

# **Co-Production in Health & Care Research: Turning Aspiration into Reality.**

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- Volunteer
- Social worker
- Operational manager
- Charity Board Member
- Applied researcher
- Leadership educator
- Implementation lead
- Editor-in-chief
- Carer

# Background

Integrated care  
“consciously adopts  
the perspectives of  
individuals, families  
and communities, and  
sees them as  
participants as well as  
beneficiaries”  
(WHO 2015)

**However, in practice,  
true co-production of  
policy, planning and  
research of integrated  
care is rarely  
developed, embedded  
or sustained.  
(Augst 2022)**



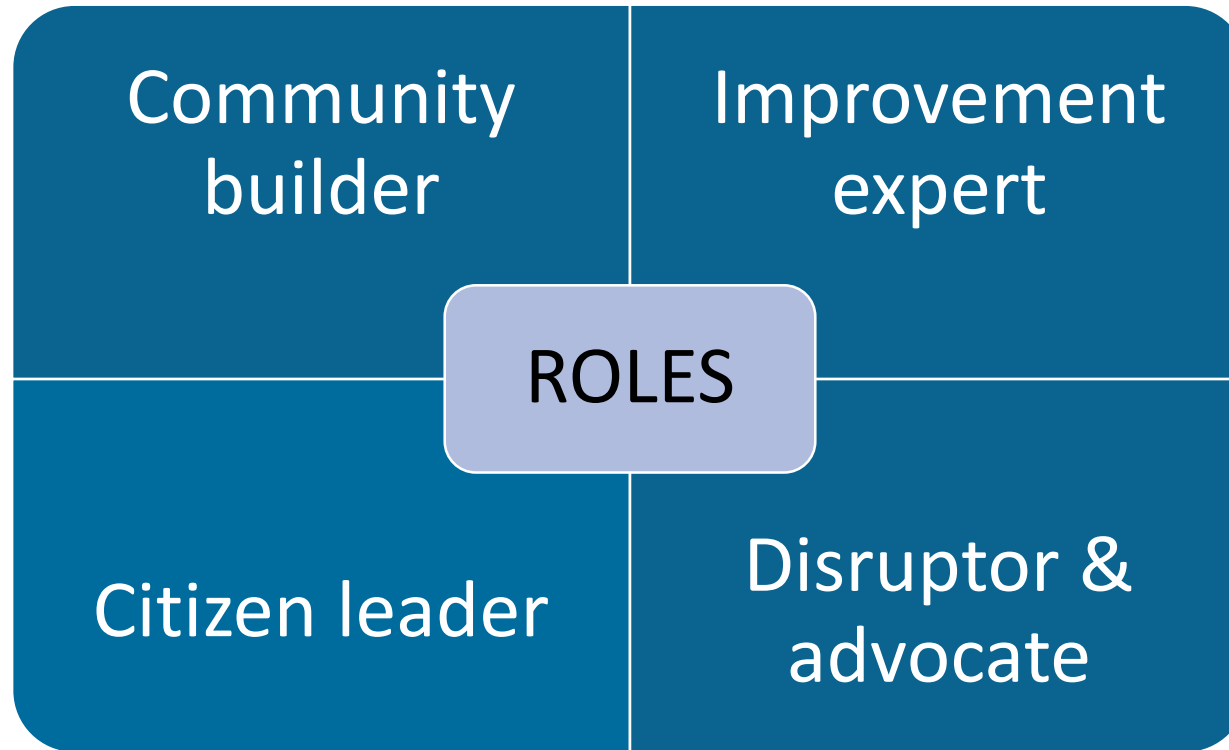
# People's stories

## Stories of care

“[The physician] looked at me and he said, ‘If you go home you’ll die’ and he walked out of the room. Well, I started to cry and my wonderful husband said ‘okay don’t worry I will go and talk to him’. [He] went out and said ‘could you be a little kinder to [my wife]? You know what she’s been through .... to which the doctor said ‘If you don’t like the way I’m treating your wife I suggest you leave’, but he went a step further, he called security... and I was left alone in emergency...”

## Stories of change

“All because that day I walked into that hospital, that day with my brother and I thought, ‘It can’t be like this. It just can’t be’. This all started because of that.”  
“where a disease is predominantly women and the system was being designed by men. And I tried to intervene in the design of the model of care and it wasn’t taken very nicely and I got kept shutting down by the clinical lead...I wasn’t being heard, I wasn’t being listened to.”



## Enablers

Investing in people over the long term

Paid opportunities and meeting of associated costs

Personal commitment of influential clinicians & leaders

Legal duties to involve people in decision making

Creating supportive systems & infrastructure including digital

Shared learning opportunities and improvement processes

## Barriers

Valuing professional opinions more highly

Tokenistic opportunities which 'tick the box'

Only engaging with those seen as 'safe' participants

Practical exclusion of marginalised communities

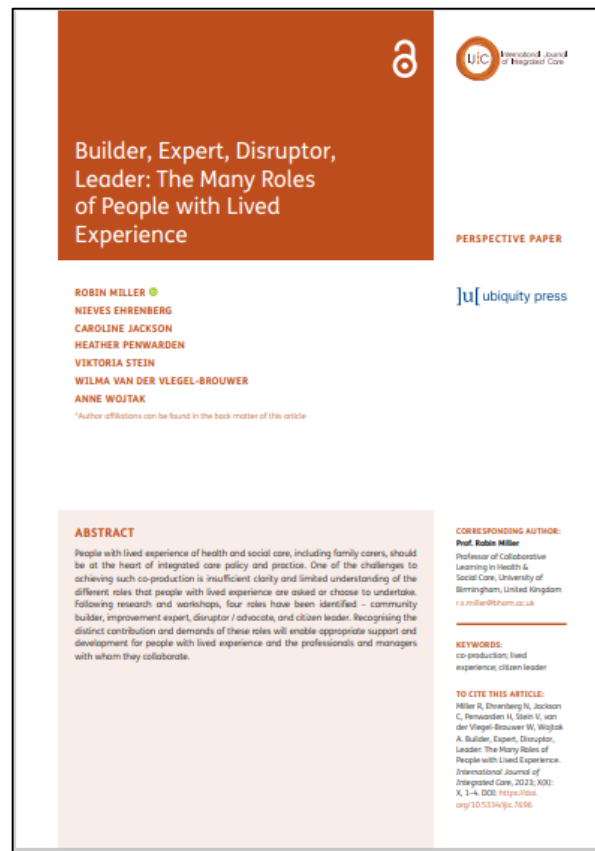
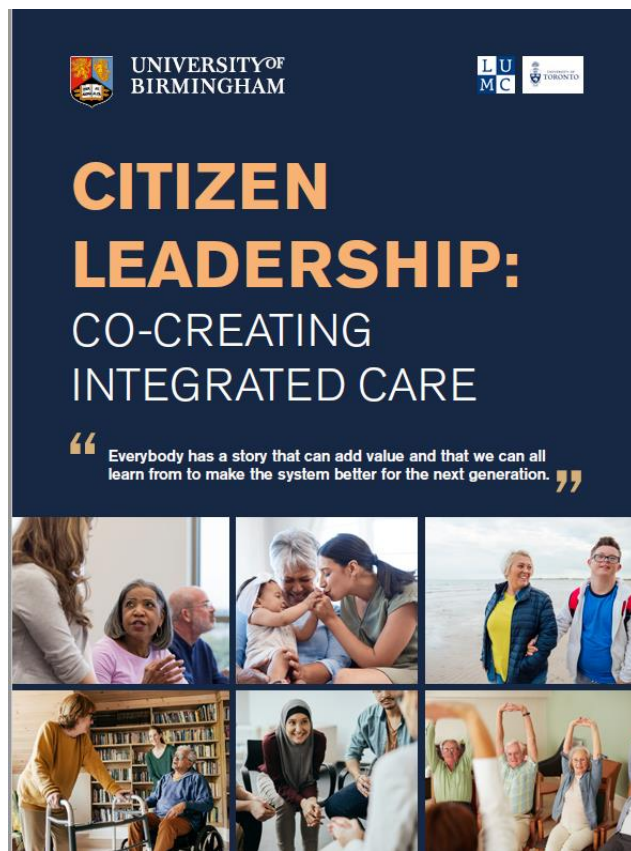
People's changing health & circumstances

New senior leaders making changes to involvement activity for the sake of it

Competency	Description
Active listening	Being able to learn about the experience of those from different backgrounds
Story telling	Interpreting life experiences into engaging narratives for different audiences
Service literacy	Understanding and using the terminology of clinicians, services and policy makers
Emotional intelligence	Demonstrating compassion to others, including professionals, and engaging with their own feelings
Assertiveness	Providing positive challenge whilst not alienating those that they want to influence
Lobbying	Recognising who has power, how best to influence their decision making and working towards this
Mediating	Facilitating meaningful conversations between communities of experience and those with power in services and policy
Resilience	Being able to battle through adversity and barriers to change
Research	Investigating in opportunities, resources and evidence to support change

*“I’ve not been able to find a course, a workshop paper on the how to of being a patient leader, the nitty gritty of it. So, I’ve been on a self-discovery path.”*

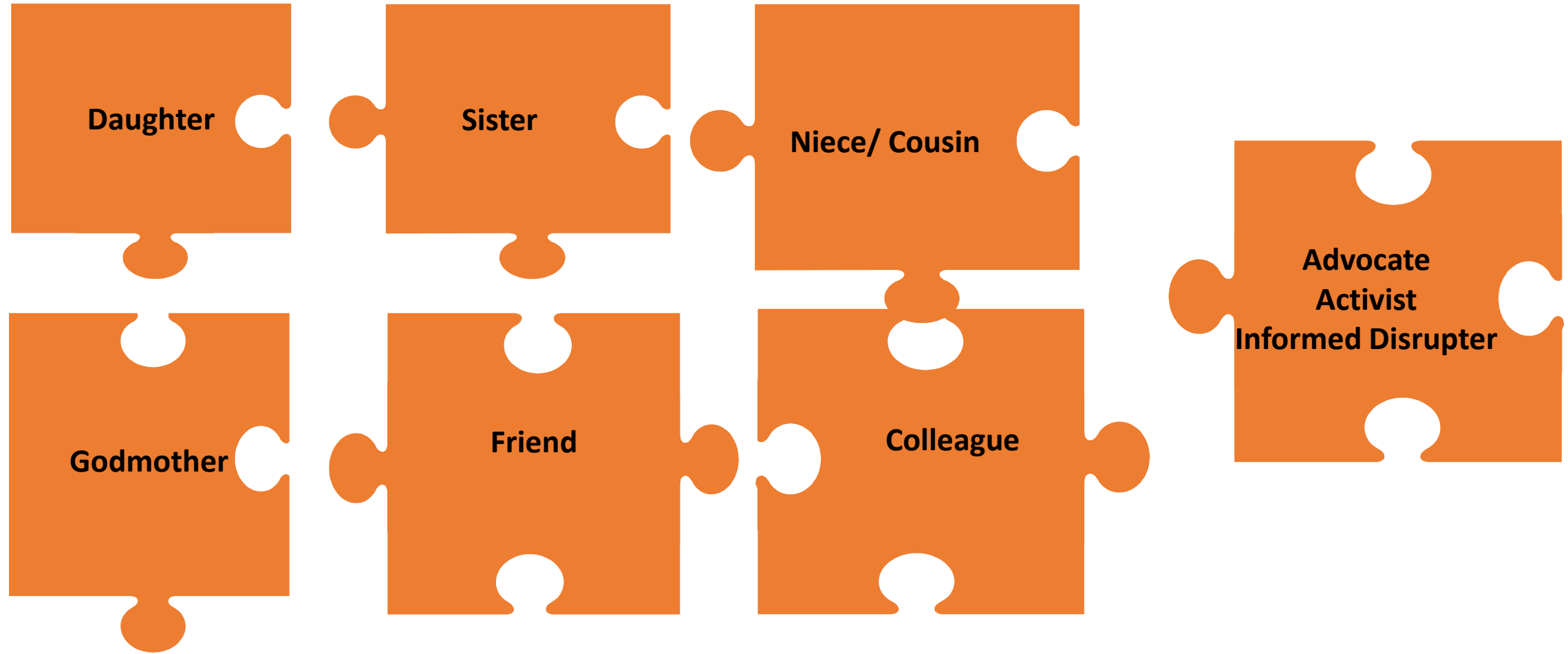




# Learning from project

- **Community Advisory Board** generated the topic and refined its focus
- **Workshops with participants** helped to interpret the findings and identify practice implications
- **Learning events** at conference involving people with lived experience (including as co-facilitators)
- Engagement with participants has led to **further collaborations and projects**

# A little bit about me:



# Why people get involved?

- Frustration
- Exclusion
- Desperation
- **Invitation**
- Passion
- Contribute to society
- Motivation to address inequalities, organisational practices etc.
- Improve access to diagnoses, treatment and education
- Curiosity and problem solving
- Career Advancement



**Citizen Leadership** "Everybody has a story that can add value and that we can all learn from to make the system better for the next generation."



[Citizen Leadership - University of Birmingham](#)

# Barriers that I have experienced

- **Culture** in Healthcare Systems and **commitment to implement**. "Meetings for Meeting" Working in Silos and no integration.
- **Lack of investment** to develop, implement and in training the people employed to co-ordinate. **Not budgeted for correctly** limits people to be at the table. General lack of resources.
- **Lack of Trust** essential for effective partnerships. Without it, partners maybe hesitant to share resources and information.
- **Power Dynamics** Clinicians and Healthcare professionals believe that they know best. **Perception and Attitude** that people with lived experiences not "equal partners" have nothing to contribute.
- Decision makers of services / policy makers have **unconscious biases**.
- **Misaligned Goals** partners have different objectives, it can be challenging to find common ground. (**Lack of expectations documents (Values and Principles), Partnership/ Collaboration agreements, or Terms of Reference**)
- **Communication Issues** Poor communication can lead to misunderstandings and conflicts. **No Grievance/Conflict resolution documents**.
- **Lack of Awareness** How can people get involved if they don't know about the opportunities
- **Tokenistic opportunities** People want opportunities that are of meaningful that add value and impact
- Who is invited to participate/engage or be involved - **see the same faces at the table - Lack of Diversity**.
- **Bureaucracy of systems** Receiving information to make equal and informed choice.
- **Accessibility** issues (Barriers like location, timing, and format) and reasonable accommodations.
- **Technology Gaps** Inadequate or incompatible technology can hinder collaboration.
- **Literacy/ Digital Literacy** skills and over use of jargon.
- **Lack of Incentives** Without clear benefits, people may be reluctant to get involved.
- **Live span of person in this space is 5 years** - People's health can deteriorate/ they have family issues.



The  
UNSEEN  
UNHEARD  
UNINVITED  
UNRESOURCED

**Citizens included**

# What citizens can bring to the table:

- Expertise by lived experience and other professional skills.
- Identify other potential stakeholders whom you have missed and how to access these stakeholder.
- The importance of **equality, diversity and inclusion** make you think of the **seldom unheard in society**.
- Make it **relevant to the needs and gaps** in society.
- Different **novel perspective**, outside the box thinking and **solutions**.
- More impactful and **relevant outcomes** and higher achievement of **end goals**.
- **Realism, grounding, reality and clarity**.
- **Improved communications** internally and externally.
- **Greater accountability** - bring layer of transparency and **public trust**.
- **Avoid the negative consequences** of NOT involving public/patients - See problems early.
- **Save costs** on not used pieces of work that ends up on a shelf and does not transition to services or policy.
- Enhance **motivation** of the work force.





# My Patient Partnership journey



Arthritis  
Ireland



eular  
EUROPEAN ALLIANCE  
OF ASSOCIATIONS  
FOR RHEUMATOLOGY

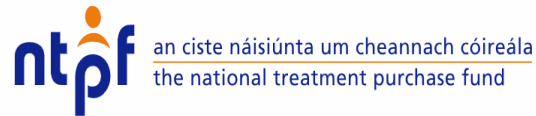


Centre in Ireland for Clinical  
guideline support and  
Evidence Reviews (CICER)



Health Research Board  
**NCTO**  
National Clinical Trials Office

**IPPOSI**





# UCD Centre for Arthritis Research

- **Real-life experiences** of patients and their families at heart of research **decision-making**.
- Restructured research centre that **3 patients** of the 10 members of the **steering committee** are in charge of governance.
- Host an **annual research conference** completely open to the public **co designed and produced by patients**.
- **News Rheum**, our patient/researcher co-produced newsletter.
- 6 projects with one or more **Patient Partners** as part of the **project team**.
- Patient Partner **co-applicants** on grant applications.
- Developed a **Research Advisory Group (RAG)**.
- We have a number of **disease registers** with patients involved.
- Patients are part of the **panel for Researcher hires**.

People with arthritis will be involved with every stage of the research cycle



[UCD Centre for Arthritis Research | UCD School of Medicine](#)





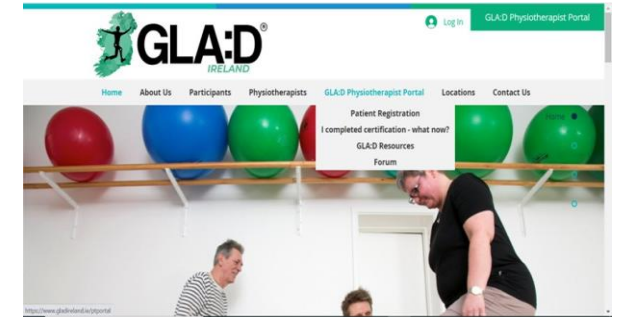
## Good Life with Osteoarthritis Denmark

Evidence-based supervised group exercise and education programme for hip and knee OA

**In 2022, GLA:D is being implemented in 12 different countries and across 4 continents**

**Partners have been involved at:**

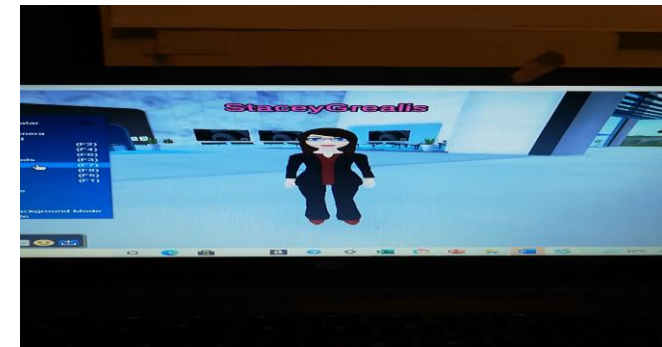
- Co Design from funding level
- Management level with 2 patients on the steering management
- Development of the methodology
- Recruitment strategy
- Review the training and observations of the training
- Analysis of the results
- Dissemination and impact. (Presentation at International Conference's and Publication)



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# How you can Enable - YOU NEED US

- **You enable better co production.** Make us part of **decision making process.** Let's work together.
- Develop roles and opportunities that are **Co-designed, Produced & Evaluated.**
- **Map all the voices** that are **unseen, unheard and not invited** to the table.
- Make time and space to **listen and reflect.**
- Create **budgets to Invest** in people over the **long term.**
- **Embedding systems and structures** to facilitate Partnership.
- **Capacity building** for all in **leadership training, mentorship** and create a space for **shared learning** opportunities.
- **Reward best practices** and of those in the system who support and invest their time and energy and **develop a collaborative relationships.**
- Bring the **local and regional voices** to the table. **Support and champion these people** to make change and improve communities for all in society.
- Ensure **communication is open and transparent.**
- Track the **missed opportunities** to ensure they do not happen again.



***"Nothing for us without us"***

# International Journal of Integrated Care

- Review of 10 years of articles identified few included lived experience in research or improvement project
- 12 months co-production panel to develop proposals
- All articles will have to declare extent of involvement
- People with lived experience on editorial board
- Network of lived experience reviewers
- Citizen science article options in future...



## Leading by Example: IJIC's Journey to Strengthen Lived Experience in Research, Improvement, and Scientific Publishing

EDITORIAL



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Putting people with lived experience of accessing health and/or social care and their families at the heart of integrated care has been the focus of several editorials within IJIC over recent years [1, 2, 3]. This reflects the increasing centrality within wider policy and practice of co-production at both micro (i.e. in the relationships between people and professions) and macro (i.e. in strategic visioning, planning and resource allocation) levels of an integrated care system. Despite the importance of understanding and acting upon the interests and aspirations of people with lived experience and their families, and indeed geographic and other communities, there has been relatively little recognition of this within the research and practice innovations that underpin the articles published within IJIC. The recent review of articles published in IJIC from 2012 to 2022 identified only 14 out of the 560 articles explicitly outlined the approach to involvement in their work [4]. This may reflect that people and families are not included in the design and implementation of these activities or that such engagement is happening, but it has not been detailed within the content provided.

The Editors in Chief and Editorial Board of IJIC have been concerned about this disparity for some time. In part, this is because it does not reflect the values which underpin integrated care and the International Foundation for Integrated Care. But also because we believe that good science should be based around what matters to individuals and communities and this necessitates the generation of evidence together with people with lived experience. An international journal has an important role in supporting academic and practice colleagues to develop their research and improvement skills. By not encouraging authors to share how they sought to embed lived experience within their projects we are therefore missing an opportunity to generate wider learning. Finally, the important contribution of citizen science to generating evidence is receiving justified recognition and again this is not currently reflected in IJIC.

To address these gaps, we (people with lived experience and journal representatives) have been collaborating over a twelve-month period to identify opportunities to strengthen related aspects of IJIC. Working group members were drawn from North America and Europe

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## Final words

***“Our qualification is our story.  
This is who I am.”***

***“I felt heard. Thank you.”***

# Keep in touch



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