

Welcome

*North East & North Cumbria Peer Research
Community of Practice*

17 January 2024



Time	Activity
10.30 - 10.40	Welcome and introduction <i>Peter van der Graaf, Fuse & Felicity Shenton, ARC NENC</i>
10.40 - 11.05	Peer research with the voluntary, community & social enterprise (VCSE) sector , <i>Greta Brunskill, VONNE & Felicity Shenton, ARC NENC</i>
11.05 - 11.30	Up-skilling 'Experts by Experience' for Involvement in Co-Production in Research , <i>Chris Gibbs, CNTW; Toby Brandon & Mick Hill, Northumbria Uni</i>
11.30 - 11.40	BREAK (5mins)
11.40 - 12.25	Carousel discussions about training needs and support
12.25 - 12.30	Next steps and next meeting
12.30	Close of event

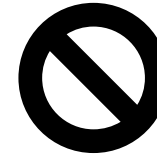
Rules of engagement



Mutual respect



Maintain confidentiality



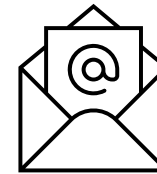
No disruptions



Ask questions if you don't understand



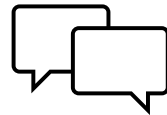
Commit to being an active participant



Keep in touch



Enjoy the community!



Use appropriate language

Background and introduction



What is a community of practice?



“ A community of practice is where a groups of active practitioners (and academic and community members) in a specific field come together to share ideas, experiences and best practice and support each other.” (the social change agency)

- Pooling valuable learning
- Creating new knowledge
- Take learning and knowledge back out to your organisations
- Shared values: openness, honesty, lack of judgement and confidentiality

Events so far ...

- 1st Event, 18 January 2023, Gala Theatre, Durham (in person) - *Peer research - sharing best practice and developing a community of practice*
- 2nd Event, 27 June, 2023 (online) - *Launch of the North East & North Cumbria Peer Research Community of Practice*
- 3rd Event, 17 January 2024, Newcastle University (in person; rescheduled from November 2023) - *Developing accredit training for peer researchers*



Peer Research Community of Practice - resources

Slides from the June 2023 launch of the ARC NENC Peer Research Community of Practice
[DOWNLOAD ↓](#)

Notes from the 'Thinking Hats' activity
[DOWNLOAD ↓](#)

Slides from the Peer Research COP development event
[DOWNLOAD ↓](#)

Level 2 accreditation in Peer Research - info
[DOWNLOAD ↓](#)

- ARC NENC repository (presentations, resources, links): <https://arc-nenc.nihr.ac.uk/nihr-arc-nenc-peer-research-community-of-practice-repository/>
- Jamboard from 2nd meeting about Community of Practice, <https://jamboard.google.com/d/1dUkAGfa6aDJI2OxyJi0IHm3uo6Sjrfir71Gj31THqS0/viewer?f=0>
- Email list: join by contacting: arcnenc@cntw.nhs.uk

Presentations

- **Greta Brunskill, VONNE**, *Peer research with the voluntary, community & social enterprise (VCSE) sector*
- **Chris Gibbs, CNTW; Toby Brandon & Mick Hill, Northumbria University**, *Up-skilling 'Experts by Experience' for Involvement in Co-Production in Research*





Peer research with the voluntary, community & social enterprise (VCSE) sector

Greta Brunskill, VCSE Health & Wellbeing
Research Partnerships Coordinator, VONNE

Felicity Shenton, Public Involvement &
Community Engagement Manager, NENC ARC

North East and North Cumbria VCSE Research
Partnerships

Growing VCSE involvement in research in our region

2018 – 2022 work led by Creating Connections

2018 National NIHR 'Reaching Out' programme

2021 NIHR SPCR funded project
Developing VCSE/Researcher partnerships
for impact and sustainability

2022 NIHR CED funded work
Developing a work programme for a new VCSE Research Partnerships role



July 2022 – new VCSE Research Partnerships Coordinator role



- Funded by NIHR infrastructure partners
- Based at VONNE
- Supporting connections and sustainable, reciprocal partnerships
- Building capacity for partnerships

NIHR Community Engagement Toolkit (2021)

10 guiding principles for researchers looking to involve communities and work with community organisations

A great starting place for preparing and planning for working with communities for research

<https://www.rdsresources.org.uk/ce-toolkit>

NIHR | National Institute for Health and Care Research
Research Design Service Resources

[print / save as pdf](#) [back to resource](#)

Community Engagement Toolkit

This toolkit is aimed at supporting researchers who are developing grant applications with, and for, diverse communities. It has evolved from what our community partners in the Reaching Out Projects taught us about how they would like researchers to engage with them to build sustainable community relationships. We have transferred their knowledge and experience to the world of health and social care research into **ten guiding principles**.

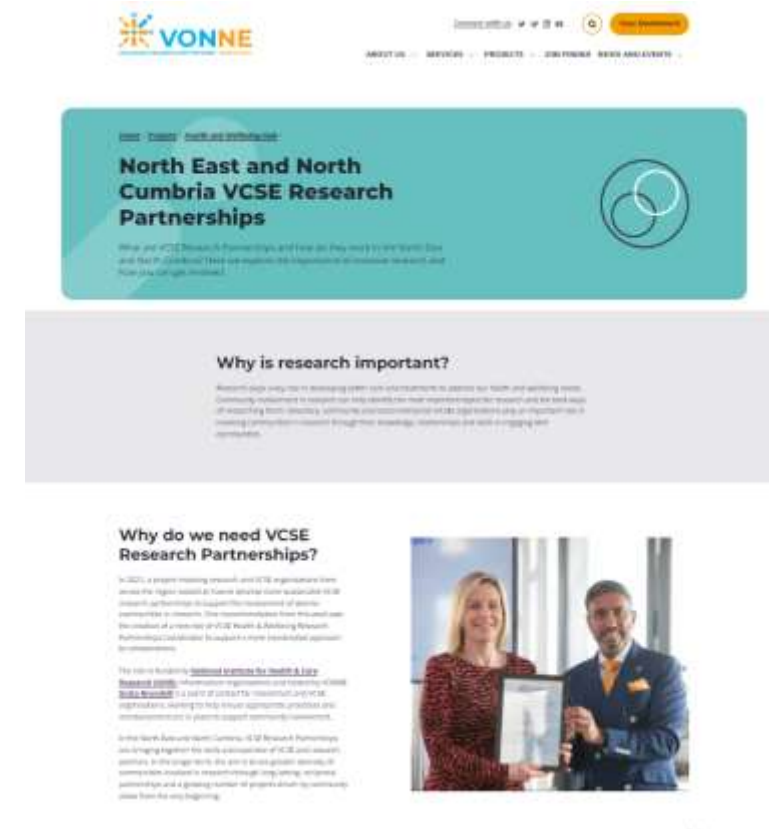
Community engagement, in this context, goes beyond simply 'involving' people. It relies on building ongoing, meaningful relationships between the community and organisations for mutually beneficial outcomes. It is a collaborative process between groups who are brought together as neighbours or through sharing a common interest or concern. It is a powerful vehicle for bringing about environmental and behavioural changes to improve the situation and wellbeing of the community. (Community Engagement for Social Inclusions)

1. Do the groundwork and prepare

Recent developments: Supporting connections



Sharing research opportunities with VONNE's Health & Wellbeing network



VCSE Research Partnerships webpage – contact forms & useful links



Recent developments: Building capacity for VCSE research partnerships



print / save as pdf

back to research

Community Engagement Toolkit

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1. Do the groundwork and prepare



Next: developing a regional code of practice & practical resources

Recent developments: Building capacity for VCSE research partnerships

**Demystifying health and wellbeing research
and evaluation: An introductory workshop**

**Tuesday 30th January 2024
10am – 12.30pm, online**



**What is the VCSE
sector?**

A session for health,
research & other
partners
(coming soon!)



Group discussion

Peer research is a key area where working in partnership with VCSE organisations can benefit research and communities

- **How can we further grow connections between peer research and the VCSE sector?**
- **What else do we need to grow greater collaborations between peer research and the VCSE sector?**

How to get in touch

Visit the VONNE VCSE research partnerships page and use contact forms for VCSE or research organisations to get in touch for support with

- Connecting for research
- Building a partnership
- Opportunities for skill sharing / training

<https://www.vonne.org.uk/north-east-and-north-cumbria-vcse-research-partnerships>

Join the VONNE Health & Wellbeing network to receive a regular eBulletin with research opportunities, events and training as well as information about health and care developments in the region.

Useful links

NIHR Community Engagement Toolkit

<https://www.rdsresources.org.uk/ce-toolkit>

NIHR guidance on payment for public contributors

<https://www.nihr.ac.uk/documents/payment-guidance-for-researchers-and-professionals/27392>



NENC Peer Research Community of Practice January 2024

**Up-skilling 'Experts by
Experience' for
Involvement in Co-
Production in Research**

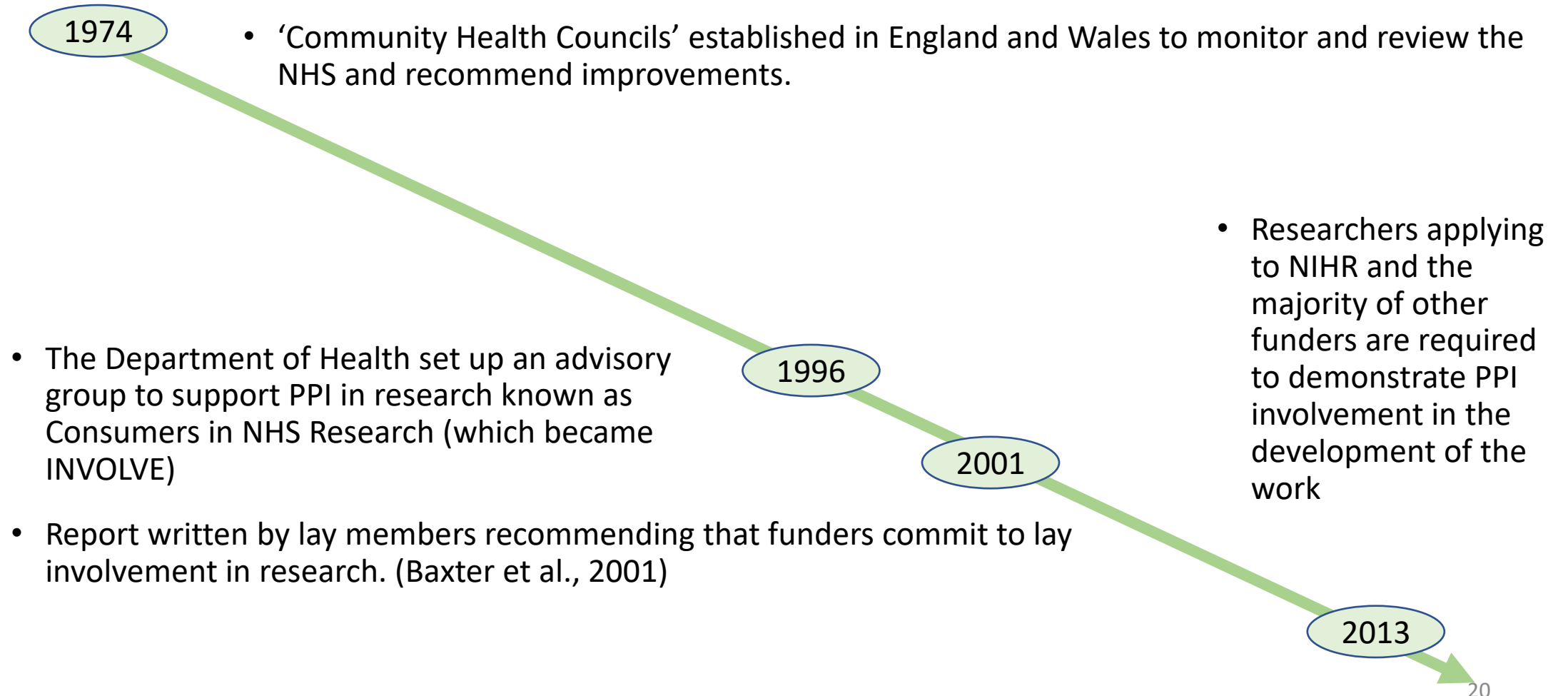
Toby Brandon
Chris Gibbs
Mick Hill

OVERVIEW

- ‘Involvement’ – a short history;
- Involvement vs Peer Research;
- Examples of service-user involvement initiatives.



A SHORT HISTORY OF 'PUBLIC AND PATIENT INVOLVEMENT' INITIATIVES IN THE UK



Definitions – Patient and Public Involvement (PPI)

The 'National Institute for Health Research' (NIHR) defines public involvement in research as research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them. It is an active partnership between patients, carers and members of the public with researchers that influences and shapes research.

By 'public' [they] include patients, potential patients, carers and people who use health and social care services as well as people from specific communities and from organisations that represent people who use services. Also included are people with lived experience of one or more health conditions, whether they're current patients or not.

(NIHR, 2021)

Definitions – Peer Research

A 'peer' is a person who has shared or relatable lived experience to the participant group taking part in the study.

'Peer research' is a methodology where research is steered and conducted by peers, who adopt the role of active researchers to collect data from their peers about their experiences.

PUBLIC AND PATIENT INVOLVEMENT (PPI) OR PEER RESEARCH?

PPI	PEER RESEARCH
Researcher holds the power	Power shared equally
Lived experience members have advisory roles	(often uses) Participatory methodologies
Community of individuals with shared experience / interest in the research topic	Community of researchers with shared experiences / interests
Advise / Shape / Influence how new data is generated	Generates new data
Democratic and inclusive to designing research	Democratic and inclusive research
Sits within traditional approaches to research	Change to traditional approaches where lived experience is often 'invited in'

Initiatives for Involvement and Co-production: Some Examples



① The Northumbria Peer Researcher Development Course (PUBLIC Course).

Co-Productive principals were employed to:

- Design and define content;
- Recruit to the course (no academic entry requirements);
- In delivering the course – mixture of voices;
- In designing the [optional] credit-bearing assessment.

Currently free at the point of enrolment – paid for through existing research and organisation budgets.

(Gibbs et al., 2024)



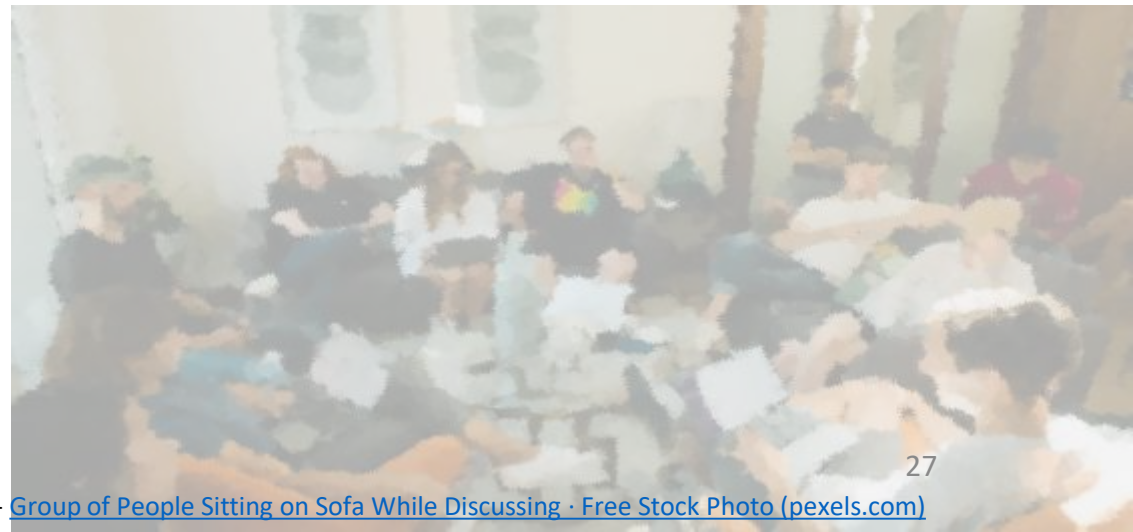
Why at University level?

- Validation;
- Sense of achievement;
- Universities (value) are more than just the classroom;
- Perceived value of an academic setting;
- Gap - can't see anybody else in the world who has already done this;
- Opportunity to access a range of people with experience and knowledge.
- CNTW a place of treatment.

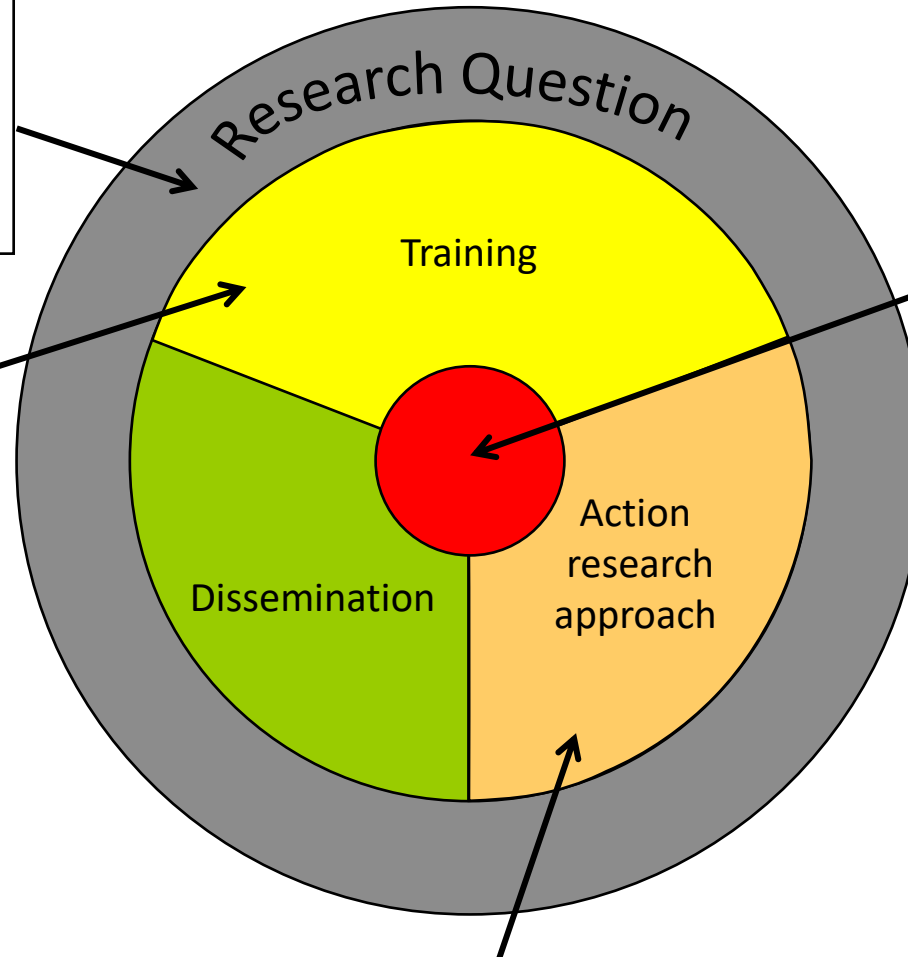


How did we develop the module?

- PPI workshops to agree learning outcomes and assessment
- Validation with University
- Modules handbook development
- Recruitment through CNTW Involvement bank
- Recruitment extended to ReCoCo, Chilli Studios and Mad Studies
- No academic entry requirements
- Pilot started April 2022



Is there a pathway to mental health recovery through care coordination?



Service User and Carer-led Research (Emancipatory)

First run of PUBLIC 1 module

Service users and carers were the researchers designing the project and the tools to be used, collecting and analysing data and disseminating the findings across three phases:

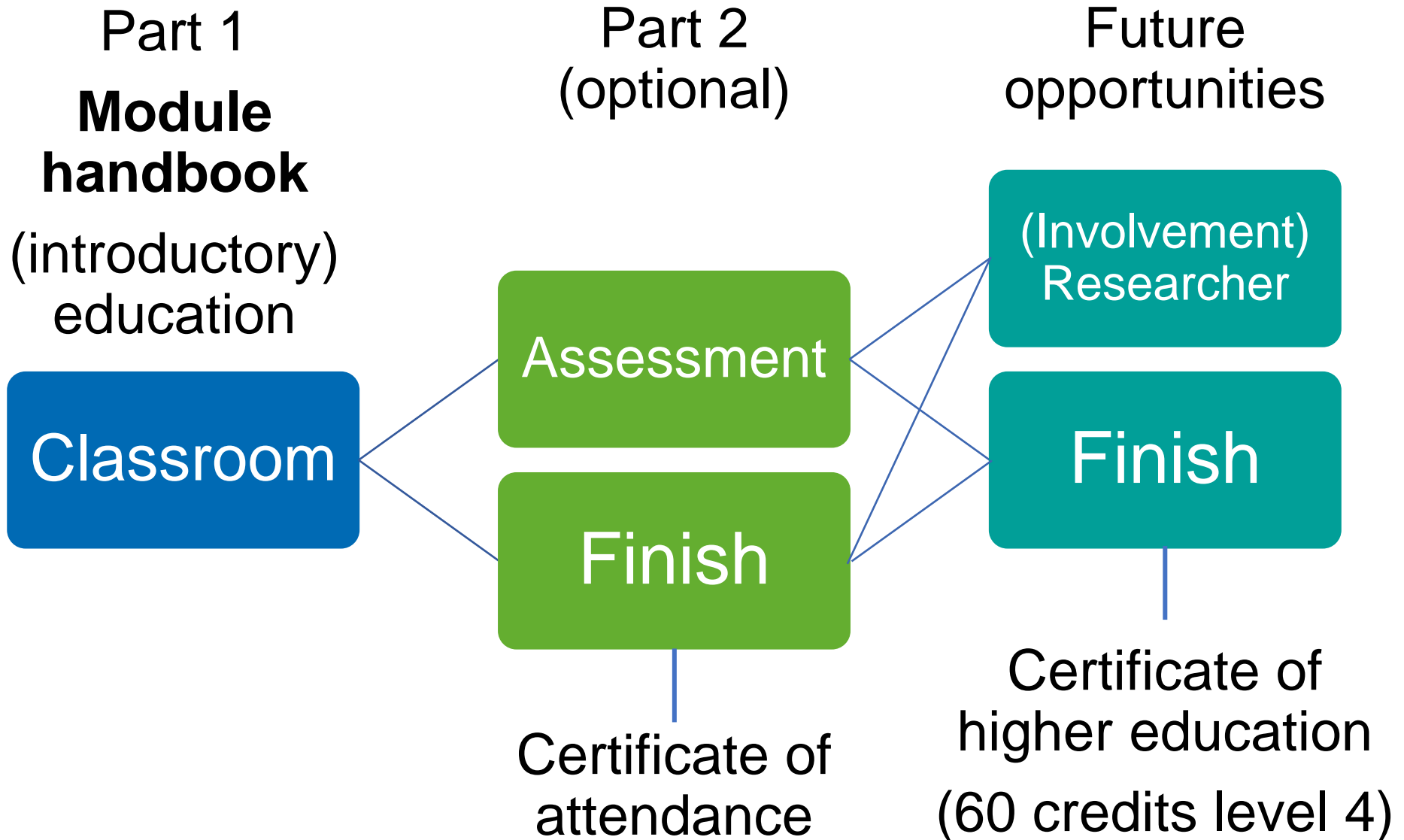
- 1) Delphi - questionnaires sent out to service users, carers, professionals.
- 2) Semi-structured interviews with service users and carers.
- 3) In-depth interviews with professionals (current).

Course Content:

- What's so good about research anyway? Removing and Translating Jargon.
- Values in research: doing research, on, with, or for people.
- How to find information. What is meant by good and poor quality research?
- How to get started with a research project. [a] Measuring 'things' and [b] Listening to people.
- The anatomy of a research report: How to write an interesting report.
- Sharing findings and being 'heard'.
- Collecting Data.
- Dealing with when things 'go wrong';
- Listening to others. Recording information. Making sense of information. How to report findings.
- Final **optional** assessment.



Course structure



Institutional and regional support for the module

“At CNTW we want to be a leader in research, because this enables us to make services better and to understand where we are making a difference to people's lives. To do this we need to work with and involve people who use our services, their carers and families in our research work. We value everyone's contribution, and it makes a real difference”

(James Duncan, CNTW Chief Executive, June 2022)

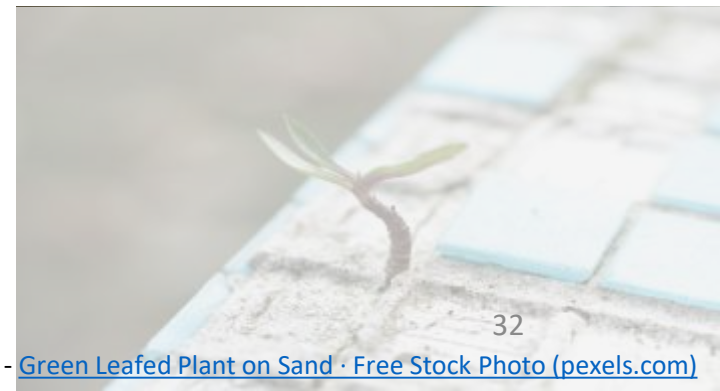
CNTW's Research Involvement Strategy 2022 sets out the priorities for PPI development:

- Working with local partners to develop collaborative approaches;
- Systematising research recruitment / opportunities across the region and specialities;
- Focussing on reducing inequalities and increasing inclusion;
- Developing a career pathway for EbE in Research;
- Developing and funding a programme of training and development. Public / staff / researchers;
- Facilitating opportunities for students of the module, to develop skills and knowledge from the module;
- Focus on continuous learning and improvement by connecting with experts; and,
- Generate income / funding to pay for it all.

The experience of being involved

Initial expectations:

- How to work more effectively with professionals in research
- Understand more regarding the interview process if used
- To appreciate and learn from other participants in the group as they all have a huge range of experience which I could learn from.
- I hope that in the future my experience working with people undertaking research that my part will be more rounded.



The experience of being involved



Actual experience:

- Feeling validated through co production of the module from the start;
- Found it useful to be aware of what the module was trying to achieve;
- Encouraging to believe that going to University was a probability;
- Working alongside academic professionals in the design was a growing experience which encouraged me to want to take part in the module.

The experience of being involved



What has happened since?

- More informed re how research is shaped and developed;
- Better understanding of the difficulties in undertaking research;
- Co working from the beginning of a piece of work so the lived experience is developed at the start of the process instead of an afterthought at the end;
- Working on several pieces of work feel more valued and have a clearer understanding of my role within the process.

Identity shift

- Charmaz (1987) sees the illness trajectory as producing **'restricted lives'**.
- **Mental health label** is not necessarily a life sentence (Wallcraft, 2005).
- Hutchinson and Lovell (2012) importance of **reciprocity, being listened too and connecting** with others.

'We have moved from being service users, to being researchers, a positive identity, which has motivated us all, yes we are useful...'

(Hutchinson and Lovell p.647, 2012).

Patient → Student → Researcher → Professional/Academic

Experiences after completing the module

International conference

Co-applicant on studies

PPI lead on studies

Led evaluation of a charity

"I feel like I have a brand-new life with a clean page. I now have something to live for and feel like I can make a difference"

Members of planning groups

Spoken at conferences

Helped write grant applications

Shaping research studies

Helped plan 2nd module

Published papers

Going Forward

- We have funding for working with innovation designers to explore creative an online version of the course.
- Working with alumni students to support them to develop their own research ideas.
- The possible development of a 'Lived Experience Academy'.



For potential discussion

- How do we prevent othering ('us and them') when people are asked to be involved because they are an 'other'?
- Is the terminology in this area confusing?
- How do we ensure equitable inclusion where often Goldilocks criteria is in play?
- How do we know the people in the room are experts?
- Anecdotally we all believe PPI makes a difference, but who defines what 'Good PPI' is?
- Is it really about achieving the highest quality research, or is it more down to achieving legitimacy in the eyes of the public?
- Does the methodology approach matter more than the outcomes?



Questions to the Panel



References and Bibliography

Charmaz, K. (1987) Identity Dilemmas of Chronically Ill Men *The Sociological Quarterly*, Vol. 35, No. 2 (May, 1994), pp. 269-288 (20 pages)

Briefing notes for researchers - public involvement in NHS, Health and Social Care Research (2021) NIHR. Available at: <https://www.nihr.ac.uk/documents/briefing-notes-for-researchers-public-involvement-in-nhs-health-and-social-care-research/27371> (Accessed: 30 October 2023).

Gibbs, C., Dr Brandon, T., Dr Cooper, C., Dr Hill, M., (2024). 'Accredited research training with people with lived experience of mental health distress', in McGovern, W., Gillespie, A., Brandon, T., and McInnes, A. *Developing and Implementing Teaching in Sensitive Subject and Topic areas: a comprehensive guide for Professionals in FE and HE Settings*, Emerald Publishing Limited: Bingley.

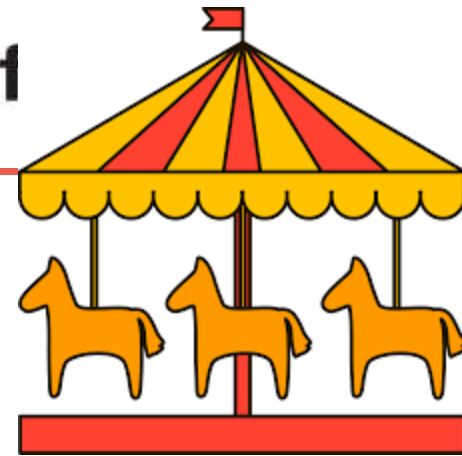
Hutchinson, A and Lovell, A (2012) Participatory action research: moving beyond the mental health 'service user' identity. *Journal of Psychiatric and Mental Health Nursing* 20 pp641-649.

Wallcraft J. (2005) 'The Place of Recovery' in *Mental Health at the Crossroads*, eds S. Ramon and J. E. Williams, Ashgate, pp127-136.

Zoccatelli G., Desai A., Martin G., Brearley S., Murrels T., Robert G., (2020) Enabling 'citizen voice' in the English health and social care system: A national survey of the organizational structures, relationships and impacts of local Healthwatch in England. *Health Expectations*. doi:23:1108–1117.

BREAK
10 minutes





Carousel discussions

3 questions at 3 'stations':

- 1. What knowledge and skills does peer research training need to address for you?*
- 2. What should the ideal training on peer research look like for you?*
- 3. What would help you to apply the learning from peer research training in your daily life?*

Each group reflects on, elaborates and adds to responses of previous groups (10 mins per table)



Next steps

- ***What topic*** would you like to discuss for the next event (online) in May 2024?
- ***Who*** would you like **to hear from?** (Any suggestions for presenters?)
- ***What*** would you like ***to share, learn, and take*** to your organisation from the next event (desired outputs/ format of discussions?)



