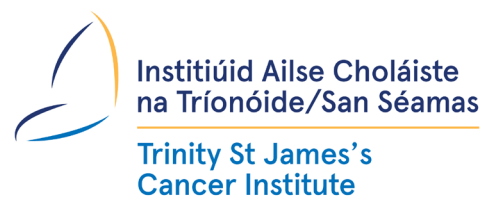




Irish Cancer Society
Research

Celebrating Patient and Public Partnership in Cancer Centres through Connection and Collaboration

Networking & Workshop Event Report | October 2024



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“Patients have a unique perspective which makes them invaluable partners in how we design, deliver, and evaluate our health services.

The involvement of patients requires us to view care from a patient perspective.”

HSE 2022

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1.0 Executive Summary

The current landscape for patient and public partnership (PPP) in healthcare in Ireland is rapidly evolving. The framework provided by the Health Services Executive's document 'Better together – a patient engagement roadmap' (2022) is currently being mobilised, through the appointment of leaders for partnership at regional level.

Many cancer centres in Ireland have the added impetus of the Organisation of European Cancer Institutes (OECI) accreditation. Parallel to the HSE's strategy to include PPP in design, delivery and evaluation of health services, the PPP Ignite Network is focused on enhancing public and patient involvement in health and social care research in Ireland.

The Irish Cancer Society, the Republic of Ireland's national cancer charity and the largest voluntary funder of cancer research, is a leading voice on PPP. PPP is built into their research processes, as well as embedded within the organisation at large.

Against this backdrop, in early 2024 at an OECI networking day, PPP Leads discussed the benefits of sharing learning across cancer centres. This led to further discourse with leads from

Beaumont RCSI Cancer Centre, Trinity St James's Cancer Institute, patient and public partners, the PPI Ignite Network and the Irish Cancer Society, as to how this could be achieved.

In October 2024, a networking workshop for patient and public partners, OECI coordinators, and PPP cancer leads from cancer centres across Ireland was hosted by the Irish Cancer Society.

This event marks the beginning of a move to work together to strengthen and enhance PPP across cancer centres. Please see Appendix One for a list of participants and Appendix Two for the Event Agenda.

The purpose of bringing OECI coordinators, PPP cancer leads and patient and public partners from cancer centres together was threefold:

- ▶ **1. To kick start a conversation** on how we can develop and strengthen PPP across cancer centres.
- ▶ **2. To share learnings** on approaches, successes, and challenges to embedding PPP.
- ▶ **3. To agree how we can work together** as a powerful network to drive the agenda of PPP.

2.0 Glossary of Terms / Abbreviations

BRCC

Beaumont RCSI Cancer Centre

CNM

Clinical Nurse Manager

CPPWG

Cancer Patient Partnership Working Group

CTSP

Cancer Thriving and Surviving Programme

HSE

Health Service Executive

OECI

Organisation of European Cancer Institutes. A body set up in Vienna in 1979 whose aim is to enable a complete quality system for cancer diagnosis, care, education and research by using OECI standards and indicators and peer review.

PPI Ignite Network

Public and Patient Involvement Ignite Network. The PPI Ignite Network focuses on enhancing public and patient involvement (PPI) in health and social care research in Ireland. The Network was established in 2021 and is funded by the Health Research Board (HRB) and Taighde Éireann – Research Ireland with co-funding from the seven lead universities in the Network.

PPP

Patient and Public Partnership

Patient and Public Partners

Healthcare professionals, researchers and people who use the healthcare service or who are affected by the research working in partnership to improve the quality, experience and safety of healthcare. This may be people with a cancer diagnosis, people who have had cancer in the past, family members, carers or friends of people who have had cancer, members of patient voluntary organisations or support groups, for example.

PRG

Patient Representative Group

RCSI

Royal College of Surgeons in Ireland

TSJCI

Trinity St James's Cancer Institute

3.0 Morning Session: Networking

The purpose of the morning sessions was to provide participants with an overview of PPP from a variety of perspectives: healthcare, research, community organisation, and PPP.

3.1 Part 1: Opening and Introductions



Dr Claire Kilty, Head of Research at the Irish Cancer Society provided an overview of the Irish Cancer Society's role in the cancer landscape in Ireland. She highlighted the core areas of research the Society funds: translational, survivorship, strategic, and clinical trials.

She detailed how our PPP partners are experts on being affected by cancer and their insights are vital for guiding, shaping and informing everything the Society does.

PPP in the Society is built into research decision making, through grant review, as well as ensuring PPP is embedded in the national cancer research landscape, driving PPP as part of our clinical partnerships and embedding PPP into the cancer care pathways.

Dr Kilty detailed how the Society also provides shared learning, training, advocacy and support opportunities for PPP.



Niamh Dillon, PPI in Research Manager in RCSI University of Medicine and Health Sciences gave an introduction to the PPI Ignite Network. She provided details of who makes up the Network and the work they do to build capacity for PPI in health and social care research across Ireland.

She gave examples of how RCSI carries out this work, for example they provide seed funding and training to researchers and review PPI plans on research grant proposals.

Finally, she shared ways people can get involved and hear about future events, by keeping an eye on the PPI Ignite Network Events Calendar and Opportunities Noticeboard (www.ppinetwork.ie)

3.2 Part 2: Building PPP into Cancer Centres



Jean Kelly, former Chief Director of Nursing and Midwifery for the Saolta healthcare group and co-author of "Better Together – Health Services Patient Engagement Roadmap" (HSE 2022) gave an overview of the development and use of the document, from examining readiness, to implementing partnership.

The talk highlighted leadership buy-in and support, and a commitment to working from a patient perspective.



Gráinne Smith, Irish Cancer Society/Trinity St James's Cancer Institute (TJSCI) PPP Lead gave an overview of her role in developing and embedding a PPP framework under 4 pillars of education, research, clinical trials and clinical care.

Examples were given of quality improvement projects the PPP representative group (PRG) have been involved in, for e.g., Lean Transformation Process for Breast Pathway; policy and educational programme development and delivery; reviewing research proposals; designing and testing of communication materials and involvement in the OECI accreditation process. The PRG has been in existence since 2020.



Caitríona Higgins, CNM3 and BRCC PPP Lead, gave an overview on the work of the Cancer patient partnership working group (CPPWG), established in 2022. Its membership includes healthcare staff from across the cancer centre, the Irish Cancer Society and PPP representatives.

Examples of projects involving the group were given. Caitríona highlighted that there is huge value for staff and researchers in engaging directly with and gaining perspective from PPP. Furthermore, embedding PPP within the governance structures of cancer centres is key. The CPPWG is represented at Cancer Executive and Cancer Research Executive by Caitríona and at Cancer Board level by a PPP partner from the CPPWG.

Although cancer centres are at different stages of their journey, coming together today is an opportunity to strengthen PPP by learning from each other and working together in the future.

3.3 Part 3: PPP Perspective



Robin Menzies is a member of the TSJCI PRG, since its inception in 2020, and gave an overview of his role as a PRG member, and some of the activities they have been involved in.

"Being part of the TSJCI PRG has involved working with fellow cancer patients to give the patient perspective on service improvement and research initiatives within the hospital. Overall, a most rewarding and enjoyable experience!"



Jacqueline Daly, Director of Services at East Galway and Midlands Cancer Support, spoke of her own experience after her diagnosis and of caring for her husband through his cancer journey and how this progressed into setting up this support service.

"I felt the turbulence that comes with a diagnosis firsthand and as a result of this I am passionate about improving and easing the cancer experience for others."

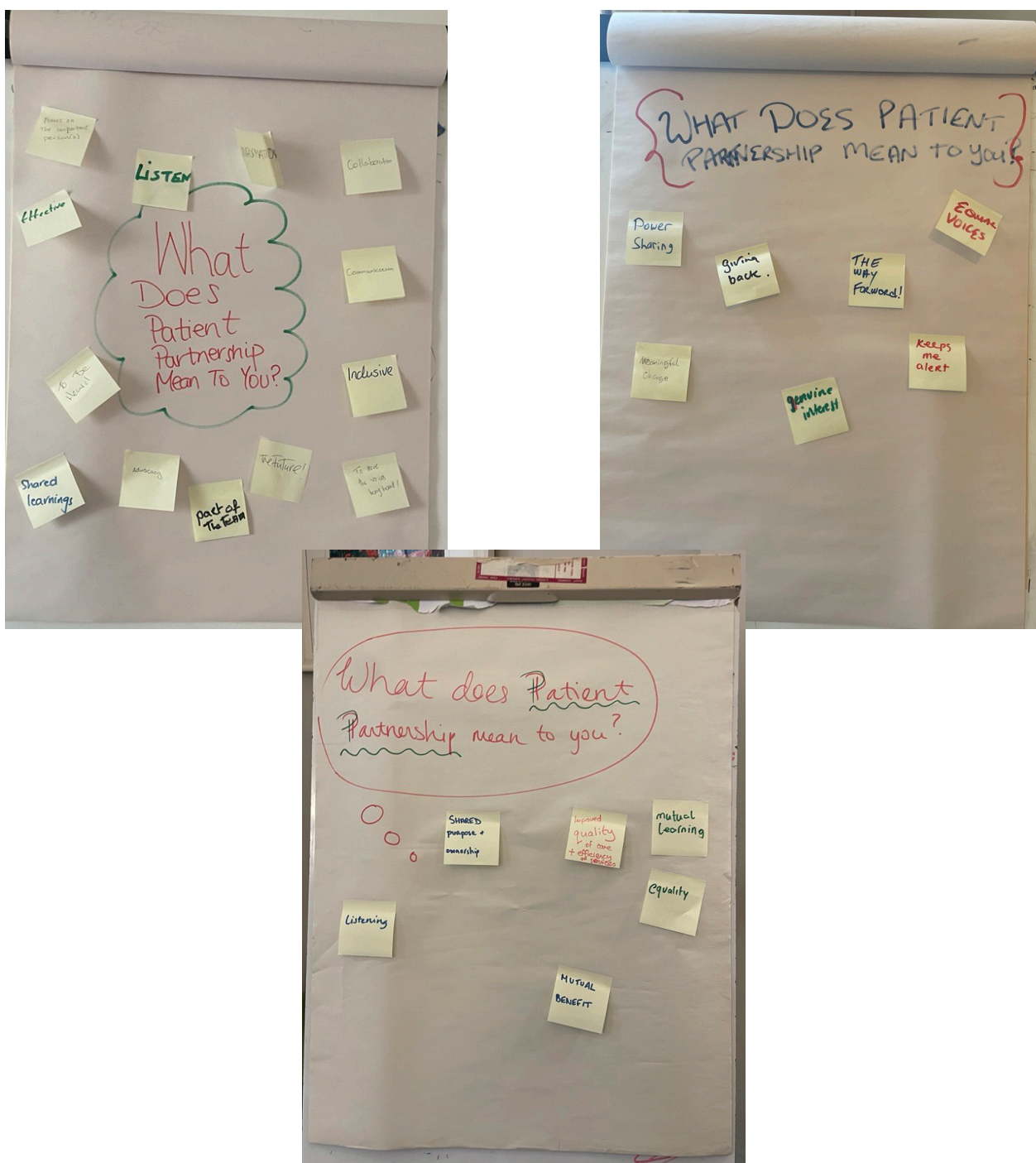


Anne Mynes, a cancer survivor, co-chair of the BRCC CPPWG and a facilitator for the Cancer Thriving and Surviving Programme (CTSP) gave an overview of her role with regards to PPP.

"For me, being part of the BRCC and the CTSP is a way of advocating for other patients in the complex arena of cancer treatment and care. We all have our part to play."

Lunch

Participants were given an opportunity to socialise, reflect and state what PPP means to them.



4.0 Workshop Overview

The aim of the workshop was to focus on some key questions relating to implementing PPP in cancer centres and next steps for the group.

4.1 Workshop Methods

Attendees were split into groups comprised of cancer centre staff and public and patient partners. Efforts were made to ensure there was limited overlap of representatives from the same cancer centre. Each group had a facilitator and a scribe. Two questions were posed to each group:

1. What will it take to implement PPP in your cancer centre?
2. What are the next steps for this group?

There was a further discussion held at the end of the breakout rooms, wherein everyone convened to discuss the conclusions from the workshop. These discussions were captured through scribes' notes, which were

written up for each of the five breakout groups alongside the overall discussion.

4.2 Workshop Outcome

The scribe notes were reviewed and an analysis of the content was conducted. There were nine distinct categories developed from scribe notes, which are noted and discussed below. These are split into two subcategories:

- Those linked to building and strengthening patient partnership in cancer centres.
- Those detailing the next steps.

Building and strengthening patient partnership in cancer centres

1. Governance and leadership structures in cancer centres.
2. Staff education about PPP.
3. Communication about PPP.
4. Network connections.

Next steps

1. Network structures.
2. Shared learning and development of PPP.
3. PPP recruitment.
4. PPP support to be involved.

4.3 Building and strengthening patient partnership in cancer centres

4.3.1 Governance and leadership structures in cancer centres

It was agreed that buy-in for the implementation of PPP at the highest level of governance as well as PPP representation at cancer Board level is necessary to further genuine patient partnership.

PPP should be included as a standing item on agendas for high-level meetings, such as Board or hospital executive meetings.

For cancer centres working towards OECl accreditation, there is a clear incentive as PPP is a defined standard to be achieved. This provides impetus for upper management support for embedding PPP.

Operating out of a hospital that was not a main cancer centre was noted as a barrier to PPP, wherein clear governance structures were not filtered down to these peripheral hospitals.

“Without their [hospital senior management] support, there will be no way to enact the change needed.”

“The upper level of influence is key; the intent is there it just needs to be operationalized.”

It was acknowledged that embedding PPP into cancer centres needs time and resources.

Change cannot occur if it is treated solely as an ‘add-on’ to healthcare staff’s workload.

It was suggested that lack of progress in embedding PPP into hospitals to date may stem from the absence of a specific lead for PPP, who can drive the cultural change required within hospitals.

Implementing PPP needs buy-in and support from management, alongside a dedicated member of staff to lead on PPP.

"There is often a lack of leadership within the hospitals for PPP, e.g. no PPP Lead."

"Time and resources are key. Change cannot occur if it is treated solely as an 'add-on' to healthcare staff workload."

"Buy in from key staff, such as newly appointed consultants, nurses, health care assistants and porters is important to ensure PPP is embedded."

"The information is not being trickled down through staff, so people who interact daily with patients are not in the know."

4.3.2 Staff education about PPP

Staff being educated about PPP is crucial and should be filtered down to all staff, and be integrated throughout the pathway of care.

There is an emergent understanding of PPP with newly appointed consultants, and through various quality improvement programmes undertaken by allied health staff.

This should be encouraged and opportunities communicated across all staffing levels.

4.3.3 Communication about PPP

Communication about PPP should involve raising awareness at local, interhospital and national level.

Suggestions included addressing the topic at all meetings from department or ward to hospital executive level and between cancer centers.

Raising the profile of PPP at a national level was also noted as a priority, via social media and/or public meetings held by cancer centres. One participant, who worked at a cancer centre, highlighted the PPP section on their website as a strong example of communicating about PPP.

"Communication is key – not just discussion amongst the most active or higher ups."

"Going to open meetings to pitch PPP. People will get used to it, understand it."

"Ensure PPP gets communicated beyond the usual people and channels."

4.3.4 Building connections between PPP active organisations

Building better connections between organisations involved in PPP was highlighted as a mechanism to strengthen PPP across Ireland.

Having a national registry of PPP work, or conducting a mapping exercise of current PPP groups was noted as a means to identify gaps.

One participant from a university setting highlighted that while there was PPP in their institution, it was not linked to the affiliated hospital. One participant who works in a clinical setting, highlighted that approaching individuals to partake in PPP for research purposes was often difficult, as researchers may not make expectations of PPP roles clear.

"It's difficult to interact with and recruit patient and public contributors."

There is no physical space for them within the hospital, and so while there is a PPP panel, it is entirely university based, not hospital."

"There is a lack of connection between the PPP panel and the clinical team."

4.4 Next Steps

4.4.1 Network Structures

It was agreed that a network group should be established with terms of reference developed to guide the group.

Meetings were proposed to be predominantly online, with PPP leads and patient and public partners from cancer centres in attendance.

The group should feedback to their associated cancer centre at large. It was also proposed that an annual event with rotating locations may be conducive to establishing and running the network.

It was proposed that an organisation like the Irish Cancer Society could collaborate by facilitating the network, and there should be representation from each cancer centre.

“A working group should include representatives from each cancer centre, as well as patient and public partners from each.”

“Connection. Building trust.
Relying on each other.
Imagining where we want
to get to – in order to
evolve into that.”

“Everyone should remain
together – as a network.”

4.4.2 Shared learning and development of PPP

Participants were very positive about the event. Cancer centres across Ireland are at different stages of development of PPP.

It was felt that there was great merit in continuing to meet as a network to collaborate and share learnings. In this way common practices in relation to PPP recruitment, managing patient and public partner groups and building PPP into governance structures can be shared. This prevents duplication of work, and effort. This may ensure consistency across how cancer centres develop and operationalise PPP.

“The end goal should be to coordinate an all-Ireland model for PPP based on shared resources and learning.”

**“Goal for future meetings
– raising each other up and supporting the development of PPP.”**

4.4.3 PPP Recruitment

Recruitment of individuals onto PPP panels was discussed. The timing of recruitment in terms of patient pathways, e.g., during or after treatment, and who is best placed to approach potential individuals was further debated.

Participants concurred that leaflets and posters should be displayed in all patient-facing areas, e.g., outpatients, oncology day ward, in-patient wards, to promote recruitment and PPP.

Nurses and clinicians have a role to play in recruitment, as they often have pre-established rapport with their patients.

A participant working in an administrative role in clinical trials felt there were opportunities to engage with individuals who may wish to partake in PPP activities that weren't being harnessed, highlighting that cancer centre office staff could also be involved.

“Sometimes there was an expectation from researchers that PPP leads will recruit patients to studies. There is a lack of clarity about what their expectations from PPPs are.”

“You want recruitment to be soft, an option you can choose at a time that you are ready to be involved.”

Using language and terminology that is clear, concise, and not overly complicated was mentioned repeatedly, highlighting the need to adapt clinical terminology and to provide support for those involved in PPP.

It was agreed that identifying what PPP support is needed should be part of the next steps for the network.

“Tiers of participation for PPPs: Maybe you just want the emails, maybe the occasional meeting, versus regular representatives.”

4.4.4

Supporting patient and public partners to get involved

Individuals involved in PPP may wish to be involved to differing extents. This should be considered from the outset of setting up the network.

While some might want to be part of the network and meet regularly, others may wish to only be involved in an individual project.

5.0 Conclusion

Participants welcomed the opportunity to come together to share experiences and learnings of how to embed PPP in cancer centres.

While advancements have been made, clear opportunities exist to develop it further. Cancer centres need to work together to advance this movement, with strong leadership, dedicated PPP partner leads and a commitment to include PPP on agendas across hospitals.

This report will be circulated to all participants who attended the event and to those cancer centres that could not attend.

► Next Steps

TSJCI, BRCC, Irish Cancer Society and PPI Ignite (RCSI) representatives will coordinate the development of the report from the first meeting for this network.

Next steps will be to discuss Terms of Reference and actions based on workshop themes, alongside general operationalising of the network.

► Acknowledgements

We would like to acknowledge those who supported this event. PPI Ignite @ RCSI provided funding towards accommodation for the public and patient partners who attended.

The Irish Cancer Society coordinated the event, hosted it in the Northumberland Rd offices, and provided funding towards lunch for attendees, and funding for travel and accommodation for the public and patient partners who attended.

Finally, we would like to thank all the attendees who gave their time to kick-off this network.

At the time of completing this report, we were deeply saddened by the passing of Robin Menzies, a patient partner from TSJCI.

Robin's contributions were invaluable, and we are grateful for the opportunity to have worked with Robin.

We honor his memory with deep appreciation.

6.0 References

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7.0 Appendix One: Attendees

Attendees included staff, patient partners, and community organisations with an interest in PPP.

Rebecca Amet (**Mater Private**); Ashley Bazin (**Tallaght University Hospital**); Tommy Bracken (**St Vincent's University Hospital**); Pádraig Carroll PPI (**PPI Ignite Network, Trinity College Dublin**); Louise Coleman (**Beaumont RCSI Cancer Centre**); Chris Crockford (**St Vincent's University Hospital**); Jacqueline Daly (**East Galway Midlands Cancer Support**); Niamh Dillon (**PPI Ignite Network, Royal College of Surgeons**); Claire Farrell (**Beaumont RCSI Cancer Centre**); Eva Gill (**Trinity St James's Cancer Institute**); Leah Harrington (**Beaumont RCSI Cancer Centre**); Caitriona Higgins (**Beaumont RCSI Cancer Centre**); Heba Kalil (**Cork University Hospital**); Alexander Kane (**Mater Private Network**); Jean Kelly (**Saolta Group Cancer Centres – Retired**); Claire Kilty (**Irish Cancer Society**); Jackie Lillis (**Saolta Group Cancer Centres**);

Robin Menzies (**Trinity St James's Cancer Institute**); Anne Mynes (**Beaumont RCSI Cancer Centre**); Mary Neville (**Cork University Hospital**); Marion Naughton (**East Galway Midlands Cancer Support**); Emily O Connell (**Cork University Hospital**); Lorraine O Connell (**Limerick University Hospital**); Rachel O'Mahony (**Saolta Group**); Jane O'Neill (**Mater Private Network**); Claire O Regan (**Cork University Hospital**); Helen O Reilly (**Saolta Group**); Finbarr Pyne (**Cork University Hospital**); Edel Ryan (**Mater Private Network**); Aanya Sagheer (**Irish Cancer Society**); Sasna Saji Thomas (**Cork University Hospital**); Gráinne Smith (**Trinity St James's Cancer Institute**); Dorothy Thomas (**National Cancer Control Programme**); Damien Traynor (**Mater Public Hospital**); Nikolett Warner (**Irish Cancer Society**)

8.0 Appendix Two: Event Agenda



Celebrating Patient Partnership in the Cancer Centres through Connection and Collaboration

A Networking and Workshop Event

Date: Friday 11th October 2024

Venue: Irish Cancer Society, 43/45 Northumberland Road, Dublin 4, D04 VX65

Time: 09.30 to 15.00

Agenda

Part One: Opening and Introductions

1. 09.30 - 10.00 Registration, Tea and Coffee
2. 10.00 - 10.15 Round Room Introductions
3. 10.15 - 10.30 National PPI Festival Overview
4. 10.30 - 10.45 Irish Cancer Society and Patient Partnership

Part Two: Building patient partnership into Cancer Centres

5. 10.45 - 11.05 Patient Partnership journey – Trinity St James's Cancer Institute and Beaumont RCSI Cancer Centre
6. 11.05 - 11.30 Open Discussion - all Cancer Centres

11.30am-11.50 Comfort Break

Part Three: The Patient Partners' Perspective

7. 11.50 - 12.30 Patients' Partnership experience

Lunch 12.30 to 13.30

Part Four: Workshop

8. 13.30 - 14.15 Participants will be split into groups to discuss key questions on how to strengthen Patient Partnership in Cancer Centres
9. 14.15 - 14.45 Spokesperson for each group and general discussion
10. 14.45 - 15.00 Conclusion and Next Steps

