“By role modelling co-production, by working truly together, building trusting relationships with people who provide our care, we can enable change together.... I am living proof that co-production changes lives.”

Iris Benson MBE,
Mersey Care Foundation Trust
**Current situation**

Involving people with lived experience in co-producing better mental healthcare gives everyone trying to improve services a far more informed base of knowledge and perception on which to draw. However, the take-up and practice of co-production in mental health improvement varies widely and the full potential of this approach is not yet being realised across the country.

Co-production with experts by experience is more demanding than ‘top-down’ improvement but its advantages clearly outweigh its demands and it is now a statutory requirement (Health and Social Care Act 2012). This group believes that involving people who use services in designing services offers an opportunity to improve service delivery, as well as other significant gains (Repper and Perkins 2003). For sustainable impact, co-production also calls for a radical and courageous rethink of deeply embedded attitudes of authority and deference.

Becoming an expert by experience needs self-confidence, belief and empowerment: co-producing professionals, for their part, need vulnerability, humility and self-awareness. The trusts belonging to this group have found that working in partnership with people who use mental health services advances service delivery in the widest sense to levels that could not be achieved without people who use services’ equal participation.

“Getting the right help at the right place as quickly as possible enables people to have access to information, support and services to improve their quality of life. It is crucial that the emphasis (where possible) is about working in partnership with them at the earliest point, to understand their difficulties and strengths in order to decide the way forward collaboratively. It is essential that people have early access to treatment and interventions after assessments, so that people are not left on long waiting lists which can be misleading and give false hope. Any standards and measurements around early access should be at the point of formulating, plans and goals, as it is these interventions at this stage of their journey that can/will have an impact and make a difference.”

Nicola Armstrong, Patient and Carer Involvement Facilitator, Northumberland, Tyne and Wear NHS Foundation Trust

*Our business is clinically and service-user led, and managerially enabled“*

Sheena Cumiskey, Cheshire and Wirral Partnership NHS Foundation Trust

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**Experts by experience**

Nothing happens in healthcare without people who use services, their carers and families.

Involving them on your improvement journey pays dividends.

Feedback from experts by experience in whatever form (complaints, compliments, Healthwatch) gives an organisation the opportunity to evaluate what aspects of its services need to improve.

However if things have not been great, there is a need to gain their trust, as well as supporting staff to accept inclusion of experts by experience in improvement.

Embedding and sustaining this approach is simple, but not always easy.
What is an expert by experience and what does co-production mean?

An expert by experience is someone who has personal, lived experience of using health, mental health and/or social care services, or of caring for someone who uses those services.

Slay and Stephens define co-production as a “relationship where professionals and citizens share power to plan and deliver support together, recognising that both partners have vital contributions to make to improve quality of life for people and communities.”

(Slay and Stephens 2013, p3)

Co-production is therefore an approach to change based on dialogue. Working together, groups of experts by experience of mental health services, professionals and other stakeholders can co-produce every stage of efforts to improve services – from design and delivery to evaluation.

“My role (as Improvement lead) can support others to become more actively involved in speaking out; we have nothing to fear by people speaking out. If we don’t say what’s wrong, we can’t make it better. By role modelling co-production, by working truly together, building trusting relationships with people who provide our care, we can enable change together. Perceptions of mental health have changed in my lifetime but there is still a long way to go. My role in No Force First shows that it can be done. I am the living proof that co-production changes lives.”

Iris Benson MBE, expert by experience at Mersey Care NHS Foundation Trust

The six defining principles of co-production with experts by experience

(adapted from Slay and Stephens 2013)

- Recognising people as assets - transforming perceptions of people as passive recipients of care and “burdens” on the system to equal partners in designing and delivering services.
- Building on people’s existing capabilities - actively supporting people to recognise and use their strengths.
- Reciprocity and mutuality - offering people who use services opportunities to develop reciprocal relationships with professionals (and with each other) and enter into mutual responsibilities and expectations.
- Peer support networks - enhancing the generation and transfer of knowledge by engaging personal and peer networks alongside those of professionals.
- Breaking down barriers - blurring the distinctions between professionals and producers and consumers of services, and reconfiguring power relations and the way services are developed and provided.
- Facilitating rather than delivering - enabling professional staff to become catalysts of change instead of sole providers of services.

Review of current thinking

The idea that people with personal experience of mental illness should be active partners in service development, support and provision for others reflects a shift from a discourse on mental illness with roots in beliefs, practices and language dating from the 19th century (Hutchinson 2016). This was a period when first-person accounts of mental illness were rare (Bateson 1974). Valuing the authority of personal accounts alongside the more traditional authority possessed by trained staff and professionals has many antecedents in the 20th century, including the adoption of gestalt, narrative and phenomenological methods in social science research from the 1960s onward, and later influences from critical theory, post-modernism and feminism (Noorani 2013).

Self-management in healthcare has been a component of government policy since 1999: the Expert Patient Programme (DoH 2001) required people who use services to be involved in developing mental health services (Tait and Lester 2005). The term ‘experts by experience’ has been in use in mental health improvement since around 2003 (McLaughlin 2009).

The ladder of participation

At the New Economics Foundation, Slay and Stephens (2013) have developed the ladder of citizen participation shown in Figure 1. The ladder distinguishes three levels of people who use services involvement in change and improvement.

Figure 1: The ladder of participation
The ladder is useful for NHS organisations wishing to reflect honestly on their progress and aspirations. It visualises a continuum from coercive levels of engagement, in which people who use services hand themselves over to the experts, through superficial involvement with people who use services, in which professionals still set the boundaries for the relationship, to transformative co-production, in which people are fully involved in all aspects of design, delivery and evaluation of services.

The characteristic defining each step on the ladder is power and its distribution between those with professional expertise and those with lived experience. It is tempting for organisations to overstate progress up the ladder, but to realise the true potential of co-production they should make an objective appraisal of where they are.

In the national mental health improvement model, co-production can be seen both in hierarchical and holistic terms. As hierarchy, it emphasises and then challenges existing balances of power in relationships between the players in a mental healthcare system, but in holistic terms each individual player (and level) can only be understood in relation to the whole.

**Why use co-production with experts by experience for improvement and what it’s like in practice**

There are clear business reasons for co-producing improvement with experts by experience. Since they are customers of services, service designs that incorporate their insights are far better than those that rely on groups of professionals alone to plan and decide.

“Co-producing delivers better outcomes. This is a caring element but it also makes business sense, ie understanding what your customers want/need is key … at the individual through to the strategic level.”

**Expert by experience**

Mental health trusts already engage with people who use services, families, carers and community members through consultations, surveys and the like. All types of participation have a role in organisational change. However, for trusts where the priority is continuously improving, people who use services’ are the value judges of the effectiveness of care, so wherever possible co-production with experts by experience is the most appropriate approach.
Supporting experts by experience and professionals in co-production

Co-production can expose vulnerabilities and conflicting perspectives. Experts by experience and professionals may need training or one-to-one support to make sure all their different perspectives are aired equally, for conflicts and challenges to surface openly and be heard, and for people to recognise that full consensus will not be possible on every aspect of a service. Co-produced projects that expect only unison and harmony can get stuck.

Paying attention to the potential needs of experts by experience and professionals under the headings below helps co-production teams form effective working relationships.

**Ability**

Do those involved have a clear understanding of the topic? Have any development needs been identified, and are they being addressed?

**Honesty**

Is everyone party to the same information? Do they have the same clear expectations about what can be realistically achieved and how power is shared? Who ultimately will take any decision that can’t be taken collectively?

**Time**

Is the time committed to the project realistic and fair for all? Co-production is a long game. The benefits will be sustainable but the approach does not always deliver quick wins. That said, as co-production skills become embedded in organisations, co-produced activities can run much more efficiently.

**Reciprocity**

What exactly can the experts by experience and professionals hope to gain in return for their involvement in the activity?

Things to keep in mind

As a co-production team starts working together, being alert to these three issues will help to keep its members working together effectively.

**Power imbalances**

Given the range of interests involved in co-productive working, people are bound to encounter power imbalances, whether consciously or unconsciously. Power dynamics that operate in clinical contexts tend to transfer to this new setting unless they are explicitly challenged. Team members need to understand and acknowledge equally what each can offer.

**Working together from the outset**

Co-production is often said to start from a blank page, meaning all partners in the piece of work are involved from the outset, before any major decisions have been taken, on the principle of ‘no treatment about me, without me’.

Experts by experience can easily see through tickbox co-production that kicks in after big decisions about a service have been taken. However, starting from scratch isn’t always possible. Where it isn’t, honesty requires that participants are given clear reasons.

**Acknowledging some resistance to the process or the outcome**

Co-production can be hard work if those involved are not familiar with or committed to this way of working. Teams may get ‘fed up’ if they feel their time is being wasted on meaningless activity and, of course, individual ideas of time well spent will differ.

Those who are new to co-producing a change may resist the new way of working. It takes time and care to see why it is worth adopting. The best case for it is made by the actual experience of co-production, supported by systematic debriefing.

**Summary**

This chapter has described a way of working on improvement that exemplifies the spirit of the national mental health improvement model. It has offered evidence from the literature for co-producing improvements with experts by experience as well as a practical approach, illuminated by experience from trusts in tips and case studies.
References


Case study 1 - Experts by experience

Involving experts by experience in recovery

Tees, Esk and Wear Valleys NHS Foundation Trust

What was the aim?

The trust’s recovery strategy, developed in 2013, aimed to ensure services gave people a sense of connectedness, hope and identity beyond mental illness. The trust sought to work in partnership with people who use services to ‘co-produce’ all aspects of care, from individual care plans to service design and delivery.

What was the solution?

A group of people who use services and survivors have formed TEWV Recovery Experts by Experience. Each member undergoes six days’ training. Initially, the training focused on their experience of distress and services; it explored what was helpful and unhelpful, and involved writing a short narrative. Now, training is broader: it encourages people to think about what recovery is and what it is not, what co-production means and the challenges it poses. The trust’s recovery lead and its experts-by-experience co-ordinator conduct the training. About 40 people have been trained so far and 27 are actively involved with the group, co-delivering staff training, sitting on steering groups and taking part in workshops.

What were the results?

Experts by experience were pivotal in setting up a recovery college and an online recovery college for people who use services in the trust. Both provide courses co-produced and co-delivered by staff and people who use services. The co-production group ensured that the trust considered cutting down on rapid tranquilisation as part of its force reduction project and that all inpatients are involved in formulation from the start of their admission; influenced the trust’s consent and medication policies; helped to write the trust’s harm minimisation policy; and helped to train staff in minimising harm on a course that almost all clinical staff have attended.

Want to know more?

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Case study 2 - Experts by experience

People with lived experience co-designing quality improvement

Lancashire Care NHS Foundation Trust

What was the problem?

People with lived experience of the learning disability service said that transition from the service and/or a change of service staff member were challenging events for them.

What was the solution?

Co-designing an ‘always event’ with people who use the service. The always event enables each person who uses services to say that: “I will always be supported in moving on in care”. To ensure this support, the co-design team developed:

- a contact card to be given on discharge to people using the service
- notification of proposed staff changes or transfers by letter, with photographs of new staff
- a monthly ‘pop in and chat’ support session.

The team used plan-do-study-act (PDSA) methodology to develop and test these ideas.

What were the results?

Between July 2015 and January 2016, 26 people were discharged using the new procedure (letter, contact card, invitation to pop in and chat). A support worker made a follow-up contact call two weeks later, and cases were discussed at the team’s weekly discharge meetings.

Picker Europe (a not-for-profit organisation that makes people who use services’ views count in healthcare) evaluated the changes and found a positive difference to the experiences of care for people using the service and for staff. People using the service commented: “I keep the card on the fridge with a magnet – so I see it all the time”, and: “My idea was chosen . . . I feel good”. Staff commented:

- “Co-design made the implementation feel real and right the way target-driven things aren’t.”
- “I was worried that it was going to be difficult to do but it’s not at all. It’s a small investment of time to have a big impact.”

Always events are now integrated into the trust’s organisational quality improvement approach, and other always events are being co-designed in many care environments.

Want to know more?

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Case study 3 - Experts by experience

Improving initial mental health assessments using experience-based design

Cheshire and Wirral Partnership NHS Foundation Trust

What was the problem?

Initial mental health assessments can be stressful for people who use services and their families: while feeling worried about their health, they must find the clinic and provide a lot of information, filling in forms in a busy reception area. The trust wanted to improve this experience.

What was the solution?

Chester Adult Community Mental Health Team used experience-based design (EBD) to improve initial mental health assessments. EBD is a methodology for working with people who use services, families, carers and staff to improve services that places equal emphasis on people who use services and staff perspectives. EBD gives teams an insight into the people who use services' emotional response to experiencing a service, challenging assumptions and perceptions about what they think the person who use services or carer feels and needs.

The trust's quality observatory trained the project team in EBD and provided support throughout. The team, which included representatives with lived experience, interviewed groups of people who use services and staff to capture their experience of receiving or delivering an initial mental health assessment. Consistent themes emerged from both groups' responses, enabling the project team to recommend key improvements.

What were the challenges?

Getting people on board initially and then maintaining momentum; there were ‘political’ barriers and concerns about the ethical issues of involving people who use services in interviewing other people who use services.

What were the results?

The project began in February 2016 and is continuing. Improvements so far include:

- redesigned letters and leaflets – for example, a welcome information sheet for the outpatient department
- better seating and signage in the reception area
- a volunteer ‘welcomer’ working in the clinic on the two days a week when initial assessments take place, who is responsible for replenishing leaflets and signposting people who use services to further support. This volunteer identified and helped implement further improvements to the outpatient department, namely baby-changing facilities and a separate reception area for people using another service in the same building
- better signage across the hospital site
- an information screen in the outpatient department.

What were the learning points?

- Representatives with lived experience needed to be checked by the Disclosure and Barring Service before the project could begin.
- People who use services enjoyed being interviewed by another ‘peer patient’ and staff were comfortable being interviewed by the project team’s representatives with lived experience.
- The trust had a process for supporting people if they became distressed while being interviewed and volunteers had an emergency contact for any concerns raised.

Next steps

The project team is working through further improvements, such as training opportunities for staff, soundproofing clinic rooms and improving the hospital site map and directions to the clinic and car parks. Someone currently accessing services was involved in testing these improvements. The project team is exploring how to improve sending copies of GP letters to people who have used the service following clinics.

Want to know more?

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Peer Experience Listening Service

Hertfordshire Partnership University NHS Foundation Trust (HPFT)

What was the aim?
The trust wanted to gather qualitative feedback on services and the experience of the people who used them and sought to do this in a way that elicited honest feedback and ‘customer’ insights.

What was the solution?
The trust established a service that provides the organisation with the ability to gain the desired insights through the use of a peer to peer approach via the use of semi-structured interviews.

The Peer Experience Listening Service (PELS) is both directed and delivered through co-productive approaches. Project requests are submitted from across the organisation and the decision about which are supported is made by a stakeholder panel that includes people who use services, carers and third-sector organisations. The stakeholder panel also holds PELS to account for delivery against the agreed timescales.

All the individual project materials (eg surveys) are co-designed and co-produced through the service and all the listening and elicitation of feedback is carried out by people with lived experience. Once all the data has been collected and collated, it is co-analysed and recommendations for service improvements are co-produced.

HPFT provides training and development to our peer listeners on actively listening and conducting semi-structured interviews. Peer listening is a paid activity that can be a route to getting experience towards gaining paid employment should they wish to.

What were the challenges?
HPFT found it challenging to manage people’s expectations about how, when or if they will be involved in a particular project or with the service at all.

HPFT works hard to balance our desire to make it easy for people to get involved against the need to have the right skills and mindset to ensure positive, subjective listening. Not everyone who would like to be a peer experience listener has the right skills, nor may they be the right person for a particular assignment.

Through their experiences HPFT has developed approaches to ensuring the most appropriate people are allocated to the work, reducing the risk that conscious or unconscious biases affect the information-gathering. HPFT sees this as part of the overall co-production ethos of the best utilisation of skills, knowledge and talent.

It has also devised sensitive approaches to managing people’s (unexpected) unavailability for work because of health and wellbeing issues through developing good understanding of peer experience listeners and having contingencies to account for unanticipated absences.

What were the results?
HPFT has gained a deeper understanding of its services from the experience of people who use them, beyond what would have been possible through standard approaches to testing experience.

One example of this is how safe people who use services felt in inpatient settings. The standard approach to asking ‘do you feel safe?’ offered little insight into what may be driving those feelings. Following the Peer Experience Listening project in inpatient services, HPFT have gained insights into what makes, when and how people feel safe or unsafe and are able to now make improvements based on these insights.

HPFT is also pleased that a number of peer experience listeners have found paid employment (including within the trust) following their time with the Peer Experience Listening Service.

What were the learning points?
• It is important to engage with the service that is being assessed from the start of the work, helping it to understand and work in a positive and co-productive manner both during the assessment phase and in the improvement phase.
• This approach provides HPFT with a greater assurance and integrity about the results of our activity - even if similar conclusions could have been gained without using peer listeners.
• The benefit of the approach is not just about the outcomes, but also the positive experience for both the listener and the listened to.
• The approach can offers positive pathways to paid employment for people.

Next steps
• HPFT are continuing the work of the service and exploring ways of better integrating PELS with the rest of the work of the Inclusion and Engagement Team.
• The trust are seeking ways to progress this work into their learning disability services and with young people.

Want to know more?
Contact the Peer Experience Listening Service at inclusion.engagement@hpft.nhs.uk

There is no single, universal model of co-production – its practice takes many different forms (Needham and Carr 2009). But co-production is in general an exploratory, ‘real’ and often tough activity, which is also enormously rewarding. As a change approach, it may feel very messy compared to well-established ‘project management’ techniques. A necessary skill is learning to live with and embrace its uncertainty, ambiguity and occasional discomforts.

“We always think of service-user time as well as professional time when improving services”

Keith Loveman, Finance Director, Hertfordshire Partnership NHS Foundation Trust
Case study 5 - Experts by experience

Appointing an expert by experience as an improvement lead

Mersey Care NHS Foundation Trust

What was the aim?
The trust wanted to move beyond the important but limited aim of inviting people who use services to take part in presentations or interview panels, and make them central to planning and implementing solutions. In particular, it wanted to involve them in reducing restrictive interventions because success would depend on high levels of collaboration between people who use services and staff.

What was the solution?
Appointing an expert by experience as an improvement lead – someone who works alongside professionals with the same title and status – enabled ‘co-production’ to flourish. Staff and people who use services co-produced and co-delivered the trust’s programme to reduce restrictive interventions, known as ‘No Force First’. People who use services talked openly during engagement sessions about the traumatic effect of physical intervention and seclusion, making a critical emotional connection with staff that reinforced the need for change.

What were the challenges?
Some staff may have felt uncomfortable hearing people who use services speak out about difficult inpatient experiences, or may not have understood how critical it was for lived experience to have much more influence in the organisation. Outdated beliefs and stigma may still have remained. But with time, continuing board-level support and the prevailing national agenda, lived experience has become central to the trust’s plans.

What were the results?
No Force First gained national recognition for good practice and reduced the use of physical intervention by 37% between April 2016 and August 2017.

The trust’s expert by experience improvement lead, Iris Benson, comments:

“A co-produced approach to learning harnesses both sets of skills in a way that wins hearts and minds, bringing lived experience to life. It really helps to reduce the stigma I have experienced over many years and stops a ‘them and us’ culture, where people like me are not seen as equals and don’t feel valued or heard.”

What were the learning points?

- Co-production must be sustained and prioritised if it is to thrive.
- Experts by experience need support to bring their abilities forward, but the benefits from this small investment are huge.
- Collaboration in developing strategies should start from a blank page. Anything less can appear tokenistic.
- Hearing people talk about their experiences of care in a constructive, balanced manner can win over hearts and minds and create the momentum for change in a way that traditional top-down directives cannot.

Next steps

- Opening more posts traditionally filled by professionals to people with lived experience.
- Exploring ways to bring more people forward to share their experiences and supporting them in doing so.
- Continually pushing for lived experience to be part of decision-making and planning at all levels in the trust.

Want to know more?
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Case study 6 - Experts by experience

Meeting carers’ needs in a secure service

Mersey Care NHS Foundation Trust

What was the aim?
The trust wanted to meet CQUIN targets for involving carers in secure services and engaging them in helping people who use services recover. Carers told the trust they wanted:
• A carers’ support group.
• Information about services available at Ashworth Hospital.
• Tours of the hospital.
• Information about mental ill health and recovery.

What was the solution?
The trust seconded a staff member to the post of carers’ lead in 2015, and introduced:
• A carers’ forum, which takes place every six weeks before visits, at Ashworth Hospital. Topics include psychosocial education and opportunities to be involved in research and networking. Guest speakers have included consultant psychiatrists, pharmacists, senior nurses, security liaison nurses, equality and diversity leads and representatives from advocacy services.
• A welcome centre next to the visitors’ entrance at Ashworth Hospital, providing information on carers’ rights, mental ill health and recovery. The centre also showcases people who use services’ art and crafts, money from the sale of which is used to buy more equipment for the recovery college.
• An expression-of-interest list of carers who want to receive updates about the hospital, research opportunities and forthcoming events, as well as copies of presentations to the forum.
• An information pack for carers, families and friends, based on carers’ feedback, which covers procedures for visits, recovery, services available in the hospital and links to carers’ support in the trust.
• Tours of the hospital for carers every weekday between noon and 1pm, visiting rehabilitation areas, the health centre and chapel.
• For staff, e-tutorials on carer awareness and face-to-face training to become a carer champion.

What were the results?
Carers say the forums have helped them promote their family member’s recovery and the trust believes the forums have helped break down barriers to engaging with carers. Guest speakers also report that listening to carers’ views has helped them.

More than 50 carers have registered on the expression-of-interest list. Those who have taken a hospital tour say they encouraged their family member afterwards to use the facilities explained on the tour, and that they feel reassured by knowing what is available for people who use services. One carer commented:

“Having a welcome centre is so very useful especially when travelling from the other end of the country. The staff are very welcoming and informative.”

A carer/professional said:

“Every secure service needs one! Very impressed and deeply touched by the thought that has gone in to the centre.”

What were the learning points?
• Sharing resources and information can benefit all services in their work with carers.
• Releasing staff for training and carers’ events benefits the organisation, its workforce and customers.

Want to know more?
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Peer-supported Open Dialogue

North East London NHS Foundation Trust (NELFT)

What was the aim?

Approximately 1.8 million people in the UK suffer from a mental health crisis such as a severe psychotic episode or suicide. The Care Quality Commission (CQC) stated in a 2014 report that 42% of people who use services were not getting the help they needed.

NELFT is part of a national pilot trialling Open Dialogue, which aims to offer a person-centred, more sustainable approach to supporting people in a mental health crisis.

What was the solution?

Open Dialogue is a model of mental health care pioneered in Finland that consistently involves a patient’s family and social network. All healthcare staff receive training in family therapy and related psychological skills. All treatment is carried out via meetings of the person who uses services’ whole system/network, which always include the person who uses services.

The key principles are:

• See people within 24 hours of them becoming unwell.
• Hold all meetings with the clinical team at home, or wherever the person using the service finds most helpful.
• From the word go, engage significant others in the patient’s life – family members or trained peer-support workers - in meetings.

What were the challenges?

Continuity of care is key to the Open Dialogue model: the clinicians who see the person who uses services in a crisis and help create the safe space of those first network meetings remain with the person throughout their journey. This is a challenge to put into practice. It has required a great deal of negotiation among NELFT’s different services. However, new services following the redesigned integrated care pathway will have continuity of care as a core element, in line with the new pathway.

What were the results?

Dr Razzaque explains:

“In normal treatment, you explore what has led to the crisis, but then the response is usually to prescribe medication. With Open Dialogue, the person using the service takes the driving seat in understanding what are the factors that have led them to be the way they are. That’s a very healing thing.”

Suzanne, an expert by experience, adds:

“If it wasn’t for Open Dialogue I wouldn’t be here now. This time last year, I was suicidal. I had totally lost faith in the mental-health services; I felt I’d been put in the ‘too difficult’ box.”

What were the learning points?

In Finland, where Open Dialogue started, 76% of all people who use services seen returned to work or study after two years in service, and never returned thereafter. This kind of outcome is pretty much unheard of anywhere else. As a result, people at NELFT were determined to trial it. Together with several partners around the country, it is now launching a multicentre randomised controlled trial - the biggest study of Open Dialogue in the world to date.

Next steps and sustainability

The trust runs an annual national conference to share the experiences of people who use services and staff using the service and to spread learning.

The trust now offers Dialogue First, a non-crisis community mental health service that follows the principles of Open Dialogue.

As the results from the pilot teams start to emerge, the trust intends to gradually roll out the Open Dialogue approach across its services and hopes to lead a national move in this direction too.

Want to know more?

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