

Wales Early Intervention In Psychosis

Service Development and Improvement

Series Six: Coproduction and Engagement



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Improvement Cymru is the improvement service for NHS Wales. Our aim is to support the creation of the best quality health and care system for Wales so that everyone has access to safe, effective and efficient care in the right place and the right time

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Early Intervention in Psychosis

Purpose

This paper provides a look at how Early Intervention in Psychosis (EIP) services in Wales can engage individuals with lived experience in the design, development, improvement and evaluation of services. It provides a brief overview of the principles of co-production,

getting started in practice and signposts to further resources.

The paper informs a variety of audiences, including individuals with early psychosis, their families and carers, the general public, EIP team members and commissioners of services.

What matters to young people

EIP services in Wales provide space for young people and families to share their stories of recovery and experiences of care, providing a perspective that helps shapehow and where services can improve. However, opportunities for individuals to actively participate in the service design process has been limited.

The Investing in the Next Generation (2022) position paper for Wales sets out a number of statements that demonstrate how EIP services are committed to improving care experience and delivery. One of these statements related to increasing the involvement of individuals with psychosis and their families and carers in the regional development of services (1).

A number of young people have shared their ideas and feelings around what matters to them when engaging with services. Themes have primarily focused on **feeling involved**, **helping others and making a change**. Many have also identified personal gains in terms of improved confidence.

Treating people as equal partners in service development acknowledges the skill and value of that individual ⁽²⁾. Embedding this principles alongside a commitment from staff and organisations can achieve services that offer and deliver more appropriate, meaningful and outcomes focused flexible care and positive experiences.

The Improvement Cymru EIP programme team, the national steering group for Wales and third sector partners have committed to collaborate on understanding this further and ensure the design and development of services are truly co-produced.

Improve
Meaning Help others

Feel listened too Change
Confidence Get involved Give back
Chance to make things better
Included Be creative
Share what I learnt
A way to say thank you
Work together

Work together
Make a difference
Learn

Word cloud: feedback from individuals under EIP services who had co-produced elements of their service.

Examples from Wales

The national EIP quality and improvement programme consists of individual working groups focused on key areas of EIP practice in Wales and provides space to share developments, promote skills and knowledge, develop leadership and work toward meeting the National Clinical Audit of Psychosis (NCAP)

standards, with key targets driving continuous improvement. Each workstream has identified a number of key objectives with agreed outputs.

Examples of how EIP services in Wales have moved toward a more co-produced way of working are illustrated by two workstream projects.

Carers Education and Skills programme

Workstream group consisting of representatives from all regions in Wales are collaborating to scope out and develop a series of modules to support carer education and skill. The group are committed to **creating an accessible and consistent approach that can be adapted to local need.** The modules developed so far are module 1: 'understanding psychosis' and more recently design has commenced on module 2: 'treatment and interventions'.

Families and carers of young people under EIP services have been engaged throughout module 1 with small focus groups exploring the content and design of training slides and a workbook. Learning from how families and carers were engaged in module 1 is now being applied to module 2 with **increased participation at the outset** and setting up of a joint working group between professionals, families and carers to work collaboratively.

Physical Health programme

It is recognised that traditional emphasis has been on screening for physical health conditions with a lack of focus on follow up or intervention. A workstream consisting of representatives from across all regions in Wales has been established and is engaging with current service users to **redesign the existing health and wellbeing programme.** The individuals engaged have completed the programme in its original format and have been invaluable in their contribution to developing new content and ensuring objectives are met to achieve an all Wales physical health and intervention programme.

These two examples have engaged service users, families and carers to some degree, however the workstream leads and clinicians involved acknowledge more could be done to truly achieve co-produced design and are in both cases demonstrating the need to engage from the outset in the planning of future developments and projects.

EIP services in Wales are keen to ensure the value and contribution of service users, families and carers is recognised and utilised to achieve effective partnerships.

Understanding co-production in design and delivery

Co-production, although not a new approach does provide a shift in how services are designed and delivered. Oliver, et al. (2020:1) describe the move as

"The mechanistic idea of healthcare being a 'product' generated by the healthcare system and delivered to patients is replaced by that of a service co-created by the healthcare system and the users of healthcare services." (3)

Within their literature review Conquer (2021:20) discusses the term 'co-production', commenting there is no 'single formula and therefore no universal definition' (4). Furthermore, it is important not to define co-production so as to allow innovation and creativity (5). The literature therefore broadly suggests that **rather than** a single definition, co-production is best understood by its key characteristics, summarised as,

- People who use services being involved as equals with professionals
- People who use services having the power to be respected, have the ability to make change and have an impact, where they move from being 'voices' to 'agents' in design, delivery and change
- An approach from the beginning of a project
- Services being an enabler and contributing to the facilitation of change rather than solely deliveryMoving from a deficit approach to asset-based through building on people's existing capabilities and actively supporting growth
- Ongoing partnership between people who design, deliver and commission services, the people who use the services and people who need them
- Doing what matters to the people involved
- Developing relationships and building networks

Summary

Co-production encompasses a number of activities and approaches.

The Social Care Institute for Excellence (SCIE) provides a useful description of terms used within a co-production approach (6), these are summarised in relation to activities as:

- Co-design, including planning of services
- Co-decision making in the allocation of resources
- Co-delivery of services, including the role of volunteers in providing a service
- **Co-evaluation** of the service

Boyle et al (2010) suggest that by changing the way we think about and act upon 'needs' and 'services' we access more resources and achieve better outcomes (5).



Opportunities within EIP services

EIP services in Wales remain in a state of development with variation in the resource, capacity and skill mix offered by services nationally. Improvement Cymru has supported services in their development and improvement in recent years, facilitating a series of workstreams with the aim of developing a consistent approach to EIP service development, design and delivery across Wales. As services continue io mature there are opportunities available to ensure co-production is prioritised.

These include opportunities to:

- inform and contribute to continuous improvement initiatives
- **provide feedback** on experience of service
- contribute to evaluation
- identify priorities for the population (what matters)
- take on a peer support role
- participate in the recruitment process
- shape and inform review of policy, procedure, and service specification
- provide a non-clinical voice to discussion



Principles for engagement

Principles for co-production are extensively discussed within the literature, resources and tools available to services within the UK and internationally. By aligning with these principles, services can support genuine co-production in practice. Engagement requires

- Clear communication on what we are asking of people, the parameters of what is and isn't possible and the commitment involved. Be clear on the resources available to support the work, the opportunities and limitations. Ensure a shared understanding of the roles and responsibilities of all those involved.
- Set objectives by defining the purpose and what we are aiming to achieve together. This is not a tokenistic gesture, there is a rationale to involve individuals with lived experience and it is important that those individuals, as well as staff are clear on this to provide value, meaning and opportunity to make a difference.
- **Transparency** around how information will be used, who will have access, and whether they will be identifiable.
- Flexibility in what engagement looks like. The format, timings of sessions and access to an inclusive, accessible physical space are necessary and may need to adapt dependant on the individuals involved. Understanding the infrastructure of a local area that will enable or hinder engagement is required. By offering a range of methods and selection of materials there is flexibility and increased accessibility.
- Reciprocity is explained as ensuring people receive something back in exchange for their contribution. This builds on an individual's desire to feel valued and promotes togetherness as an inclusive wider team. This may be guided by local policy.

- Recognition of skill and strengths of the individuals we engage. Everyone comes with their own experience, history, interests and motivations. The knowledge and expertise of someone with experience will ensure solutions address the need ⁽⁷⁾.
- Be inclusive and accessible by engaging with individuals from diverse backgrounds.
 Services need to involve more than one person and ensure representation to understand the needs, experiences and priorities for all. Be mindful of language and cultural norms and consider if interpreters are needed to support sessions.



Getting Started in practice

As a starting point it is worth assessing how a service currently engages individuals with lived experience in co-production. ProMo-Cymru's TEC Model - ProMo-Cymru provide a list of questions to consider. When reading through the following, remember this is an asset-based approach, it is not deficit focused so avoid conversations around 'What's wrong?'

- **Who produced** information for your young people, families and carers?
- Is it accessible? How can you improve?
- Can people who use services feedback on what they need? In what formats?
- Can you increase opportunities for coproducing information?
- How do you work with people who use services to arrive at an outcome they want?

- What are the benefits and challenges of this way of working?
- How can we overcome these barriers?
- When do you engage and consult with the people who use your services?
- How do you engage with them?
- Who do you engage with? Is everyone represented?
- What do you do with feedback? Do you implement any of the suggestions? Is this reviewed?

Online resources are available to support thinking and planning. Some examples are collated within the further resources section.

Considerations for practice

The following list is not exhaustive but serves to provide some initial pointers for services on what to consider when looking to improve the way they engage individuals with lived experience and their families and carers to become partners and co-creators.

- Organisational procedures should be consulted to fully enable the participation of individuals. Co-design and co-production require planning to ensure a safe space for meaningful engagement is achieved. It is important to confirm the appropriate process and requirements as per local health board policy, particularly around reimbursing individuals for their time and contribution. Depending on age of the individual, consent may be needed.
- Co-production and co-design requires time and resource investment, and in some cases, consultation will be a valid form of participation (8). If this is the approach taken however there should be an ability to justify why consultation is being used (a doing for approach) rather than

- co-production or co-design (a doing with approach).
- From a management viewpoint, ensure frontline staff are involved and have the time, space and resources to support coproduction in practice.
- Ensure the people engaged reflect the diversity of the area and client group, by incorporating multiple perspectives there will be an added richness to understanding of how services are received and experienced.
- The co-production process should be seen as continuous and not a one-off event or engagement workshop.
- There needs to be a shared understanding of what co-production is and looks like within a service and within the wider organisation. There may be opportunities for developing training packages around the approach and/ or outside agencies such as third sector may be in a position to provide training around the value and principles of co-production.

- It would be appropriate to conduct regular reviews to ensure co-production is making a genuine difference and that local processes are following the agreed principles.
- how people participate, particularly with vulnerable client groups such as individuals under EIP services. **Creative activities** can help to engage but also help to capture unique experiences and perspectives by enabling exploration of solutions that will be most effective in meeting needs (9). There are resources and activities available online to support co-design and co-production that make the most of opportunities to gain the most value.
- Time spent focused on contingency planning is needed early on to highlight potential concerns and actions to follow for

- each individual involved, for example, if a young person were to become distressed during their involvement, the plan would outline what works for them in that situation. Ensure plans are **person centred** and support staff are available at all times.
- Partnership working will provide opportunities for services to support individual personal development of those involved, such as promoting confidence, facilitation skills and public speaking. Consider this and promote opportunities through discussions with individuals.
- pieces of work can be **celebrated and promoted**, there will be opportunities to
 share both locally within the health board
 organisation and to do so on a national
 stage.

The difference co-production makes

A literature review by the New Economics Foundation (2013) commissioned by Mind provides a summary of the positive impact coproduction can have for an individual ⁽¹⁰⁾. The themes identified across a number of studies include,

- Improved social networks
- Improved social inclusion
- Addressing stigma
- Improved skills and employability
- Preventing deterioration
- Well-being-related outcomes, including improved mental and physical well-being

The report identifies that where evaluations have taken an outcomes-focused approach, outcomes have included improved social networks, feeling valued, greater community cohesion, reduced stigma, and reduced isolation. Similar themes were expressed in the discussion with a small number of EIP service users in Wales in preparation for this paper.

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Conclusion

The level of co-production within Welsh EIP services has varied over the years, however there is momentum, interest and commitment to embedding principles into practice by recognising the benefits it can yield for individuals and for services.

Crucially, co-production isn't just about services, it's changing the way we work and as such requires a commitment at all levels. A change in approach and a change is culture needs to be supported and encouraged. The ambition should be that co-production is part of the culture of a service and wider, the organisation. There needs to be a shared understanding of what co-production is and what it looks like in practice.

There is an opportunity within the development of EIP services to implement new approaches, opportunities and initiatives that place people with lived experience at the heart. Services must however aim for engagement in all aspects including planning, development, delivery and evaluation.

The resources available online and the learning from literature discuss the benefits and also the challenges of co-production in practice, but with a consistent message that a commitment to working in partnership supports innovation and the transformation of services.



Further Resources

Coproduction Network for Wales Co-production Network for Wales (copronet.wales)

Coproduction Network for Wales Knowledge base Co-production Network for Wales Knowledge Base – Co-production Network for Wales Knowledge Base (copronet.wales)

National Development Team for Inclusion MH_Coproduction_guide.pdf (ndti.org.uk) for discussion on context and challenges specific to mental health services

NESTA People powered health co production catalogue co-production_catalogue.pdf (nesta.org.uk) includes case studies and practical tools to support co production in practice

ORYGEN centre of Excellence for youth mental health Engaging young people and their families in youth mental health - Orygen, Revolution in Mind

Podcast series (2023) Exploration about co-production in public services [Audio] A podcast series of exploration about co-production in public services – Co-production Network for Wales Knowledge Base (copronet.wales)

Scottish co-production network (2021) 100 Stories of Coproduction: short films to help you spread the word about co-production 100 Stories of Co-production — Scottish Co-production Network (coproductionscotland.org.uk)

Social Care Institute for Excellence (SCIE) What is co-production and how to do it Co-production: what it is and how to do it | SCIE

The Health Foundation (2010) What is Co production? vbhc.nhs.wales/images/helpful-materials/what-is-co-production/

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Improvement Cymru

2 Capital Quarter Tyndall Street Cardiff CF10 4BZ

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