



## Appendix 1

### Co-Production Explained

Co-production is the active involvement of citizens in service planning, design and delivery including the direct involvement of users in the production, at least in part, of their own services. Source: Wallace (2013) [393] cited in Colgan, A. et al (2016) [61] People's Needs Defining Change – Health Services Change Guide.

It is “a meeting of minds coming together to find shared solutions and involves people who use services working together with staff, from the start to the end of any project that affects them. When co-production works best, people who use services and carers are valued by organisations as equal partners, can share power and have influence over decisions made” (Think Local, Act Personal (TLAP) National Co-production Advisory Group).

#### Co-production:

- acknowledges that people with ‘lived experience’ of a particular condition are often best placed to advise on what support and services will make a positive difference to their lives.
- helps to ground discussions in reality, and to maintain a person-centred perspective.
- is part of the range of methods of patient engagement, is a commitment to sharing power and decisions with patients and is a cornerstone of self-care and of person-centred care.
- involves patients in equal partnership in the earliest stages of any project.



## Appendix 1

# Summary Report of Stakeholder Consultation Sessions

### Introduction and background:

This report provides a summary of the wider stakeholder consultation sessions which were designed and run by Jean Kelly and Irene Maguire (Project team) and Libby Kinneen (Organisational Consultant). The sessions were conducted virtually between March- July 2021.

### Purpose:

The purpose of the wider stakeholder consultation sessions was to:

- increase the depth and breadth of the patient voice in the development of the document, whereby their contributions would be used to inform the content of the Roadmap.
- sense-check the themes identified in the literature to ensure they aligned with the experiences of people using current healthcare services.
- ensure there was representativeness in the design of the Roadmap.
- contribute to the definition of Patient Engagement developed by the working group.
- ensure that the content of the Roadmap would be fit for purpose.

### The consultation focused on:

The definition of patient engagement, what good engagement looked like and experiences where people did not feel engaged.

### Questions asked:

1. How would you define patient engagement?
2. Describe an experience where you felt engaged, what did the staff do to make you feel that way?
3. Describe an experience where you did not feel engaged. What was it that staff did or didn't do that made you feel that way?

### Identifying stakeholders

We sought to reach out to patients who were not represented on the working group, and those whose voices are seldom heard. The final groups consulted were agreed by the working group as being a good cross-section of patients.

We conducted 8 stakeholder consultation sessions with representation from:

- parents of children attending healthcare services.
- the Youth Advisory Council.
- people with a physical disability and people with an intellectual disability attending healthcare services.
- people with mental health illness attending healthcare services.
- people who are homeless.
- people using addiction services.
- people from ethnic minorities including the Travelling community, Roma and African communities.
- the National Patient Forum.
- a range of frontline staff working in different roles and settings.
- staff in senior management roles.

Comprehensive notes were taken during each consultation session, where the focus was on documenting key words and key themes. Anonymity of feedback was guaranteed unless otherwise requested. Participants were advised that the findings would be brought back to the working group and used to inform the content of the Roadmap.

- Patients need to be treated as an equal in all interactions, where their lived experience is respected and acknowledged as being as important as clinical expertise.

## **Connectivity**

Patients need:

- strong communication and cohesion between different teams involved with individual patients.
- consistency in approach and the option to work with the same staff where possible (e.g. healthcare staff informing themselves about the patient – reading the file before the appointment).

## **Some specific themes emerging from particular groups:**

### **Parents:**

A need for:

- healthcare teams and staff within teams to talk to each other.
- being treated as an individual person.
- their child to be the centre of and included in discussions and decisions.
- reduced delays in actions in response to decisions made.
- more involvement at service design level.

### **Mental Health:**

The need to:

- include family, carers and friends, as identified by the patients, in care plans.
- address the lack of opportunity to become more involved in policy making and service design. (Gap between the service user forums and the decision-makers)

### **Social Inclusion:**

- Power: There is a feeling of imbalance of power between patients and healthcare staff. Patients do not feel empowered after many interactions and would value staff not mis-using power.
- Patients have a wish to be treated the same as everyone else, to be respected and for staff to be kind to them.
- Patients need to:
  - feel more empowered after interactions.
  - be given choice.
  - have communication methods which meet their individual needs used.
  - have things explained/ written down for them.
  - have staff check in with them to ensure they understood the discussion or information.

### **Disability:**

Patients need to be:

- supported all the way.
- encouraged and invited to say what they don't like.
- put in the driver's seat.
- setting the goals of their care, in a service that is goal oriented.

### **Youth Advisory Council:**

A need:

- for healthcare staff to show interest in learning more about the person.
- to have how they feel be respected.
- for clear information about transition from child to adult services.
- to be involved, as well as their parents.
- for continuity of engagement with the staff they meet – a familiar face means a lot.

### **Staff groups:**

- Staff were aware of shortcomings in engagement, but not all knew how to address this.
- The need to have training in patient engagement available to in order to build engagement capacity, and to have a way to monitor and evaluate the impact of the training on patient engagement skills.
- Having the time to be prepared for appointments, to be able to engage with patients in a meaningful way.
- The need to actively seek feedback from patients in a more open way especially regarding experience of care and concerns.