Cancer Pathways Improvement Programme

Phase 1: Understanding the issues and opportunities

November 2024

- In February 2024, we kicked off a major programme to find out how we could make our cancer care pathways work better for patients and their families, drawing directly on their views and ideas as well as those of our staff and care partners. While our clinical outcomes continue to be good, we noted increasing concerns about poor communications and coordination of care. We also wanted to do more to respond to an increase in referrals and new diagnoses, fully reset pathways that had been adapted during the Covid pandemic and make the most of continuing advances in cancer diagnosis and treatment.

- We have now completed the first ‘discovery’ phase of the programme – drawing on feedback and working with patients, families, staff and care partners to discuss and understand the problems and their root causes, as well as opportunities for improvement.

- This is a summary of these insights, produced by the Helix Centre, part of Imperial College London’s Institute of Global Health, who are supporting the programme on co-design with patients and the public. The programme steering group is chaired by our chief executive supported by the programme leads, our chief operating officer and lead cancer clinician, and includes patients with lived experience as well as care partners, such as a local GP and our local cancer alliance, RM Partners.

Overview of who we gathered insights from

> 200
people
in total

32
Patients through interviews, surveys or a workshop

5
Family members through interviews or a workshop

15
Trust Staff and other support services through interviews

>80
Trust Staff at playback and prioritisation workshops

>150
Trust Staff and other support services at **13 Cancer Pathway Mapping** workshops

Additional insights gained from:
Patients and supporters attending the Chinese cancer support group at Maggie's West London

Please keep in mind

We have focused on hearing from people who did not have the best experience, as this is how we will learn what most needs to be improved.

While we have focused on presenting what needs to be improved, we also heard about the many positive aspects of Trust cancer care.

In the outpatient clinic, some of the nurses would recognise you and say “Hey, how are you?” One of them recognised me and the day I was really upset she put her arm around me, and that really made a difference.

The chemo nurses would always just make you calmer, you know you're going through a horrible process but you know they are looking out for you and always offered you a cup of tea and biscuits

Insights from patients, families and staff

Detection	Diagnosis		Treatment	Follow up
Patient identified and referred to service	Patient attends investigations	Patient receives diagnosis	Patient receives treatment	Patient followed up after treatment
1. Inconsistent GP support and interactions	**2. Diagnosis delivered badly** **3. Delays in diagnosis and tests** **4. Lacking information or overwhelmed with information** **5. Insufficient support to talk to family**		**6. Delays in treatment** **7. Lack of allied health professional input and strategy** **8. Inconsistent access to treatment**	**9. Lack of follow-up care**

Across the patient journey

10. Not knowing who to contact
11. Unclear patient communication
12. Key parts of compassionate care overlooked
13. Lack of appropriate physical space
14. Uncoordinated appointment management
15. Lack of IT system integration
16. Lack of clarity and control over cancer pathway processes
17. Unable to see where a patient is in the process
18. Limited staff capacity and support
19. Lack of awareness or access to patient support services
20. Overemphasis on phone appointments
21. Issues with patient facing digital tools
22. Lack of joined up care and transfer between hospitals
23. Issues getting to appointments
24. Disjointed staff communication and ways of working

Insights | Detection & Diagnosis

Detection

1. Inconsistent GP support and interactions

- Patients don't feel listened to by GP
- Patients feel they must chase referrals and tests
- Lack of advice and guidance from the Trust to GPs
- Unclear and inconsistent triage and referral process
- Lack of radiology access for GPs

Diagnosis

2. Diagnosis delivered badly

- Poor communications with staff during investigations cause anxiety
- Realise about to receive diagnosis due to sudden appointment changes
- Not prepared to receive diagnosis at appointment
- Diagnosis not delivered in kind, compassionate manner
- Diagnosis delivered inappropriately over phone

3. Delays in diagnosis and tests

- Earlier testing for high-risk groups
- Patients need support to prepare for and attend tests
- Limited imaging capacity and frequent breakdowns
- Limited pathology capacity and results delays
- Manual and complicated referral and MDT pathways
- Inter-Trust referral delays
- Anxious time for patients waiting to hear results
- Prolonged diagnostics process for inpatients with no clear point of contact

4. Lacking information or overwhelmed with information

- Patients don't have all information about treatments and side effects
- Patients don't feel part of decision-making process
- Patients are overwhelmed by information

5. Insufficient support to talk to family

- More guidance and support to speak with loved ones about cancer

> I got told that I had cancer and that's a shock… it's a cliche like you see on TV. You can't really take it in.

Insights | Treatment & Follow-up

Treatment			Follow-up
6. Delays in treatment	**7. Lack of allied health professional (AHP) input and strategy**	**8. Inconsistent access to treatment**	**9. Lack of follow-up care**
Chemotherapy unit delays due to pharmacy or capacity	Lack of AHP input into outpatient services	Under-served groups experience longer pathways	Growing demand for surveillance
Outpatient prescription delays	Limited AHP input into inpatient care	Limited visibility of clinical trials	Lack of follow-up support and info about next steps
Limited pre-assessment capacity	Disjointed and insufficient prehab care	Inconsistent access to certain inpatient services	
Limited theatre capacity and unclear processes	Broader holistic needs of patients not being met	Unaffordable treatments if not eligible for NHS funding	

Cancer treatment has advanced so much, but it feels like the rehab we're providing them is scaled back.

Insights | Across the patient journey (1/2)

Across the patient journey

10. Not knowing who to contact

- Patients not clear who is their main point of contact
- Lack of continuity of care
- No CNS support for some pathways
- Issues with out of hours and emergency support

11. Unclear patient communication

- Confusing medical jargon
- Uncoordinated communications lacking important info
- Patients not clear on next steps
- More support for people with communication needs
- Unclear when no cure or what palliative care means

12. Key parts of compassionate care overlooked

- Patients feel not listened to or spoken kindly to
- Staff lacking compassionate skills
- Patients uncomfortable at intimate exams or after inappropriate comments
- Patients feel inpatient care was lacking or rushed home
- Patients' mental health not checked on

13. Lack of appropriate physical space

- Lack of private physical space in outpatients
- Unhygienic, crowded or poorly designed spaces

14. Uncoordinated appointment management

- Multiple appointments challenging for patients to manage
- Uncoordinated and manual appointment management processes
- Overbooked disorganised clinics

15. Lack of IT system integration

- Lack of IT system integration within Trust and with external organisations

16. Lack of clarity and control over cancer pathway processes

- Lack of flexibility in external screening processes
- Lack of clear processes for all pathways e.g. inpatient
- Patients not removed from cancer pathway
- Lack of consultant upgrade/ incidental findings pathway
- Patients feel they must chase things e.g. test results

> He said "Can we have your bed? Can you go home?" That was far too soon… I went home but I didn't last long. I ended up that night in the emergency department and admitted again.

Insights | Across the patient journey (2/2)

Across the patient journey

17. Unable to see where a patient is in the process

- Staff can't easily see where a patient is in their journey
- Lack of visibility results in duplication of work

18. Limited staff capacity and support

- Lack of staff capacity and service resilience
- Recruitment and retention issues
- Lack of psychological support for staff

19. Lack of awareness or access to patient support services

- Lack of knowledge about services available
- Not supported to access services e.g. Macmillan Centre closed
- Limited community services for referrals
- Complicated and slow fast track discharge
- Limited palliative care in community

20. Overemphasis on phone appointments

- Overemphasis on virtual appointments

21. Issues with patient facing digital tools

- Patient Knows Best is helpful, but support needed to interpret results
- Patients not having access to tests or scan results
- Additional patient support needed to use digital tools
- Some patients prefer paper consent processes

22. Lack of joined up care and transfer between hospitals

- Lack of joined up care and transfer between hospitals
- Lack of joined up care when present for emergencies

23. Issues getting to appointments

- Issues with patient transport service
- Limited treatment and test locations
- Accessibility and public transport issues
- Lack of parking and difficulties paying
- Signage and wayfinding issues

24. Disjointed staff communication and ways of working

- Lack of clarity among staff about roles and poor communication
- Trust organisational structure affects cancer care

What might be happening is people in the cancer pathway don't understand each other's roles.

Detection

Key Insights

1. Inconsistent GP support and interactions

1. Inconsistent GP support and interactions

Patients often don't feel listened to by their GP, leading to delayed diagnosis and greater patient burden. GPs also struggle with inconsistent advice, processes and communications with the Trust, which can lead to processes not properly followed and things falling through the cracks.

- **Patients don't feel listened to by their GP** about concerns when presenting with initial cancer symptoms. Some patients we spoke to had self-referred to the Trust or went to another country for initial investigations.
- **Patients feel that they must chase their referral and initial investigations themselves**, although there should be processes in place for practices to manage this.
- **Lack of sufficient advice and guidance from the Trust** to GPs may result in inappropriate referrals as GPs cannot manage care locally.
- There is an **unclear and inconsistent triage and referral process**, with services rejecting cancer referrals although against national guidance. GPs struggle to find out what is happening for patients in Trust cancer services, relying on the Imperial GP liaison to chase services.
- **Lack of radiology access for GPs** limits their ability to request initial imaging or view upcoming appointments to reassure patients.

Key improvement areas:

- Ensure that GPs know where patients are in the cancer journey and can easily contact Imperial services to follow-up on appointments and investigations.
- Ensure that GPs receive sufficient and timely advice and guidance from Trust cancer services.
- Ensure that the triage and referral process is standardised and adheres to national recommendations.
- Ensure that GPs have broader radiology access to view and make imaging requests.
- Work with GPs and community services, to design or redesign an integrated healthcare model which works for patients.

> Imperial is one of the best are getting back to people, but some services are better than others. For example, I referred a patient to dermatology and they rejected it – they said ophthalmology. Then it went backwards and forwards and delayed the patient by weeks and they did have skin cancer in the end.
>
> **GP**

Diagnosis

Key Insights

2. Diagnosis delivered badly

3. Delays in diagnosis and tests

4. Lacking information or overwhelmed with information

5. Insufficient support to talk to family

2. Diagnosis delivered badly

Patients may not have been prepared to receive the diagnosis and didn't have support around them during this difficult time. Sometimes the person delivering the diagnosis may not have told the patient in the best way possible.

- Before diagnosis, **poor communications from staff during initial investigations** can scare and upset patients before they have had the chance to talk to a member of their cancer team.
- Other patients we interviewed **realised that they were about to be given a cancer diagnosis**, when phone appointments were suddenly changed to in-person or appointments were brought forward, causing sudden anxiety and worry.
- Patients may **not know they're going to get a diagnosis that day**, for example nothing was included in the appointment letter about bringing someone with you, and they may receive the diagnosis on their own.
- The **delivery of the diagnosis in a kind, compassionate manner** is important and has a lasting impact on the patient's experience.
- Some patients we spoke to were **given their diagnosis over the phone and their own**, despite Trust pathways specifying this should always happen in-person.

Key improvement areas:

- Ensure that patients are prepared to receive the diagnosis and have the option to bring someone with them.
- Ensure that patients receive their diagnosis in-person with medical professionals.
- Ensure that staff are supported to deliver the diagnosis compassionately and kindly.

> The senior person came in – she was the first person to say out of the blue something was wrong, I felt she hit me with a sledgehammer, she wasn't very gentle about that.
>
> **Patient with ovarian cancer talking about getting initial ultrasound**

3. Delays in diagnosis and tests

Investigations were often delayed due to Trust or patient issues, such as limited operational capacity, insufficient imaging from inter-Trust referrals, with this feeling particularly long for inpatients. Patients talk about the anxiety while going through this process and waiting for results before meeting the team.

- Patients support **earlier testing for high-risk groups** e.g. Black men and prostate cancer.
- Staff roles such as diagnostic coordinators **help patients to attend and prepare for tests** by reminding them about the appointment and providing information.
- **Limited imaging capacity**, particularly PET scanning, are major bottlenecks that cause delays, with frequent breakdowns limiting service resilience.
- **Lack of pathology capacity** causes delays and not uplifted to cope with additional demand, with genomic test turnaround times a key delay.
- **Manual referral and MDT pathways means that things can get lost and take up lots of time**, which is particularly an issue when multiple teams are involved.
- **Inter-Trust referral delays** arise as additional diagnostics may be needed.
- Patients find **waiting for test results stressful**, particularly as they often don't have a main point of contact at that stage.
- **Inpatients have a long, drawn-out diagnostics process** passing through multiple MDTs which can be confusing and worrying while in hospital.

Key improvement areas:
- Ensure there is sufficient diagnostics capacity resilience to cope with increasing demand.
- Ensure that all patients, whether inpatient or outpatient, are supported during the initial diagnostics phase.

> A lot of patients coming to IR don't come prepared and their imaging can't happen. We put some CNSs in place who rang people in advance. This made a difference, people turned up and the preparations had been done.
>
> **Staff member**

4. Lacking information or overwhelmed with information

Sometimes patients feel like they aren't given all the information needed to make an informed decision or are overwhelmed by information at diagnosis.

- **Patients can feel that they are not given all the information they need about treatment options and side effects** to make an informed decision and feel unprepared for the physical toll of treatment.

- **Sometimes patients don't feel part of the decision-making process or felt pressured into certain routes**, such as particular treatment plans or to receive cancer care privately**.**

- **Patients can be overwhelmed by information from healthcare professionals and the speed with which they must decide.** It can be overwhelming to take in all the information presented at initial diagnosis and some people may need another time to chat with the team.

Key improvement areas:
- Ensure that patients are given all the information needed about side effects and treatment options.
- Ensure that patients are involved in the decision-making process about treatment options and next steps.
- Ensure that patients are provided with the opportunity to digest information and come back with any questions.

If someone had told me all the side effects of radiotherapy, I might not have done it. It wasn't presented as a choice.

Patient treated for head and neck cancer

5. Insufficient support to talk to family

Some people would like further guidance on how to talk to friends, family and children, and whether there is psychological support available for their loved ones.

- **Some people find it hard to talk to friends and family about their diagnosis and treatment and would appreciate further guidance and support.** This was particularly highlighted for patients looking for more support on how to speak to their children and provide them with any support they need. Patients spoke about challenges helping their young children or teenagers cope with their diagnosis and whether they should tell their grown children, who they didn't want to worry but also may feel obligated to inform them in case there is a genetic component.

Key improvement areas:

- Ensure that patients are supported with guidance on how to talk to family and friends about their diagnosis and treatments.

> Me and my husband dealt with it, but our 13-year-old isn't dealing with it very well and there wasn't much support for him.
>
> **Patient treated for breast cancer**

Treatment

Key Insights

6. Delays in treatment

7. Lack of allied health professional input and strategy

8. Inconsistent access to treatment

6. Delays in treatment

Patients can wait long times to receive chemotherapy or collect their drugs from the hospital pharmacy. Meanwhile surgery delays arise due to limited pre-assessment capacity, theatre capacity and process issues.

- **Delays in patients getting chemotherapy** may arise due to issues with **unit capacity or chemotherapy drugs not being prepared beforehand by pharmacy**. This medication issue may occur due to patients not having blood tests done in time or poor communication with between the chemotherapy unit and pharmacy about which patients are being seen that day.

- **Pharmacy delays can result in long waiting times for patients to pick up their medication** after chemotherapy clinics. This may be due to clinics running late and pharmacy staff not available to screen medications after 5pm or the safety checks required to be completed before issuing drugs to patients.

- There are **pre-assessment delays due to limited capacity**, meaning that patients may not get seen and prepped before their surgery as quickly as possible.

- **Theatre capacity is limited** across the Trust due to high demand, with **unclear processes about which services get prioritised**. This can result in **last-minute theatre changes and cancellations** which delays treatment and affects Trust performance.

Key improvement areas:

- Ensure that patients have any results required for chemotherapy available on time to prevent delays.
- Ensure that relevant staff are aware of real-time changes to chemotherapy schedules.
- Ensure there is sufficient pre-assessment capacity for all services.
- Ensure there is a transparent, fair process for allocating theatre capacity which is carried out sufficiently far in advance.

> On average you wait about an hour, which is fair enough, but sometimes the doctors might put two items on my prescription. One time I was there for 3 hours which is unacceptable.
>
> **Patient talking about waiting for drugs from outpatient pharmacy**

7. Lack of allied health professional input and strategy

There is a lack of allied health professional input across the patient journey due to limited staff capacity, resulting in poorer patient experience and outcomes.

- There is a **lack of allied health professional input**, including physiotherapy, occupational therapy, dietetics and speech and language therapy, **into outpatient services**. For example, there is no dedicated outpatient therapy cancer service for patients undergoing cancer treatment, despite documented a unmet need and there is often no therapy input into late effects clinics.

- There is a **lack of allied health professional input into inpatient care** due to limited staffing. This means that patients are not receiving the best possible care to support their recovery, with some not being seen at all.

- **Prehab is a major area highlighted as disjointed and lacking** across the Trust, with pockets of funding resulting in a 'postcode lottery' across Imperial's cancer pathways to access this care.

- A **broader strategy for allied health professional input** across Trust cancer services is needed to identify **holistic patient needs** across the journey and ensure they are being met.

Key improvement areas:
- Ensure that allied health professionals provide outpatient care as part of ongoing MDT clinics or in separate specialist clinics.
- Ensure there is sufficient allied health professional staffing to support all inpatient and outpatient needs.
- Ensure there is a consistent high-quality approach to prehab across all cancer pathways.

Our staffing is not as optimal as it could be, to meet the truly holistic rehabilitation needs for the patient. This is especially the case for patients surviving longer with treatments.

Allied health professional

8. Inconsistent access to treatment

Not all patients treated at the Trust have the same experience of cancer care, with some patient groups not able to access certain services or within the same timeframes as others.

- **Under-served groups experience longer pathways**, as those not suitable for the 'straight to test' pathway, due to unique needs such as requiring interpreters or having a learning disability, are not seen as quickly. Prisoners are a specific patient group highlighted as experiencing longer pathways due to challenges in informing them about preparation required for tests.

- There is **limited visibility of clinical trials** to all patients, with opportunities to participate unclear and uncoordinated for patients and staff across the Trust.

- **Access to important inpatient care** varies, with no weekend palliative care service available for inpatients and the acute oncology service not available at all Trust sites.

- Patients may be **offered drugs not funded by the NHS** from Imperial College Healthcare Private Care, that are **available privately at other Trusts at much cheaper costs**, resulting in patients seeking care elsewhere.

Key improvement areas:

- Ensure that under-served groups are supported throughout the cancer pathway without compromising on care or speed.
- Ensure that patients and staff have easy visibility of potential clinical trials.
- Ensure that all inpatients experience the same high-quality level of palliative care.

> I hear that the clinical trials team have to close trials because they can't get enough patients. From my side everyone wants to be on a clinical trial. So there seems to be two groups of people who both really want each other, but no one can find each other properly.
>
> **Patient talking about access to clinical trials**

Follow-up

Key Insights

9. Lack of follow-up care

9. Lack of follow-up care

After seeing healthcare staff frequently during treatment, when someone is being followed up or has been completely discharged from the service, patients don't know what to expect, what to look out for and who to contact. With patients living longer, this is also creating an increased demand for surveillance and support.

- Patients **don't know what to expect or to look out for once** they have been treated for cancer and are no longer being seen as regularly by their medical teams. This worries them as they often have anxiety about the cancer recurring and **don't know who to contact** if they have concerns.

- **Surveillance and follow-up comprises significant workload** for staff, with patients living longer with complex post-treatment needs. This is particularly important from an allied healthcare professional perspective due to the holistic input these specialties have in patients' day-to-day lives.

Key improvement areas:
- Ensure there is a clear follow-up process and information to look out for explained to patients at the end of their treatment.
- Ensure that patients know who to contact with concerns at any stage after treatment.
- Ensure a coordinated and holistic approach to follow-up care is provided by the Trust and its partners.

It's very intense during it and then the last day they sign you off and then off you go. I want more info about the discharge process.

Patient treated for breast cancer

Across the patient journey

Key Insights

10. Not knowing who to contact
11. Unclear patient communication
12. Key parts of compassionate care overlooked
13. Lack of appropriate physical space
14. Uncoordinated appointment management
15. Lack of IT system integration
16. Lack of clarity and control over cancer pathway processes
17. Unable to see where a patient is in the process
18. Limited staff capacity and support
19. Lack of awareness or access to patient support services
20. Overemphasis on phone appointments
21. Issues with patient facing digital tools
22. Lack of joined up care and transfer between hospitals
23. Issues getting to appointments
24. Disjointed staff communication and ways of working

10. Not knowing who to contact

Patients are often unsure who to contact and lack of continuity of care makes this worse, as they often don't see the same doctor or CNS. Patients also had issues with emergency support through the chemotherapy phoneline, which didn't always provide support or directed them to other services.

- **Patients are often unsure who to contact** and might turn to the Macmillan cancer navigator, their GP or the clinical nurse specialist. This is particularly an issue for patients **before they receive a cancer diagnosis**, as they don't know who to contact during the confusing and stressful diagnostics phase. Some services have specific diagnostic CNSs that liaise with patients, while others have no one or it is taken on ad hoc by motivated admin staff.

- **Lack of continuity of care makes this situation worse** as patients may see different staff and are not able to build a trusting relationship with one person over time.

- For some **less common pathways**, such as neuroendocrine tumours, there is **no CNS support available** and therefore no clear point of contact for the patient. These patients have a poorer experience because of having a rarer cancer, despite their high needs.

- There are **issues with out of hours and emergency support**, for example with the chemotherapy emergency phoneline not being answered or not providing helpful information.

Key improvement areas:

- Ensure that patients are provided with a main point of contact, in the role of the clinical nurse specialist, throughout the cancer pathway, with this person ideally remaining the same throughout.
- Ensure high-quality out of hours and emergency support is always available to patients.

> I could probably have called the cancer nurse from Macmillan, but I didn't know I had cancer, I didn't want anything to do with her. I hadn't received a diagnosis.
>
> **Patient treated for lung cancer**

11. Unclear patient communication

Patient communication from Trust cancer services can be confusing, uncoordinated or lacking important information. As a result, patients often feel unclear about what's next or that they must chase things themselves. There is also more we could do to improve communication accessibility with patients.

- **Medical jargon confuses patients** and even wider support services, for example local hospital teams not understanding the highly specialist cancer information shared by the Trust.
- Communications **are often uncoordinated, confusing or lack important information**. The same letters are often used to communicate with both patients and health professionals, resulting in patients not having the proper support to understand medical content.
- Patients may **not be clear on what the next steps are**, which may be due to lack of clear communication.
- Medical staff may **not be sufficiently transparent** about when **treatment is not curative** or explaining **what palliative care means**.
- Patients with **unique communication needs require improved support**, such as enhanced interpreter services, personalised communications to specific languages and improved support for people with accessibility needs.

Key improvement areas:

- Ensure that clear, easy to understand language is used in all communications with patients and support services.
- Ensure patients are clear on what their next steps are.
- Ensure patients with unique communication needs are supported.

> They're so specialist that they get lost in their own lingo. Not only do their own patients not get it, but lots of consultants in early pregnancy units don't get it also.
>
> **Patient treated for gestational trophoblastic neoplasia**

> When you're ready to answer, they're already talking about something else… Sometimes I feel left out of a conversation.
>
> **Patient with hearing loss describing challenges talking to staff**

12. Key parts of compassionate care overlooked

Patients sometimes didn't feel listened to or cared for by staff and appreciated those who acted kindly and created a welcoming environment. Patients in particular spoke strongly about bad experiences of inpatient care, where they didn't feel looked after.

- Some patients felt that they were **not listened to or spoken to kindly by staff**. However, moments where staff or volunteers remembered someone's name or made them a cup of tea had a lasting impact on patients as they went through difficult times.

- **Compassionate skills are lacking particularly among medical staff**, who are overburdened working in high pressure environments and not provided with their own emotional support.

- Female patients may feel **uncomfortable when male doctors carry out examinations or provide treatment in intimate areas. Insensitive comments about someone's sexual activity** during their cancer journey can make patients feel uncomfortable.

- Many people spoke about **negative and upsetting experiences of inpatient care** where there were significant lapses in quality of care or they felt they were **rushed to go home too early**.

- Patients with **mental health conditions**, such as bipolar disorder, were surprised that this wasn't mentioned or checked on by anyone at the Trust at any stage.

Key improvement areas:
- Ensure staff have the skills and support to provide kind and compassionate care at all stages of the patient journey.
- Ensure sensitivity and awareness during intimate examinations, with the ability for patients to request a female or male clinician or have another staff member present.

> I was told I could eat 12 hours after I was admitted… I was not fed for three days, because no one took the nil by mouth down, at the end of each ward round no one updated my notes.
>
> **Patient treated for breast cancer and admitted as an inpatient on the ward**

13. Lack of appropriate physical space

There are not enough well-designed, confidential spaces in outpatient clinics for private conversations and multidisciplinary care. Patients also felt that some spaces were unhygienic, crowded and poorly designed, putting them at increased exposure to infection.

- There is a strong need for more appropriately designed **private, confidential spaces in outpatient clinics** as this lack of space results in patients being given bad news or getting tests done in corridors with others overhearing. The lack of space **limits the care that can be provided** and results in rushed appointments and long waiting times at clinic. For example, a patient may not have the chance to chat with a CNS after getting bad news or be seen by allied health professionals. The lack of space is also **preventing hiring of key staff members**, including trainee psychologists in the psycho-oncology team.

- **Spaces could be improved** to make more conducive to providing compassionate and comprehensive care from a patient and staff perspective. **Unhygienic or crowded** environments can worry patients with weakened immune systems, while artwork and natural light is important to create a pleasant experience for patients and staff.

Key improvement areas:

- Ensure that there are sufficient well designed, private spaces in outpatient clinics for patients to receive confidential, dignified care.
- Ensure there is sufficient space at outpatient clinics for patients to receive care from all relevant members of the multidisciplinary team.
- Ensures spaces where cancer care is provided are sufficiently maintained and aesthetically designed using natural light, colour and artwork.

> The day that I was told that I had cancer, I don't know if you've ever been to the clinic at Queen Charlotte's, it's a mad clinic, there's not enough doctors, there's not enough rooms. When I'd been told I had cancer, I had to walk through the waiting room to the CNS nurses' room.
>
> **Patient treated for endometrial cancer**

14. Uncoordinated appointment management

Patients struggle to manage many appointments, which is why they appreciated one-stop clinics. Staff find the appointment management process highly manual and uncoordinated, resulting in overbooked and disorganised clinics.

- It's **hard for patients to keep on top of multiple appointments**, with letters arriving late or appointments changed last minute, and there is nowhere for patients to see an up-to-date view of all their appointments. As a solution to this, patients told us that **one-stop clinics** where they could see their medical team and get investigations done at the same time were helpful. However, some staff thought that this upfront bundling of appointments can be too much for some patients.

- **Uncoordinated and manual appointment management** is frustrating for staff and can result in errors and a disorganised patient journey, such as getting appointments in the wrong order or scheduling appointments that patients don't need.

- Poor clinic management results in **overbooked clinics** and patients at different stages or diagnoses attending the same outpatient clinic.

Key improvement areas:
- Ensure that patients have a central real-time view of all appointments.
- Ensure a coordinated and streamlined appointment management and booking process.

> The NHS application helps me very very much. Helps me find the address, information, because for some operations the letters were not coming on time for me from hospital... So it gives me time to book holiday for the appointment.
>
> **Patient treated for thyroid cancer who needs to book annual leave to attend appointments**

15. Lack of IT system integration

Lack of interoperability between many IT systems used by the Trust and external partners results in duplication of work and no joined-up view of patient care.

- **Multiple IT systems** are used within the Trust and by external partners that are **not integrated to share patient information**. This means that patients have to repeat information to staff that they've already shared and staff cannot view important information from elsewhere. For example,

  - There are notes for cancer patients in both Cerner and Somerset for staff to review, which can result in duplication of work or there may be information discord.
  - Staff should be able to view other imaging from NWL via Soloton Share+ to prevent duplication. However, imaging from outside NWL is transferred via the Imaging Exchange Portal which is a highly manual way to access previous external imaging files.
  - The pathology laboratory information management system is separate to the electronic patient record.

Key improvement areas:
- Ensure the cancer team have easy access to all relevant investigations and results for patients.
- Ensure interoperability between all IT systems used at the Trust to enable a joined-up approach to patient care.

> A big problem about genomics is interoperability, you've got a great system that does the genomics results, I've got a great system that does patient records, but your system won't talk to my system and we're different companies. If we could overcome that problem, if there was a unified system that could talk to each other.
>
> **Doctor**

16. Lack of clarity and control over cancer pathway processes

Cancer pathways and processes aren’t always clear for both patients and staff. As a result, patients might feel lost within the system or staff create their own ad-hoc unwritten processes to manage the uncertainty.

- **There is a lack of flexibility in external screening processes,** which Trust staff find frustrating as they are not able to contact patients by phone prior to appointment or change appointment letter templates.
- **Less common pathways**, such as patients admitted and diagnosed with cancer as an inpatient, have **no clear or documented process for staff** to follow.
- Patients may **not be removed from a cancer pathway** even though they don’t have cancer as staff know that they will get other tests carried out faster.
- The Trust **lacks a robust consultant upgrade/incidental findings pathway** where patients are seen quickly. Some staff members suggested that there should be a consultant upgrade co-ordinator to work across all pathways as currently upgrades can get missed.
- Patients often **feel that they must chase things** to make them happen or get important test results.

Key improvement areas:
- Ensure there are clear, documented processes for each cancer pathway for both patients and staff.
- Ensure there is sufficient flexibility when needed within external screening processes.
- Ensure there is a clear consultant upgrade/incidental findings pathway for staff to follow.

> Sometimes we don’t remove people from the cancer pathway even though we know they don't have cancer as otherwise they won’t get the tests done for ages. This means they will get sent letters that will still reference the cancer pathways which can be confusing.
>
> **Gynae pathway mapping workshop**

17. Unable to see where a patient is in the process

Staff often worry that they don't know how a patient is being followed up with as they can't see an overview of where someone's at along the pathway. This lack of visibility results in duplication of work from different medical teams.

- Staff **can't easily see an overview of where a patient is at in their cancer pathway**, which would provide them with a centralised view of all patients in their care. Staff currently keep track of patients using manual systems or email chains, which results in extra work and patients can get missed.
- This lack of visibility results in **duplication of work** as teams on different care pathways may order the same tests for a patient.

Key improvement areas:

- Ensure that staff can easily see where a patient is at in their journey, what investigations they have had and what is happening next.

> It's almost like we need some sort of live thing – for every single patient on the diagnostic pathway – where they are and what they're waiting for, are they green yellow or red? Where are we and what's the delay? The trackers do kind of do this, but we don't have massive oversight of it. There is a mechanism for keeping an eye on everybody, but it feels like it could be better. There isn't something visual that you can see as to where people are at.
>
> **Allied health professional**

18. Limited staff capacity and support

Reduced staffing capacity across many services and roles limits care and does not provide resilience when staff are unavailable. This results in a stretched and overwhelmed workforce with limited psychological support.

- There is a **lack of staff capacity across several job roles and services**, with CNS capacity, allied health professionals and psychologist support specifically highlighted by staff resulting in patients not being seen according to guidelines. Services also may not be staffed sufficiently to provide **service resilience** when team members are off, resulting in patients not getting seen.
- **Recruitment and retention** of some staff working in cancer services is affected due to the limited learning and development opportunities available at the Trust. Short staffing and the inability to rotate and build skills in a wide range of patient areas contribute to this, compared to opportunities presented by other London Trusts.
- There is a **lack of psychological support for staff** working in emotionally challenging services. The support provided between the psycho-oncology team and CNSs works well and is a model that could be expanded if there was more capacity.

Key improvement areas:
- Ensure sufficient service staffing capacity to always meet best practice guidelines.
- Ensure learning and development of staff is a priority to attract and retain the highest quality candidates.
- Ensure sufficient psychological support for all staff working in cancer services.

The therapy world is small, people talk, they know what it’s like...we’re not giving staff the opportunity to rotate and build the workforce for the future.

Allied health professional

19. Lack of awareness or access to patient support services

Staff are sometimes unsure about where to signpost patients to for support or patients wanted to access services but couldn’t. A lack of community services significantly affects care, with particular issues around receiving palliative care at home.

- There are some **issues with accessing support services**, due to patient and staff lack of knowledge about what is available. There is also demand from patients for more **signposting and awareness of wider holistic therapies** that are available to them, such as self-hypnosis during radiation therapy or attending a complementary health therapist.
- Patients may have **wanted to use support services but couldn’t**. For example, the Hammersmith Macmillan centre was closed or they couldn’t leave the outpatient waiting room to visit Maggie’s.
- There is a severe **lack of community services** to discharge patients into, specifically community mental health and allied health services.
- The ‘fast-track’ process for **palliative discharge home is complicated and slow**, resulting in significant stress and anxiety for patients and family members at the end of life. Hospice care is also limited due to lack of services available locally.
- The Trust does not provide a **palliative outpatient service**, which is an issue for patients needing symptom control but who are not suitable for community palliative care.

Key improvement areas:
- Ensure staff are aware of the wider support offer available to patients.
- Ensure patients are supported to access support services on-site.
- Expand the offering of support services provided to patients by Trust and partners.
- Ensure access to mental health and allied health services in the community.
- Ensure patients receiving palliative care are supported when discharged home.

> We feel that access to community services and support needs to be worked upon. Often it is very difficult to support discharges and see patients along the pathway if they [community services] do not have the capacity to support.
>
> **Allied health professional**

20. Overemphasis on phone appointments

Patients and clinicians are often unhappy with clinics defaulting to phone appointments, due to the importance of face-to-face communication when providing cancer care.

- A **lack of face-to-face appointments where necessary** can result in poor patient experience. While patients might prefer to meet healthcare professionals in person to build rapport and ask questions, staff also shared the clinical relevance of meeting a patient in-person to observe them and see how they are. Meanwhile, clinics such as lung nodules that are monitoring benign disease, could be made virtual to free up time for more face-to-face communications where necessary.

Key improvement areas:

- Ensure that patients are seen in the most appropriate format for that stage of the cancer journey, whether in-person or virtually.

> If you phone someone up as an oncologist to check they're alright, I'm not sure if that's good, they could say they're alright when they're not. There's probably some where it's totally fine, but certain cancers because they get multiple complications due to the nature of their cancer and it's all quite difficult to navigate. I think somebody like that could deteriorate at home and you wouldn't notice on the telephone.
>
> **Doctor**

21. Issues with patient facing digital tools

Most issues with digital tools concern Patient Knows Best, which many patients find helpful to keep track of their results. However, they may need reassurance about some information or struggle not having access to certain results on the platform.

- Many patients use Patient Knows Best to easily view results and letters in one place. However, **seeing abnormal results or language they don't understand** can cause anxiety and **need reassurance**.

- Patients struggle **not having access to scans or test results** in a timely manner on Patient Knows Best, instead having to call someone or wait for their next outpatient appointment to discuss it with a clinician.

- Some patients with poor digital literacy skills need **additional support to be able to use these tools** to manage their care.

- Services are using **digital consent tools** more often; however, some patients find it overwhelming to be presented with so much information and not in a traditional paper format.

Key improvement areas:
- Ensure patients are supported to view and understand their latest medical communication and results using digital tools all in one place.
- Ensure that patients are consented for treatment in a way that meet their communication and information needs.

> I wish all the results were available on Patient Knows Best instantly, currently they're treating us like babies, we're only able to see it after 2 or 3 months, and I think that's a long wait.
>
> **Patient treated for breast cancer**

22. Lack of joined up care and transfer between hospitals

Patients often feel that there isn't a joined-up approach to their care, as they don't understand why all NHS services can't see the same information. This is particularly an issue in emergencies, where information is needed urgently.

- Some patients have positive experiences of **care handovers between Imperial services and other Trusts**, while other feel there was a lack of joined up care and transfer between hospitals. Patients say that they had positive experiences about specialist cancer care coordination when multiple specialties were working together within Imperial.

- **Patients feel that this is particularly an issue for presentations at the Emergency Department.** Often patient turn up at their local emergency department, which may be external to the Trust, and staff can't access their cancer record or results. This causes additional stress for the patient and more time taken to retrieve previous information and provide appropriate care.

Key improvement areas:
- Ensure there is a more joined up approach to transfers between the Trust and external services.
- Ensure that cancer patients can attend any NHS England Emergency Department and for the staff there to have sufficient access to their cancer care records.

> Feel like I got lost in the systems, I was referred back to Hillingdon and then I didn't hear anything and when I called them, they were surprised to hear from me. It was a bit like something had got lost.
>
> **Patient treated for multiple myeloma**

23. Issues getting to appointments

Getting to appointments can be challenging due to issues with public transport, parking and the Patient Transport Service. This is compounded by limited diagnostics and treatment locations for patients to choose from. Signage could be improved to support patients to find their appointments easily.

- The **Patient Transport Service** is an issue for patients, particularly after surgery, as there were long waiting times, and it was an uncomfortable journey.
- **Limited treatment locations** for some cancers mean that patients must travel long distances for regular treatment. Patients also would like to get more tests done closer to home.
- Regarding **accessibility**, patients we spoke to with **mobility issues** found the hospital easy to navigate, but others had issues with escalators not working in Charing Cross. Patients using **public transport** found it difficult to get to the hospital for early morning appointments.
- There is a **lack of parking availability** at sites and issues with **paying for parking**, as often machines are broken, making it a stressful experience trying to find somewhere to park and pay before appointments.
- **Signage** was an issue where patients didn't know where they were going, making them stressed about missing important appointments.

Key improvement areas:

- Ensure that patients are supported to attend in-person appointments, for example support with parking or public transport.
- Ensure that patients are given a variety of appointment locations to choose from where possible.
- Ensure there is clear, coordinated signage across the Trust to support wayfinding.

I went by an ambulance. It was a long wait and also the driver was not very good. He should have been a bit slow, but he was in a hurry to drop. I had a lot of pain with the bumps, but he didn't care.

Patient talking about going home after surgery for kidney cancer

24. Disjointed staff communication and ways of working

Staff aren’t always clear what each other's roles are and who is doing what for the patient. This leads to a lack of clarity and unclear communications across teams.

- There is **lack of clarity among staff about roles** within the multidisciplinary cancer team. This means that staff don’t know who is responsible for what in the patient’s cancer pathways and there is a lack of communication between important staff members. In particular, **medical staff do not understand the CNS role and responsibilities** and how they can work together as a team to provide cancer care.

- The **multidisciplinary nature of cancer pathways** makes it **structurally challenging to engage all relevant services in planning and governance activities**. Cancer support services and therapies such as dietetics and physiotherapy are not consistently engaged in service development work and business case development, and this can lead to capacity challenges upon implementation.

Key improvement areas:

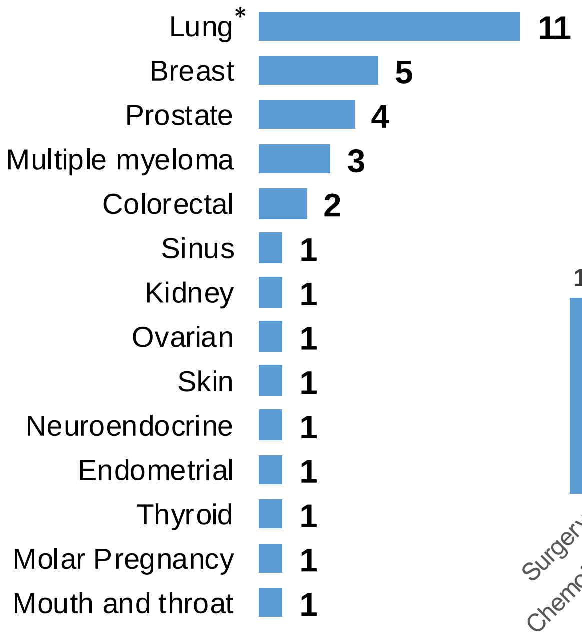
- Ensure clarity across all Trust staff working in cancer pathways about the roles and responsibilities of the multidisciplinary cancer team, particularly the CNS role.
- Ensure the appropriate organisational design that facilitates cross-divisional cancer pathways.

> What might be happening is people in the cancer pathway don’t understand each other's roles. I probably don’t understand the site-specific CNS roles, like the breast CNS role. When I was a doctor in training, what I thought was in their role might not be anymore. It’s a miscommunication about who’s responsible for what. If I don’t know it to some degree and can’t describe it to you, there’s probably no hope for the patient.
>
> **Doctor**

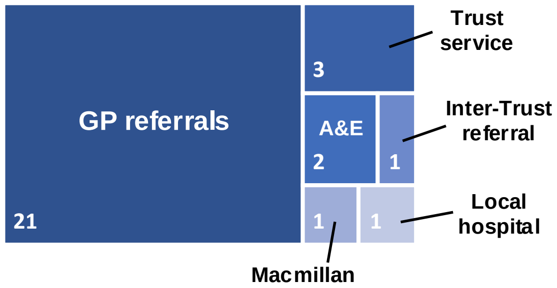
Diversity of public members we spoke with

Participants initially selected based on set criteria*
- Cancer type (max 3-5 per type**)
- Treatment type
- Care location
- Referral source
- Unique needs

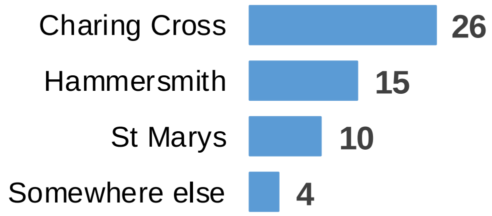
Cancer type



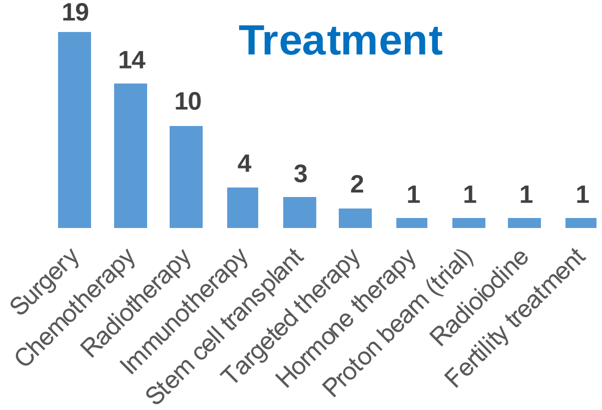
Referral source



Care location



Treatment



Unique needs

3 Disability or physical access needs

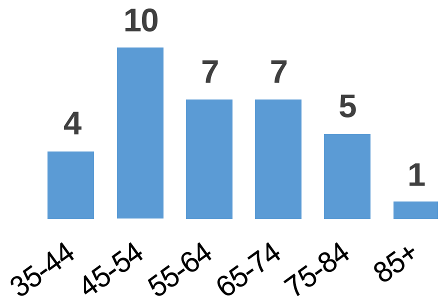
1 Bipolar disorder

1 Low digital literacy

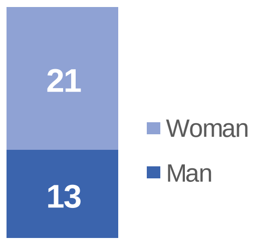
0 Interpreters required although we spoke indirectly to a Chinese cancer support group

Participants then reviewed to ensure representative of NWL demographics
- Age
- Gender
- Ethnicity
- Deprivation

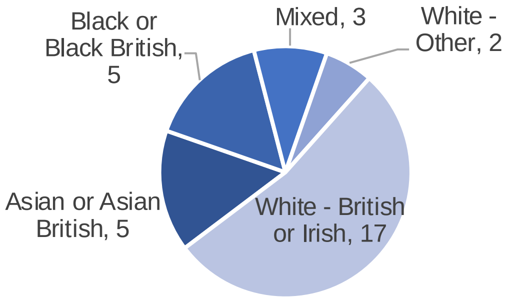
Age



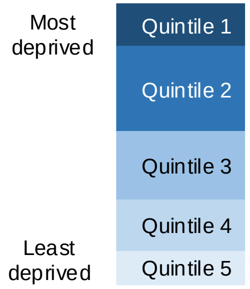
Gender



Ethnicity



Deprivation

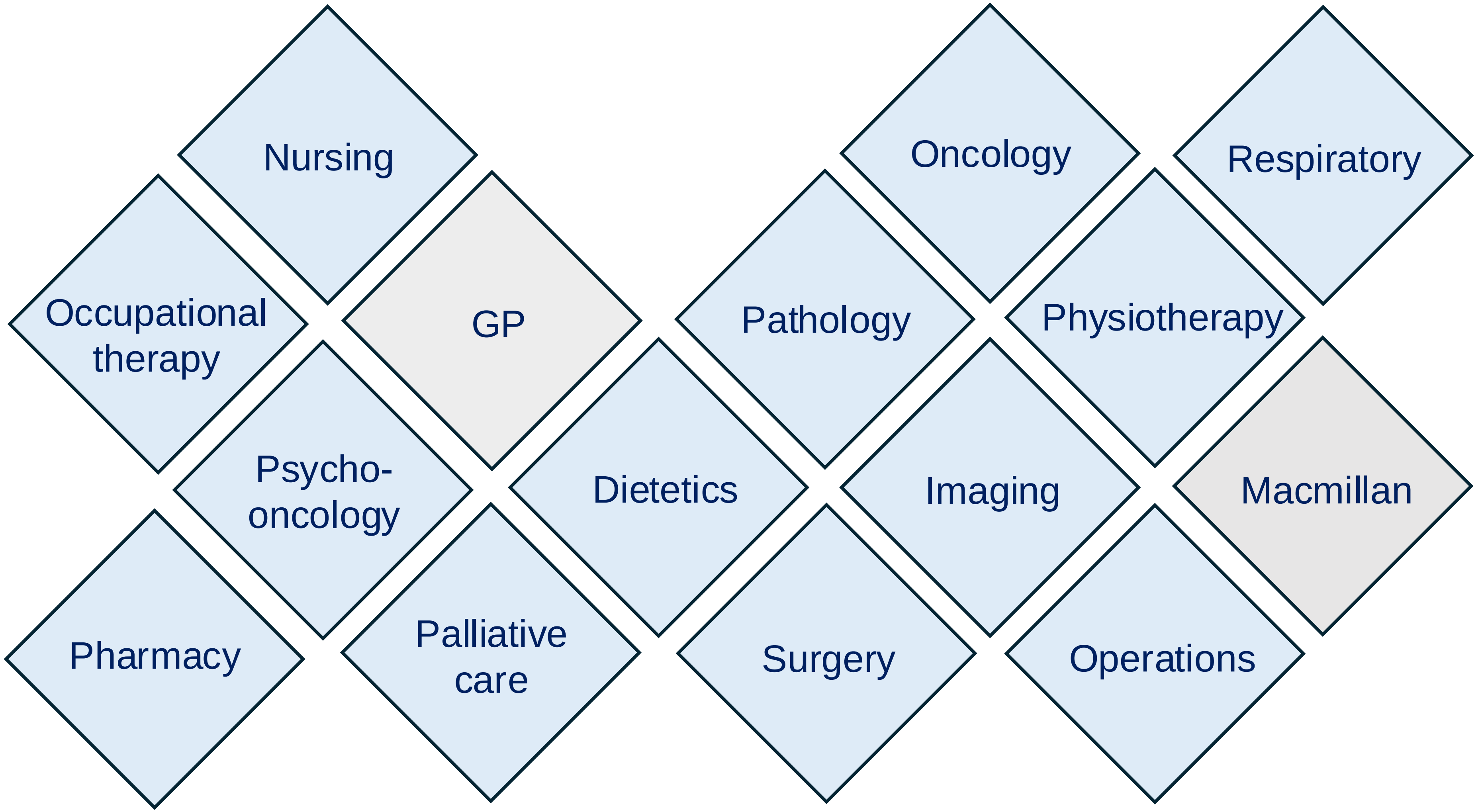


*All information self-reported by patients or family members; not included if unanswered. Where both patient and family member was interviewed, only patient details were included.

**Lung cancer has > 5 participants as this was part of initial project to deeply understand lung cancer care

Breadth of staff we interviewed

We spoke to 15 staff or support services across the following areas



Nursing

Oncology

Respiratory

Occupational therapy

GP

Pathology

Physiotherapy

Psycho-oncology

Dietetics

Imaging

Macmillan

Pharmacy

Palliative care

Surgery

Operations

◇ Trust staff

◆ Other staff

How we recruited participants

	Patients	People supporting patients	Staff
Recruitment strategy	• Text message invitations sent to cancer patients [see inclusion/exclusion criteria] • Recruitment flyers at range of Trust and community locations e.g. Maggie’s, White City community Centre • Trust/IGHI social media • Shared opportunity with local partners e.g. Healthwatch, GP network • Shared opportunity with community organisations e.g. Black Women Rising • Included link to sign-up in CNS email signatures	• Asked patients to bring someone with them to interview or workshop • All recruitment methods as for patients, except text messages	• Identified and emailed by project team

Helix Centre

NHS
Imperial College Healthcare
NHS Trust

Share your experience of cancer care at our hospitals

We want to understand the experiences of patients who have recently had cancer care or treatment at Imperial College Healthcare NHS Trust, and those who are supporting them. We know we can do more to support people, and the insights we learn will inform future improvement work.

Who can take part?

- If you have been **diagnosed with, or treated for cancer at Hammersmith, Charing Cross or St Mary’s hospitals within the last 12 months**.
  or
- If you have **supported someone important to you who meets the above criteria**. For example, you have attended appointments with them or helped them understand information.

We want to speak to people from a range of backgrounds, including underrepresented communities and neurodivergent people. We can provide an interpreter and accommodate different individual needs and preferences.

What will it involve?

We will ask you to share with us your experience of cancer care. You can get involved in a way that makes you feel most comfortable and we will ask your preference when you apply.

There are a range of ways you can take part and you can choose which method suits you best:

- Group session by video call
- Group session in person
- Chat over the phone or video call
- Chat in person

As a thank you, you will receive a **“One4all” voucher** valid at a range of shops at the value of **£25**

Apply by 23:59 on Monday 22 July to get involved

Please apply through the link below or call:

Visit www.imperial.nhs.uk/cancer-pathways or scan the QR code
Call a member of the project team 07561 873 711
Email imperial.userinsights@nhs.net

*Please note: This is a service evaluation project. The people conducting this study are not medical professionals. They are not able to answer any questions you might have. If you have any concerns abut the medical care that you have experienced, you should contact pals at imperial.pals@nhs.net (020 3312 7777) or the complaints team at ICHC-tr.Complaints@nhs.net