


Your Cancer Care & Cancer Research


Hosted by NI Cancer Research Consumer Forum

Help us understand how cancer care and cancer research can be more inclusive and accessible to everyone.

We would like to hear from you if you are living with cancer or caring for someone with cancer.

Come along to our workshop:

 Thursday 20th February 2025

 10.30am - 1pm

 Clayton Hotel,
22-26 Ormeau Avenue
Belfast, BT2 8HS

Light lunch will be provided



Register to attend by scanning or clicking the QR code:

To contact us please email nictn@belfasttrust.hscni.net or phone 028 9615 2652

Your Cancer Care & Cancer Research 20 February 2025

Workshop Report August 2025



Thank you to all who took part in the workshop

- 50 in attendance
- 44 involved in table discussions
- 7 table facilitators
- 6 speakers
- 3 interpreters
- 2 workshop facilitators
- 1 artist



Your Cancer Care & Cancer Research

20 February 2025, Clayton Hotel, Belfast

Workshop Agenda

Registration and refreshments will be available from 10.15am.
Event will start promptly at 10.30am



	Topic	Presenter
1	Welcome	Mr Aidan McCormick Chair, NI Cancer Research Consumer Forum
2	Making your mark	Ms Beth McComish Artist in Residence, Belfast Trust
3	Overview of inequalities in cancer care	Ms Sarah Christie Macmillan Cancer Support, Nation Lead and External Affairs Manager
4	Cancer Research – The path to care today and tomorrow - why inclusion matters	Miss Ruth Boyd CRUK Sn Research Nurse, NI Cancer Trials Network, NI Cancer Research Consumer Forum
5	The role of patient advocates in cancer research – something for everyone	Mrs Margaret Grayson NI Cancer Research Consumer Forum
6	Example - Patient advocacy increasing access and inclusion	Mrs Debbie Keatley NI Cancer Research Consumer Forum
7	What can research and researchers do to make cancer care more inclusive and accessible	Dr Ethna McFerran Post Doctoral Research Fellow Cancer Health Economics
11.15 Comfort break		
8	Workshop Table Discussion and Feedback Help us make Cancer Care and Cancer Research more inclusive and accessible to everyone!	Miss Ruth Boyd CRUK Sn Research Nurse, NI Cancer Trials Network, NI Cancer Research Consumer Forum
9	Next steps	Miss Ruth Boyd and Ms Beth McComish
10	12.30 Close and Lunch (end 1pm)	

Thank you to our presenters



Aidan



Beth



Sarah

Ruth



Margaret



Debbie



Ethna

Some Key Messages

MACMILLAN
CANCER SUPPORT

Close the Gap

Cancer diagnosis delayed by skin colour, say patients



Health gap between rich and poor 'unacceptable'



Elderly patients' five-day wait in 'intolerable' A&E



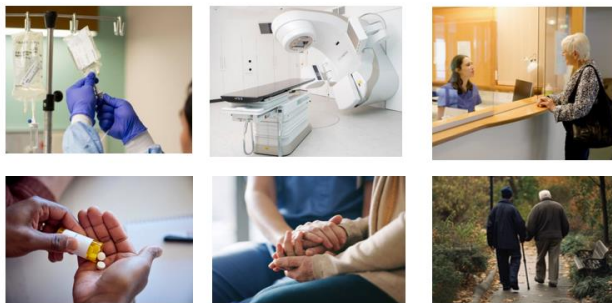
Cancer: Call for more all-Ireland cross-border co-operation

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Cancer Research

The path to care today and tomorrow



'We can have the best cancer therapies that target the certain receptors in these cancers but if patients can't come in for their treatment because they have no transportation, or they can't get off of work or they can't afford to be off work, then all these therapies will not be of use'

Lori Pierce

Identify and Address Disparities in cancer care

The challenge:

- Disparities in cancer care persist across the four UK nations.

The consequence of inaction:

- Without targeted research, health inequity remains entrenched—some populations experience poorer access, delayed diagnosis, and worse outcomes.

What research can do:

- Use data-driven approaches to expose hidden inequalities (e.g., Bowel Cancer UK Grant where recruitment strategies consider non-attenders).
- Ensure innovations benefit all, not just select groups (e.g., NI Symptomatic FIT Launch—evaluating early detection impact across diverse populations).



You are needed as a patient advocate

- Partnership
- Inclusive
- Important





Table discussions

- Each table discussed questions to help understand how cancer care and research can be more inclusive and accessible to everyone.
- Everyone at a table was encouraged to discuss a series of questions. They also documented thoughts on tablecloths to 'make their mark' in words or pictures.
- The information collected at the workshop is summarised in this report.

In cancer care.....what barriers have you experienced or what barriers have you seen others experience?

Table facilitators' summary

- Unconscious bias (including but not limited to): rurality, age, language (non-English), have a hearing impairment, lifestyle (obesity, smoking), LGBTQ+, cultural differences (non-UK native). In each of these there is a danger in making assumptions
- “Sneaky symptoms” –can be difficult in presenting to GP / women’s experiences; Embarrassing symptoms / late symptoms
- Money - Patient expenses, costs of travelling
- Geography – treatment not available in NI or even some types of support, ideally treatment close to home
- Assumptions made on ‘standard diagnoses’ e.g. not considering bowel cancer in younger patients because they’re ‘too young’
- Lonely cancer journey – Covid

In cancer care.....what barriers have you experienced or what barriers have you seen others experience?

Table Facilitators' summary (continued)

- Psychological and socio-economic barriers just as important as practical ones like hearing etc.
- Service users may be migrants or asylum seekers and often lonely
- Need to explain terms (even common ones) to non-native speaker – e.g. metastasis. What does that mean?
- Sometimes concerns aren't listened to appropriately – symptoms are expressed but not taken seriously
- 'Established pathway' often quoted but the rationale for that not explained – needs an attempt to personalise the treatment to the person

In cancer care.....what barriers have you experienced or what barriers have you seen others experience?

Participants' tablecloth comments

Equality does not necessarily equal equity – equity is the goal

Not treated seriously

Language barriers and lack of understanding of medical terms by non-English speakers

Funding

System too complex

Awareness and education for all generations – we need early diagnosis

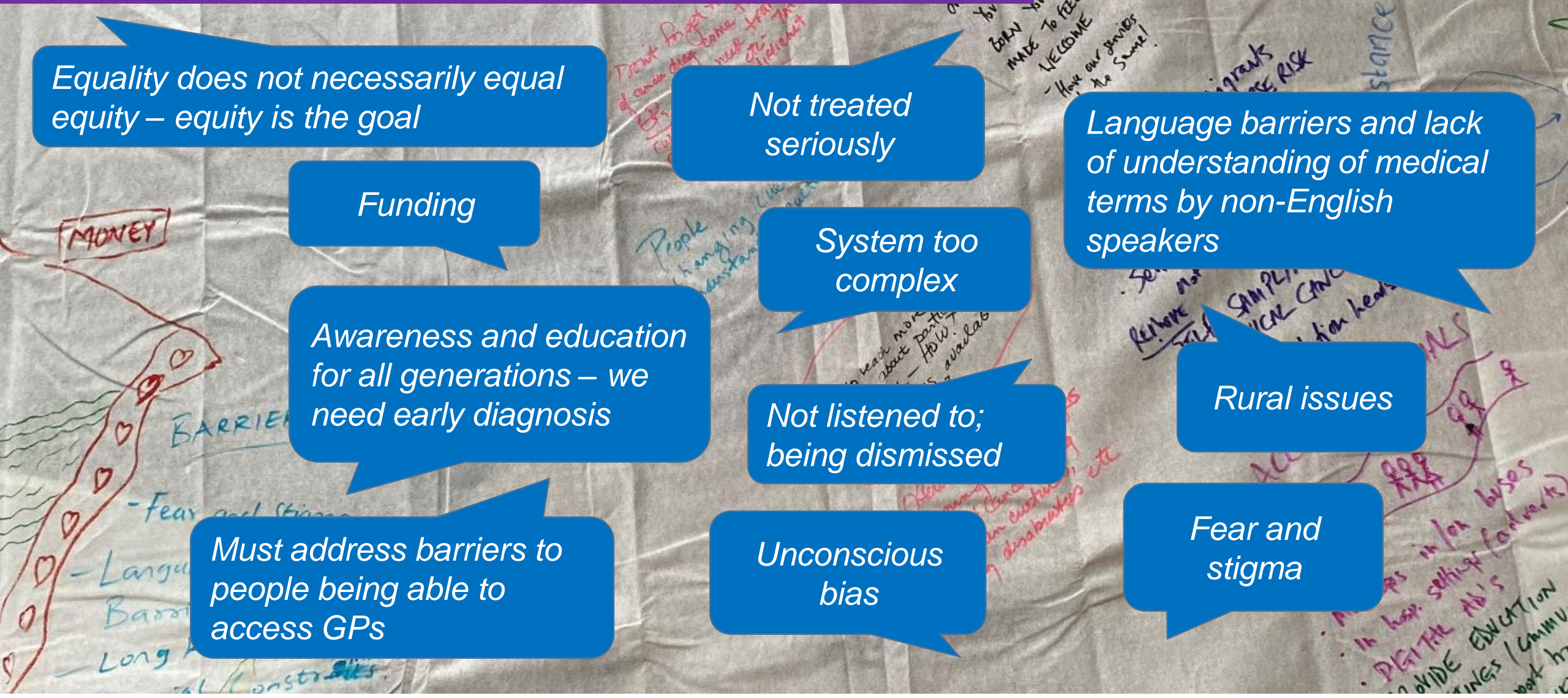
Not listened to; being dismissed

Rural issues

Must address barriers to people being able to access GPs

Unconscious bias

Fear and stigma



What would help reduce the barriers?

Table Facilitators' summary

- Educate the public/patients – most people don't need to go to A&E, education on where you should turn for care depending on your symptoms/severity etc., clearer pathways for getting the help you need, getting people to speak up with experiencing symptoms, would it be helpful to have the 111 service as in England?
- Open and inclusive conversations are critical – face-to-face better than online, critical to actually listen to patients including their stories, more cultural awareness and sensitivity, could set up virtual meetings with families for support if they are far away. Cultural competency training?
- Systematic barriers in place; waiting lists, need to improve transport in rural areas, need more diversity in health staff at all levels. Address proximity to treatment where possible (community hubs in England for example)

What would help reduce the barriers?

Table Facilitators' summary (continued)

- Education for all decision maker roles (or all staff?) as to what barriers are and how to address
- Breaking down barriers and challenging assumptions should start with GPs
- Remove stigma
- Loneliness; volunteer support could be helpful
- Learning from previous experience e.g. covid
- Technology e.g. translation should be used more
- Take part in community activities

Participants' tablecloth comments

What would help reduce the barriers?

Use basic terminology for better understanding

Need better/clearer communication

Consistency in care and support

Need to teach more about participating in research – how? More studies available? More locations?

More support needed – pathways to help

Starts at reception – non-medical staff – educate people on awareness of pathways, cultural competence for all

Inclusion

Decision makers need to be educated in inequalities and inequality as they are not experts

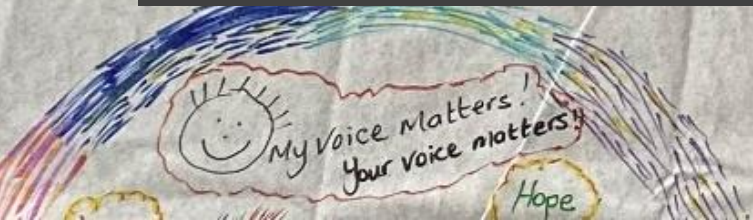
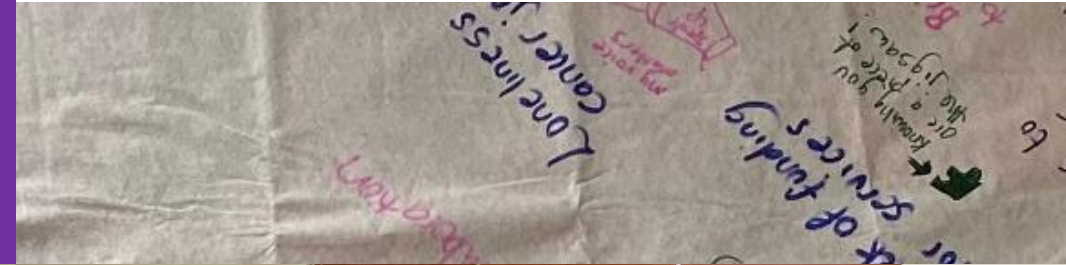
Importance of data

More healthcare professionals to meet the number of patients

Active listening

Who all should be involved in this conversation?

- Everybody
- Minority Groups
- Personal and Public Involvement and Engagement (PPIE) advocates
- Need to get into communities
- Deprivation and rural areas
- People with learning disabilities
- People with a diagnosis
- Service users
- People who have been through the experience already
- Carers
- Community organisations and links
- Researchers and clinicians
- Staff etc.



What would encourage you to take part in a cancer research study?

Table Facilitators' summary

Participants' tablecloth comments

Seeing the benefit of results

- Improved care
- Better outcomes
- The legacy of participating in research
- Giving hope
- Research is excellence in health and social care

Support to get involved

- What is required of me?
- Need clarity regarding time commitment
- Financial support to allow inclusion in research/trials
- What are the side-effects?
- Do I have to travel to Belfast?
- How will I be kept informed?
- Being inclusive – researchers aware of challenges and not excluding patient due to culture / language / age / disability / sexual orientation / education levels / social background

What would encourage you to take part in a cancer research study?

Table Facilitators' summary

Participants' tablecloth comments
(continued)

Reducing barriers relating to language and culture

- Avoid use of acronyms and technical language
- Awareness of those with English as a second language
- BME community need more awareness education
- Video clips to allow family conversations

Will this improve outcomes for the person with diagnosis?

- Will this study help me?
- Listening to peoples' stories
- Digital stories from those involved in clinical trials

Possibility of more local trials

- Asking – being told no trials here – why not?
- Availability of cancer research locally – access to more trials in NI

What's the best way to get the message out about cancer research?

Table Facilitators' summary

Participants' tablecloth comments

Highlighting the power of collective data and stories

- Personalised research, not just a statistic
- How my experience can contribute
- Hear about good news stories

Raising awareness of research with health professionals

- Information about research shared with GPs, nurses, consultants etc.
- Clinic consultation to mention research
- Researchers to provide more relevant information

Both old and new ways of communicating

- Colourful posters
- Messages in/on buses and bus shelters
- Digital adverts
- Social media
- Visual presentation – QR code
- Clear information in oncology units about research opportunities
- Involve more people and increase community awareness



Now that you've heard from members of the Forum
what would encourage you to get involved as a patient
advocate in cancer research?

Barriers in lack
of professional
understanding of
new pathways
i.e. GFT +
Vague Sympo
Pathway.

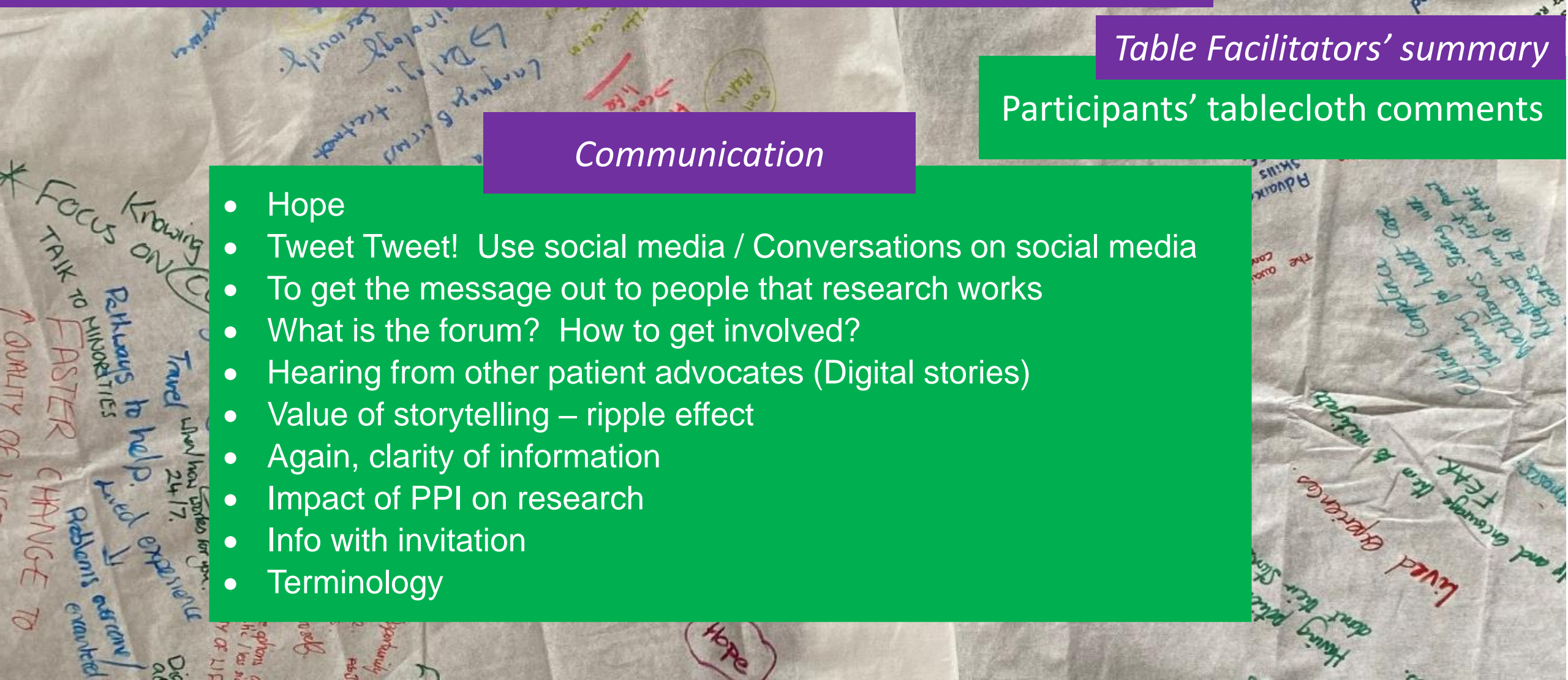
as they are not experts
be educated in
tion makers need

Table Facilitators' summary

Participants' tablecloth comments

Communication

- Hope
- Tweet Tweet! Use social media / Conversations on social media
- To get the message out to people that research works
- What is the forum? How to get involved?
- Hearing from other patient advocates (Digital stories)
- Value of storytelling – ripple effect
- Again, clarity of information
- Impact of PPI on research
- Info with invitation
- Terminology



Now that you've heard from members of the Forum
what would encourage you to get involved as a patient
advocate in cancer research?

Barriers in lack
of professional
or understanding of
new pathways or
Vague symptoms
as they are not experts.
Education makers need
to be educated in
oncology and in
oncology.

Table Facilitators' summary
Participants' tablecloth comments
(continued)

Support

- Open
- Financial help – travel/food/heat costs
- Interpreters
- Involve as wide a group as possible / Involving people from all backgrounds / diversity / cultures
- Have these events outside of Belfast - need rural events across province / province wide
- Support Workers
- Cultural awareness



Participants' tablecloth comments

How could we make our patient / carer representation more inclusive?

- Recruitment should be active
- Important to let people know that they are important
- To get the message out to people that research works
- Macmillan have partnerships with organisations such as iAssist NI and BDA (British Deaf Association) which can help with links and inaccessibility as well as the Rainbow Project and Farming Community Network
- Invite personally to other communities / Talk to minorities
- Make the message relevant to the community & the cohort you want to involve or engage with





Information and Support Services displayed at the Workshop

Creating the art work

The artwork captures the thoughts, words, images, 'marks' made by the participants throughout the event, onto the tablecloths. All the tablecloths were woven together to symbolise the multiple layers of experiences, voices needed to understand how cancer care and research needs to be inclusive and accessible for all.

The interlaced 'marks' provide the foundation for the felted silhouettes of those with lived experience and expertise of cancer care and research. Overlaying the entire tapestry are words of action and hope to tie the artwork together.

The tapestry has physical weight and presence emphasising the breadth and importance of the involvement and shared learnings from the event.

Beth McComish, Belfast Trust , Artist in Residence



be part of
the
Research

equity
access

voice

hope

Listen just

not

inspire

statistic

Workshop
tapestry by
Beth McComish,
Belfast Trust
Artist in Residence



Workshop Feedback

- Participants were invited to complete an evaluation form
- There were **18** responses

Feedback Questions / Responses	Yes	Maybe	No
Did the event meet your expectations?	94%	6%	0
Did the event help you understand the importance of inclusive and accessible Cancer Research?	94%	6%	0
Did you feel you were able to contribute to the workshop discussion?	100%	0	0
Did this event increase your awareness and understanding of inequalities in cancer care? 94% responded positively: <i>e.g. 'Definitely. Great experience. Very interesting and informative'</i> <i>'Yes made me consider perspectives I hadn't before'</i>			
Comments about workshop discussion: <i>e.g. 'Was amazing hearing everyone's stories & experiences'</i> <i>'There was so much to hear/ share would have liked longer'</i> <i>'Informal conversation style with facilitator worked well'</i>			

Workshop Feedback (continued)

Feedback Questions / Responses	Yes	Maybe	No
Did you feel you had the opportunity to discuss barriers in cancer research?	100%	0	0
Did you feel you had the opportunity to discuss ways to make cancer care and cancer research more inclusive and accessible?	100%	0	0
Before today, had you heard about the NI Cancer Research Consumer Forum?	56%		44%

Comments about discussing barriers in cancer research and how to make it more inclusive and diverse:

e.g. 'I felt listened to and valued'

'Involve partners and organisations that support the seldom heard'

'There is a lot of work to do in communicating with people and communities who face challenges in lots of different ways'

Where do you hear about cancer research in Northern Ireland?

Social media/internet 50%, Voluntary sector/other response 22%, Healthcare staff/setting 17%, I do not hear about cancer research in NI 11%

Workshop Feedback (continued)

Feedback Questions / Responses

What you enjoyed about this event:

e.g. 'Networking, the discussion'

'The atmosphere was lovely & relaxed. I felt safe sharing my own story & not only listened to but actually heard'

'Meeting a diverse range of contributors and participating in discussion. Also hearing different perspectives'

'I loved the fact that everyone at each table were able to write their thoughts/opinions down - everyone was treated equally'

'The friendliness of the atmosphere and quality of the presenters. Liked the drawing in the table clothes and the use of art as part of the process'

What we could improve for our future events:

e.g. 'Longer time'

'More time to discuss often complex questions'

'More advertisement'

'More of similar, please, expand feedback about prior research involvement'

Additional thanks

Project Grant:

- Macmillan Cancer Support – World Cancer Day ‘Close the Gap’ initiative

Project Planning:

- NI Cancer Research Consumer Forum (NICRCF) Project Working Group
- Ruth Boyd, NI Cancer Trials Network/Belfast Experimental Cancer Medicine Centre
- Grainne Murphy, Belfast Trust Personal and Public Involvement Team

Table Facilitators:

- NICRCF – Margaret Carr, Tim Kerr, Peter Newman, Aileen O’Dwyer, David Rodgers
- HSC R&D - Janet Diffin, Alan McMichael

Cancer support and information table:

- Margaret McManus, Belfast Trust Cancer Services



Next Steps

- Thank you to all our workshop participants and presenters for sharing their lived experience and expertise in cancer care and research
- Their knowledge and experience of barriers in cancer care and their ideas about reducing barriers and making cancer care and research more inclusive and accessible to everyone is really helpful
- The NI Cancer Research Consumer Forum, NI Cancer Trials Network and Belfast Experimental Cancer Medicine Centre are co-developing an action plan informed by this workshop in conjunction with other Macmillan World Cancer Day 'Close the Gap' activities, HSC R&D [Equity in Research Manifesto](#) and other guidance
- Participants will be informed when the action plan is published on the Cancer Trials NI website
- If you wish to be part of this work, please get in contact



Contact Information



NI Cancer Research Consumer Forum:

E-mail Ruth at nictn@belfasttrust.hscni.net
or see website

<https://cancertrials.hscni.net/ni-cancer-research-consumer-forum/>

Cancer trials in Northern Ireland:

See website <https://cancertrials.hscni.net>

[Portfolio - Open Trials - CancerTrials NI – NICTN](#)

[By Cancer Type - CancerTrials NI – NICTN](#)

NI Cancer Trials Network- Tel: 028 9615 2652