



Patient Collaboration Toolkit

**This toolkit was co-produced with
patients, staff and the Patient Experience
and User Involvement Team, North
Central and East London Cancer Alliance
(2019)**

Sarah Josefsberg (Patient Experience and User Involvement Lead) would like to thank all of the patients and staff who gave their time to collaborate with her in order to co-design these resources

Thank you!

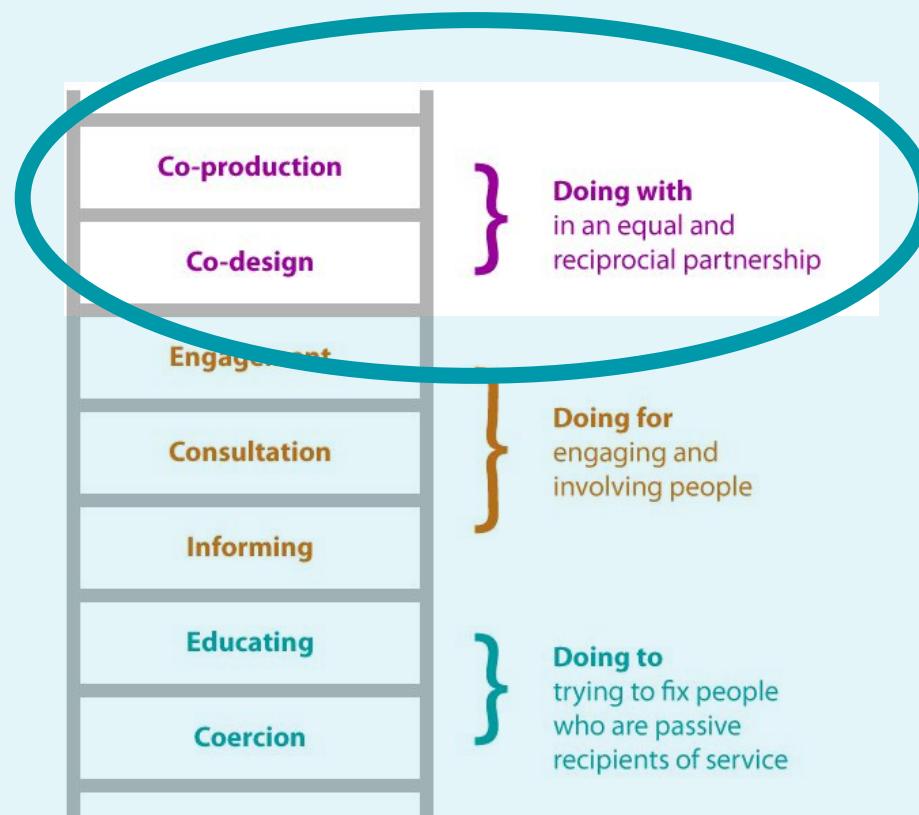
Levels of Involvement

This tool kit will help you guide you when doing work with patients.

The aim is to make things easy and help you move up the coproduction ladder towards higher levels of patient involvement.

We will save you time and give you all our resources so you can run amazing collaborative sessions.

Greater collaboration and patient empowerment...



Involving patients

Good collaboration is when patient involvement is meaningful. This means that both the patient and staff member are bringing something to table in order to achieve a shared goal.

Inside this toolkit are resources to help you work in more collaborative ways with patients.

These include tools and session materials to help when working with patients on service improvement projects.

We will also include general tips to help you bring more meaningful patient involvement to all of the work you are doing



Project & Pathway Board Roles		Explore the problem		Plan a collaborative session	
14	Patient role descriptions	20	Idea sheets	7	Three quick ways to be more collaborative
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Three quick ways to collaborate

"I have no time!"



Top tips

If you have an idea for some improvement project 'phone a patient'. Run your idea past one of your patients to see if it makes sense.

Before you start writing the script for that amazing video invite a patient or two to be part of the initial idea planning session.

Three quick ways to collaborate

"I can't get this project off the ground."



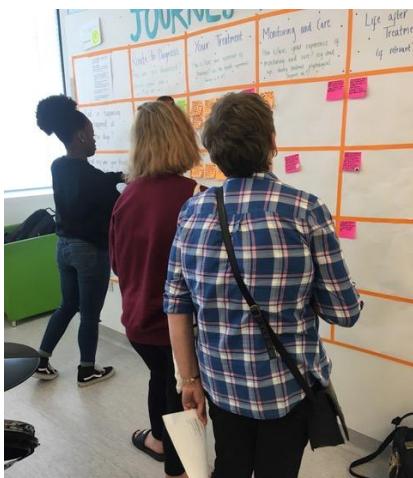
Top tips

You have a project that you know will help patients but no one will get behind it?

Find a patient to partner with! ([Patient representatives](#), [Patient Partners](#)) They can accompany you to meetings and ensure patient involvement throughout the process. It is an opportunity to have someone with lived experience advocating with you in meetings

Three quick ways to collaborate

"Everyone has the same complaint, I hear patients telling me the same thing all the time."



Top tips

Patients come to you and constantly give you the same message about what doesn't work, form a working group.

Patient voice is power! Capture patient quotes ([Patient journey wall](#)). Providing a space on the ward to capture feedback can help guide projects and find patients to partner with or connect with improvement projects related to their interest and skills.

Ways to keep conversations on track

How can I keep the conversation focused when working with patients?



Top tips

Car park- Encourage patients to write their thoughts and insights on post-it's and place in car park if not specific to the conversation

Designated signpost- Assign a person to signal people back into the conversation. They can take conversations outside if needed. "I am the person that will give this signal if we are going off track and I will make this hand sign. When I do let's get back on track"

Ways to keep conversations on track

Use posit-it's to write down any ideas or thoughts you have that are not related to the session and are still important!

Can we make this leaflet electronic?

What about younger people who want this service?

I like the badges!
:)

CAR
PARK

Patient Roles and Responsibilities



Levels of Involvement

Here are some template job descriptions and support materials for patients and staff.

Please feel free to amend and change according to what you discuss.

Creating clearly defined roles with your patients will help promote more meaningful ways of working together.

Patient role descriptions



Patient Involvement

Step 1. Find a patient who may be interested in a role within your team via staff on cancer boards or trust level PI teams.

Step 2. Meet with patient and discuss and amend the job description to fit your service or project and their needs.

Step 3. Agree on supervision times and level of required support

Step 4. Meet Trust Volunteers Lead to set up a volunteer role training, DBS and contract.

Patient Partner-Pathway Board / Project: Template role description

General information

Role title: Pathway Board Project Advisor [*adapt for specific Pathway Board/ ERG*]

Expenses: Voluntary (travel expenses will be remunerated)

Hours: Attendance at [*quarterly*] Board meeting; ad-hoc contributions between meetings as required

Responsible to: Patient Experience and User Involvement Project Manager (/relevant London Cancer Project Manager)

Responsible for:

- *To be determined individually with relevant Chairs/ Project Managers*
- *Providing feedback to the ERG or Boards i.e. chemotherapy ERG on any issues that may be important to patients relevant to that group i.e. chemotherapy patients receiving services or who have recently received treatment*
- *To provide real time feedback and ideas from face to face interactions with patients and present this to members of the board/ ERG.*

- *To build relationships with patients who are undergoing treatment and receiving services and get their feedback and input into current projects which are relevant to them*
- *The role will have a priority agenda item scheduled for each meeting proving a 2-5 min slot for regular updates*

Job summary:

As a Pathway Board Project Advisor, you will work alongside relevant members of your Pathway Board or ERG to develop *X project ...*

Main duties and responsibilities:

- *To be determined individually with relevant Chairs/ Project Managers*

Patient Partner- Pathway Board / Project: Template role description

Person Specification

Essential

- Experience of working with a Pathway Board/ ERG for at least two years
- Experience of either living or being treated for cancer within the area covered by NCEL Cancer Alliance ([see map](#)).
- Ability to provide objective input about the needs of people affected by cancer and to represent the diverse range of people treated in the NCEL Cancer Alliance.
- Ability to communicate your ideas to a wide range of people, including senior healthcare professionals.
- Confident about participating in group discussions and presenting the views of people affected by cancer.
- Ability to offer constructive challenge to senior professionals when necessary.
- Ability to listen to and respect different perspectives, display empathy, and be open to other points of view.
- Ability to understand and evaluate a range of information and evidence to support different approaches to service delivery.

Essential Continued

- Have an awareness of and commitment to equality and diversity.
- Reliable and trustworthy
- Are willing to sign up and adhere to our Ways of Working, Conflict of Interest and Confidentiality Agreement.
- Good organisational abilities
- Good IT skills including the use of email

Desirable

- Belong to, or are willing to join, a cancer support group or a community group. As well as cancer-specific groups, this could also include a patient participation group, local Healthwatch, a peer support group, a faith or cultural group.

Patient Partner- Pathway Board / Project: Template role description

What you will get from us

- *Ongoing support from NCEL Cancer Alliance's Patient Experience and User Involvement Team in the form of peer to peer meet ups with other patients involved with the cancer alliance in formal roles. The PI lead will also provide supervision and catch up sessions via the phone or in person.*
- *Ongoing support from Programme Lead/ Project Manager and Cancer Board Lead via scheduled meeting or phone call between sessions to fully report and provide feedback*
- Travel expenses remunerated for all opportunities you take part in
- Experience of working closely and directly with clinical and managerial staff across NCEL Cancer Alliance, as well as other patient and carer representatives
- Learning about current developments in the provision of services for people living with and beyond cancer
- The opportunity to become more involved in the work of NCEL Cancer Alliance and relevant NHS Trusts

Cancer Alliance Peer Mentor: Template Role Description

General information

Role title: Cancer Alliance Peer Mentor

Expenses: Voluntary (travel expenses will be remunerated)

Time Commitment: *Up to 5 hours per month (depending on your availability and support needs of patient and carer representatives)*

Job summary:

Peer mentors use their knowledge, skills and experience of influencing services to support new patient and carer representatives as they develop into their roles within Pathway Boards, Expert Reference Groups and Project Steering Groups.

The support provided by Peer Mentors can take the form of peer training, peer inductions, or ad-hoc troubleshooting and may be provided in one-to-one meetings, groups, online or by phone.

Main duties and responsibilities:

- Serve as an energetic, empathetic and enthusiastic volunteer to help new patient and carer representatives influence work at NCEL Cancer Alliance
- Develop, maintain relationships with and provide assistance and support for new patient and carer representatives (focus on supporting the Patient Experience and User Involvement team to induct new members, and answering questions related to any challenges or issues which arise)
- Collaborate closely with the Patient Experience and User Involvement team to develop workstreams which align with the needs of patients and carers
- Help facilitate Induction Days and Peer to Peer Events for patient and carer Representatives
- Participate in training and development opportunities related to supporting meaningful patient and carer involvement
- Serve as a positive role model for patient and Carer representatives across NCEL Cancer Alliance

Cancer Alliance Peer Mentor: Template Role Description

Person Specification

Essential

- Experience of working with a Pathway Board/ ERG for at least two years
- Experience of either living or being treated for cancer within the area covered by NCEL Cancer Alliance ([see map](#)).
- Ability to advocate for the needs of people affected by cancer and to represent the diverse range of people treated in the NCEL Cancer Alliance.
- Confident about facilitating group discussions with people affected by cancer.
- Ability to listen to and respect different perspectives, display empathy, and be open to other points of view.
- Have an awareness of and commitment to equality and diversity.
- Reliable and trustworthy
- Are willing to sign up and adhere to our Ways of Working, Conflict of Interest and Confidentiality Agreement.
- Good organisational abilities
- Good IT skills including the use of email

Desirable

- Belong to, or are willing to join, one or more cancer support groups or community groups. As well as cancer-specific groups, this could also include a patient participation group, local Healthwatch, a peer support group, a faith or cultural group.

What you will get from us

- Ongoing support from NCEL Cancer Alliance's Patient Experience and User Involvement Team
- Travel expenses remunerated for all opportunities you take part in
- Experience of working closely and directly with patient and carer representatives
- Learning about current developments in the provision of services for people living with and beyond cancer
- Developing leadership and facilitation skills
- The opportunity to become more involved in the work of NCEL Cancer Alliance and relevant NHS Trusts

Patient Representative: Template role description

General information

Role title: Patient Representative

Expenses: Voluntary (travel expenses will be remunerated)

Hours: Flexible

Responsible to: Patient Experience and User Involvement Project Manager (/relevant Project Lead)

Responsible for: Conducting interviews with patients and carers, transcribing interviews, collecting other feedback where required

Job summary:

patient representatives conduct interviews and/ or focus groups to help us gather insights into the experience of patients and carers accessing NHS cancer services in North and East London, providing us with information which will help us improve cancer services across the Collaborative.

The role will involve working under the direction of the Project Lead and taking part in a group training session on **DATE**.

Desirable:

- Experience of working with people being treated for cancer or their carers (in paid or unpaid capacity)
- Experience of conducting qualitative exploratory interviews
- Experience of conducting other interviews or surveys

Main duties and responsibilities:

- To seek written, informed consent from service users to participate in a recorded interview.
- To conduct interviews as directed by the project lead with consenting service users and digitally record these interviews.
- To transcribe audio interviews into computer documents.
- To give vouchers to exploratory participants on completion of an interview (where relevant) and obtain a written receipt.
- To reimburse participant travel expenses (where relevant) and obtain a written receipt.
- To return study documents and equipment promptly following an interview, as directed by the relevant project associate.

Patient Representative: Template role description

Main duties and responsibilities continued :

- To attend relevant training as directed by the Patient Involvement team.
- To promptly inform the Project Lead and Patient Involvement team of any circumstance that could restrict your ability to conduct the role competently and safely.
- To promptly inform the Project Lead and Patient Involvement team of any concerns you have following an interview about the interviewee's safety or well-being.
- To adhere to UCLH policies during work on the study, including policies on confidentiality, data protection, valuing diversity, health and safety and risk management and lone working. (patient representatives will be given a Ways of Working document that outlines these policies before working on the study. The policies will also be explained during training).
- To feed into local PPI and Patient Experience Learning eg. Presenting at the UCH Patient and Engagement Committee or local trust equivalent.

Please note that this job description does not provide an exhaustive list of duties and may be adapted with your agreement as the project develops.

Person specification

Essential:

- Experience of either living or being treated for cancer within the area covered by NCEL Cancer Alliance ([see map](#)).
- Ability to follow procedures and direction from the study team
- Good communication, listening and interpersonal skills
- Reliable and trustworthy
- Good organisational and time management skills
- Willingness to work independently

What you will get from us

- Ongoing support from NCEL Cancer Alliance's Patient Experience and User Involvement Team
- Travel expenses remunerated for all opportunities you take part in
- Experience of working closely and directly with clinical and managerial staff across NCEL Cancer Alliance, as well as other patient and carer representatives
- Learning about current developments in the provision of services for people living with and beyond cancer
- The opportunity to become more involved in the work of NCEL Cancer Alliance and relevant NHS Trusts

Trainer/ Co-facilitator: Role description

General information

Role title: Volunteer trainer/ co-facilitator

Payment: Voluntary (travel expenses will be reimbursed)

Hours: Flexible

Responsible to: Patient Experience and User Involvement Project Manager (/relevant Project Lead)

Responsible for:

- Co-developing and co-facilitating patient involvement training for clinical and managerial staff across NCEL Cancer Alliance (alongside Patient Experience and User Involvement team)
- Co-developing and co-facilitating training for NCEL Cancer Alliance's patient and carer representatives (alongside Patient Experience and User Involvement team)

Job summary:

We are looking for patients and carers who will work with us to develop and deliver two training packages – one for staff and one for patient/ carer representatives across NCEL Cancer Alliance. The Learning Objectives for each of these training sessions will address the areas which relevant participant groups have told us that most valuable to their patient involvement work.

Main duties and responsibilities:

- Develop and co-facilitate involvement training programmes for staff and patient/ carer reps
- Co-chair NCEL Cancer Alliance's quarterly Patient Experience and User Involvement Steering Group (when required)
- Write up minute and actions following meetings or training sessions (examples will be provided)
- Liaising with Project Leads/ Patient Experience and User Involvement Steering Group closely before and after meetings as necessary

Trainer/ Co-facilitator: Role description

Person Specification

Essential

- The ability to encourage and motivate others
- A non-judgemental, patient and supportive approach to others
- The ability to sensitively represent the views of service users
- Clear thinking and the ability to summarise key points effectively
- Good organisational abilities
- Good IT skills including the use of email

Desirable

- Some knowledge/experience of the kinds of cancer that affect people within the services – in particular the way these can present, experience of treatment and the possibility of recovery from them
- Some knowledge/experience of the way Cancer services work
- Experience of facilitating a group

What you will get from us:

- Ongoing support from NCEL Cancer Alliance's Patient Experience and User Involvement Team
- Travel expenses reimbursed for all opportunities you take part in
- Experience of working closely and directly with clinical and managerial staff across NCEL Cancer Alliance, as well as other patient and carer representatives
- Learning about current developments in the provision of services for people living with and beyond cancer
- The opportunity to become more involved in the work of NCEL Cancer Alliance and relevant NHS Trusts

Conversation guide for patients In patient representative and board Roles

Here are some tips and guidance for when meeting with patients to learn about their experiences and get their feedback and ideas.



Conversation guide for patients In patient representative and board Roles

Helpful Questions:

Do you have any questions you would like answered about your treatment experience?

What one thing is important to you in terms of your treatment right now?

Have you thought of anything that could be done differently?

How do you think this could be implemented here?

Conversation guide for patients In patient representative and board Roles

Everyone is different!

We understand that because of your experience you want to make a difference for other patients and we have therefore developed a conversation guide to help you get feedback from patients that will be useful for you to take back to the ERG or board that you are a part of.

Your role is to be a patient voice and therefore you need to have very productive discussions with patients. As a patient, we feel you are very well placed to understand and explore what other patients may want to say to the medical team or organisation.

Conversation guide for patients In patient representative and board Roles



'Hi, I am _____ and I have also had cancer. I am here to learn more about your experience and listen to your ideas. My aim is to find out more about _____ so you might notice me pulling us back towards this topic if I feel we are going off track. My role is to take this feedback and share it with the cancer boards and ERGs so they can understand your experience and this can help them improve services for others'.

Question Guide For Boards And Expert Reference Groups

Here are some tips and guidance for supporting board members to gain feedback and ideas from other cancer patients experiencing the pathway.

Helpful Questions:

What are some questions you would like to know about patients' experience?

What do you think patients understand/ know about _____?

What is the most important message for patients to know from you?



Idea sheets

When working with patients and staff ask them to draw their ideas using the relevant sheet. These ideas sheets help with the brainstorming process.

These sheets help patients and staff show their ideas of what good looks like or the solution to the problem you have identified.

This is a pen and paper task that keep people focused and guide conversations. People complete the sheets and then show their ideas to the rest of group. Discussion and voting for best ideas to work on can then follow.

Co-design

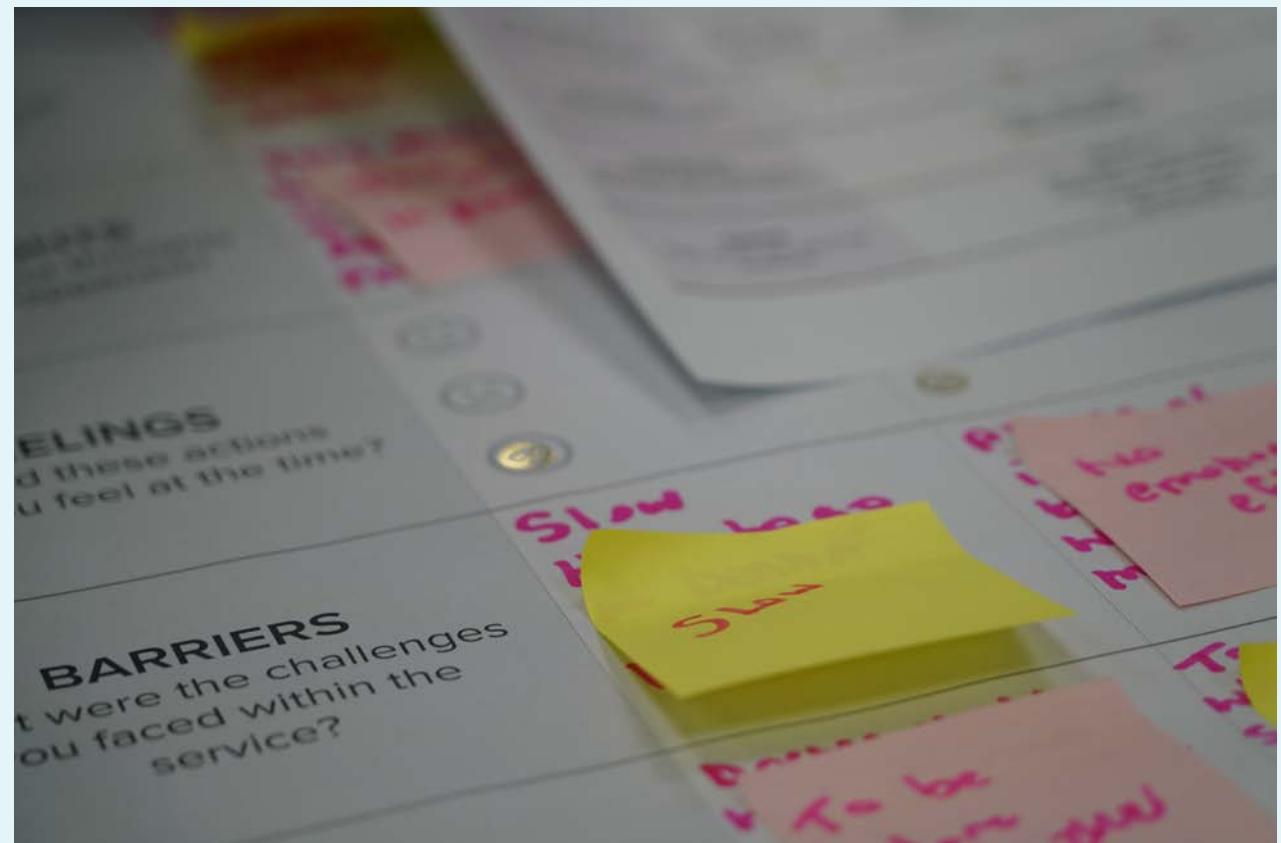


Instructions

Step 1. Before using ideas sheets and brainstorming solutions we recommend you spend some time understanding the experience and issues facing patients and staff. You may run a workshop using journey mapping, personas and case studies based on face to face interviews, focus groups and or information from written research papers and surveys.

It is important to ensure you have really explored the issues before launching into problem solving!

Co-design



Instructions

Step 2. Present information to patients and or staff in workshop setting in the form of personas, case studies, journey map with a main sentence defining the problem.

You may wish to create a How Might We Question, or use a case study to outline the issues raised.

Step 3. Does this make sense to those involved in the service improvement project?

Always test your ideas and ask for feedback. Get patients and staff to vote for most important issue they wish to work on together

Co-design

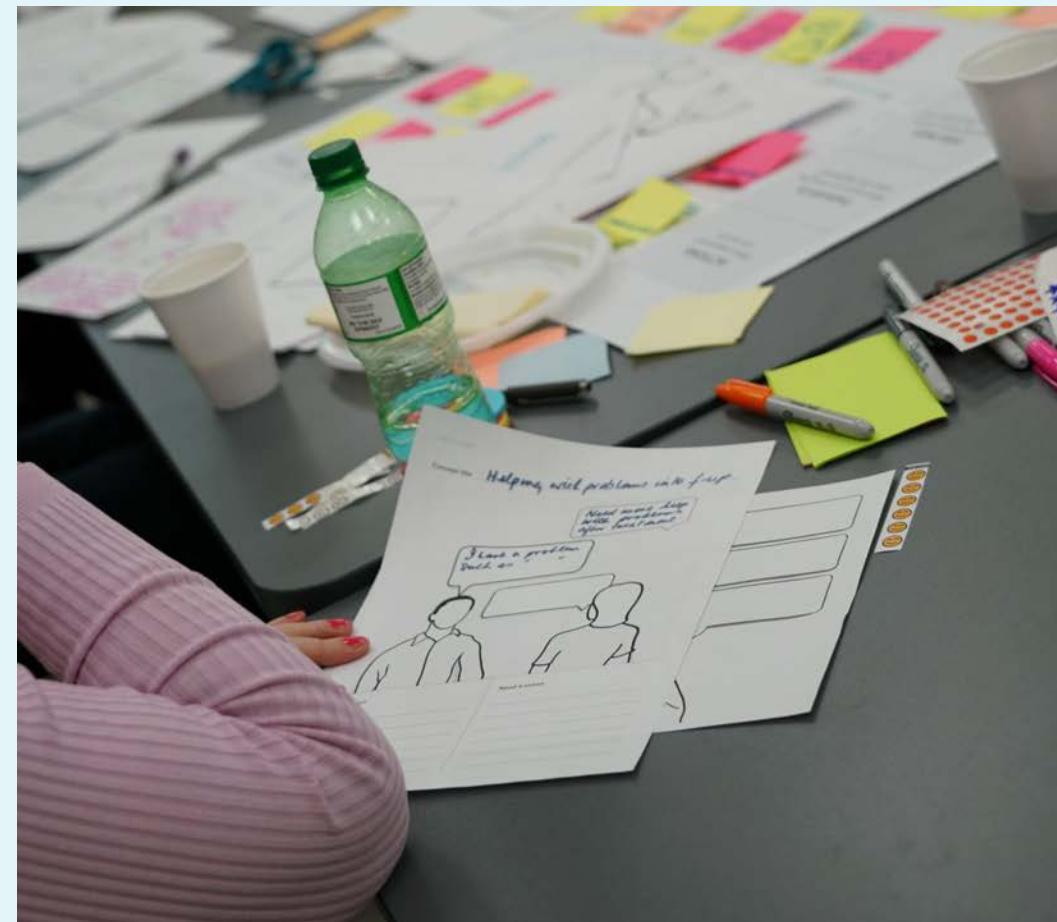


Instructions

Step 4. Introduce the ideas sheets. Refer to the main problem/s patients and staff voted to address.

'We are now going to take the next 20 mins to brainstorm a range of ideas we think may help solve the problem. We would like you to use the ideas sheets to help capture your ideas. You can use a storyboard to retell the experience with your proposed change or the conversation sheets to show what communication would be involved. If you have an idea that involves mobile phone or computer services you can draw them on the screens. We also have a blank sheet where you can draw anything you think of.'

Co-design



Instructions

Step 5. Come together and share ideas as a group and vote for ideas to work on or present to boards for proposed service improvement.

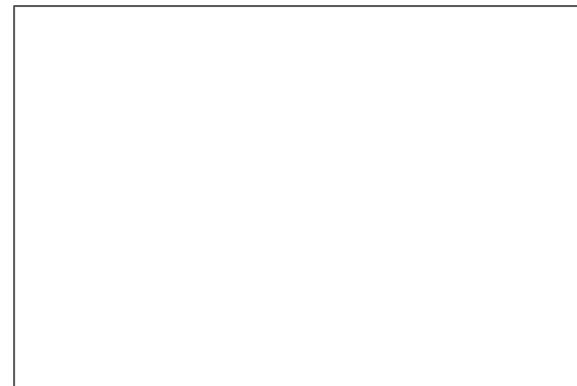
Ask groups to work together on presenting an idea they all wish to work on

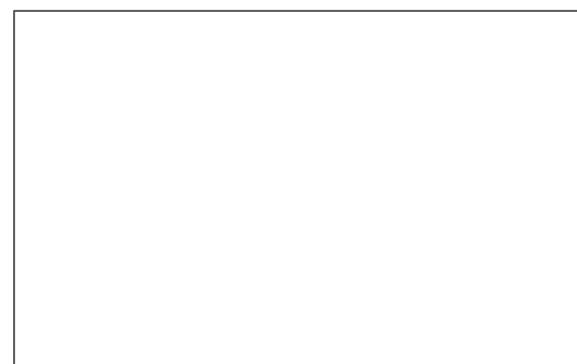
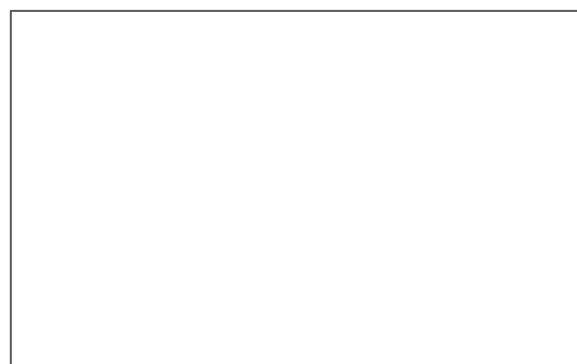
Co-design



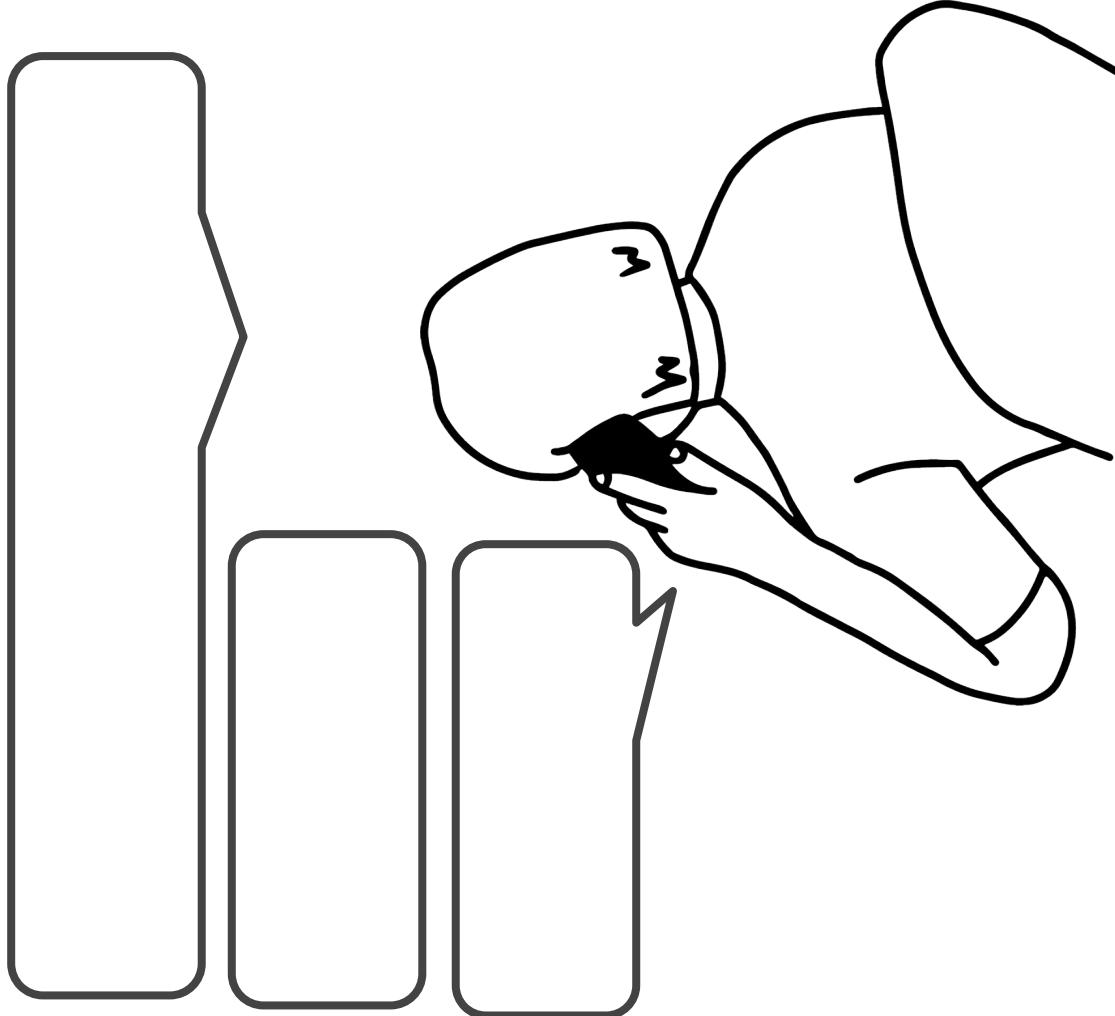
IDEA SHEET

Concept title _____





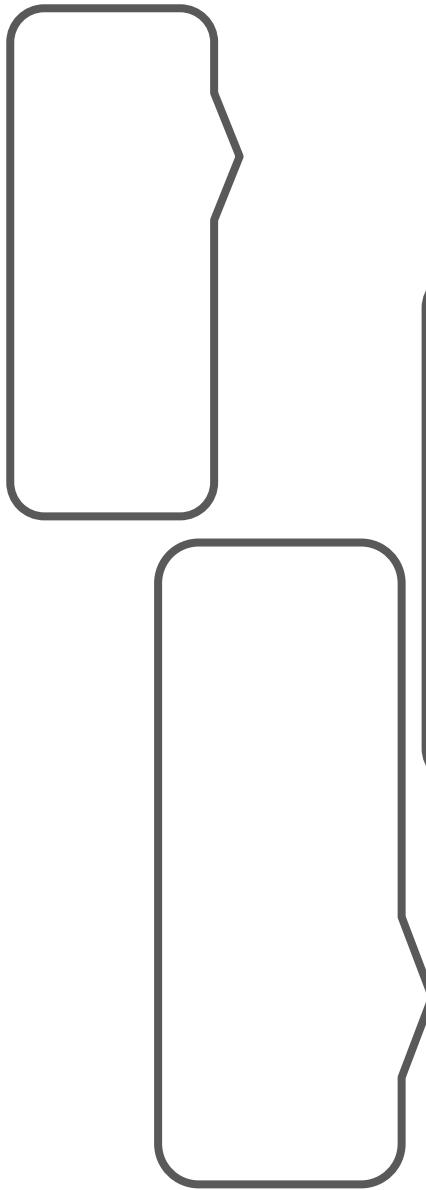
Concept title



Description

Need it solves

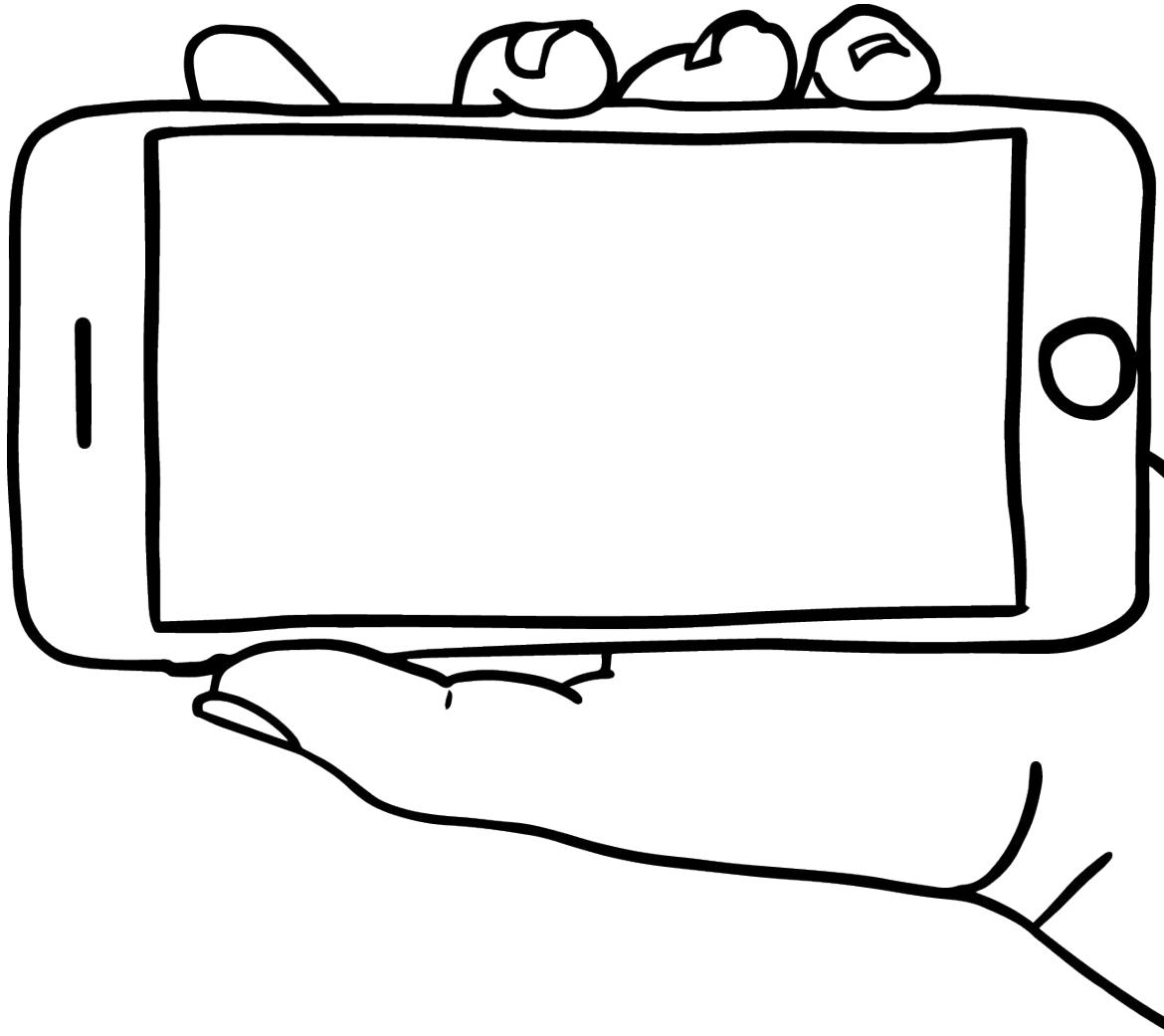
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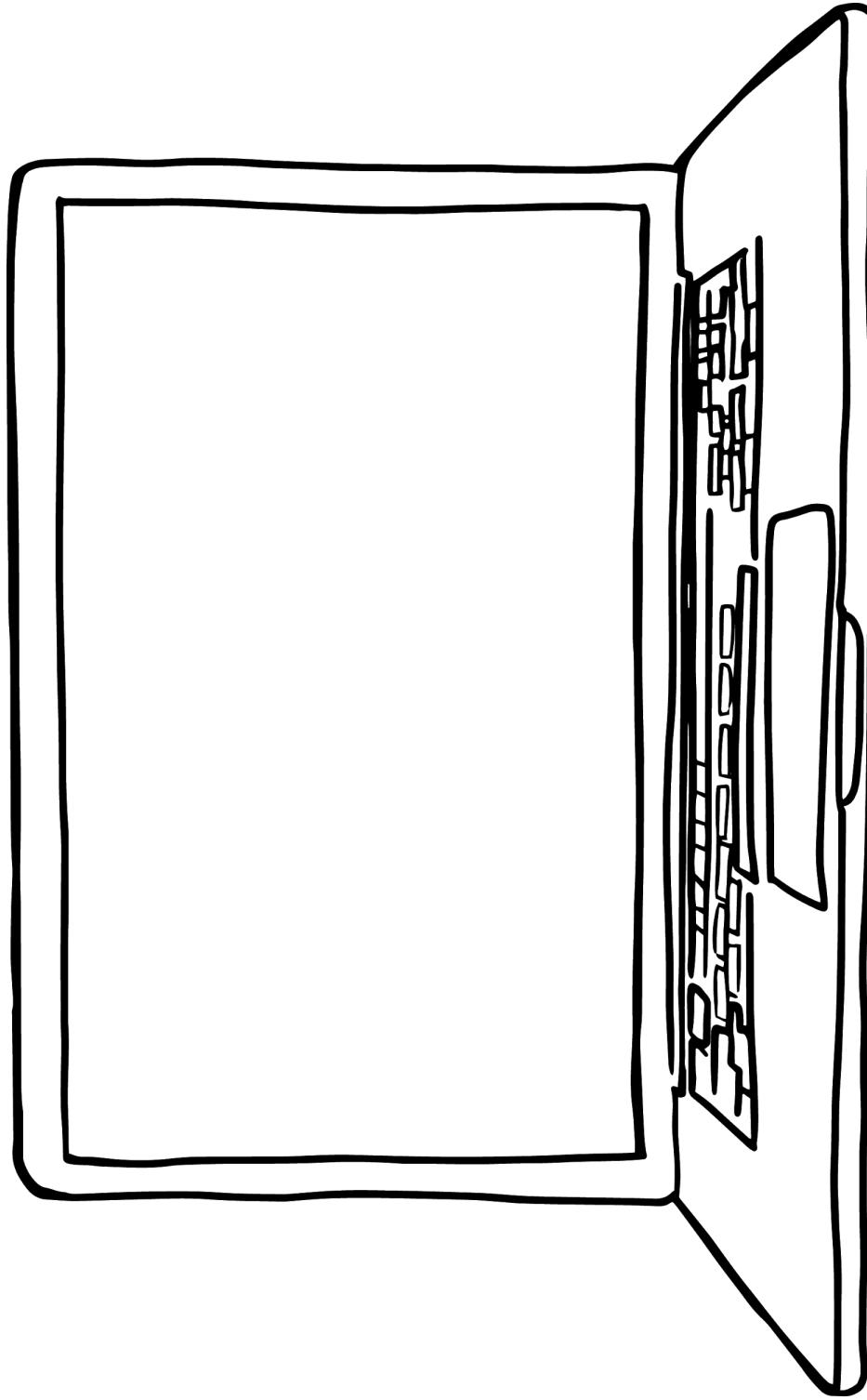
Concept title



Description

Need it solves

Concept title



Description

Need it solves

Concept title

Personas

Used to help us understand the range of stakeholders participating in or being affected by the product or service.

When exploring a problem this is a way to bring patients and staffs' needs into the room to ensure whatever we work on meets their needs. This is also a way to present findings from focus groups and workshops

INSERT IMAGE HERE	Name/ Short description
Feelings and Motivations What does she/he feel and experience?	Needs What does she/he need to improve the experience?

	<p>Name/ Short description</p> <p>Patricia is a 58 year old carer. She is currently looking after her father Jide who has the early stages of dementia. She visits him every morning on her way to work. She works part time providing admin and reception for a small supportive local business. In the past she has had contact with mental health services having been diagnosed with bipolar affective disorder. She also attends her local church regularly for support and has been feeling mentally strong since undergoing treatment for breast cancer a year ago.</p>
<p>Feelings and Motivations What does she/he feel and experience?</p> <p>Patricia feels guilty that she cannot be there all the time to support her father. She feels as though she is in a good place and does not identify with 'cancer'. She feels a desire to give back to her community and wants to put the experience behind her. While most of her experiences with staff were positive, she felt there were times it was difficult to balance her mental health needs. She has a lot to offer and she could support and help to others going through the similar experiences.</p>	<p>Needs What does she/he need to improve the experience?</p> <p>Patricia needs flexibility to be involved. She needs to know how to best use her experience can help others. She has read the statistics and she needs to know that people with mental health needs will be supported to have better outcomes for treatment. She wants to support others who don't know how to navigate the health system.</p>

Step 1. Run a focus group/ talk to a range of staff and patients about an experience you wish to understand. You may also do some telephone or face to face interviews.

Step 2. Look for common themes and find an image that represents this group.

Step 3. Fill in some description under each of the headings from your insights.

Step 4. Bring Personas into planning and solution focussed sessions.

Step 5. Be clear that personas while potentially based on aspects of many real-life people are always fictional and can never be tied back to any real person. It's reassuring to those that assume these are real and many do.

	<p>Name/ Short description</p> <p>Patricia is a 58 year old carer. She is currently looking after her father Jide who has the early stages of dementia. She visits him every morning on her way to work. She works part time providing admin and reception for a small supportive local business. In the past she has had contact with mental health services having been diagnosed with bipolar affective disorder. She also attends her local church regularly for support and has been feeling mentally strong since undergoing treatment for breast cancer a year ago.</p>
<p>Feelings and Motivations What does she/he feel and experience?</p> <p>Patricia feels guilty that she cannot be there all the time to support her father. She feels as though she is in a good place and does not identify with 'cancer'. She feels a desire to give back to her community and wants to put the experience behind her. While most of her experiences with staff were positive, she felt there were times it was difficult to balance her mental health needs. She has a lot to offer and she could support and help to others going through the similar experiences.</p>	<p>Needs What does she/he need to improve the experience?</p> <p>Patricia needs flexibility to be involved. She needs to know how to best use her experience can help others. She has read the statistics and she needs to know that people with mental health needs will be supported to have better outcomes for treatment. She wants to support others who don't know how to navigate the health system.</p>

Example 1. I used a persona of Patricia to personalise a talk I was giving about patient and carer involvement in cancer services.

Sourcing Macmillan and NHS online sites, I read a range of stories of people with similar background and needs and synthesised what I learn into Patricia.

The findings I presented was more personal and relevant. The persona grounded the conversation about patient involvement in a tangible experience and brought the patient and their needs into focus.

Cancer Patient

Lucy is a 57 year old receptionist who works at a local medical clinic. She is finally finished her treatment and feels like she finally has some energy. She wants to use her spare time to help ensure other patients have positive experiences of services.

Lacking confidence in her reading and writing abilities she is also unable to attend day time meetings due to her work schedule.

Lucy wants to be involved but she doesn't know what role she has or how to help.

Needs...

Lucy needs a flexible and inclusive approach to involvement. Lucy needs some guidance and opportunities to grow her skills and confidence.

"...A lot of patients want to get involved but they don't know how? There is a sense of wanting to give back and then, 'how do I do that?, how do I get involved?'."



Example 2. This is a different way of presenting a persona. These two personas were used in a workshop with patients and staff.

At the workshops people were asked to read the personas and then write post-it's to brainstorm ways to help these patients become involved with the Patient Experience and User Involvement Team.

The personas are a synthesis of discussions, interviews and focus group information we have collected from the people we have met and worked with.

An alternative is to ask people to brainstorm solutions to the problems faced by the person

Cancer Patient

Adam is 52 year old cancer patient who previously worked as a head teacher. He is very proactive and has many ideas about things that could help improve patient experience.

Adam advocated and got a support group off the ground at the Macmillan information centre. Nurses facilitate while patients informally support one another. He feels frustrated when the same ideas are discussed without any action taken

He wants to collaborate with patients and staff on projects but is not sure of the best way to do this.

Needs...

A patient role that utilises his skills and talents and a process to support his ideas informing trust projects.

“...when I was deputy head I was used to either people coming up with ideas or me and then I would be cracking on and implementing it whereas as a patient all I could do was make suggestions.”



PERSONA EXAMPLE



Name/ Short description

Patricia is a 58 year old carer. She is currently looking after her father Jide who has the early stages of dementia. She visits him every morning on her way to work. She works part time providing admin and reception for a small supportive local business. In the past she has had contact with mental health services having been diagnosed with bipolar affective disorder. She also attends her local church regularly for support and has been feeling mentally strong since undergoing treatment for breast cancer a year ago.

Feelings and Motivations

What does she/he feel and experience?

Patricia feels guilty that she cannot be there all the time to support her father. She feels as though she is in a good place and does not identify with 'cancer'. She feels a desire to give back to her community and wants to put the experience behind her. While most of her experiences with staff were positive, she felt there were times it was difficult to balance her mental health needs. She has a lot to offer and she could support and help to others going through the similar experiences.

Needs

What does she/he need to improve the experience?

Patricia needs flexibility to be involved. She needs to know how to best use her experience can help others. She has read the statistics and she needs to know that people with mental health needs will be supported to have better outcomes for treatment. She wants to support others who don't know how to navigate the health system.

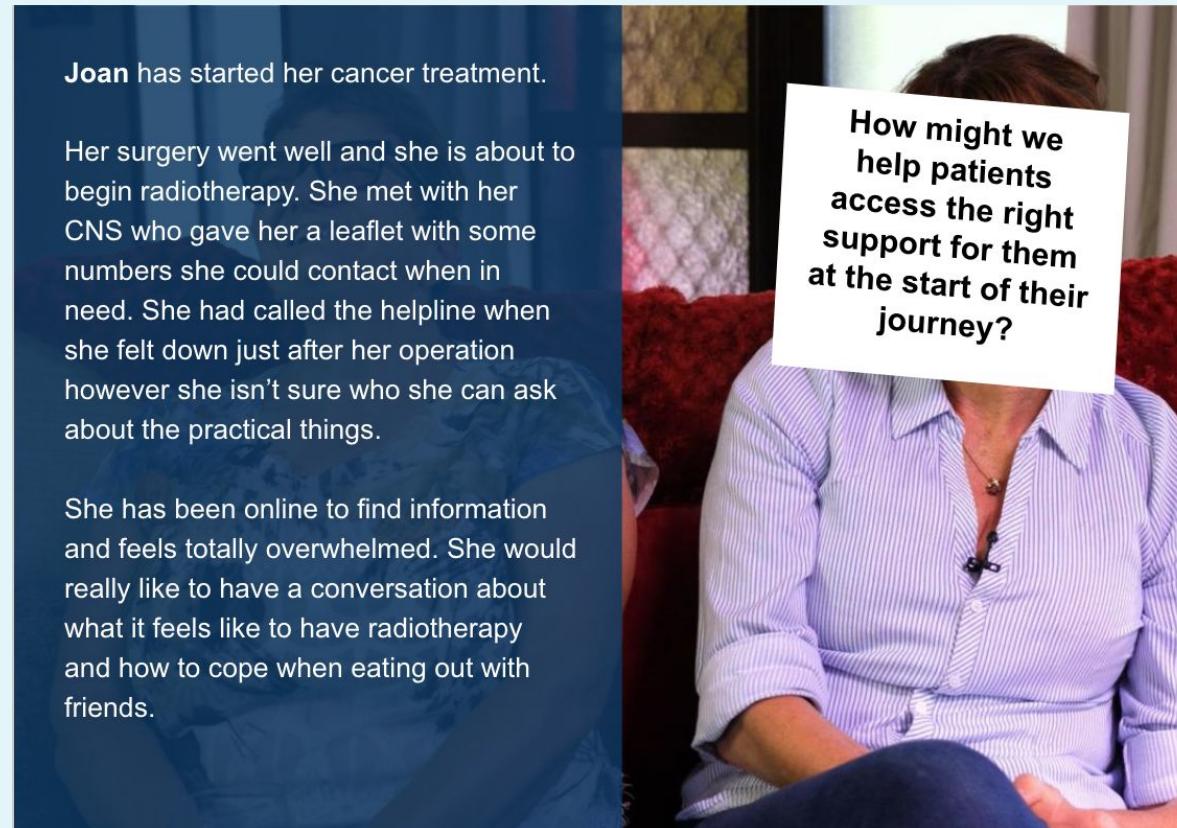
INSERT IMAGE HERE	Name/ Short description
Feelings and Motivations What does she/he feel and experience?	Needs What does she/he need to improve the experience?

Case Studies

Case studies are a good way to depersonalise issues facing patients and or staff. Addressing the issues and discussing them via a case study can help focus the group on the issues you want to tackle.

Rule 1. No more than two paragraphs! A case study needs to be short and convey meaning.

The following are some examples for you to use.



Joan has started her cancer treatment. Her surgery went well and she is about to begin radiotherapy. She met with her CNS who gave her a leaflet with some numbers she could contact when in need. She had called the helpline when she felt down just after her operation however she isn't sure who she can ask about the practical things.

She has been online to find information and feels totally overwhelmed. She would really like to have a conversation about what it feels like to have radiotherapy and how to cope when eating out with friends.

How might we help patients access the right support for them at the start of their journey?

Joan has started her cancer treatment.

Her surgery went well and she is about to begin radiotherapy. She met with her CNS who gave her a leaflet with some numbers she could contact when in need. She had called the helpline when she felt down just after her operation however she isn't sure who she can ask about the practical things.

She has been online to find information and feels totally overwhelmed. She would really like to have a conversation about what it feels like to have radiotherapy and how to cope when eating out with friends.

How might we help patients access the right support for them at the start of their journey?

What is the question we are trying to answer?

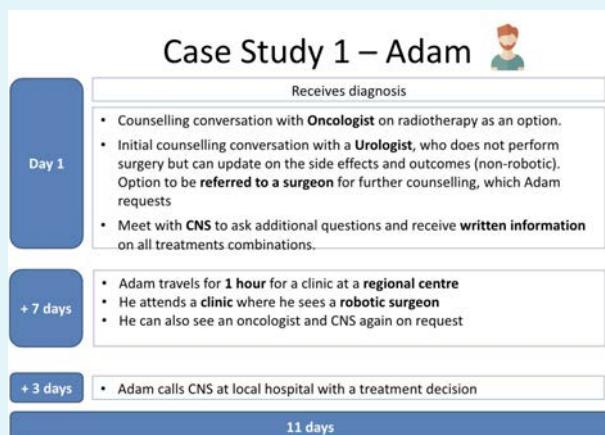
What is the focus of the discussion/ workshop?

1. Describe the context
2. Describe the problem
3. How do they feel?
4. What do they need?

Example

There are a number of ways in which **treatment counselling can be delivered**, we are going to present a series of case studies, we want you to carefully consider your opinions on the following:

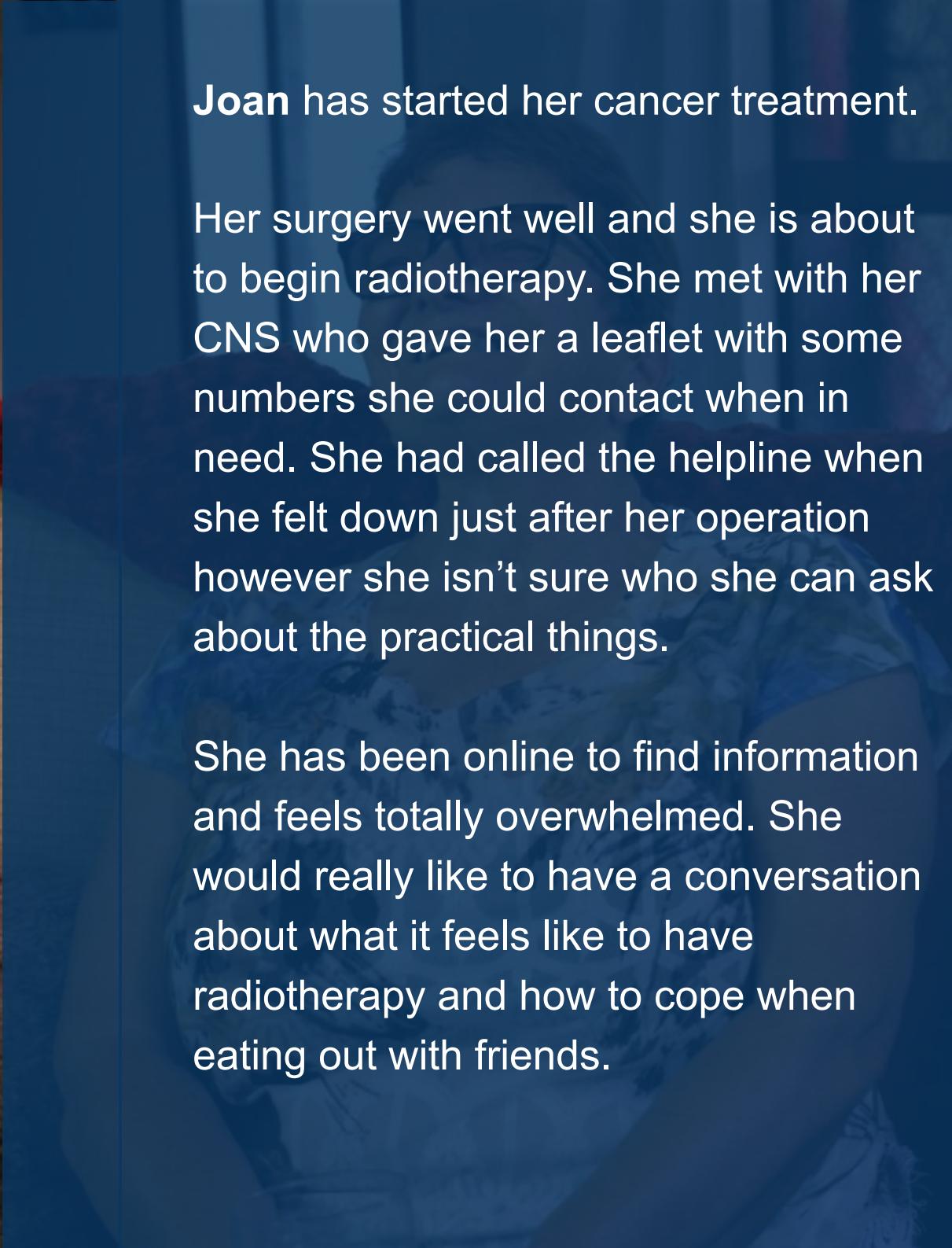
- **Who** do you need to hear from when considering your **radical treatment option**?
- **What intervals** are appropriate between conversations about different options?
- Do you have a **preference** on **where** these conversations would take place?
- What **time period** is appropriate allow sufficient processing time before making a decision?



Considerations for case studies

You may wish to use your case studies as the basis of discussion.

In this case you may wish to create some guiding questions for people to consider.



Joan has started her cancer treatment.

Her surgery went well and she is about to begin radiotherapy. She met with her CNS who gave her a leaflet with some numbers she could contact when in need. She had called the helpline when she felt down just after her operation however she isn't sure who she can ask about the practical things.

She has been online to find information and feels totally overwhelmed. She would really like to have a conversation about what it feels like to have radiotherapy and how to cope when eating out with friends.



John is halfway through his treatment.

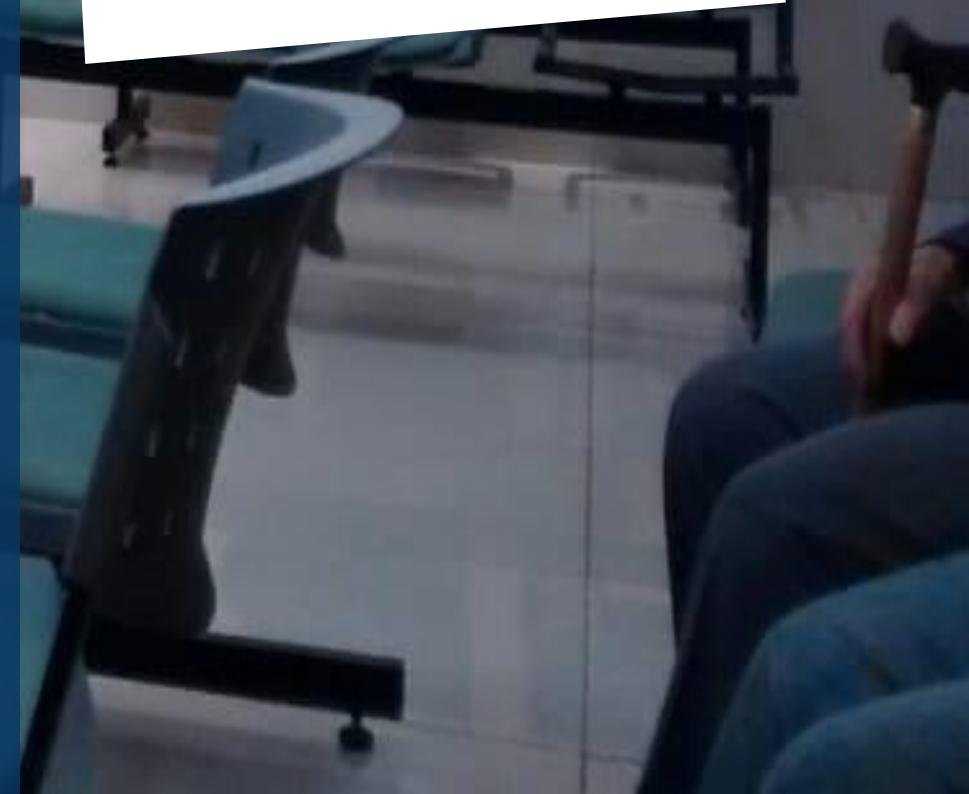
He settles into the waiting room and hopes he'll be seen much quicker this time - He waited two hours last time!

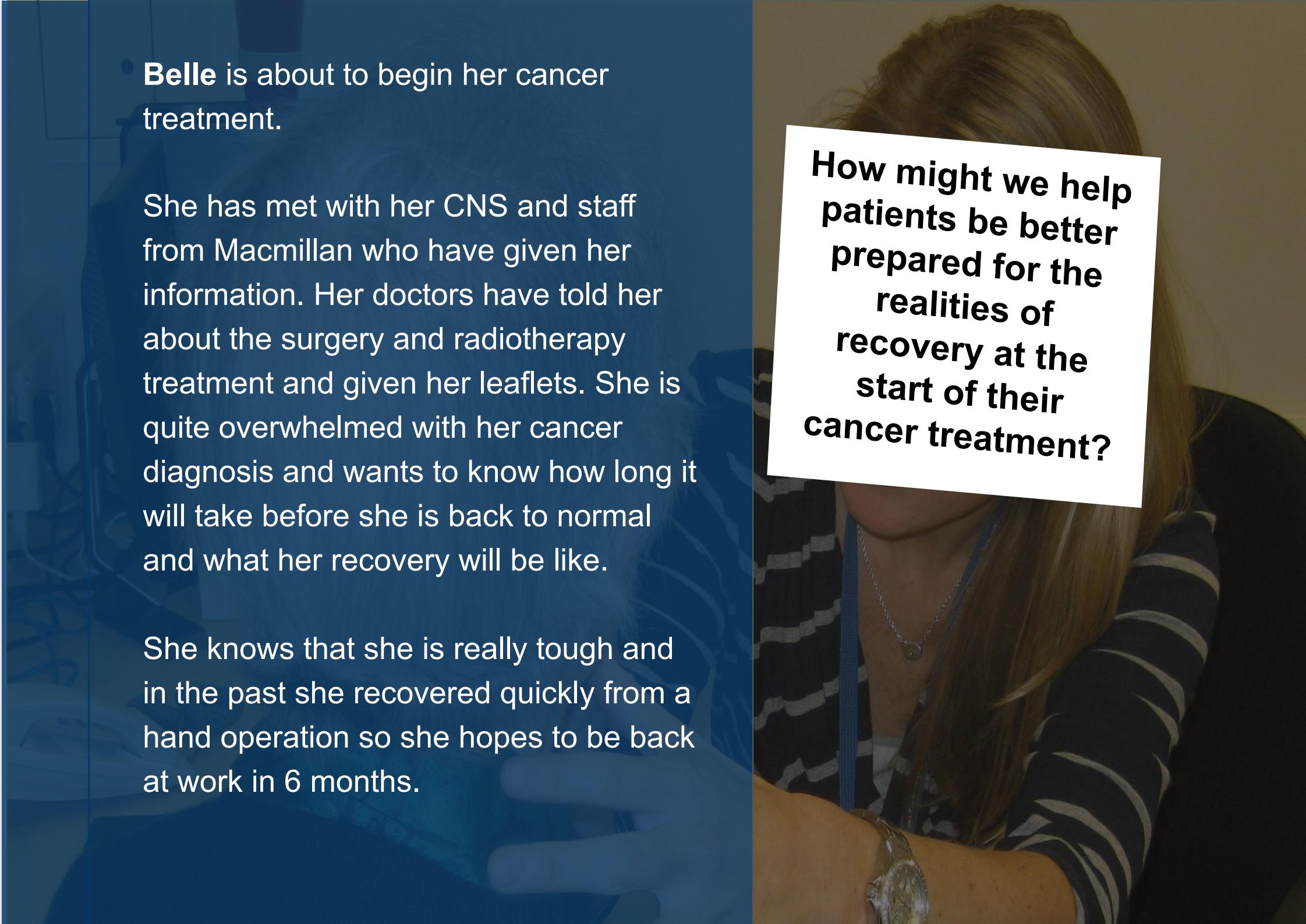
The nurse comes out and writes on the whiteboard. There is a 45 minute delay. He looks around the bare room and sees another patient looking frustrated.

He notices an anxious feeling in the pit of his stomach and wonders what to do for the next hour or so?

How might we make the experience of waiting more pleasant and meaningful for patients?

Assuming wait times are out of our control.





Belle is about to begin her cancer treatment.

She has met with her CNS and staff from Macmillan who have given her information. Her doctors have told her about the surgery and radiotherapy treatment and given her leaflets. She is quite overwhelmed with her cancer diagnosis and wants to know how long it will take before she is back to normal and what her recovery will be like.

She knows that she is really tough and in the past she recovered quickly from a hand operation so she hopes to be back at work in 6 months.

How might we help patients be better prepared for the realities of recovery at the start of their cancer treatment?



Day 1

Receives diagnosis

- Counselling conversation with **Oncologist** on radiotherapy as an option.
- Initial counselling conversation with a **Urologist**, who does not perform surgery but can update on the side effects and outcomes (non-robotic). Option to be **referred to a surgeon** for further counselling, which Adam requests
- Meet with **CNS** to ask additional questions and receive **written information** on all treatments combinations.

+ 7
days

- Adam travels for **1 hour** for a clinic at a **regional centre**
- He attends a **clinic** where he sees a **robotic surgeon**
- He can also see an oncologist and CNS again on request

+ 3
days

- Adam calls CNS at local hospital with a treatment decision

11 days



Day 1

Receive diagnosis

- Initial conversation with CNS stating that they will be referred to a one-stop clinic at their local hospital to discuss options
- Written information on options provided

+ 7
Days

- David travels for 20 minutes attends a one-stop clinic at his local hospital
- He attends a **one stop clinic** where he sees a visiting **surgeon, oncologist and a CNS**

+ 2
Days

- David returns to see his own CNS to state treatment option

10 Days

Case Study 3 – Frank



Day 1

Receive diagnosis at regional centre

- Initial conversation with CNS stating that they will be referred to a one-stop clinic to discuss options
- Written information on options provided

+ 7 Days

- David travels for 25 minutes attends a one-stop clinic at the regional centre
- He attends a **one stop clinic** where he sees a **surgeon based at the site, oncologist and a CNS**

+ 5 Days

- Frank meets with CNS at regional centre and decides on treatment

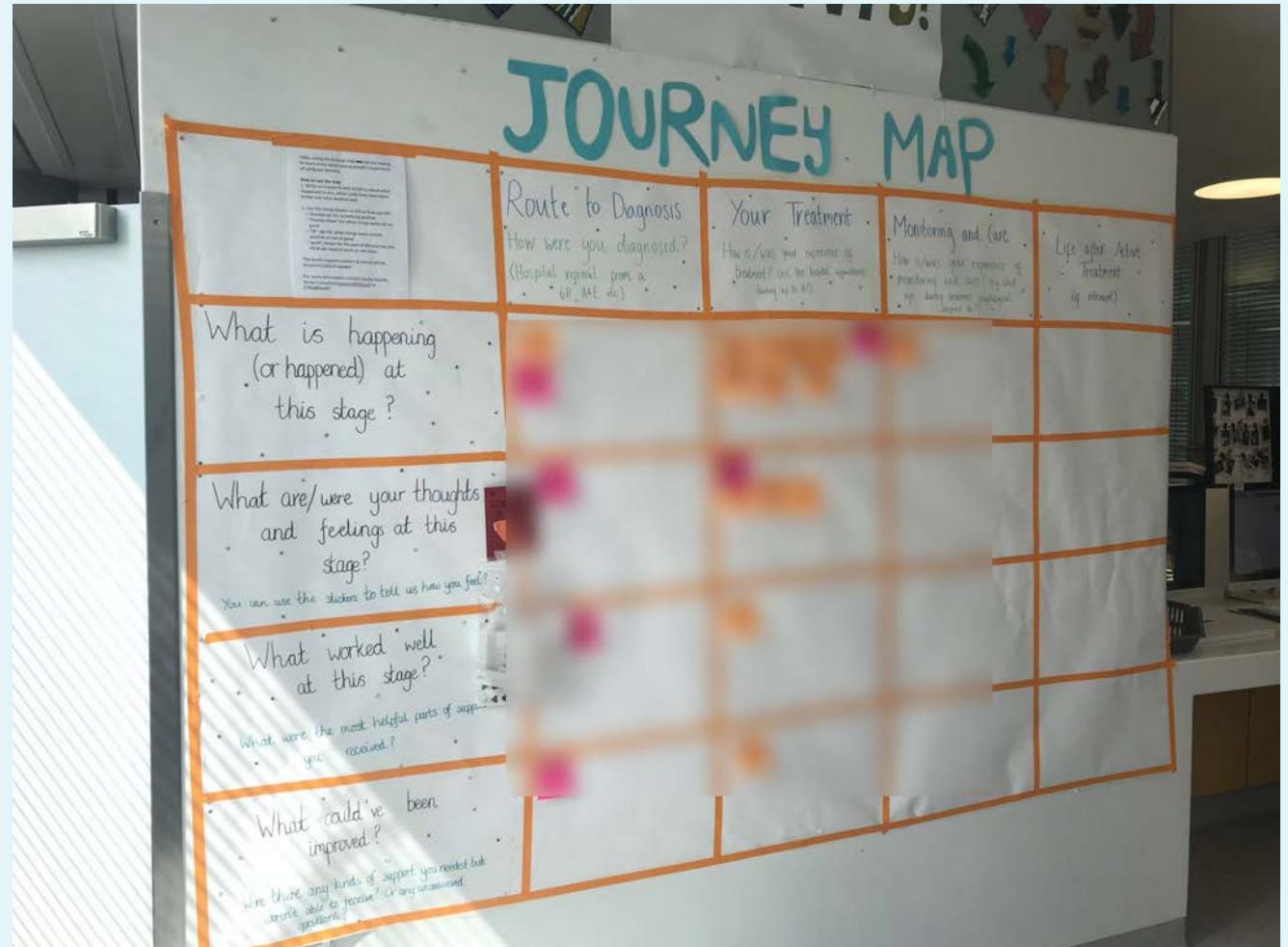
14 days

Journey Mapping

This is an example of a journey map used in a Teenage and Young Persons Cancer Ward.

Experience or Journey mapping is a great way to understand the challenges for all those involved in a pathway from start to finish.

By understanding experiences alongside processes we are able to create better solutions to the issues patients and staff face.



Why use journey maps?

Feedback is invaluable to organisations wishing to create or improve on a product or service

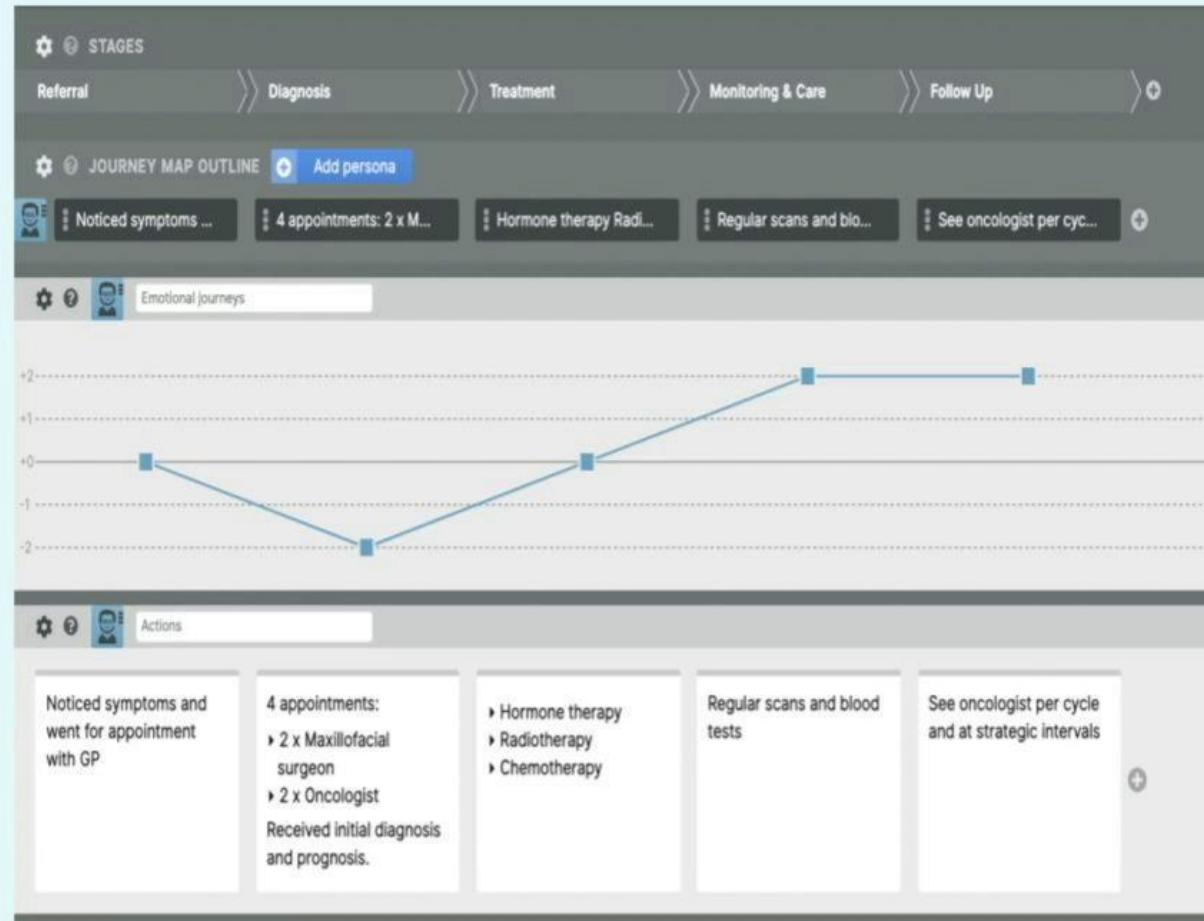
Historically this has been challenging to execute and get value back

Surveys: Requires a large number of recipients & respondents to be valuable; Questions often closed and rarely carry nuance or solicit personal experience; Questions often less accessible to some groups over others or carry implicit / explicit bias

Interviews: Requires significant resource to gather a generalisable/actionable dataset; inconsistencies between interviews make results challenging to use broadly; Often a tiny subset of the audience is ever reached

Journey Maps: *Can be distributed to a large target group (with guidance); Can gather both closed and qualitative, emotional responses; Less likely to contain bias or accessibility issues if designed well, focusses on the patient and their experience not the process/product*

Journey Mapping video (7 mins)



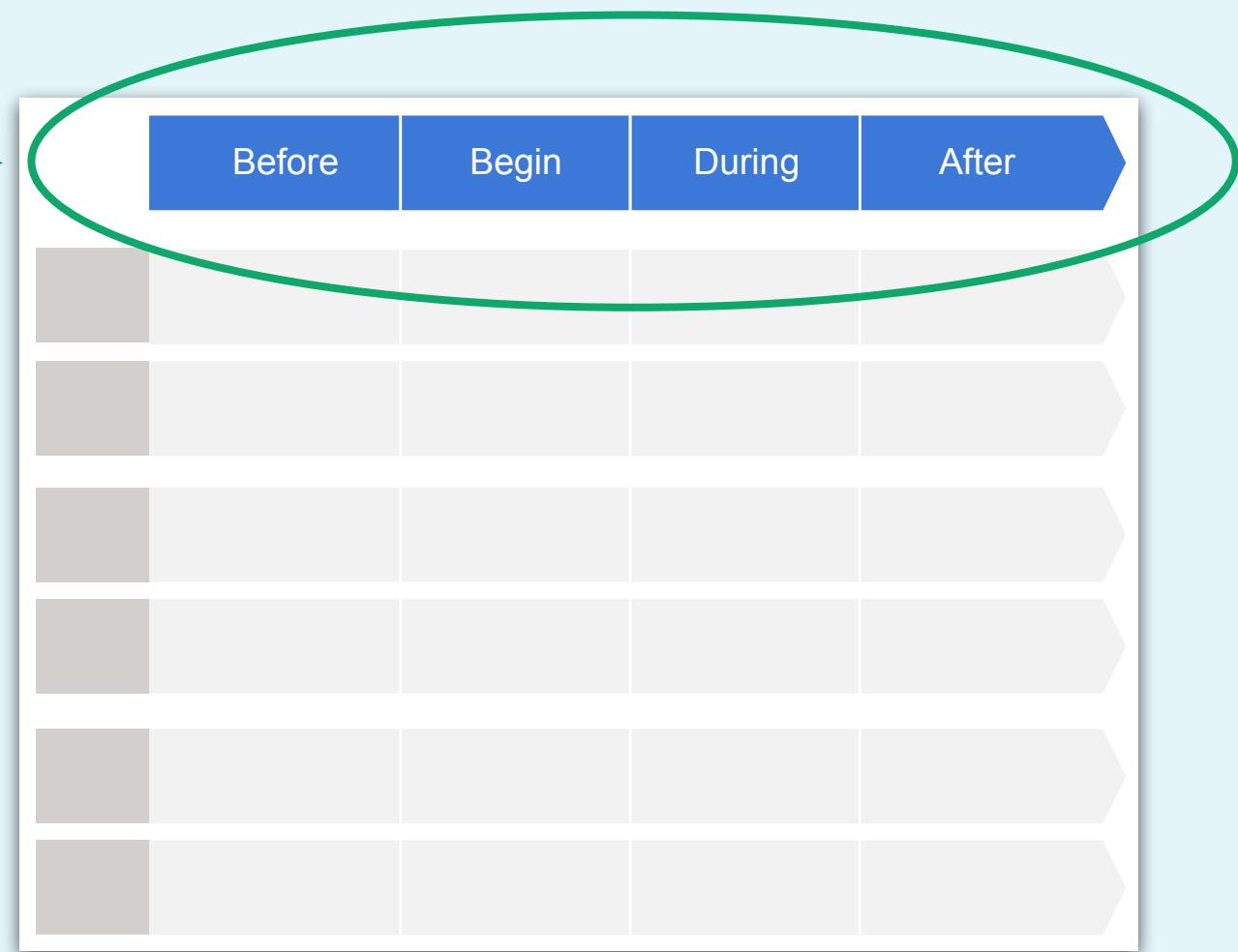
<https://drive.google.com/open?id=1GKIPJiNQDNvjWi8KlxvTbny1Blswnz4v>

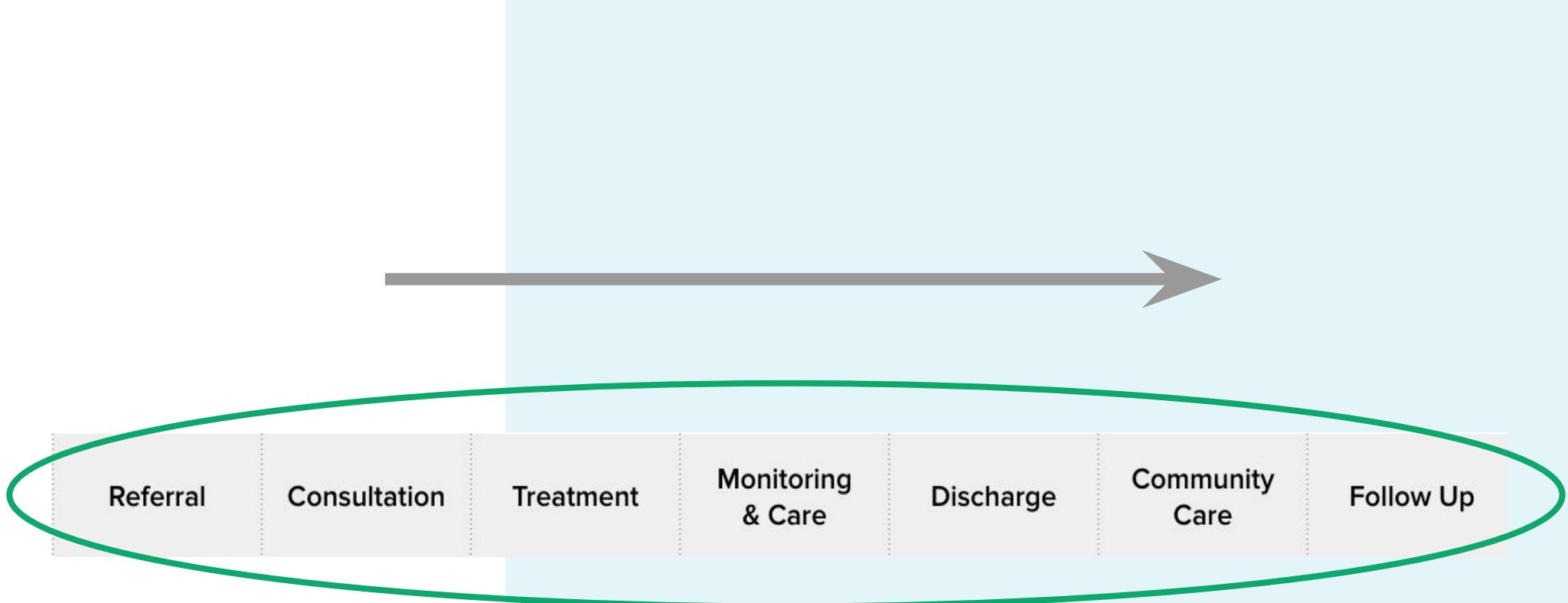
Patient journey framework

Chronological steps in a process or 'journey'

Points of feedback to capture for each step

Journey maps are a way to understanding patient and staff experience across time. The top headings will follow chronologically through from becoming aware through to leaving the services.





It's important to make sure that the headings make sense to staff and patients. Agree on headings with participants and sense check before use. Consider language and accessibility carefully. Headings and number of vertical steps will change depending on area of exploration.

Using the work 'Treatment' instead of 'surgery' means that patients and staff who may be involved with different types of treatment can use this heading and share experiences.

Other cancer care pathway examples...



Radiation Treatment:

Arriving at hospital / care cntr	Waiting to be seen by radiographers	Shown to the machine and getting in position	During the treatment	Treatment concluded	Leaving / Journey Home
----------------------------------	-------------------------------------	--	----------------------	---------------------	------------------------

Chemotherapy:

Arriving at hospital / care cntr	Waiting to be seen by nurse	Bloods taken and tested	During the chemotherapy	Pharmacy	Leaving / Journey home
----------------------------------	-----------------------------	-------------------------	-------------------------	----------	------------------------

Consultation Visit

Arriving at hospital / care cntr	Wait to be seen by consultant	Consultation	Conclusions & next steps from consultation	Leaving / Journey Home
----------------------------------	-------------------------------	--------------	--	------------------------

Vertical headings change rarely across journey maps. They seek to capture key practical and emotional experiences
Barriers and Ideas attempt to gather feedback around how aspects of the journey could be improved.

A These are the main questions for the vertical column.

B You may wish to change the wording to make sense in a different context. This is an example of vertical headings that were used by Teenage and Young People's Cancer

A

ACTIONS

What happened?
List events

THOUGHTS

What were your thoughts when this happened?

FEELINGS

How did these actions made you feel at the time?



BARRIERS

What were the challenges you faced within the service?

IDEAS

How would you solve the problem?

B

What is happening (or happened) at this stage?

What are/were your thoughts and feelings at this stage?

You can use the stickers to tell us how you feel?

What worked well at this stage?

What were the most helpful parts of what you received?

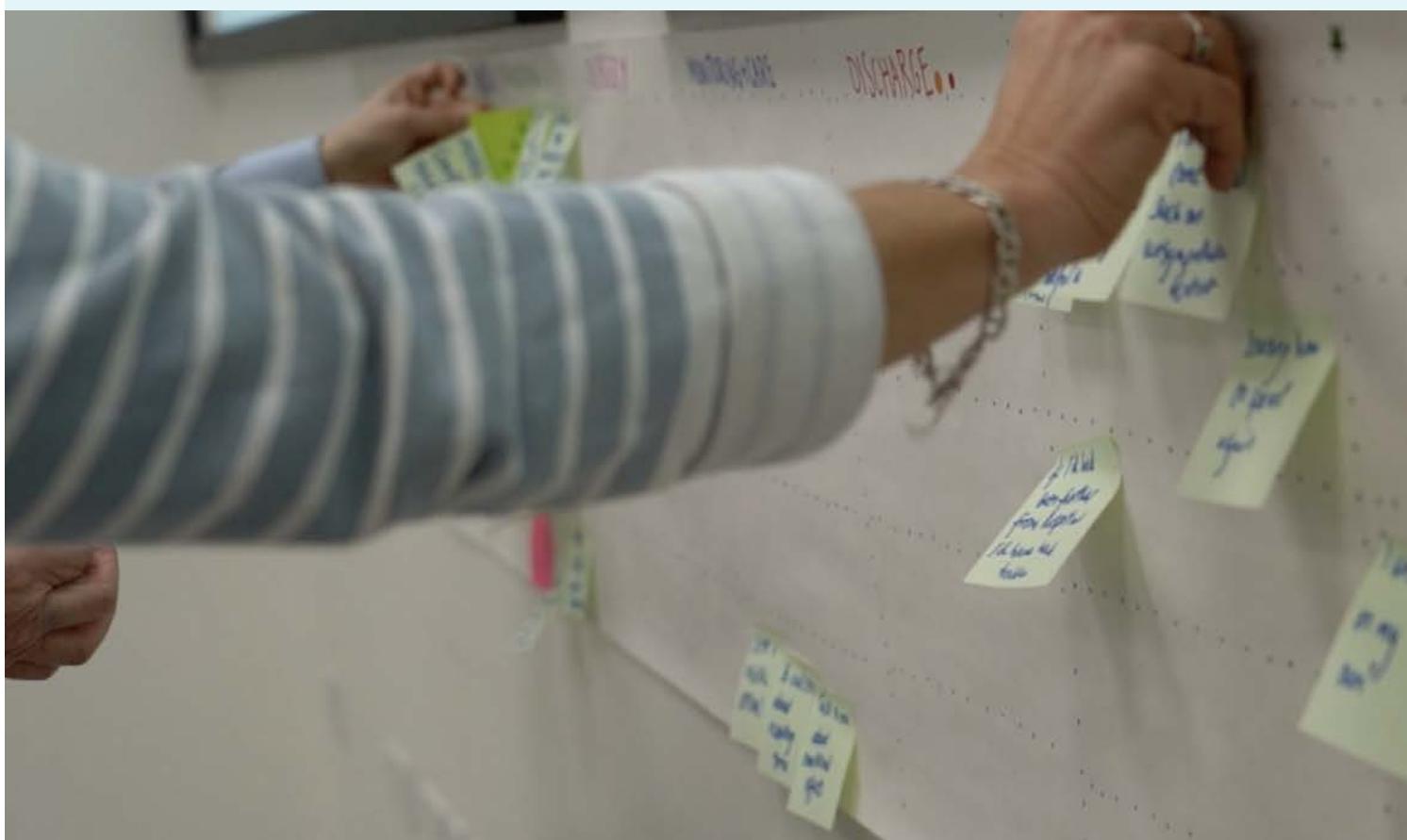
What could've been improved?

Were there any kinds of support you needed but weren't able to receive? Or any unanswered questions?

You may wish to print A3 sheets for individual patients to complete or you can create a large board with headings and get patients and/or staff to perform this as a group activity.

When patients place their post-it's on the board you can visually map where the main issues within a service appear.

You then ask those involved to place stickers and dot vote which areas were most important for them. You may then plan interventions and solutions together for prioritised areas.



JOURNEY MAP EXAMPLE

	Referral	Consultation	Treatment	Monitoring & Care	Discharge	Community Care	Follow Up
ACTIONS What happened? List events		I received my diagnosis					
THOUGHTS What were your thoughts when this happened?		'I have cancer!"					
FEELINGS How did these actions made you feel at the time?							
BARRIERS What were the challenges you faced within the service?		It moved so fast, I didn't have time to process all the information					
IDEAS How would you solve the problem?		Meeting a cancer patient like me and talking to them helped					

At each stage...

- What was the action- your **main point of contact** with services? (e.g. letter, phone call from staff, meeting with staff etc.)
- **What happened** for you/ what did you do? (e.g. received information about involvement, opportunities and roles, looked for further information, asked for further support from staff etc.)
- What were your **thoughts** when this happened? (Did you have any questions? What was helpful, and what wasn't helpful?)
- How did you **feel** at this time? (Was the overall experience: positive, neutral or negative?)
- What were the **barriers** to getting your needs met?
- How would you solve the problem? What would help fix this?

Now you can complete your own Journey Map!

BUT...before you begin, consider the **3 BIGGEST** problems/challenges you experienced.

What did you find helped you at the time?

What would improve the situation?

Can you incorporate these in your Journey Map?

JOURNEY MAP SHEET

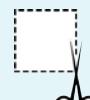
	Referral	Consultation	Treatment	Monitoring & Care	Discharge	Community Care	Follow Up
ACTIONS What happened? List events							
THOUGHTS What were your thoughts when this happened?							
FEELINGS How did these actions made you feel at the time?	  						
BARRIERS What were the challenges you faced within the service?							
IDEAS How would you solve the problem?							

Patient Involvement Cards

These cards are to be used as prompt questions when patients first become involved and following their involvement experience. You may print the cards on normal paper, cut them out and stick the front and backs together.

It is important to ensure patients are ready to be involved and have support in place.

The idea is to let patients select questions to answer rather than going through a checklist. If they do not wish to answer they can set the question aside and move on to the next one.



Cut



Fold



 North Central and East London Cancer Alliance

Why use these cards?

Why use these cards?

It's important to understand how patient involvement works for you! Getting to know you cards ask questions that patient involvement teams should review with patients prior to getting involved. Reflection cards guide conversations after involvement and can be used by project managers, staff and patients themselves as a trigger for meaningful feedback.



Glue



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London Cancer Alliance

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London Cancer Alliance

How to use the cards?

How to use the cards

Cards may be selected at random from each deck. Getting to know you decks should be completed prior to involvement. Select cards from Part 1 and discuss before moving on to Part 2. You do not have to cover all of the question cards and can stop whenever it feels right. The reflection deck can be used in conversation with staff to review patient experience in their role. Patients may take the reflection cards to use in their own time, feeding back to staff how best suits them.



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Instructions

Instructions

Step 1. Explain that the cards are questions to guide conversation to learn more about the patient and their involvement experience.

Step 2. Spread cards out across even surface question side down.

Step 3. Patients' select a card and answer the question if they wish to do so. If not, set the card aside and select another card to answer from the pile.



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Getting to know you cards

PART 1

**How will I contribute
beyond just my own
personal experience?**



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Getting to know you cards

PART 1

**What skills and experience
can I share outside my
cancer experience?**



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Getting to know you cards

PART 1

**What skills do I have to
help me influence
situations within board
meetings or projects?**



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Getting to know you cards

PART 1

**What does good
patient involvement
look like?**



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Getting to know you cards

PART 1

**Why did I decide
to become involved?**



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Getting to know you cards

PART 1

**What areas am I
particularly interested in?**



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Getting to know you cards

PART 2

**How would I let you
or the team know
how I am doing?**



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Getting to know you cards PART 2

**How do I deal with
disappointment
in a professional
capacity?**



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Getting to know you cards PART 2

**Do I know of any
triggers for
getting upset?**



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Getting to know you cards

PART 2

**How would I handle it, if
something challenging
occurred within the role?**



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Getting to know you cards

PART 2

**If I have a problem, how
would I indicate this to
others within the team?**



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Getting to know you cards

PART 2

**Do I have experience
speaking up in
group settings with
senior professionals?**



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Getting to know you cards

PART 2

**How do I listen effectively
and work in a group?**



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Getting to know you cards

PART 2

**How do I react
if something happens that
takes me off guard in a
session or a meeting?**



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Reflection cards

**How am I feeling
in my role?**



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Reflection cards

**Has the work being done
improved something for
patients?**



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Reflection cards

**What were the difficult
parts?
What helped me feel
better?**



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Reflection cards

**What would I do
differently to facilitate a
greater impact?**



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Reflection cards

**What went well with my
contribution?
How will this help me in
the future?**

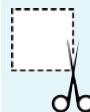
Ways To Be Inclusive

Here are some quick tips to help be more inclusive.

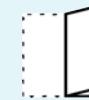
When working to involve patients it is always important to have a flexible approach.

There is always a way to include more diverse patient groups, we need to start by opening up conversations and asking patients what they need.

You can print these out as cards if that is useful.



Cut



Fold

NCE
North Central and East London Cancer Alliance

Ways To Be Inclusive

Fatima has difficulty understanding English



What does Fatimah need?

Inclusion Tips

- Have a translator present
- Leave time for translation and clarify and repeat main points
- Use images and visuals as opposed to lots of text
- Assign a scribe to sit with, explain and take notes
- Conduct a 1:1 feedback session or interview



Glue

Ways To Be Inclusive

STEP 1

Ask the person what support they need to be involved.

Understand the needs of a more diverse range of people in order to improve services.

Being as inclusive as possible helps us understand patient perspectives we may not normally see.

We can always find a way to be more inclusive if we start by asking patients, what do you need?

Ways To Be Inclusive

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Leave time for translation and clarify and repeat main points

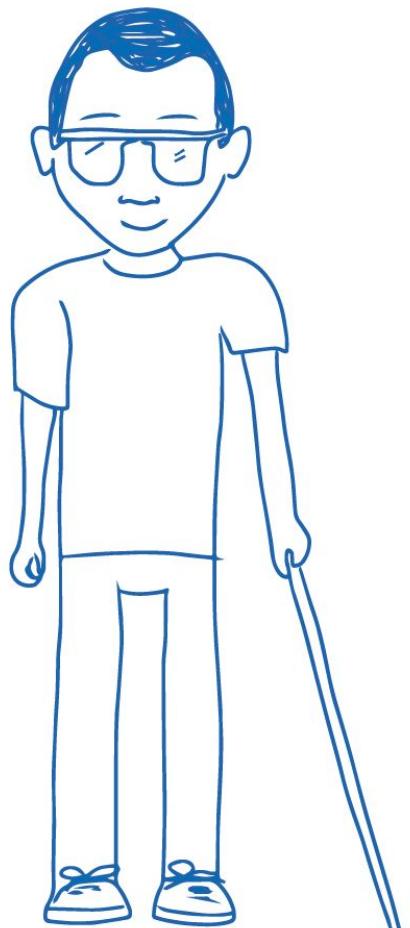
Use images and visuals as opposed to lots of text

Assign a scribe to sit with, explain and take notes

Conduct a 1:1 feedback session or interview

Ways To Be Inclusive

Roger is visually impaired



What does Roger need?

Inclusion Tips

Describe visuals and read and read out all information clearly

Use audio recorded scenarios and role plays

Use discussion based activities

Search for larger fonts to print easy read sheets

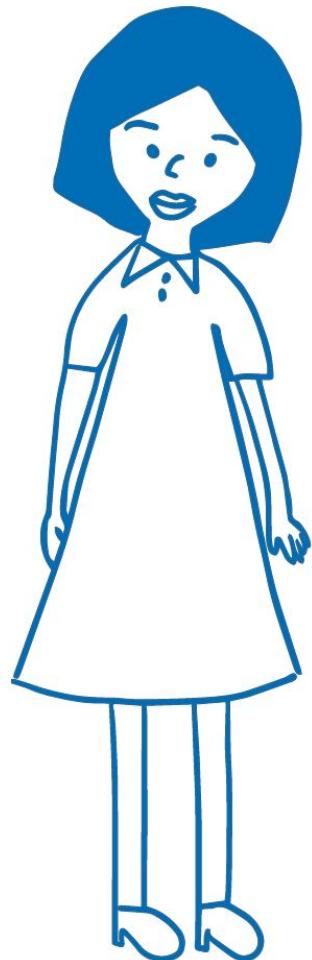
Use textured papers for different sections and bright colours for differentiation

Assign a designated scribe

1:1 phone call for feedback and interviews

Ways To Be Inclusive

Rhonda has Autism



What does Rhonda need?

Inclusion Tips

Create a quiet low stimulus environment i.e. each person talks one at a time

Have a quiet space available outside for time out

Use a 1:1 interview in person or by phone

Nominate a facilitator to offer support

Individual tasks and activities

Provide instructions and always ask if they are clear

Ways To Be Inclusive

Irene is 12 years old



What does Irene need?

Inclusion Tips

Always talk directly to the person and not down to them

Use gamification and play to encourage participation

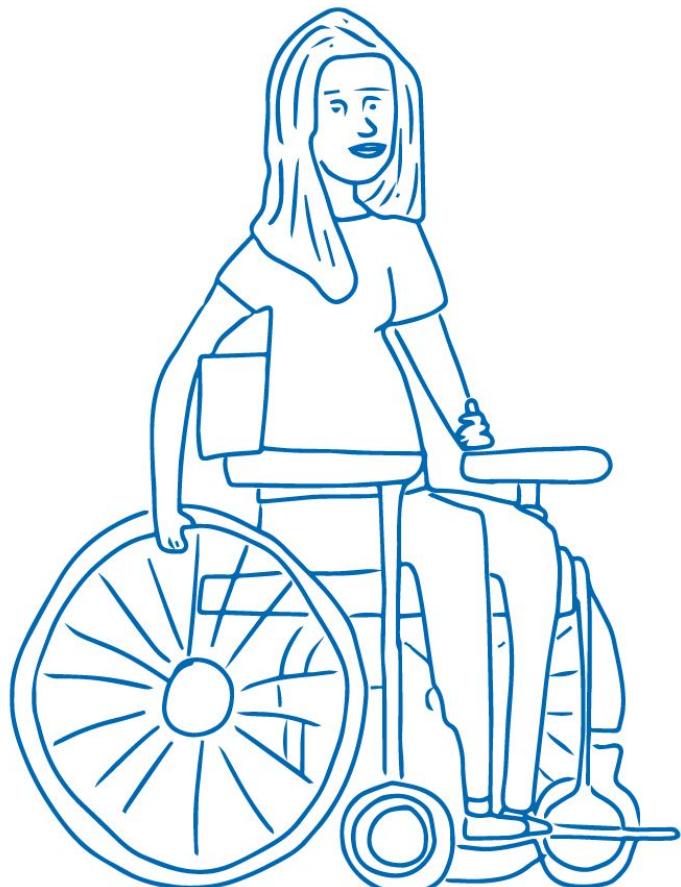
Use creative activities such as collage and drawing to encourage expression

Instead of discussion encourage discussion around images and group work

Use tools such as reflective journals and photography

Ways To Be Inclusive

Simone uses a wheelchair



What does Simone need?

Inclusion Tips

Ensure your venue is accessible and has easy access disabled bathrooms

Set up the room to ensure there is easy access for wheelchair movement.

Ensure desks, tables and all material on walls is the right height to be seen and used for tasks

Ways To Be Inclusive

**Khadeja is a working
mother**



What does Khadeja need?

Inclusion Tips

Capture feedback when at hospital appointments

Email and text brief questions

Arrange a home visit at a convenient time

Skype interview and or phone into sessions

Plan sessions during pre-school/ school time

Arrange payment for childcare

Ways To Be Inclusive

Simon has a hearing impairment



What does Simon need?

Inclusion Tips

Provide written text and time to read

Provide interpreter for session

Use task based activities as opposed to discussion

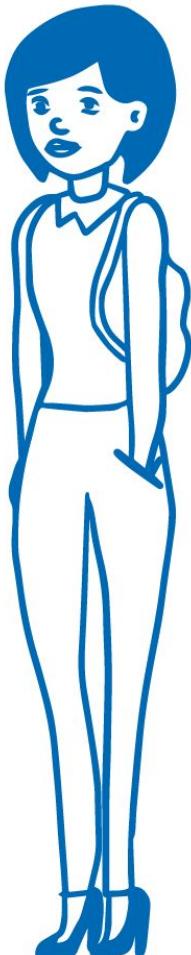
Leave time to check for understanding and go over discussion points

Split into small discussion groups and write notes to share

Face the person directly and ensure adequate lighting for lip reading

Ways To Be Inclusive

Trish hears voices



What does Trish need?

Inclusion Tips

1:1 interview by phone or in a quiet space

Check in and ask about coping strategies and what helps when in group settings

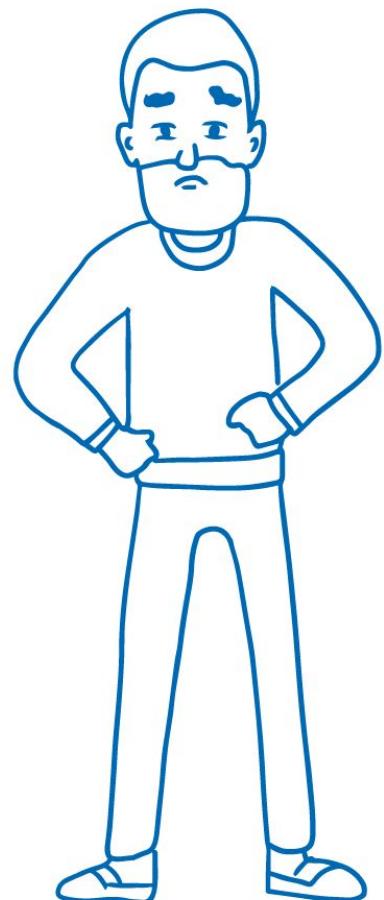
Create a quiet space if the person needs to leave the room

One facilitator to sit beside and support conversations and discussions

Provide tasks with short clear instructions

Ways To Be Inclusive

**Boris is upset and angry
about his experience**



What does Boris need?

Inclusion Tips

Provide 1:1 discussion space via phone or face to face and check in with person prior to session

Provide a 'car park' space for Boris to vent and write thoughts

Allocate a facilitator to take discussion outside for 1:1

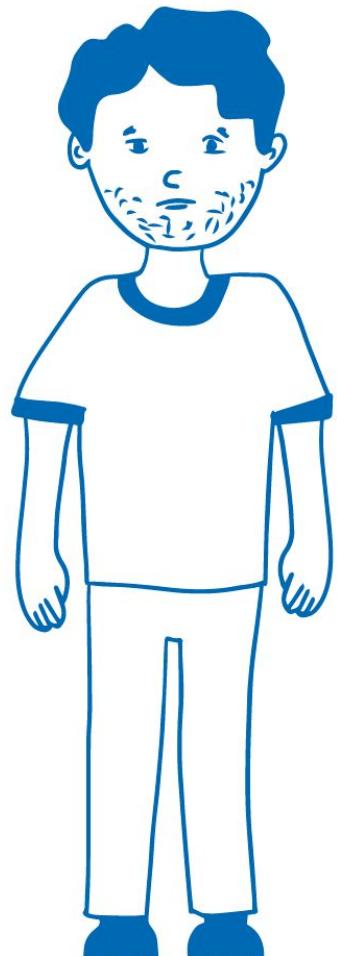
Help Boris report to PALS

Use ask based activities as opposed to discussion

Create a 'conch' to take turns at speaking

Ways To Be Inclusive

Joe is homeless



What does Joe need?

Inclusion Tips

Provide phone call support prior to session to discuss needs and offer support

Conduct a 1:1 interview instead

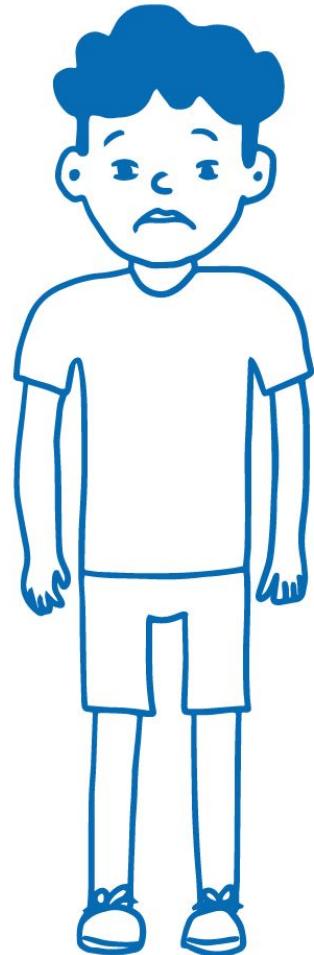
Assign a facilitator to sit next to the person and check in

Ask staff close to Joe to conduct an interview or ask specific questions

Approach Joe and ask for feedback at appointment sessions

Ways To Be Inclusive

Jim gets anxious in groups



What does Jim need?

Inclusion Tips

Provide phone call support prior to session to discuss needs and offer support

Conduct a 1:1 interview instead

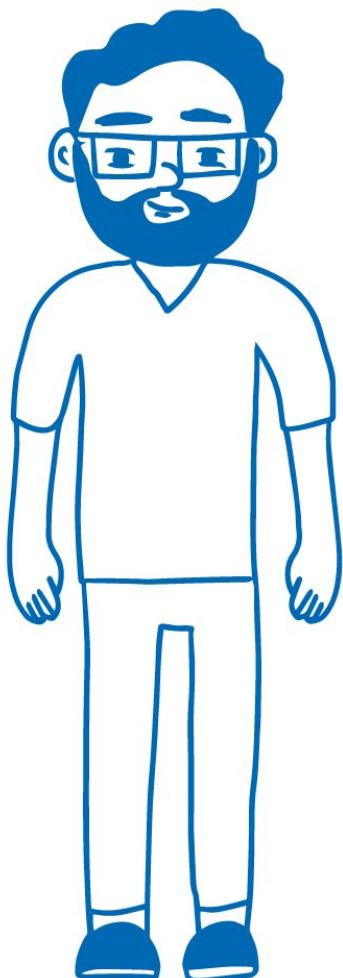
Assign a facilitator to sit next to the person and check in

Play ice-breakers to warm up the group so people get to know one another

Create a space away from the group. If feeling anxious the person can leave at any point.

Ways To Be Inclusive

Mathew can't read



What does Mathew need?

Inclusion Tips

Use images to represent ideas
and themes

Use stickers to 'dot vote' and
discuss ideas

Draw a comic and get person to
fill in blanks

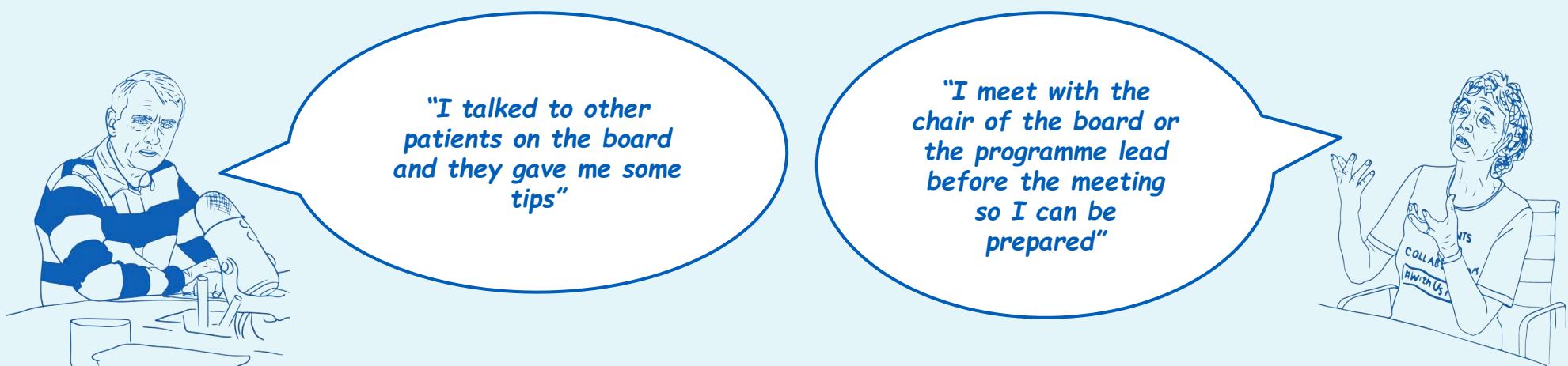
Assign a facilitator to be a
scribe and work along side the
person

Guide for patients in roles

Here are some tips and advice from other patients who have been in your position. If you are feeling stuck or a bit unsure in your current role it's always good to speak to someone from the patient involvement team.

We recommend giving this guide to patients as part of their orientation. This information can form part of their welcome pack.







"I want to make a difference and really change things for the better"

It's important to be aware that sometimes just being present in the room will change conversations for the better. It takes time to understand terminology and get to know staff and those involved. It's important to remember that change takes time and every contribution you make as a patient or carer is an important part of service improvement.

"I am feeling uncomfortable, frustrated or upset by this situation"

It can be difficult to go back into services after your experience. We know feelings can come up while performing your role. Staff are there to support you within projects, boards and expert reference groups. Agree on a regular supervision plan with your project manager. When in meetings, take a minute if you need a minute. Having a pause, taking a deep breath or leaving the session for a break can help. Let a staff member know if something isn't right.

"I don't feel like there is enough space for me to contribute"

Talk to your project manager and chairperson! Not every topic discussed in meetings will be relevant to you. It's important for patients to have space to contribute within the agenda when relevant. Agree with the chairperson and project manager how you will be involved when taking on a role.

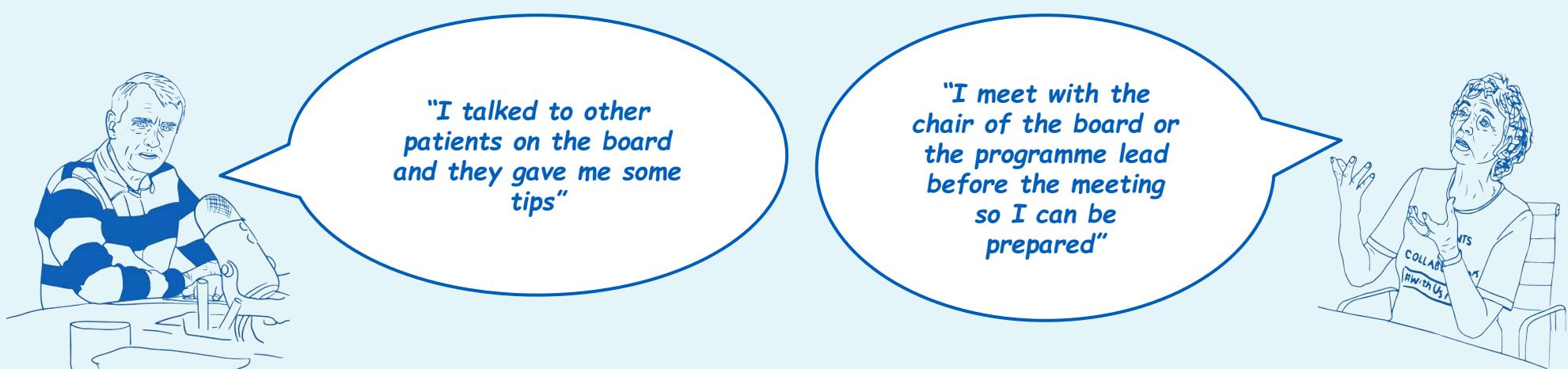
Easy Print Guide for patients in roles

Two page, double sided print
version on next page.

Give copy to patients as part of
printed welcome pack and
information



Guide for patients in roles



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Session outline templates and materials

We have included some examples of session agendas and ways in which we have used these tools in patient and staff sessions.

You can use these materials as a basis for planning your own sessions. We recommend using an icebreaker to start your sessions, some may be found [here](#).

Feel free to change or add as required

Aims

- Identify key themes across the experiences of patients and staff. Further information is required.
- Identify priority opportunities to initiate projects in order to improve patient experience
- Identify opportunities for Pathway Board and PEs to support the work of the group.

Time	Activity
15 mins 6pm – 6.15pm	Arrivals and sign in <i>Participants arrive; sign in; write their names on the board; introduce themselves</i> <ul style="list-style-type: none"> · Request that participants sign in and receive summary resources created by the group.
15 mins 6.15 - 6.30pm	Welcome <i>Facilitator 1 to welcome everyone</i> <ul style="list-style-type: none"> · Go round – Each person to say something they enjoyed about the video they watched · Housekeeping – toilets, outline of the day
10 mins 6.30 - 6.40pm	Introduction <i>Facilitator 2 to talk through slides on the agenda</i> <ul style="list-style-type: none"> · Reiterate the aims of today and the purpose of each stage of treatment.

<https://www.scienceofpeople.com/meeting-icebreakers/>

Exploring problems: Workshop 1 - Patients and Staff

Aims

- Identify key themes across the experiences of patients diagnosed with head and neck tumours – e.g. areas where delays are most frequently experienced or further information is required.
- Identify priority opportunities to initiate projects across Pathway Board in order to address points of delay or inefficiency across the Head and Neck Pathway, in order to improve patient experience
- Identify opportunities for Pathway Board and PE & UI team to create patient information resources which would improve patient experience across the Pathway

Time	Activity	Lead	Resources
15 mins 6pm – 6.15pm	<p>Arrivals and sign in</p> <p><i>Participants arrive; sign in; write their own name badge; get food</i></p> <ul style="list-style-type: none"> · Request that participants sign consent form if they are happy to be recorded/ for quotations to be used in summary resources created from the workshop 	Nominate facilitator for each part	Sign in sheet Name stickers Consent forms
15 mins 6.15 - 6.30pm	<p>Welcome</p> <p><i>Facilitator 1 to welcome everyone and thank them for coming</i></p> <ul style="list-style-type: none"> · Go round – Each person to share their name, where they travelled from today, and the last good TV show they watched · Housekeeping – toilets, outline of day, Ways of Working, Car Park, directions to quiet space if needed 		Car Park flipchart Ways of working flipchart
10 mins 6.30 - 6.40pm	<p>Introduction</p> <p>Facilitator 2 to talk through slides or show journey mapping video:</p> <ul style="list-style-type: none"> · Reiterate the aims of today and the purpose of gathering information about the patient journey across each stage of treatment. · Outline the general Patient Journey framework and how to interpret a mapping resource · Explain background research which has been undertaken to identify key stages across the experience of a Head and Neck Cancer patient, and share example journey map. Stages = GP referral, Consultation (1. diagnosis, 2. Understanding), Treatment, Monitoring and Care, Discharge, Community Care. <ul style="list-style-type: none"> o <i>Discussion point – Do these stages resonate with you? Anything to add or remove?</i> 		Slides

Exploring problems: Workshop 1 - Patients and Staff

20 mins 6.40pm-7pm	<p>'My experience' – individual journey mapping</p> <p>Facilitator 1 to share template journey map tool (A4 print outs), with each stage mapped out. At each stage, participants are asked to write their answers to the following questions:</p> <ul style="list-style-type: none"> o What interactions did you have with clinicians? o How well (or not well) were your appointments organised? o What questions did you have? o What was helpful? What wasn't helpful? o Was the overall experience: positive, neutral or negative? 	Facilitator to introduce Both facilitators to provide 'floating' support	A4 Print Out of individual journey mapping template A4 Print Out of example journey mapping template
15 mins 7pm-7.15pm	<p>BREAK</p> <ul style="list-style-type: none"> · Take photos of completed journey maps · Tidy up wall flipchart and ensure all is ready for next exercise. 		
30 mins 7.15pm-7.45pm	<p>Sharing and Discussion</p> <p>Bring group back together and sit in a circle. Facilitator 2 to lead group discussion.</p> <ul style="list-style-type: none"> · Participants invited to place Post Its from individual journeys onto roll map. Each participant shares their overall experience rating at each stage (positive, neutral or negative) and a brief explanation as to why they have chosen this rating · Participants group and identify key themes within each row. · After the discussion, participants are given 3 'dot vote' stickers. Each participant to vote for the 3 challenges they think should be treated as the highest priority areas to address 		Roll-up paper with large version of journey mapping template (on wall) Post it notes

Exploring problems: Workshop 1 - Patients and Staff

7.45pm-8.15pm	<p>Identifying next actions</p> <p>Facilitator 1 spreads template ideas sheets out on tables. Facilitator 2 introduces the next activity and explains that we will start by working as individuals/ in pairs:</p> <ul style="list-style-type: none"> · [Test activity] – Participants are asked to name a few tools which are used by clinicians, and draw these roughly on blank ideas Sheets – Facilitator 2 to emphasise that this is not about quality of the drawings! · For each of the top 3 challenges identified, participants sketch ideas in response to prompt questions: <ul style="list-style-type: none"> o Round 1: How would we address this issue if we were working for Google? o Round 2: How would we address this issue if this was a private hospital for A list celebrities? o Round 3: How would we address this issue if we were a criminal organisation? o Round 4: How would we address this issue if we were running an investigation? · Group activity: Individuals/ pairs share their favourite ideas with the rest of the group 		Sketch Sheets
15 mins 8.15pm-8.30pm	<p>Next steps and close</p> <ul style="list-style-type: none"> · Summarise actions and next steps · Reminder of what happens next – collating recommendations and sharing with _____ Pathway Board · Ask all to share feedback via Evaluation Flip Chart 		Evaluation Flip Chart – Happy face to sad face scale. Sections for each question.

Identifying Solutions: Workshop 2- Patients and Staff

Aims

- Identify key themes across the experiences of patients diagnosed with _____ – e.g. areas where delays are most frequently experienced or further information is required.
- Identify priority opportunities to initiate projects across Pathway Board in order to address points of delay or inefficiency across the _____ Pathway, in order to improve patient experience
- Identify opportunities for Pathway Board and PE & UI team to create resources which would improve patient experience across the Pathway

Time	Activity	Lead	Resources
15 mins 6pm – 6.15pm	<p>Arrivals and sign in</p> <p><i>Participants arrive; sign in; write their own name badge</i></p> <ul style="list-style-type: none"> · Request that participants sign consent form if they are happy to be recorded/ for quotations to be used in summary resources created from the workshop 	Nominate facilitator for each part	Sign in sheet Name stickers Consent forms
10 mins 6.15 - 6.30pm	<p>Welcome</p> <p><i>Facilitator 1 to welcome everyone and thank them for coming</i></p> <ul style="list-style-type: none"> · What item would you bring to a desert Island – Each person to suggest an item they could not live without, ‘my sunscreen’, etc.... · Housekeeping – toilets, outline of day, Ways of Working, Car Park, directions to quiet space if needed 		Car Park flipchart Ways of working flipchart

Identifying Solutions: Workshop 2- Patients and Staff

15 mins 6.30 - 6.45 pm	<p>Introduction</p> <p>Facilitator 2 to talk through work from previous week:</p> <ul style="list-style-type: none"> · Reiterate the aims of today and the purpose of building solutions based in service user need · Outline the problems shared last time and dot sticker vote top 2. Split into 2 teams to work on priority area. Explain that we want quick wins and things we can do in the here and now however we will feedback about more complex suggestions that involve resources out of our scope. Provide information from previous session on proposed solution. Give briefs containing information to patient groups and get them to work together on how their solutions would look. When would people get it? What would their proposed service look? etc. 		Talk through the info we have stuck on the walls and do a walking tour of our work from last week- Write out main problems identified on flip chart paper
30 mins 6.45pm-7.15pm	<p>'Prototyping groups' – Form groups and work on building your idea</p> <p>In two groups containing staff and patients you will work on building an idea and drawing it out and or role playing how it would work and what the interaction would be like in real life:</p> <ul style="list-style-type: none"> · What is the problem this solution is trying to solve? · What does this information/ peer support look like? · How is it given in what format? · What is the content/ what does it or do they say/ do? · How would this help solve the problem? 	Both facilitators to provide support to each group	
10 mins 7.15pm-7.25pm	<p>Creating a pitch and run through (? See how up for it they are and alternatively do as discussion)</p> <p>Groups work together to create a role play of how their solution would work in real time</p> <ul style="list-style-type: none"> · Each group to create a scenario in which their solution would be used · Be clear at the start about what problem this addresses and show the others how it would solve the issue 		Roll-up paper (on wall) Post it notes
15 mins 7.25pm-7.45pm	<p>BREAK</p> <ul style="list-style-type: none"> · Tidy up wall flipchart and ensure all is ready for next exercise. 		

Identifying Solutions: Workshop 2- Patients and Staff

10 mins 7.45pm-8.05pm	Bring group back together and sit in a circle. <ul style="list-style-type: none"> · Each group will now pitch their idea and show it to the other group (10mins p/group) 		Post-it notes
15 mins 8.05pm-8.20pm	Identifying next actions <ul style="list-style-type: none"> · Discuss projects currently underway i.e. patient information design and ask for input, interest and feedback · Discuss potential of presenting ideas to staff at board meeting and working with them to create solutions · Discuss potential of testing ideas in real time with patients in waiting room etc? 		'Dot' stickers
15 mins 8.20-8.35pm	Sharing and Discussion Facilitator 2 to lead group discussion. <ul style="list-style-type: none"> · Each participant shares their overall experience of the process, concerns and hopes for what they would like to happen next? How would they like to be involved? 		Evaluation Form
	<ul style="list-style-type: none"> · Summarise actions and next steps · Reminder of what happens next – Pitch ideas to staff in follow up joint workshop or at board meeting · Ask all to complete Evaluation Forms- post-its with feedback 		Evaluation Form Post-its with feedback

Solution Building: Workshop 3 - Patients and Staff

Aims

- Identify key themes across the experiences of patients diagnosed with head and neck tumours – e.g. areas where delays are most frequently experienced or further information is required.
- Identify priority opportunities to initiate projects across Pathway Board in order to address points of delay or inefficiency across the Head and Neck Pathway, in order to improve patient experience
- Identify opportunities for Pathway Board and PE & UI team to create patient information resources which would improve patient experience across the Pathway

Time	Activity	Lead	Resources
15 mins 6pm – 6.15pm	Arrivals and sign in <i>Participants arrive; sign in; write their own name badge</i> <ul style="list-style-type: none"> · Request that participants sign consent form if they are happy to be recorded/ for quotations to be used in summary resources created from the workshop 	Nominate facilitator for each part	Sign in sheet Name stickers Consent forms
10 mins 6.15pm - 6.25pm	Welcome <i>Facilitator 1 to welcome everyone and thank them for coming</i> <ul style="list-style-type: none"> · 'Yes and...' – Divide group into pairs. One asked to start a story (e.g. planning a holiday), which the partner then builds on, starting with the phrase "Yes and..." The original person then continues to build on the story, and so on. E.g "We are going on holiday to Latvia". "Yes and, I will bring my umbrella", "Yes and we will set up on the beach" etc. · Housekeeping – toilets, outline of day, Ways of Working, Car Park, directions to quiet space if needed 		Car Park flipchart Ways of working flipchart
15 mins 6.25pm - 6.40pm	Introduction Facilitator 2 to talk through work from previous week: <ul style="list-style-type: none"> · Reiterate the aims of today (Put up work from previous weeks and ask group to do walking tour to recap last week's work) · Explain: We have brought in some ideas to work on based on last weeks identified needs. Brief introduction to all prototype resources i.e.– mock up of patient information leaflet, diagram of new service process, job description for new role etc. In two groups you will work on developing these ideas further and filling in the details... 		Talk through the info we have stuck on the walls and do a walking tour of our work from last week-

Solution Building: Workshop 3 - Patients and Staff

30 mins 6.40pm-7.10pm	<p><i>This is an example of ideas from staff and patients that we brought in to develop. You can bring in pre-existing materials and mockups based on ideas from previous sessions as the basis for this work.</i></p> <p>'Prototyping brought to life' – form groups and work on building your idea</p> <p>Group splits into two (same groups as last week)</p> <p>1) Information</p> <ul style="list-style-type: none"> · Business card: <ul style="list-style-type: none"> o What are the two most important numbers you need? Everyone take a card and write your top numbers/ contacts you think you need in emergency... o Show cards to one another and vote and rank for top 3 numbers/ contacts · Leaflet <ul style="list-style-type: none"> o Share 2 x new draft leaflets. Which do you prefer? o Anything missing in terms of content/ information? o Rank information on the leaflet in order of importance o When should this be given out, and by whom? <p>2) Peer Support</p> <ul style="list-style-type: none"> · Design a peer support role and conversation - what is the main purpose of the role? Do's and don'ts list, support needed. · What message is best on the t-shirt? Invite participants to draw on t-shirts... · Send link to Breast Cancer website - what do you like/ not like about how this service operates? · How would the conversation go? What are the boundaries? What parameters need stating before you begin? (Role play and write down draft guidelines) 	Both to provide support to each group	
20 mins 7.10pm-7.30pm	<p>Bring group back together and sit in a circle.</p> <ul style="list-style-type: none"> · Each group will now share their updated ideas to the other group (10mins p/group) 		
15 mins 7.30pm-7.45pm	<p>BREAK</p>		

Solution Building: Workshop 3 - Patients and Staff

10 mins 7.45pm-7.55pm	<p>Evaluation</p> <ul style="list-style-type: none"> Decide as a big group - what does success look like for each of these mini-projects? How would we show/ measure this? (Feedback, survey etc.) 		Post-it notes
10 mins 8.05pm-8.15pm	<p>Discussion and next steps</p> <p>Facilitator 2 to lead group discussion:</p> <ul style="list-style-type: none"> Each participant shares their overall experience of the process, concerns and hopes for what they would like to happen next and how would they like to be involved. Discuss projects currently underway re: information design and ask for input, interest and feedback Discuss potential of presenting ideas to staff (e.g. in next Head and Neck Pathway Board meeting?) Discuss potential of testing ideas in real time with patients in waiting room etc. 		
15 mins 8.15-8.30pm	<p>Evaluation</p> <p>Each participant is given 3 post it notes and asked to write down an answer to each of the following questions:</p> <ul style="list-style-type: none"> What was the experience of working together in this way like for you? How would you describe it to others? How did it make you feel? 		Post it notes
Follow up	<p><i>Invite patients to partner with staff and present their project ideas to cancer pathway boards.</i></p> <p><i>Invite patients to assist in testing ideas and concepts i.e. present a leaflet in a waiting area to other patients by inviting them into a project role - see patient roles.</i></p> <p><i>You should share updates and progress with the group via email or in post regarding the outcome of the sessions and project progress.</i></p>		Video recordings and or photos of sessions can be used to help highlight patient and staff issues

Cancer Pathway Mapping Workshop

Information and Consent Form

This workshop has been organised by NCEL Cancer Alliance, the Cancer Alliance for north and east London. We provide leadership to NHS cancer services across the area, producing guidance to improve patient experience and quality of care.

At this workshop we will be asking people with recent or ongoing experience of Head and Neck Cancer to share your experience throughout the treatment process. This will help us identify areas where the current process is working well, and where patient experience could be improved. Please note that taking part is completely voluntary – this means you can leave at any time, and you won't have to give a reason. The information you share with us will not affect the individual care you receive.

What will the workshop involve?

Working in small groups, we would like to explore:

- The steps you went through before receiving treatment (including referrals etc.)
- Where services are working well together, and where they are not working so well
- Points at which patients are having a good experience of care, and points where patients are experiencing challenges and/ or concerns
- Further information which could be provided to patients to support them at different stages in their journey

How will my information be used?

The information you give us will be used to create resources for staff members working in cancer services across North and East London. All the information you give us will be anonymised before it is shared (this means your name will never be used, and we will remove any identifying details before it is made public.)

Sarah Josefsberg, Patient Experience and User Involvement Project Lead at NCEL Cancer Alliance, may also use this information within a piece of independent research she is conducting, as part of a Service Design Masters at London College of Communications. Again, all information will be anonymised before it is shared.

The rest of this form should be completed by a member of UCLH staff

I have explained to the patient/relative signing this form that photographs / video recording / interview may be used for the purposes outlined above.

I give permission for this workshop to be audio-recorded, and for a transcription of my contributions to be stored electronically (without my name)	Yes	No
I give permission for photograph/video footage to be taken at this workshop	Yes	No
I understand that if this photograph / video recording is used in any resource by NCEL Cancer Alliance and/ or London College of Communications, I will not be identifiable in the image	Yes	No
A member of NCEL Cancer Alliance staff has explained to me that comments I make may be quoted without my name in any resource that the Trust feels is appropriate. I understand this may include being used in staff training, Trust publications and service development reviews (on the Intranet and Internet) and agree that my quotes may be used for these purposes.	Yes	No
Signature:		

Counter signature of staff member	
Print Name	



North Central and East
London Cancer Alliance



**Are you a carer or patient?
Contact us to get involved
in shaping cancer services.**

NCEL Patient Experience
and User Involvement Team

uclh.getinvolvedwithcancer1@nhs.net



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Along with leaflets we thought the best promoters of our work are patients who have been involved in projects and boards. To increase awareness of patient involvement within the alliance we gave patients and staff involved in our work simple badges. Patients were proud to feel part of something and wearing the badge raises awareness and promotes discussion of work being done.

Step 1. Speak to your comms lead to get the correct logo and setting.

Step 2. Create a template. You can contact badge making company (we used [Sticker Mule](#)) for technical support.

Step 3. Provide badges as part of welcome pack and orientation events.

