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

Robin Miller, University of Birmingham / IMPACT

Stacey Grealis, Patient Partner, University College Dublin-Centre for Arthritis Research February 2025











- 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)

International research team

Community Advisory Board

Listening to the stories of people from across the world

Policy, practice & research networks

Shared listening & interpretation

People's stories

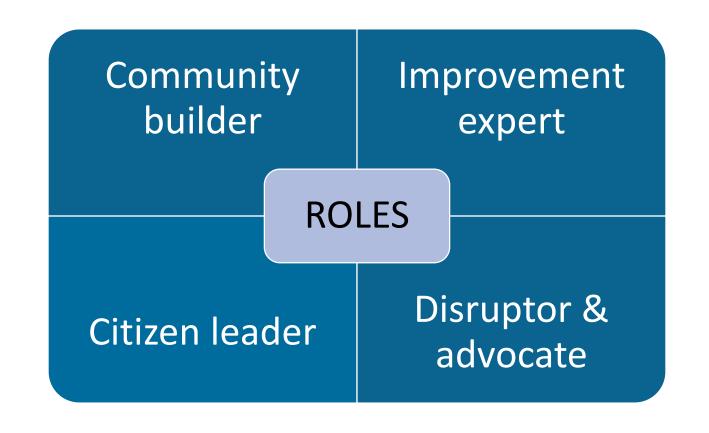
Stories of care

"[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

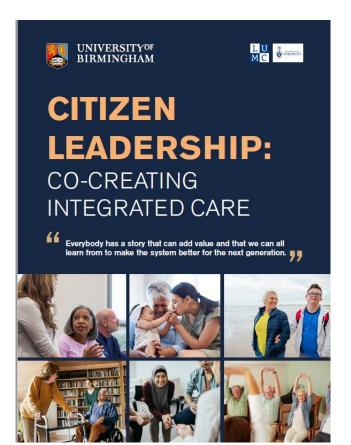
Practical exclusion of marginalised communities

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 selfdiscovery path."





Builder, Expert, Disruptor, Leader: The Many Roles of People with Lived Experience

PERSPECTIVE PAPER

u ubiquity press

ROBIN MILLER @ NIEVES EHRENBERG

CAROLINE JACKSON HEATHER PENWARDEN

VIKTORIA STEIN

WILMA VAN DER VLEGEL-BROUWER

ANNE WOJTAK

ABSTRACT

People with lived experience of health and social care, including family carers, should be at the heart of integrated care policy and practice. One of the challenges to achieving such co-production is insufficient clarity and limited understanding of the different roles that people with lived experience are asked or choose to undertake. Following research and workshops, four roles have been identified - community builder, improvement expert, disruptor / advocate, and citizen leader. Recognising the distinct contribution and demands of these roles will enable appropriate support and development for people with lived experience and the professionals and managers

Prof. Robin Miller

Professor of Collaborative Social Care, University of Birmingham, United Kingdom

KEYWORDS: co-production; lived experience; citizen leader

Miller R, Ehrenberg N, Jackson C, Penwarden H, Stein V, van der Viegel-Brouwer W, Wojtak A. Builder, Expert, Disruptor Leader: The Many Roles of People with Lived Experie International Journal of Integrated Care, 2023: XXX X, 1-4. DOE: https://doi. org/10.5334/ljic.7696

Received: 17 December 2023 Revised: 6 May 2024 Accepted: 9 May 2024

ORIGINAL ARTICLE

WILEY

Just a story? Leadership, lived experience and integrated care

Robin Miller PhD, Professor of Collaborative Learning in Health and Social Care¹ 0 Nieves Ehrenberg MSc, Senior Associate² | Caroline Jackson PhD, Research Fellow¹ | Viktoria Stein PhD, Assistant Professor for Population Health Management³ Wilma Van der Vlegel-Brouwer PhD, Participatory Action Researcher⁴ Anne Woitak DrPH, Adjunct Professor⁵

⁵School of Social Policy, University of Birmingham, Birmingham, UK

²VM Partners Integrating Health and Care, ³Department for Public Health & Primary

Care, Leiden University Health Campus, The Hague, Netherlands ⁴SevenSenses Institute, Nieuwegein, The

⁵Dalla Lana School of Public Health, Univers of Toronto, Toronto, Canada

Robin Miller, PhD. Professor of Collaborativ Learning in Health and Social Care, Department of Social Work and Social Care, School of Social Policy, University of Birmingham, Birmingham, UK.

Funding information National Institute for Health and Care

Research Applied Research Collaboration West Midlands, Grant/Award Number:

Background: Integrated care is based around values of involvement and shared decision-making, but these are not often reflected within planning and implementation. Barriers include continued emphasis on professional and managerial perspectives, skills gaps on how best to engage people and communities and insufficient investment in involvement infrastructure. Despite such challenges, people with lived experience have still led changes in policy and services.

Design: Qualitative study involving 25 participants with lived experience from 12 countries. Participants shared their background stories and engaged in semistructured interviews relating to leadership identity, experience of influencing and personal learning. Transcripts were analysed through a framework approach informed by narrative principles.

Results: Participants were motivated by their own experiences and a wish to improve care for future individuals and communities. Sharing their story was often the entry point for such influencing. Participants gained skills and confidence in story telling despite a lack of support and development. Many felt comfortable being described as a leader while others rejected this identity and preferred a different title. No common alternative term to leader was identified. Influencing services required considerable personal cost but also led to new networks, skills development and satisfaction when change was achieved.

Discussion: Leadership within integrated care is often awarded to those with structural power related to management or clinical seniority. People with lived experience are though uniquely placed to identify what needs to change and can develop inspiring visions based around their personal stories. Claiming identity as leader can be challenging due to traditional notions of who is eligible to lead and unwillingness by professionals and managers to grant such identity.

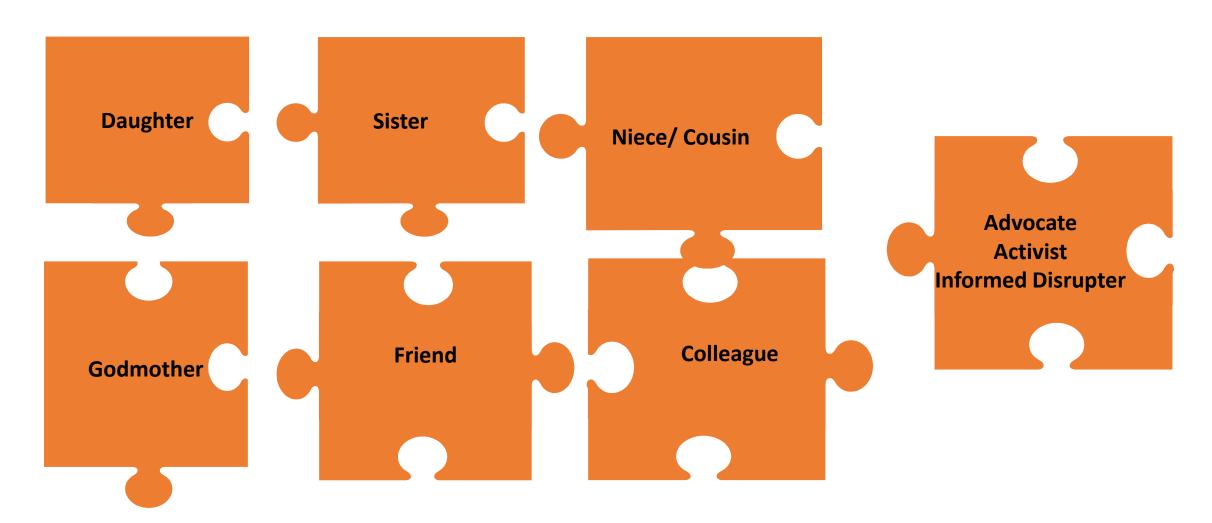
This is an open access article under the terms of the Creative Commons Attribution License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited. © 2024 The Author(s). Health Expectations published by John Wiley & Sons Ltd.

Health Expectations, 2024;27:e14084

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

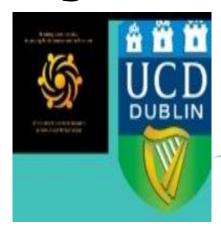
What citizens can bring to the table:



- 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





















Implementation of osteoArthritis Clinical **Guidelines Together**









agus Cáilíocht Sláinte



Health Research Board National Clinical Trials Office











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 deisgned 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.





of Medicine















Email: gladireland@ul.ie

Website: www.gladireland.ie

Twitter: @gladireland



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
- Devlopment 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)

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...

8



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

EDITORIAL

ROBIN MILLER ®
VIKTORIA STEIN ®
HEATHER PENWARDEN ®
ESKIL DEGSELL ®
GHISLAINE ROULY ®
IVETTE FULLERTON
SUSAN ROYER ®

*Author affiliations can be found in the book matter of this article

Putting people with lived experience of accessing health and/or social core and their families at the heart of integrated core has been the focus of several editorials within LIIC 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 improtrance 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 LIIC. The recent review of articles published in LIIC 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 Editors in Chief and Editorial Board of LIIC have been concerned about this dispority 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 shore 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 LIIC.

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

CORRESPONDING AUTHOR:

Professor of Collaborative Learning in Health & Social Care, University of Birmingham, United Kingdom

r.s.miller@bham.oc.uk

KEYWOR

co-production; lived experience; integrated core research; patient involvement; citizen

TO CITE THIS ARTICLE:

Miller R, Stein V, Penvourden H, Degaell E, Roully G, Fullerton I, Royer S. Leading by Example: 11fc's Journey to Strengthen Lived Experience in Research, Improvement, and Scientific Publishing. International Journal of Integrated Care, 2024; 24(1): 21, 1–3. DOI: https://doi. org/10.5334/ijic.8622

Final words

"Our qualification is our story. This is who I am."

"I felt heard. Thank you."

Keep in touch





Twitter: @RobinUoBham

Email: r.s.miller@bham.ac.uk

Linkedin: Professor Robin Miller

Email: stacey.grealis@ucd.ie

Linkedin: Stacey Grealis

