Valuing Lived Experience Learning Report

Are you ready to commit to the work of co-production?

Build experience, grow confidence with lived and learned experience

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May 2022
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What is Voices for Improvement?

Voices for Improvement is a project which seeks to strengthen collaboration between those with lived experience and decision-makers, in the service of improving health and social care. The project supports those with lived experience to provide coaching and mentoring to those in senior positions in health and care. The coaching allows clients to gain deeper understanding of lived experience perspectives and promotes the confidence to try new approaches to co-production in their own work.

Originally funded by The Health Foundation’s Q Community, Voices for Improvement began in May 2020 with an advisory group drawn from a variety of lived and learned experience backgrounds. Together the group explored ‘what works well’ to promote productive relationships and improve lived experience insight and influence in health and care improvement. The findings of this work – that lasting change comes from the depth of understanding and fresh ideas which emerge from high quality relationships – resulted in the development of the coaching and mentoring programme.

Why is Voices for Improvement needed?

Collaboration between individuals, teams, organisations and sectors is vital if we are going to tackle the stark health inequalities amplified by the COVID-19 pandemic. The burdens of ill health are distributed unequally; underlying and unaddressed issues of racism, paternalism and exclusion contribute to poorer experiences and health outcomes for those from marginalised and underserved communities. These challenges are complex and require meaningful involvement from those with lived experience in order to create sustainable change.

People with lived experience have a wealth of knowledge about how health and care could be improved, but very rarely get the chance to influence this at a strategic level. Equally, many leaders want to develop their own practice and embed co-production across their organisation in order to improve outcomes, but traditional methods like committees and advisory groups can be limited – in their effectiveness. Going beyond these surface-level practices is necessary to develop trusting relationships which facilitate collaboration, deep thinking, and positive change. Good decisions can only be made on the basis of good conversations.
How does Voices for Improvement work?

Voices for Improvement offers a programme for people with lived experience to become coaches and mentors to health and care leaders. It builds on the Co-Active coaching model (see Further Reading), where coaches and clients form a one-to-one relationship of equals. Drawing on the principles of co-production, Voices for Improvement brings together lived and learned experience to create safe spaces for questions, constructive challenge, and conversations which lead to action. The coaching relationship provides the conditions to enable change.

Lived Experience Partners participate in two days of co-designed coaching and mentoring training. They are initially selected and then matched with clients through a careful screening process, as well as supported with ongoing supervision, coaching and peer action-learning sets. They are paid for their time and gain skills applicable elsewhere in their lives and work, in addition to insight into the health and care system and access to further opportunities for influence.

Clients gain the space for reflection and the opportunity to deepen their understanding of lived experience, be stretched as a leader, and strengthen connections with those they serve. The coaching is an invitation to develop their confidence to take new approaches and commit to the work of co-production at a strategic level. Ultimately, it is directed at addressing inequalities and improving health and care.

Who is involved in Voices for Improvement?

National Voices is the leading coalition of health and social care charities in England, with more than 190 members covering a diverse range of health conditions and communities. They work together to strengthen the voice of patients, service users, carers, their families and the voluntary organisations that work for them.

Voices for Improvement is a National Voices project originally formed in partnership with Q Community. It is co-led by two National Voices team members: Rachel Matthews, Head of Experience, and Keymn Whervin, Lived Experience Manager. Rachel is a certified Co-active Coach and brings experience of working in health and research roles from a professional perspective, whilst Keymn, who was originally a lived experience member of the advisory group, brings 23 years of experience as a carer to her role. Keymn cared for her mother Elsie, from Jamaica, and brokered the services Elsie needed to ensure that her mother lived a full life. This experience helped influence the personalised care approach. Sadly, Elsie passed away from Covid in 2020.
Learning with Voices for Improvement

Lizzie Cain, Co-production and Learning Manager from Co-Production Collective at UCL has supported the development of Voices for Improvement as a Learning Partner. This role involved embedding evaluation and learning activities to provide check and challenge, and to explore the project’s outcomes and enabling conditions. In keeping with this Voices for Improvement ethos, Lizzie was joined by two Co-Learning Partners with lived experience for some of this work: Marlon Patrice and Richard Falvey.

This report brings together learning amassed during Voices for Improvement’s pilot phase, from August 2021 to March 2022. Methods used to generate the evidence for this report include:

- Document analysis.
- Weekly reflective practice.
- Observations of meetings, workshops and training.
- Interviews with key figures.
- Co-designing, co-delivering and co-analysing pre-and-post interviews with coaching and mentoring training participants.
- Co-designing and delivering ‘Valuing Lived Experience – Learning with National Voices’, a webinar held on 9 February 2022.

This report

This report represents a snapshot of the accumulation of two years’ work and the strength of community behind Voices for Improvement. It builds on the learning shared at the Valuing Lived Experience webinar – the full recording and content shared at this event can be accessed via the National Voices website.

A written report can never do justice to a project which is fundamentally about people and relationships. The power of Voices for Improvement, as with co-production more generally, is in what is felt, experienced and shared. We invite you to watch the Valuing Lived Experience webinar to get a sense of this for yourself.
02 What is changing as a result of Voices for Improvement?

This section explores the changes experienced by those involved in Voices for Improvement, and for National Voices as an organisation. Learning is drawn from individuals including Rachel and Keymn, the wider National Voices team, those on the advisory group, and those who have participated in the first pilot training and coaching.

What is changing at National Voices?

The development of Voices for Improvement has had a transformative impact on National Voices. Their journey is indicative of what happens when organisations shift their mindset and approach to learn from and work alongside those they exist to support.

Reach and representation

The most significant change experienced by National Voices has been in the communities they are reaching and representing as an organisation. Keymn is the clearest example of this; her involvement began as a lived experience member of the Voices for Improvement advisory group before becoming an associate, and ultimately a National Voices team member. Her co-leadership of Voices for Improvement alongside Rachel is fundamental to the project’s development but also visibly embodies its co-productive and inclusive approach.

You see a black woman from a working-class carer background co-leading with a white woman with a middle-class professional background; we openly check and challenge each other.

Keymn Whervin, Lived Experience Manager, National Voices

Keymn and the Advisory Group brought extensive networks of people with lived experience to National Voices, diversifying those who are involved in and influencing the organisation’s activity. For example, Charlotte Augst, the Chief Executive, wanted to ensure that their trustee recruitment did not contribute to the systematic overrepresentation of middle-class white people at this level, particularly in an organisation whose mission is to understand and advocate for those with greater health and care needs. For the first time (at Keymn’s suggestion and with her involvement), a lived experience panel was part of the recruitment process, and the resulting appointments mean that the National Voices board is now the most diverse it has ever been.
Language and approach

A shift in language and approach is both created by improved diversity and inclusion, and reinforces it. National Voices no longer refer to people with lived experience as patients, focus especially on the needs of marginalised communities in their work, and systematically take the time to stop, step back, and challenge their assumptions. For example, the organisation now sees it as essential to involve those who bring relevant lived experience to a problem or situation at the beginning of a project, not least to check whether what has been identified is the issue at all.

These changes are visible across the organisation, from communications and policy to project delivery. Charlotte highlighted the Voices for Improvement advisory group as “one of the best things National Voices has ever done” and they are trying to grow this approach – learning by doing, co-production and deep thinking – across all their work. For example, they are advocating for more co-leadership in externally commissioned activities exploring complex health issues, creating space for knowledge drawn from lived experience to be incorporated into dominant clinical perspectives. Similarly, the organisation has created a Lived Experience Partner agreement. This is based on their agreement for associates but uses language that better reflects collaborative relationships, includes clauses to allow payment for reasonable adjustment and travel time, and for mediation processes should any issues arise.

Reputation and credibility

National Voices has not always been well regarded in relation to its involvement (or not) of those with diverse forms of lived experience. As the team themselves fully admit, practice could have been better in the past.

However, as a result of Voices for Improvement and the examples highlighted above, the organisation is now increasingly being recognised as having undergone real change; they are building a reputation as a credible, trusted leader in this space. Again, the visibility of Keymn and her role has contributed significantly to this; one of the Lived Experience Partners only agreed to participate in the training because they trusted her, but described it afterwards as “the real thing” and is keen to continue with the project. This shift in attitude was also reflected by attendees at the Valuing Lived Improvement event on 9 February.
What is changing as a result of Voices for Improvement?

I was also interested to find out about National Voices’ work with bringing in more lived experience, as historically it has been a perspective that has been noticeably absent from the organisation. Delighted to see the changes that have been happening and the fantastic work that’s been happening and am sure will continue to happen!

Valuing Lived Experience event attendee

Making a difference

These shifts in practice, people and reputation mean that National Voices is in a stronger position to support alliances between member organisations and others who want to promote the value of lived experience in making what matters to people, matter in health and care.

Working with people from a wider range of communities and more diverse backgrounds, including as associates, is providing greater insight to support effective decision making and accountability. National Voices is already attracting potential new members and clients as a result.

Voices for Improvement has had a focus on sustainability built into it from the start. Many other similar initiatives elsewhere have fallen by the wayside once grant funding has ended. However, the Voices for Improvement coaching offer can be invested in by health and care organisations as training or part of a wider involvement offer. The interest is evidently there; 250 people attended the Valuing Lived Experience virtual event, with 95% of those who completed the feedback survey responding positively and 71 completing expressions of interest to explore further involvement.

I am part of a community interest company that has never joined National Voices purely because of the lack of lived experience representation within and by the organisation – perhaps it is time to revisit that.

Valuing Lived Experience event attendee

I’ve taken away an intention to get more involved with the work of National Voices and a desire to increase the amount of work I do with my own organisation.

Valuing Lived Experience event attendee

Voices for Improvement has enabled National Voices to become an organisation which works authentically with people with lived experience to influence system change across health and care.
What is changing at a personal level?

The organisational changes represented by National Voices result from the new ideas, shifting mental models and deeper understanding enabled by collaboration between lived and learned experience. Direct personal outcomes for those participating in the coaching programme – both as coaches and clients – include improved knowledge and confidence, as well as changed attitudes in relation to their work. They also reported additional benefits in terms of their personal development (see case studies).

Learning through active listening

The coaching and mentoring training specifically covers the skills needed to carry out this role, including the power of asking questions, the importance of inclusive communication and different forms of listening. Participants came away equipped with specific tools and practices which they could apply to their lived experience work and more broadly.

The nature of the project encourages others to listen in different ways. For example, the presence of Keynm is changing the nature of conversations with National Voices’ potential clients and partners; they are more willing to reflect on their own practice and consider alternative ideas when presented by someone bringing both lived experience and strategic knowledge.

Anindita Ghosh, Innovation and Development Lead for the Q Community at The Health Foundation, highlighted that her time on the advisory group broadened her understanding of the issues faced by those with lived experience, and changed how she uses relevant language. Similarly, Shahana Ramsden, an NHS leader coached on the programme, gained a greater understanding into the potential of co-production to enhance her own work.

I often talk about inclusivity, but never REALLY thought about how to make it inclusive for others – not consciously. It’s important to practice it, not just in training but in the day to day, to be mindful of needs – even in ordinary conversation.

Lived Experience Partner

It gave me a real reality check around some of the programs we’re running.

Shahana Ramsden, Director of Vaccination Workforce and Vaccine Equality Lead NHS England and Improvement
What is changing as a result of Voices for Improvement?

Outcomes for training participants

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<th>Attitudes</th>
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<td>Active listening</td>
<td>Assumptions challenged</td>
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<tr>
<td>Feeling validated</td>
<td>Asking questions</td>
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<td>New relationships</td>
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The opportunities to practice really opened my eyes about how you ask great questions – short, short questions – not long complicated ones. Coaching or guiding isn’t about giving answers or finding solutions. It’s about the power of asking questions, not trying to solve the problem.

Lived Experience Partner

Letting go of assumptions

A great deal of the learning experienced by those involved with Voices from Improvement comes from being able to let go of pre-existing assumptions – about themselves, about those with different forms of experience, and about what could be possible in the health and care system. Both Rachel and Keymn feel the challenge they offer each other is one of the most important benefits of their co-leadership relationship.

This is what the Lived Experience Partners offer to potential clients as a coach. When coaching Shahana, Keymn was able to respectfully challenge her assumptions about her own work, particularly in relation to including lived experience perspectives. In parallel, the Lived Experience Partners finished the training able to let go of prior assumptions about themselves, but also about those working in the health and care sector.

When we go to meetings together, we will bring different perspectives and challenge each other. We don’t always agree, and we both have blind spots, and that’s what is so valuable – when I don’t see something, Keymn may spot something and vice versa.

Rachel Matthews, Head of Experience, National Voices

We shouldn’t come with any preconceived ideas about people just because they’re either somebody like me who’s just an unpaid carer, but equally the same for somebody that’s worked their way up the ladder and they’ve got senior positions within the Health and Social Care system.

Lived Experience Partner
Helen has been a carer for her son, who has complex medical needs, for 25 years. She came to the Voices for Improvement training feeling fatigued and tired from decades “battling a system that doesn’t really want to work with me”. She felt that her lived experience involvement in health and care spaces has sometimes been tokenistic, used to tick a box rather than through any genuine interest in working together for change. She also felt doubtful about her own skills and abilities to coach a senior leader, seeing herself “even after all this time as just an unpaid carer”.

However, the co-active coaching model focuses on forming a relationship free of hierarchies, meeting people where they are without any preconceived ideas – on both sides.

“The coaching and mentoring really is a leveller... I learned that we could have conversations.”

Similarly, the open and inclusive nature of the course and the safe space it provided for self-reflection, allowed her to not only to develop new skills but also recognise the strengths she already had.

“I really learned that... you know, I have got skills, I have got experience that I can bring to bear to help shape the system that will work for people like me but also my son, who has a learning disability who finds accessing services really difficult.”

Helen now feels excited about how she’s going to take her skills and apply them in practice, building relationships with senior leaders to influence change.

“Let’s start this off again let’s put us on a level footing... there is no hierarchy, there is no power.”
Building confidence and taking a different approach

Ultimately, these shifts in knowledge and attitudes result in the confidence to take a different approach – in relation to the meaningful involvement of those with lived experience in health and care and beyond. The training participants developed greater confidence in themselves, their own abilities and voices, and the value they have to offer.

I feel able to be myself again

Lived Experience Partner

A number noted that they had already used their new skills in their personal lives as well as in their lived experience roles. The Voices for Improvement team are supporting this, identifying opportunities for the Lived Experience Partners to bring their skills and insight to inform National Voices’ policy and advocacy work.

More broadly, Anindita Ghosh from the Q Community feels that her involvement with the advisory group helped her rethink how she conceives of the systemic challenges relating to power within health and care improvement.

Join a learning community

It helped me move from seeing the problem with all of that context and all of those layers and all of those themes to be in a much more creative, energetic and the imaginative space of what could be possible, and how we could really take action.

Anindita Gosh, Innovation and Development Lead, Q Community

Learn with our Lived Experience Partners

We can help you work through your challenge
We can share our experience

Strategic Co-production

Finally, coaching enabled Shahana to gain assurance about how she could work differently, both through explicit conversations but also through the very experience of being coached by someone with lived experience insights.

What the sessions did was, they gave me the confidence to really articulate what I want to see for patients, and what I want to see for people using services, so seeing people as part of the workforce solution.

Shahana Ramsden, Director of Vaccination Workforce and Vaccine Equality Lead, NHS England and Improvement
Shahana has received coaching from Keymn and found it gave her some much needed time and space to reflect on her work, something she hadn’t been able to do since the beginning of the COVID-19 pandemic.

The trust she formed with Keymn allowed her to be genuinely open and vulnerable, try out ideas without fear of being judged and have her own assumptions gently challenged.

The impact of this relationship has been a shift in Shahana’s attitude and understanding of the potential role those with lived experience can play in the work she does, even when that wasn’t the focus of the conversations.

“What it’s helped me to realise is that people who use services and patients are not a problem to be solved. They’re actually part of the solution... not just part of the solution, but absolutely essential for us to be able to address the issues we’re facing”

As a result, Shahana is building specific co-production approaches into her work on inequalities, recognising the importance of working alongside those who experience these every day.
What is needed to support meaningful partnership between lived and learned experience?

This section explores the conditions which support meaningful partnership between lived and learned experience. These lessons are drawn from the development of Voices for Improvement but are applicable more broadly to other initiatives exploring working in this way.

Very little shared below will be new to anyone working in this space – Voices for Improvement itself builds on decades of activity across the health and care sector and beyond. However, we hope that viewing these issues through the Voices for Improvement lens illustrates the commitment needed to genuinely embed lived experience at the heart of health and care improvement. Doing so requires a fundamental shift in mindset, culture and practice, but this starts at an individual level. Listening to, learning from, and valuing the lived experience perspective allows traditional power relationships to be reset and enables the real possibility of change.
Commit to the work of co-production

Over the last few years, co-production has become a buzzword across health and care. But there has been considerably less attention to what it actually takes to make co-production work; the time and patience to create inclusive spaces, to avoid jumping to solutions before identifying what’s really getting in the way, and to prioritise the needs of people ahead of project frameworks or key performance indicators (KPIs). Voices for Improvement has worked in this way from the beginning, which has meant two years of listening and learning to develop its current model.

Developing shared aims and values are crucial to ensure that those involved at every stage feel connected and invested in the overall purpose. Starting small and with attention to context – what works for us all, here, now? – provides the foundation. In the Co-Active Coaching model, this is embodied by the cornerstone ‘Dance in this moment’. However, this also requires flexibility, living with uncertainty, and accepting that routes or destinations may shift and change along the way. Similarly, some of those originally involved in the project began to step away as its direction shifted and changed; it is not possible to meet the expectations of everyone when the outcomes of a project are truly emergent rather than pre-determined.

The health and care system is not set up to facilitate this way of working and it can be a real challenge to balance a co-productive approach with the need to drive a project forward. But the support from National Voices and the Q Community meant that these considerations were not considered unacceptable risks; rather, it was acknowledged as what is necessary to move practice beyond tokenism, short-termism and truly begin to tackle the complex issues underlying structural inequalities.

Take a strengths-based approach

Central to co-production is recognising people’s strengths and building on what works. Nowhere was this more visible than in the coaching and mentoring training, based on the Co-Active Coaching Model. Another of its four cornerstones is ‘People are naturally creative, resourceful and whole’: the first pilot made it abundantly clear that the participants already had, and used, many of the skills required to be effective coaches. What they did not necessarily have were tools, language, or confidence to operate in this way. The training is now explicitly framed to acknowledge this, presenting the coaching and mentoring model as a structure to underpin the value the lived experience partners already bring to health and care spaces. It also conveys legitimacy on their lived experience in the eyes of a system which still prizes ‘professionalised’ knowledge over experiential knowledge – and evidence as to why Voices for Improvement is needed in the first place.

Nevertheless, a strengths-based approach should not ignore that using lived experience in the service of change is work with real emotional labour, exposing and potentially reinforcing negative experiences at a cost to the individual sharing them. The depth of self-reflection and personal experience shared during the training made this evident.
What is needed to support meaningful partnership between lived and learned experience?

We’re all carrying baggage by definition of who we are – that’s the core factor.

Lived Experience Partner

The passion which often drives those behind culture-change initiatives like Voices for Improvement, challenging existing practice with little capacity or resource, similarly requires significant emotional energy. Emotions need to be recognised and welcomed in this work but also appropriately supported, whether through signposting, advice around resilience and boundaries, and taking steps to create safe spaces.

Develop relationships with purpose and accountability

Productive relationships are those which achieve outcomes. They require the dismantling of hierarchies and removal of labels and identities which can get in the way of forming person-to-person connections. ‘Focus on the whole person’ is another cornerstone of the Co-Active Coaching model, where the coach and coachee are peers – equals – with power granted to the relationship. This makes it a natural partner for co-production and provides both those with lived and learned experience with a framework to try to achieve a new understanding between different kinds of knowledge.

In Voices for Improvement, the coaching relationship is an enabler – it creates the conditions to open up new possibilities and ways of working. Importantly, this relationship is also focused on action and accountability, facilitating conversations which scaffold the uncertainty of co-production with a shared sense of purpose, moving forward what matters. This enables difference, disagreement and even conflict to be welcomed as potential for growth.

Keymn and Rachel’s co-leadership is underpinned by the Voices for Improvement offer – using coaching as the foundation to build productive relationships directed towards meaningful co-production in health and care. The trust they’ve built means that they can challenge each other’s assumptions, recognise the complementarity of their perspectives, and ultimately bridge the gaps between lived and learned experience.

Sometimes we don’t think the same, and I have to say ‘Rachel I need to challenge you there’ and we’ve got a way of just thrashing it out, behind the scenes! But we’ve got that relationship where I can feel confident to say ‘no, that’s not right, that’s not what’s happening outside’.

Keymn Whervin, Lived Experience Manager National Voices
What is needed to support meaningful partnership between lived and learned experience?

Build a diverse community

Since its inception, Voices for Improvement has been co-created with a diverse and growing community, drawn from lived and learned experience across the health and care sector. Relatively early in the Voices for Improvement journey, the team made the decision to focus on working with champions and allies, those who already see the potential of partnerships between lived and learned improvement, rather than waste scarce resources on trying to convince sceptics. A group of potential partners have acted as a sounding board as the project developed, sense-checking and challenging assumptions. This, in combination with an inclusive and co-creative approach, means that the project has steadily built momentum as its reputation has grown. Consequently, as its profile becomes greater and those involved more visible, the effort required to convince doubters becomes lesser.

The delivery of the coaching and mentoring model is also predicated on a community approach, with Lived Experience Partners forming training cohorts who will go on to support each other through action-learning. A similar model is being developed for coaching clients, acknowledging and attempting to address the isolation of being a changemaker within a hostile system. Whist individual relationships act as a catalyst and foundation for this work, they cannot create change in isolation.

The diversity of the group was genuine… so different to other spaces elsewhere. It can be lonely being ‘the lived experience one’ in a room and the training showed me the value of working with a team and having a community.

Lived Experience Participant

Such diversity doesn’t just happen – it requires conscious effort and consideration around whose voices are heard and whose are missing, as well as what they might need to be able to participate. In shaping this community, Rachel and Keymn took conscious steps to ensure that the participants were drawn from a range of different backgrounds, paying people for their time, investing in inclusion, and creating opportunities around the needs of individuals.

Invest in sustainability

Voices for Improvement’s overarching aim – to facilitate meaningful partnership between lived and learned experience in health and social care – is shared by many other initiatives. But a key factor in the success of this project to date is an investment in its sustainability. Both Q Community and National Voices accepted and supported the long timescales and resourcing costs necessary to grow and co-produce with a diverse community. The funding was given to National Voices with very few conditions and the freedom this offered has allowed the project to grow organically, aligned with the needs and strengths of those involved. National Voices recognised that they had to change as an organisation and were willing to take risks to explore how this might be possible.

This is a privilege that many others do not have, but it is still time limited. Developing a financially sustainable model – the coaching and mentoring offer – has been priority for Voices for Improvement from the start, to ensure it can continue to build on these foundations. This requires very different skillsets and expertise to those held by the Voices for Improvement team, and it can feel uncomfortable to put a price on a values-based and person-centred way of working.
Pursuing this model in practice can also mean difficult decisions around when and how to compromise – the project needs income from clients to stay afloat, but at what cost to its quality, approach and co-productive ethos? This is an ongoing tension which will have to be negotiated as the project grows.

Nevertheless, the work which sits behind authentic co-production is substantial, often invisible and rarely properly resourced. Just as the health and care system sees more value in the insights of those with lived experience when presented through a coaching model, so charging client organisations to access Voices for Improvement sends the message that this work has financial value. It is not an add-on, which can be achieved on a shoestring, but an investment. Without an ongoing funding stream, the projects like this will never be able to expand and embed co-production beyond a small minority of people and organisations.

Learn alongside each other

A commitment to ongoing learning and improvement underpins co-production; people need the confidence to ‘try and see’, with the understanding that failure or missteps will ultimately lead to better outcomes. Again, this requires intention, creating spaces for shared reflection and cultivating a culture of honesty and challenge. Voices for Improvement was committed to this ethos, and to evaluating the project, but a learning partnership, rather than a traditional evaluation approach, was identified as the most appropriate fit for its iterative and co-productive nature. A learning partner works with the team, bridging the insider/outsider role and responding flexibly to the needs of the project rather than adhering strictly to any predetermined agenda. Learning by doing offers greater, more immediate value to the project’s development. Co-Production Collective at UCL were commissioned to take on this role, with Lizzie Cain acting as a thinking partner and critical friend to Rachel and Keymn through weekly reflective meetings, in addition to more traditional evaluation activities.

However, it is also important to ensure that a project like this does not develop in a bubble, working only with those who already believe in its value. Inviting a wide range of voices into the process is necessary to mitigate this, such as appointing co-learning partners with lived experience to complement the learned experience brought by Lizzie. Similarly, the coaching and mentoring training was designed using a Plan Do Study Act cycle, testing-and-learning with each cohort, making improvements with participants to support experience and outcomes.

Some organisations want to access a neat and easy package – access the benefits but not the sometimes messy, often uncertain process of getting there. If you want authenticity, it isn’t necessarily going to be easy. We need to be aware of the danger of validating and supporting bad practice, work which isn’t making a difference.

Charlotte Augst, Chief Executive, National Voices
03 What is needed to support meaningful partnership between lived and learned experience?

Communicating and sharing this ongoing learning more widely also brings multiple benefits. Not only does it ensure opportunities for check-and-challenge from believers and sceptics alike, it builds awareness of this work and the evidence generated as to its value. These reflective processes align with the fourth cornerstone of the Co-Active model to ‘Evoke transformation’. The Voices for Improvement team did this through publishing blogs, meeting with potential stakeholders and holding the flagship Valuing Lived Improvement event on 9 February.

Much of the feedback from this webinar was very positive, but there was perhaps even greater benefit in the questions raised around the clarity of what was on offer, and how it was being presented.

With the event being attended by 250 people, it became very visible that there is real appetite and interest in this work. Those in the room felt part of something, learned more about what might be possible for them and their organisations, and could take this back to senior leaders as evidence that others are wanting to do this kind of work – so they should too.

My takeaway – That there is a trend of positivity out there. Organisations working collaboratively to change and or improve care for all – patients, families, carers and professionals will all benefit from in the near future.

Valuing Lived Experience event attendee
I’m a full time caregiver for aging parents and live with bipolar diagnosis since the age of 17. I joined the Voices for Improvement programme initially as a learning partner, and I think the idea behind that was to ensure that the co-production ethos ran through the learning and development side as well – I brought a bit of balance to Lizzie’s learned experience. Then later on, and having heard about it from the first participants, I had the opportunity to go on the coaching and mentoring training as well. This made the dynamic interesting again, as I’m more emotionally connected, seeing the work from two different perspectives.

I really got hooked when we began working together on my idea to develop some pre-training questions for the pilot participants. I automatically went back to my professional career, went through the documents and looked at the funder expectations, then framed the questions to meet those. But Lizzie gently nudged me and said – ‘what about the participants? If we focus on their needs, then we’ll probably end up meeting the funder needs and hopefully identify different ideas that they hadn’t thought of’. This approach felt qualitative, different to anything I’d done before.

I think back to my working experience, and I know it can be difficult to let priorities emerge from the bottom up, to take risks and be creative. But the ethos of this programme creates the time and space for that, addressing how it supports the participants. Not reasonable adjustments, but adjustments to whatever people need in order to make it work for them and everyone else. I think that support ethos will be what drives the sustainability of the program going forward.

Somebody I’ve been working with recently who is a senior leader in the health system said about themselves – ‘I’m passionate about co production, I believe in it, I strive to make it central to what I do. But with work pressures and deadlines and everything, sometimes reflexively and without noticing it, I default back to the standard model and the co-production slips away. And what I really need is a guardian angel sitting on my shoulder and just gently pointing out to me when I’ve defaulted back to the standard way of doing things.’

I think Voices for Improvement has the potential to meet that need.
Working with Richard, and for a shorter time with Marlon, has brought a level of insight and depth which I would never have been able to achieve on my own. Our collaboration was both structured and informal: lots of conversations to get to know each other, establish ways of working together, and develop trust.

In keeping with the Voices for Improvement approach, Richard and Marlon challenged my assumptions about all aspects of the training evaluation, from the kind of questions we should be asking to what the evidence we generated might mean. Additionally, their delivery of these activities added to their value. For example, Richard established an immediate connection with the participant he interviewed based on their shared lived experiences, leading to a different kind of conversation emerging.

Both were actively involved in shaping the Valuing Lived Improvement event, with Marlon reminding us to be inclusive and think about how we would welcome those in the audience who may not necessarily feel comfortable in professional-dominated spaces. Similarly, Richard’s multi-layered insight into the training process, as both participant and evaluator, gave a stronger foundation in identifying aspects of the process which could be improved.
The challenge of working differently is to capture what you do and how you did it when you are fully immersed in testing ideas and bringing them to life.

With traditional evaluation approaches, the relationship between the team delivering work and the evaluation team can be tense. It is both exciting and scary to build something new and formal evaluation can foreground unintentional judgment that may drain energy and stifle courage.

We placed learning at the heart of what we delivered. It is an ethos of constructive check and challenge and brought perspectives that were more distant from day-to-day delivery. Lizzie, Richard, and Marlon each offered valuable questions and reflections to get underneath our actions.

Over two years, Voices for Improvement was conducted in 4-6 month blocks of rapid and intense activity working remotely. The presence of a learning partner held our changing narrative together, week in and week out. It enabled us to see what worked and what was stuck. I’d encourage any team to appoint a learning partner who acts as critical friend when embarking on change.

Rachel

I’m not sure why I haven’t worked in this way before. To work with Lizzie our learning partner at UCL has been enlightening and extremely constructive. I will find it hard to work in any other way in future.

Lizzie’s style and approach factored in time which I now call “work therapy”. A space was created to reflect on the journey step by step and challenge by challenge.

In all my time of supporting co-production, I have never had a lived experience peer evaluate my work so closely. Getting regular constructive feedback was a gift which allowed me to stretch my thoughts and ideas!

Keymn
Our health and care system does not meet the needs of those it exists to serve, particularly those from marginalised backgrounds. Inequalities are worsening and issues such as the inverse care law, racism and paternalism are complex and systemic.

We know that real and lasting change comes from the depth of understanding and fresh ideas which emerge from high quality relationships. They provide the conditions for co-production, for a way of working in which power is shared and all forms of knowledge are valued. This is what leads to the shift in mental models which influence practice, begin to reshape structures, and ultimately change outcomes.

Voices for Improvement offers a foundation for those relationships. It demonstrates how meaningful collaboration between those experiencing poor outcomes, and those who hold the power to tackle them, can be supported and facilitated. It starts small, with two people forming a relationship, but, as the experience of National Voices has shown, has the potential to lead to wider changes in practice and policy. The strength of the project is that it has already done this work for itself – Rachel and Keymn’s co-leadership, embedded within the organisation, embodies what is possible when diversity is valued, resourced, and invested in.

The commitment required for this approach to work is substantial, but it is also not complicated. It’s about building on people’s strengths, a willingness to be flexible and embrace new ways of working, and the recognition that we need to learn together to create real and lasting change. It’s the bravest step we can take right now.

Through Voices for Improvement, National Voices has committed to the work of co-production. This is our journey – we hope Voices for Improvement can set you on yours.

Courage calls to courage everywhere and its voice cannot be denied.

Millicent Fawcett, suffragist
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Glossary of terms

This glossary explains what we mean by the following terms in relation to Voices for Improvement. Others may have their own terms and definitions.

**Lived experience**
The experience of people(s) on whom a social issue, or a combination of issues, has had a direct personal impact.

**Learned experience**
The experience gained through training, education, employment or professional activity.

**Co-production**
A way of working together underpinned by principles which support inclusion, equity, shared decisions and ownership for what is produced and the impact it has, at all levels.

**Strategic co-production**
A way of working at a strategic level which enables decisions to be made with people with lived experience, to influence policy, service design and delivery, evaluation and resource allocation.

**Lived Experience Partners**
People with lived experience taking part in the Voices for Improvement coaching and training programme or supporting National Voices work in other ways.

**Clients**
Senior leaders in health and social care organisations who invest in Voices for Improvement and receive coaching or other support from Lived Experience Partners.
Further reading

Below is a reading list of texts which have influenced the development of Voices for Improvement.

- Sheila McKechnie Foundation: The Power Project, It’s All About Power (2022)