

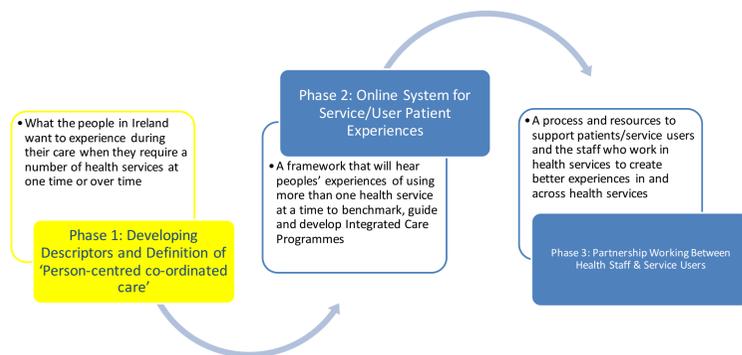
INTRODUCTION

Although ‘integrated care’ has many definitions, it is commonly agreed that its realisation has to result in better outcomes and experience of health services for the individuals who use them, whereby services are well co-ordinated around the needs of the user.

Also, discussions on the development and delivery of services should hold the voice of the user at its core and seek ‘to impose the patient perspective as the organising principle of service delivery’.

The ‘Patient Narrative Project’ was initiated in late 2016 to deliver, for the first time in the Republic of Ireland, the patient / service user perspective on what should be expected from person-centred coordinated care and to guide the development of current and future services and strategy through the four Integrated Care Programmes being established within the Irish Health Service Executive under the office of the Clinical Strategy and Programmes Division (CSPD).

WHAT IS THE PROJECT?



The goal is that the descriptors + definition of what good integrated care and support looks and feels like for people will be adopted nationally. They will be used to guide policy, strategy and design, and as a guide to what teams at local levels should be aiming to achieve practically, in their efforts to integrate services around patient, family and carer needs.

WHO ARE IPPOSI?

IPPOSI – The Irish Platform for Patient Organisations, Science and Industry is a patient-led organisation that works with patients, government, industry, science and academia to put patients at the heart of health innovation. With 105+ patient organisations as members, IPPOSI have proven experience and expertise in harnessing a coherent and critical voice of patients / service users and has led the first of three phases of this project.

WHO ARE THE STAKEHOLDERS?



METHODOLOGY

As part of this phase of the project, IPPOSI led an evidence-based, narrative enquiry methodology developed in collaboration with, and implemented by a UCD research team*. The experiences of service users and patients in Ireland who need care over time from multiple services, as well as their carers and families was heard and thematically analysed.



4 Regional Workshops



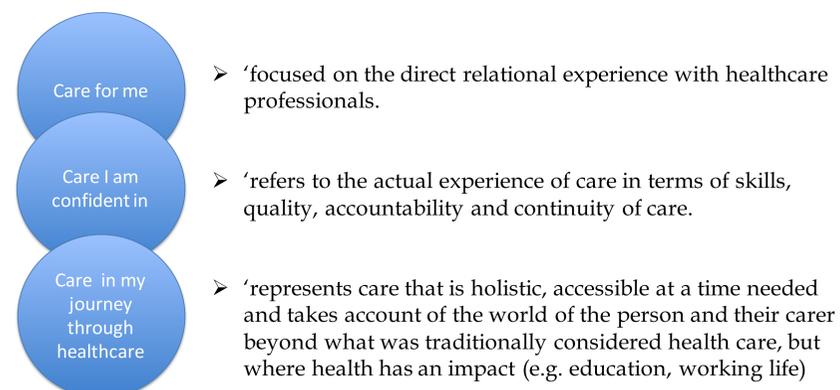
11 Focus Groups



2 Online Surveys

MAIN FINDINGS

Both the focus groups and the surveys yielded rich narratives on the experiences of health care in Ireland. In addition, people stated what needed to change to orientate Irish health services to provide person centred co-ordinated care. **The narratives focused on three areas:**



DEFINITION

The experiences of patients, carers, and their organisations were translated into a definition of person-centred co-ordinated care that is written not just for the experts, but for patients, people, families and carers.

Definition of Person Centred Co-ordinated Care in Ireland

‘Person centred co-ordinated care provides me with access to and continuity in services I need when and where I need them. It is underpinned by a comprehensive assessment of my health and my world together with the information I need to make choices. It demonstrates respect for my preferences, building care around me and those involved in my care.’

DESCRIPTORS

Care for me

- I want to be communicated with in a way that is understandable to me.
- I have up to date information on my health condition(s), treatments, and available support services. I am supported to understand the choices and services available to me and future planning for my care.
- Healthcare staff listen to me to understand my world and what is important to me
- I am treated with empathy, respect and dignity in all interactions with healthcare staff.
- I make my own choices that are based on my preferences and goals in partnership with healthcare staff.
- I want my information shared so I do not have to repeat myself.
- I can ask questions important to me and my carer at any time and can access the relevant healthcare professional to help answer these questions.
- My decisions allow me as much involvement as I want and involve my carers if I choose

Care I am confident in

- I am cared for by staff who have the right knowledge and skills to plan care with me.
- I experience care that is delivered competently.
- I expect to have care that is delivered safely and of a high quality.
- Healthcare professionals are accountable for care that is delivered to me.
- As I meet with different professionals in different settings, I experience continuity of care and my information is shared between relevant professionals.
- I know I can access appropriate care when I need it.

Care in my journey through healthcare

- I know all my healthcare staff will co-ordinate my care in a holistic way which incorporates my complete health status and my world.
- I have a nominated key person who oversees and follows up on all my care.
- I, and my carer, are aware of issues related to my current health and my health care in the future.
- I want my care to incorporate issues not traditionally seen as health but that health impacts on (i.e. education, housing, employment, ability to travel or access transport).
- I have services delivered by the most appropriate professionals in the correct setting at the time I require the service.

As of May 3rd, 2017. Validation exercise with IPPOSI members to be completed by mid-May 2017

SUMMARY

- A single shared definition of Person Centred Coordinated Care in Ireland has been defined through patient narratives.
- Irish patients and their carers also developed 19 descriptors of care that meets their needs. These will guide the HSE Integrated Care Programmes and teams at local levels in their efforts to integrate services around patient, family and carer needs.
- Phase 2 of the project has already begun to develop a framework to hear patient/service user experiences and use these to aid partnership-driven local & national service development.

REFERENCES + CONTACT

- **Contact:** Derick Mitchell, Chief Executive, Irish Platform for Patient Organisations, Science & Industry. dmitchell@ipposi.ie
- **Reference:** Phelan A., Rohde D., Casey M., Fealy G., Felle P., Lloyd H. & O’Kelly G. (2017) Patient Narrative Project for Person-Centred Co-ordinated Care. UCD, IPPOSI & HSE, Dublin.
- **Funding:** The Patient Narrative Project is funded by the Health Service Executive. Phase 1 is led by an IPPOSI Steering Group of patient representatives and academic researchers.

* University College Dublin (Dr. Amanda Phelan) is the Technical partner for Phase 1 of the project.