Patient Narrative Project
for Person Centred Co-ordinated Care

Final report
June 2017

Phelan, A., Rohde D., Casey M., Fealy G., Felle P., Lloyd H. & O’Kelly G.
Acknowledgements

We would like to thank Ms Clare Hudson (HSE, Patient Narrative Project) and Dr Derick Mitchell (IPPOSI) and the IPPOSI Steering group for their support in this study.

We would also like to thank all of the participants and respondents who gave their time and narratives towards the generation of the study findings.

Foreword

Improving experience of healthcare is recognised internationally as one of the key components in the delivery of quality health services. In order to improve experiences it is vital to understand what service users and patients expect from the healthcare system.

This ‘narrative for person centred co-ordinated care’ is developed from peoples’ experiences of healthcare in Ireland. Health services users have described what matters most to them as well as what they believe are essential components of their healthcare. It contains 19 statements and a definition of ‘person centred co-ordinated care’, co-produced with service users and their organisations, and written from the perspective of people needing care over time from multiple health services.

The statements and definition emphasise that people want to be empowered in a seamless journey through the health services; they want to take an active, informed role in their care and to be treated as people, not health conditions. In addition they expect staff to live the values of the Health Service Executive (HSE); care, compassion, trust and learning, as they go about their work.

The narrative is designed for the people who use health services and all staff working in them.

It will:

- **Empower** patients, service users and families by enabling person-centredness to become a real experience for them.
- Prompt staff to view healthcare from the **perspective of service users** and what matters most to them.
- Facilitate **partnership** approaches to healthcare design and delivery from individual care planning to local and national healthcare improvements.

The next phase of the patient narrative project is to develop a framework of service user engagement. This framework will combine the statements from the narrative with an analysis of peoples’ lived experiences of healthcare. It will indicate for the first time the extent to which person-centred coordinated services are understood and implemented across the HSE.

We wish to thank all those who contributed to this project, its writing and production, in particular the team of Dr. Amanda Phelan, University College Dublin and the members of the IPPOSI-led Steering Committee for the first phase of the ‘Patient Narrative Project’.

On behalf of the HSE

Dr. Aine Carroll

On behalf of IPPOSI

Dr. Derick Mitchell
Executive summary

This report describes how person centred co-ordinated care should be experienced within Irish healthcare services. Within the global literature on health service delivery, it is recognised that current systems are generally fragmented and inflexible. In particular, healthcare is not experienced as an individualised continuum of care within different care settings and from different healthcare staff. Despite a plethora of policy documents being underpinned by an ethos of person centred care, the reality is that health systems are not person centred, which impacts negatively on care outcomes and on satisfaction with care.

Responding to such care challenges, the Clinical Strategy and Programmes Division (CSPD), Health Service Executive (HSE), developed the Patient Narrative Project. The Project, through a series of engagements with healthcare service users, will deliver perspectives on what constitutes person centred co-ordinated care. Funded by the CSPD, phase one of the Patient Narrative Project was led by the Irish Platform for Patient’s Organisations, Science and Industry (IPPOSI). The technical partner appointed was a team of researchers from the School of Nursing, Midwifery & Health Systems, the School of Medicine and Medical Sciences University College Dublin and Dr Helen Lloyd, School of Medicine, University of Plymouth, agreed to act in the capacity as research collaborator.

Phase one’s objectives were to:

- Develop a set of generic statements for what person-centred co-ordinated care looks and feels like from the Irish service user perspective.

- Develop a definition for ‘person-centred co-ordinated care’ that is shared, understood and used by service users and staff at all levels of the health service in the Republic of Ireland (hereafter referred to as Ireland).

The study utilised a co-design, participatory action research approach which involved prioritising the voices of service users, individuals who support service users and patient representative groups within an ethos of researching with, rather than researching on people. Narrative data were collected in eleven regional focus groups and an online qualitative survey. Analysis resulted in three overarching domains

---

1 IPPOSI is a patient-led organisation that works with patients, government, industry, science and academia to put patients at the heart of policy and medicines development.
containing a total of nineteen statements which represent what people want to experience within person centred co-ordinated care in Ireland. The findings also led to a definition of person centred co-ordinated care:

“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”

The findings of this study offer important foundations on which healthcare services should be delivered. Essentially, what people want to experience is an authentic partnership approach that fosters individualism, autonomy, and choice within a seamless continuum of care. The domains, statements, and definition offer an opportunity to enhance the quality of the healthcare experience by identifying objectives for staff and expectations for service users within person centred co-ordinated care.
### Table of Contents

Acknowledgements ........................................................................................................... ii

Foreword (HSE & IPPOSI) ................................................................................................ iii

Executive summary ............................................................................................................. v

1. Literature review .......................................................................................................... 1
   1.1 Introduction ............................................................................................................ 1
   1.2 Ireland, Irish Health and Irish healthcare ............................................................... 2
   1.3 Person centred care ............................................................................................... 2
      1.3.1 Person centred care frameworks ................................................................. 5
   1.4 Person centred co-ordinated care ..................................................................... 8
      1.4.1 What is person centred co-ordinated care? ............................................... 8
      1.4.2 Components of person centred co-ordinated care ................................ 10
      1.4.3 Advantages and potential limitations of person centred co-ordinated care .... 11
      1.4.4 Facilitators and barriers to person centred co-ordinated care ............... 13
   1.5 Indicators of person centred co-ordinated care ............................................. 14
   1.6 House of Care .................................................................................................... 15
   1.7 Using narratives for person centred care ........................................................... 16
   1.8 The present study ............................................................................................... 20

2. Methods .......................................................................................................................... 21
   2.1 Introduction .......................................................................................................... 21
   2.2 Aims and objectives ............................................................................................ 21
      2.2.1 Research Question ....................................................................................... 21
   2.3 Study Design, co-inquiry and co-researchers .................................................... 22
   2.4 The present study ............................................................................................... 24
   2.5 Data collection ..................................................................................................... 25
      2.5.1 Sample and inclusion criteria ...................................................................... 26
      2.5.2 Focus groups ............................................................................................... 27
      2.5.3 On-line survey ............................................................................................. 27
   2.6 Data analysis ........................................................................................................ 28
   2.7 Validation survey ................................................................................................ 29
   2.7 Ethical considerations ........................................................................................ 29
   2.8 Summary .............................................................................................................. 30

3. Findings .......................................................................................................................... 31
   3.1 Introduction .......................................................................................................... 31
   3.2 Demographic profile of participants .................................................................. 31
      3.2.1 Focus group participants ............................................................................ 31
      3.2.2 On-line survey respondents ....................................................................... 33
   3.3 Qualitative data findings ...................................................................................... 35
   3.4 My care experiences .......................................................................................... 37
      3.4.1 Communication that is understandable to me ............................................. 37
      3.4.2 Communication that provides me with the required information I need ...... 40
      3.4.3 Care that understands my world including those who care for me .......... 42
      3.4.4 Care that demonstrates empathy and positive regard for me .................... 44
      3.4.5 Care that is based on authentic and genuine partnership and respects my choices ... 46
   3.5 Care that I am confident in ................................................................................... 47
      3.5.1 Staff that are competent in delivering my care .......................................... 47
      3.5.2 Care that delivers me high quality and safe care ....................................... 48
      3.5.3 Care that is accountable ............................................................................. 50
      3.5.4 Care where I experience continuity ............................................................. 51
   3.6 Care in my journey through healthcare ............................................................... 53
      3.6.1 Care that has a holistic approach to my health .......................................... 53
      3.6.2 Co-ordination of my care in health and areas outside health .................. 55
      3.6.3 Access to services when I need them ......................................................... 58
1. Literature review

1.1 Introduction

Globally, health systems focus on the delivery of care that can comprehensively meet the needs of a population and offer sustainability of care provision. As populations grow, the challenge is to deliver care that is underpinned by the principles of dignity, compassion and respect (Department of Health and Children 2001; NICE 2006; Royal College of Nursing 2008; McCormack & McCance 2017). Despite the advantage of improving outcomes and patient satisfaction of care, the experience of person-centredness can be fragmented (Ekman et al. 2011), and system and staff focused (Entwistle & Watt 2013). Yet, it is recognised that meeting the needs of the individual within a person centered care approach is paramount within a quality based, effective and efficient healthcare service (HIQA 2012; Kitson et al. 2013; Olsson 2013). Similar to other countries (Australian Commission on Safety and Quality in Healthcare 2009; Department of Health 2008; McCormack & McCance 2017), Ireland’s focus on person centred care is evident in service development, policy, and quality and patient safety documents (HSE 2013; Gavin & Brady 2013) as well as being fundamental in healthcare regulation (HIQA 2012; HIQA 2013; HIQA 2014; HIQA 2016a, 2016b; MHC & HIQA 2016). Person centred care prioritises the individual to direct their own care and demands that care systems centralise the expectations, needs, wishes and preferences of the individual, recognising the person beyond the medical condition (WHO 2015).

Of most importance, care delivery does not occur within a therapeutic uni-disciplinary vacuum, but needs to be a collaborative process that facilitates multi-directional communication and coordinated, integrated care delivery for each person. Equally, existing care demands reorientation as it can predominately reduce the care encounter to the presenting episodic acute care issue or the presenting care specialism, particularly in the context of long term conditions (Eaton et al. 2015). The World Health Organisation (2016) framework for integrated, people-centred health services identifies five strategies, namely facilitating an enabling environment, strengthening governance and accountability, reorienting the model of care, coordinating services within and across sectors and empowering and engaging people.
1.2 Ireland, Irish Health and Irish healthcare

In the 2016 census, Ireland’s population stood at 4,761,865 people, with 11.6 per cent non-Irish nationals and an increase of 102,174 people aged over 65 years since the 2011 census (CSO 2017). In 2014, life expectancy in Ireland was 79.3 years for males and 83.5 for females (DoH 2016a). The number of births in 2015 was 65,909 (DoH 2017), however, the 2016 census noted a fall in births since 2009 (CSO 2017). Major challenges to health and causes of morbidity are diseases of the circulatory system, cancers, and diseases of the respiratory system (DoH 2016b). In 2015, there were 1.66 million acute hospital discharges (DoH 2016b). The number of adults and children waiting for in-patient and day care procedures in November 2016 was approximately 24,000 and 4,500 respectively. The waiting list for out-patients was significant; in November 2016, approximately 440,000 adults were waiting longer than 52 weeks for appointments, while the figures for children were recorded as approximately 80,000 (DoH 2016b).

Irish healthcare is a mixture of private and public care. Ireland is divided into seven hospital groups and nine community health organisations. In addition, there are a number of private hospitals. Health is also delivered through mental health services, intellectual disability services, day care services, nursing homes for older people and other community based services. There are approximately 2,500 general practitioners in Ireland, many of whom work within private practices, but also provide services on behalf of the HSE for people with medical cards, GP visit cards and other schemes (HSE 2017). At the end of January 2017, the number of people with medical cards was recorded as 1,669,721, while the number of people with GP visit cards was 473,726 (HSE 2017). The Irish Times reported that in 2016, 46 per cent of the population had private health insurance. The main healthcare regulatory bodies in Ireland are the Health Information and Quality Authority (HIQA) and the Mental Health Commission.

1.3 Person centred care

Person centred care has emerged from a recognition of the reductionist approach of healthcare, which obscures an individual’s personhood at the expense of viewing the person within a unique bio-social context (Olsson et al. 2013). A move to person centred care challenges the covert power hierarchy of healthcare professionals and fosters the individual’s active choice and decision-making according to their will and
preference. This active engagement in health results in a co-production of care between the individual, health services and others who support the person (Health Foundation 2016). This approach focuses on building the care system around the person’s needs and choices, rather than the person being streamlined into a rigid system of care. Essentially, this incorporates a culture of working collaboratively within a participatory framework and using transformational leadership approaches to enable effective care outcomes driven by people’s expectations (Manely 2017). This reorientation is underpinned by outputs that focus on quality of life, independence, and autonomy (DoH 2014). Much work in person centred care has focused on residential care settings (Clissett et al. 2013), while other healthcare sectors have a limited integration of the approach.

Research from Sweden (Ekman et al. 2011) described person centred care as being typified by three main components. Firstly, initiating the care relationship encompasses the explicit commencement of the therapeutic partnership through patient narratives. Secondly, making the partnership work effectively involves the development of shared deliberating and decision-making, where the choices are enmeshed in the authentic decision-making by the person. Thirdly, safeguarding the partnership is where the narratives are documented, acknowledged and respected by health care providers. In 2016, the United Kingdom (UK) Health Foundation advocated a transformation to new care models that focused on engagement and empowerment.

Although person-centred approaches can be viewed as building on the work of Rogers (1969) and Burber (1984) among others, its formal origins are attributed to the work of Kitwood and Bredin (1991), Kitwood (1997), Brooker (2004) and McCormack and McCance (2017). Initial commentaries observed how healthcare systems often delivered care to older people with dementia in a dominantly biomedical, dehumanising approach. Thus, in countering this, the challenge for healthcare staff is to explicitly recognise and articulate personhood. McCormack (2004) furthers understandings of person-centredness in describing four modes of ‘being’. These are detailed below in Table 1.1:
Table 1.1 McCormack’s (2004) four modes of ‘being’

<table>
<thead>
<tr>
<th>Mode</th>
<th>Meaning</th>
</tr>
</thead>
<tbody>
<tr>
<td>Being in relation</td>
<td>This mode considers the person within relationships with others and the sustainability of these relational processes. Authentic relationships in healthcare are underpinned by empathy and unconditional positive regard which recognises the individuality of the person and respects the will and preference of the person</td>
</tr>
<tr>
<td>Being in a social world</td>
<td>Central to being in a social world is to understand the person’s reality within their subjective narratives. Only through such processes can the individual be understood, eliciting their unique perspectives, ways of seeing their health, their availability of choices and their perceptions of options and preferences.</td>
</tr>
<tr>
<td>Being in place</td>
<td>People occupy and interact in multiple settings and healthcare can be delivered in multiple settings. The design of ‘place’ can</td>
</tr>
<tr>
<td>Being with self</td>
<td>Being recognised, treated as an individual and respected has an impact on how a person conceptualises self.</td>
</tr>
</tbody>
</table>

Person centred care has been defined in several ways (Table 1.2), but the common component is that it constitutes an individualised approach where the person’s will and preferences are elicited and respected.

Table 1.2 Definitions of person centred care

<table>
<thead>
<tr>
<th>Author</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kitwood (1997:8)</td>
<td>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.’</td>
</tr>
<tr>
<td>McCormack (2017: 3)</td>
<td>Person centred care is ‘…an approach to practice that is established through the formation and fostering of therapeutic relationships between all care providers, service users and others significant to them. It is underpinned by values of respect for persons, individual right to self-determination, mutual respect and understanding.’</td>
</tr>
<tr>
<td>World Health Organisation</td>
<td>People Centred Care is ‘…an approach to care that consciously adopts the perspectives of individuals, families and communities and sees them as participants as well as beneficiaries of trusted health systems that respond to their needs and preferences in humane and holistic ways. People centred care requires that people have the educations and support they need to make decisions and participate in their own care. It is organised around the health needs and expectations of people rather than diseases’</td>
</tr>
</tbody>
</table>

This reorientation supports the person receiving services. Value is established in a number of ways, for example, enhancing self-care, supporting those who care for
others, and placing value in volunteering activities (Health Foundation 2016). Three dimensions of value have been identified based on empowering relationships with people who are involved in the healthcare context. In a report by Wood and colleagues (2016), these value dimensions have been identified as impacting on:

**Mental and physical health and wellbeing:** Through increasing people’s self-efficacy and ability to manage their care, improving health outcomes, improving healthcare experiences, reducing isolation and loneliness and potentialising community capacity.

**Health service sustainability:** Person centred and community centred care can lessen demand on services, particularly in accident and emergency departments.

**Wider social outcomes:** Acknowledging that health has an impact on other areas of life, person centred and community centred approaches can enhance school attendance, volunteering and potentially reduce health inequalities.

### 1.3.1 Person centred care frameworks

There are a number of frameworks that represent the components of person centred care. Kitwood (1997), a seminal author in person centred care, recognised the detached and objectifying way older people with dementia could experience care. In countering this, person centred care required a focus on the psychological aspects of a person’s wellbeing and was comprised of five components as detailed below:

<table>
<thead>
<tr>
<th>Component</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Love</strong></td>
<td>A sense of experience, social connection, acceptance and engagement</td>
</tr>
<tr>
<td><strong>Inclusion</strong></td>
<td>Being part of a community</td>
</tr>
<tr>
<td><strong>Occupation</strong></td>
<td>Having an activity that interests you and that gives worth and purpose to you</td>
</tr>
<tr>
<td><strong>Identity</strong></td>
<td>Having a sense of who you are and what you have achieved</td>
</tr>
<tr>
<td><strong>Attachment</strong></td>
<td>Maintaining close link with family and friends</td>
</tr>
<tr>
<td><strong>Comfort</strong></td>
<td>A sense of ease and wellbeing</td>
</tr>
</tbody>
</table>
Later, Brooker (2004; 2007) further developed perspectives on how person centred care can be fostered in interactions through the VIPS framework. Again, this predominantly focuses on the area of care of older persons and people with dementia. The VIPS framework centres on issues such as rights, individualism, and the facilitation of a positive social environment:

V  *Values people* – Values and promotes the rights of the person

I  *Individual’s needs* – Provides individualised care according to needs

P  *Perspective of service user* – Understands care from the perspective of the person with dementia

S  *Supportive social psychology* – Social environment enables the person to remain in relationship.

As the philosophy of person centred care advanced, understandings moved beyond the immediate dyadic context. Person centredness evolved to include a systems based perspective and incorporated the wider dimensions of a person’s world, such as the multiple aspects of their life, interacting social contexts including education, life history, what matters to the person, employment, and family commitments, as well as perspectives of others who support the person.

Glasby (2017) argues that person centred care has three fundamental aspects. Firstly, care is focused on integration (national/structural); secondly, care is compassionate (local) and thirdly, the personalisation and individualisation of care (individual level). Within the integration of care, there is a danger that the rigidity of services prevents a translation to flexibility to suit people. Rather, as Glasby (2017) observes, it is experienced as the person having to ‘fit into’ separate services rather than a scaffolding of care around the person, which accommodates expectations and preferences. Glasby (2017:71) also points to the care culture, which can, when challenges such as staff shortages occur, lead to a ‘corruption of care’. Consequently, supporting staff is fundamental to the experience of care. In relation to the individual level, Glasby (2017) draws on the personalisation agenda in the UK, where direct payments and personal
budgets focus on enabling the person to be the purchaser of care or to have a knowledge of available budgets for service delivery and be able to make decisions on how money is spent on care.

Using a wider conceptualisation, McCormack and McCance (2010) developed a framework for person centred nursing which has recently been adapted to accommodate a multidisciplinary approach within a person centred practice framework (McCance & McCormack 2017). This framework acknowledges that there are many levels within person centred care (Figure 1.1). Such an approach is conducive to an ecological framework (Bronfenbrenner 1979) of person centred care that looks at the micro, meso, exo and macro systems which impact on the experience and outcomes of care to the person. For example, the competencies of the service provider are fundamental to the delivery of care, but care is delivered with organisational systems through (dys)functional processes which result in particular outcomes. In addition, the delivery of care to an individual is influenced by macro factors such as policy, strategy, leadership and workforce development. Thus, it is the alignment of all systems that facilitates and fosters person centred care.

Figure 1.1 Person-centred practice framework (McCormack & McCance 2017)
In conclusion to this section, while person centred care began within older person care, its philosophy has extended to care of people within healthcare services. What is central is the empowerment of people and supporting people who use the healthcare system to become leaders and masters of their own care. Consequently, care is scaffolded around the person as a supportive system. However, care is rarely delivered in isolation by one professional or setting. As people journey along the healthcare experience, care needs to be co-ordinated according to need, expectations and preferences.

1.4 Person centred co-ordinated care

Existing fragmented health systems, traditionally focused on the treatment of single diseases, are no longer able to cope effectively or efficiently with the rising care demands of an ageing population and its associated burden of chronic long-term illness and multi-morbidity (Koch 2013; WHO 2015; Damery et al. 2016). Simultaneously, there is increased awareness of non-medical and social determinants of health (Sherry et al. 2016) and a general consensus that the current provision of care requires reorganisation, with increased patient engagement, patient empowerment, and services that are coordinated across sectors and organisations (Phanareth et al. 2017). Research in the UK has also identified barriers to care, such as services only dealing with one condition rather than the person, fragmentation in services, a lack of care co-ordination, a lack of informational continuity, reactive rather than predictive services, a lack of care planning consultation, and a lack of emotional and psychological support (People and Communities Board 2017). In responding to these challenges, there has been a determined focus on reorienting services to person-centred co-ordinated care to holistically meet people’s needs and care preferences in an individualised and empowerment based way.

1.4.1 What is person centred co-ordinated care?

Person-centred health and social services benefit both people and health systems and are key to achieving universal health coverage (WHO 2015). Person centred co-ordinated care is a priority for people in receipt of health services, families and carers, professionals, commissioners and policy makers (Chard et al. 2016). The concept of co-ordinated care, however, is not clearly defined and there is a lack of agreement and clarity on core concepts and terminology (Ehrlich et al. 2009; Koch 2013; Scholl et al. 2014). Various terms have been used to denote these concepts, including person-
centred, patient-centred, or people-centred, co-ordinated, integrated, or collaborative care. Ehrlich et al. (2009) further highlighted the simultaneous and interchangeable use of the term co-ordinated care to denote various facets of care delivery, including structural, process, philosophical and interpersonal aspects. Regardless of the precise terminology used, the main goal of co-ordinated care is the delivery of quality care to the individual through improved organisation and coordination of services around the needs of the person and their families (Shojania et al. 2004; WHO 2015). Consequently, the co-ordination and integration of services share a common cross system purpose to potentialise the value of services being delivered (Health Foundation 2016).

Coordinated care has been defined as the delivery of “systematic, responsive and supportive care” (Ehrlich et al. 2009:622). The underlying ethos of person centred co-ordinated care is that it does not presume to know what care people want, but instead works with individuals and their families to identify what is important to them and organises care accordingly (McShane & Mitchell 2015). People are seen as partners and managers of their own health and care, involved in the co-design of services (Taylor 2014). Person centred co-ordinated care involves service provision that is matched to an individual’s needs, ensuring that the person has control over their own care (Wertenberger et al. 2006; Ehrlich et al. 2009): delivering the “right care to the right person in the right place at the right time” (Ehrlich et al. 2009:625).

In 2017, the People and Communities Board, National Voices set out a vision for the strategic development of the National Health Service in the UK. Six high impact actions were identified to change the culture of the healthcare system and enhance person-centred co-ordinated care. These are based on localised responses to meet needs:

1. Make person-centred community approaches part of normal business.
2. Make a clear commitment to develop new, simplified cross-sector outcome measures.
3. Support a small number of super demonstrator sites to develop person and community centred approaches at scale.
4. Clarify the key success factors for social prescribing, including how to make it systematic and equitable, benefiting from the current interest in this family of approaches.
5. Revive and champion the Inclusion Health agenda.

6. Commission a framework agreement of Voluntary, Community and Social Enterprise partners to support person-centred community focused interventions in defined geographical areas.

Koch (2013) conceptualised person centred co-ordinated care as addressing both the provision of care across health and social care service boundaries and within care teams, as well as an evolving person/care provider relationship characterised by increased service-user involvement. Co-ordinated care should be synchronised and responsive to the needs and preferences of an individual and their particular situation (Goodwin et al. 2013; WHO 2015). Through increased patient contact, treatment and follow-up in the community, care co-ordination and integration aim to improve patient outcomes, for example, by reducing the number of admissions to hospital and facilitating timely and effective discharge to other settings (Damery et al. 2016).

1.4.2 Components of person centred co-ordinated care

Despite difficulties in defining and measuring the concept of person centred co-ordinated care, a number of key components have been identified. Care co-ordination should occur at multiple levels: at a systems level, a service provision level, and a service-user level (Ehrlich et al. 2009). For co-ordinated care to be successfully designed, Goodwin and colleagues (2013) point to a number of alignments within care levels as demonstrated in Table 1.3.

| Table 1.3: Levels and application of person centred co-ordinated care |
|--------------------|------------------------------------------------------------------------|
| **Level**          | **Application**                                                        |
| Personal           | To increase self-efficacy of people in receipt of services and their carers and to optimise function, independence and resilience. |
| Clinical and Service | 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 interdisciplinary teams |
| Community          | Building community awareness and trust as a fundamental basis for care co-ordination |
| Functional         | 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 |
| Organisational     | 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 |
System Integrated health and social care commissioning for sustainable development with a supportive political narrative on person-centred co-ordinated care.

Care co-ordination is required between medical care providers, including primary, secondary, and tertiary care; between health and social care services, including housing, education, employment, welfare and disability support programmes; and between social service providers (Higgins et al. 2015; WHO 2015). Furthermore, care coordination is not limited to co-ordination across services, but also includes co-ordination over time (Van Houdt et al. 2013; WHO 2015).

Person centred co-ordinated care involves close communication between generalist and specialist providers and effective referral and discharge systems (WHO 2015). It requires multiple organisations to be willing to work together across the boundaries of health and social care, primary and secondary care (Acton 2013). Key components of person centred co-ordinated care include goal setting, empowerment, self-management, family and carer involvement, care planning, case management, monitoring and review, a single point of contact, care co-ordination within and across teams, involvement in decision-making, and continuity of care (Ehrlich et al. 2009; National Voices 2013; Sugavanam et al. 2015; Damery et al. 2016). Desired elements of an ideal system include choice of health and social care providers and increased co-ordination among and between providers (Higgins et al. 2015). Difficulties with current systems of care include barriers to accessing providers, transitions from hospital to home or long-term care settings, transitions from paediatric to adult services, frustration dealing with medical staff rotations and difficulties with care co-ordination (Higgins et al. 2015).

1.4.3 Advantages and potential limitations of person centred co-ordinated care

Healthcare systems are inherently multifaceted and complex and can be experienced as fragmented, confusing, inadequate and uncoordinated by those using them (Ehrlich et al. 2009). This lack of co-ordination can result in a number of adverse consequences, including medication mismanagement, service gaps, and difficulties accessing services (Higgins et al. 2015). A lack of co-ordinated care can also lead to stress for patients, as well as service duplication and inefficiencies (Acton 2013). Conversely, empowerment
and engagement of patients and families can have a number of positive outcomes, including improved health literacy, improved patient experiences and service utilisation, decreased costs and better outcomes (WHO 2014; WHO 2015).

Care co-ordination facilitates communication and co-ordination between healthcare professionals, patients, and families, leading to improved quality of care (Borycki et al. 2015). Person centred co-ordinated care has been associated with improved patient outcomes, reductions in errors and improved patient and family satisfaction with healthcare services (Ehrlich et al. 2009; McCarthy et al. 2013; Ryan et al. 2014; Huber et al. 2015; Borycki et al. 2015). Person centred co-ordinated care can also lead to greater efficiencies, reduced duplication of and more streamlined services, improved quality and closing of service gaps (Ehrlich et al. 2009; Higgins et al. 2015; Sherry et al. 2016). Improved responsiveness and more accessible, less fragmented care could in turn positively impact health outcomes and lead to potential improvements in equity and cost-effectiveness (Higgins et al. 2015; WHO 2015). Indeed, person centred co-ordination of medical and non-medical care leads to stronger collaborative relationships and health and social care provision that better meets the needs of the people served and has been reported to reduce acute health events and associated costs (Sherry et al. 2016)

In spite of many benefits of person centred co-ordinated care, potential limitations must be noted. There is difficulty in defining and measuring the concept of person centred co-ordinated care and in exploring its potential impact on patient outcomes. The World Health Organisation highlighted a discord between conceptualisations of people-centred and integrated care and the evidence base to date (WHO 2015). In addition, evidence regarding the effectiveness of integrated care in reducing use of healthcare resources is limited (Damery et al. 2016). Person centred co-ordinated care may not necessarily result in better outcomes and could potentially increase costs by uncovering unmet needs and enhancing access to and uptake of services (Ehrlich et al. 2009). However, by concentrating only on overt and immediate cost benefits or tangible health outcomes, longer-term or less tangible benefits, such as increased user satisfaction and patient reported outcome measures, such as subjective wellbeing and quality of life, may be obscured (Ehrlich et al., 2009).
1.4.4 Facilitators and barriers to person centred co-ordinated care

Facilitators that may assist co-ordination and collaboration between services in the delivery of person centred co-ordinated care include flexible financing, shared leadership, shared data and a shared vision and commitment towards person centred care (Sherry et al. 2016). The delivery of co-ordinated care requires collaboration of integrated organisational networks, management of resources and effective and efficient transfer of information (Ehrlich et al. 2009). Technology is essential to the coherent, person-centred provision of healthcare (Phanareth et al. 2017), as shared data and adequate ICT infrastructure, including the use of electronic health records that are accessible to both patients and service providers, are key elements in strengthening communication and co-ordination (WHO, 2015). Further, the use of mobile and internet services can facilitate access to care for geographically isolated communities (WHO 2015). However, there are challenges regarding patient confidentiality and the development and implementation of interoperable information management systems (Wiljer et al. 2008; WHO 2015; Sherry et al. 2016), which may impede the implementation of person centred co-ordinated care.

Sherry et al. (2016) describe five case studies of community-oriented programmes that successfully co-ordinated medical and non-medical services. The authors report that all programmes were committed to meeting both medical and social needs of individuals. Focusing on the wants and needs of an individual as a person rather than as a patient facilitated identification of critical mismatches between the capacity of existing healthcare services and the services and supports that would be of greatest benefit to the person (Sherry et al. 2016). Efforts to close gaps in service delivery led to greater collaboration among and between health and social service agencies and public health systems.

Governments and funding agencies can facilitate person centred co-ordinated care through effective and supportive legislation and regulation (Acton 2013; WHO 2015), while financial incentives and funding mechanisms must align with the overall focus of person centred co-ordinated care (WHO 2015). Flexible payment structures that enable organisations and services to deploy resources in non-traditional ways are critical to the successful coordination of health and social care services (Sherry et al. 2016). Thus, management of resources, information and organisational integration and collaboration are important system components of coordinated care (Ehrlich et al.,
2009). At a service level, multi-disciplinary primary care teams play a key role in delivering co-ordinated care, moving across care settings and supporting collaboration and knowledge exchange (Ehrlich et al. 2009; WHO 2015).

Potential difficulties to the implementation of person centred co-ordinated care include administrative, informational and funding barriers between different care sectors and providers (Hofmacher et al. 2007; WHO 2015). Furthermore, there are potential difficulties in bridging traditional silos of healthcare, public health, and social services (Sherry et al. 2016). As highlighted by Ehrlich et al. (2009:624), “coordinated care cannot exist unless healthcare providers work within a structured framework that facilitates the coordinated delivery of services”. Moreover, the Health Foundation and Nesta (2015) noted that systems of care could also be limited by a lack of localised mapping of supply and demand for services, with the onus of joining up services being on the person themselves rather than on the service provider and a lack of clarity on purpose and process in the health engagement process between the person and the service provider.

1.5 Indicators of person centred co-ordinated care

The introduction of reforms to support person centred co-ordinated care has been accompanied by the development of a set of indicators that allow system performance monitoring (WHO 2015). Identification of the critical components of co-ordinated care, the cost-effectiveness of providing or not providing these components and methods for implementation are essential if care providers are to recognise and rectify missing elements of person-centred co-ordinated care (Ehrlich et al. 2009). Possible indicators include system-level measures of community wellbeing and population health, service proxies for improved health outcomes, resource utilisation, and organisational processes and characteristics (see WHO 2015). At the individual level, statements of person centred co-ordinated care include personal health outcomes and user and carer experiences, as well as patient-reported outcomes that span the health and social care system, such as quality of life and subjective wellbeing (McShane & Mitchell 2015; WHO 2015).

In the UK, Lloyd and colleagues have identified a number of existing measures that tap experiences of person centred co-ordinated care for routine practice (Sugavanam et al. 2009).
Work on the development of an Organisational Change Tool to monitor progress and development towards person centred co-ordinated care is on-going. However, the available evidence strongly suggests that “the development of measures and indicators in specific country-contexts needs to be locally developed and negotiated” (WHO 2015:40). This provides a valuable opportunity to engage key actors and stakeholders, supports an inclusive process for developing a vision of person centred co-ordinated care and ensures that outcomes frameworks and indicators are person centred (WHO 2015). Individuals should shape the fundamental assumptions behind person centred co-ordinated care, defining the problems with existing models of care as well as what should be considered a successful outcome (Harding et al. 2015).

### 1.6 House of Care

Recognising the health challenges within populations, such as finite budgets, changing demographics and chronic illnesses, ten health and social care organisations in the United Kingdom identified key components to deliver care quality (King’s Fund 2010). These were a) co-ordinated care led by a nominated key professional, b) patients engaged in decisions about their care, c) supported self-management, d) prevention, early diagnosis and intervention and e) emotional, psychological and practical support. In particular, the need for systems to support a person through chronic illnesses or lifelong conditions was identified in the context of managing the health issue or managing multi-morbidity over time and responding comprehensively to fluctuations of health and crisis points (King’s Fund 2010). In 2013, the King’s Fund (Coulter et al. 2013) developed a co-ordinated model of care that accommodates multi-morbidity and fosters a continuous partnership based, collaborative, active role for people receiving care and their carers. The model is called the ‘House of Care’ and emphasises a link between individualised care planning and commissioning care for local populations to enhance traditional models of care. Figure 1.2 demonstrates how the elements of the House of Care link interdependently together.
1.2 House of Care (Coulter, Roberts and Dixon 2013)

The House of Care (Coulter et al. 2013) has personalised care planning which integrates the values and preferences of the person as a core focus. The person and their carer(s) work with the professional(s) to identify what lifestyle choices, changes and self-management techniques meet their specific needs. This leads to a co-production of a care plan that is tailored to the person. Consultations are based on risk stratification so the greater and more complex the presenting issue is, the more specialised the care referral becomes. Nurses manage straightforward cases and a person’s care is escalated as required and involves a team of professionals who work collaboratively across disciplines and settings. This is facilitated through reorganising supportive services such as information technology, work and community relationships, workforce deployment and other processes that streamline care coordination. Commissioning is targeted at being responsive to the local need to match the service to both the person and the population.

1.7 Using narratives for person centred care

The significance of narratives in contributing to a person centred healthcare system has been identified in the literature (Clark 2008; Buckley 2016; Buckley 2017). Giving voice to the experience from people who have used the healthcare service was also identified as essential in the Francis report (2013), which pointed to the lack of
collective responsibility for the deficits in the Mid-Staffordshire Hospital. In eliciting what people want from good quality healthcare, National Voices (2013) in the UK produced a narrative of what integrated care looks like from a person’s perspective:

‘I can plan my care with people who work together to understand me and my carer(s), allow me control, and bring together services to achieve the outcomes important to me.’

Within the narratives, there are a number of particular expectation of services users which are articulated through ‘I’ statements, which support individual empowerment (National Collaboration for Integrated Care and Support 2013). These ‘I’ statements act as care indicators under six care domains (Table 1.4), as well as standards for healthcare professionals to aspire to when care is being delivered. Further work has also been undertaken to identify the ‘I’ statements in relation to research and innovations and focus on a) setting research priorities, b) having a voice in research design, c) making treatments available and d) empowered to make individual decisions on using new treatments (National Voices 2016).

Another recent publication, the CAHPS Patient Narrative Elicitation Protocol (2016, 2017), recognises the importance of personal storytelling and how this can assist healthcare staff to understand the experience of services and point to how service delivery can be enhanced. The structured, open-ended questions are designed to provide a standardised, generic description of care experiences. This protocol underpinned the data collection in this study and is further discussed in the methodology chapter.
<table>
<thead>
<tr>
<th>Domain</th>
<th>‘I’ Statement</th>
</tr>
</thead>
</table>
| **My goals and outcomes** | • All my needs as a person are assessed and taken into account  
• My carer/family have their needs recognised and are given support to care for me  
• I am supported to understand my choices and to set and achieve my goals  
• Taken together, my care and support help me to live the life I want to the best of my ability |
| **Communication**     | • I tell my story once  
• I am listened to understand about what works for me, in my life  
• I am always kept informed about what the next steps will be.  
• The professionals involved in my care talk to each other. We work as a team.  
• I always know who is co-ordinating my care.  
• I have one first point of contact. They understand both me and my condition(s). I can go to them with questions at any time. |
| **Information**       | • I have the information and the support to use it that helps me manage my condition(s).  
• I see my health and care records at any time. I can decide who to share them with. I can correct any mistakes in the information.  
• Information is given to me at the right times. It is appropriate to my condition and circumstances. It is provided in a way I can understand.  
• I am told about other services that are available to someone in my circumstances, including support organisations.  
• I am not left alone to make sense of information. I can meet/phone/email a professional when I need to ask more questions or discuss the options. |
| **Decision-making including budgets** | • I am as involved in discussions and decisions about my care, support and treatment as I want to be.  
• My family or carer is also involved in these decisions as much as I want them to be.  
• I have help to make informed choices if I need and want it.  
• I know the amount of money available to me for care and support needs, and I can determine how this is used (whether it’s my own money, direct payment or ‘personal budget’ from the council or NHS).  
• I am able to get skilled advice to understand costs and make the best use of my budget. |
**Care planning**
- I can access the money quickly without over-complicated procedures
- I work with my team to agree a care and support plan
- I know what is in my care and support plan.
- I know what to do if things change or go wrong.
- I have as much control of planning my care and support as I want.
- I can decide the kind of support I need and how to receive it.
- My care plan is easily entered on my record
- I have regular reviews of my care and treatment, and of my care and support plan.
- I have regular comprehensive review of my medicines.
- When something is planned, it happens.
- I can plan ahead and stay in control in emergencies.
- I have systems in place to help at an early stage to avoid a crisis.

**Transitions**
- When I use a new service, my care plan is known in advance and respected.
- When I move between services or settings, there is a plan in place for what happens next.
- I know in advance where I am going, what I will be provided with and who will be my main point of professional contact.
- I am given information about any medicines I take with me-their purpose, how to take them, potential side effects.
- If I still need contact with previous services/professionals, this is made possible.
- If I move across geographical boundaries, I do not lose my entitlements to care and support.
1.8 The present study

No single approach to person centred co-ordinated care can be applied in all contexts, and what matters most to individuals varies across settings, areas of care, and individuals (Harding et al. 2015). Therefore, the World Health Organisation recommends that policies and strategies to support person centred co-ordinated care need to be evidence-informed, rather than evidence-based (WHO 2015). A number of approaches have been suggested to facilitate the development of person centred co-ordinated health services, including community engagement and consultation, eliciting people’s views through the use of survey-based methods, and enshrining rights and responsibilities using patient charters and legislation (WHO 2015). Thus, the aim of the present study was to develop a set of generic statements on what constitutes person centred co-ordinated care in Ireland, with a view to developing an e-care evaluation template for health service users.
2. Methods

2.1 Introduction
The Clinical Strategy and Programmes Division (CSPD) of the Health Service Executive (HSE) aims to facilitate the delivery of person centred co-ordinated care, in order to improve experiences and outcomes for people during their care. The Patient Narrative Project was established to progress this objective. This project, through a series of engagements with service users and stakeholders, highlights expectations of person centred co-ordinated care from the perspectives of people who use healthcare services, families, and service user representative groups. This chapter describes the methods used to conduct the study, which was based on an action research methodology.

2.2 Aims and objectives
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. These statements will then be used to develop an e-care evaluation template for health service users. The emergent research question arising from the aim of the study was:

2.2.1 Research Question
How can we co-create and develop statements of what constitutes person centred co-ordinated care?

The following key objectives were addressed:
1. To map essential constituent elements and supporting processes, ethos, activities and structures of person centred co-ordinated care within the literature and Irish policy.
2. To describe person centred co-ordinated care from a ‘person’ perspective, to express what the person should experience in care and how treatment and support can be well organised to meet individual needs and preferences.
3. To engage and gain traction with health service users in a partnership relationship (person, carers and representative groups) to co-create integral components of person centred co-ordinated care in an Irish context.
4. To develop a single common cross-system definition of person centred co-ordinated care that is shared, understood, and used by people using the healthcare service and staff at all levels of the health service in Ireland.

2.3 Study design, co-inquiry and co-researchers

To enable person centredness to become a real experience for patients, it is important that person centred co-ordinated care is ‘guided by and organised effectively around the needs and preferences of the individual’ (Plymouth University 2016). Action research has been traditionally defined as an approach to research which is based on a collaborative issue-resolving relationship between researchers and clients which aims at both addressing an issue and generating new knowledge. It has its origins in Aristotelian praxis, pragmatic philosophy, phenomenology, constructivism, and Lewinian social psychology among others and finds expression in several modalities, such as action science, clinical inquiry/research and participatory action research (PAR). Action research works within an extended epistemology and seeks to generate practical knowledge in the present tense through cycles of systematic process of planning, taking action, and evaluating that action that leads to further cycles. Action research involves people directly in the co-design of the technologies and services they use and has been demonstrated to reduce the gaps between research and practice by applying the concept of researching with, rather than researching on people. The aim of co-design is improve the service for the user, by focusing on the experience of moving through the service and making the service user integral to the service design process (Bate & Robert 2006).

The term ‘action research’ is generic and refers to a family of participative and collaborative methods aimed at bringing about some change and at its core it focuses simultaneously on action and research. Within this approach are multiple paradigms or methodologies, each of which has its own distinctive emphasis (Alder et al. 2004; Greenwood & Levin 2007), and participatory action research is one of these approaches. Participatory action research emerged as an important methodology for intervention development and change within groups and communities particularly by development agencies and local community organisations. Orlando Fals-Borda and Paulo Freire were among the first promoters of this methodology

Participatory action research (PAR) generally involves egalitarian participation outside the immediate organisation in a more community-based context that aims to transform
some aspect of its situation. It focuses on concerns of power and powerlessness and how people who experience powerlessness are excluded from decision-making. Hence, the research approach is complementary to person centred co-ordinated care, since to achieve person centred co-ordinated care, there is a need to stimulate bottom up service re-design and implementation efforts, learning from innovations in practice. PAR encourages people to construct and use their own knowledge to become more empowered to take action (Lykes & Mallona 2008). PAR recognises the role of non-experts and values people’s experience and knowledge from the everyday lives (Park 2001). Moreover, there is uncertainty about how to achieve person centred co-ordinated care participation and inclusion of key stakeholders and those directly experiencing the particular phenomenon are critical to finding a solution.

Typically, action research is concerned with the creation of living knowledge. It achieves this by drawing on diverse forms of knowing and understanding, including experiential and tacit knowledge, presentational and propositional knowledge, relational, spiritual and dialogical and practical knowing. Recognising the significance of a bottom-up approach to healthcare involves prioritising the voice of the person in receipt of care and ensuring such narratives are integrated to describe how services that provide care, treatment and support are experienced and scaffolded around the individual’s needs and preferences. Since the processes of action and research are inextricably linked through the action research cycle in a group context (Reason & Heron 1999), outcomes of the study can therefore be both “informative and transformative” (Hostick & McCelland 2000:307). Rolfe (1994) advocates that the researcher, practitioner and research subject are seen as equal partners and “give way to a relationship based on bilateral initiative and control so that all involved work together as co-researchers and as co-subjects” (Reason 1999:74). Therefore, action research seeks to generate practical knowledge that includes the creation of areas for collaborative learning where the research is with people, “not on them or about them” (Heron 1996:19); people are co-researchers and co-inquirers. Thus, this study utilised a PAR approach involving a partnership with IPPOSI, the HSE, and University College Dublin.

As action research has a dual purpose, it facilitates the collection of data for research purposes as well as an approach to problem-solving. It comprises iterative cycles of collecting data and feeding it back to those involved, jointly analysing the data, jointly planning action and taking action and jointly evaluating that action leading to joint data
collection and so another cycle begins. In this way, it is the application of the scientific method of fact finding and experimentation to find workable solutions involving collaboration and cooperation of the action researchers and members of the community in this study context. Thus, there is a duality of the intended outcome of the action research approach as related to not only finding a solution to the immediate problem but also important learning from the process and outcomes and therefore a valuable contribution to scientific knowledge and theory (Coghlan & Brannick 2014). Finally, action research provides the embedded methodology and provides a way of overcoming paradigmatic tensions since "action research is a method per se which can be fruitfully combined with other methods...and in that respect it does not require specific epistemological commitments" (Spjelkavik 1995:291). The important issue is that the planning and use of these tools is well thought out with the members of the organisation and clearly integrated into the action research process. It must be remembered that "data collection tools are themselves interventions and generate data" (Coughlan & Coghlan 2002:225). Hence, a range of data collections tools such as surveys and focus group interviews may be used within an action research study.

2.4 The study
This study was undertaken in partnership with the HSE and IPPOSI, underpinned by a PAR approach. Action research involves people directly in the co-design of the technologies and services they use and has been demonstrated to reduce the gaps between research and practice by applying the concept of researching with, rather than researching on people. Undertaking action research involves three concurrent areas of inquiry and practice, namely first, second and third person inquiry/practice. Typically, first person research is characterised as a form of the researchers’ (all participants are co-researchers) inward inquiry and reflection. This information can be captured in narrative reflective discussions or in written format in reflective journaling. Second person inquiry addresses the researchers’ ability to inquire into and work with others on issues of mutual concern though conversation and action. As action research is “integrally collaborative and democratic the quality of the second person inquiry is critical” (Coghlan & Brannick 2010:6). Third person inquiry aims at creating a larger scale of inquiry at community level involving people beyond direct second person inquiry towards creating greater impact (Hynes 2013).
The focus of this study was on inductively developing statements of how the health service can be enabled to build care to fit around the individual’s health and social care needs. Thus, the specific approach was grounded in the collaboration of researchers and stakeholders and in the implementation of the research process. The aim of co-design is to improve the service for the user, by focusing on the experience of moving through the service and making the service user integral to the service design process (Bate & Robert, 2006). Bate and Robert (2006) suggest that the challenges of service improvements through experience-based co-design lie in gaining a deep understanding of the experience of care and using this understanding to design and create a more successful and fulfilling healthcare experience.

In this study, the participatory research design involved gathering data from service users and other key stakeholders to identify the key moments and places – the touch points (Gage 2002) – where service users come into contact with a service and that shape their subjective care experiences (Bate & Robert 2006). These touch points are from the perspective of the person using the healthcare service, family, caregiver and representative patient groups and can differ from the perspective of staff. This enables a unique insight into areas that really matter to service users and other relevant stakeholders and can reveal unexpected areas of improvement and align with organisational quality agendas, service redesign and potentialise people’s experiences of healthcare (Naylor et al. 2016). The approach facilitated the development of generic statements and an Irish definition of person-centred co-ordinated care.

2.5 Data collection

In order to gain access to and understand service user experiences, this study used focus groups to gather data from service users, people who support service users, and members of service user representative groups in addition to an online survey instrument featuring open-ended questions. One of the difficulties with studying people’s experiences is that they cannot be observed or assessed directly, but only gathered indirectly through the words and language used to describe each experience (Bate & Robert 2006). Stories and narratives thus form the basis of experience design, providing a deep understanding of the strengths and weaknesses of an existing service and suggesting future improvements and re-design (Bate & Robert 2006; Greenhalgh et al. 2005; Hurwitz et al. 2004). Focus groups provide a deep understanding of social experiences and allow participants to
become agents of change by telling their stories, voicing their perspectives on their experiences of healthcare and recommending solutions that are based on their individual circumstances and experiences (Kieffer et al. 2005).

Survey data were collected using an online questionnaire using open-ended qualitative questions. Unlike quantitative surveys, which aim to describe numeric distributions of variables, qualitative surveys aim to determine the diversity of a topic of interest within a given population (Jansen 2010). The survey was open to all members of IPPOSI and its constituent organisations and was thus able to reach a larger number of potential participants than the focus groups would have alone.

The rationale for using these two data collection tools within the context of PAR rests with the concept of triangulation. Triangulation, through the use of different data collection methods and data sources to address similar questions, increases the credibility of findings (Gilchrist & Williams 1999; Kieffer et al. 2005). Thus, an online survey was used in addition to the focus groups and provided an opportunity for some additional participants to share their experiences. Triangulation provides a more complete exploration of the topic by strengthening the comprehensiveness and accuracy of data (Shin 1998). The purpose of data triangulation is to merge data gathered through the utilisation of different methods to promote rigor, develop a deeper meaning of the data and finally to gain a more complete picture of the area under review (Tashakkori & Teddlie 1998; Creswell et al. 2006).

2.5.1 Sample and inclusion criteria
Participants for the focus groups were recruited from IPPOSI membership groups and HSE networks. IPPOSI and the HSE engaged in purposive sampling of membership for the focus groups according to 1) being a service user, family or caregiver, or member of a representative group, 2) regional representation (rural/urban), and 3) representative of clinical groups. The HSE and IPPOSI circulated the Participant Information Leaflet (Appendix 1) to potential participants, who then self-selected and were invited to contact the research team. In order to be eligible to participate in the focus groups, participants had to 1) be either a service user, someone who supported a service user or a member of a representative organisation within the IPPOSI network; 2) be over 18 years of age; and 3) have capacity to give consent to participate. In order to be eligible to participate in the online survey, participants had to be a member of IPPOSI or its constituent organisations.
Exclusion criteria were being under 18 years of age, lack of capacity to give consent to participate, and not being a patient, carer, or member of a representative organisation.

2.5.2 Focus groups
A total of 11 focus groups were held with 78 participants in four geographical regions in Ireland, with both rural and urban representation. Focus groups took place between 17th February to March 6th 2017 in hotel conference rooms or a health related facility, with refreshments provided for participants. Eight focus groups were held with service users, while three focus groups were comprised of family members, carers, and/or members of patient or carer representative organisations. Each focus group was comprised of between two and ten participants (see section 3.2), and lasted between 60 and 90 minutes. A brief demographic questionnaire was used to describe the demographic profile of participants (Appendix 2).

Focus groups were facilitated by two members of the research team: a moderator and a note-taker. The facilitators were mindful of Cook and Crang’s (1995:56) advice that focus groups should provide “a means to set up a negotiation of meanings through intra- and inter-personal debates”. Consequently, we used the topic guide flexibly and gave participants scope to debate their perspectives. The objective was not to achieve consensus but to “encourage a range of responses [to] provide a greater understanding of the attitudes, behaviour, opinions or perceptions on the research issues” (Hennink 2007:6). Topic guide questions were based on an adaptation of the CAHPS® Patient Narrative Elicitation Protocol (Agency for Healthcare Research & Quality 2017) (Appendix 2), which has been pilot tested previously. All focus group interviews ended with the question “Is there anything else you would like to add?” to ensure that participants had the opportunity to raise unanticipated issues not covered by the topic guide. Focus groups were audio recorded and transcribed verbatim with the permission of participants.

2.5.3 On-line survey
An e-link for the online qualitative survey was distributed to the 110 organisations affiliated with IPPOSI, using the Bristol on-line survey platform. The survey was open for completion between 17th February to 10th March, 2017. The survey instrument contained a demographic questionnaire (Appendix 3), as well as questions based on an
adaptation of the CAHPS® Patient Narrative Elicitation Protocol (Agency for Healthcare Research & Quality 2017) (Table 2.1).

**Table 2.1. Online qualitative survey questions**

<table>
<thead>
<tr>
<th>Online Survey Questions</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1.</strong> When you think about the things that are important to you /your relative/friend/people you represent, how does your/your relative/friend/people you represent experience(s) of healthcare measure up?</td>
</tr>
<tr>
<td><strong>2.</strong> Now we would like to focus on anything that has gone well in your/your relative/friend/people you represent experiences in the past 6 months with your/your relative/friend/people you represent healthcare provider and the staff who work there. Please explain what happened, how it happened and how it felt to you/your relative/friend/people you represent?</td>
</tr>
<tr>
<td><strong>3.</strong> Next we’d like to focus on any experience in the last 6 months with your/your relative/friend/people you represent healthcare provider and the staff who work there that you/your relative/friend/people you represent wish had gone differently. Please explain what happened, how it happened and how it felt to you/your relative/friend/people you represent?</td>
</tr>
<tr>
<td><strong>4.</strong> Please describe how you/your relative/friend/people you represent and your/your relative/friend/people you represent healthcare provider relate to and interact with each other.</td>
</tr>
<tr>
<td><strong>5.</strong> Have you any further comments you want to tell us about relating to your /your relative/friend/people you represent experience of healthcare provision?</td>
</tr>
</tbody>
</table>

**2.6 Data analysis**

Focus group interviews were transcribed verbatim. Data analysis for both data generated from the focus groups and the online survey was guided by Braun and Clarke’s (2006) thematic analysis pathway. This ensured that all data were systematically analysed enabling the recognition of emerging and embedded themes. Two members of the research team were responsible for data analysis to ensure consistency. The initial open codes (itemised in the coding framework) broke the data down into smaller units of analysis. During further iterations of coding, initial codes were collapsed into categories. These categories were compared using selective coding. This process resulted in the clustering and collapsing of codes and the final identification of themes. NVIVO 10©
qualitative data research software was used to organise, explore, and manage the data (QSR International).

Demographic data were imported into IBM SPSS Statistics 21® for Mac and summarised using descriptive statistics, including frequencies and proportions as appropriate.

2.7 Validation survey
Following data analysis, the research team generated nineteen statements describing key aspects of person centred co-ordinated care in three domains, as well as a single definition of person centred co-ordinated care in Ireland. A bespoke survey was then generated which asked members of IPPOSI to review 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. Respondents were also asked if they had any suggested improvements. The 36 returned validation surveys were then reviewed by the research team, representatives from IPPOSI and the HSE. Some amendments were made to the text of the statements, resulting in the final nineteen statements. The text of the domains and definition of person centred co-ordinated care was retained. Finally, the text of the domains, statements and definition was reviewed using the National Adult Literacy Agency’s guidelines on ‘Checklist for documents’ and subsequently reviewed by the National Adult Literacy Agency.²

2.7 Ethical considerations
Only participants with capacity to consent were eligible to participate in this study. Where a person with language difficulties participated, the researchers asked that such issues were flagged beforehand and efforts were made to ensure an appropriate method of communication was available (e.g. sign language interpreter or translator). All participants received participant information leaflets prior to taking part in the study. All focus group participants gave written informed consent. Data collected from focus group participants was subsequently de-identified and rendered anonymous. Permission to

² Available
record the focus groups was included in the written consent form and participants were reminded of this in the oral introduction to the focus group.

For the online survey, the introduction provided information on the research, with consent based on the respondent’s decision to proceed with and complete the survey. By virtue of completing the survey, participants were considered to have consented to the study. Ethical approval for this study was granted by the Human Subject (Sciences) Research Ethics Committee at University College Dublin (approval number LS-17-20).

### 2.8 Summary

This study aimed to generate what person centred co-ordinated care looks like and how it should be experienced in Ireland using the narratives of people who use the healthcare service, those who support people who use the healthcare service and patient representative groups. Using a co-design PAR approach, data were gathered from focus groups and a qualitative survey. The data were analysed using a thematic analysis approach. Following the production of the penultimate domains, statements and definition, a validation survey was conducted to establish the acceptability and clarity of the findings.
3. Findings

3.1 Introduction
This chapter presents the findings from the eleven focus groups and the online survey data. In total, 123 people participated in the data collection process. Each of the two data collection methods involved a demographic survey. In this chapter, the findings from the demographic surveys are presented first. Following this, the qualitative findings are presented as themes developed from both the focus group narratives and the survey.

3.2 Demographic profile of participants

3.2.1 Focus group participants
A total of 78 individuals participated in the focus groups, 25 in Dublin, 24 in Kerry, 18 in Galway and 11 in Cavan. Of these, 36 identified themselves as service users or patients, 23 as carers of service users or patients, and 34 as members of a patient or carer representative group (Table 3.1).

Table 3.1. Focus group participants

<table>
<thead>
<tr>
<th>Focus group location</th>
<th>Dublin</th>
<th>Kerry</th>
<th>Galway</th>
<th>Cavan</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient or service user</td>
<td>12</td>
<td>13</td>
<td>11</td>
<td>0</td>
<td>36</td>
</tr>
<tr>
<td>Member of a patient representative group</td>
<td>12</td>
<td>9</td>
<td>9</td>
<td>4</td>
<td>34</td>
</tr>
<tr>
<td>Carer of a patient or service user</td>
<td>3</td>
<td>7</td>
<td>5</td>
<td>8</td>
<td>23</td>
</tr>
<tr>
<td>Total</td>
<td>25</td>
<td>24</td>
<td>18</td>
<td>11</td>
<td>78</td>
</tr>
</tbody>
</table>

The majority of focus group participants were female (n=55, 71%) and aged between 36 and 65 years (Figure 3.1). A total of 34 participants (47%) were living in a rural location, with 39 (53%) living in an urban area.
Focus group participants represented a wide variety of population groups, including older persons, people with health conditions such as diabetes, heart failure, dementia and mental health problems, musculoskeletal diseases, neurological conditions and people with physical and intellectual disabilities (Table 3.2). Just over half of focus group participants identified in one population group only (n=40; 54.1%), the remaining participants identified two or more conditions (n=34; 45.9%) (missing n=4).
Table 3.2. Population group self-identifier reported by focus group participants

<table>
<thead>
<tr>
<th>Population group identifier</th>
<th>Number of participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Older persons (aged &gt;65)</td>
<td>20</td>
</tr>
<tr>
<td>Diabetes</td>
<td>13</td>
</tr>
<tr>
<td>Heart failure</td>
<td>14</td>
</tr>
<tr>
<td>COPD</td>
<td>7</td>
</tr>
<tr>
<td>Dementia</td>
<td>8</td>
</tr>
<tr>
<td>Mental health problems</td>
<td>15</td>
</tr>
<tr>
<td>Chronic musculoskeletal disease</td>
<td>19</td>
</tr>
<tr>
<td>Disabling neurological condition</td>
<td>18</td>
</tr>
<tr>
<td>Cancer</td>
<td>3</td>
</tr>
<tr>
<td>Intellectual disability</td>
<td>11</td>
</tr>
<tr>
<td>Physical disability</td>
<td>21</td>
</tr>
<tr>
<td>Rare diseases</td>
<td>9</td>
</tr>
<tr>
<td>Travellers</td>
<td>3</td>
</tr>
<tr>
<td>Blind or visually impaired</td>
<td>1</td>
</tr>
<tr>
<td>Skin conditions</td>
<td>1</td>
</tr>
<tr>
<td>Coeliac disease</td>
<td>1</td>
</tr>
<tr>
<td>Deaf or hard of hearing</td>
<td>3</td>
</tr>
<tr>
<td>All patients/carers</td>
<td>5</td>
</tr>
<tr>
<td>Other (not otherwise coded)</td>
<td>5</td>
</tr>
</tbody>
</table>

3.2.2 On-line survey respondents

Invitations to participate in the online survey were distributed by IPPOSI to 218 email addresses. A total of 45 individuals responded to the online survey. Of these, six did not complete the survey, leaving a sample of 39 participants, corresponding to a response rate of 17.9%. Of the respondents, 30 were female and 7 were male. The majority of participants were aged 36-50 years (Figure 3.2).

3 The remaining respondents chose not to answer this question
Figure 3.2. Online survey respondents’ age

The majority of respondents identified themselves as carers of service users (n=21, 58%), with 4 (11%) patient representative group members and 11 (31%) people directly using healthcare services also responding to the survey (Figure 3.3, missing n=3). Twenty-three respondents (62%) lived in a rural area, while 14 (38%) lived in an urban area (missing n=2).
Figure 3.3 Online survey respondents

Table 3.3 details the population group self-identifier represented by the online survey respondents. The majority of respondents stated that they had or represented people with mental health problems (n=10), intellectual (n=16) and/or physical disabilities (n=10). Survey respondents identified between 1 and 4 population groups, with 66.7% (n=22) identifying one group only. The remaining 11 respondents identified two or more conditions (33.3%) (missing n=6).

Table 3.3. Population group self-identifiers reported by the online survey respondents

<table>
<thead>
<tr>
<th>Population group self-identifier</th>
<th>Number of respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Older persons (&gt;65 years)</td>
<td>3</td>
</tr>
<tr>
<td>Mental health problems</td>
<td>10</td>
</tr>
<tr>
<td>Intellectual disability</td>
<td>16</td>
</tr>
<tr>
<td>Physical disability</td>
<td>10</td>
</tr>
<tr>
<td>Autism</td>
<td>1</td>
</tr>
<tr>
<td>Cancer</td>
<td>1</td>
</tr>
<tr>
<td>Sensory disability</td>
<td>1</td>
</tr>
<tr>
<td>Other health issue (not specified)</td>
<td>9</td>
</tr>
</tbody>
</table>

3.3 Qualitative data findings

In addition to the demographic data, qualitative data were generated via both the focus groups and the survey. The focus group topic guide and the qualitative survey questions were developed from the CAHPS Patient Narrative Elicitation Protocol (Agency for Healthcare Research & Quality 2017), which allows the generation of care experiences and the identification of desirable care. Data from the focus groups were recorded and transcribed and imported into NVIVO 10©. Data from the surveys were also imported into NVIVO 10©. Following careful coding, three over-arching domains of person centred co-ordinated care were identified with constituent elements. In line with a co-design methodological approach, it is the voices, narratives and expertise of the participants that form the basis of the domains and constituent elements, which describe
healthcare expectations of patients and citizens (Figure 3.4). Similar to the National Voices (2016) publication, this study recognises that care experiences are not exclusive to the person as a direct health service consumer but to others who provide care support and are involved in the person’s world. For the purposes of the findings, the term ‘my’ includes both person as patient and meaningful others who are significant in the care provision for the person.

**Figure 3.4 Themes and their constituent elements**

These three domains represent what the people expect in relation to the micro-perspective of interpersonal communication, individual service experiences and inter-service co-ordination as demonstrated in Figure 3.5. This represents a ‘care without walls’ approach where care is integrated, person-centred and collaboratively scaffolded around the person and meaningful others, regardless of setting.
Figure 3.5 Interpersonal communication, individual service experiences and inter-service coordination

3.4 My care experiences

The participants who contributed to the focus groups and the survey identified the quality of relationships with healthcare professionals as a dominant and very important element of care expectations. There were a number of foci in this theme, namely, a) communication that is understandable to me, b) communication that provides me with the required information I need, c) care that understands my world including those who care for me, d) care that demonstrates positive regard for me and e) care that is based on authentic partnership and respects my choices.

3.4.1 Communication that is understandable to me

There were a number of dimensions within the sub-theme of ‘communication that is understandable to me’. The first relates to cultural competence and understanding the unique aspects of culture was viewed as an essential aspect of care. The data related to cultural competence generally refers to the experiences of the Traveller population, who were recognised as a distinct ethnic group in early 2017. Other participants did not self identify as being from another ethnic group in the demographic survey. One participant

---

4 For the purposes of presenting the data in the qualitative section, the term participants will be used to describe both participants in the focus groups and respondents from the surveys.
observed her positive experience of healthcare which demonstrated a cultural understanding:

‘Yeah, which [care] is very good. Now my own doctor I find is very, very good and I find he’s very Traveller friendly.’ [FG 6]

Yet, participants in the focus groups observed how professionals needed to understand the reality of the participant’s world in the context of culture and how it impacts on care provision:

‘And she [doctor] says to me, ‘How can I get more close to the Travelling women?’ she said. Well, I said, ‘First of all you have to think where that Traveller woman is coming from, the conditions that she is after coming out of. But also again, you have to think can she even sign her name or whatever. And if you start telling me that you’re afraid to talk to her and she is afraid to ask you questions, and that is the way it is, you know you’re going to have that. Unless you try and break down them barriers, and I know that is hard enough all day and things to do, but if you try to break down those barriers and say and understand more and say, when you’re going to put her on medication or him on medication that what it is for and things like that.’ [FG1]

In particular, understandable communication could be hampered by assumptions of literacy by healthcare professions.

‘Well in the Traveller Movement we have all that information but it’s to Travellers we give it out because Travellers [don’t] have a lot of literacy skills. And I would have been the first one of my family to have been educated’ [FG6]

‘If they [Travellers] go to A&E, some people can’t access the forms – they might not [have] literacy [skills]. So when they go and they’re asked questions, they might not understand the language, like some of the words. Where they’re going for operations, they might not understand what they’re signing’. [FG 11]

‘Forms were shoved in front of me at different times by service providers for filling by me without any regards to my literacy. I was ashamed to ask for help as I have very poor literacy. At the end, I filled the forms with lots of mistake. I was given out to.’ [Survey]

Equally, literacy could be a challenge for other people availing of services, yet this was not accommodated for by healthcare professionals:

‘And the vulnerable people, the people like my brother who can’t read, who doesn’t understand the stuff, who as well as having severe depression and rheumatoid, he can’t read the stuff and is terribly afraid, full of anxiety’ [FG2]

The interactions with healthcare staff could also be compromised when a person presented with sensory challenges and the system did not accommodate for this. For example, the lack of signers for people who have a hearing deficit:
‘We have a deaf person who was in a car crash, in January, has been in hospital eight weeks up in [city] and has no provision of sign language interpreter. And last night we had a deaf person who is partially blind as well with a learning disability but is in a residential service here with Rehab Care. Rehab Care brought him to the doctor, they didn’t look for…Rehab Care didn’t look for an interpreter, the doctor didn’t ask for one, was moved over to A&E, they didn’t look for one and now he’s on the ward and it is only now that that person has texted us.’ [FG 11]

In such cases, this could lead to a very anxious state of not knowing what was happening:

‘I needed to sign a consent form and I had to get what it is that they were miming. And that created anxiety in me, because I wasn’t quite sure what it is that I was signing up for and I had to go straight into surgery because it was an emergency.’ [FG 11]

One hard-of-hearing focus group participant demonstrated his experience of a lack of comprehensive understanding of English which also caused anxiety in the absence of a qualified sign language interpreter:

‘English is my second language, I’m not English proficient so I need anything that’s said to me done through sign language. If you write to me I would be unsure as to what’s being said. So can you imagine sitting there, lying there, getting the epidural done, the surgery is done, going to recovery and I have found myself unsure about my health.’ [FG 11]

Another participant spoke of experiences when her father became a hospital patient.

‘I’m a carer for my dad who is blind. It’s nearly the same thing. When his food is brought up to him, it’s put there, sure he can’t see it and they’ll just walk on. So like if it was labelled if he was blind, I don’t know, he could never get access to his food because I always feed him at home anyway because he doesn’t see.’ [FG 11]

Advances in technology could also be challenging as the service assumes technological literacy. One carer spoke of her older mother’s difficulties in attending an out-patients appointment, when on entry to the hospital, patients were required to navigate a key system to book in for the appointment:

‘I am not able to do that’, she [Mother] said, ‘That kind of technology is beyond an aul’ one like me’ so she said, ‘I have to kind of’…and see generally what happens is…she might get my brother to drop her at the door and she is an independent lady. So, getting up there is fine, she can, she is very mobile, she is very, you know she can get her way around the hospital no bother. So, he drops her at the door, she goes in and she does her own stuff and then she says, ‘I have to nail some stranger to key in my stuff’ [FG 8]

Equally, the language used by healthcare professionals could contain excessive jargon, rendering it too complex to understand as demonstrated by the excerpts below:
‘Since my daughter's diagnosis, we've had a lot of doctors talk about her and negatively about the syndrome in front of her in language that is well beyond her level of understanding. This has had a negative effect on her and how she views herself and her syndrome.’ [Survey response]

‘Yeah, the big words. You know, it can be, even myself and I would probably have it in me to say, ‘Excuse me, I can’t understand’ or ‘What is this tablet for?’ or something like that you know what I mean? But I have known people to go and to come out nearly worse, because they’re worked up.’ [FG 1]

Consequently, a major component of person-centred co-ordinated care described by the participants was communication that was understandable and accommodated for the individual’s culture, level of understanding and compensated for communication difficulties. This is demonstrated in the survey response below:

‘…plain simple language, understanding of culture and difference.’ [Survey response]

In evidencing understanding, one focus group participant articulated precisely the approach healthcare professionals needed to take to elicit understanding:

‘When you’re giving somebody information the question is not, ‘Did you understand that?’ because nobody wants to admit that they haven’t understood what has just been said to them, because you feel like you are less than the person sitting across from you. So, if they have used the big words and they have used the medical jargon and you’re sitting there they ask you, ‘Did you understand that?’, ‘Yes doctor.’ And, ‘Do you understand why you are getting that medication?’, ‘Yes doctor.’ The question is, ‘What have you understood from what I have just said to you? You tell me what you think I just said and why do you think I have given you that medication?’ So, then you’re getting really solid information back from that patient that they have really understood.’ [FG 1]

3.4.2 Communication that provides me with the required information I need

A second sub-theme under ‘my care experiences’ was the provision of information that would help the person navigate the condition and the supports available. Information was key to empowerment, as demonstrated below:

‘But it all comes down, if I were asked, like, what about our group and stuff, it all comes down to information. People need information… the people out there, us, we need information because at least with information you can do something.’ [FG 9]

‘…information is power.’ [FG 9]
When empowered with information, participants felt they could manage their care in a much better way:

‘We were given all these big folders [about diabetes]…I actually cried when I came in here [because of getting the correct information]… and I couldn’t praise it enough – but when we were first diagnosed, it was just unbelievable [previous poor experience at another hospital].’ [FG4]

‘Definitely, patient empowerment is hugely important and information and providing information to them early on and because when you’re in those initial stages after diagnosis or something it’s very important that you have all the information.’ [FG 2]

However, there were many narratives which described the struggle to get information:

‘You need motivation to go and look for these things, and if you are wrecked you don’t have the motivation to go and look for your entitlements.’ [FG 1]

‘That is, certainly, along with that it is information from other people that have found out things, because people [in the HSE] don’t tell you.’ [FG 3]

Such a struggle could lead individuals to attempt to negotiate knowledge through the internet, yet it was recognised that such knowledge could be dubious:

‘I mean a lot of what’s going on is what I’d refer to as Dr. Google and, you know, sometimes Dr. Google can be great and sometimes it can be questionable and sometimes it can be downright dangerous.’ [FG 7]

A lack of information on entitlements and adaptations could also impair the ability to adjust to new and emerging care issues which required practical accommodation and adjustments:

‘Like domiciliary care allowance, nobody gets told about that or say, occupational therapy adaptations to cars, nobody knows about the VRT [Vehicle Registration Tax]. Like, you know, why not?’ [FG 1]

A lack of information could also have potential serious consequences:

‘And my brother wasn’t aware of them [support services]. My mother wasn’t aware that time and she always regrets the day, that if she had been involved more with the services maybe my brother would have been alive.’ [FG 6]

A major source of specific information was through support organisations and services outside healthcare. In particular, participants valued information around practical issues and psychological support.

‘Well it’d be worth it talking about [where support groups can help] anyway. And maybe they should be probably told they should go into these courses because I mean they [patients] require an awful lot of information about managing the condition. So there’s no link, like [from health services]’ [FG 10]
In particular, peer support was valued:

‘When I got up to my forum for arthritis for children, all the parents, you put up I don’t know … and all these parents come back, loads of information. This is what we did, this is what we did, try this, ring blah, blah, blah and it’s brilliant.’ [FG 4]

‘I think the role of the patient organisations and the knowledge in a family, you know that patient experience and passed from one to the other and there’s a huge benefit in that, in the connectivity, the peer support.’ [FG 2]

The need for information was seen to be addressed by having the right information and being able to access appropriate supports. In this context, guidance and support could be structured within information sharing to potentialise managing health issues and being reassured:

‘Yeah, no there’s no handbook for anything and people… they do their best but if there’s any way of sort of information sharing and networking of information around. I know people don’t want to hand out stuff, you know, really and say this is what you do and this, you’ll be fine and it’s not that, it’s just, it’s just to be able to tap into something and just know and that you’re going to be okay and that you’re doing things right.’ [FG 6]

Such information was also seen to transcend direct healthcare services to particular support groups and organisations indicating a need for more inter-sectoral linkages:

‘So it’s more of an integrated, an involvement from people that would probably have the knowledge. The medical personnel mightn’t have all of the answers.’ [FG 10]

3.4.3 Care that understands my world including those who care for me

Participants spoke of the difficulties in structuring their health appointments and care around the rigidity of healthcare provision in terms of availability and practical considerations. There appeared to be little negotiation or choice in terms of accommodation for participants’ reality.

‘I have to say, I have the same problems where I ask the receptionist who gives the appointments, I say, ‘I have a sick child at home, I am sick too, can I have an appointment in the morning’ and it is just ‘Computer says no.’’ [FG 1]

‘You know, it [appointment] is inflicted. You take the appointment at 8.30am in [hospital] on a Thursday morning when traffic is at its worst or whatever. You take that because that is all there is. There is no sense of what would suit.’ [FG 8]
This aspect of rigidity was also evident in community. In the scenario below, the inflexibility of the service is seen to cause unnecessary and distressing consequences.

‘Her [older lady] carers come in the morning for 45 minutes, in the evening for 45 minutes and we collect morning and evening by bus and we’re supposed to be there for 9:45. Now with transport, dealing with older people, you may have to be there at 9:45 because you can’t rush somebody who’s her age. And last Thursday week the carer, we were there at 9:43 because the bus driver noted it and they wouldn’t wait with the lady because there was a massive hailstorm shower and they insisted on pushing her out to get her on the bus to be gone and she got soaked. Because we asked, three minutes. They insisted. She landed up in our centre absolutely soaked. Now this poor woman is well into her eighties, mobility issues, lots of health problems. She could have got pneumonia.’ [FG 9]

What was desired was care that was built around the needs of the person and which included the meaningful others in the construction of a tailored plan:

‘…you’d love to see a liaison nurse, a team of liaison nurses that comes in and introduces themselves and sits with the family and this is what’s going to happen, this is what is going to happen, this person is going to assess you, that person is going to assess you, then we’re going to talk the occupational therapist, they’re going to set up a package that suits you and then I’m still going to maybe stay on with the family, go to their home and when the support officer comes from whichever company, sit down with them and then…’[FG 5]

When this was experienced, it enhanced the world of both the person as care receiver and the caregiver, as expressed below:

‘She [district nurse] got the occupational therapist to call, who outlined all the places in the house where grab rails were to be put, and I even had a bidet in the bathroom, she said that has to go, because the door didn’t open wide enough, because he [husband] uses two canes to get into the bathroom. Then she said a ramp must be put at the front of the house, the back of the house. So she was wonderful, absolutely, so we were...we couldn’t praise both of them enough’ [FG 9]

A very common feature of the focus groups was a discussion on out-patients appointments in the public health system which were considered non-person-centred. There were many narratives describing how discommoding this process was in terms of frequently having to wait a long time to see the doctor. Consequently, appointment times were meaningless and lacked a respect for the person’s own time and commitments as described by the multiple narratives detailed below:

‘You get a nine o’clock appointment and maybe 50 people are called for the same time and they’re all inside in the waiting area and they’re all looking at each other.’ [FG 10]
‘It’s timing that’s the issue. Give a child an appointment at a time that they can make, we find that a big thing. And I suppose it’s the same for adults. We have kids from [County] and [County] getting appointments for services at 9 o’clock in the morning [Where the family lives in a county a very long way from the hospital]. And we’ve kids from [County], [County] getting appointments for two o’clock in the afternoon [Where the family lives in neighbouring counties]. Same doctor. Give them time to get in and time to get out.’ [FG 9]

‘The ear, nose and throat clinic in [Hospital], I know you can delete all this out but I’d prefer if you didn’t because I want to get something changed there, everyone gets the same appointment. Everyone goes in nine, half nine, ten. Nobody is seen, he [doctor] doesn’t come in until about eleven o’clock so nobody is seen until around that time and then everybody’s seen within five or ten minutes because it’s an ENT clinic so it’s not usually [a] complicated consultation.’ [FG 4]

‘Our experience is of long waiting times for appointments, then long waiting times at appointments almost without exception, which is very hard especially for young children. The wait can be 3 hours for a 10-15 minute appointment.’ [Survey]

Participants also offered ways of suiting people which allowed a more person-centred approach and enabled choice in the allocation of appointments:

‘I don’t know if anyone has ever looked at that, like appointments for the new car license? This is the date I want, this is the time I want.’ [FG 6]

‘…like the tax office, or even inside in Penneys [shop], a simple place, a number so that if you’re blind, you’ll hear it and if you’re deaf you’ll see it, you know, simple.’ [FG 11]

‘I would agree 100%. I would say it is like, you know when you bring your car for the NCT and you can see there is a screen up there telling you what your place is and how long it is going to take and why can’t it be like that in a hospital, where humans are more important than cars, aren’t they?’ [FG 1]

Frustration with waiting times was also observed in the accident and emergency departments:

‘A&E, but recently had to access A&E and after a twelve and a half hour wait.’ [FG 11]

3.4.4 Care that demonstrates empathy and positive regard for me

While some participants spoke of good communication and person-centredness, there were many incidences of experiences that devalued personhood both for the service-user and caregiver. In many cases, this was evident in poor communication and behaviours. In
the excerpt below, the participant considers how all people need to be treated respectfully and accepted for who they are:

‘Yeah, because every individual walking in the door… you shouldn’t be discriminated against because of your age, because of your gender, because of your ethnicity, because of your different ability, your religion, your sexuality. There should be no discrimination; people should be able to be respected when they walk in the door.’ [FG 11]

One participant remarked on having to remind staff of basics of getting to know the person:

‘So that people, but they even did it wrong because they [Hospital] did a poster, I think with the [Hospital] and it was ‘we’d like to introduce ourselves or we’d like to know who you are’. Please ask us to introduce ourselves’. Like the whole thing is you shouldn’t have to ask a doctor to introduce themselves. It should naturally … it’s gone back to basic skills.’ [FG 4]

The simple act of truly listening to the person and believing the person was also considered as important:

‘I always knew there was something wrong but people were laughing at me but they would say there was nothing wrong with her [about a daughter with intellectual disability].’ [FG 3]

‘I was starting to get cognitive problems and I really wasn’t listened to at all and it was me that had kind of find the way through the community and I had to find where I needed to go to.’ [FG 2]

Participants also identified that staff need to be inclusive of the person being cared for. For example, in the excerpt below, the caregiver indicates how a professional could direct the conversation to them rather than the person in receipt of care:

‘…and it is important for the doctor to aim, to speak to him. I am not the person with the… I only took him in. I am not the person with the ailment, you know, just a point yeah?’ [FG 11]

Sensitivity was also identified as essential, particularly for issues which could demand privacy:

‘That can respect privacy. My niece was in a gynaecological ward recently, but the woman across the ward, she was being tested for a sexually transmitted infection. She was a married woman. So, you know, they said it to her in front of the whole ward.’ [FG 11]

Understanding the person’s feelings in an empathetic way was also particularly important as can be seen in excerpts below relating to a difficult diagnosis:
‘When the person, the registrar told me of the diagnosis, I got very upset and he thought ‘but has somebody not already said this to you already?’ And I said well it was sort of mentioned in passing and somebody, and I don’t mean to say this in, I’m going to say it out but I don’t want to be offending anybody, but the December, one of the registrars said, I said well could it possibly be MS and he said well we don’t know but we’re going to check for sure. And then he said ‘well if it is this, it’s not as bad as a cancer diagnosis, is it?’’ [FG 4]

‘I agree, a computer [than a professional who lacked empathy] would be better because it is just so upsetting to have another human being talk to you like that.’ [FG 1]

‘We had a private consultation with the geneticist in [Hospital] which was probably the worst 20mins of my entire life. He was cold, lacked all empathy, gave us unnecessarily horrific anecdotes about research on the condition and painted a very negative picture of our child’s possibilities in the future that were completely unfounded. Not to mention that he was saying all this awful stuff to a first time mum of a 4 week old baby…. he didn't stop until he broke me which seemed to be his goal during the consultation. This cost us €600 after which he refused to break down the receipts into 3 individual receipts as the consultation was for us as parents and our daughter. So we were left bereft and without the option for claiming back the expenses through health insurance.’ [Survey]

Equally, sensitivity was needed when engaging with relatives:

‘It was difficult with the GP that I was engaged with at the time. He had no rapport with old people and his comment to me one day was, I had two small children and he said, ‘Put him [Uncle] in a nursing home and go off and take a holiday’, they were his actual words.’ [FG 3]

3.4.5 Care that is based on authentic and genuine partnership and respects my choices

The relational experience described by the participants could also demonstrate a paternalistic approach in healthcare, where the voice of the person was rendered marginal.

‘And you’re talking about, like, I mean, are you involved? Sometimes you’re not, you’re just told the best way to do it, ‘I’m the doctor, you’re the patient, this is the way it should be done.’ [FG 10]

Such a perspective by healthcare professionals (generally doctors) was considered within the context of the power of medical knowledge and was the consequence of having the ‘correct’ decision-making authority.

‘That’s probably in a lot of care actually, the doctor a lot of the time assumes they know best, which really isn’t always the case, they’re medical professional but they don’t always know best what’s personally for you.’ [FG 11]
Even when the person might express alternative views, these could be discounted:

‘And the doctors try to force their own wishes, or their own opinion on you. Even you might have a desire for something else.’ [FG 11]

Professionals were seen to have the ability to be inclusive but that they needed to positively focus on empowerment:

‘You have to empower a patient to have an involvement in their own care or their care provider, who is their principal carer. They should be empowered to make decisions.’ [FG 9]

When the patient was in a vulnerable position, the caregiver would have to lobby on their behalf and advocate for them:

‘Because you, you know, when somebody can’t speak up for themselves you have to really stick up for who they are, what their baseline is.’ (FG 7)

Choice was considered being made aware of what options were available and being able to review these and that the person could independently choose what was best. In the excerpt below, the participant sees this process as akin to shopping in a supermarket:

‘It is like, you know, I want to know what is on the shelf in the supermarket. What can I have, how much does it cost and how long will it take to get it?’ (FG 1)

3.5 Care that I am confident in

The second theme in the participants’ articulation of person centred co-ordinated care was related to the experiences of care. This contains four sub-themes: a) staff that are competent in delivering my care, b) care that delivers me high quality and safe care, c) care that is accountable and d) care where I experience continuity.

3.5.1 Staff that are competent in delivering my care

While many participants acknowledged the medical knowledge of healthcare staff, there was a recognition that they wanted care tailored to their individual conditions with the appropriate expertise. This was particularly evident when conditions were less common within the population:

‘I look for professional[s] who are experienced and knowledgeable on the condition 22q11ds. They must have awareness of the overall condition when dealing specifically with 1 symptom and treat not only the symptom being presented but treat it as part of (possibly) a number of symptoms as part of the condition.’ [Survey]
At times inexperience of professionals may be an issue, as is their familiarity with certain conditions. Competence could also relate to knowing the appropriate referral pathways for the person when care requirements demanded this. A lack of knowledge resulted in distress and a lack of confidence in the professional, as detailed below:

‘So, I went to… and the doctor there, an older person, an Irish, local doctor said to me about bringing him to [Hospital]. And I said, ‘[Hospital], are you messing?’ And he said to me, ‘How dare you speak to me like this’ and was totally horrified that I spoke back to him. I said, ‘[Hospital]?’ and he said, ‘Yes.’ And I said, ‘Could you actually give me a letter for [Hospital] please?’ OK, a paediatric child to [Hospital]. Now, this is five years ago only, right? And he said, ‘Yes, yes, yes’ and so, he wrote the letter and I said, ‘Can I just say, that I worked in [Hospital] myself ten years ago and it was closed down as an infectious hospital I would say 15 to 20 years ago and it is a drug rehabilitation centre. So, if I wasn’t a health professional myself and able to speak up here I would be driving up at midnight to an adult imaginary hospital for my child.’ [FG 1]

3.5.2 Care that delivers me high quality and safe care

There were examples of care that participants described as high quality care and expressed satisfaction in that care:

‘I had my own event [illness] about 20 years ago and from day one I could say that the doctors and the nurses that were involved at the beginning when I had the major operation, they were brilliant, absolutely, couldn’t do enough…. It was all positive. I couldn’t say enough about those people.’ [FG 9]

Care quality could be closely impacted by competency, particularly when the participant recognised that they needed more specialised care. Some professionals chose to continue delivering services rather than discharging or referring on the patient. In the excerpt below, this is observed by the participant:

‘Speech & language teacher has taken it on herself to continue giving us classes even though we should be moved on.’[Survey]

When care levels were more complex or the gatekeeper (health professional) lacked expertise, a referral to the appropriate professional was required:

‘That they [doctors] actually own up and say, ‘I actually don’t know’ and step aside and let you get to the guy who does know.’ [FG 1]

‘…they used to stand at the end of the bed and just say, ‘Yes, yes, yes, you’re fine, you’re doing great’ and walk on and I’d be left like just sitting there kind of going, ‘Well you know I’ve all these questions that I want to ask you,’ you
know. And they just didn’t [answer the questions] and basically I kept reiterating that I needed to see an occupational therapist and I need to see a speech and language therapist, this went on for months and eventually they referred me to the rehab in [hospital].’ [FG 2]

Care quality could, however, be impacted by resource issues and the limits of current service provision. In the excerpt below, when a family sought additional supports in the community due to increased care demands, there was an explicit statement that this would impact on the reduction of services to another person:

‘And they were told well if you shout for more hours then we’ll have to take hours off another child. And you’re putting parents in that situation, which is kind of…’ [FG 9]

Equally, care quality was impacted by lengthy delays in accessing the required services and, while waiting, this could lead to a preventable deterioration in the condition as well as a crisis situation as observed by the participant below:

‘Then I had to wait to hear from them and I was getting impatient so I knew somebody and he looked for somebody and she had it done within six weeks And then regarding services like that and communication, my middle daughter, it took her three years to be diagnosed with juvenile arthritis. They put it down to psychological. They said it was post-viral, told her to her face that she was lying about her pain, it took two and a half on a waiting list to see a rheumatologist in [another city] and when we got there, she’d 15 active joints throughout her body and was put straight on chemotherapy to help treat her.’ [FG 3]

‘You’re lucky to get one [visit] a week. Yeah one, three quarters of an hour and the rest would be half hours.’ [FG 5]

Community services’ quality of care was also observed as being impacted negatively by having just a Monday to Friday care provision. Care requirements did not disappear through the weekend and this resulted in a struggle to manage:

‘It’s [community care] a huge problem in the [Region] trying to get access to caring hours and patients are severely struggling from the middle of Friday until Monday morning and it’s really hampering their quality of life so something really needs to be done in that area as well.’ [FG 6]

The lack of availability of a quality and comprehensive service could lead to acts of resistance, for example, a refusal to accept back a person to the community from acute care as families recognised the impoverished services and that their struggle to provide care would not be addressed, leaving them in a stressful situation:

‘Don’t take them [family member] out [of hospital] or you’re back to square one.’ [FG 7]
The lack of resources also led to many accounts of struggling to obtain care with evocative descriptions of fighting or battling to get care as detailed below:

‘I was very unhappy, because when I fight for [Name] I hope to God I am fighting for everybody else.’ [FG8]

‘Having to battle for basic needs to be met. Overly bureaucratic.’ [Survey]

‘And we’re constantly fighting to try to get services into the [day] centre and back up to make sure that the clients are cared for properly in a structured environment and staff was always an issue for us...’ [FG 9]

3.5.3 Care that is accountable

Confidence in care was also related to accountability. Participants wanted to see care where deficits were followed up. Such deficits could have a significant impact on the person and the family. In the excerpt below, a mother describes visiting a General Medical Practitioner with a child with undiagnosed diabetes. A decision was made by the parents not to wait to attend accident and emergency, but to bring the child immediately. On admission, the child was found to have very high blood sugars which untreated would have led to a hyperglycaemic coma:

‘[Hospital] Diagnosed him then...about the doctor who left him home [saying] ‘Put him into bed and go [to A &E] in the morning’, like, there was no follow up about that doctor [who said to bring the boy home from GP service and go to hospital in the morning].’ [FG 11]

Another participant observed that when staff are being held accountable, the care quality improves:

‘It was because he was being held accountable and he knew it that things got done now. Now thank God he came out of it and he was fine, but to have to go through that, you know, for him not to just stop for a minute and listen. He had been told by the nurse, I’m sure, as well at this stage he’s not right.’ [FG 4]

Accountability was also identified in terms of care provision through the HSE ‘s sub-contracting work out, which was not carried out, yet paid for:

‘There is just, the carers would be a major, major thing and the HSE do not hold the companies responsible if the carers don’t turn up. And because of my experience I now know that there are people in their homes and carers don’t turn up. And they are left there.’ [FG 8]
In addition, accountability could be related to the overly bureaucratic nature of response systems, which were seen as lacking efficiency:

‘Yeah, common sense stuff. There is a phone number you lift and somebody comes out and fixes you bed, you don’t need, your bed is not working, you don’t need somebody to come out and look at it to tell you that it’s not working. That is exactly what happened to me and then they go back and take another couple of days for somebody to come.’ [FG 8]

In observing the impact of deficit care, participants could point to problematic management systems which fail to understand the reality of care and that accountability was needed for such oversight:

‘Lack of accountability for decision-making by managers that impacts on daily life of person with disability.’ [Survey]

3.5.4 Care where I experience continuity

Continuity of care related to two aspects of care. Firstly, some participants commented on the multiple different staff met when visiting a service and secondly, the continuity of care related to not having to endlessly repeat the same information on multiple occasions. Continuity of healthcare staff contributed to the perspective that person centred care was being delivered as demonstrated in the narrative below:

‘Yeah [person-centred], because he’s attending the same people so… they’re nice, now.’ [FG 11]

However, there was frustration when staff were different at each health appointment and this led to needless repetition of the same information:

‘The interns keep moving and you might not get the same intern even though they are still here when you’re going to the clinic and the clinic now cracks me up.’ [FG 10]

‘I’m talking about children predominately, that’s what we deal in children, they [parents] have to re-educate every single person involved in the child’s care every time, rather than them being already briefed as a team, about my child.’[FG 9]

The idea that this could be avoided if staff actually read the correct history was a common experience. In the excerpt below, the participant also points to the frustration of having to repeat historical information:

‘Like a child may have a health passport, has everything [the] child needs… requirements, requests, just a little synopsis, this is the child’s manual as we call it. But they don’t actually read it, they question the parents over and over
again, it’s very frustrating to have to explain the child’s conditions over and over again.’ [FG 9]

‘Get a proper system where all healthcare professionals have access to medical notes regarding the patient. Between hospitals, GPS, clinical nurses, private consultants. So less time is wasted explaining EVERYTHING over and over again by the parent or carers.’ [Survey]

Continuity of care could also be jeopardised by high staff attrition rates, which led to a struggle to re-negotiate care:

‘…people have left their jobs there and there is no one to fill that place. Case workers change like the weather, Nothing [sic] is ever followed threw [sic] as case-worker has left, our sick and no one to fill the place so you have to fight all over again.’ [Survey]

Continuity of care was also considered as staff from different settings having access to shared information. This could be problematic in the current reality as the participant below describes his/her experience:

‘I’m at huge risk of infection now I’m meant to carry a card with me but there’s no way of my GP connecting with that, he’s 30 miles away from the hospital, the private hospital…and he sits back and he laughs at the fact that I’m the one that’s telling him that, so to a certain extent I think there’s a lot of responsibility left on the patient’s head to make sure they don’t get it wrong.’ [FG 2]

The current limitations of paper based records was identified as limiting access and availability and added to frustration:

‘But when she went back in the other day they still didn’t have the charts. Then she had to go, we brought her and she had to go in there and wait all day for them to build this up. She said, it’ll never happen again because there was something there on all the files that they would recognise them, to just have a look through. But you know.’ [FG 1]

One area which was highlighted as having continuity of care with shared information was cited as X-Ray:

‘And it’s there, you know, even if you go to a private consultant now, they can access it [X-Ray] now.’ [FG 5]

However, the participants did consider that advances in health technology would assist in care continuity. There was support for the full implementation of the electronic health record and this was considered a method of having all the information available for staff which would be easily transferable and accessible:
Another thing that I wanted to say is that this whole, I am a big supporter of the electronic health records thing and my son, he is 10 now and he got very sick when he was three. It was a normal delivery and I swear to God, if another doctor in the same hospital asks me that.’ [FG 1]

3.6 Care in my journey through healthcare

The third theme related to the person’s journey through the health system. Three sub-themes were identified. These were a) care that has a holistic approach to my health and world, b) co-ordination of my care in health and areas outside health (i.e. education and e) access to services when I need them.

3.6.1 Care that has a holistic approach to my health

It was recognised that health is not experienced in a vacuum and that availing of healthcare requires a person-centred approach that takes into account the world, preferences and the reality of the person’s life. Consequently, care needs to be negotiated and accommodated in a way that acknowledges individualism and context:

‘But again this is person-centred again. It’s [care] not just person-centred, it has to be individual. Always bespoke.’ [FG 9]

This included healthcare services focusing on the fact that people have other obligations and what may appear straightforward in terms of health services could be complex to translate to the person’s reality of family, as articulated by the participant below:

‘Because I kind of feel strongly about that, about the family unit that as a whole all the appointments, all the notes, so I don’t think it can be taken individually [as only the person] really, I think it should be taken as a unit. Especially if you have got older parents and younger children, like a lot of people in Ireland do now.’ [FG 1]

This required health professionals and systems of care to be flexible and to tailor care according to the options which suited individuals:

‘…because everybody’s toolbox would be different and it doesn’t all just follow on protocol and care or pathway or you know he [experience of consultant care] wasn’t trying to fit me into a pathway. He was listening to me and then saying, ‘This is your toolbox, this is what you need now’ [FG 2]

Understanding context involved seeing the world from the person’s and meaningful others’ point of view and understanding the challenges and being able to respond in an appropriate way. In some cases, caregivers observed the reality that although their input was fundamental in care delivery, their voice was not always acknowledged. Thus, holistic care meant care inclusive of the caregiver’s perspective:
‘There’s an awful lot more talking to the carer [needed], and respect the carer. You know they’re [healthcare staff] not going to focus on the patient as much… as in the public sector it’s the carer… isn’t even looked at.’ [FG 5]

In the excerpt below, the carer’s context was not fully understood leading to a stressful process of seeking assistance and then having to re-negotiate through acute services:

‘…the reason I was here actually was for one of my carers in [Town], she has her mother who is elderly and I suppose she is caring for her for seven years and during Christmas, well on and off she has a chronic illness. And she has been in and out of hospital and on Christmas day I think she was something like 13-14 hours in casualty. But she finally got a bed and when they had seen her they wanted to send her home. So, she said to them there was no way she could take her home because she wasn’t able to manage her. So finally anyway they kept her for another week and then she had respite and she is back in again two weeks later and still had to go through casualty. And it is the same system. And like four weeks she says to her for respite is not... is not enough’ [FG 3]

Holistic care also meant that care took into account the multiple issues a person had within co-morbidities. Many of the participants spoke of how isolationist specialist services were in the context that they only focused on the specialist issue not the whole person:

‘A realisation about the illness and the variety of issues involved. No one thing should be looked at in isolation.’ [Survey]

‘The only person that’s in charge of managing all that is the patient themselves, the only person, there is nobody, there’s nobody who’s literally looking over your whole condition.’ [FG 2]

When such an isolationist approach occurred, this could lead to potential problems in areas such as medication:

‘I see lots of different consultants and one of them gave me a new drug and it would have had an actual, it wouldn’t have been too toxic or it wouldn’t have been too bad, but it would have had, it wouldn’t have had any benefit because it would have interacted with one of the other medications I was on.’ [FG 2]

‘But it’s ridiculous when you go into hospital, for us personally there’s no connection between medications.’ [FG4]

So a more holistic approach involved specialists working together in harmony as suggested by the participant in the following excerpts:

‘But it’s part of the whole medical system that people have specialisms in different parts of the body, you know, the doctor for the big toe doesn’t see the rest of the body. Like, you know…’[FG 7]
‘I just feel there’s been times that, because I was under a heart specialist, I was under bowel inflammation, rheumatology and there was a lot of back and forward in decision making.’ [FG6]

‘I feel a lot of the time we have to push for various appointments for our daughter and that the various teams do not necessarily interact with each other and share information including with her GP.’ [Survey]

Holistic care was also considered to transcend western medicine to include alternative treatments, which could complement existing therapies and help manage chronic illness symptoms as observed by the participant:

‘I think access to alternative therapies or a budget for alternative therapies especially for people with MS and arthritis would be very beneficial in reducing pain and fatigue levels.’ [FG 6]

3.6.2 Co-ordination of my care in health and areas outside health

Closely linked to holistic care is the experience of co-ordination of care. Care was often experienced as disjointed between settings and it was suggested that more integration of services is desired to link the person’s care journey:

‘I think sort of connection between primary care and secondary or tertiary care, connection I think you know connection in relation to information and communication, health professional or whatever you know.’ [FG 2]

‘Transitional care from acute services to community services, the transition is not seamless at all, it’s full of obstacles, especially if you have multi-symptomatic care requirements, trying to coordinate several different disciplines, to look after an individual…’ [FG 9]

This could mean the person and his/her family and carers struggled to navigate services:

‘Patients and carers are coordinating care, no one person in HSE system managing my son’s care only his family.’ [Survey]

A lack of co-ordination could also mean that important areas such as a patient’s understanding of what was going on, was neglected. The excerpt below demonstrates the continued lack of co-ordination experienced by a person with a hearing deficit who was exposed to multiple care interactions in different settings:

‘Rehab Care brought him [man with hearing deficit] to the doctor, they didn’t look for…Rehab Care didn’t look for an interpreter, the doctor didn’t ask for one, was moved over to A&E, they didn’t look for one and now he's on the ward and it is only now that that person has texted us. So, when I finish here, I have to go to the hospital. So, it is a pity when we have a policy and we have a
practice of paying for it but then, the coordinated services aren’t adhering to the policies.’ [FG 11]

The lack of co-ordination could mean services were not in place when the person was moving from acute care to the community, which put pressure on service provision:

‘And then Friday we checked again, so there was no word back about [Name], and on Monday we got an email to say, ‘[Name] is home, get your care worker to attend, she was discharged on Friday from the respite setting’. [FG 5]

Equally, the lack of co-ordination in streamlining people within services could mean wasted time waiting:

‘So, that is all the disparity, all these stories that, I can think of another one, my own shoulder injury. It happened abroad, I had an MRI, I had everything I needed, I still had to go to casualty [back in Ireland] and sit in casualty for six hours to tell me, ‘Thank you but you need to go to the orthopaedic clinic in the morning.’ So, they let me take up space for six hours. Somebody already with an MRI, everything they needed, I needed to see an orthopaedic.’ [FG 3]

‘The consultant must have went for his dinner or something because it was the afternoon before we got seen again and all he could do was apologise that no, he didn’t really want to see us at all.’ [FG 4]

Co-ordination could be assisted by having a key person who oversees the person’s care:

‘A nurse shouldn’t have to be liaising between patients and there should be a co-ordinator, I think, someone who’s educated on how to use the system and they take on a certain amount of people and they walk them through the system, now they’re not a healthcare professional themselves but they know how it works. So they educate people in how it works, who you need to go to next.’ [FG 4]

‘My son was diagnosed with 22q11.2 Deletion syndrome when he was 4 years & 5 months. He had previously been misdiagnosed with Constitutional Development Delay. Since then my husband and I are the ones researching his condition & asking for referrals to different departments hoping we don't miss any crucial issues like the scoliosis that hasn't yet been followed up on by the relevant department. We need a care coordinator for 22q11 Deletion Syndrome to help our children reach their full potential & ensure every area of concern is noted & referrals made.’ [Survey]

Parallels were also made to other health services outside the Republic of Ireland. For example, it was noted that travel to other countries was necessary when there was no specialist in Ireland. Yet, this could be on the own person’s initiative, rather than being coordinated by healthcare in Ireland:

‘He [Consultant] said he never saw it and nobody in [Hospital] saw it. It was such a rare condition. And what were we to do? We tried [City A], and we
tried [City B] and there was nobody could deal with it. I would have had to go to London.’ [FG4]

In some cases, such care had to be accessed privately by and at a personal financial cost to the person:

‘We currently have had no speech and language therapy with our early intervention team, as a result we have gone private with an expert in the US. I would hope that both liaise with each other to fully support my son with a collaborative plan.’ [Survey]

Within some narratives, there was a complete parallel but separate care provision without a co-ordinated approach:

‘So what that means is, when I go to [Irish hospital] they work with this ear, they [UK Hospital] cannot change the setting of the Irish ear, they can only work with the English ear, so, what they can do this, both teams can test the function of both ears but they can not make changes to one, if I happen to be at one clinic and I say, I’m not sure about this thing could you remap it…’ [FG 2]

‘We had a case where [Name] was going into hospital to get her peg [Feeding] changed, right and she was on Warfarin and the doctor is standing there with her notes, didn’t read them, right? They came to take blood, took blood and I said to them, ‘You do know she’s on Warfarin?’ ‘No, no, no, I’m here to deal with her peg, not her head’ [FG 8]

Care co-ordination was also observed to involve non-traditional foci. For example, related to the cultural aspect of care, participants who were Travellers observed that health appointments sent by post may never reach the Traveller person due to the lack of a physical postal destination and could result in non-attendance to healthcare appointments. Therefore, care coordination needs to take such realities into account:

‘And it might not be the hospital’s fault but the local authorities and them, like why do we have to fight for so long just for post? People get tired, sometimes you could see mothers crying because why can they [Local Authorities] not just put up a post box and deliver out a letter?’ [FG 1]

For children who have developmental delays, educational issues could arise which could be important in supporting global development of the child. Again, co-ordination was not experienced:

‘She [daughter] is with the Brothers of Charity now. So, at the very, very beginning like I mean it was crazy trying to get her... She went through mainstream, started off through a mainstream school and then I fought for a remedial teacher, a resource teacher whatever it was at the time and I organised all the schools in my area to see how many children needed help. And I rang the inspector and his words were to me, and I was sitting in the
couch and I nearly fell off it. He said, ‘Maybe your child won’t get any better.’” [FG 3]

Thus, a wider perspective of care co-ordination was suggested:

‘And then it wouldn’t just be coordinated care, it would be integrated care because we need to integrate the health, education and social care departments because a huge amount of, once we get our children’s medical stuff kind of fixed as best we can we’re into school and they’re struggling in school.’ [FG 7]

‘I think what [Name] is saying as well is something I would agree with completely, that sometimes we look at the health service in isolation as just the health service but yet, it is housing, it is transport, it is all the departments we don’t, social welfare because you need an income. And it is all the departments as well that we don’t traditionally associate.’ [FG 8]

3.6.3 Access to services when I need them

This sub-theme was persistently prevalent in all data sources. The participants experienced long waits for services, which proved frustrating:

‘Please do something to help!! The [waiting] lists are so long. So so so long.’ [Survey]

‘They can’t get an appointment, but the biggest problem with a stroke is when you come out, when you’re released from hospital. Only for the [County] Stroke Group, there’s nothing there for people. They’re forgotten about. I saw an occupational therapist after a year and a half.’ [FG 11]

‘Notting [sic] has gone right as still stuck on waiting lists. It's been over 2 years now.’ [Survey]

‘Our 7 year old son was diagnosed with scoliosis almost 18mths ago & no sign of an appointment. Also waiting on appointments for Rheumatology, psychiatry & cardiology.’ [Survey]

‘I’m the lucky one to sit there because I know there’s, from being in support groups and helping run the branch down in [Area] that we have, well there 2,500, nearly 2,600 on the waiting list to be seen and it’s 18 to 24 months depending on where they’re lying on that priority list so I know I’m the fortunate one that gets to sit there.’ [FG 6]

Or access to services may be prevented altogether if the person was on the public system:

‘As the doctor said in hindsight, ‘He [Consultant] should have MRI’ed’ but they’re not going to do that because you’re on medical card.’ [FG 3]
‘Going privately seems to be more of a necessity to get services.’ [FG 3]

‘We have failed to get an appointment publicly with a heart doctor so that my daughter’s heart can be checked before she goes on vital growth hormones we have had to go privately and the app has been cancelled. Once on top of that our private appointment is being held in a public hospital at a cost of 150€’ [Survey]

Even when appointments are given, there was a danger of being cancelled:

‘Cancelled appointments without sufficient notice, long delays in access to services.’ [Survey]

‘What I was told is that once surgery was going to happen, that I would be told to come back. I was told to fast 24 hours before the surgery when it was due, but they cancelled the surgery. The following morning I was told ‘no, no, no you are going to have surgery after all’ [FG 11]

Access was also noted to be lacking when it was outside ‘office hours’:

‘And the other thing is, you know, that the external supports as well like, you know, you might be an outpatient who has got a rheumatoid condition who goes to see the rheumatologist and then your rheumatoid nurse on a bank holiday weekend on a Friday at four o’clock, you’re in absolute need to talk to them and your rheumatologist says ‘Well I can’t help, I’m going on my holidays, I’m going off, I finish at four o’clock today, it’s a bank holiday so well actually you’re better off going to the emergency department’. You know, and so there’s that disconnect in our services that just is so frustrating for a person.’ [FG 7]

Access to services could also be impacted by geography, with some commenting on the lack of equality in services:

‘The one thing we’d like to bring up here today actually is, the fact that [County] is quite a large county and it doesn’t have a stroke unit. The fact that [Name] has had a stroke I suppose highlights it more to us, but [County] University Hospital as it stands doesn’t have a stroke unit, it doesn’t have a specific stroke doctor and it doesn’t even have a stroke nurse. [Name] accesses all his care, stroke care at [City] University Hospital, so it means last week he had to have a pacemaker check, he has to go to [City], I’ve a job back down the road. Next week he has to go to [City] for a pacemaker change, back up the road to [City] and down again, they call it a University Hospital, it’s not. You know the fact that it doesn’t have… I think it’s the only county in Ireland that doesn’t have a stroke doctor.’ [FG 11]

Another issue regarding access was a mismatch in supply and demand for services:

‘If we want respite [for MS] we have to go to [County] which is hard to get, they have only one bed or two beds.’ [FG 8]
The lack of access to services could also lead to a decision to enter private care:

‘And I am extremely lucky, I have gone – right this is so important and it has been so debilitating in my life, I have gone and seen the best possible person because I have been able to afford it, I have made it my priority to do that.’ [FG 1]

‘And the same with you know when you’re actually seen by a doctor as to accessing a hospital bed, VHI definitely makes a difference as opposed to…’[FG 11]

Yet, it was acknowledged that, once accessed, the public system could meet need:

‘So, I’m slightly different, but what my experience from people with arthritis, was that, getting in to the system was the problem, once you get in the system, the services are available but getting in is the problem.’

[FG 10]

‘In general services are good, experience of waiting list is dire.’ [Survey]

3.7 Conclusion

The study findings drew upon two methods of data collection, namely, from focus groups and an on-line survey. The data revealed three themes, ‘My experiences of care’, ‘Care that I am confident in’, and ‘Care in my journey through healthcare’, which were based on experiences of current services and how such services need to be re-oriented to facilitate person centred co-ordinated care. The three categories presented in the data demonstrate what is important for individualised care to be scaffolded around the person and their carer and represent important areas of focus for individual health professionals, health and social care disciplines, organisations and policy directions.
4. Discussion

4.1 Introduction

Person-centredness is a priority in the health systems of developed countries. Person-centred care is both a philosophy and a way of organising and delivering care. As a philosophy, it is underpinned by the principles of dignity, compassion and respect (DoHC 2001; NICE 2006; Royal College of Nursing 2008; McCormack & McCance 2017). As a way of delivering healthcare, it explicitly prioritises the individual in the care system, recognising the expertise and resourcefulness that the individual may possess, thereby reducing the pre-eminence of either the care system or the professionals within the system. In this way, it seeks to enable care recipients to direct their own care and requires the care system to focus on the individual’s preferences, needs and wider life circumstances, including family and work, and not just the medical diagnosis (WHO 2015). By promoting individual preferences, choice, and independent and autonomous decision-making, person-centred care challenges the hegemonic power of healthcare professionals. It also recognises and affords legitimacy to the individual person’s own supports and carers outside of the formal healthcare system.

As currently understood, person-centred care reflects an ethos of person-centred coordinated care, whereby the care system and care professionals work with individuals and their families to identify what is important to them and organise care accordingly (McShane & Mitchell 2015). Person-centred care is consistent with principles of care quality and with the provision of an effective and efficient healthcare service (HIQA 2012; Kitson et al. 2013; Olsson 2013). Achieving person-centred care in the health system is not possible by merely relying on individual healthcare professionals’ good intentions and practices; rather, it requires a systems-level strategic approach that incorporates several elements: facilitating an enabling environment, strengthening governance and accountability, reorienting the model of care, coordinating services within and across sectors, and empowering and engaging people (WHO 2016).

Like other developed countries, the Irish Government and the agencies responsible for governing and delivering the health services in Ireland have embraced the philosophy of person-centred care and have explicitly made efforts to instil the philosophy into healthcare regulation, clinical governance and service delivery. This is evident in several Health Information and Quality Authority publications (HIQA 2012; HIQA 2013; HIQA
2014; HIQA 2016a, 2016b; MHC & HIQA 2016). The philosophy has also been adopted by those responsible for delivering care services, as evident in several policy and planning documents (HSE 2013; Gavin & Brady 2013).

To date, much of the focus on person centredness has been in residential care settings (Clissett et al. 2013), with limited application in other healthcare settings. When adopting person centred care across the entire healthcare system, it is not possible to apply a one-fits-all approach, since it is individuals themselves, and not the care settings, that reflect variance; they vary in their perspectives, preferences, and needs according to their circumstances and the setting (Harding et al. 2015).

To achieve person centred co-ordinated care across multiple care settings, it is therefore necessary to first establish the evidence on what is considered person centredness by the individuals who use the services. This requires direct consultation and engagement with communities and individuals who interface and engage with the care system, in order to elicit their views and experiences. Importantly, this represents the recognition that people are experts in living with their own health conditions and as such, although clinical outcomes are important, a sense of wellbeing is a priority (Finnis et al. 2016). It was on this premise that the present study was undertaken. The aim of the study was to identify statements of what constitutes person centred co-ordinated care in Ireland. The resultant evidence would, in turn, inform the development of an e-care evaluation template for health service users.

4.2 Study design and sample
This study was conducted in partnership with the HSE and IPPOSI and was underpinned by a PAR approach. A key tenet of PAR is that it involves people directly in co-designing the research, including identifying the research questions, identifying the good and bad practices in the setting of interests, and co-creating actions and solutions to address the problems.

For this study, we invited service users and other key stakeholders to act as co-researchers in informing the evidence of what counts as person centred co-ordinated care in various settings in the Irish health services. This involved gathering information from people who directly use the healthcare service, families, caregivers and patient
representative groups to identify the key moments and places in which service users directly experienced a service that gave rise to their subjective experiences of the care system (Bate & Robert 2006). The aim was not just to identify evidence of absent or poor person centred care, but also exemplars of good care and to identify unanticipated areas of improvement and quality.

Using a narrative approach to develop services has been identified as addressing failures in previous structures of integrated healthcare (Redding 2013; Francis 2013). Similar to work undertaken in the UK (National Voices 2013), an inductive approach sought to develop what health service users want within an integrated healthcare system. In using this approach, participants reflected on the experiences they had and what needed to change to orient health services to provide person centred co-ordinated care using the CAPHS Patient Narrative Elicitation Protocol (Agency for Healthcare Research & Quality 2017). Such a reorientation mobilises and enables individuals, families and communities to become partners and managers in their health with a focus on quality of life within the journey of health optimisation, regardless of setting (Taylor 2014). Our overall aim was to develop a generic definition and related statements of person centred co-ordinated care.

Consistent with the idea of evidence-informed practice, we adopted a wider range of information sources than would typically be used in an evidence-based practice inquiry (Woodbury & Kihnke 2014). Accordingly, we used a combination of focus groups and an online qualitative survey to gather information from service users, families, and service user representative groups. The focus groups drew on the principle that a group relating a shared experience can give much wider and richer information than individual interviews. Open to all members of IPPOSI, the qualitative survey gave us the potential to reach a wider sample than our focus groups and enable a determination of the diversity of the topic within our population of interest (Jansen 2010).

The overarching aim of our methods was to generate narrative accounts of people’s experiences of interacting with the health services, either as care recipients or as family carers, and thereby procure nuanced and subjective accounts that would inform a definition of person centred co-ordinated care and its main components. Using individuals’ narratives enabled us to build up a conceptual explanatory model, which
consisted of the three major components of person centred co-ordinated care, discussed below (Figure 4.1).

We conducted eight focus groups with people who directly used healthcare services and three focus groups comprising families, carers, and/or patient representative organisations. The focus groups were conducted according to best practice recommendations (Agency for Healthcare Research and Quality 2017) and a total of 78 individuals participated. While our sampling strategy was purposive, we nevertheless secured a relatively heterogenous sample in respect of age and urban-rural mix; however, the majority of our sample was female. The gender profile of the sample is perhaps unremarkable, reflecting as it does the fact that one third of our sample was caregivers and the majority of caregivers are female (CAI 2015; CSO 2012; Lafferty et al. 2014). Additionally, focus group participants represented a wide range of care-recipient population groups, including older persons and persons with a variety of chronic illnesses, including diabetes, heart failure and dementia, and individuals with functional limitations related to musculoskeletal and other diseases. Again, this profile is unremarkable and reflects the profile of the wider population of service users (CSO 2012). Further interpretation is not warranted since the sample was purposive and some participants reported themselves in more than one population category. Another aspect of the data collection methodology is that there could be a blurring of narratives as people who were carers or in representative groups could also speak of their individual experiences of healthcare and vice versa.

The online survey yielded a total of 39 valid responses. While this is a small number, it may be explained by the fact that the population from which the sample was drawn was circumscribed as being a member of IPPOSI or of its constituent organisations. Further, while web-based surveys are cheaper and faster to administer and analyse than surveys using postal questionnaires or face-to-face interviews, they generally result in lower response rates (Pederson & Nielsen 2016). Additionally, a strategy of multiple contacts was not deployed to promote increased responses. The majority of the survey respondents were family carers and, unremarkably, more women than men were represented in the sample (CSO 2012). The majority of self-reported issues that pertained to the respondents were physical disability, intellectual disability and mental health problems. Equally, the validation survey was conducted to ensure the domains, statements and definition provided clarity and comprehensively described what person centred co-
ordinated care should look like and what constituted it as an experience. This resulted in some refinements to both the definition and the statements.

4.3 Components of person-centred coordinated care

4.4 My relationships with care professionals

In reviewing the narratives in this study, participants had three foci of care: ‘My care experiences’, ‘Care that I am confident in’ and ‘Care in my journey through healthcare’. Firstly, a dominant feature was in the context of relationships with healthcare professionals. Communication and partnership were considered essential, as was the need to have information that concerned the health condition(s), the choices available, the services that may be helpful (statutory, voluntary, community) and information concerning anticipatory guidance that could enable preparedness for possible health condition status changes. Equally, healthcare professionals need to understand the world of the person and those who support him/her and work in partnership to direct care that aligned with the individual’s preferences. Thus, the context of the person’s world resonates with approaches in child welfare and protection (TUSLA 2016, Scottish Government nd) and person centred care (McCormack 2004; WHO 2015) pointing to the
need to healthcare staff understanding how I experience health and social care, what I and my care require from people who assist me and what my wider world involves.

4.4.1 Communication and partnership
As a way of delivering quality healthcare that prioritises the individual’s self-identified preferences, priorities and needs in the care system, person centred care focuses on the care recipient and not the care system. To render person centred co-ordinated care effective, communication is essential and this must be multi-directional, between the person and the healthcare staff member and among others involved in the person’s care. Fundamentally, communication should be conducted in a way that facilitates the individual to express preferences, priorities and needs in the health system (Robert et al. 2011; National Voices 2013; Van de Ven 2014). This aspect of person centred care was evident in the participants’ narratives, which described two key dimensions of communication: communication that is understandable to the individual, and communication that provides the individual with the required information. The need for good partnership and communication is evident in recent publications in the UK (Finnis et al. 2016:12), as people require “support to develop knowledge, skills and confidence to manage their health and well-being” through both formal and informal access pathways for health. This represents a culture shift in care, which authentically centralises the person (Coulter & Oldham 2016).

Several participants, including those representing the Traveller Community and those for whom English was not their first language, expressed the need for health professionals to communicate in a language and/or method that was understandable to them and took account of cultural differences between health professionals and the service user. Studies in Ireland have demonstrated health inequalities related to the Traveller population (School of Public Health, Physiotherapy & Population Science 2010). In a publication, which examined cultural competence in health and healthcare, Mathews (2008) states that socio-cultural barriers can contribute to health inequalities and are due to poor access to and uptake of health services. Research in the UK which involved Travellers (including those identifying as Irish Travellers) pointed to the need to understand the Traveller way of life, the need for service flexibility and accommodation of cultural norms and perspectives. In Jackson et al.’s study (2016), it was also noted that the Roma people experienced additional barriers in healthcare such as having to acquire a new language and being in a new country. Although our study did not have Roma participants, there is
an estimated 5,000 Roma people in Ireland and research has shown that there are challenges in accessing health, a common experience of poverty and gender-related issues such as abandonment of women in hospital (NASC 2013).

The assumption of competency in literacy and numeracy is a common feature of healthcare, yet, a survey undertaken in Ireland between August 2011 and March 2012 reported that 1 in 6 Irish adults experienced difficulties in literacy, with one in four finding it difficult to do simple maths calculations (National Adult Literacy Agency 2012). In our study, some participants suggested that the provision of written information, such as consent forms and information leaflets, presupposed a level of literacy that not all persons possess, leading to unnecessary anxiety for service users and presenting a potential barrier to accessing services. Equally, having communication challenges in terms of sensory deficits such as deafness can impact on the quality of healthcare to the person (McKee et al. 2011). This lack of preparedness of healthcare professionals and environments can lead to a poor, non-person centred care service where choice is limited and the development of self-care competencies unfulfilled (Sirch et al. 2016). Moreover, the anxiety and distress of deaf people can be compounded by not understanding the diagnosis, what treatment was being offered, what medication was being prescribed, and its side effects (Sheppard 2014). These findings concur with the experiences described in this study, as the non-provision of qualified sign language interpreters presented a significant communication barrier for individuals with hearing deficits.

Issues such as accommodation for other vulnerable populations were also highlighted in the context of being able to provide tailored care in acute settings for people with dementia or people with an intellectual disability. In these contexts, caregivers spoke of the real concern they had for their relatives in such environments, which were unable to accommodate people who had different care needs. Other Irish research supports this experience. For example, Timmons et al. (2016) reported on the challenges in relation to older people with dementia accessing acute care in Ireland. From 35 hospital surveys, there were a number of areas of sub-optimal care, such as staffing, impoverished discharge planning, access to specialist services and an appropriate knowledge base. These were considered to impact on increased adverse care outcomes. Equally, in a qualitative study, Phelan and Meighan (2017) identified challenges experienced by parents when their child with intellectual disability required acute hospital services.
Robert et al. (2011:70) reported that service users of the UK National Health Service expressed the view that “good communication helps people feel that they are being seen as individuals, with a range of needs”, and one dimension of communication was being listened to. Similarly, based on longitudinal data from patients and staff on what matters most to patients, Van de Ven (2014) observed that communication represents a two-way flow of information in which patients are enabled to explain their concerns and ask questions, and the service provider listens and provides answers that are understandable to the patient. In our study, a dominant and persistent theme was the experience of poor communication with and between health professionals and settings.

While health professionals and service providers recognise that information is essential, if patients and their carers are to be equal partners in decisions relating to treatment and care, they need to have the appropriate knowledge. However, there is evidence that inadequate information occurs at all stages of the healthcare experience (Robert et al. 2011). Data from the present study indicated that participants valued communication that provides the individual with the necessary information with which to self-identify priorities and needs. This is consistent with the expressed views of individual service users in the National Voices (2013) study, in which people articulated the need to have information, including personalised information, with which to make decisions and choices about their care and support.

Information needs included information about the condition particularly at diagnosis, information on community and national supports (peer and voluntary groups), information on care planning and prognosis, as well as information on statutory supports and services available. It is only when such information is available to the person and those supporting the individual that informed decision-making and choice can be articulated and the optimisation of positive outcomes (Stacey et al. 2017). Thus, knowledge is power and knowledge empowers decision-making, which can be conducive to the person’s individual lifestyle choices. Such information has been associated with better adherence to medications, behavioural change, and self-efficacy (Greco et al. 2016). The need for information to be specific to the person and to the condition(s) is evidenced by the plethora of publications tailored to specific information needs of people. These include relatively common health conditions such as diabetes (Ball et al. 2015; Weymann et al. 2016), coronary syndromes (Greco et al. 2016), asthma (Loerbroks et al. 2016), post-traumatic stress disorder (Watts et al. 2016), as well as less prevalent
conditions such as 22q11 (22QIreland (nd); Kerin 2015; Kerin 2016) and rare cancers (Ladd 2107). However, it is not simply information that people need, but explanation and support to achieve person centred care (Coulter & Oldham 2016).

In addition to effective two-way communication, participants also spoke of the need to experience the healthcare system in a way that demonstrated an understanding of the individual’s and their carer’s life world. Data from the National Voices (2013) study demonstrated the importance of including the individual’s family or carer in decisions, if the person him/herself desired this. Participants in this study similarly expressed the view that people supporting their care should be included in decisions and in care coordination. Service organisations have expressed the wish to have greater involvement of service users and family carers in aspects like measuring the patient experience (Robert et al. 2011). Rather than the person and those supporting care having to fit into a rigid system, the focus of person centred co-ordinated care is to scaffold care around the person according to their preferences. Coulter and Oldham (2016) argue that this approach of personalisation enables clarity of the person’s own goals and facilitates healthcare staff to work in partnership with the person to reach their goals. Thus, knowing about the world of the person and carer is fundamental to building a realistic, mutually agreed care plan.

One aspect of ‘My care experiences’, as described by the participants, involves care that is attuned to the individual’s world and demonstrates empathy and positive regard for the person (Rogers 1969). Choice included being made aware of what options were available and being able to review and choose the best option based on an individual’s own circumstances and preferences. Higgins et al. (2015) similarly described the inclusion of choice of health and social care providers as elements of ideal care provision. Service provision that is matched to an individual’s needs and ensures that the individual has control over his/her own care is viewed as an important aspect of person centred co-ordinated care (Wertenberger et al. 2006; Ehrlich et al. 2009).

‘My care experiences’ also describes care that recognises the person’s individuality and is based on partnership and respect for the person’s choices (McCormack & McCance 2010; McCormack & McCance 2017). The converse of this is paternalism, a concern expressed by some participants in this study, who experienced the healthcare system as one in which professionals had primacy in relation to decision making. Participants in this study desired independent choices in decision-making that were based on
information shared by the healthcare staff. Hence, making the partnership work effectively requires shared decision-making, an essential component of person centred care (Ekman et al. 2011). For participants, person centred co-ordinated care is care in which the care system and healthcare staff work with individuals to identify what is important to them and organise care accordingly (McShane & Mitchell 2015).

This re-orientation in health approaches involves a transformation of understanding of the role of the healthcare staff and the role of the person as well as a transformation of the health system itself (Ehrlick et al. 2009; Health Foundation & Nesta 2015). Such re-orientation challenges the traditional power hierarchy of professionals. Five approaches to enable a reorientation were piloted in the UK under the Realising the Value programme (Finnis et al. 2016). Firstly, peer support programmes enabled shared understandings and mutual support mechanisms. Findings demonstrated the inherent value of organisations that provide peer support, which has been shown to increase emotional wellbeing, mental health, and self care strategies (Finnis et al. 2016). Secondly, the delivery of self-management programmes for health conditions has been demonstrated to improve self-care techniques, wellbeing, and relationships with both family and healthcare professionals (Finnis et al. 2016). Thirdly, health coaching is a method of person centred care that assists the person to target behaviour change, emerging from the concept of motivational interviewing. Health coaching has shown to be beneficial in a number of areas, such as in quality adjusted life years in chronic obstructive pulmonary disease (Oksman et al. 2017), less diabetes distress and better glycaemic control for people living with diabetes (Delaney et al. 2017), and a higher knowledge and better management of the disease in congestive cardiac failure (Rosen et al. 2016). Fourthly, group activities to promote health and wellbeing incorporate a range of various supportive activities, such as focusing on healthy living with cookery classes and exercise groups (Finnis et al. 2016). Finally, an asset based approach in health and wellbeing has been demonstrated as building on existing strengths of people and has shown to both enhance health and to have a positive financial social return (Finnis et al. 2016). In enabling people to become authentic partners in health and wellbeing in Ireland, such programmes may have utility in shifting traditional power dynamics and empowering people to own their health and have a more continuous and individual experience of care.
4.5 Care that I am confident in

The second domain of person centred co-ordinated care related more to the experiences of care. Participants wanted care delivered by professionals who were competent, who could assess risk stratification and refer to more specialist care when required. This included having a system of care that was safe and provided quality care as well as care that was accountable. What was important was that care continuity was experienced, and that information was shared amongst staff rather than having to repeat information.

4.5.1 Having confidence

Participants indicated that person centred co-ordinated care included confidence in the care provider, the provider’s respect for the person, and the involvement of the person in provider-carer interactions (Van den Ven 2014). Among the most important aspects for people in acute care is having confidence and trust in the hospital staff who treat them, and this includes confidence in the clinical competence of doctors and nurses (Robert et al. 2011). Participants in this study provided information that supported this need to have confidence in the healthcare staff that cared for them and confidence in the wider health service. This was expressed as the theme ‘care that I am confident in’ and described four aspects of confidence: staff competence in care delivery; safe and high quality care; care that is accountable; and care that is continuous.

What was desirable to the participants was that they could rely on staff to manage their individual care at particular points in time and to recognise when referral was to a more specialised practitioner was necessary. Person centred co-ordinated care, as described by the participants, is therefore consistent with care that is co-ordinated and involves close communication between generalist and specialist providers, and includes effective referral and discharge systems (WHO 2015). Co-ordinated care is care that aims to deliver quality care to each individual through improving the organisation and co-ordination of care services based on the needs of individuals and their families (WHO 2015), and when combined with an integrated service, aims to enhance the value of service to the individual (Health Foundation & Nesta 2016).

When asked what matters to them, patients frequently cite confidence in the competence of staff (Selman et al. 2015). The clinical competence of staff impacts on care quality, particularly when care recipients have complex care needs. Participants in the present study similarly highlighted the perceived association between competence and care
quality. Some saw the organisation of the care system, such as the limitation of services to Monday to Friday and the availability of limited resources, as contributing to poor continuity of and gaps in care. As early as 2003, competency was linked to person centred care delivery, but also related to the ability to work in an inter-disciplinary team, employ evidence based practice, apply quality improvement mechanisms and integrate the use of health informatics in care delivery (Institute of Medicine 2003). In addition, issues related to service transparency, safety and anticipatory care support were identified as important elements of competency. Similar to findings in the literature, all of these issues were raised in the narratives of the participants in this study and were highlighted as being important in relation to a person centred co-ordinated care approach to healthcare.

The participants in this study spoke of person centred co-ordinated care being delivered via a quality service that provides safe care. Various serious case reviews and reports have pointed to sub-optimal healthcare provision and the resultant poor quality outcomes. For example, in the UK, the Mid-Staffordshire Inquiry (Francis 2010) highlighted serious care deficiencies, which led to poor treatment of people in receipt of care services and high mortality rates in the hospital. Equally, reports in Ireland have demonstrated sub-standard care leading to serious care deficiencies (HSE 2013; Holohan 2014; Phelan & McCarthy 2016). Following on from care deficits, some participants pointed to the great need to have services and staff accountable for care delivery. Denis (2014) argues that accountability in healthcare is underpinned by three fundamental principles, namely, a clear articulation of goals and purpose, the ability to measure and monitor achievements, and defined consequences where goals are unmet. However, it is also noted that there are challenges to accountability in healthcare, as increased quantitative outputs may not translate to maintaining or improving care quality (Denis 2014). This is particularly so when resources are both limited and rationed (Higgins et al. 2015; Phelan & McCarthy 2016)

While the Health Information and Quality Authority in Ireland monitors quality in residential and acute settings, there concern has been raised regarding the quality of care in community settings, both in terms of a lack of support services and a lack of continuity of care. Haggerty et al. (2013) proposes that continuity of care can be defined as a care experience that is interconnected in a coherent and consistent way, meeting the person’s health preferences and personal lifestyle. It can be considered as providing relational
continuity, which comprises the relationship between one or more healthcare professional(s) connecting care episodes. Additionally, continuity of care incorporates informational continuity on the acquisition of information about past events (Hildingsson & Thomas 2007), while the third component, management continuity, refers to the co-ordination of the person’s experience through services (Haggerty et al. 2013). Continuity of care is an important indicator of care quality (Ehrlich et al. 2009; National Voices 2013; Damery et al. 2016). It provides security (Haggerty et al. 2013) and is reported as a common theme in people’s responses to the question of what matters to them (National Voices 2013). However, there can be an experience of frustration and stress at poor continuity of care in relation to aspects such as frequent medical staff rotations and difficulty in accessing services (Acton 2013; Higgins et al. 2015). For participants in this study, poor continuity of care was experienced as having to meet different staff at each appointment and having to repeat the same information about their history on multiple occasions. For the participants, these two aspects of the care experience were also represented in practices such as staff not reading their case notes and staff not having access to all of their information. Some participants saw the implementation of an electronic health record as a way of addressing this fractured care. Indeed, sharing of patient information and good ICT infrastructure, including electronic health records, are key elements in strengthening communication and care co-ordination (WHO 2015).

4.6 My experiences between professionals and settings
The final component in our findings refers to the experience of co-ordination of total care which transitions through disciplines and settings and the ability to access care when required and according to preferences.

4.6.1 Journey through the healthcare system
Co-ordinated care is care that is synchronised and responsive to the needs and preferences of an individual and their particular situation (Goodwin et al. 2013; WHO 2015). Patients themselves have identified the importance of care that is responsive to their needs, values, and expressed preferences (Mulley et al. 2012). Participants in this study spoke of the experiences of their journey through the health system, and in the process, described a key component of person centred co-ordinated care, that of ‘care in my journey through healthcare’. This component comprised three sub-elements: holistic care, coordination of care within and across services, and access to services when needed.
Holistic care describes the fundamental aspect of what person centred co-ordinated care is. Although there were experiences of good care, many participants described care that was fragmented, had long waiting times, and had multiple, separate entry points. This is contrary to person centred co-ordinated care, which enables a seamless joining up of different services and settings (Ehrlich et al. 2009; Goodwin et al. 2013). As the person’s health experience can be a journey over time and settings, person centred co-ordinated care is also concerned with chronological progression as well as being able to adapt to fluctuations of need as the person requires additional or reduced input. In addition, person centred co-ordinated care demands the harmonisation of co-morbidity management and a move away from a siloed approach to health conditions. Practitioners should not just manage a single disease condition, but consider the burden of each health issue, its related care impact and the preferences of the person and carer. This requires not only a practice shift, but an educational shift where healthcare practitioners move away from a single, simplistic systems based approach to healthcare. To achieve this, inter-disciplinary working is fundamental. This is characterised by active collaborative interdependence and on-going communication between key members of the healthcare team and the person and carers (Boyd & Lucas 2014). Although the UK model of the House of Care (Coulter et al. 2013) has a different healthcare financing system based on commissioning, there is transferability to Ireland in relation to people who have co-morbidities. Based on a chronic disease model, the focus of care is on the co-creation of a care plan with the person at its centre, and recognises both health and supporting services that are built around the person’s needs and preferences. Recognising that health is not static, the commissioning of care is based on risk stratification and accessing the right professional at the right time.

Poor care co-ordination can lead to difficulties in accessing services (Higgins et al. 2015) and can also result in stress for patients (Acton 2013). Participants in the present study described the struggle and the considerable time involved in trying to coordinate and manage their own care, or that of the person they care for. Some participants suggested that the healthcare service needed to recognise that patients had lives and identities outside of their current health problems and highlighted the need for healthcare professionals and the care system to be flexible and to tailor care according to the particular needs and circumstances of individuals. Participants also discussed the importance of having access to services when required, with several expressing
frustration at long waiting lists and pointing to the disparity between public and private services, and across geographical locations. This concurs with statistics on waiting lists (DoH 2016b). While there was some agreement that once accessed, individual services could work well, a prominent concern in this study was in relation to the lack of co-ordination and efficiency in out-patients departments, where many participants spoke of long hours of waiting.

Participants also spoke of their experiences of disjointed care between various care settings and indicated a wish for better integration of services through the journey of care. Some participants also suggested that care coordination might be improved through the presence of a key person to oversee a person’s care. Van den Ven (2014) identified the personal relationships of a patient with his/her doctor and clinical staff as the strongest predictors of patient satisfaction. Hence, these relationships become critical to the way that the patient experiences the journey through the care system.

4.7 Developing domains, statements and an Irish based definition of person centred co-ordinated care

This study aimed to develop an Irish definition of what person centred co-ordinated care looks like. The nineteen statements of care have been developed under three domains as demonstrated in Figure 4.2.
Figure 4.2. Person centred co-ordinated care statements

4.7.1 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”
4.8 Conclusion

Person-centredness is a priority in the health systems of developed countries. Person-centred care is both a philosophy and a way of organising and delivering care. As a philosophy, it is underpinned by the principles of dignity, compassion and respect (DoHC 2001; NICE 2006; Royal College of Nursing 2008; McCormack & McCance 2017). As a way of delivering healthcare, it explicitly prioritises the individual in the care system, recognising the expertise and resourcefulness that the individual may possess, thereby reducing the pre-eminence of either the care system or the professionals within the system. In this way, it seeks to enable care recipients to direct their own care and requires the care system to focus on the individual’s preferences, needs and wider life circumstances, including family, work and so forth, and not just the medical diagnosis (WHO 2015).

This project utilised an inductive, co-design approach to elicit what constitutes people’s experiences of healthcare and to use these experiences to identify what needs to change to orientate the Irish healthcare system to one that is underpinned by person-centred coordinated care. This resulted in three important areas identified by the participants and respondents, which were considered as enabling to scaffold person-centred care around the individual and carers and which facilitated integration and collaboration within interdisciplinary care and inter-setting care. These three areas provide an important first step to transforming attitudes, healthcare staff’s educational preparation, practices, policy, legislation and systems of care in health to enable individual experiences which authentically centralise the preferences of people who are the consumers of healthcare and those who provide people with support.

4.9 Limitations of the study

• Due to the tight timeframe, the potential to recruit ‘hard to reach’ populations was limited. For example, there are no refugees or homeless people in the participant/respondent population and experiences might have led to additional findings.

• The participants were limited to those with capacity to consent to the study. Although we did have proxy participants as carers, family members or representative organisations, the data does not directly represent the experiences and preferences of this population.

• The people who participated were those who were empowered to speak of their
experiences. Again, it is likely that this may not represent experiences of people who are disempowered within their experiences of the healthcare system.

- Due to ethics challenges, we were unable to have children as participants. It may be that their experiences and perspectives might differ.
- Recruitment was via the HSE and IPPOSI; a wider frame of sample population may have added to the depth of narratives.
- The findings in this study present what constitutes person centred co-ordinated care representing the voices of people who use healthcare services, those who support them and representative organisations. The narratives of healthcare professionals and others such as policy makers might also be different.
References


Care Alliance Ireland (CAI) (2015) Family care-giving in Ireland Care Alliance Ireland (CAI), Dublin.


longitudinal study on the information needs and preferences of patients after an acute coronary syndrome, *BMC Family Practice*, 17, 136.


Health Service Executive & Quality (2013) *National Standards for Residential Services for Children and Adults with Disabilities*. HIQA, Dublin.


Health Service Executive (2017) General practitioners or family doctors. Accessed on line 20th March: http://www.hse.ie/eng/services/list/2/gp/


evidence base for measuring and improving patient experience. London: Department of Health and NHS Institute for Innovation & Improvement

22QIreland (nd) Proposal for a co-ordinated care model for 22Q11deletion syndrome in Ireland. 22QIreland, Dublin.


Appendices

Appendix 1. Participant information leaflet

Participant Information Sheet: Focus Groups

My name is Dr. Amanda Phelan; I am a lecturer and researcher in the School of Nursing, Midwifery & Health Systems in University College Dublin. I am part of a research collaboration with the Health Service Executive and the Irish Platform for Patient Organisations, Science and Industry (IPPOSI) to explore what a person centred co-ordinated care system would look like in the Irish health system.

The project will see patients/service users and their representative organisations co-produce a set of statements outlining what good care and support looks and feels like from their perspective when they have needed care over time from multiple services. The statements will act as the voice of patients / service users and carers in the design and delivery of health services.

I would like to invite you to take part in our research study. Before you decide I would like you to understand why the research is being done, what it would involve for you and your personal information. If you are interested in participating, please contact me and I will further discuss the study and if you are happy to continue, I will arrange for you to complete the attached consent form and I inform you of a focus group which will be in your region and which you can attend. If you have any queries, I am happy to respond to these at any point in the research study.

What is this research about?
This study aims look at exploring your experiences of care and describing what person centred co-ordinated care could look like for people who use the public health service in Ireland. The HSE through its Clinical Strategy and Programmes Division is developing ‘Integrated Care Programmes’; that is, services that are well co-ordinated around the needs of the people who use them. In order to do this, it is vital that the needs of the patients/service users and carers are known and become central to the design of these programmes. This study aims to explore your experiences of care, particularly if you require care over time from multiple services. The research team will identify key themes from the experiences of everyone who takes part and develop a set of statements of what ‘person-centred coordinated care’ looks and feels like.

Why are we doing this research?
It is important that people experience quality healthcare that is organised around the individual’s needs and preferences. The Health Service Executive want to develop a way of evaluating healthcare based on the experiences and expectations of people who use the service.

Who is conducting the research?
A team of researchers, from the School of Nursing, Midwifery & Health Systems in University College Dublin, is conducting the research in collaboration with the Health Service Executive and IPPOSI. The research is being funded by the Health Service Executive.
Why have you been invited to take part?
We want to hear your experiences of care and your views of how care should be co-ordinated and delivered to individuals. We are asking people to participate so that we can hear the views of people who use the service, people who support service users and organisations who represent patient groups. We will have separate focus groups for each of these three perspectives.

What are you being asked to do?
You are being asked to consider participating in a focus group to tell us about care experiences, give your thoughts on how person centred co-ordinated care could be provided and to tell us what areas are important to you when giving the Health Service Executive feedback on care provision.

What will happen if you decide to take part in this study?
If you decide to take part in the study:

• Focus groups will be held in Dublin, Tralee, Galway and Cavan. You will be able to choose a venue which suits you. We will provide refreshments at the venue.
• In the focus group, we will discuss issues related to your experience and your expectations of person-centred care within the Irish public health service.
• With your permission, the focus group will be audio-recorded and transcribed so that we can make sure we have an accurate record of what was said. Your name and any other identifying characteristics will be anonymised from the audio recording, and we will only retain the anonymised version of the audio recording.
• We will then combine the findings from all the focus groups we conducted with another part of the study which involves a survey to build a comprehensive picture of what person centred care looks like in Ireland, how it is defined and how we can describe it.
• We will then develop a set of common indicators of care which can be used to examine how people experience the public health service in Ireland.

How will we protect your privacy?

• The information recorded as part of your participation in this study (being your name, contact details, membership of a particular patient organisation, your audio-recorded participation (anonymised, as above), any written transcript or notes of your participation (which again will be anonymised)) will be stored securely in password protected computer and any hard copy locked in a filing cabinet in a locked office in UCD. As we will use direct quotations to support the development of Person Centred Co-ordinated Care indicators in our report, please note these may be potentially identifiable but will be cited using a pseudonym.
• All the information you give will be rendered anonymous; your details will be given a special code so that they cannot be traced to you by anyone apart from the research team. Within the focus groups, we will not identify you apart from being a focus group member who is either a service user, a person who supports a service user or a representative of a patient organisation.
• While the focus group facilitators will advise participants that issues discussed should remain confidential, the researchers cannot guarantee that participants will respect the confidentiality of what is said.
• Following anonymisation and de-identifying the data, that anonymised data will be accessible to the UCD research team, the Health Service Executive and IPPOSI.

Can you change your mind at any stage and withdraw from the study?
Your participation is completely voluntary. This means you can say no to participating, or if you start but change your mind you can withdraw from the focus group. After the focus group is completed, you will not be able to withdraw as it would be very difficult to isolate an individual voice within a focus group recording.

How will the data from my participation be used?

• The research team at UCD will arrange for the focus group recordings to be transcribed confidentially but transcripts will not in any way identify you.
• Any demographic material will also be anonymised apart from being an urban or rural area.
• The research team at UCD will then analyse the focus group material, combine this with other focus groups and survey findings and integrate this with data from the international literature.

What are the risks of taking part in this study?
There are no risks associated with taking part in the study. The study is fully supported by IPPOSI and the Health Service Executive and is funded by the Health Service Executive.

You are entirely free to decide whether or not to participate in the study, and we assure you that if you
decide not to participate this will not in any way affect any care you receive or otherwise prejudice you in any way.

**What are the benefits of taking part in this study?**
The outcomes of the study will benefit individuals who use the health service in Ireland and enable a more person centred experience of care. The study will also enable a service user evaluation based on the areas you see as being most important in a co-ordinated person centred care system.

**How will you find out what happens with this project?**
A final report of the study will be made available on the IPPOSI and Health Service Executive websites and the study findings may be published in academic journals for and presented as a discussion paper at conferences. If you would like the research team to forward you a short fact sheet with the study findings when the project is complete please let the research team leader, Dr. Amanda Phelan, know.

**Additional data protection information**
The Health Service Executive will be the data controller of your personal data that are processed as part of this study, and UCD and IPPOSI will be data processors of your personal data on behalf of the Health Service Executive.

The relevant person in the Health Service Executive who will be responsible for data protection matters in relation to the study will be: Ms Clare Hudson, Project Manager, Patient Narrative Project, Clinical Strategy & Programmes Division, Health Service Executive. *Contact:* 0766956931, clare.hudson@hse.ie

The legal basis for the processing of your personal data as part of the study will be your consent.

The intended retention period for any identifiable personal data relating to you will be up until the focus groups are transcribed (estimated 3 weeks).

You have rights to access your personal information and, in certain circumstances, to have it corrected or deleted (noting what we explain about withdrawing from the study), to restrict its processing, to “be forgotten”, to object to processing and to data portability. If you wish to exercise any of your rights, please contact the HSE data protection contact above. You also have the right to complain to the Irish Data Protection Commissioner about any concerns you may have about the processing of your personal data.

**Contact details for further information**
If you would like any further information, please feel free to contact me.

Thank you,

Dr. Amanda Phelan
Phone: (01) 716 6482
Email: amanda.phelan@ucd.ie

Please see the attached consent form for completion and signature if you wish to participate in the study and for your personal data to be processed (as outlined above) as part of the study.
Appendix 2. Focus group topic guide

Patient Narrative Project on Person Centred Co-ordinated Care

Focus Group: Topic Guide for service user, family and patient representatives

1) Care services used
2) Experiences of care provision?
3) Person centred care plan
4) Decisions on care
5) Identify important aspects of care
6) Consider what needs to change
Appendix 3. Demographic questionnaire

Qualitative Survey: Patient Narratives for Person Centred Coordinated Care

Section A

1) Are you:
   a) Male_____  b) Female_____

2) What age group are you:
   a) 18-20_____ b) 20-35_____ c) 36-50_____ d) 50-65_____ e) 65 +_______

3) Are you a:
   a) Service user/ Patient ____  b) Carer of service user____  c) Patient Representative Group____

4) Please tick which area(s) would be most applicable to you/your relative or friend or representative group:
   a) Older Person_______(over 65 years)

   b) Chronic Illness (defined as long term conditions which can be treated but not cured) Please tick which is appropriate:

<table>
<thead>
<tr>
<th>Condition</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Diabetes</td>
<td></td>
</tr>
<tr>
<td>Heart Failure</td>
<td></td>
</tr>
<tr>
<td>Chronic Obstructive Pulmonary Illness</td>
<td></td>
</tr>
<tr>
<td>Dementia</td>
<td></td>
</tr>
<tr>
<td>Mental Health Problems</td>
<td></td>
</tr>
<tr>
<td>Musculoskeletal Disease</td>
<td></td>
</tr>
<tr>
<td>Disabling Neurological Condition</td>
<td></td>
</tr>
</tbody>
</table>

   c) Intellectual Disability_______

   d) Physical Disability_______

   e) Other (please state the health issue if not identified above) _________________

   (eg Rare Genetic Diseases, arthritis)
5) Would you describe yourself as living in a:

a) Rural Area______ b) Urban Area______

Thank you for completing this survey