Patient Narrative Project
Person Centred Co-ordinated Care

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1) Care services used
2) Experiences of care provided
3) Person centred care plan
4) Decisions on care
5) Identify important aspects of care
6) Consider what needs to change
Research Team

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- Lead Agency: IPOSSI
- Funder: HSE
Healthcare
Fragmented Healthcare

Me as a person

Gaps in Care

No voice in care

Communication

Transitions

Stress in care

Financing silos

Access

Paternalism
Our policy is patient centred care, so you have to fill out forms, AB6-12, MR7-9 and XE113.

Umm don’t you mean paper centred care.
‘Quality of Care’ isn’t about ‘other people’

It’s about every single one of us!

This MATTERS

Health

Social Care

Every one of us is a potential patient
Person Centred Care

Person centred care is ‘…a standing or status that is bestowed upon one human being by others, in the context of relationship and social being. It implies recognition, respect and trust.’ (Kitwood 1997:8)
Person centred Co-ordinated care

“...right care to the right person in the right place at the right time” (Ehrlich et al. 2009:625).
<table>
<thead>
<tr>
<th>Level</th>
<th>Application</th>
</tr>
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<tbody>
<tr>
<td>Personal</td>
<td>To increase self-efficacy of people in receipt of services and their carers and to optimise function, independence and resilience.</td>
</tr>
<tr>
<td>Clinical and Service</td>
<td>Multiple referrals being channelled to a single entry point for co-ordination. Care co-ordinators to provide continuity and support the person and carer through multiple inter-disciplinary teams.</td>
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<tr>
<td>Community</td>
<td>Building community awareness and trust as a fundamental basis for care co-ordination</td>
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<tr>
<td>Functional</td>
<td>Effective communication between team members. Use of electronic records, but also face to face meaningful communication for enhanced depth in discussions about a person with complex care needs</td>
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<tr>
<td>Organisational</td>
<td>Targeting of service users to prioritise care provision. Localisation of care to meet local need. Local leadership which has a long term commitment from commissioners to generate a shared vision and collaborative approaches</td>
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<tr>
<td>System</td>
<td>Integrated health and social care commissioning for sustainable development with a supportive political narrative on person-centred co-ordinated care.</td>
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Aim

- The aim of this study was to inductively co-create and develop generic statements on and a definition of what constitutes person centred co-ordinated care in Ireland with key stakeholders, using a participatory research approach.

- *Researching with,* rather than *researching on* people.
Project

CAHPS® Patient Narrative Elicitation Protocol
(Agency for Healthcare Research & Quality 2017)

Analysis: Thematic analysis (Braun & Clarke 2006)
NVIVO
Descriptive statistics (SPSS)
Refining statements

- **Validation survey**: review of each statement and the definition for a) clarity of language, b) relative importance of each statement and c) if the statement should be retained, rephrased or removed.

- National Adult Literacy Agency’s guidelines on ‘Checklist for documents’ and subsequently reviewed by the National Adult Literacy Agency.
My journey through healthcare

Healthcare experiences

Healthcare I am confident in
My Healthcare Experiences

• Staff communicate with me in a way that I understand.

• I have up-to-date information on my health condition(s), treatments, and available support services.

• Staff help me to understand the choices and services available to me now and for my future care.

• Healthcare staff listen to me so that they understand my world and what is important to me.

• I am treated with empathy, respect and dignity in all dealings with healthcare staff.

• In partnership with healthcare staff, I make choices based on what I prefer and my goals.
My Healthcare Experiences

- If I choose, my information can be shared securely with relevant healthcare staff.
- I do not have to repeat myself each time I meet new healthcare staff involved in my care.
- I can contact the relevant healthcare staff to ask questions that are important to me and I get timely responses to my questions.
- Decisions about my care include me as much as I want and involve my carers if I choose.
Healthcare I am confident in

- Healthcare staff have the skills, knowledge and expertise to plan my care with me.
- My care is of a high quality and is delivered safely and efficiently.
- Healthcare staff are accountable for care that they give to me.
- I know I can get appropriate care when and where I need it.
- I know healthcare staff will co-ordinate my care to include my complete health status and my world.
My journey through healthcare

• My care includes issues that my health influences, such as finances, housing, employment, ability to travel and access to transport.

• I have services delivered by the most suitable healthcare staff in the correct setting and when I need them.

• I can have one person who will oversee and follow up on all my care.
Definition of Person Centred Co-ordinated Care in Ireland

“Person centred co-ordinated care provides me with access to and continuity in the services I need when and where I need them. It is underpinned by a complete assessment of my life and my world combined with the information and support I need. It respects my choices, building care around me and those involved in my care”
Any other biddings - no
So…

First of all," he said, "if you can learn a simple trick, Scout, you'll get along a lot better with all kinds of folks. You never really understand a person until you consider things from his point of view […] until you climb into his skin and walk around in it.”

To Kill a Mocking Bird Harper Lee, 1960