CITIZEN LEADERSHIP:

CO-CREATING INTEGRATED CARE

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

RESEARCH TEAM:

Robin Miller – University of Birmingham

Caroline Jackson – University of Birmingham

Nieves Ehrenberg –The International Foundation for Integrated Care

Viktoria Stein – University of Leiden University Medical Centre

Wilma van der Vlegel – SevenSenses Institute

Anne Wojtak – University of Toronto

To discuss the findings of this research and share your thoughts of how we can better co-produce integrated care please contact Robin Miller: r.s.miller@bham.ac.uk who will share your insights with the rest of the team.

UNIVERSITY OF BIRMINGHAM

CONTENTS

LIST OF TABLES, BOXES AND DIAGRAMS

Table 1: *Key Definitions*

Term used in the report	How the term is being used in this project
Family	A group of people who may be related by blood, adoption, marriage or other bonds. May include multiple generations, extended and blended families and may or may not live in the same household.
Community	A group of people who share common ties and interact with each other based on personal characteristics, place/geographical area, experience, customs, norms, religion or belief, attitudes or interests
Integrated care	Care that works across professional and organisational boundaries to be holistic and person centred, co-produced and coordinated to deliver good services and outcomes for individuals, families and communities.
Lived experience	The experience of a person who may have a disability, a health condition, be a carer or have interacted in some way with health or care services as a result of someone they care for or their own needs.
Co-production	'Co-production is not just a word, it is not just a concept, it is a meeting of minds coming together to find shared solutions. In practice, co-production involves people who use services being consulted, included and working together from the start to the end of any project that affects them. When co-production works best, people who use services and carers are valued by organisations as equal partners, can share power and have influence over decisions made'. Definition by Think Local Act Personal
Participants	People with lived experience of health and social care services who were interviewed about their experience of co-production in health and social care contexts for the purposes of this project

Direct quotations from participants in the research are included in this report in "quotation marks".

1. WHY DO PEOPLE MATTER TO INTEGRATED CARE?

Integrated care is at its heart about health, social care and wider services being better co-ordinated around people, families, and communities. This requires those who plan, design, and deliver services to understand what is important to people on an individual and collective basis. People's circumstances and aspirations may change with their health conditions and social situations and through new challenges arising in wider society. It is therefore important that opportunities to influence and co-produce services are not a one-off exercise, but rather are on-going and responsive to people's interests and perspectives.[1]
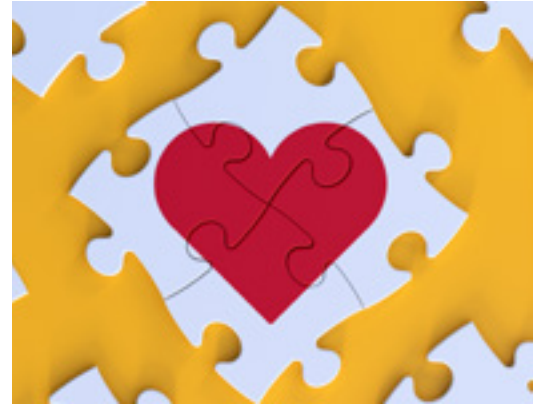
The centrality of such engagement to integrated care has been widely recognised. For example, the World Health Organisation states that integrated care "consciously adopts the perspectives of individuals, families and communities, and sees them as participants as well as beneficiaries"[2].

Similarly, a core principle of the International Foundation for Integrated Care is that 'people are partners in care', and that this will require a 'shift in power – to make the voices and choices of all, not just a few, count'[3].

Despite the importance of co-production to integrated care, all too often people, families, and communities report that this is not what they experience in practice[4]. This applies to all aspects of integrated care – how needs and opportunities are initially understood and set out in national and regional policy, how resources are allocated, and services designed and organised, and in how people are personally supported by professionals and teams. Integrated care research often provides limited opportunities for people to set the questions to be explored and therefore the evidence gathered has limited impact on their day-to-day lives.

Opportunities to engage for those from communities which are often marginalised in society seem particularly lacking, despite the recognition that integrated care needs to be responsive, flexible, and pro-active in engaging with diversity[5]. This is crucial if integrated care is to understand the needs of those it seeks to serve and play its part in enabling fair access to and fair treatment by health and care services for everyone[6].

> " I often noticed that conversations about my care, my journey, would be done outside the room without me, and it drove me nuts, and I longed for the day that I could be part of those conversations because I thought, I'm the one living with this and nobody's asking me. "

[1] Gray, C. S., Grudniewicz, A., Armas, A., Mold, J., Im, J., & Boeckxstaens, P. (2020). Goal-oriented care: a catalyst for person-centred system integration. *International journal of integrated care*, 20(4). Available here.
[2] Ferrer, L. (2015) *Engaging patients, carers and communities for the provision of coordinated/integrated health services: strategies and tools*. Available here.
[3] IFIC (2013) *Nine pillars of integrated care*. Available here.
[4] Augst, C. (2022). Putting the 'I'Back into Integrated Care. *International Journal of Integrated Care*, 22(2). Available here.
[5] Goodwin, N., Brown, A., Johnson, H., Miller, R., & Stein, K. V. (2022). From People-Centred to People-Driven Care: Can Integrated Care Achieve its Promise without it?. *International Journal of Integrated Care*, 22(4). Available here.
[6] Khosla, R., Allotey, P., & Gruskin, S. (2022). Reimagining human rights in global health: what will it take?. *BMJ Global Health*, 7(8). Available here.

2. WHAT DOES THIS RESEARCH HOPE TO ADD?

The research team are aware of the limited evidence available about impactful and truly co-designed services and activity in integrated care. They are committed to the benefits that a more integrated approach to care can bring and are convinced of the need for a purposeful move towards people-driven health and care services. They advocate for this to happen in both practice and research and seek to encourage meaningful engagement with people and communities. This project grew from the intention to help close the gap between the many well-intentioned words about co-production and the reality of limited activity in practice.

The project aims to increase understanding about the motivations and role of people with lived personal experience of health and social care who get involved with shaping health and care systems. It also considers what has supported or hindered them once engaged. It is intended that learning about this may support health and care organisations and professionals understand more about what is needed at a practical level to make co-production an embedded reality in integrated care.

To conduct the research, the team listened to people who have sought to influence health and care systems based on their lived experience and have heard their stories about being involved. Participants were patients, family caregivers, and community members who engaged in health and care system design in different parts of the world.   Using their personal experience and that of their wider communities and networks, participants have helped to shape how professionals, organisations and indeed local and national governments have understood what is important to those in similar situations, and what person-centred and co-ordinated care will mean for them. Through hearing about their experiences, the study looks to identify what needs to change to achieve people-driven integrated care.

The research took a narrative approach and people's experiences were heard through online interviews and group discussions conducted in Europe, the Americas and Australasia. Importantly, the work was overseen by a Community Advisory Board of people with lived experience of health and social care. Participants were also invited to two workshops to discuss and respond to findings. (See Appendix 1: Methodology for further information).

The team are pleased to now share this report to amplify the voices they heard and share participants' perspectives on their contribution to integrated care and how health and social care systems can better embed co-production in the future.

Despite the diversity of their circumstances and experience, all of the participants shared three common characteristics:

their personal connection with integrated care through being current or previous patients and/or users of social care, or were spouses, parents, siblings, children, friends and/or community members of such people

> "
>
> People were drawn to a story, so I started telling [relative's] story on social media and showing lots of photographs. I had to share my [relative] with the world to be able to engage.
>
> "

their emotional and practical understanding of lived experiences of health and social care in relation to their own care or that of those they love

> They committed to partnering with patients and families and so that's really where I started to see the healthcare system in a totally different way. I learnt more about healthcare systems and how fragile and broken they are, but I've seen the beauty of when my voice and many other patients and families' voices were brought in.
>
> "

their strong commitment to making a difference to improving the future experience of others.

> Yeah, but I thought this for a very long time and what I believe is right because I am the loudest voice at the table. So what I say is correct, and I'm sorry that you feel that way, but I know better.
>
> "

3. WHAT IMPACTS HAVE PEOPLE ACHIEVED?

> **…from day one it's been about how can I use my experiences to help make it safer and better for other patients and families, so they don't have to endure what I did.**

Through speaking to participants the research team learnt about the work they had done to influence health and care systems that were important to them. The impacts of their work were hugely impressive (Box 2). These included – developing the skills of the current and future professional and managerial workforce at both local and national level, influencing national and regional policy to improve standards and options for care, developing new supports to guide people and families through the health and care systems, meeting gaps in current provision, and strengthening the quality of care in the community and in hospital settings.

Some participants spoke about big changes that had come about due to their campaigning or influence. These are impressive due to the scale of change that has been effected as a result of their action. For example, influencing whole services, large groups of staff or national training or policy activity.

> **…training has been co-designed and co-delivered absolutely alongside… people… And their voices have been heard absolutely throughout because of course we cannot understand about [their experience] unless we are [them]…. we've just had the evaluation for [this] training…And I think it's been 98% positive with Health and Social Care staff saying they are changing the way they will do things going forward. The biggest impact has been hearing those voices of experience. They're the ones that change the way they are doing things. So I would say [the] campaign has been incredibly successful in that engagement really.**

> **…they'd been part of the pilots for… [the] training. And they were saying that it was…like a lightbulb moment, they didn't know what they didn't know. And … [the] training has given them those skills to actually…address subconscious biases and prejudices, how to engage…, how to engage better with families. But also the real importance of listening to those patients and listening to those carers and families around them.**

Others noted impact at a personal level for individual people receiving services, which although not grand on a large scale, were extremely significant for those they touched. For example, through sharing their lived experience with other people going through similar situations during organised groups they participated in or led, or in the wider work they did.

> …when I remember the person in one of my sessions around dementia who cried; not because I upset her but because it had triggered an emotion. She said, 'I know now how to speak to my mother…' That will always stay with me.

> I can't imagine as a woman making a bigger decision than to terminate a pregnancy and yet, …I feel so sad that so many women are terminating because they don't have that information and that support. And we support women who do terminate you know, I am not remotely anti-abortion, I am anti-coercion and anti-misinformation so…the impact [of support and information] is huge.

Some participants talked about specific changes to local practices due to their involvement with services regarding their own experiences:

> After a year I went back to the CEO of that hospital and I shared all my stories about what my dad experienced, and together her and I made changes to the health care system… to create that safe environment and allow that person to pass in peace. And so we made changes together where…we would create that space so family could be with their loved ones…because that patient really doesn't need medical intervention, they just need a place to be together.

> We developed a care pathway with… [the] hospital… because no one else was and our babies are at higher incidence of arriving early and sadly a still birth beyond… 37 weeks. So, when they [professionals] got that information and when they have got the right attitude our parents are well supported.

The examples provided below are just some of the many instances that the team heard about where people's commitment to citizen led activities had made a difference. Many participants could list multiple occasions when their input had been meaningful and resulted in change.

Box 1 *Examples of impact*

Skills & knowledge development: providing education sessions within qualifying programmes for health and social care professionals, on-going continuing professional development training for professional and managerial workforce, orientation programmes for new employees, for people taking on engagement and advocacy roles

National & regional policy: new financial support for care givers, access to disabled parking, equitable distribution of medication, standards of care for people with a disability and their families, national education frameworks, legislation regarding assisted dying

Support for people and families: development of patient advocacy, information and advocacy services, recruitment and training of volunteers, acting as mentor for people taking on such roles, self-management programmes

Networks: creating local and national networks of organisations to support people and families with similar needs or to respond to a major challenge such as covid

Meeting gaps: care centres for people with dementia, dementia cafes to provide informal support, vaccination programmes for indigenous communities

Quality improvement: development of community based multi-disciplinary teams, strengthening of care pathways, better data systems in hospitals, good practice guides for health and care professionals, new evidence informed relationship between patients and professionals

Research: undertaking research as citizen, publishing co-authored papers, informing local and national research projects and programmes, training research staff on how to engage with people and families

4. WHAT MOTIVATED PEOPLE TO GET INVOLVED?

" I just see myself as someone who's had a not so happy experience in the health system and thinking this is just not good enough. We've got to do something about this together, and I've just been sharing what helped me the most with other people. "

Often, participants described their starting point of getting engaged with integrated care as a response to a strong emotion about their own experience and/or someone who they care for.

" I was absolutely rock bottom and that still motivates me. "

" To put it quite simply, I wouldn't be alive if it wasn't for those people, on that day, making those decisions, involving my family when I clearly was not in a state to and then all the follow up care that carried on. "

These emotions included – frustration at the poor quality of support that had been received, exclusion from being able to access or influence services or their own care, desperation that no support was forthcoming, or gratitude for the professional care and interventions that were provided. This highlights that co-production is not a purely intellectual or practical process, but one in which people are being asked to draw upon intensely personal and often difficult experiences.

" The wards were closing, and I fought so passionately because of my own experience but I didn't feel heard at all. That remains a sadness to me. "

For some, they had received an initial introduction from someone within health and social care to participate in an engagement activity which led to further opportunities emerging over time. For others, no such opportunities were presented and so instead they lobbied and challenged from outside of the established system of organisations and policy processes. In time, as their influence grew, they were often asked to participate in organisational and policy processes.

" But nobody can tell me what to say and when I see things not done properly I will absolutely call them out and I have done. I will not think twice about it, and I will hold people to account for it as well so that's been a strength not being employed by anybody from within…I think that's really been a strength, it's been a positive because nobody can clip my wings. "

" I've got my own advent calendar because every time I've opened a door, there's been some new opportunity behind it. And those opportunities have grown and grown and grown. "

Being involved in citizen leadership activities is hugely demanding on the person's time and can require considerable sacrifices by them and their families.

" Don't do it [laughs]. You will have no life... but it is brilliant. "

" I am trying to do a little less[laughter], although that's not working out. "

" I was working on that over 13 hours every single day. "

" This is my life journey. It's not a storybook. "

Despite such costs, participants were committed to bring about change for people, families and communities. Common motivations included - to address discrimination in wider society which results in poorer quality and length of life, to encourage services to reflect diversity of communities in how they organised and deliver services, to change professional and organisational practices so that they respond to what is important to people, to prevent people experiencing poor quality of care in the future, to improve choice through enabling access to information, treatment, and wider support patient choice, and to meet a current gap in service.

What was shared by all was that they wanted to see practical changes being achieved – having the opportunity to contribute and be listened to was appreciated but for them these had to lead to tangible differences to be worthwhile.

" I feel really strongly that women deserve better...just as a woman, as a mum, as a potential grand mum - I have a daughter and when she is pregnant, I don't want her to go through all the crap I went through, we've got to change. "

"
I got myself an appointment and talked to the chair of the board and say, 'Well this is all well and good, but what about all those people that need that additional support?' ..he said, 'Well that's terrific. You sound like you should be an advocate…my son has Downs syndrome, so his attitude was– 'You go and join the Down syndrome association and advocate there.' And I went, 'This isn't about a particular disability.
"

"
When I have done hard work and have expectations for big things to happen, I involve my spare time, I involve my feelings and engagement, then I can be rather disappointed.
"

5. WHAT ROLES DO PEOPLE TAKE?

Participants were asked to share how they would describe their role to others (Diagram 1). This was often a challenging question to answer as their focus was on achieving change not defining how they had contributed. The roles that they shared ranged from those which could be seen as more responsive to the interests of services and policy makers (advisor, contributor), to those which sought to set an agenda based on what was important to them, other people, and communities (disruptor, activist, advocate, champion). All these roles could lead to impacts, and some participants had played both roles dependant on the circumstances and opportunities that were presented.

The title of "leader" was divisive– whilst few participants initially saw themselves as leaders, on reflection they recognised that they were seeking to influence others to achieve a common goal and therefore leadership was a fair description.

Others did not agree, as they saw leaders as those who were employed in positions of power in organisations or governments, and this was not how they saw themselves (or indeed what they wanted to be).

> **I am a patient within the healthcare system, so I see myself as a patient leader, I'm a patient partner first and foremost.**

> **In the academic world sometimes there's lots of labels on the role as patients, like citizen scientist or lived-experience professional and I'm just me.**

> **…'you're not just a mum' and I go, 'yeah, I am, and I am quite proud to be just a mum' and actually, I don't have a problem with that.**

Similarly, there was much disagreement about how they would define their core 'constituency', i.e. whose views and interests they were seeking to share.

Many described their basis as being a 'patient' or 'consumer' of health and social care services, or being a 'parent', 'child', or 'sibling' of someone who had accessed such services. Others had a more collective and rights-based perspective – that of being a 'citizen' or a 'community' representative.

Other important aspects of their roles which were shared were the processes through which they sought to achieve change – as 'story tellers' who engaged those with influence, as 'networkers' who could connect groups and interests, and as 'partners' who were seen as equals by providers, managers and policy makers.

Diagram 1: *Self-described roles of people with lived experience in shaping integrated care*
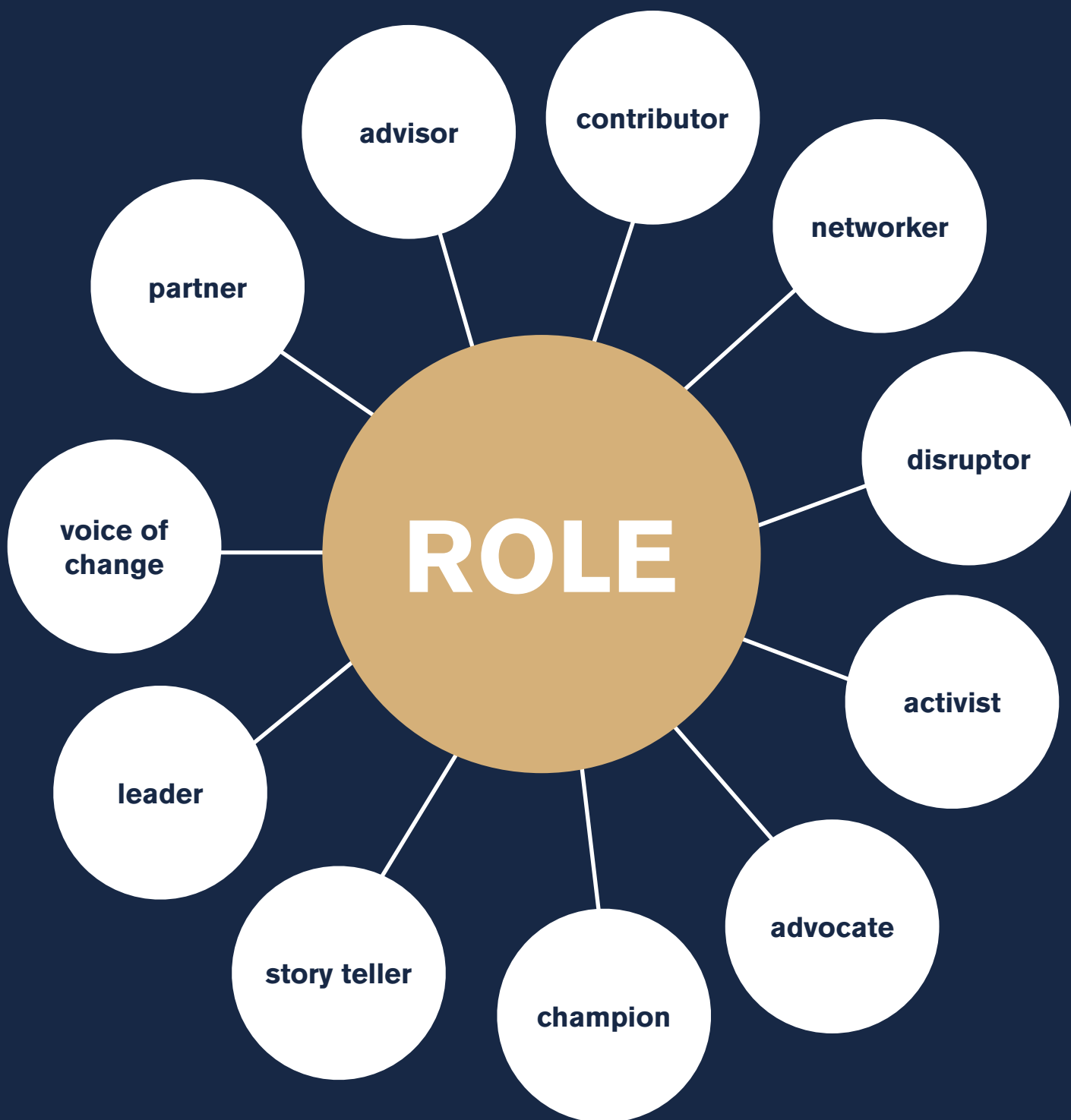
6. WHAT ENABLERS AND BARRIERS DID PEOPLE EXPERIENCE?

Participants shared stories of actions and attitudes that had either supported or hindered their activities. These included the tools they used to make their voices heard, the competences they personally had, supportive staff or systems, and the difficulties that minority groups experienced when seeking to influence.

ENABLERS

> **The key is to be at the table with those who make the decisions. Although it is voice and not vote. Many times I have wanted to have a vote, but I only have a voice. What I have learned is to use my voice well, even if I don't have a vote. Nothing about us, without us.**

Unlike a health or social care professional, or those with a management or policy role, people who seek to shape integrated care are not automatically allocated resources or authority to make decisions. Instead, they develop their own approaches to influencing those with access to resources and influence.

Many of these are related to communication – sharing their and others' experiences through storytelling to individuals or groups, facilitating conversations between stakeholders, and using social media and more traditional press routes to engage a wider audience. They develop expertise in related processes such as quality improvement, community activism, political lobbying, and education and training of health and social care professionals and managers. Developing and maintaining relationships with those with power is often key to inform the understanding of these individuals, be aware of emerging opportunities and to effect change.

> **"It's never about shouting at people; it's never about blaming people. It's about giving them, speaking to them how best I can help them, what can I do to make the changes.**

Some people have created their own organisations to meet an identified need or networks to connect people with similar experiences and aspirations.

The diversity of tools and impacts highlight that seeking to influence integrated care through lived experience requires a testing set of competences (Table 2). Many of these are similar to the competences that have been identified for staff who are employed as managers and leaders of integrated care.

Table 2: *Competences for people who seek to influence*

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 learned to make sure you sprinkle sugar rather than salt because you never know who you're going to meet and when you're going to meet in the same room again.** "

The lack of support about what would be expected of them and how best to prepare themselves caused many people considerable anxiety.

> " For a long, long time getting very intimidated in a lot of those meetings and projects because every now and then, people would wheel out. 'Well, what's your qualification?' In the early days, your qualification was your story, and you'd go, you know what? This is who I am. "

Sharing a personal and often traumatic story to audiences of strangers was understandably seen as intimidating. Many participants in the research described being able to grow in confidence and skills as time went on.

> " So long as you're not abusing anybody or insulting anybody and you're just giving your own voice, then I would encourage anybody to do that, even if it makes you anxious. My advice is it will [to] start with, but the more you do it, the easier it does get when speaking out in that kind of way. "

However, for other people the lack of preparation and support, and the connected stress will have led to them dis-engaging from such opportunities. The participants in this study are possibly therefore those who were resilient in the light of minimal support and able to keep going with involvement activity when others may not have either wished to continue or been able to get involved in the first place. The lack of structured induction and access to information also means that people may have missed opportunities for influence – as one workshop participant put it "you don't know what you don't know". It is worth noting that this is a very different learning approach to that provided to professionals, who have a phased process of education and experience before they are expected to take on their full responsibilities.

> " 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. "

Participants tended to learn these competences through necessity, by doing, rather than by participating in education and development programmes for citizens involved in health and social care. Most described experiences of being expected to just get on with their roles, do the best that they could, and learn themselves how to get better over time. As many of the participants were not formally invited to join in with organised involvement activity this is perhaps not surprising.

Participants often had parallel careers in business, health and social care, education or academia which gave them skills to draw upon. This will not be the case for many people who would be willing to contribute which will result in their perspectives being lost. There were a few examples of people undertaking leadership or quality improvement courses with professionals or bespoke development programmes for people with lived experience. Such learning programmes were seen as positive through the knowledge and skills that they taught and through the opportunity to get to know professionals, managers, and others with lived experience. Mentoring opportunities in which someone with more experience would meet regularly to share insights, connect with resources, and help people to think through different approaches were also seen as constructive approaches to development.

"
I did the course along with lots of other health staff from my local health district and a couple of other consumers, and we ended up with a basic certificate. That opened my eyes as to what best practice was. So I started to learn about safety and quality, and I grew more and more confident that I wasn't being unreasonable as a carer or a consumer to ask for things that I needed, that would make me feel safe and comfortable in healthcare.
"

Participants discussed activities and supports which could make a practical difference to enabling greater engagement and influence. Long term investment in people who were undertaking such roles through training, mentoring and access to new opportunities helped to maintain people's commitment and help them grow in skills and confidence. Meeting of related expenses such as travel, technology costs, and support for alternative care arrangements for those who were carers were basic necessities. Paid roles enable people to dedicate more of their time and ensure that such opportunities are not only open to those with personal wealth.

"
I question how the organisations that I work for are developing future leaders in my space. What more can they do to encourage the growth and development of the more vulnerable people that aren't being reached at the moment - lifting them up to enjoy the confidence that I have now.
"

It was striking that many participants could identify a senior leader or professional who had taken a personal interest in their contribution and met with them as a respected equal. Such relationships were seen as helpful for progressing a particular issue and in developing a wider understanding and credibility.

"
He's skilled in dialogue and conversation. He's believable and he doesn't talk corporate speak to us. He talks as a human being and as an individual. You know where you stand. He's also approachable. He's doing it with us and not to us.
"

> " She was really good at communicating and she was always friendly and open. She took the flack and could deal with it and not get defensive, not get cross with us and not patronise us but frustratingly, still hold her position. "

> " She's a very strong chair. She demands full equity, full inclusion, increases psychological safety of the group, and there's so many things that we've been able to change through that. So definitely, having that strong leadership is key. "

Policy makers introducing a legal duty and/or policy guidelines which set out clearly that participation is a key principle and introducing related processes can help to create a minimum standard of involvement. Local organisations and partnerships can develop and invest in new opportunities and pro-actively seek out different voices alongside investing in more established contributors. One helpful way to approach such community engagement is for senior leaders to attend existing forums organised by communities, rather than always expecting communities to be the ones who need to be flexible.

> " They [community groups] should invite people [from statutory services] to their meetings and in just a very open and honest way, have conversations with them from the community….and hearing individual stories and community organisations' stories helps them to learn about processes but also about an individual community. "

However, once engaging with communities the need for relationship building and commitment was seen as a key enabler.

> " A lot of it is very, very relational and especially in [place]…. with our… communities, if you don't give that engagement right, don't bother coming back for your second cup of tea and biccies because you're not going to be welcome. It's simply that. Some of those initial engagements, they can take hours and if you don't spend those hours, you're not going to get anywhere. "

BARRIERS

" There are so many barriers that I think people put up - that's super frustrating because it just pushes us away. "

Barriers to people being able to influence integrated care were seen on multiple levels (Diagram 2). Many were related to the practical processes such as limited communication and poor coordination, meetings being confirmed or changed at the last minute, insufficient investment in the infrastructures and people who support engagement, a lack of skills in facilitating events and engagement activities, and financial processes to meet people's expenses being overly bureaucratic.

" My hesitation in a role like I have is the pressure that's going to come. Okay, we need consumers in this, this and this. Great, fantastic, but we don't have the infrastructure to support it all. We can't meet all your needs overnight. We still need time and we're still building up, essentially, a voluntary workforce. "

" For 200 advisors (she) had no administrative support, which says a lot in an organisation that has a thousand beds. One person. And all of us knew she was in over her head. "

Navigating the complexity of health and care systems was also viewed as a challenge for some:

" I don't know all the who does what, where and… it's really tricky to navigate the systems and who is responsible for what, I have no idea around guidelines and protocols and all those things and I kind of feel I don't need to, that's not my job but…as someone who is campaigning, if you want to have any impact it feels like you do need to know that and I have to sort of try and educate myself on it and…I find it really boring so, it doesn't work you know, I try and…so, I think it is tricky as someone who is trying to effect change…to yeah, navigate the system, because it is just ginormous. "

Increasing virtual opportunities for people to engage were seen as helpful for some groups but further excluding others, particularly as it was common for agencies to expect people to fund their own technology and internet access.

Such practical barriers were seen to particularly affect people from marginalised communities who may not have access to the resources necessary to participate or may have difficulty in fulfilling criteria regarding their educational or employment backgrounds.

The traditional culture and values of health and care services were also seen as major barriers to positive change.

> " **There are some clinicians who have the most overwhelming arrogance that makes it very difficult to engage with. When you are talking to them, they are seeing you as a patient or they're seeing you as someone's mum, they're not seeing your knowledge. And so it's very difficult to have any traction.** "

> " **They don't create psychological safety in their environments.** "

For example, a belief that professionals do know best, bias towards which type of people and communities are invited to engage (and those who are seen as less acceptable), following tokenistic approaches which 'tick the box' of co-co-production, and the tendency for new senior leaders to want to impose their own ideas and networks. It was observed that it was rare for diversity within minority communities to be reflected in their representation and one person was expected to speak for many different experiences.

> " **I realised that most of the consumers were very affluent, middle class, retired, Anglo and that they had absolutely no awareness of what it is for people who have broken English to have access, that there was no equity of care. Because when you are privileged you don't know you're privileged.** "

Barriers outside the health and care system were the current lack of people with lived experience who were ready and able to take up such opportunities, and that there was a constant turnover as people experienced changes in their health condition or social circumstances.

> " **I've had concerns about being a professional public contributor because I know I'm picked up sometimes as one of the usual suspects but I'm aware of that… and actually, I'm beginning to learn with some of the high-level stuff that you need public contributors at that level to do that networking whilst also being in touch with the grassroots stuff so that you hear the voices coming through.** "

Some participants were clear about the barriers that exist due to the lack of appreciation of people's personal situations and also the requirements which were prerequisites for engagement:

> " Oh my gosh, like the police check. And I said, "I'm sorry. What?" Like, what if they have a drug charge because they've struggled with drug abuse and they're a lovely person. "

> " I don't care about that mate because I'm busy getting through today, my car's just broken down, my kids are half an hour away at school, I've got no way to pick them up, I've got no money to pay for the car repair and I'm really worried about how I'm going to put a meal on the table, and you want to talk to me about the future? "

The need for organisations to reflect on issues of social justice and consider who does, and perhaps more importantly, does not, engage in citizen leadership activity in integrated care is notable. Many participants were skilled at identifying things that had supported and hindered their own involvement. We have much to learn from their insights. It may be that asking those from groups not yet involved, what will work for them, what they need in terms of support, and engaging people in their own contexts is the most helpful way to approach a widening of opportunities.
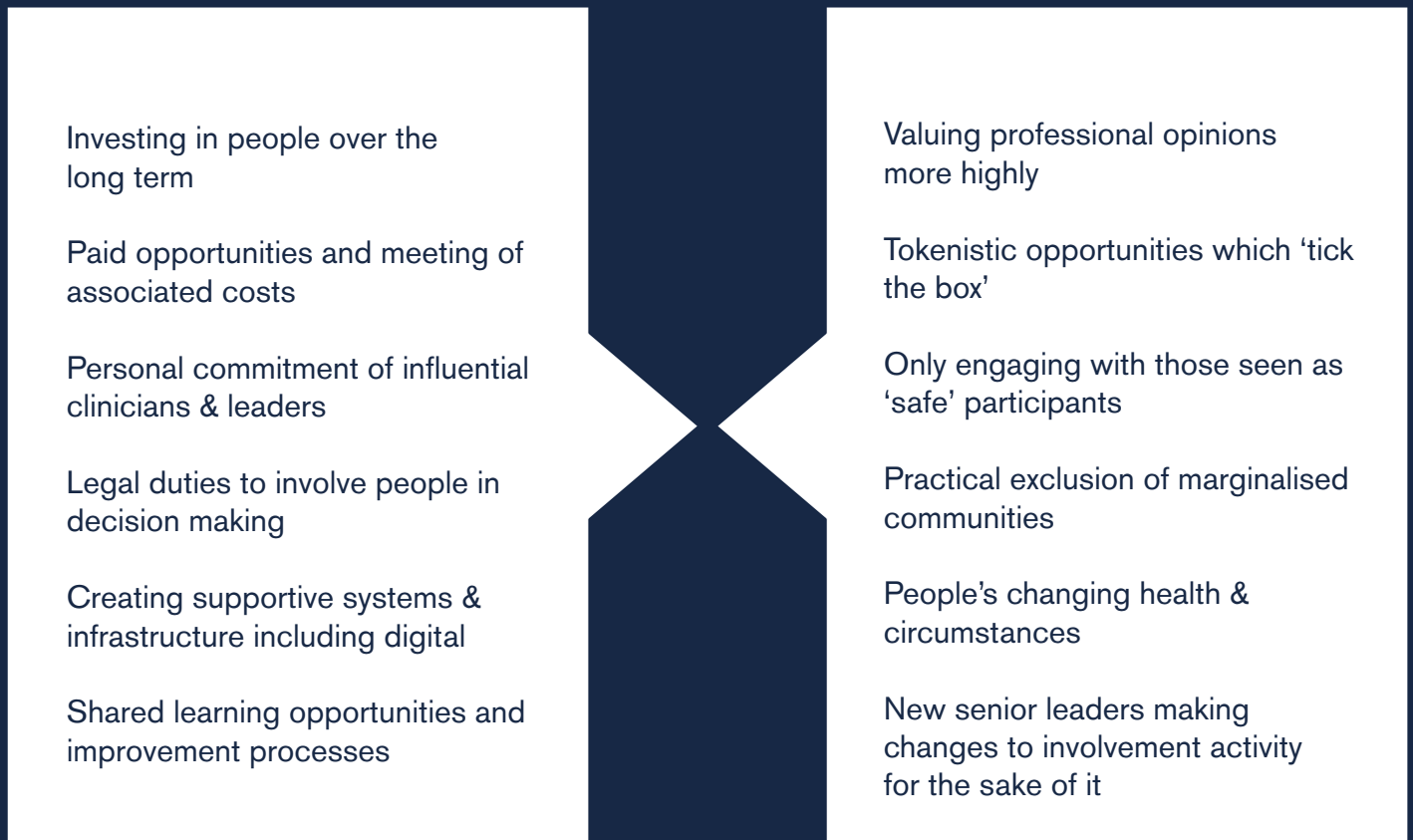
> " As an indigenous society the very politics that we operate in and culture beliefs that we have are so much more holistic than any hierarchical bureaucratic colonial system that's been superimposed on what we do. "

Diagram 2: *Enablers and barriers of co-production*

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

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

7. CONCLUSION

The participants in this project have generously shared their experiences of speaking up and engaging with health and social care to improve services. The joint impact from, breadth of, and insight into their own work is impressive, inspiring, and humbling. From their raised collective voices there are important lessons to be learnt regarding good practice in co-production and citizen leadership activity.

Through their shared experiences of the competences required of them and the emotional and time-consuming toll that engagement can take, their passion, hard work and determination stood out.

The actions or inaction from professionals and organisations were notable as being the difference between positive or more challenging interactions with the systems and services they sought to influence.

It is hoped that the findings from this project will act as a reminder to health and care organisations to not underestimate the power and ability of citizen voice for improving services and making them more person centred.

Also that it will be a clarion call to give thought to the processes, policies, activities and attitudes which need to be in place to enable everyone's voices to be heard in a supportive and encouraging environment.

Following the analysis of the data, to provide ideas about practical steps for integrated care organisations to consider when seeking to co-produce, the team worked on the recommendations below.   These came directly from the participants, from team discussions, and from the two online workshops which were held to share findings.

The recommendations offer suggestions for good practice which may support the inclusion of more voices in all aspects of integrated care, including from those groups of people who are currently less listened to.

" I 'feel' heard… thank you! And this topic is so important to be discussed.

8. RECOMMENDATIONS

These recommendations were developed based on our interviews and workshops with participants. They identify practical steps which can be made across the health and care system to facilitate greater and more impactful co-production of integrated care.

REMOVING BARRIERS TO PARTICIPATION

People from all backgrounds can engage in digitally based opportunities.

Examples of supporting activities:
- Loaning or funding required technology
- Paying for access to wifi with required bandwidth
- Providing training and IT support
- Allowing time for people to become confident in using technology

The contribution and costs of people with lived experience are financially recognised

Examples of supporting activities:
- Financial recognition for time spent participating
- Expenses for travel, carer costs etc. reimbursed promptly
- Accessible forms and processes for claiming
- Choices provided about how to be reimbursed (e.g.: money, vouchers, other)
- Clear information about the implications of payment for people's individual circumstances (including taxation and social security benefits)
- Providing documentation to inform relevant bodies of additional payments

People with lived experience understand the opportunity to contribute and what is expected.

Examples of supporting activities:
- Jointly set boundaries and expectations for everyone involved - professionals and citizen leaders
- Provide relevant induction activities or materials
- Co-create ground rules for equal partnership

There is a diversity of voices and perspectives that reflects the local populations

Examples of supporting activities:
- Pro-actively including people from less listened to communities
- Reflecting on who is not involved and why this may be the case
- Setting aside sufficient time and resource to change the status quo
- Building relationships with communities of people over the long term, rather than as a one off
- Recruitment forms should be straightforward and inclusive
- Avoiding a tokenistic approach and recruiting multiple people

There are flexible options for co-production which reflect people's personal commitments to work and caring.

Examples of supporting activities:
- Consulting and acting on people's preferences for timings of meetings
- Using a variety of methods for engagement so people can participate in the way that fits with them and those they support
- Asking people what they need to engage with you
- Considering people's busy lives and the time that will be expected of people

Safe spaces are provided in which people can express their viewpoints including criticisms of the status-quo.

Examples of supporting activities:
- Choice of meeting location
- Preparation with health and care leaders to 'listen' including ground rules
- Preparation with citizen leaders to engage to support their wellbeing
- Accessible documentation and materials that everyone can understand (including easyread)
- Opportunities to debrief plus support (if needed) after the engagement
- Asking what could be done better next time.

EDUCATION AND DEVELOPMENT

Facilitating support from peer mentors to build skills, confidence and networks.

Examples of supporting activities:
- Practical and emotional support for mentor and mentee
- Care and safeguards in matching people appropriately
- Clear boundaries and expectations of those involved
- 'Reverse' mentoring where citizen leaders mentor professional leaders (and vice-versa)

Support citizen led groups to create a library of resources and stories, about their lived experiences and good practices in co-production

Examples of supporting activities:
- Curation process is owned and managed by people with lived experience
- Shared, with permission, with health and care leaders for service improvement, education of professionals and relevant research

The necessary values, skills and knowledge for co-production are developed across the health and care system.

Examples of supporting activities:
- Developing / adopting competences required by the key stakeholders
- Co-producing training and development offers
- Providing flexible and accessible training opportunities and development resources
- Facilitating inter-professional opportunities in which people with lived experience can participate

Develop individual training and development plans with each person with lived experience who is interested in co-production.

Examples of supporting activities:
- Listening to them about the roles they want to play
- Celebrating their strengths and supporting them to grow
- Offer practical support and opportunities to progress their aspirations as a citizen leader
- Free access to courses which will support people's understanding of integrated care, co-production and their own health and wellbeing

POLICY, GOVERNANCE, ORGANISATION & DELIVERY

National structures encourage and mandate minimum levels of co-production within health and care systems.

Examples of supporting activities:
- National guidance and requirements are developed through co-production
- Clear and achievable standards are set relating to co-production
- Coherent national policy about payment and reciprocity for citizen leaders
- Performance monitoring includes co-production within its standards and processes

Health and care systems have the necessary infrastructure of capacity, resources, and skills to embed co-production.

Examples of supporting activities:
- Investing in roles to facilitate co-production
- Plan for long-term engagement to enable trust to be developed
- Connect integrated care developments with communities and voluntary sector organisations
- Actively seek the inclusion of locally less listened to groups
- Embed co-production as a core value of integrated care in all stages of service delivery including planning, delivery, and evaluation

The regulation of health and care systems considers co-production practices and outcomes.

Examples of supporting activities:
- Co-production is reflected in the standards used by regulators
- The views of people with lived experience are captured by regulatory processes
- People with lived experience are members of regulatory teams

RESEARCH & EVALUATION

There is better equity within the overall planning and funding of research grants and bid development.

Examples of supporting activities:
- Decisions about research prioritisation are co-produced
- People with lived experience are able to access research grants and development funding
- Research funders mandate that people with lived experience must be involved in the design and implementation of research bids

Citizen science is developed as a robust scientific approach.

Examples of supporting activities:
- Listening to citizen leaders and communities about their priorities for research in their localities and lives
- Training citizen leaders to develop their own research skills
- Fund projects that capacity build citizen science
- Fund projects which include citizen science in their research methods

Academic journals embed the perspectives of people with lived experience in their processes and facilitate access to the insights from their content.

Examples of supporting activities:
- Including citizen leaders on journal editorial boards
- Supporting citizen leaders to engage in review processes
- Encouraging citizen leaders to author & co-author papers

Citizen leaders can participate in the range of academic and research learning and networking activities.

Examples of supporting activities:
- Conferences offering free places for citizen leaders
- Research bodies subsiding places and expenses for citizen leaders at academic events
- Research bodies offering library access to book and journal collections for citizen leaders
- Universities offering IT and other support to facilitate access to those they engage with

Co-production becomes a core academic competency

Examples of supporting activities:
- Co-production is included within the role requirements for research and teaching academics
- Opportunity for co-production skills development provided to research and teaching academics
- Universities and other related bodies invest in necessary infrastructure and support

Research culture adapts to enable better partnership with people with lived experience

Examples of supporting activities:
- People with lived experience enabled to have research identification numbers to support with building their profile, accessing funding and (co-)authoring papers
- Research teams provide feedback on how lived experience perspectives have been acted on alongside general updates about research project progress to those who have engaged with project
- Support and training offered to enable people with lived experience to have sufficient understanding of research processes and terminology

APPENDIX 1

METHODOLOGY

Participants for the project (n= 25) were recruited based on purposeful sampling through integrated care practice and academic networks including those facilitated by the International Foundation for Integrated Care. To participate in the study people needed to have used their lived experience to speak out and help to shape integrated care services for individual benefit and for the general good.

Participants needed to have responded yes to the following questions:

■ Have you accessed health and / or social care services as a patient / service recipient or as a family caregiver?

■ Have you contributed to activities relating to the review, development or oversight of health and care services, or spoken out as a campaigner or activist to make services better?

■ Have these activities been seeking to make services more integrated (i.e. person-centred and coordinated across professionals and services)?

Interviews were conducted from February to June 2022. Focus Groups were held in December 2022 and January 2023.

Australia	3
Canada	5
Costa Rica	1
England	6
Ireland	1
Malaysia	2
New Zealand	2
Norway	1
Panama	1
Sweden	1
Scotland	1
The Netherlands	1

APPENDIX 2

INTEGRATED CARE AND CO-PRODUCTION RESOURCES

Useful information and case studies about co-production and person-centred care in integrated care can be found on the following webpages. For example:

Organisations & Networks

- Health Consumers News South Wales (Australia): https://www.hcnsw.org.au/

- Centre of Excellence on Partnership with Patients and the Public (Canada): https://ceppp.ca/en/

- Ontario Caregiver Organization (Canada): https://ontariocaregiver.ca/about-oco-2/

- Tamarack Institute for Community Engagement (Canada): https://www.tamarackcommunity.ca/

- European Patients Forum (Europe): https://www.eu-patient.eu/Capacity-Building-programme/

- Health CASCADE (Europe): https://healthcascade.eu/

- TransForm Integrated Care (Europe): https://transform-integratedcommunitycare.com/resources/

- National Carer Learning and Wellbeing Resource Service (New Zealand): https://carematters.org.nz/about-us/

- Health Research Authority: https://www.hra.nhs.uk/planning-and-improving-research/best-practice/public-involvement/resources/

- Nesta (United Kingdom): https://shorturl.at/av169

- Social Care Institute for Excellence (United Kingdom): https://www.scie.org.uk/co-production

- Think Local Act Personal (United Kingdom): https://www.thinklocalactpersonal.org.uk

- Coalition for Personalised Care (United Kingdom): https://www.coalitionforpersonalisedcare.org.uk/

- American Hospital Association Institute for Diversity & Health Equity (USA): https://ifdhe.aha.org/

- Centre for Public Impact (Worldwide): https://shorturl.at/bfY38

- Co-Production Collective (Worldwide): https://www.coproductioncollective.co.uk/about/who-we-are

- Rand (Worldwide): https://www.rand.org/pubs/technical_reports/TR850.html

- World Health Organisation (Worldwide): https://shorturl.at/JO238

Training & Development

■ Online Certificate in Integrated Care, International Foundation for Integrated Care:
https://integratedcarefoundation.org/integrated-care-academy-2/online-certificate-in-integrated-care

■ Family engagement in research, McMaster University: https://continuing.mcmaster.ca/courses/fer-101/

■ Leadership & Advocacy Training, EURORDIS: https://openacademy.eurordis.org/

■ Interactive course for new and experienced public reviewers of health and social care research,
National Institute for Health & Care Research: https://shorturl.at/cfxBC