Example of good care : a nurse taking over the duty of holding my family member's hand when I had to go to the washroom, or to get a coffee.”

Bangladeshi, Muslim, 35 - 44, Female

Improvement opportunity area 1

How can we help to ensure that patients are checked on frequently in the last hours of life and just after death?



Sometimes it can be hard to communicate with healthcare staff and understand what they are telling you, for health literacy reasons or for language reasons

“Thinking back maybe the staff could be more detailed about the reality, it’s not that they were dishonest. For them to make the call to the support worker they must have known he was about to go. I would have appreciated being called,”

White, Christian, 45- 54, Female

“Some of my siblings don’t speak good English and it might be difficult for people to understand sometimes. It was difficult when my mum came to the hospital, it was hard for doctors to understand what they were saying. I had to help with interpretation and tell them this is what my mum was trying to say...”

- Black, Christian, 25-34, Male

Improvement opportunity area 2

Making translation services easier to access and more of a policy around using them.

This could also be part of co-design opportunity area 1



It can cause distress for both the family and staff if wider hospital staff are unaware that a patient is in their last moments and therefore don't act appropriately

“Also there was presence of unnecessary people in A&E and after he died – e.g. a cleaner walked in and started cleaning the floor. For me it felt like my father’s condition and death was a show, something to watch. Their presence doesn’t help so they shouldn’t be there at that moment in that place ”

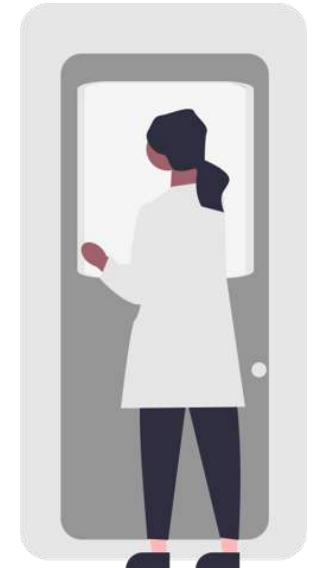
Persian, Muslim, 50, Male

“Just before my dad passed away, a cleaner just came in and started changing the bins. I felt that was so inappropriate and disrespectful”

Bangladeshi, Muslim, 35 - 44, Female

Co-design opportunity area 3

How might we co-design a way for people to know that someone is near end of life so that cleaners and other staff in the hospital are aware and can act accordingly?



Religious, cultural needs and end of life preferences should be asked about. Meeting these needs and preferences is really important

"Dad was a practising Muslim and observing prayers around death would have been important to him. However I wasn't in the right frame of mind to prioritise this. None of the medical staff prioritised this either, but it would have helped to have somebody ask – if there was a general person with good understanding of religious practices who would know what to do it would be beneficial, they don't have to be a religious official necessarily."

Persian, Muslim, 60, Male

Co-design opportunity area 4

How might we co-design a way for people to share or be asked their religious and cultural needs and general preferences?

A lack of space, amenities and chairs makes visitors feel unwelcome. Accessible food and drinks helps makes things a little more comfortable

“One nurse asked me if I wanted a coffee but you end up saying no because you don’t want to give the nurses extra things to do.”

British Bangladeshi, Muslim, 25-34, Female

“I did go around picking up chairs and I guess I was quite selfish really but there really weren’t very many chairs. I felt like they didn’t have chairs like they did not want visitors .”

White, Roman Catholic, 45-54, Female

Improvement opportunity area 8

Could we enable people to have more easy access to tea and coffee facilities? A microwave? Free or reduced rate parking near end of life? More chairs? Things to make sleeping at the hospital more comfortable?



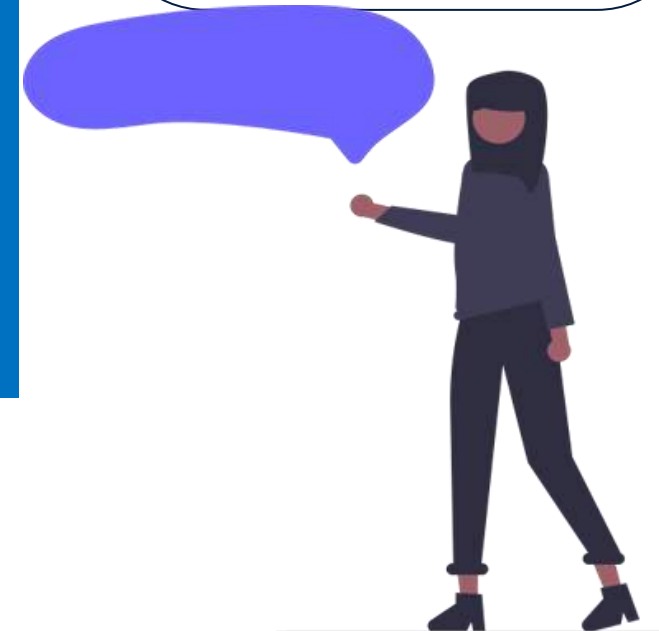
Loved ones sometimes need support to have the difficult conversations about preferences at end of life and afterwards

"What would have helped was having an open and honest communication with the healthcare team about what to expect and what choices are available. That would have been very helpful. Secondly, having a plan in place for after death, such as funeral arrangements and financial affairs, would have made the transition easier."

Black African, Christian, 18-24, Female

Co-design opportunity area 6

How might we co-design a way for people and their loved one to feel more prepared for EOL and to ensure they have shared their wishes and preferences?



Following insights gathering in phase one, there were two improvement areas which staff and lay partners chose to prioritise during phase two.

Providing information, guidance and signposting to support

How might we share information about what services, amenities and support is on offer? How might we empower people to feel like they are able to do their best to support and care for their loved ones and themselves near the end of their life in a hospital environment?

Gathering continuous feedback and acting upon it

How might we best gather continuous feedback about end-of-life experiences in the future and ensure it is acted upon?

Who did we speak with?

- 6 participants joined the two co-design workshops
- 2 people with lived experience helped to guide and co-design the prototypes throughout the project
- 8 staff members from across different areas joined the co-design workshops (chaplaincy team members, medical director's office, senior medical officer, deputy chief nurse, representatives from the patient affairs team)

3.Quick ideas

ACTIVITY: 10 mins

What could we do to improve the way the Trust gathers and acts upon feedback?

- If people have negative feedback it would be good if they go through FALS, I think a written response to a complaint is not satisfactory for this topic.
- Should ward managers have a routine to have a follow up conversation with a bereaved family. This used to be the case.
- There should be an option on form for 'would you like someone to call you back'
- Next of kin details? Are we GDPR compliant?
- Expanding accessibility - posters with QR codes?
- So survey goes to more than 1 names person
- Who owns responsibility to make sure feedback is acted upon?
- Translation. Particularly issue in neonatal deaths
- Make this look friendly - people will cross the street rather than talk to someone who is bereaved
- Who is responsible for taking data out of IQVIA
- Could we ask at the end of the form if people are willing to have a further conversation with us and if so to provide us with contact details?
- qualitative info is useful but difficult to interpret - contradictory
- Could we link a visit to the mortuary with giving them info about feedback or asking for feedback
- add to teh prototype how long ago did your loved on dies?
- previous friends a family work - won awards and found a way of analysing qual data
- Speaking to people in the hospital and other settings that they have visited as a family and not just the chaplain who have most contact managing a second set of needs.

6.Ideas around ways to share the information

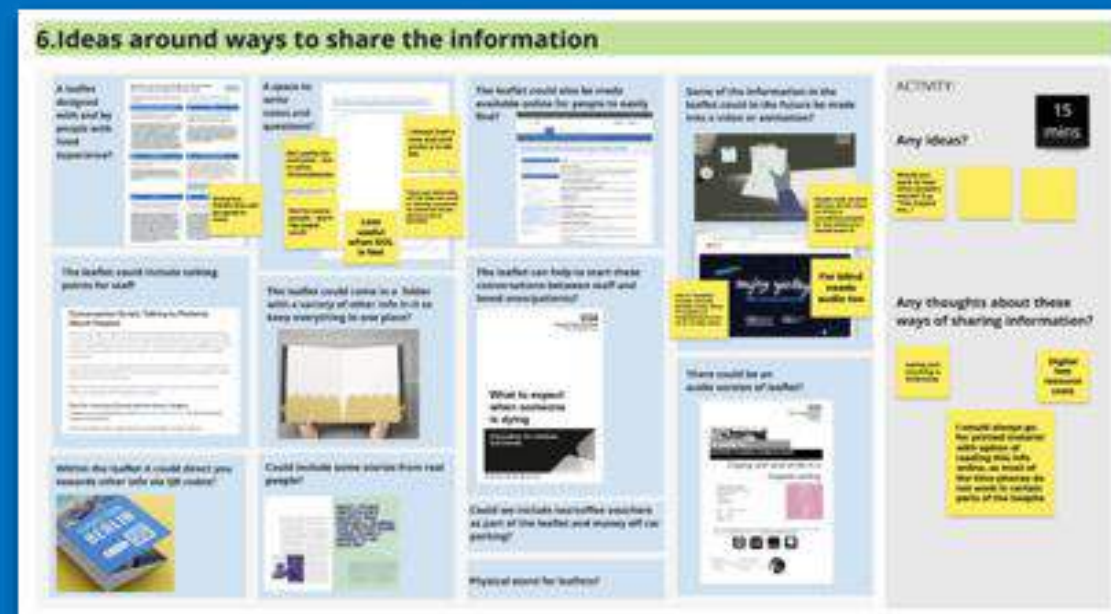
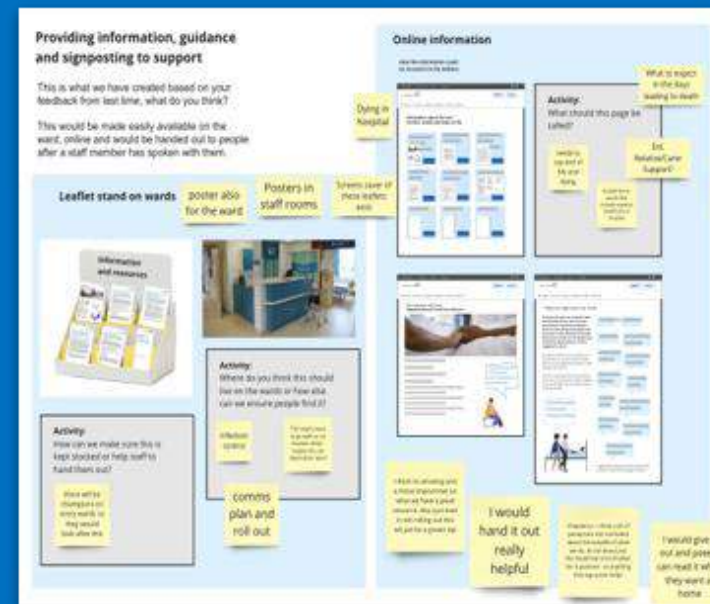
ACTIVITY: 15 mins

Any ideas?

- A leaflet designed with and by people with lived experience?
- A space to write notes and questions?
- The leaflet could also be made available online for people to easily find?
- Some of the information in the leaflet could in the future be made into a video or animation?
- The leaflet could include talking points for staff
- The leaflet could come in a folder with a variety of other info in it to keep everything in one place?
- The leaflet can help to start these conversations between staff and loved ones/patients?
- What to expect when someone is dying
- There could be an audio version of leaflet?
- Within the leaflet it could direct you towards other info via QR codes?
- Could include some stories from real people?
- Could we include tea/coffee vouchers as part of the leaflet and money off car parking?
- Physical stand for leaflets?
- Would you want to hear other people's stories? E.g. "This helped me..."
- People look at their phones all the time so if this was on a phone app it would work better
- For blind needs audio too
- Any thoughts about these ways of sharing information?
- Digital less resource costs
- I would always go for printed material with option of reading this info online, as most of the time phones do not work in certain parts of the hospital

Codesign workshops

- Ideation with patients and with staff
- Prototyping with patients and with staff



The outputs




 Imperial College Healthcare
 NHS TRUST

Let's talk about end of life care

Supporting a person in their last hours and days of life

This leaflet was co-created with a group of people who have had someone important to them die in our hospitals. It includes information they would like to have known but was not easily available to them at the time.

If you have any questions or concerns, please do not hesitate to talk to a member of staff. There are no questions or concerns too big, or too small.

We have more information online. Please scan the QR code or visit: www.imperial.nhs.uk/lets-talk



"This is the information and guidance that I needed and wanted during this time, we hope it's useful for you."



Insights from others

It is sometimes hard to know what to say and do. The following suggestions have been shared by people who have experienced someone important to them die in hospital. Everyone is different, you don't need to do any of these.

Being involved in care

- Massage their hands and feet
- Brush their hair or help them to shave
- Bring in food and drinks they really like to taste
- Keep dry mouth comfortable by wetting their lips with

Being present

- Read a book out loud
- Sit with them without talking
- Listen to recitation from religious texts
- Quietly favourite

Sharing memories

- Create and share a memory box
- Take an imprint of their hand or a cutting of their hair
- Talk about special memories or experiences you've had together

Visiting the hospital

Visiting
When someone is dying, spending time together is important. We try to be as flexible as possible with visiting hours and individual needs. Please speak to staff about your requirements.

Parking
Car parking spaces are often limited at our hospital sites. Please check the Trust website at www.imperial.nhs.uk/our-locations and click on the hospital you are at, to see parking guidance for that specific site.

If you are unable to visit
We understand that sometimes people are not always able to visit. Please do not worry, staff and volunteers will continue to provide care and support. You may like to share pictures or videos from home.

"It's nice for children to say goodbye. My grandchildren couldn't visit but they drew pictures and we put them up on the wall for my husband to see."

"My auntie couldn't visit and my mum wasn't able to have phone conversations anymore, so we played videos and voice messages to her"

Taking care of yourself
You may be spending a lot of time at the hospital. It's important that you look after yourself, take breaks and eat and drink regularly. Please talk to staff about what facilities are available on the ward. Information on cafes and canteens within each hospital are here: www.imperial.nhs.uk/our-locations. Click on the hospital you are at, and then 'places to eat'.

"I needed fresh air so would go for a walk every few hours. I would ask a nurse to be with dad and call me if anything changed."

"You don't know how long you might need to be there - taking breaks, eating properly are important as otherwise you can make yourself ill!"

Chapels and prayer rooms
There are chapels and prayer rooms at each hospital, for patients and visitors to use. They are open from 09.00 to 17.00 for private prayer and reflection.

“The insights we've gained will influence what we're sharing and teaching our staff. Going forward, we'll adopt the purple butterfly model of care – acknowledging when the focus of a person's care needs to be comfort and symptom control, and how to identify their priorities and needs.”

Tori Martin, lead nurse for palliative and EOL care.

“This project has helped us to develop a model for collecting and triangulating meaningful feedback and insights from our service users and it has also enabled us to work in partnership with our local communities to develop improvements that are most important to them. This is a model that we will now use continuously for improvement across all services - the work was the catalyst for real change and its outputs are continuing to empower our staff to genuinely put patient at the centre of everything we do.”

Michelle Dixon, director of engagement and experience

Project team

Imperial College Healthcare Care NHS Trust end of life care leads

- **Katherine Buxton** - Consultant in palliative medicine & clinical lead for end of life care
- **Tori Martin** - Lead nurse for palliative care
- **Anne Middleton** - Deputy chief nursing officer

Imperial College Healthcare Care NHS Trust user insights and user experience team

- **Lucy Trevallion** - Patient information manager
- **Rachel Watson** - Head of user insights and user experience design

Subject matter expertise

- **Lived experience representatives** - Anthony Arhin, Saleha Islam, and Aisha Zahir
- **Clinical team** - Katherine Buxton and Tori Martin
- **Ivor Williams** - EOL subject matter expert (Helix)

Helix Centre core team

- **Charley Pothecary** - Project lead & design support
- **Alex Dallman-Porter / Alice Gregory** - Design lead
- **Jodie Chan** - Public & patient involvement & engagement (PPIE) lead
- **Fiona O'Driscoll** - ICHT relationships (light touch)

Oversight

- **Leila Shepherd** - Managing director, Helix
- **Michelle Dixon** - Direction of engagement and experience, Imperial College Healthcare NHS Trust