

**Patient-led workshop**  
**Putting the patient into person-centred care**  
**13:30-14:30, May 9<sup>th</sup>, 2017**  
**ICIC Conference, UCD, Dublin**

A patient and carer-focused workshop took place at the ICIC 2017 conference in University College Dublin on May 9<sup>th</sup> 2017. The objective of the session was to brief the 60 participants on the outputs of the Patient Narrative project as well as the concepts of co-design and co-production and how these concepts can be implemented in Ireland.



**Chair of workshop:**

Derick Mitchell, Chief Executive, IPPOSI

**Other Speakers:**

Clare Hudson, Health Service Executive  
Anne Lawlor, 22q11 Ireland Patient Support  
Gina Delaney, Advancing Recovery Ireland  
Margaret Sweeney, Advancing Recovery Ireland

**Summary:**

Derick Mitchell introduced the patient narrative project, and what patients/service users in Ireland are actually saying they want to see in a health service that is person-centered and coordinated.

Phase 1 of the project developed a 'torch to go forward' and has produced 19 'statements' and a 'definition' of person-centered, coordinated care which is based on Irish patient's care perspective. Once these are validated by stakeholders, the objective will be to take these generic statements forward and to adapt according to local, regional and national service provision needs.

The definition and statements give confidence to patients that the HSE are responding to patient needs and experiences. The next step is to make them actionable, and to further co-production and co-design through involvement of providers into the project.

Clare Hudson introduced Phase 2 and 3 of the project and what they are designed to achieve - an online framework that people can log onto to share their experience of healthcare and make sense of it in the context of the statements developed in Phase 1. The HSE will be able to quantitatively and qualitatively analyze this information and use it in the design and development of services both nationally and locally. The information will allow local areas to see how much of a reality person-centred coordinated care is (or is not) from the lived experiences of the people who use the services. The most important element of the project is the partnership between HSE, service users, patients and care givers in the design, delivery and review of healthcare services into the future.

Anne Lawlor, 22q11 Ireland, described being involved in this project as ‘the difference between a recipient of care vs. an active participant’. Anne is delighted to hear this kind of work is happening with the HSE and that this project will give patients and carers a sense of control and say in their care. Currently some integrated care organizations are too disease-focused rather than person-centered, with disciplines being ‘too siloed’. ‘To be asked to join and have an opportunity to co-design and coproduce, and to have an input on care is truly amazing’, she said.

Introducing the concepts of co-design and co-production, Derick defined co-design and coproduction as ‘partnerships between health service users and providers’. In co-production, patients define the need or problem, and contribute to design and delivery of the solution.

Gina Delaney, Advancing Recovery in Ireland (ARI) described the recovery model working in mental health services in Ireland. Co-production for her is about ‘listening, hearing and respecting the skills you can contribute’. It’s about partnership and collaboration. It’s about genuine equality for each member in the group. For example - attending Multi-Disciplinary-Team meetings regarding a loved one’s care - Gina learned to assert her equality at the table during the conversation, especially about planning and caring. In her co-production work, Gina has been involved in selecting 10 priority areas for mental health services. It also gave her a space for her and her mother to be around other people in a similar situation. It helped her overcome a fear of the unknown of working in a different way. She believed it gave providers the opportunity to let go a little and empower patients, moving from passive to involved.

Margaret Sweeney (ARI) is involved in a recovery center (based on a wellness recovery plan) that is oriented around recovery-based mental health services. She co-facilitates some of the services, and finds that each voice is important in giving people a platform to share their experiences. Co-production has to be more than just a service user telling their story. “We cannot be token story tellers, we have to make sure our lived experiences are absolutely valuable”, she said. Both service users and providers have concerns about working in a coproduced way. In providers, there’s a big expectation to lead and perform. The team approach of their workshops has been vital.

An open discussion followed to ascertain other examples of coproduction that can be shared with the efforts in Ireland.

**Main point: How to find / recruit patients to help with co-design? There are numerous patient and carer associations, but not a culture of co-design and coproduction.**

- Margaret: It’s very much the relationship between the service provider and users. For example, I got involved through a nurse, and our relationship built up from there.
- Clare: It’s also important to find people that were previously employed by services who had built up those relationships. When the project process and vision were communicated in an easy-to-understand way, these individuals were much more keen to be involved. The important bit is finding these key people.
- Anne: Surely providers are ‘surrounded by service users’ so they need to make the effort to get to know them. Everyone has different talents, so perhaps initiate a focus group or a one-to-one interview. It is about opening up and getting to know the people and what they want to get out of the services. Look into older established patient groups, who want to be part of this patient initiative and who want to do things together.