Health Service Design for Older People

The Role of Community, and the Community and Voluntary Sector in the Implementation of The Living Well at Home Piece of the Integrated Care Programme for Older People in Kilkenny

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Abstract

The Integrated Care Programme for Older People (ICPOP) is part of how health and social care delivery is being envisaged in Ireland (ICPOP, 2018). The Living Well at Home piece of ICPOP, includes community and the community and voluntary sector in healthcare delivery (ICPOP, 2018).

This research looks at the role of co-designing with community the implementation of the Living Well at Home piece of ICPOP answering two questions –

1. Through co-design investigating what is important to all stakeholders in the design and delivery of healthcare for older people.
2. What role can the community in which an older person resides, and the community and voluntary sector play in the delivery of healthcare, enabling people to age well in place.

The literature review investigates

- the concepts of co-production, integrated care and person-centredness mentioned in ICPOP
- in addition, it examines the impact of power, perceived or real, within and across medical disciplines and systems and, between patients and clinicians, and how it can be alleviated
- furthermore, it considers the impact Covid-19 had on older people and its implications on healthcare delivery
- finally, it explores social prescribing and how it can improve health and wellbeing alleviating pressure on healthcare delivery.

Research through design (RtD), a qualitative methodology, was used over three stages of field research: interviews, a co-design session with older people and a stakeholders' co-production workshop. Data were thematically analysed using grounded theory and findings from one stage informed the next, allowing a 'collective voice' to emerge (Smithson, 2000. P. 109).

The research findings show:

- an organisational culture and leadership style of innovative and collaborative practice is essential to the implementation of ICPOP
- a culture of person-centredness, as espoused by McCormack and McCance (2017), is important
- good communication between disciplines and practitioners and, practitioners and the older person is critical
- and key to ICPOP delivery is the involvement of community and the community and voluntary sector.

Finally, the research examined the practice of co-design and concluded that co-design is the first stage of the co-design process which includes co-production and co-creation. It is a reflective, iterative, and democratic practice involving all stakeholders at all stages.

Areas for future research include

- widening the geographical area to verify the findings nationally
- examining the concepts of person-centredness and co-production to ascertain a universally accepted definition in a healthcare context
- using the framework developed through this project, examining how a comprehensive understanding of RtD can be put in place
- and finally further investigation into power and trust in the co-design process is warranted for a comprehensive understanding of its practice.

Publications and Presentations

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Glossary of Acronyms

AIEB	All Ireland Endorsement Body for Community Work Education &
CHO	Community Healthcare Organisation
CKCS	Carlow Kilkenny Clinicial Society
CSO	Central Statistics Office
DOH	Department of Health
FITT	Frail Intervention Therapy Teams
GEMS	Geriatric Emergency Medical Service
GOI	Government of Ireland
GP	General Practitioner
GT	Grounded Theory
HCD	Human Centred Design
HIQA	Health Information and Quality Authority
HSE	Health Service Executive
ICPOP	Integrated Care Programme for Older People
KKCC	Kilkenny County Council
KLP	Kilkenny LEADER Partnership
NGO	Non-Government Organisation
RtD	Research through Design
The Alliance of Age Sectors NGOs	The Age Alliance
TILDA	The Longitudinal Study on Ageing
UN	United Nations
WHO	World Health Organisation

1.0 Chapter One - Introduction

1.1 Topic and Context

The number of people living well with chronic illness and into old age (over 65 years of age) is increasing globally (WHO, 2015a). With that comes an increased demand on health and social care (TILDA, 2020) necessitating a change in how health and social care is delivered at an international, national and local level. This is particularly relevant for older people with complex care needs who are classed as 'high cost, high care' patients (ICPOP, 2018). In Ireland older people account for 13.82% of the population (CSO, 2016a) while requiring 50% of the health and social care resources. They occupy 54% of acute hospital beds and account for 90% of delayed discharges. In addition, the over 75s spend three times longer than the average person in the emergency department (ED). Furthermore, for the over seventy age group 35% show functional loss on discharge from hospital, rising to 65% for the over nineties (ICPOP, 2018). A 2015 Age Friendly Ireland study into older people's perceptions of the Irish healthcare system showed that they have reservations about accessing the ED of their local hospital anticipating long delays. They perceive a lack of information about their care, uncertainty around access to care, poor quality when accessed and, communication between and across the health and social care services as lacking (HSE and Age Friendly Ireland, 2015).

Sláintecare – the ten-year plan to reform the Irish healthcare system – has at its core co-produced, person-centred, integrated care. How healthcare is being delivered to older people in Ireland is changing. The Integrated Care Programme for Older People (ICPOP), commenced roll out in 2016 with pioneer projects in six areas across Ireland reaching thirteen just prior to Covid-19 (HSE, 2022). It envisages moving healthcare provision for older people from the acute hospital system to the community – treating people closer to home and avoiding admission to hospital where we have seen outcomes are poor (HSE, 2018). A ten-step framework for the implementation of the plan at local level suggests engaging with older people from the outset through a co-production paradigm (HSE, 2018). The effects of the Covid-19 pandemic, and with it a renewed focus on how healthcare is delivery for older people, has seen an increase in funding for ICPOP (Government of Ireland (GOI), 2022).

A literature review was undertaken looking at the how international and Irish policy envisages healthcare being delivered to older people and the concepts mentioned within policy documentation at both levels. Databases used included Lenus - the Irish Healthcare Repository, reports from the Oireachtas Committee on the Future of Healthcare and the Committee on the Response to Covid-19. Furthermore, reports from TILDA in Trinity College Dublin and from third sector advocacy agencies including ALONE, SAGE Advocacy and Age Friendly Ireland were studied. From an international perspective, reports from the WHO and UN databases were examined. In addition, Google Scholar, Ebesco and Jstor were investigated for articles pertaining to health and social care delivery. The concepts of co-production, person-centredness and integrated care were explored specifically. As they are the core principles underpinning the delivery of healthcare to older people both internationally and nationally it was important to get an understanding of them and link this understanding to practice in an Irish context.

Through the exploration of these concepts the importance of building trust and how power influences the delivery of co-produced, person-centred, integrated care was highlighted and investigated. ICPOP mentions the community and the community and voluntary sector being incorporated into the delivery of health and social care at a local level. In addition, though field research this aspect of ICPOP was considered by all stakeholders as important to enabling older people to age well at home. Therefore, supports such as social prescribing were examined in detail, in particular how the HSE envisages rolling out the practice. Coming from a community development background the principles underlying co-produced, person-centred, integrated care resonated with me as being similar to the principles of community development practice. In addition, with the use of a community link worker in the delivery of social prescribing in ICPOP a brief exploration of the similarities between the practice of community development and co-produced, person-centred integrated care was undertaken. Finally, the impact of Covid-19 on older people and if this will change the delivery of health and social care was explored.

1.2 Focus and Scope

This research project is timely and relevant to the implementation of ICPOP across the country. The initial title was ‘Healthcare Design for Older People in the Southeast of Ireland’. The Southeast of Ireland encompasses five counties – Waterford, South Tipperary, Wexford, Carlow and Kilkenny – with a combined population of 510,000, of which 74,302 are aged over 65 (HSE, 2018). To include older people across the Southeast in the project as is befitting a Research through Design (RtD) ethos would not be possible in the two-year timeframe of the project. It was, therefore, agreed with the two research project supervisors that the geographic area would be confined to County Kilkenny. Kilkenny was chosen for a number of reasons:

- The healthcare catchment area includes Co Carlow, providing a greater impact for the research.
- In addition, from the initial reading of the literature it was clear that an integrated approach to healthcare delivery had been in place in Kilkenny/Carlow for some time through local innovation (Courtney and Fawsitt, 2016).
- Furthermore, the researcher lives in Kilkenny and had many contacts that could be accessed to further the research.

The broad scope of the research was iteratively revised as the literature around healthcare design for older people was examined. The final title of the research project was - Health Service Design for Older People - the role of community, and the community and voluntary sector in the implementation of the Living Well at Home piece of ICPOP in Kilkenny.

1.3 Relevance and Importance

Despite numerous reports since 1968 advocating policies that enable older people to age well in their communities (GOI, 1968, 1988; Ruddle *et al,* 1998; National Economic and Social Fund (NESF), 2005; Moriarty, 2009; Donnelly *et al*, 2016; Department of Health (DOH), 2019; Browne, 2020) little progress has been made to design and implement policies that will facilitate this. In fact, policies have been enacted that encourage and promote the building of privately owned nursing homes (Kelleher *et al,* 2020) at odds with what the reports cited above and The Age Alliances 2021 report suggest most people wish for in old age, that is to age well at home. Experience before and at the onset of Covid-19 brought home in a very personal way the faults that lie within the Irish hospital healthcare system. As an adult child of a parent that required hospital care due to a fall I saw first-hand how older people decline physically and mentally the longer they spend in hospital (HSE, 2018). It was also apparent that while the HSE and Department of Health speak of a person-centred, holistic approach to care, the systems and culture in place within the HSE and hospital did not allow for an integrated holistic system of care to be delivered. Families and carers of the older person in hospital are not consulted with or included in the formation of care plans.

It is clear both from the literature and personal experience that an alternative way of caring for older people needs to be conceived and enacted. An integrated, person-centred, holistic delivery of care is required within the acute, primary and community systems of healthcare delivery in Ireland. It is required not just for the older person themselves but also to reduce the cost of healthcare provision on the State. Hospitals were initially built to cure those that entered. With advances in the management of chronic disease people are now able to live longer and healthier despite having long term conditions(WHO, 2015a). The management of patients with chronic disease needs to be removed from the acute system and into the community, particularly for the older person whose outcomes from admission to hospital are poor (HSE, 2018; ICPOP, 2018). The impacts of Covid-19 on older people are well documented and most, if not all, have been adverse (McGarrigle *et al*, 2020; Oireachtas Committee on Covid-19 Response, 2020; 2020a; The Alliance of Age Sector NGOs (The Age Alliance), 2021; Lima, 2021). It has added a new emphasis to the roll out and implementation of the ICPOP. ICPOP outlines how healthcare delivery is envisaged for those aged over 65. It includes a section on non-medical supports and services that are required to enable people to age well in place. They entitle this piece of ICPOP Living Well at Home and include twelve non-medical supports some which can be implemented by or in conjunction with the community in which people live and the community and voluntary sector. This research project investigates how ICPOP can be implemented through a co-design process eliciting a ‘collective voice’ from those that deliver healthcare for older people, older people themselves, their families and carers, the communities in which they reside and, the community and voluntary sector (Smithson, 2000, p. 109).

1.4 ICPOP in Kilkenny and the Living Well at Home Piece

It has been suggested by numerous participants in this research process that The Living Well at Home piece of ICPOP is the most important part of the programme. It concentrates on a social model of health and social care and is conscious of the importance of the social determinants of health that impact negatively on those from lower socio-economic backgrounds. It includes collaboration with the community in which one resides and the community and voluntary sector in the implementation of social supports. There are twelve parts of the Living Well at Home piece – (see figure 1)

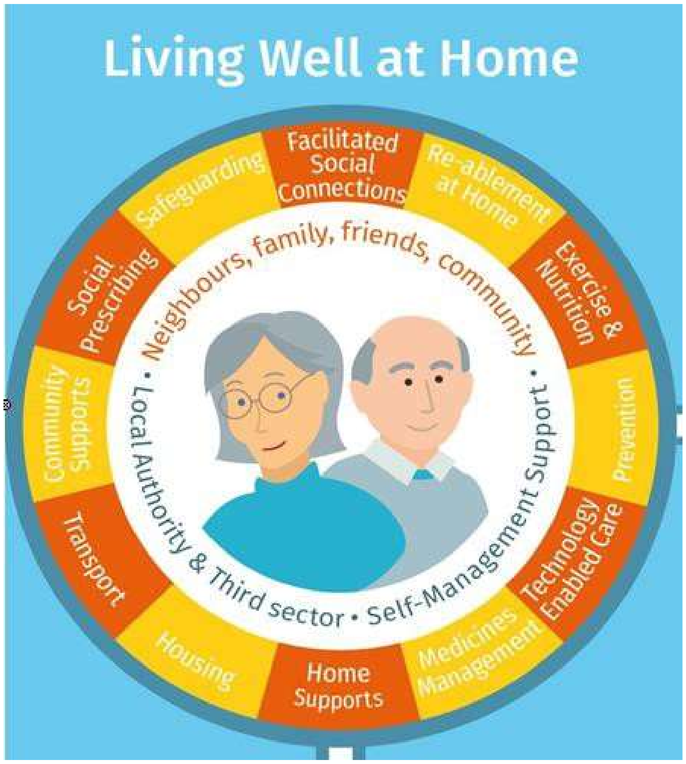

Figure 1 Living Well at Home Piece of ICPOP

Some supports mentioned, such as housing and transport, are planned and delivered by statutory organisations separately from the HSE but are as important as health and social care delivery to enable people to age well at home. Other aspects such as the prevention and facilitating social connections pieces are being implemented at local level through programmes delivered by Healthy Ireland and Kilkenny Sports and Recreation Partnership. For instance, the Health Promotion Unit in County Kilkenny liaises with Age Friendly Kilkenny and the library service to deliver programmes aimed specifically at older people such as Taking Stock (Kilkenny Age Friendly County Alliance, 2017). However, these supports are delivered separately from ICPOP Kilkenny. Social prescribing, which was mentioned throughout all stages of this research process as being important to the delivery of integrated care for older people, is the lynchpin that pulls the community, and the community and voluntary supports available together in a personalised care plan co-designed with the older person. In the feedback session of the field research it was suggested that the social prescriber in Kilkenny would have a dedicated clinic every Thursday in a primary healthcare centre. This initiative is an example of collaborative practice between the local Community Development Company, the Health Promotion Unit, primary healthcare practitioners and ICPOP.

Funding for ICPOP has been accelerated post Covid-19 (Government of Ireland (GOI), 2022). However, most of this funding is directed towards the recruitment of clinical personnel (GOI, 2022) to deliver care in the ambulatory hub that is yet to have a designated space in Kilkenny (Feedback Session). The longterm vision for ICPOP in Kilkenny is to have social supports delivered by the community and voluntary sector co-located in the hub alongside the medical services and to have clinics in communities around the county – what was referred to as a *'hub and spoke style service'* in the feedback session held after the stakeholders co-production workshop

1.5 Questions and Objectives

The questions to be answered by this research project are what are termed 'wicked problems' (Cross, 2006).

Question 1: Investigate through co-design what is important to all stakeholders in the design and delivery of healthcare for older people

Question 2: What role can the community in which an older person resides, and the community and voluntary sector play in the delivery of healthcare, enabling people to age well in place

Wicked problems are complex with no right or optimal solution and involve numerous stakeholders and therefore numerous perspectives that need investigation. Due to the many stakeholders involved in a complex wicked problem a qualitative methodology is required to examine it. A Research through Design (RtD) methodology was employed in determining the many perspectives that needed to be listened too and taken into consideration. It employed designerly ways of eliciting what was important to all participants utilising the community development and co-design principles of collaboration, participation and empowerment with a human rights and social justice approach. RtD looks to find potential solutions to the problems that it sets out to investigate. While it was not the remit of this research to design and test potential solutions, they were identified and noted.

1.6 Overview of Chapters

The literature review will examine how an ageing global population is changing healthcare delivery for older people at an international, national and local level. It will investigate the concepts of co-production, co-design and human centred design and how they can be used to design health care services through collaborative practices based on a human rights and social justice approach. In addition, the literature review will consider person-centred integrated care concepts particularly in relation to the older person. Furthermore, it will examine the idea of social prescribing and how it can be used to enable people to age well at home. It will analyse how power and trust impact the delivery of co-produced health and social care services both from a patient/clinician and an inter-disciplinary viewpoint. Finally, it will look at the effect Covid-19 has had on older people and their care and how it is impacting the delivery of health and social care for them.

Chapter three outlines the social constructivist epistemological stance of the researcher. She understands people as connected relational beings who depend on one another for their physical and mental wellbeing while acknowledging that health and wellbeing is also impacted by our social determinants of health. In addition, she recognises that people construct their reality through their interaction with one another and their lived experiences. The research draws on a feminist perspective that believes in equality of condition, power with others and shared decision-making. Furthermore, it explains the reflective nature of the research through the co-design methods used in all stages of the field research. It outlines how and why participants were recruited for each stage of the process. Moreover, it describes the methods used for gathering and analysing the data and outlines any limitations to the research. Finally, it explains the ethical considerations involved and how the data gathered is used.

Chapter four – the discussion and findings chapter outlines and considers in detail the themes that emerge from the three stages of the field research. Stage one interviews six clinicians and representatives from two third sector agencies involved in advocacy for older people. These are semi-structured in nature and provide the researcher with information on how healthcare is delivered to older people in Kilkenny, how ICPOP will change that delivery and what the participants see as important in enabling older people to age well. The themes that emerge from this stage inform the next, an older persons co-design session. This session elicits from the participants what problems they perceive in how healthcare is being delivered and what they view as important in delivering effective healthcare for them. The final stage of the field research involved all the participants that engaged in the first two stages plus representatives from community in a stakeholders' co-production workshop. It discussed the meaning of community and how community can be involved in the delivery of non-medical supports enabling older people to age well in place. The preliminary findings from this stage were discussed with three clinicians involved in the delivery of healthcare to older people in Kilkenny who could not be present at the co-design session. Finally, it summarises the findings from the field research process eliciting the 'collective voice' from the participants over the three stages (Smithson, 2000, p. 109).

Chapter five outlines and discusses the process and practice of both RtD and co-design. It outlines the learnings that can be taken from the researchers experience which could inform future research projects.

Chapter six summarises the research project and its process. It outlines the findings that are important to the implementation of ICPOP:

- Communicating between disciplines and systems of healthcare as well as with the older person themselves, their families and informal carers is paramount to delivering person-centred, integrated, holistic healthcare.
- Supporting older people to remain in their homes for as long as possible is more than medical.
- Person-centred holistic care includes all those delivering and in receipt of care – clinicians, home support workers, the older person themselves, their families and informal carers.
- The community in which one resides in conjunction with the community and voluntary sector are vitally important to the delivery of non-medical supports and services enabling people to age well in place.

Finally, chapter seven makes recommendations for future research that will add to the knowledge generated by this dissertation.

2.0 Chapter Two - Literature Review

2.1 Introduction

Welsh and Gray (2013) suggest that health and social care partnerships which demonstrate compassion, have continuity, clear communication and shared decision-making are important to the delivery of effective person-centred, co-produced, integrated care. This literature review will investigate from a global and national perspective how the growing number of older people (aged 65 plus) is changing the delivery of health and social care both worldwide and in Ireland. It will examine prominent research sources in order to understand the principles underlying co- design, co-production, and human centred design. It will investigate how the practice of co-production and its process can be used to deliver health and social care that is based on a human rights and community development approach. These approaches incorporate the principles of empowerment, connectivity, collaboration, and participation underpinned by a social justice perspective of equity and shared decision-making. Furthermore, it will establish what person-centred care is and will give an overview of integrated care particularly in relation to the older person and look at the role of social prescribing in enabling people to age well at home. It will analyse how power and trust impact the delivery of co-produced health and social care services both from a patient/clinician and an inter-disciplinary viewpoint. Finally, it will look at the effect Covid-19 has had on older people and their care and how delivery of health and social care has changed for them.

2.2 Demographics

The world is ageing and with an older population comes an increase in healthcare provision. The World Health Organisation (WHO, 2018) defines ageing as both biological and societal. Ageing occurs at a biological level with changes over time at a molecular and cellular level leading to a gradual decrease in physical and mental ability. However, WHO (2018) argues that these changes are ‘neither linear nor consistent’ and ‘only loosely associated’ with a persons chronological age. Ageing is also associated with life changes such as retirement, children leaving home, and the death of family members and friends. As ageing healthy is now not just a possibility but the norm (Kenny, 2022) it is important when planning health and social care delivery for an increasingly ageing demographic that ill-health and its implications are not the only issues focused on. Furthermore, WHO (2018) include in their conception of aging the impact of life changes such as retirement, children leaving home and the death of family members and friends. This reminds us that to restrict consideration of health and social care delivery for older people to those measures exclusively associated with ill-health is to overlook options which provide for, and reinforce, recovery, reablement and psychosocial growth.

A global ageing population has become a key policy issue for countries around the world (WHO, 2015a). In 2012 Japan was the only country where thirty percent of the population were aged over sixty. Ireland will reach this percentage by 2050 along with many other countries, not just in Europe and North America but also in the Middle East (Iran), Far East (China) and South America (Chile) (WHO 2015a). The pace at which countries are ageing is accelerating. It took France 150 years for the numbers of those over 60 to grow from ten to twenty per cent of the population. Brazil, China and India have just twenty years to adapt to the same growth (WHO, 2015a). The increased rate of global population ageing is due in part to a longer life span, a decrease in infant mortality, better healthcare provision, and better socio-economic conditions worldwide (WHO 2015a). However, inequity still exists both at a global level for poorer countries and within richer countries at a societal level. Wilkinson and Pickett (2009) argue that raising living standards was once the best way to improve quality of life and hence longevity. However, they suggest that the world has ‘got close to the end of what economic growth can do’ (ibed, p.5). There has come, particularly in what is known as the Western World, a tipping point, where economic standards in a country no longer have the same impact on the health and wellbeing of a nation as they once had. As WHO (2015a) and Wilkinson and Pickett (2009) suggest even within a country, older populations are characterised by great diversity, the more wealth one has, and the more access to healthcare, the better the ageing process will be.

2.2.1 Multi-Morbidity

Multi-morbidity occurs when people experience more than one chronic condition at a time (WHO, 2018). This is more prevalent as we age and with it comes challenges, for the provision of health and social care. Marengoni *et al,* (2011), suggest that the prevalence of multi-morbidity in those aged sixty and over ranges between 55-98% and is associated with lower socio-economic status. The consequences for the older person are functional decline and poor quality of life, and for the State, higher healthcare costs (Marengoni *et al,* 2011). It is this increase in the cost of health and social care that has prompted national governments and global organisations such as WHO, to look at how ageing populations can be effectively cared for without an increase in the cost of healthcare delivery. The Irish Longitudinal Study on Ageing (TILDA, 2020) has established a relationship between co or multi-morbidities and frailty with an increase in health service ultilisation. Based on information from the 2016 census, and their own data collected through the longitudinal study, they have shown that as one ages, more visits to the GP and Emergency Department are required. They have also shown an increase in the number of visits from the Public Health Nurse and the number of Home Care hours (TILDA, 2020).

2.2.2 South East Ireland and Kilkenny

Pertinent to this research are the demographics of the southeast of Ireland and in particular County Kilkenny. The population of Ireland has increased steadily since the 1990s due to natural increase and a decline in net outward migration, bringing the total population of Ireland to just under five million in 2016 (Central Statistics Office (CSO) 2016). Between 2011 and 2016 the population of Kilkenny County grew by approximately three percent (CSO, 2016). The 2016 census shows an increase in the number of older people (those aged over 65) in the southeast of Ireland of approximately 10,900 since 2011. The CSO estimate that the number of older people will increase dramatically by 2036 projecting a seventy percent plus increase in all regions of Ireland (CSO 2020). This increased projection equates to an additional 89,900 older adults in the southeast of Ireland over twenty years from 2016 to 2036. It is predicted that the number of dependent older adults will account for 35% of those aged over sixty-five in the southeast (CSO, 2020). As shown, this increase in the over 65s as a percentage of the population, and the subsequent challenges for healthcare provision is not only an Irish challenge but a global one. It requires a shift from an acute healthcare system to one provided mainly at primary and community level, that enables and empowers individuals to age at home and communities to provide health and social care (WHO, 2015; HSE, 2018). Through Sláintecare, the ten-year programme to transform the Irish health and social care services, a co-produced, person-centred, integrated care system of provision is envisaged. (Oireachtas Committee on the Future of Healthcare, 2017; HSE, 2018)

2.3 Co-Design - Co-Production – Co-Creation – Human-Centred Design in Healthcare

While the term co-production is used by the HSE (2018) and Sláintecare (Oireachtas Committee on the Future of Healthcare, 2017) an understanding of what is meant by co-production needs to be explored. Participatory design or co-design are the first stages of the design process which includes co-production and co-creation. Ehn (2008, p.1) suggests the co-design phase is the challenge of 'anticipating, or envisioning, use before actual use'. It is a democratic process, involving all stakeholders as equal partners where the experiences of all are accepted as valid and expert (Ehn, 2008; Freire and Sangiorgi, 2010; Langley *et al,* 2018). Wenger (2006, p.1), calls this inclusive, collaborative process 'communities of practice', Langley *et al* (2018, p. 5) describe it as 'collective making'. Regardless of how it is described what occurs is that the lived experiences of all stakeholders are shared and used to design a product or service that can be implemented, in the first instance as a prototype or pilot. Freire and Sangiorgi (2010) and Langley *et al* (2018) say that co-design is a process implemented and led by professionals, however, Langley *et al* (2018) go further and suggest that it is both a practice and a process. They suggest that in a healthcare context participatory design and co-design are interchangeable. According to Freire and Sangiorgi (2010) co-design implies a partnership between the person at the centre of care, their carers and families, practitioners and the wider community. Furthermore, Langley *et al* (2018) maintain that with 'an ethos of empowerment and real engagement', co-design in partnership with others is placed on the higher rungs of Arnstein's Ladder of Participation[1] (Langley *et al,* 2018, p.5). The second stage of the process is the co-production process, the delivery of services 'in an equal and reciprocal' fashion between professional practitioners, informal carers and family members and, the person at the centre of care themselves (Friere and Sangiorgi, 2010, p.41). The third stage of the design process is co-creation or iteration where those that use the service are included in its evaluation and continuous development (Friere and Sangiorgi, 2010). Valuing the experiences and views of all stakeholders is essential to the process requiring all stages to be participatory, democratic and person-centred.

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[1] Arnstein (1969), in his Ladder of Participation sets out eight levels of citizen involvement in decision-making and power sharing. On the bottom rung is manipulation which he sees as non-participation. It climbs to the top rungs 6, 7 and 8 of partnership (6), delegated power (7) and citizen control (8). It is these top rungs of citizen participation in power sharing and shared decision-making that Langley *et al* (2018) put co-design.

2.3.1 Co-Production

The term co-production was coined by Elinor Ostrom and her colleagues in the 1970's in the belief that citizens involvement in the production of services achieved better outcomes for the community as a whole (Bovaird, 2007; Boyle and Harris, 2009). Ostrom (1996, p. 1079) developed the term co-production to describe 'the potential relationships that could exist between the 'regular' producer. and 'clients' who want to be transformed by the service into safer, better educated, or healthier persons.' She goes on to say that co-production is the result of collaboration between 'what a government does and what citizens can do' (1996, p. 1079). While not a new concept (Ramirez, 1999; Bovaird and Loeffler, 2013; Welsh and Gray, 2013; Batalden *et al,* 2015)[2], its use has been confined to the production of tangible products, and in more recent times services within an industrial setting (Ramirez, 1999; Batalden *et al,* 2015). Ramirez (1999) speaks of 'value creation' and 'value co-production', charting the idea of value creation from a nineteenth-century industrial perspective where 'unproductive work' was one that did not create income, to a twentieth century perspective where services were seen as having some input into income generation. While Ramirez and others speak of co-production in terms of how valuable it is to the creation of wealth and income for business organisations, Ostrom (1996) suggests the concept can be used in how the provision of services for citizens is undertaken within the State, particularly how co-production can add value to, and improve the efficiency of, services. Ostrom (1996) makes a distinction between co-production of products and services. She suggests that the production of a service is 'difficult without the active participation of those 'receiving the service' (1996, p. 1079). Like Ramirez (1999), Ostrom (1996) uses the example of a business organisation to show how co-production adds value to the service being produced. .

2.3.2 Definitions of Co-production

Bovaird (2007, p. 847) combines Ostrom's 1996 concept of co-production as a process of inputs by individuals in more than one organisation, with Ramirez's (1999) understanding of 'value creation by more than one actor for themselves and perhaps others and, Joshi and Moore's (2003) definition of co-production as a long-term relationship, and defines 'user and community' co-production as

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[2] Ramirez (1999) charts its progress as a concept from the 1700's

> 'the provision of services through regular, long-term relationships between professionalised service providers (in any sector) and service users or other members of the community, where all parties make substantial resource contributions'.

The result of co-production should be 'better outcomes or improved efficiency' (Bovaird and Loeffler, 2013).While products can be produced without the input of the final consumer, services are always co-produced (Boyle and Harris, 2009; Batalden *et al,* 2015; Batalden, 2018). Batalden *et al* (2015) go on to suggest, that by failing to understand this concept, health service providers limit their ability to improve health care for their patients. Furthermore, they contend that viewing healthcare as a consumable product, is to deny the relational aspect to delivery and the users role in producing the service. Osborne *et al* (2015) propose a SERVICE Framework for the delivery of public and private services. As with income generating enterprises, public service organisations also cannot act in isolation, there must be inter-organisational policy and implementation networks to deliver services effectively and efficiently (Ostrom, 1996; Ramirez, 1999). Osborne *et al* (2015) suggest that organisations must recognise that they are delivering intangible services and that efficiency is not about reducing the costs of the service but is also about how the service is delivered. Reducing staff costs through a reduction in numbers or qualification of the employee, 'can reduce the quality of the service which ultimately undermines its sustainability' (Osborne *et al,* 2015, p. 4).

Sláintecare's tagline: 'Right Care, Right Place, Right Time given by the Right Staff,' indicates that sustainable, efficient, effective care needs the right qualified staff to deliver (Health Manager, 2019). However, it must be remembered that service users are not passive recipients of care but co-producers (Ostrom, 1996; Bovaird, 2007; Batalden *et al,* 2015; Osborne *et al,* 2015 and Batalden, 2018). The question is how to engage the user of the service in its design and delivery so that the outcomes for both the patient and the provider are improved. Like Bovaird (2007) and Osborne *et al* (2015), Batalden (2018) suggests that co-production is based on the interdependence of service providers and users working together to design, produce and assess the 'relationships and actions that contribute to the health of individuals and populations' (2018, p. 2). It is important, he attests, that a practitioner listening to the lived experiences of patients/service users beyond their illness, is not just seen as a 'matter of courtesy' but as necessary to understanding and 'limiting the burdens of illness and treatment, and optimising health' (2018, p. 2).

2.3.3 Models of Co-production

While Ostrom is accredited with the concept of co-production Cahn developed the 'idea of co-production into a practical proposition' for public services and system change (Boyle and Harris, 2009, p. 11). Boyle and Harris' 2009 discussion paper for the UK government suggests that co-production has a vital role in reforming public services to make them more efficient and cost effective. They go on to suggest that to change how public services are delivered, the State must recognise the resource that is the lived experiences of those who use the services, their families and their communities. How public services are designed and produced needs to be reconfigured to make use of this 'hidden resource' (2009, p. 11). They suggest this will reduce the demands on professionals and the services, and enable better outcomes for all, service providers, users, the wider community, and society as a whole (Boyle and Harris, 2009). As has been previously stated, co-production is not a new concept (Ramirez, 1999; Bovaird and Loeffler, 2013; Welsh and Gray, 2013; Batalden *et al,* 2015). In terms of real world case studies it is used successfully in health promotion programmes to reduce the instances of cancer deaths such as Quit It for smokers and cancer screening, BreastCheck, CervicalCheck and BowelScreen. The success of these programmes relies on the user engaging willingly with them. This is co-production in practice, as is self-management of chronic disease by the patient to reduce the impact of symptoms by maintaining a healthy diet or regular exercise. However, it is not fully engaging with the resources available from the service user, their families, carers or community. Coulter *et al* (2013) devised a House of Care model that explores the concept of collaboration between doctors and patients in the management of chronic health conditions (see figure 2).

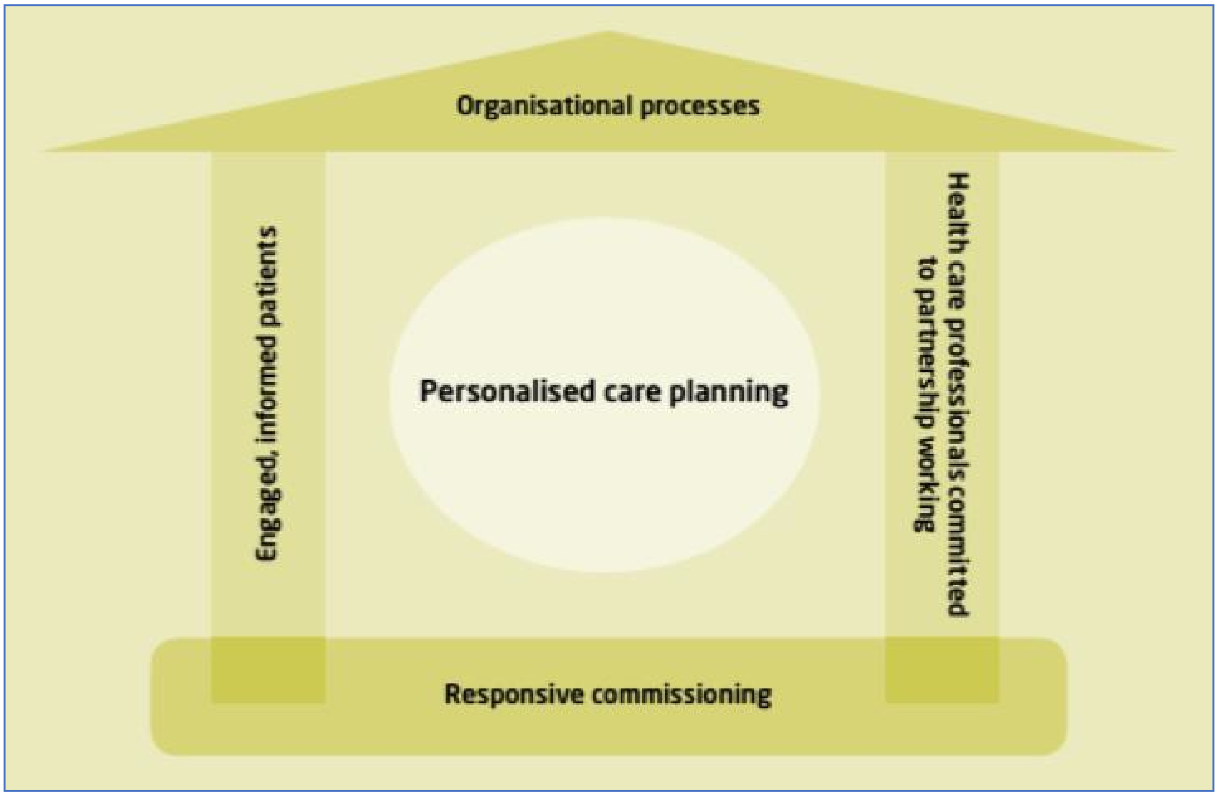

Figure 2 Coulter *et al* (2013) House of Care Model ©

It ‘assumes an active role for patients, with collaborative personalised care planning at its heart’, moving decision-making away from primarily the professional to a partnership approach (Coulter *et al,* 2013, p.1) According to Batalden *et al* (2015) this system of care also suggests that patients and doctors working collaboratively have the power to shape the entire system. Using Coulter *et al’s* (2013) House of Care, and Wagner’s (1999) Model for Improvement of Chronic Illness Care (see figure 3), both of which concentrate on the management of chronic disease. Batalden *et al* (2015) designed their own model of healthcare co-production (see figure 4).

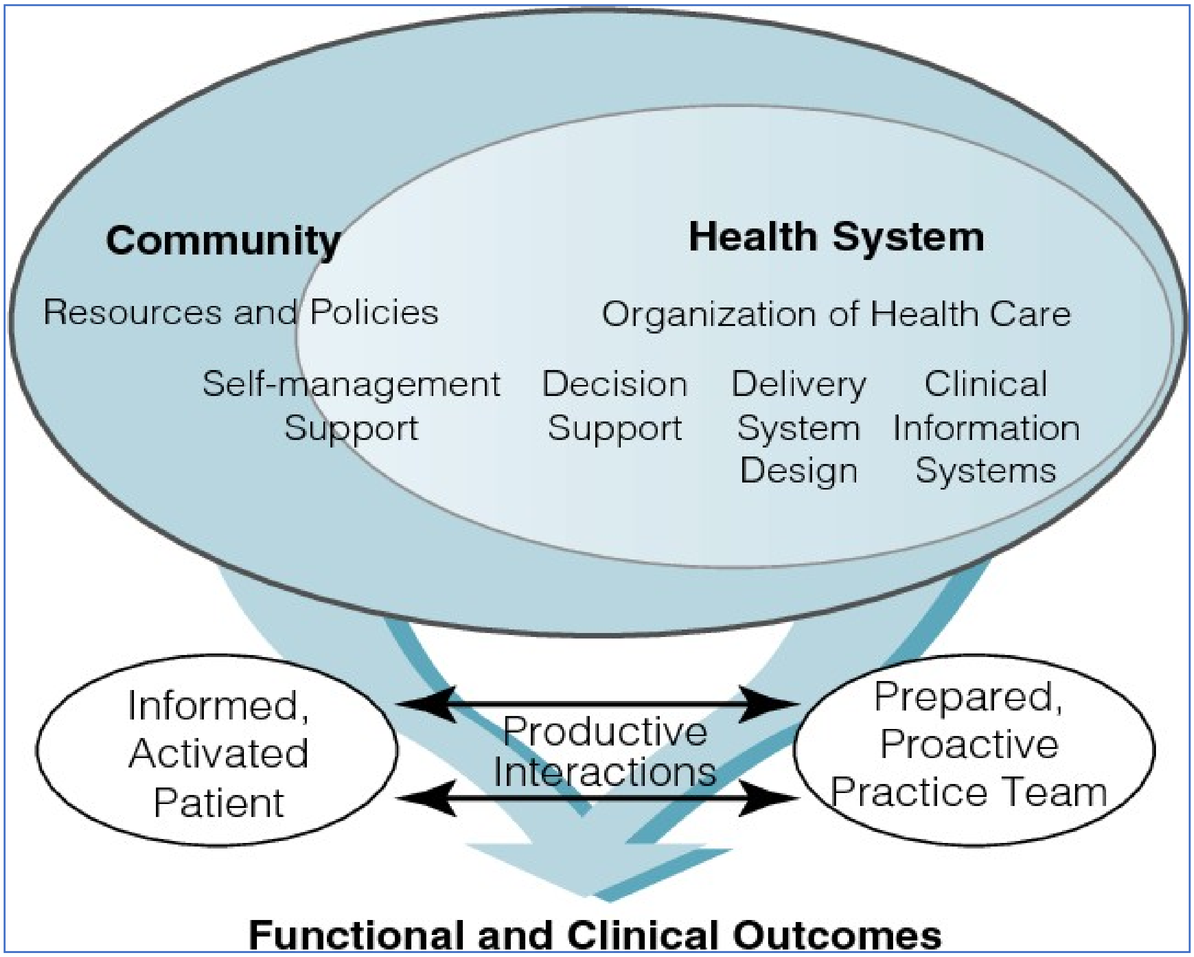

Figure 3 Wagner (1999) Model for Improvement of Chronic Illness ©

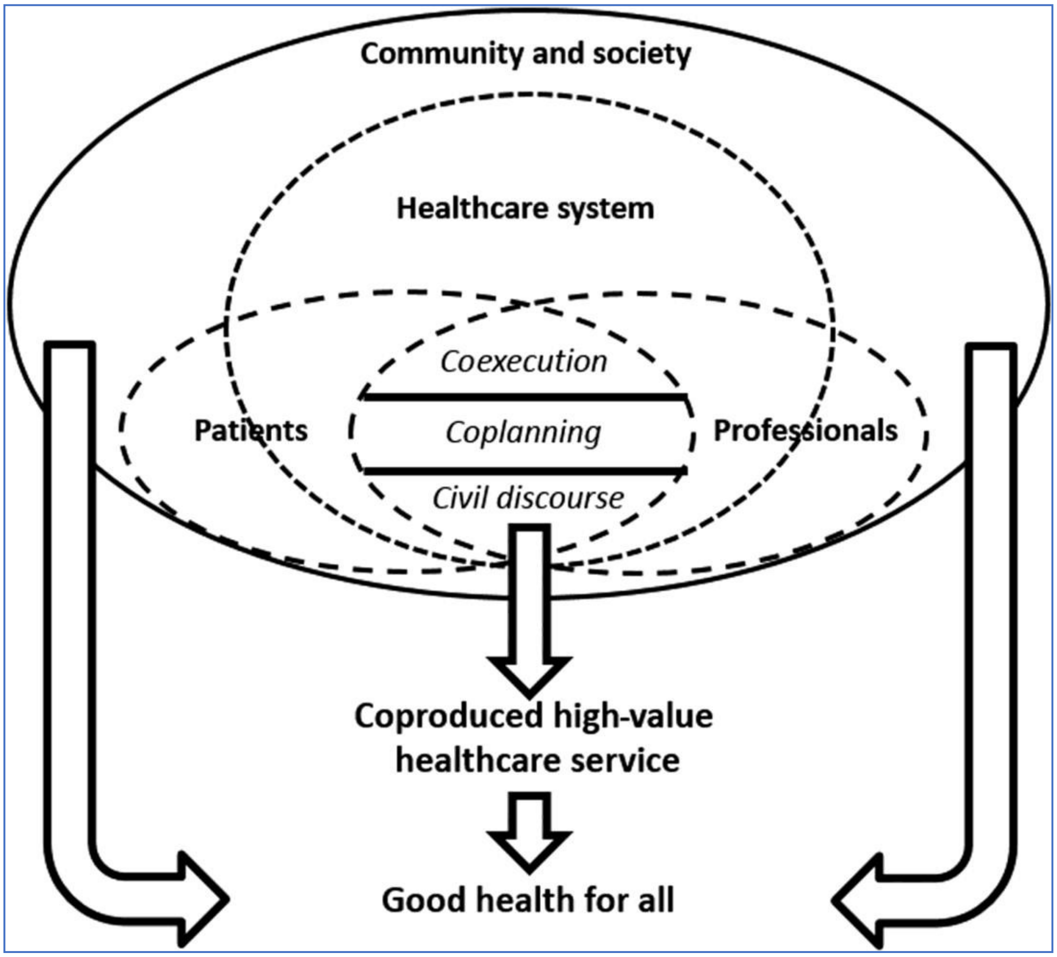

Figure 4 Batalden *et al* (2015) Model of Co-Production

Their view is that co-production is always present in healthcare delivery within a system that either helps or hinders it. Recognising that co-production is embedded in healthcare delivery, they suggest their model looks for opportunities for innovation and improvement The dotted lines in their model implies 'blurred roles for patients and professionals' and the blurred 'boundaries' between the 'healthcare system and within the larger community' (Batalden *et al,* 2015, p. 511).

<u>2.3.4</u> <u>Human Centred Design</u>

Designer Don Norman (2002) devised the concept of Human Centred Design (HCD), putting the person at the centre of any design or production of a product. While Norman's background is in Product Design, he argued that the four principles of human centred product design could also be used in the design and production of services (Norman, 2000). The four principles are:

1. putting people at the centre of the process
2. defining the problem to be solved rather than just the symptoms
3. being aware that 'everything is a system' and is inter-related, that by solving one issue we may need to address another connected issue and,
4. iteration, design a product or service, discuss and analysis, redesign - it is an ongoing process.

For Norman (2002) what is important is putting the person at the centre of the process. Bazzano *et al* (2017) suggest that Norman's HCD with its focus on 'empathy, ideation and iteration is well suited to addressing population health' (p. 2). It is very similar to co-production in that it is both a practice and process that includes stakeholders at all stages. Adam *et al* (2020, p.151) argue that HCD provides an 'opportunity to strengthen human agency' and to 'amplify the voice' of those with less power enabling them to fully engage through its four-stage framework. The process of HCD, and its success, is based on trust and reciprocal relationships, particularly in healthcare design, where trust is indispensable due to its relational aspect (Gilson, 2003; Tronto, 2013; Adam *et al,* 2020). It can be argued that the co-design, co-production, co-creation process, with its emphasis on the inclusion of all stakeholders at all stages, also strengthens human agency and gives voice to those with less structural power, and that trust is indispensable to the co-production process. Adam *et al* (2020) suggest that the positive outcomes for HCD and co-production are based not just on trust but on reciprocal relationships of those involved in the process. They outline three inter-relational elements of the reciprocal relationship-

a) achievement of common goals under three principles of shared power, shared responsibility and shared authority;
b) the fulfilment of shared self-interests which keeps the parties engaged in the process, and
c) gratitude and indebtedness which is critical to the sense of fairness and builds empathy for the others point of view (Adam *et al,* 2020).

Healthcare reform through the co-design process needs to be conscious that a reflective, emphatic practitioner facilitating the process is vital to good outcomes (Norman, 2002; Karasti, 2014; Bon Ku and Lupton, 2020). While some would suggest that a professional designer is required to facilitate the co-design process Burns *et al* (2006) contend that as design has moved from the creation of things to designing services, and from a designing for paradigm to one of designing with, the co-design process can be facilitated by non-professional designers. However, they suggest that facilitators must be versed in the art of design-thinking. As we have seen healthcare services are always co-produced with the patient (Boyle and Harris, 2009; Batalden *et al,* 2015; Batalden, 2018) but not always co-designed [an example of this in an Irish context is discussed in chapter 4]. Co-design groups are facilitated by practitioners who are neutral on the topic or very aware of their bias and have built reflexive practice into their work. Experienced design-thinkers are required to guide the democratic process of co-design allowing the solutions to arise organically.

2.4 Trust, Power and Shared Decision-making

2.4.1 Trust

In their article 'Trust is the engine for change', Adam and Donelson (2020, p.1) state that 'trust is essential' to cooperation, coordination, and performance at all levels of human interaction. They go further and suggest that 'reciprocity is central to the process of building trust in health system partnerships' (Adam and Donelson, 2020, p.2). It is through sharing power, responsibility and authority within the co-production or HCD process that trusting relationships are built. Misztal (1996) ascertains that by listening to, and engaging with others with an open mind, trust serves communication and dialogue. Gilson (2003, p.1456) contends that there are two types of trust, strategic and altruistic. Strategic trust is given in the hope that when you require assistance it will be given in return. Altruistic trust is 'a belief in the goodwill of others' (Gilson, 2003, p.1456). It communicates respect, facilitates cooperation and perpetuates trusting relationships, which Adam and Donelson (2020) interpret as reciprocal. Trust cannot be coerced, it has to be earned, therefore, the more fulfilling the engagements, the more 'the partners fill the bucket of goodwill' to draw on in times of conflict (Adam and Donelson, 2020, p.5). In addressing trust and reciprocal relationships Adam and Donelson (2020) also discuss the inequity of power. They ascertain that when those with less powerful positions enter into the HCD process, their power base builds, moving them from passive recipients of services to shared decision-making and co-creators.

2.4.2 Power and Shared Decision-Making

Power can be viewed as ‘positive, productive and cooperative’ or as an unproductive, divisive ‘zero-sum, competitive interpretation of power’ (Nugus *et al,* 2010, p.899). Trede and Higgs (2003) state that intentionally, or unintentionally, power impacts on the process of co-production. McAuliffe *et al* (2006) suggest that where power resides within healthcare organisations is not as easily identifiable as in non-healthcare settings, and that it is important to know the location of power before attempting change. While organisational charts show the hierarchical structures and relationships, power is not just confined to these clearly defined roles. It is also embedded in relationships between colleagues, disciplines and patients, between primary and secondary care and, between organisations within the health and social care system. The HSE’s Change Guide (2018) outlines the key drivers of change that will be used when moving from a centralised perspective to a local level one.

This change of direction can be seen in the programme of integrated care for older people, being developed at a local level around a framework of ten steps. It moves the locus of power for change and delivery of services to a co-production model where power is shared between all stakeholders (Harnett, 2020). WHO and United Nations (2008) and WHO (2017) suggest that meaningful participation in the design and delivery of healthcare is an entitlement of a rights-based approach. Heimans and Timms (2014) call this ‘new power values’ where members of todays society expect to actively shape or create aspects of their lives through collaboration and transparency. The HSE (2018, p.4) refers to Heimans ‘new power values’ being used to facilitate change where ‘everyone has the opportunity (and the responsibility)’ to be involved in how health and social care services are designed and delivered. They acknowledge that there must be a move away from power held by a few to power made by many (HSE, 2018). The way forward, they argue is through engagement with services users, their families and carers, staff and clinicians, building capacity to enable them to be co-producers in the system (HSE, 2018). As co-production involves all stakeholders including patients (Ramirez 1999; Joshi and Moore 2003; Bovaird 2007; Bovaird and Loeffler 2013), it is important to know where their power or lack of power lies. Joseph-Williams *et al* (2013, 2014) indicate that there are several factors that impact on the power imbalance between the physician and patient. They imply that in order to participate in shared decision making they require knowledge, but that knowledge alone is insufficient, patients must be empowered to use knowledge. Joseph-Williams *et al,* (2013, 2014) and Frosch *et al, (*2012) argue that physicians do not encourage their patients to be involved in shared decision-making. In addition, patients are reluctant to ask questions, the emphasis is on being a ‘good patient’, rather than a ‘difficult one’ which they may perceive as having poor outcomes for their care (*ibid).*

Labonte (2010, p.181) argues that the physician, as the empowering agent, generally has more power through their perceived status and legitimacy as the expert, along with their access to and control over resources. Tronto (2013) articulates the unequal nature of a care setting, the person in receipt of care is automatically less powerful and more vulnerable than the physician or care-giver. How a physician uses this power Labonte (2010, p.182) proposes is either ‘power over’ or ‘power with’ the patient. Power over suggests that the physicians way of looking at the issue is correct, that s/he will tolerate other viewpoints, but ultimately their view will prevail. Power with, respects the others point of view, understands the lived experience of the other as valuable and collaborates to find common ground and a way forward (*ibid*).

The co-production process involves power with all stakeholders through the building of trusting relationships and collaborative practice. As this research process involves co-design, co-produced sessions with both older people and their clinicians it is essential to acknowledge the perceived or real imbalance in power and find ways to reduce or eliminate it. Joseph-Williams *et al* (2013) indicate that patients often do not value their own lived experience or perceive it to be expert knowledge. Addressing this through a co-design session with older people prior to a stakeholders’ co-production workshop is important for the process in this research project. It will empower the older person to believe their lived experience is relevant and valuable to the process by building capacity and confidence in their ability to contribute without apprehension. WHO and UN (2008, p.3) says that the ‘right to health is an inclusive right.’ It is important that the system enable this co-production practice as to not do so ‘could be construed as disempowering patients, even as manipulative’ (Trede and Higgs, 2003, p.68). WHO (2015) refer to the social justice aspect of co-production when they determine that all sections of society must be included in the co-production process in order to address health equity.

Power does not only reside between patient and clinician. Tronto (2013, p.152) states that 'doctors do not provide healthcare alone, they are increasingly involved in a complex set of social relationships of care.' Relationships that involve work colleagues and management. These relationships have their own power dynamics separate to those of the patient/clinician and have an impact on the type and quality of care received by the patient (Liberati *et al,* 2015; HSE, 2019). Nugus *et al* (2010) observe that healthcare organisations contain communities within it that are bounded by their own rules of engagement and power structures outside of the official hierarchical organisational chart. They go on to suggest that within these smaller units or teams, power can be 'competitive or collaborative' and can be 'negotiated' (Nugus, 2010, p.899).

Competitive power pitches one discipline against another on wards or in multi-disciplinary teams. Collaborative power is interdependent participation and decision-making and the use of reflective practice on behalf of all clinicians (Nugus *et al,* 2010). The power imbalances between disciplines within a team and between teams impacts on the care received by the patient but also has an impact on the care-givers (Liberati *et al,* 2015). Management theories suggest that when morale is good within an organisation and staff feel valued and listened too, outcomes are better (Tiernan *et al,* 2001). In addition, while pay and working conditions need to be satisfactory, they are not motivating factors towards empowering fulfilling work, rather this comes from personal development, bearing responsibility and advancement in work (Tiernan *et al,* 2001). McAuliffe *et al* (2006) and the HSE (2018) speak of servant leadership being important in changing the power dynamics within the Irish healthcare system and enabling co-design of healthcare delivery. Robert Greenleaf (1970) who coined the phrase defines servant leadership thus:

> 'one that attempts to simultaneously enhance the personal growth of workers and improve the quality and caring of our many institutions through a combination of teamwork and community, personal involvement in decision making, and ethical and caring behavior'.

Both Greenleaf (1970) and Northouse (2016) suggest it is ideally suited to health and social care provision as it is more likely that an ethic of care exists and, more likely that power is shared. It involves interpersonal interaction, empowering and enabling strong relationships, and building trust (Greenleaf, 1970; Northouse, 2016). It is, Northouse (2016, p. 240) says, the 'only leadership approach that frames the leadership process around the principle of caring for others.'

2.4.3 Co-production of Healthcare - Power With or Power Over?

Both Fotaki (2015) and McGimpsey (2016) suggest that the global financial crisis of 2008 precipitated governments looking at other ways of delivering public services, including health, that would reduce costs through a value for money lens. Dahl and Soss (2014) suggest that neoliberal politics have aligned state with market concepts and value in economic terms only. They further contend that contrary to common perceptions, neo-liberalism has not shrunk the state and 'kept its hands off the market' (p. 497), but instead it has blurred the boundaries between market and state and reorganised their relationship.

How public services are delivered is based on corporate structures where the state actively creates markets. McGimpsey (2016) argues that co-production does not involve power with but a more subtle form of power over. He suggests that co-production as delivered by the state is an extension of the neo-liberal agenda involving disseminating responsibility for providing services to volunteer led patient representative organisations and individuals under the guise of empowerment. Farr (2018) agrees, arguing that the adoption of co-production and co-design principles does not guarantee equal partnerships and shared power between participants. Inglis (1997) and Farr (2018) make a distinction between empowerment and emancipation. Empowerment enables people to work within the existing structures of an organisation or state. Emancipatory power, on the other hand, involves a change in culture and values, removing power and decision-making from the few and sharing it with all. This can be achieved through reflexivity and co-production practices emerging 'through the human ability to act together' (Farr, 2018). How co-production is conducted impacts on whether it is empowering or emancipatory (Farr, 2018; McGimpsey, 2017). The people involved in the process, the structures in which it is set, the environment in which it is conducted and how solutions are arrived at and implemented are all important aspects to emancipatory change. Dahl and Soss (2014) contend that what is equally important both at state and organisational level is countervailing power, balancing the interests of all parties and favouring none.

Through the neoliberalist agenda this has been ‘under used or lost’ resulting in a relationship between business and state being ‘almost entirely collaborative and supportive’ (Dahl and Soss, 2014, p. 499). McGimpsey (2017) goes further and suggests that the market practices of public service governance where value is articulated as only economic, plus the economic crash of 2008 had led the state to use the concept of co-production to invent a role for civic organisations in the provision of public services. As the state apparatus is reduced or withdrawn – co-production is used as an extension of the neo-liberal agenda and not an emancipatory concept where citizens are involved in shared decision-making with the state. McGimpsey (2017) suggests that a change in organisational culture is needed if co-production is to be implemented and used correctly. It could be argued that it is not just a change of culture that is required but an understanding of what co-production is and how it should be implemented. Boyle and Harris (2009) outline what co-production is not. They state clearly that it is not consultation, nor is it volunteerism but if implemented properly it is transformative or in the words of Inglis (1997) and Farr (2018) emancipatory. Furthermore, it promotes equal participation, is sustainable and must have a key role in commissioning public services beyond merely economic outputs (Boyle and Harris, 2009). The HSE (2018, p. 4) speak of ‘the opportunity (and the responsibility)’ that all citizens have to be involved in how healthcare is delivered. They also speak of ‘power held by a few to power made by many’ (HSE, 2018, p. 5). What is not clear is the level of responsibility on recipients of healthcare and at what point in the design of healthcare systems is power held by many envisaged.

2.5 Community Development Principles and Human Rights

The All-Ireland Standards for Community Work (2016) outlines the principles and values underpinning community development- empowerment, participation, collective action, social justice, equality, human rights and anti-discrimination. The European Community Development Network (2015) define the overall purpose of community development as transforming the inequality of society through the involvement and actions of people as their own agents of change. Analysis of the definitions of co-production would suggest that in practice co-production involves all the values and principles of community development. From the outset, health was defined by WHO and the UN as being a human right (WHO, 2017). The WHO constitution of 1946 envisaged ‘the highest attainable standard of health as a fundamental right of every human being' (WHO, 2017). This was to be underpinned by a rights-based approach to health that required prioritising the needs of the disadvantaged and marginalised before the better well off in society (WHO, 2017). Both WHO and the UN agree that meaningful participation is an entitlement of a rights-based approach to healthcare (WHO, 2017; WHO and UN, 2008). By participation, they mean empowering citizens to engage so that their expectations are recognised by the State in which they reside through meaningful engagement in all areas of 'health-related decision making at national and community levels' (WHO and UN, 2008, p. 4). Furthermore, they state that in devising health policy, importance must be given by the State to the 'underlying determinants of health', by that is meant other 'factors and conditions that protect and promote the right to health beyond health services' including participation (p.6). Both community development and co-design are based on trusting reciprocal relationships and built on a platform of power with others and shared decision-making through collaborative practice. These theories are central to this research project. They enable an understanding of what is important to all stakeholders – clinicians, the older person and their families, their informal and formal carers, the community and voluntary and third sector organisations and the local community - for healthcare delivery with a human rights and social justice perspective.

Social prescribing is included in the Living Well at Home piece of ICPOP. It is a method of referral to non-medical supports that may alleviate the physical manifestations of a person's social determinants of health. Its inclusion in the Living Well at Home section of ICPOP (2018), and the recommendation that it should be delivered through a community link worker with a community development background merits further explanation (Brandling and House, 2007; Case, 2021).

2.5.1 Social Prescribing

Kimberlee (2015) contends that the interest in social prescribing is growing as an older demographic increases the burden on healthcare systems globally. While it is in place in many global health care systems, it is seen as difficult to evaluate and therefore little empirical evidence of its benefits exist (Keenaghan *et al,* 2012; Kilgarrif -Foster and O'Cathain, 2015). Recently, the HSE has endorsed its use to combat the underlying social determinants of health and has developed a framework for its implementation and evaluation

(Walsh and Sheridan, 2021). Social prescribing is part of the integrated care programme for older people, mentioned in the Living Well At Home piece as important to keeping people at home for longer (HSE, 2020). While there are numerous definitions of social prescribing it is generally understood to be a referral to non-medical interventions normally based within the community and delivered in the main by the community and voluntary sector (Branding and House, 2007; Keenaghan *et al*, 2012; HSE, 2015a; HSE and DOH, 2020; Walsh and Sheridan, 2021). The HSE (2015a, p. 4) explains social prescribing as 'the process of accessing non-medical interventions; it is a mechanism for linking people with non-medical means of support within the community to improve physical, emotional and mental wellbeing'. Kimberlee (2015) explores the concept in some detail interviewing forty social prescribing practitioners and suggests that there is no clear agreed definition of what social prescribing is and how it should be undertaken. Through analysis four models of social prescribing emerge – 'signposting, light, medium and holistic' (Kimberlee, 2015, p. 102). Holistic social prescribing has a formal referral process to a link worker with good knowledge and connections to locally available supports delivered through the community and voluntary sector as well as state organisations. The link worker needs to co-produce with the individual a social prescription based on their needs and interests while being conscious of the underlying reasons that negatively impact physical and mental health (Kimberlee, 2015).

The HSE framework for social prescribing (2021) defines social prescribing as a holistic intervention and recognises that an individual's health is determined by a range of social, economic and environmental factors. Social prescribing it suggests 'addresses barriers to engagement and enables people to play an active part in their health and wellbeing' (Walsh and Sheridan, 2021, p. 10). It uses and builds on a community's assets at a local level through developing and delivering socially prescribed activities and services in conjunction with the community and voluntary sector (Walsh and Sheridan, 2021). Recognising that evaluation of the concept is challenging the framework sets out key components and principles of social prescribing that should be adhered too and have put in place recommended evaluation tools (Walsh and Sheridan, 2021). Key to effective social prescribing is the link worker who needs to have good people and communication skills (HSE, 2015; Polley *et al,* 2017; HSE and DOH, 2020). They should ideally come from a community development background rather than a clinical one (Brandling and House, 2007; Case, 2021) building a relationship with the participant based on trust, equality and shared decision making (Keenaghan *et al,* 2012; Polley *et al,* 2017). There are challenges to the implementation of social prescribing in Ireland, not least the lack of empirical evidence to its effectiveness (Keenaghan *et al,* 2012; Kilgarrif -Foster and O'Cathain, 2015; HSE, 2021). However, an evaluation of the social prescribing project in Donegal over six sites showed statistically significantly positive changes in scores for wellbeing, anxiety and depression and, community involvement for participants (HSE, 2015a, p. 2). A more recent evaluation of a six-year project in Newcastle Upon Tyne found improvements in patient reported wellbeing and reduction in the cost of healthcare (Case, 2021).

In order for it to be effective it requires strong trusting relationships between the primary care practitioners, the community and voluntary sector and the social prescriber link worker and a clear referral pathway (Edmonds, 2003; Branding and House, 2007; Keenaghan *et al,* 2012; Polley *et al,* 2017; Walsh and Sheridan, 2021; Case, 2021) In addition, if it is to be sustainable and gain trust of all stakeholders it must be adequately funded (Edmonds, 2003; Branding and House, 2007).

2.6 Person-Centred Care and Personhood

Today, in healthcare systems globally, it is seen as standard to have person-centredness at the core of care delivery (The Health Foundation, 2014; McCance *et al,* 2011; WHO, 2015; Edgar *et al,* 2020). However, there is not a universal definition of what person-centred care is nor who is at the centre of person-centredness (McCance *et al* 2011; Buetow *et al* 2016; Edgar *et al* 2020). It is important to this research to understand the concept of person-centredness and how that fits with the HSE's understanding as it is embedded in their policies of change for the delivery of health and social care (Oireachtas Committee on the Future of Healthcare, 2017; HSE, 2018).

Mc Cormack and McCance (2017) contend that although the concept is a familiar one it is also complex and there are many definitions and meanings. To understand the concept of person-centred care 'personhood' must first be defined. McCormack and McCance (2017, p. 14) argue that if personhood is defined soley as a set of 'physical and psychological attributes' then those with dementia or profound intellectual disabilities would not be viewed as a person. They are not alone in suggesting that personhood goes beyond mere physical and psychological traits. Liebling (2008, p. 180) describes what is beyond the physical and psychological as the 'inner person' or the 'interiority' of the person. She suggests that there are several hypotheses that can explain 'interiority'- including personhood in certain social and human sciences' (p. 180). She contends that personhood is 'that which really matters' - the values of the person and what is valued by the person (Liebling, 2008, p. 180). Sabat *et al* (2011) use Social Constructionist Theory to explain personhood suggesting that, there are three aspects to the Self. Self-one pertains to our understanding of ourselves as an individual, our personal self. Self-two relates to our physical and mental capabilities and Self-three with our social connectedness to others, all of which go to the heart of our personhood. Whilst McCormack and McCance's (2017) emphasis is on people living with dementia, they argue that the loss of Self-Three can be seen with all kinds of illnesses when the ill person is seen as a condition rather than a holistic person. Person-centred care goes beyond the illness to the person at the heart of the diagnosis. Rogers (1961) understood that the person should be placed at the heart of the treatment, not the illness. It is important as a physician, he argues, to have an 'understanding of the other persons inner world', that 'insofar as I see him only as an object, the client will tend to become only an object' (Rogers, 1961; p. 201). While Rogers was a mental health therapist, his observations can also be applied by clinicians in the physical health disciplines and how they view their patients. It is important to remember that humans are relational, connected beings (Buetow *et al,* 2016; Larson *et al,* 2019) and that as McCormack and McCance (2017, p. 17) suggest, without meaningful connections to others 'the personhood of people in receipt of care is placed in a vulnerable state'. McCance *et al* (2011, p. 2) outline 'four core concepts' at the heart of personhood and person-centred care-

1. being in relation- emphasises the importance of the therapeutic relationships of care
2. being in a social world - understands that people are social beings who through connections and how they experience the world, create and recreate meaning to their existence.
3. linked to being with self - a person's values and what they value,
4. and being in place - not just the built environment of the persons world but the atmosphere and the culture of the environment in which the care takes place

There are many wide-ranging definitions of Person-Centred Care. The title of Edgar *et al*'s (2020) discussion paper is *'Which is it, person-centred culture, practice or care? It matters',* and so it does. It matters which definition is taken as universal when devising policy on person-centred care at national and international level. It matters if it is culture, practice or care that is person-centred. It matters who the person at the centre of care is. Person-centred care is broader than patient-centred care (Tresolini and Pew-Fetzer, 1994; Nolan *et al,* 2006; Edgar *et al,* 2020; Phelan *et al,* 2020). Buetow *et al* (2016) describe it as the spotlight on the person at the centre of care being expanded outward to encompass their family and carers, those that provide professional care, the organisations that provide the care and the community in which they reside. There must be a practice and culture of person-centred care where everyone involved in the provision of, and receipt of care is valued, respected and afforded dignity (Tresolini and Pew-Fetzer, 1994; Dewing and McCormack, 2017; Edgar *et al,* 2020).

While Tresolini and Pew-Fetzer (1994) and Nolan *et al* (2006) speak of relationship-centred care and others, amongst them Dewing and McCormack, 2017; Phelan *et al,* 2020 and, Edgar *et al,* 2020, speak of person-centred culture and practice, all talk of the same concept. Edgar *et al* (2020, p. 7) suggest that individual 'welfare is interdependent with flourishing for all' and that everyones welfare is important 'rather than the health of the patient being the primary focus'. It is a rights-based approach to care (WHO, 2015) that includes the rights of all those involved in the provision and receiving of care. It is a whole community approach to care that evidence would suggest brings better outcomes for all those involved in health and social care provision (Nolan *et al,* 2006; Ekman *et al,* 2011; Phelan *et al,* 2020).

Dewing and McCormack (2017) define person-centred care as an approach to practice established through the formation and fostering of healthful relationships' between all those delivering and in receipt of care. It is underpinned by values of respect and is enabled by cultures of empowerment that foster continuous approaches to practice development. The WHO (2015, p.5) separately define person-centred and people-centred care. Person-centred care they suggest incorporates care approaches and practices that view the person as a whole, with needs and goals that come from their own personal social determinants of health. People-centred speaks of the people at the heart of care being broader than just the patient and goes as far as to suggest shared decision-making in shaping health policy and services.

In Ireland the Health Information and Quality Authority (HIQA) (2012, p. 19) defines person-centred care and support as that which 'places service users at the centre of all that the service does by advocating for the needs of service users, protecting their rights, respecting their values, preferences and diversity and actively involving them in the provision of care.' However, this definition speaks only to the 'service user', like the WHO's (2015) definition of person-centred care it does not go beyond the person who uses the service to their family and carers, or to the wider community of people who provide the care required. The HSE (2018, p. 196) has built on HIQA's definition and put in place nine principles outlining person-centred care expanding on on the HIQA (2012) definition of person-centred care. Principle five speaks of enabling, where possible, the person to build on their strengths. Principles eight and nine go beyond the patient to a whole system approach to person-centredness. Moving the spotlight out from the person at the centre of care to their family and carers, to the clinicians and professionals that care for them, to the organisation in which the care takes place (Buetow *et al,* 2016). Changing how care is delivered in an already established and functioning healthcare system such as the HSE is a daunting task. From 2007 to 2010, a national practice development programme was undertaken by the HSE to support staff in residential settings for older people to develop a framework for person-centred nursing (Peelo-Kilroe *et al,* 2017). Due to its success, in 2017 the HSE introduced a three-year programme involving all services using the same methodology so that care and practices can be more fully integrated from a workplace culture perspective. In 2016 a national programme to enable cultures of person-centredness was established in the HSE to facilitate a change in organisational culture around how person-centred care was delivered (HSE, 2019). According to Phelan *et al* (2020) the framework for person-centred care used most globally is McCance and McCormack's 2017 model (see figure 5). This framework has been translated into ten languages and has been used by the HSE in their national programme (Phelan *et al,* 2020). WHO (2015) has outlined five strategies for the implementation worldwide of person-centred integrated care healthcare systems.

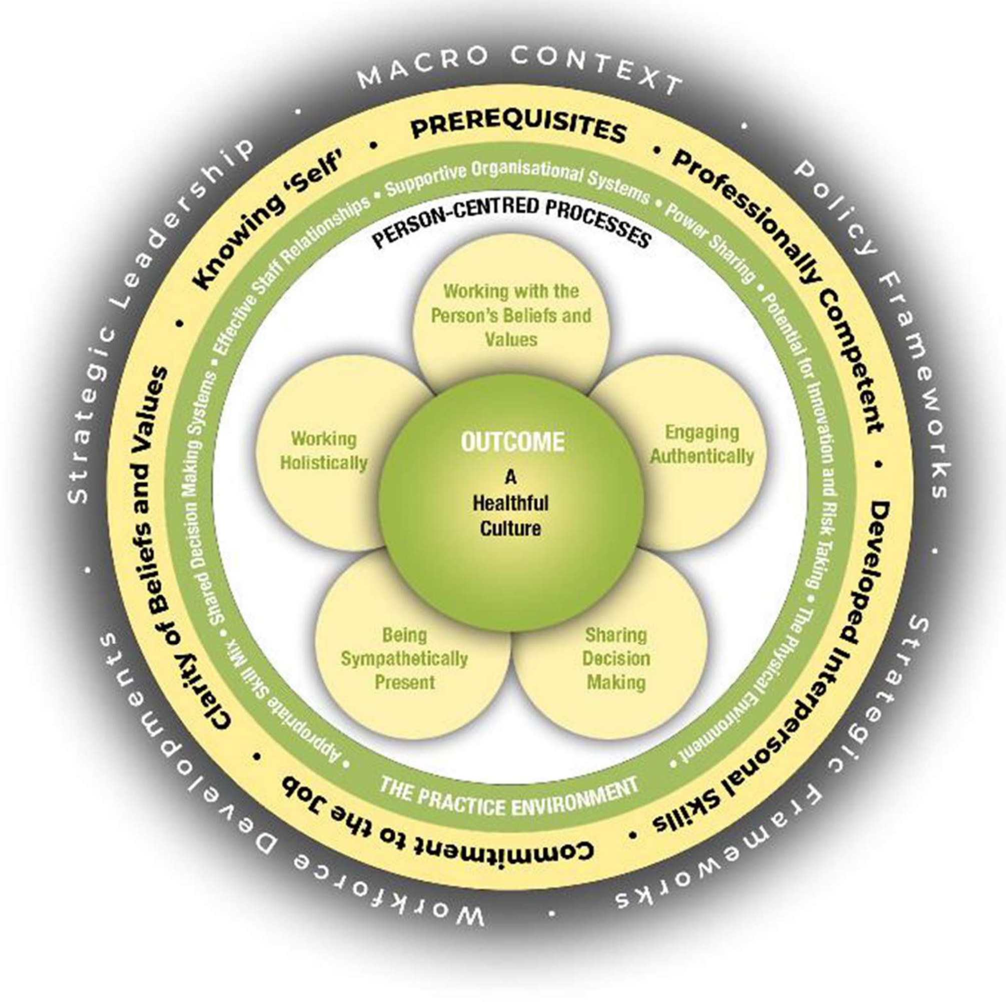

Figure 5 McCormack and McCance (2017) Model of Person Centred Care ©

This way of providing healthcare is important they assert, as 'the focus on hospital-based, disease-based and self-contained "silo" curative care models undermine the ability of health systems to provide universal, equitable, high quality and financially sustainable care' that are easily able to respond to the demands placed upon them (WHO 2015, p.9). They reference the Ebola outbreak in West Africa where a lack of coordinated integrated care proved to be a key contributor to the spread of the disease. This observation has, unfortunately, proven correct in the spread of Covid-19 and the inability of global health systems to respond in a timely, integrated, coordinated way (Integrated Care Foundation, 2020). Person-centredness as defined by McCormack and McCance underpins the co-design process. It involves a human rights approach based on collaboration with, and equal participation from, all those who deliver and receive healthcare. The co-design process will enable all those involved in the delivery and receipt of healthcare to become co-designers of the integrated care pathways envisaged by global healthcare providers including the HSE.

2.7 Integrated Care

McCance and McCormack's (2017) diagram of person-centred care mentions working holistically, taking a whole community approach to care for the people involved in caring and those being cared for. This person-centred approach to health and social care requires integration across organisations and between clinicians (WHO, 2015; McCance and McCormack, 2017; HSE, 2018). It also requires an individuals care to be integrated at a personal level co-designed by the person themselves, their carers, clinicians and community supports (Goodwin, 2016). While Goodwin (2016) suggests that the concept of integrated care cannot be narrowly defined he maintains that there are four different but commonly used definitions which have two shared characteristics- the bringing together of key aspects in the design and delivery of care systems and, the delivery of care to patients. While integrated care is a whole systems approach, he suggests that each area/discipline involved should design an integrated care pathway that fits their specification. This is apparent in the design of the Irelands Integrated Care Programme for Older People (ICPOP) which has a ten-step framework implemented by local committees based on the requirements of the local older person population. Goodwin (2016) and Kodner (2009) suggest that integrated care is essential to providing good outcomes for the person at the centre of care, particularly those living with chronic disease and the older person. For, as Kodner (2009 p.12) argues, it is this cohort 'that bear the brunt of access, continuity, fragmentation and quality problems, found in all healthcare systems'. Statistics quoted in ICPOP (2018) regarding older people's use of the healthcare system confirm this in an Irish context. Classed as 'high cost, high care' patients (ICPOP, 2018) with multiple illness they require 50% of the health and social care resources while accounting for 13.82% of the population (CSO, 2016a).

In Kilkenny, the number of people aged 65 and over is higher than the national average at 14.2% (CSO, 2016) and is projected to grow by 1% over the fifteen years to 2031 (Kilkenny County Council, 2021). A 2015 study into older people's perceptions of the Irish healthcare system showed that they perceive information about their care, certainty around access to care, the quality when accessed and, communication between and across the health and social care services as lacking (DOH and Age Friendly Ireland, 2015). Despite acknowledgement by the Irish health system of an ageing population and a subsequent increase in health and social care requirements (HSE, 2008; ICPOP, 2018), there has been a decrease in the overall number of geriatricians and specialised clinicians (ICPOP, 2018).

The HSE's 2008 report, while recognising there were some projects that provided integrated care, recommended a fully integrated healthcare system. The report suggested that a 'fully integrated healthcare system can deliver better services, better outcomes and better value' by moving the locus of care from the acute hospital to the community (HSE, 2008, p. 4). The DOH (2012, p.16) and the HSE Healy Report (2013, p. 31) suggest that integrated care can 'improve the quality and outcome of care for patients and their immediate families and carers'. They go on to say that integrated care 'is preventative, enabling, anticipatory, planned, well-coordinated and evaluated.' It means, they go on to suggest, looking at processes and care outcomes rather than at structural or organisational concerns and that organisational integration is not necessary. Integrated care, they argue, requires clinical and service level integration only (DOH, 2012; HSE and Healy Report, 2013). The HSE's own report made it clear that an integrated healthcare system by 2020 was a 'realistic target' through a strategy that put primary care at the centre of the health system (HSE, 2008). Recently there have been moves to achieve this strategy, particularly in the care of older people and those living with chronic disease through the formation of integrated care programmes. Kilkenny have led the way with a cross discipline committee of clinicians and managers from both primary care and the hospital system. Meeting since the early seventies, this multi-disciplinary committee has put in place systems which have been replicated throughout Ireland. Kilkenny physicians Courtney and Fawsitt, (2016, p. 2) assert that the current healthcare system requires a move towards a GP-led 'community-based team-care which is more preventive, predictive and anticipatory'. ICPOP's ten-step framework for pioneer sites across the country began a process of integrated care for older people in their catchment areas.

ICPOP (2018, p.17) suggest that integrated care is essential at the intervention and preventative stage of care, in order that people grow old healthily, ‘reducing social isolation and co-morbidity’. Harnett *et al* (2019, p. 289) suggest that there is evidence of *‘what works’* to improve care for older people, what is not clear, they ascertain is ‘*how’* to implement integrated care (authors italics). They suggest that a top-down approach is problematic as those at the top of an organisation may have the ability to introduce and embed the change required but do not have the capacity to do so. Therefore, the ten-step framework should deliver integrated care at local level based on the needs of the local population, building on what is already in place and the capacity in the system to deliver (Harnett *et al,* 2019). The ICPOP steering committee (2017, p.6) suggest that designing and delivering integrated care is a ‘multifaceted collaborative process between providers, users and carers.’ However, they go on to say that they will seek to build ICPOP through ‘active collaboration with clinicians and managers across the system’. What seems to be missing from the initial design of ICPOP is representation from the older person.

Input from the older person seems to be confined to listening to their voices ‘within local areas’ (ICPOP, 2017). However, the design and implementation of integrated care requires co-design with all stakeholders (Goodwin, 2016). While it seems that there has been a lack of collaboration with older people at the commencement of this progress, partnership with Age Friendly Ireland in co-produced workshops have led to a number of guidance documents around engagement with local stakeholders on how to implement integrated care in communities (ICPOP, 2018). Following on from this engagement a series of service improvement workshops were undertaken with key personnel in Community Healthcare Organisation 5 (CHO 5) in the southeast of Ireland and representatives from older person councils and third sector organisations. Two themes that emerged from these workshops from the older persons perspective and are relevant to this research are:

1. Patients as partners in care, and
2. good communication and information being vital, particularly when moving from one setting to another (ICPOP, 2018).

These themes are further developed in relation to this research in the Discussion and Findings Chapter on page 85.

Referring to Bandura's theory of self-efficacy Harnett *et al* (2019) suggest that by placing the change required in the hands of those who will have control over how it is delivered, they will be more invested and committed to its implementation (Harnett *et al,* 2019). Furthermore, feedback from networking days, convened regularly with the pioneer sites to enable learning, would suggest that from a practitioners point of view Harnett *et al* (2019) were correct in this assumption. The framework confers local agency on the teams involved in rolling out integrated care. It contains aspects that are fundamental to all sites but recognises that the local landscape will differ, allowing innovation practices to be developed, what the ICPOP (2018, p. 26) calls 'direction without dictate'.

2.7.1 Co-Design and Co-Production in Integrated care

The HSE and ICPOP wish to take a co-production approach to the re-design and improvement of services (ICPOP, 2018, 2019). Co-production they suggest

> 'is not just a word, it is not just a concept, it is a meeting of minds coming together to find a shared solution. In practice, it involves people who use services being consulted, included and working together from the start to the end of any project that affects them' (ICPOP, 2018 p. 6).

It also includes the evaluation process of the service (ICPOP, 2018). Care process metrics were introduced to ascertain the positive and negative effects of integrated care in the pioneer sites. While international consensus would suggest it takes three to five years to embed properly and, therefore, too early to have definitive results, there are early indications of positive outcomes. The emphasis on a co-production localised approach to integrated care delivery is supported by the WHO (WHO, 2015). They outline five interdependent strategies that underpin their framework for integrated care –

- empowering and engaging people and communities;
- strengthening governance and accountability;
- reorienting the model of care;
- coordinating services within and across sectors and,
- creating an enabling environment. (WHO, 2015)

Strategy one, empowering and engaging people and communities, incorporates self-management of chronic disease and health promotion with enabling communities to become actively engaged in ‘co-producing healthy environments, providing care services in partnership with the health sector and other sectors, and contributing to healthy public policy’ (WHO, 2015, p. 11). This is to be achieved through shared clinical decision-making and co-design and co-production of locally delivered integrated services (*ibid*). WHO (2015, p.4) emphasises the importance of co-production of health suggesting that through co-production care is delivered through ‘equal and reciprocal relationships between professionals, people using care services, their families and the communities to which they belong’. They go on to suggest that what is important in the design and delivery of health and social care is that the process of co-production involves all segments of society particularly those communities that are marginalised and underserved.

2.7.2 Covid -19 and Why Co-Designed Integrated Healthcare Care is Important for Older People

Covid-19 has had a considerable impact on older people both nationally and globally. Since the first reported death in Ireland on 11th March 2020 until 29th June 2020 there were 1735 deaths from 25,435 confirmed cases of the disease – 19,627 within the community dwelling population and 5,808 older people residing in nursing homes (Oireachtas Committee on Covid-19 Response, 2020). Of the 1735 deaths, 967 occurred in nursing homes throughout Ireland accounting for 55 per cent of all reported deaths during that period. To understand the impact on those aged 65 and over this needs some perspective. While 92% of all deaths in this period were older people (Kelleher, 2020) 3.9% of those who contacted the disease outside of nursing homes died, while 16.5% of those residing in nursing homes who contracted Covid-19 died. Furthermore, while the majority of incidents of Covid-19 in the second and third wave were in younger people, ie: those under 45 years of age, the number of deaths in our older population remained significantly higher (McGarrigle *et al*, 2020; The Age Alliance, 2021; Lima, 2021). The question is why was the disease more deadly for this cohort of people and in particular for those living in nursing homes.

The Oireachtas Committee on Covid-19 Response (2020a) argues that previous government policy decisions to incentivise private long term residential care had led to 80% of nursing homes being privately owned and run. This policy is in direct opposition to the findings of report after report since the first in 1968 on ageing well in Ireland. They have recommended enabling older people to remain at home through the delivery of health and social care in the community rather than in congregated settings (GOI, 1968, 1988; Ruddle *et al,* 1998; NESF, 2005; Moriarty, 2009; Donnelly *et al*, 2016; DOH, 2019; Browne, 2020). In the Final Report of the Oireachtas Special Committee on the Impact of Covid-19 (2020a) Professor Cillian Twomey (2020a, p. 34) reiterates concisely what previous reports have stated when he says 'What we need, in my view, is a single integrated system of care for older people which allows the person to choose where they avail of that support and care.'

Despite over fifty years of reports advocating for older people to be enabled to remain at home as they age and the understanding that this policy would be more financially advantageous (The Age Alliance, 2021) there has been a lack of urgency to put in place and fund what is required (NESF, 2005). Kelleher *et al* (2020) are stark in their assertion that many of the recommendations contained in the 1988 report on services for the older person are still relevant today. The effect of Covid-19 on the older population has led to a call from all quarters that how health and social care is delivered needs to change and that funding must be provided to implement that change (Oireachtas Committee on Covid-19 Response, 2020a; Kelleher *et al,* 2020; HIQA, 2020; The Age Alliance, 2021). Ageism is mentioned as to why older people were impacted so badly by Covid-19 and why the recommendations of so many reports have not been implemented (NESF, 2005; The Age Alliance, 2021; Connolly, 2021; Kenny, 2022). Society sees older people as dependent on both State and family for support when in fact only a small number of those over 65 years of age are dependent. Most older people continue to give to society well into old age (Moriarty, 2009; McGarrigle *et al,* 2020; The Age Alliance, 2021; Connolly, 2021). Kenny (2022, p. 4) provides scientific evidence that the key to ageing well involves

> 'having a purpose in life, being curious, having lots of variety, laughter, friendship and enjoying a sense of belonging and close strong connections with friends and family.' (2022, p. 4)

As we have seen in the discussion on person-centred care humans are relational connected beings (Buetow *et al,* 2016; Larson *et al,* 2019) that rely on those connections for good physical and mental wellbeing (McCormack and McCance, 2017). McCance *et al's* (2011) concepts of therapeutic relationships of care and being in a socially connected world was lost to older people 'cocooning' alone or in congregated settings (Oireachtas Committee on

Covid-19 Response, 2020a; The Age Alliance, 2021). The physical and mental health effects of this well-meaning and necessary policy have been documented as early as July 2020 four months into the pandemic by Ward *et al*, 2020. A sense of belonging both to family and/or friends and to a community of place or interest is important for overall health and wellbeing offering protection against emotional distress, cognitive decline and physical decline (Ward *et al,* 2020; Finegan and Cawley Buckley, 2022). Loneliness amongst older people along with physical decline increased during Covid-19 (Ward *et al,* 2020; The Age Alliance, 2020; Kenny, 2022). A move away from a medical model of care to a more social model for older people has been advocated for some time (GOI, 1968, 1988; Ruddle *et al,* 1998; NESF, 2005; Moriarty, 2009; Donnelly *et al*, 2016; DOH, 2019; Browne, 2020). ICPOP, as espoused by Sláintecare and in the process of being implemented, promotes a social model of care combined with medical care available through community healthcare practitioners (ICPOP, 2018). ICPOP supports the inclusion of community supports in order that older people remain in or are supported to become part of the community in which they reside (ICPOP, 2018). Funding is required to ensure a faster roll out of ICPOP changing how health and social care is delivered to Irelands older population (Oireachtas Committee on Covid-19 Response, 2020; 2020a).

2.8 Conclusion

An ageing global population living healthily with multi-morbidities has necessitated a change in how effective, efficient healthcare is delivered (WHO, 2015; 2015a, HSE 2018, 2019; TILDA, 2020). In Kilkenny, where this research is located, there is a higher than average population of older people (Kilkenny County Council, 2021). It is timely and relevant, therefore, to undertake research investigating through co-design what is important to all stakeholders in the design and delivery of healthcare for older people. In addition, this research project will explore what role the community in which an older person resides, and the community and voluntary sector can play in the delivery of healthcare, enabling people to age well in place?

A move towards co-produced integrated care delivered at a local community level is evident world-wide (Boyle and Harris, 2009; WHO, 2015; 2016; ICPOP, 2018). The literature has established that the process of co-production is one of inclusivity, where all stakeholders are included in the design, the production and the continuous evaluation of the service or product (Ehn, 2008; Freire and Sangiorgi, 2010; Langley *et al,* 2018). In an Irish context the HSE are committed through Sláintecare towards a person-centred, co-produced model of integrated care (DOH 2019) evidenced by ICPOP and its ten-step framework implemented by a multi-disciplinary team at local level.

The literature indicates that a consensus around the model of person-centred care is based on the McCormack and McCance (2017) concept that puts the interests of not just the person at the centre of care to the fore but is inclusive of the needs of family and informal carers, health and social care practitioners and the wider community (Edgar *et al,* 2020). It is clear from the literature that to have an effective model of service delivery through the person-centred, co-produced process, there needs to be an acknowledgement of the power imbalances that exist, both at a patient/clinician and an inter-disciplinary level (McAuliffe *et al,* 2006). The foundation for co-production lies with trust building and reciprocal relationships (Langley *et al,* 2018; Adam and Donselson, 2020) and requires an organisational culture that empowers and enables delivery at local level (HSE, 2018; DOH, 2019).

Furthermore, the literature review shows that in order for an holistic integrated model of care to be implemented and, to reduce the burden on primary and secondary healthcare provision, the community resources in which people reside needs to be harnessed (ICPOP, 2018). This can be achieved through the introduction of social prescribing on a national level linking community and voluntary organisations with primary and community healthcare teams (Walsh and Sheridan, 2021; HSE, 2021).

Finally, Covid-19 has had an enormous impact on older people (McGarrigle *et al*, 2020; The Age Alliance, 2021; Lima, 2021). The pandemic has revealed how poorly older people and their needs have been addressed over the years by successive governments (The Age Alliance, 2021). Despite repeated calls since 1966 to enable people to age well in place nothing much has been done to provide the necessary resources to do just that. By not providing adequate funds to implement policy it is, as The Age Alliance (2021) says, self-defeating as we all age and wish to do so well and in familiar surroundings.

3.0 Chapter 3 - Methodology

3.1 Introduction

This chapter firstly outlines the research questions based on the conclusions of the literature review. It outlines the epistemological stance behind the research into healthcare design for older people in County Kilkenny. It explains the methodology used to undertake the research addressing the research questions and outlining how and why participants were recruited for each stage of the process. In addition, it describes the methods used for gathering and analysing the data outlining any limitations to the research. Furthermore, this methodology section offers a reflection of the co-design process relating to question three. Finally, it explains the ethical considerations involved and how the data gathered is used.

3.2 Epistemological Position

What Frayling (1993) calls Research through Design (RtD) and Bon Ku and Lupton's (2020) health design thinking were the approaches undertaken in this research project. Frayling (1993) outlined three aspects to design research – research into design, research for design and research through design. It is his RtD concept that will underpin this research project. It is Zimmerman *et al* (2010) suggest, a process of inquiry which revolves around the creation of a product or service. They contend that RtD helps solve what are called 'wicked problems' – those problems that have no right or optimal solution and involve numerous stakeholders. Bon Ku and Lupton described health design thinking in much the same way suggesting that it is an approach that generates 'creative ideas and solutions to enhance human well-being'(2020, p. 7). Moreover, they suggest that it encompasses all stakeholders through an 'open mindset rather than a rigid methodology' (2020, p. 7). As this research sought the perspectives of all those involved in the delivery and receipt of healthcare for older people the methodologies underpinning RtD and health design thinking were used to gather and analysis the data. Furthermore, RtD and health design thinking fitted well with the researcher's community development background where the equal participation of all stakeholders is considered fundamental to the research process.

A social constructivist paradigm underpins the research holding that people actively construct their reality from their interactions with others (Gray, 2004; Creswell, 2007). In addition, the researcher understands human beings as active agents in shaping their own lives influenced by their social position in society and by their interactions with others rather than as ‘passive recipients of larger social forces’ (Charmaz, 2006, p. 7). This is strengthened by the ontological view of the researcher that as connected, relational beings we depend on one another for our well-being. However, she understands that individual health and well-being are influenced by the social determinants of health as outlined by WHO (2008). The unequal distribution of power, income, goods, and services affects equal access to health and social care and has detrimental outcomes for those from poor and disadvantaged communities. The research draws on a feminist perspective that believes in equal relationships and participation in a collaborative process. It is underpinned by reflexivity before, during and after the process that enables the researcher to hear the participants voices in the data. RtD and health design thinking are inductive processes, using reflexivity and iteration to solve a problem through design (Frayling, 1993; Bon Ku and Lupton, 2020) (see figure 6). The research uses an interpretivist approach looking to explore the lived experience of participants. It is a phenomenological model of enquiry focussing on the meaning emerging from the data leaving any preconceived ideas of the phenomena under investigation aside (Gray, 2004).

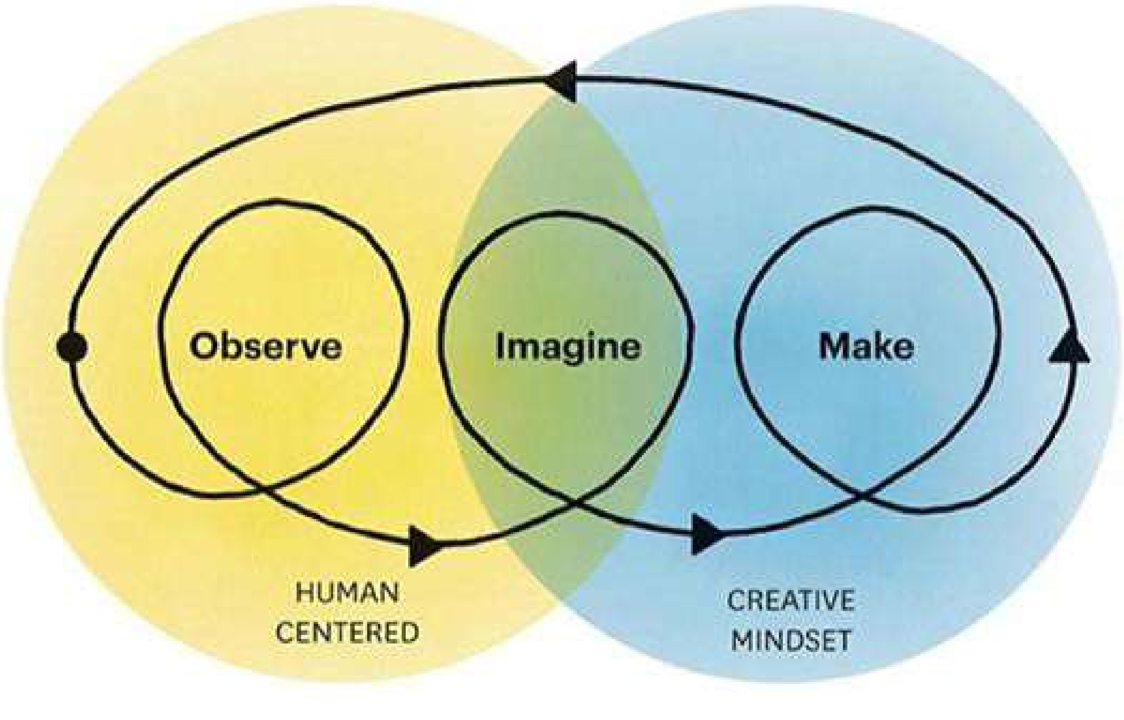

Figure 6 Health Design Thinking from Bon Ku and Lupton (2020)

3.3 Methodology

The interpretivist approach and phenomenological enquiry that underpinned this research required a qualitative methodology. An interpretivist approach understands a persons lived reality is developed through their interaction with the world. A phenomenological enquiry uses the lived experiences of participants and their interaction with one another to gather data and develop theory. Grounded Theory (GT) as espoused by Strauss and Corbin (1998) encourages the development of theory from the data gathered and analysed in an iterative process (see figure 7).

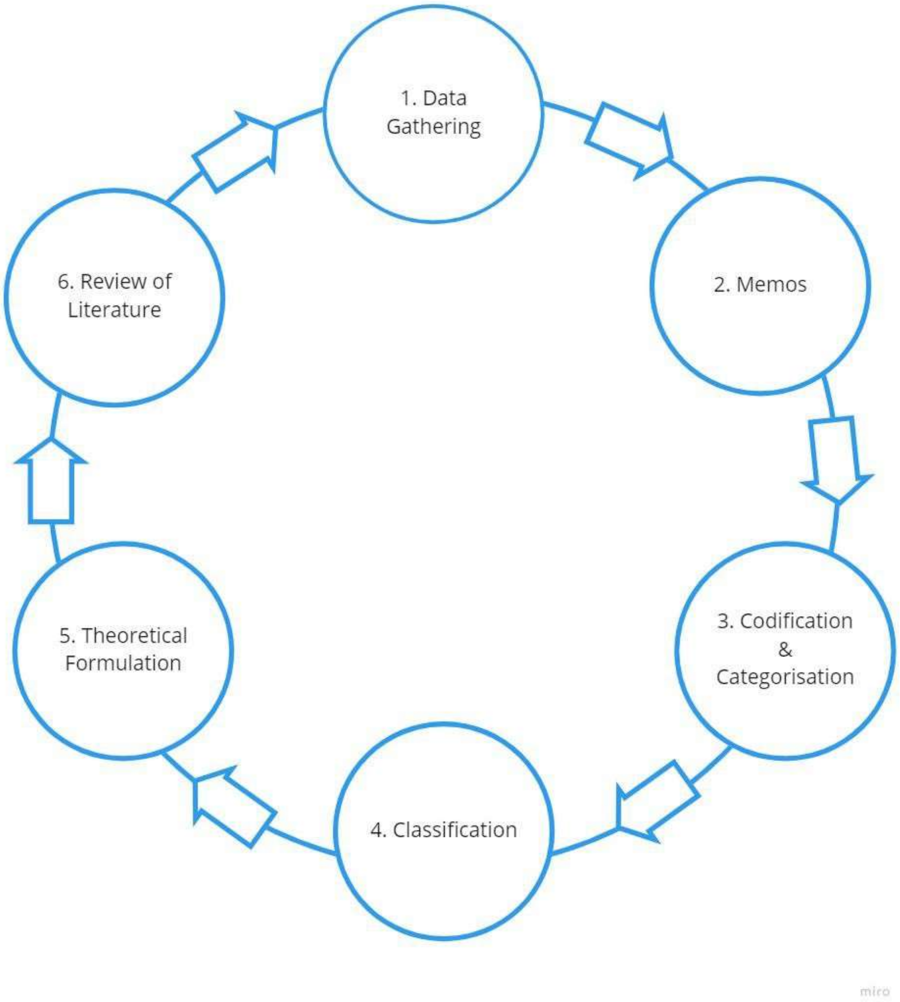

Figure 7 Strauss and Corbin (1998) Grounded Theory Methodology

Furthermore, it is a qualitative methodology that supports RtD and health design thinking's human centred approach allowing for the 'exploration of the lived experience' of stakeholders (Wilson, 2012).The stakeholders involved in the delivery and receipt of healthcare had different perspectives on what was important. Grounded Theory allowed the exploration those differences, extracting from the data gathered in the first two stages a consensus on what was important and through the stakeholders' co-production workshop verifying what had emerged from the data – giving a 'collective voice' to the conclusions (Smithson, 2000, p. 109). In addition, the writing of memos immediately after each stage of the process enabled reflexivity on behalf of the researcher, jotting down initial thoughts on what had gone well and what needed to be improved on. It also allowed a quick review of the data before the first stage of data analysis -open coding - took place documenting first impressions. Corbin (2009) suggests that memo writing is an integral part of GT. It is the combination of the researchers own interpretations, reflexive practice and the data interacting together that produces an outcome (Corbin, 2009). It is an inductive approach establishing patterns, consistencies and meaning from the data collected from different sources and through different methods – what Gray (2004) calls the triangulation of data.

While GT was used to analyse the data gathered from the field research the methodology underpinning the process was co-design. While Frayling (1993), Cross (2006) and Bon Ku and Lupton (2020) speak of design in terms of products or technology this research is concerned with designing a health service pathway that may or may not use technology within its design. However, 'designerly ways of knowing' (Cross, 2006) and 'design thinking' (Bon Ku and Lupton, 2020) is an appropriate methodology in this instance for the following reasons:

1. Designing requires the involvement of all stakeholders and uses creative, innovative methods of eliciting workable solutions to a 'wicked problem'.
2. It is an 'actively constructed solution' (Cross, 2006, p. 8) concerned with how things ought to be.
3. Design is about knowing how to structure the conversations required to inform the best solutions (Martin and Hanington, 2012).

The knowledge that is required to come to a solution resides in three areas 'people, processes and products (Cross, 2006). In this research the people are the stakeholders involved in the delivery and receipt of healthcare, bringing with them different perspectives on how healthcare delivery should be designed. The processes are the methods of data collection, in this instance semi-structured interviews, co-design sessions and a stakeholders' co-production workshop. The products containing the knowledge that is required to undertake and inform this research are investigating the advantages and disadvantages of the service pathways already in place as well as examining healthcare delivery policies at a global, national and local level.

The guiding principles for design methodology are:

- Putting the person at the centre of the process
- Building trust and mutual respect,
- Communicating clearly about the research itself and how the process will be conducted
- Enabling and empowering participants to collaborate on an equal footing and
- Through power with, rather than power over, collective decision-making.

(Slay and Stephens, 2013; Evans and Terrey, 2013; Blomkamp, 2017; Adams and Donselson, 2020).

3.4 Literature Review before or after Fieldwork?

Strauss and Corbin's (1998) GT suggests that a review of the literature around the research topic be conducted after the field research. However, Charmaz (2012) suggests that in keeping with a reflective practice, reviewing the literature before, during and after the field research is also in keeping with a GT methodology. To inform herself of the topic under investigation the researcher started reviewing the literature before starting the field research. As the field research unfolded areas of interest to the project - healthcare design for older people in Ireland – added to the knowledge of the researcher and the literature review was augmented. At various points in the accumulation of knowledge and as data was gathered the original research title was considered too board and underwent several iterations (see figure 8). This is in keeping with many research projects as the process of research is undertaken and the voices of participants listened to through the analysis of the data, the focus of the research narrows and adjustments are made to the title (Dawson, 2002; Gray, 2004; Bryman, 2015).

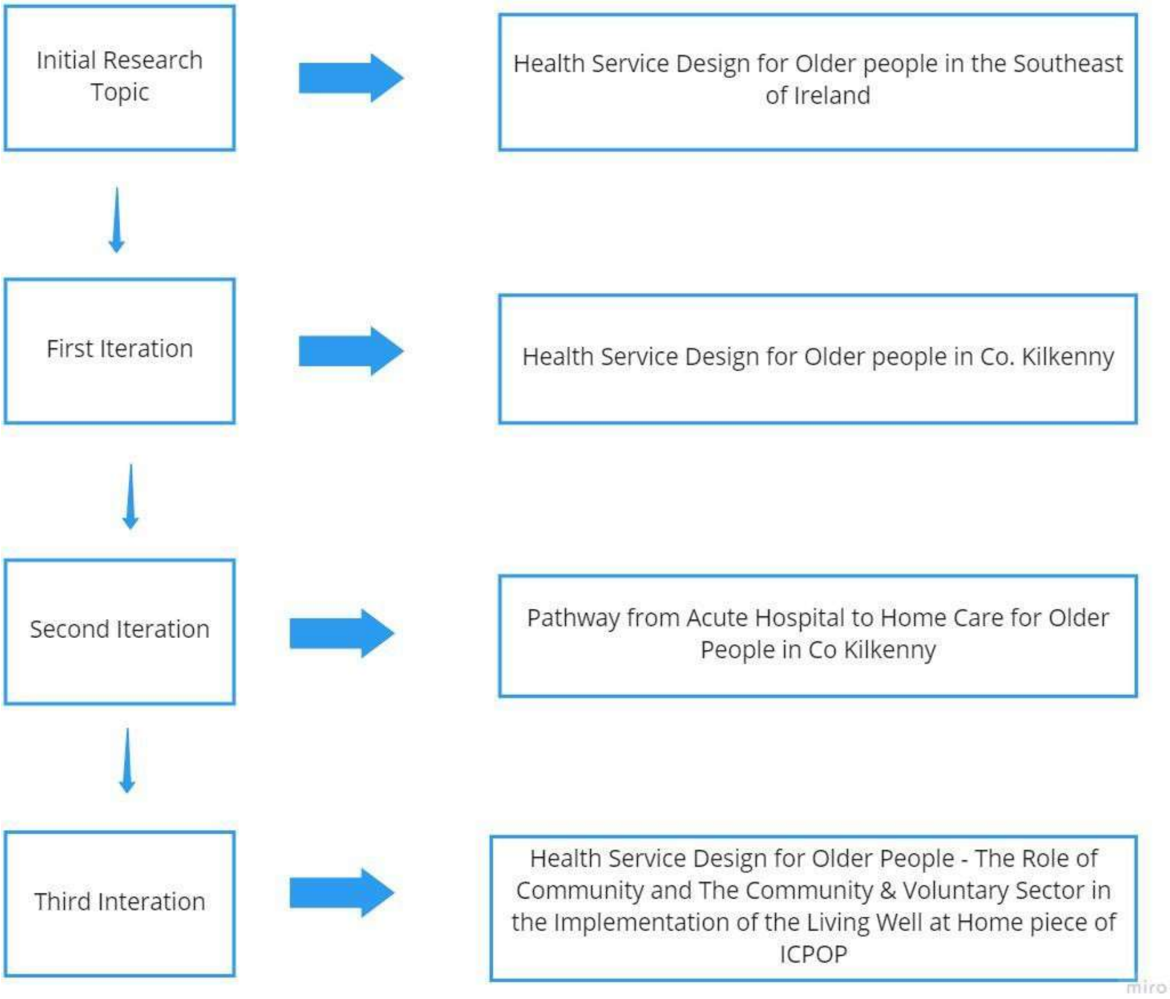

Figure 8 Iterations of Research Title

3.5 Positionality Statement and Rigor

Charmaz (2009, p.155) says that for her 'the researchers own subjectivity is always socially and temporally located'. As socially constructed beings connected to others researchers bring their own bias, preconceptions (Charmaz, 2009), pre-understandings (Hopkins *at al,* 2017) or baggage with them into the research process. As Charmaz (2009) suggests preconceptions are inevitable, are considerable and influence the analysis of data. However, through self-awareness, reflexivity and, memo and journal writing throughout the process, they can be mitigated against and the rigour of the research process validated (Charmaz, 2009; Hopkins *et al,* 2017*;* Holmes, 2020). Previous recent experience of the acute hospital system of care for my elderly father meant that I brought a large amount of pre-understandings relevant to my and my families experience to the research process. In the first instance being aware of these preconceptions mitigates against them. In addition, by engaging in empathic practice when conducting the field research by looking at the wicked problem under investigate from the participants stance also helped alleviate bias. Furthermore, reflexive practice or what Charmaz, (2016) calls methodological self-consciousness, during the entire process through the writing of memos and journals made me continually aware of the preconceptions I had brought into the process. Finally, peer debrief sessions where the data analysis process and findings were discussed was an important part of verifying the process and outcomes. All of these undertakings made the research process rigorous.

3.6 Limitations to Research

Co-design is a solution focussed methodology. It is an iterative process with all stakeholders that facilitates the prototyping of potential answers to a problem and a consensus on a final solution. Due to the time constraints of two years placed on this research project it was not possible to progress to actual iterative co-production or to a 'paper prototyping' of possible alternative service systems. However, all participants were enabled to shared their lived experience and develop a consensus on what needs to change and what supports and services need to be developed so that older people are enabled to age well at home.

3.7 Research Process

The research involved engaging with older people, those that provide formal and informal health care for older people and the community and voluntary organisations who offer supports that enable people to stay living at home. Bate and Robert (2006, p. 308) suggest that designing health services places 'the experience goals of patients at the centre of the design process and on the same footing as process and clinical goals'. Patients and their families become 'lead users' with what Bate and Robert (2006, p. 309) call 'that precious and very special kind of first-hand knowledge' - experience. The aim of the research was to keep the older person at the centre of the process participating equally with those that the older person may perceive to have more power (Joseph Williams *et al,* 2014; Tronto, 2013). Data gathered at each stage underwent thematic sampling and analysis. As in keeping with a health design thinking paradigm and a grounded theory approach each stage of the research informed the next building on the knowledge gained from all perspectives and narrowing the focus of the research to the Living Well at Home piece of ICPOP and the role of community and the community and voluntary sector in its implementation (see figure 9).

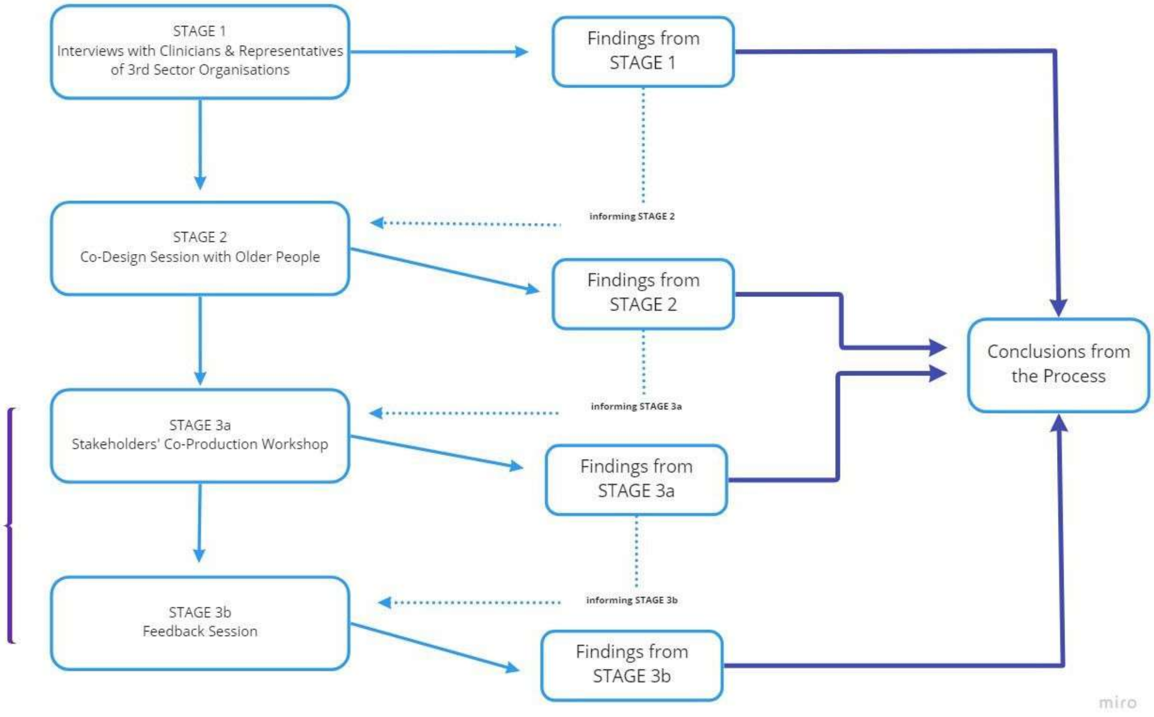

Figure 9 Stages of Research and Analysis of Data

Stage one involved semi-structured interviews with clinicians and representatives of third sector organisations in the area of advocacy for and with the older person. They were undertaken to gain an understanding of how healthcare was being delivered, what challenges were present with the system and how ICPOP would change healthcare delivery. Building on the knowledge that had emerged from the interviews the second stage involved a co-design session with older people. They discussed their perspective on healthcare delivery and what was important to them. In addition, the session built their confidence to engage on an equal basis at the stakeholders co- production workshop. The final part of the process enabled a discussion on the themes that had emerged from the first two. It was following by a feedback session with three people who could not be present at the stakeholders co-production workshop but who wished to be involved

3.7.1 Field Research Stage One – Interviews

3.7.1.1 Methodology & Methods of Analysis

The first stage of the field research undertaken were interviews with clinicians providing health and social care for older people in County Kilkenny. In addition, two representatives of national third sector organisations – ALONE and SAGE Advocacy[3] - engaged in advocacy work on behalf of older people were also interviewed. It was essential to this research to determine what healthcare practitioners see as important in the delivery of healthcare for older people in Kilkenny. It was also important, at this stage of the process, to talk to those that advocate on behalf of the older person both within the hospital itself and in the promotion of policy that enables older people to age well at home. Their perspective, as advocates, added a different dimension and depth to the data. Furthermore, it was important for the research to gain an understanding of how healthcare is delivered and if, from the perspective of clinicians and advocacy agencies, the introduction of ICPOP will see a positive impact on older people themselves, their carers and those that are involved in the delivery of the programme.

3.7.1.2 Recruitment of Participants

The clinicians were recruited through the researchers connection with the chair of the Carlow Kilkenny Clinician Society (CKCS), a group of multidisciplinary healthcare workers in the primary, community and, acute sectors that meet in Kilkenny once a month. Both participants from the advocacy groups were recruited through direct email to their organisations outlining the premise of the research. Six semi-structured interviews took place with eight participants as detailed in table 1**.** Due to the Covid19 pandemic restrictions in place at the time, all interviews were conducted online through Microsoft TEAMS and recorded. All participants received an information sheet outlining the premise of the research. A consent form was signed by all beforehand where permission was obtained to record the interview and where it was agreed that all information gathered would be anonymised so that participants could not be identified

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[3] SAGE Advocacy is an independent national support and advocacy service for older people. ALONE is a national organisation that enables older people to age well at home.

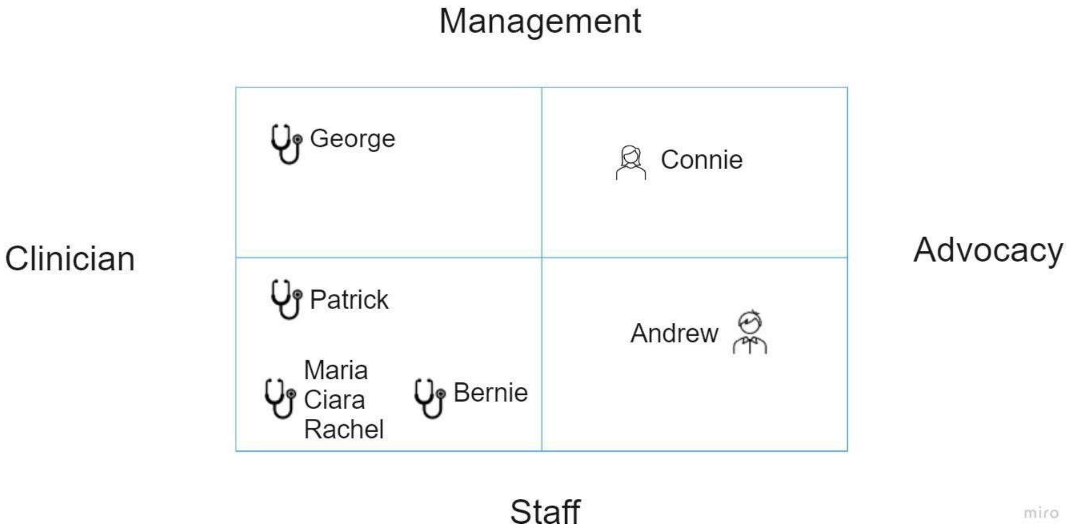


Table 1 Interview Participants

3.7.1.3 Methods of Analysis

.-The data was analysed using Colaizzi's (1978) framework (see figure 10). This structured approach to the data matches with a Grounded Theory process (see figure 7) fitting Strauss and Corben's (1998) concept of 'theoretical comparisons' that looks beyond the properties of the spoken word to the 'dimensions' behind them – contrasting the phenomenon under analysis with other types.

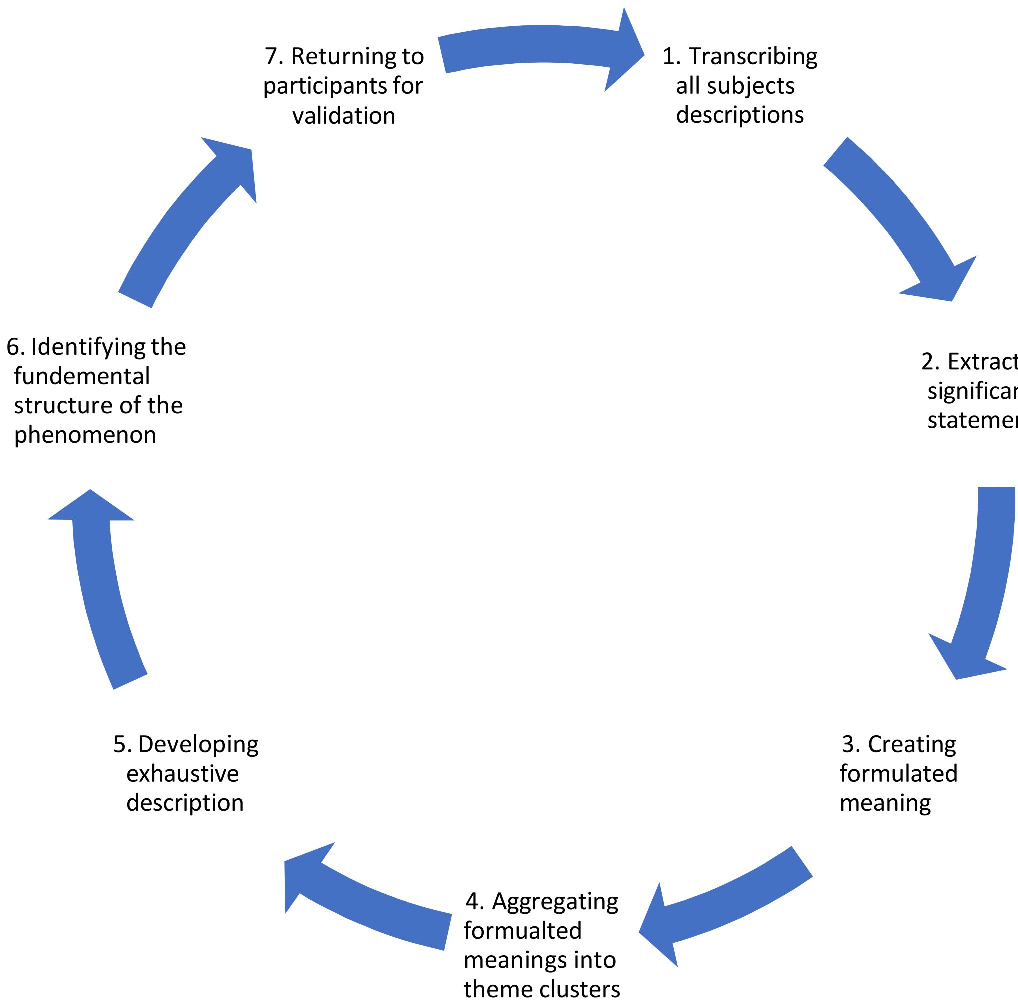


Figure 10 Colaizzi (1978) Framework of Analysis

Each interview was recorded, uploaded to Nvivo™ and transcribed manually as soon as possible after the interview took place. While manually transcribing the interviews took time, it enabled a greater understanding of what was said and the context in which it was said (White, 2012; Maher *et al,* 2018; Cohen *et al*, 2018). The information gathered from the preceding interviews influenced what questions were asked and themes explored in the next. Before transcribing, a journal entry of each interview was written with notes on what the researcher deemed important and/or interesting (see figure 11).

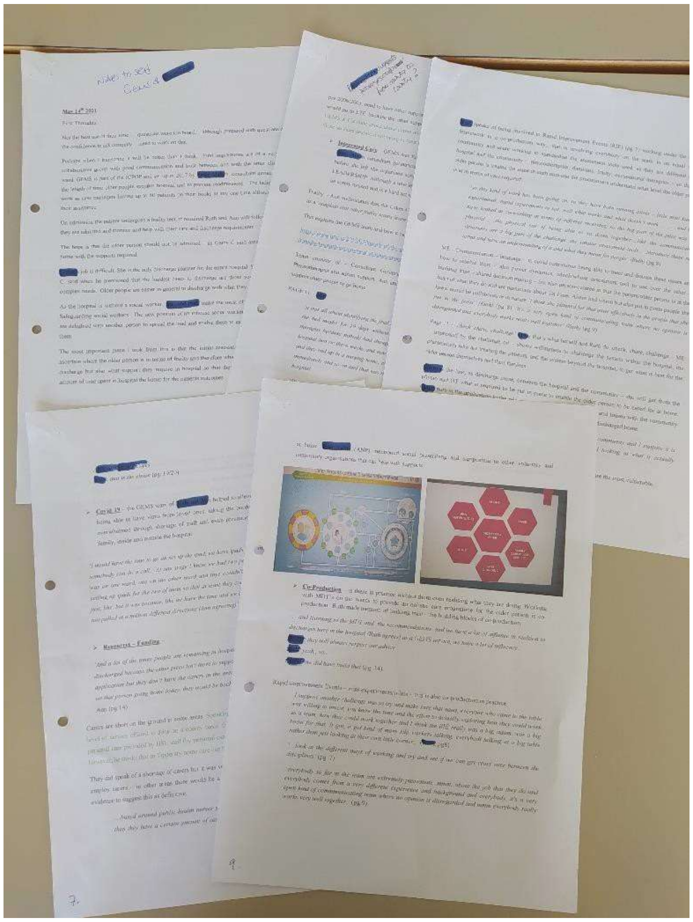


Figure 11 Journal Entry for INterview with GEMS Team

As each interview was completed and transcribed, notes connecting themes and topics that were similar across the interviews were recorded. On completion of all interviews, the transcripts and journal notes were printed and analysed in detail, highlighting themes and topics that emerged. (see figure 12) (White and Devitt, 2021) Quotes were extracted, clustered together into categories or themes and, through theoretical sampling and comparison an in depth understanding of all eight perspectives was gained, and theory developed.

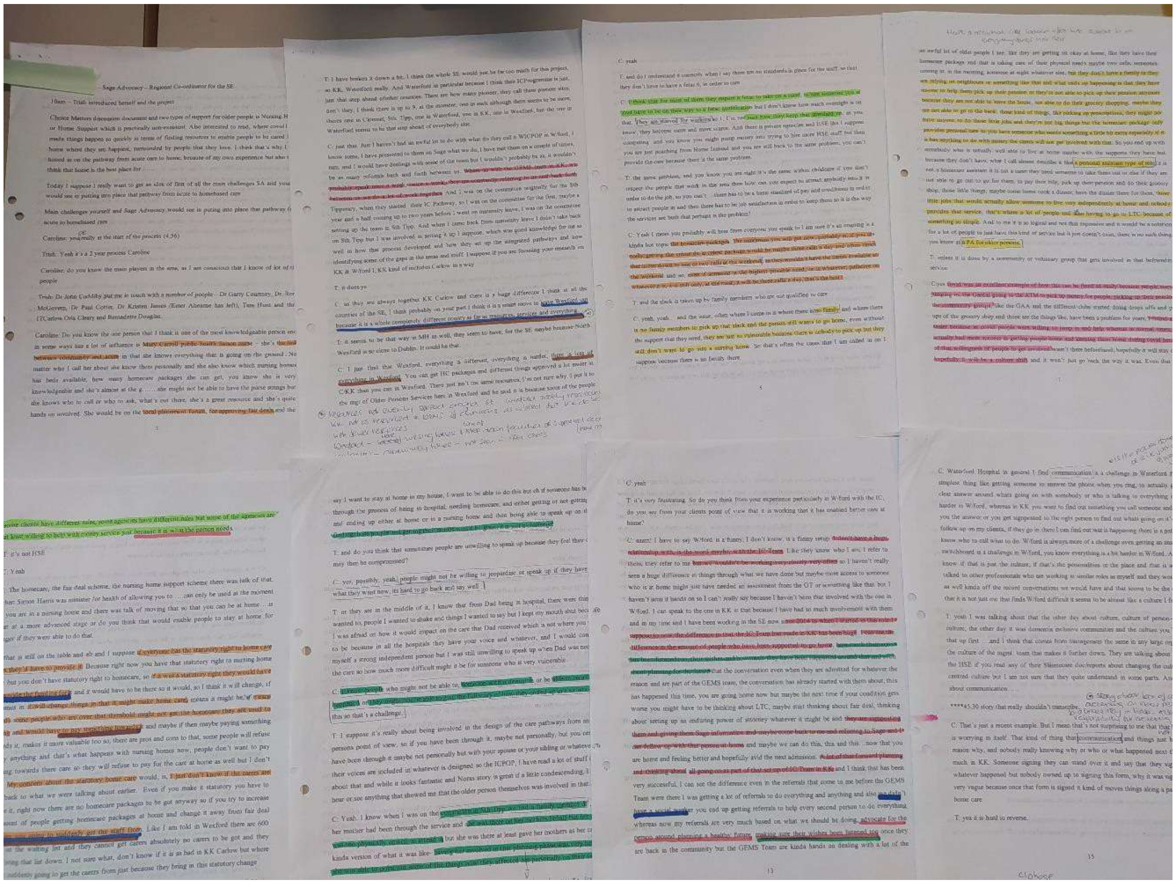


Figure 12 Colour Coding of Interview with SAGE Advocacy

The data was then further scrutinised for words, quotes and statements that pertained to the twelve Living Well at Home' categories outlined by ICPOP. The researcher added an additional eight categories to be explored in the data – integrated care, funding, collaboration and the older persons voice, communication, culture, inequality, standardisation of care and the impacts of Covid19 on older people. Quotes, statements and words collated under these categories were analysed again for similarities and differences Categories were combined, discarded or retained and organised in a MindmapTM for clarity. A peer debrief session took place to validate the process and analysis of data gathered (see figure 13).

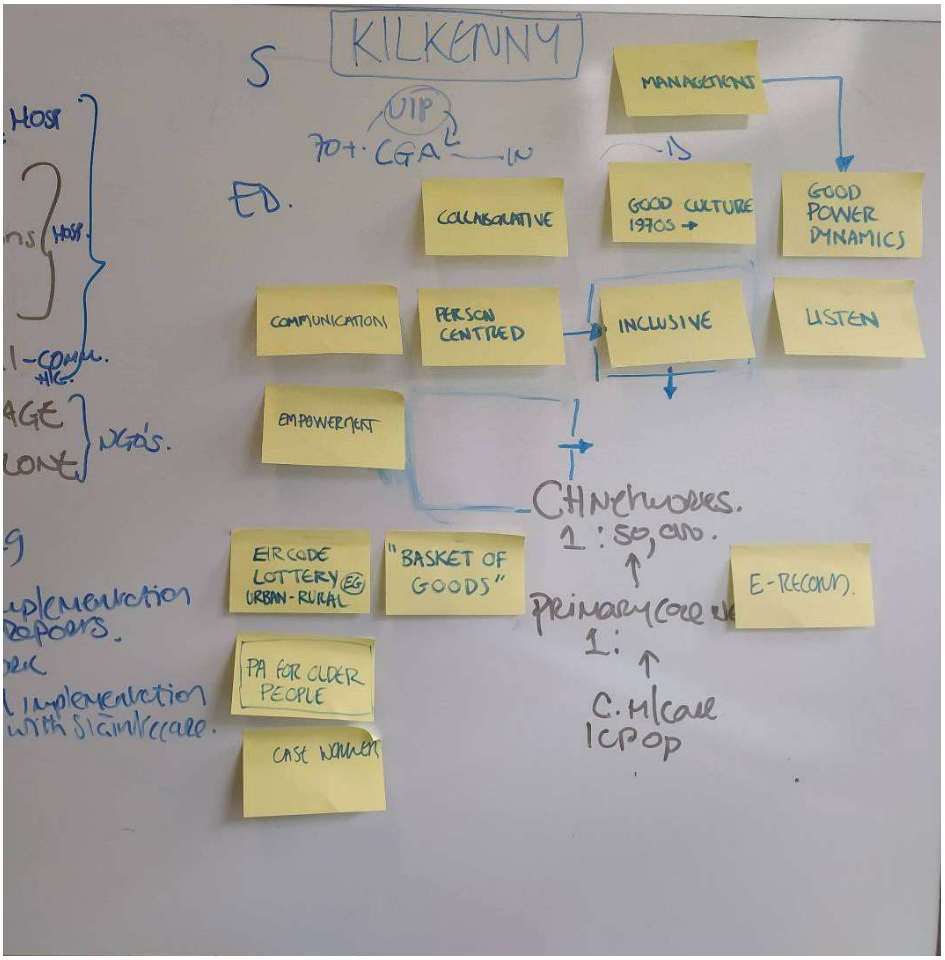


Figure 13 Peer Debrief Session after Interview Stage of Field Research (1)

<u>3.7.2</u> <u>Field Research Stage Two – Co-Design Session with Older People</u>

3.7.2.1 Why a co-design session is not a focus group!

While there are similarities between a focus group and a co-design session there are many important differences that make a co-design session more applicable to this research. Both are a form of what Kitzinger, 1995; Morgan, 1996; Dawson, 2002 and Creswell, 2007 call group interviews in that they are a group discussion on a topic prescribed by the interviewer or facilitator. Frey and Fontana (1991) suggest that unless a focus group is held in a formal setting, using direct interviewing techniques with structured questions it is not a focus group. Morgan (1996, p. 131) agrees that focus groups are ‘a structured discussion amongst six to ten homogenous strangers in a formal setting’. While Fey and Fontana (1991) suggest that the interviewer can take a more informal approach by leaving the participants to discuss the question posed and offering only ‘reinforcement to keep a discussion going’ the premise of a focus group remains one of a structured group interview around a specific topic chosen by the researcher. In addition, focus groups are used to consult rather than collaborate with service/product users on a concept already envisaged, to gain feedback on how it can be improved upon.

A co-design session is convened to collaborate on the design itself what Ehn (2008, p. 1) calls ‘anticipating or envisioning, use before actual use’. This entails a human-centred approach (Bon Ku and Lipton, 2020), listening to and acting on the views of those that will use the product or service being designed. A co-design session is semi-structured and while the topic to be explored is set beforehand it is broad in nature. This allows a wide-ranging discussion to take place with input from the facilitator limited to clarifying their understanding of what the participants are saying. It results in rich data being gathered that is then used to inform the next stage of the co-design process. In addition, the tools used in a co-design session differ from those used in a focus group. Miles (1979) refers to them as compelling and fun, building trust, which we have seen is important to the process, with participants through activities. Miles (1979) references collage making and mapping as tools used to gain an understanding of the participants worlds. Bon Ku and Lupton (2020) suggest design sessions are creative and hands on. Through activities such as story-boards, journey maps and role playing the participants ‘embody a service or process in a physical way’ (p. 11). This adds to the researchers understanding of how the participants would see a solution to the ‘wicked problem’ under investigation. Furthermore, while focus groups require some pre-planning, co-design sessions require a significant amount. They require a researcher to plan creative and engaging activities while at the same time being aware that on the day it may not go to plan compelling the researcher to find other ways for the participants to engage with the session.

While co-design sessions are fundamentally different from a traditional focus group the advantages for participants and facilitators are the same. Kitzinger (1995) suggests that focus groups help include those not comfortable with a one-to-one interview and encourages those who may feel that they have nothing to contribute through listening to other participants views and engaging in conversation with them. Smithson (2000, p.109) speaks of the ‘collective voice’ that emerges from a focus group discussion. Langley *et al* (2018) call this concept ‘collective making’ in co-design. Smithson (2000) propose that a ‘joint perspective’ on the issue under discussion develops ‘which leads to a consensus’ rather than any individual opinion (p. 109). Langley *et al* (2018, p.5) call the result of collective making an ‘negotiated model’ that ‘embodies inclusion and a shared understanding’ of the phenomena being discussed. Smithson (2000) goes on to suggest that the views expressed by a participant within a group may be different from privately expressed views – a more authentic view, as they are more comfortable speaking within a group (Kitzinger, 1995; Smithson, 2000). Kitzinger (1995) and Sim and Wakefield (2019) also argue that focus groups provide a supportive environment that enables participants to express views on issues that may be emotionally difficult for them. There is a large amount of data gathered from co-design sessions (Miles, 1979; Cross, 2006; Martin and Hanington, 2012; Bon Ku and Lupton, 2020). Design research is generative providing ‘human-centred insight’ that divulges ‘new ways of framing opportunities and inspiring new ideas’ (Fulton Suri, 2008, p. 56). In addition, it is evaluative by providing opportunities through an iterative practice of ‘learning loops’ for ‘continual learning throughout the process’ (*ibid*). Finally, Fulton Suri (2008) suggests that design research is predictive helping to estimate the potential of an opportunity or solution.

However, facilitators of co-design sessions need to be aware of some drawbacks to the process. There may be a domineering voice or power imbalance in the room. It is important to encourage and enable other voices to be heard while not becoming involved as a participant and perhaps skewing the data. Good facilitating skills are required with agreed ground rules at the beginning of a session, enabling the advantages from a data collection viewpoint to outweigh the disadvantages (Kitzinger, 1995; Fitzpatrick, 2016). Smithson (2000) states that it is important that facilitator bias, which everyone carries with them, does not influence the discussion and therefore the data that emerges. The facilitator must also be aware of the participants perceptions of them and how this too may affect group behaviour (Smithson, 2000).

3.5.2.2 Rationale for a Co-design Session with Older People

From the analysis of the data gathered from the interview process where the theme of communicating with the older person was strong, a co-design session was envisaged with the older person. It is a key principle of co-design to elicit the knowledge and listen to the lived experience of those that are and will use the service/product that emerges from the process (Ostrom, 1996; Norman, 2000; Bovaird, 2007; Osborne *et al,* 2015; Batalden, 2018). It was also important to speak to older people before the stakeholders' co-production workshop for the following reasons:

1. To demonstrate that their voice was important to the research by speaking to them as a stand-alone group about how healthcare provision in its present form addresses the needs of the older person.
2. To support them in the view that their lived experience is knowledge gained through experience as a patient or carer and that it is as valid as the knowledge of clinicians and others involved in the care of the older person (Joseph Williams *et al,* 2014).
3. While some of the participants knew each other, sharing their personal experiences and discussing how their experiences were the same and different enabled them to bond as a group. Empowering them in this way gave a collective voice to their experience (Smithson, 2000). This allowed them to be more comfortable in the stakeholders' co-production workshop with those they may have perceived as more powerful and knowledgeable (Kitzinger, 1995; Smithson and Diaz, 1996; Smithson, 2000; Moll *et al*, 2020).
4. Finally, it was essential from a co-design perspective to get the views of the older person and compare it to that of the clinicians and third sector organisations already interviewed so that the similarities and differences could be analysed and inform the third stage of the field research – a stakeholders co-production workshop.

3.5.2.3 Recruitment of Participants

Moll *et al* (2020, p. 2) refer to 'individuals who frequently contribute to research projects' as 'super users' and suggest that they do not reflect the typical population. While there is a vibrant, connected and engaged Older Peoples Forum in Kilkenny who are very involved in the local political system through representation on the Strategic Policy Committees (SPC) of the County Council, and in all areas of the Public Participation Network (PPN), new voices were considered important to this process. Using the researchers contacts through volunteerism in Kilkenny a number of older people were purposively recruited. Through their contacts they then enlisted older people that have had lived experience of a recent hospital stay and/or with caring for siblings, spouses and/or parents. Initially six participants were recruited but, on the day, due to illness there were five – four women and one man. As most caring is undertaken by women in society (McGinnity and Russell, 2008; Tronto, 2013; Russell *et al,* 2019) gender imbalance was not deemed a limitation but representative. All participants received an information sheet outlining the premise of the co-design session. A consent form was signed by all beforehand where it was agreed that all information gathered would be anonymised so that participants could not be identified.

3.7.2.4 Venue and Room Layout

As the research was looking at healthcare delivery for older people in Kilkenny the co-design session was held in a venue in the city. As Covid-19 was still prevalent and the participants were older adults it was prudent not to have them travel to a busy college campus. The venue, St Patrick's Parish Centre in the city, was centrally located and easily accessed. Covid-19 restrictions and protocols influenced the room layout. The room was spacious with good ventilation but also good acoustics to enable the participants to hear one another as they were required to be socially distanced. Five tables were set in a hexagonal shape – one participant to a table. To make them feel welcome and appreciated tea/coffee and cakes were served as they arrived at their individual table ensuring that participants felt safe (Fitzpatrick, 2016). Introductions were made during tea/coffee and an outline of the co-design session, its purpose and rationale, was given emphasising that all input is valued, relevant and important. (Kitzinger, 1995; Fitzpatrick, 2016)

3.7.2.5 Tools Used and Questions Answered

The tools used were designerly, engaging participants in a creative process (Bon Ku and Lupton, 2020). The focus of the session was how older people experienced the pathway from acute care to home care at three stages before discharge, at discharge and post discharge. To facilitate the telling of their stories on this pathway a journey map was created beforehand to be populated by the participants during the session. It underwent a number of design iterations with input and advice through two peer review discussions with experienced designers taken into consideration. The first iteration was too busy with images that could have biased the participants contributions (see figure 14).

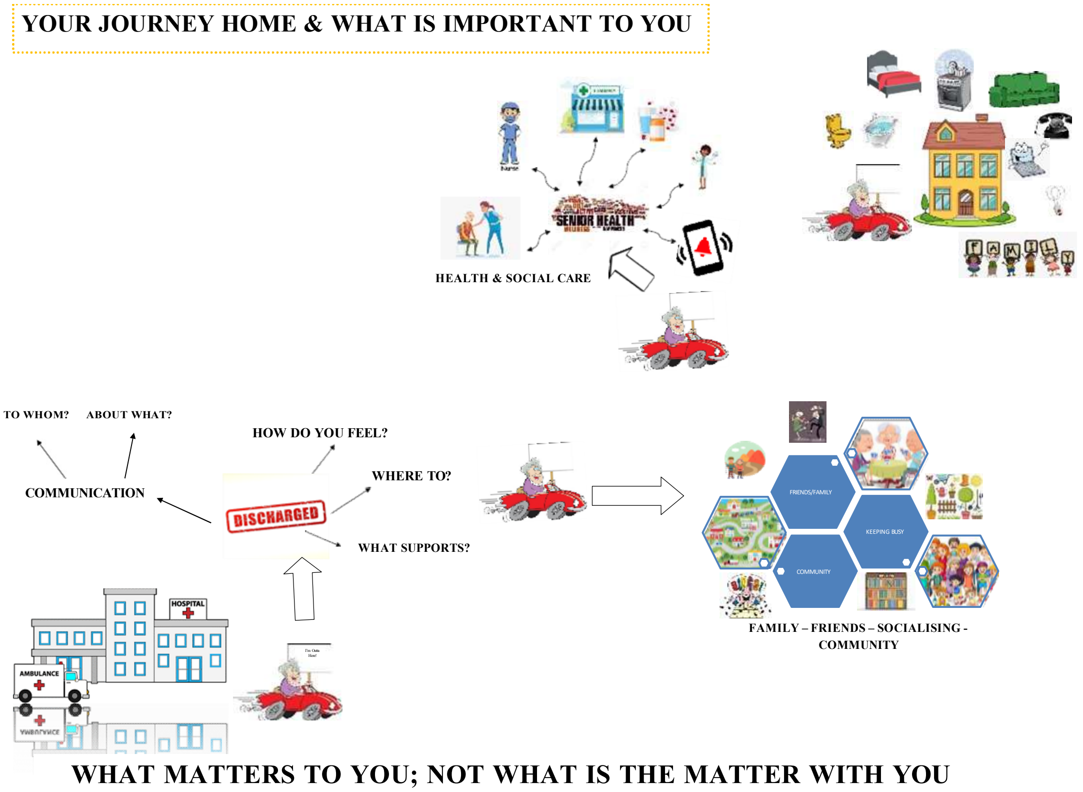


Figure 14 First Iteration of the Journey Map to be used in the Co-Design Session with Older People

The aim of the co-design session was to get the older persons view, listen to their experiences and get their solutions to the problems they saw. This would have been impossible to do with the first iteration of the journey map. The revised map was cleaner with just three images giving the participants room to populate it with their own thoughts, ideas, challenges and solutions (see figure 15).

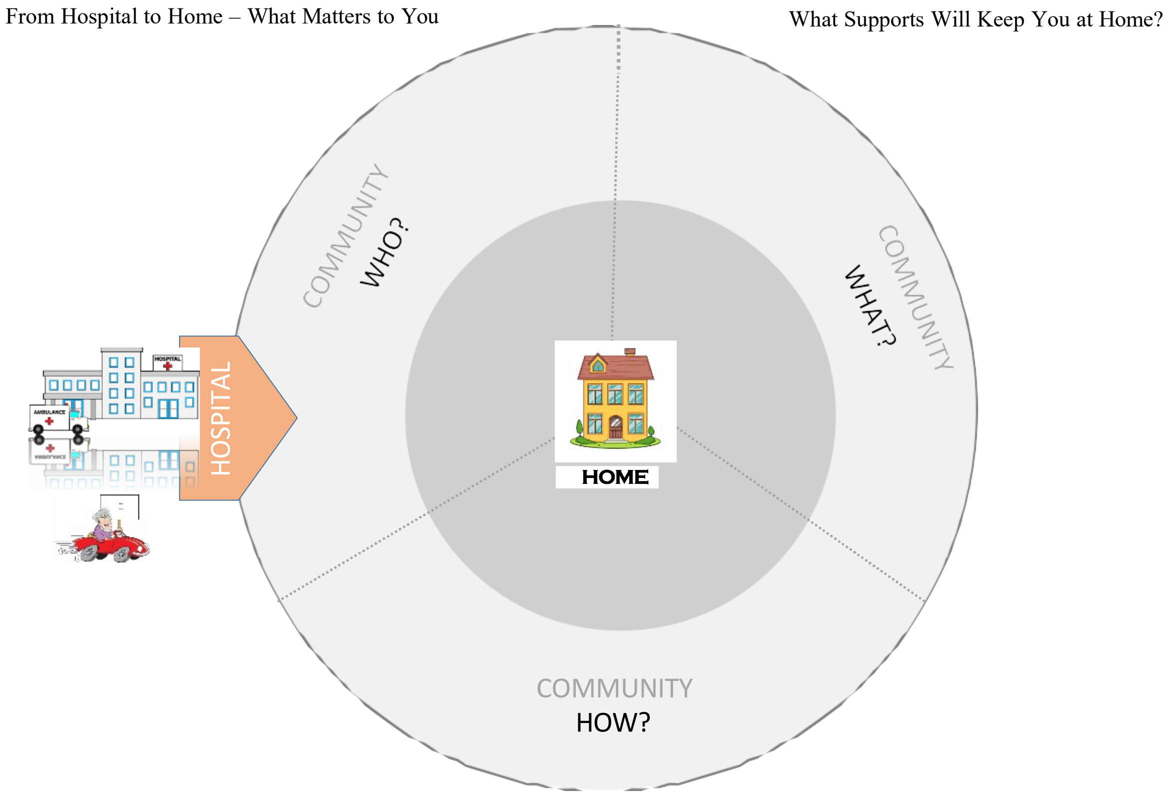


Figure 15 Second Iteration of the Journey Map used at the Co-Design Session with Older People

Except for one participant, who wrote their views on the journey map retrospectively, they were not used. However, they were not altogether redundant as the participants used it as a prop going back to it for guidance. While it wasn't used as intended, a researcher needs to be prepared to change how they expect the co-design session to unfold by allowing the participants to lead the discussion and use the props given to them as they wish (Fitzpatrick, 2016). As the participants conversed, told their own stories, discussed and, in some instances argued, the researcher and scribe captured what was being said on post its (see figure 16).

Figure 16 Data Gathered from the Co-Design Session with Older People

During the course of the co-design session the facilitator guided the conversation to each part of the journey, clarifying points raised and summing up what was being said. After the session had concluded the 'Living Well at Home' graphic from ICPOP was shown to the participants (see figure 17). The plan had been to discuss this section with them at the beginning of the co-design session. In discussion with peers it was agreed that it would bias their thinking and guide their conversation towards these twelve areas when what was sought was their initial views on the pathway home from hospital and what was important to them. As with the first iteration of the journey map we needed to be aware that we could influence the participants towards a way of thinking or an area that we felt was important but may not be to the participants. It is essential to remember that researchers are facilitators, guiding participants to reveal their views, ideas, thoughts and experiences without influence.

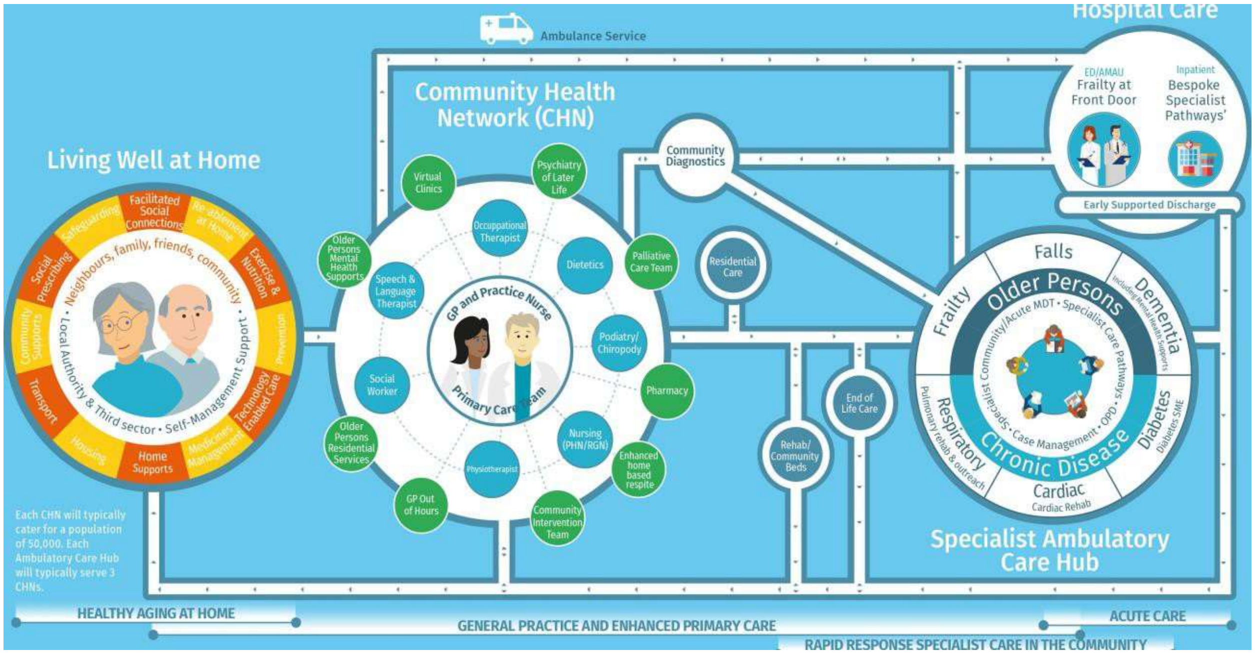


Figure 17 Service Pathway for ICPOP withtheLiving Well at Home Piece on the Left

3.7.2.6 Methods of Analysis

Gathering data from a co-design session is qualitative in nature and therefore requires a method of analysis that is also qualitative. Grounded theory 'allows for the exploration of the lived experience' searching for meaning and understanding in the data. (Wilson, 2012). Through the process of iterative analysis and coding theories will emerge (Strauss and Corbin, 1998; Charmaz, 2006; Breckenridge and Jones, 2009). Immediately after the co-design session a journal entry was made to record initial thoughts on the process and the issues raised. Open coding of the post-its then took place, recording the statements on a Word^{TM} document as they were taken from the flipchart. A second analysis categorised the statements into pre, at and post discharge on an unpopulated journey map, documenting the participants views on each stage (see figure 18).

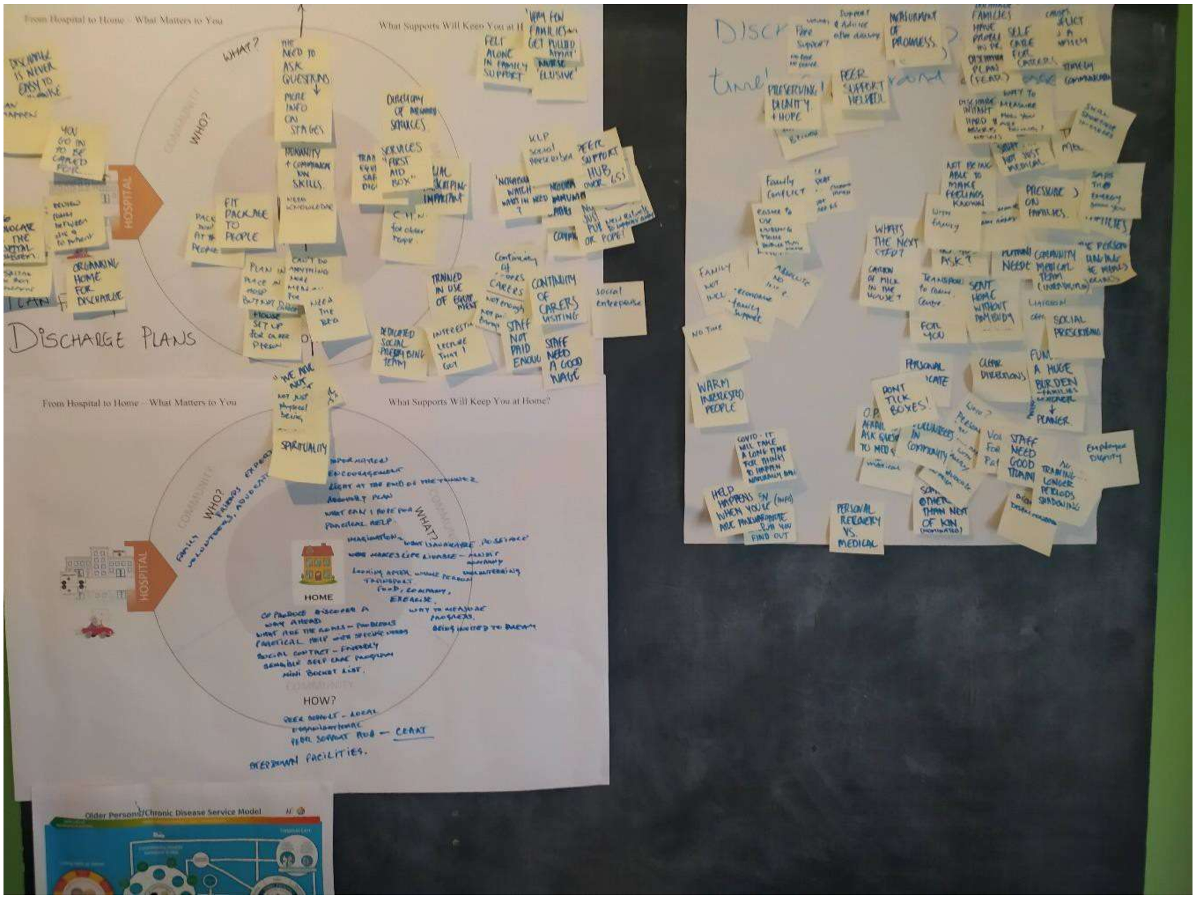
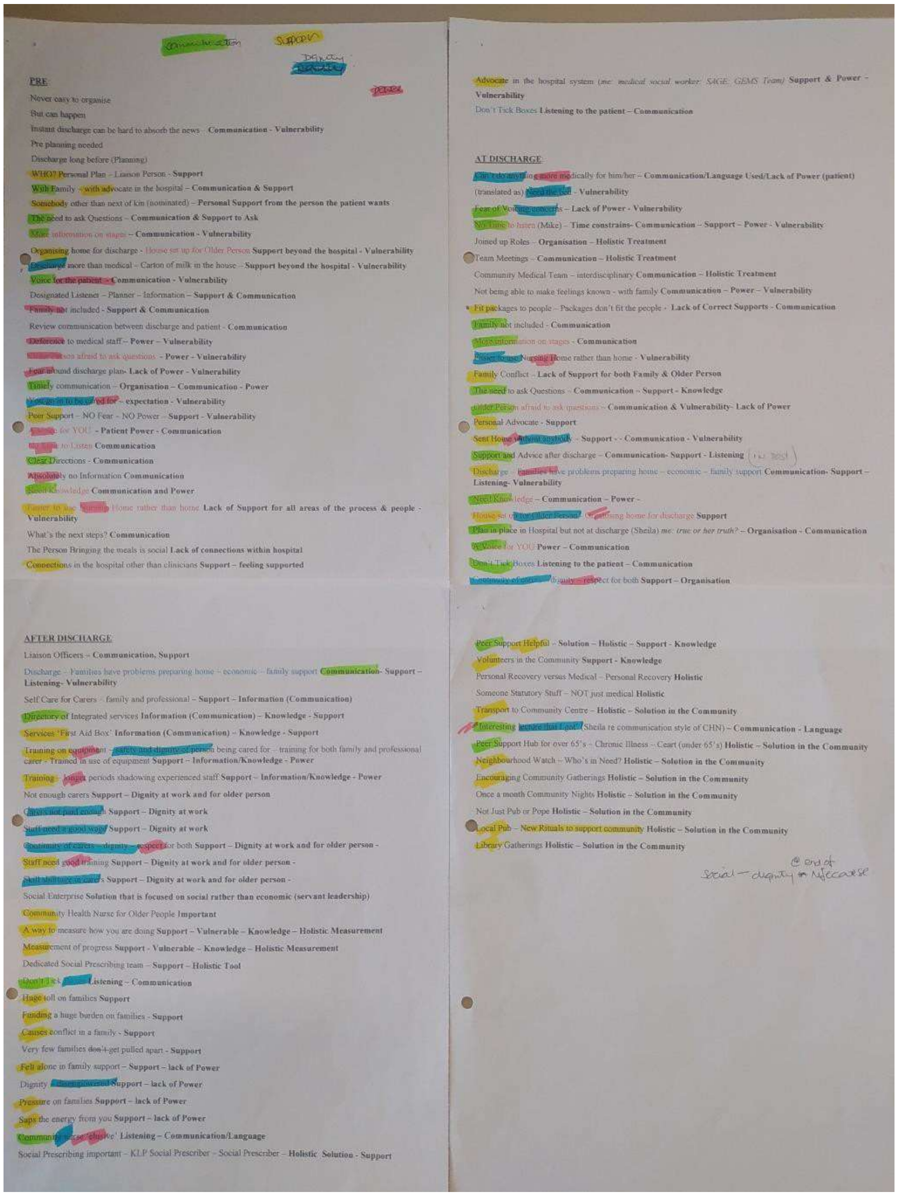


Figure 18 Open Coding of Data from the Co-Design Session with Older People

The statements were then transcribed, under these headings, onto a separate Word™ document manually highlighting similar themes across the three categories. The themes that emerged were communicating, supporting, dignity, respect and power, and holistic care (see figure 19)



Communication
Support
Dignity
Power

PRE

Never easy to organise
But can happen
Instant discharge can be hard to absorb the news - **Communication - Vulnerability**
Pre planning needed
Discharge long before (Planning)
WHO? Personal Plan – Liaison Person - **Support**
With Family – with advocate in the hospital – **Communication & Support**
Somebody other than next of kin (nominated) – **Personal Support from the person the patient wants**
The need to ask Questions – **Communication & Support to Ask**
More information on stages – **Communication - Vulnerability**
Organising home for discharge - House set up for Older Person **Support beyond the hospital - Vulnerability**
Discharge more than medical – Carton of milk in the house – **Support beyond the hospital - Vulnerability**
Voice for the patient – **Communication - Vulnerability**
Designated Listener – Planner – Information – **Support & Communication**
Family not included - **Support & Communication**
Review communication between discharge and patient - **Communication**
Deference to medical staff – **Power – Vulnerability**
Older Person afraid to ask questions - **Power - Vulnerability**
Fear around discharge plan- **Lack of Power - Vulnerability**
Timely communication – **Organisation – Communication - Power**
You go in to be cared for – **expectation - Vulnerability**
Peer Support – NO Fear – NO Power – **Support - Vulnerability**
A Voice for YOU - **Patient Power - Communication**
No time to Listen **Communication**
Clear Directions - **Communication**
Absolutely no Information **Communication**
Need Knowledge **Communication and Power**
Easier to use Nursing Home rather than home **Lack of Support for all areas of the process & people - Vulnerability**
What's the next steps? **Communication**
The Person Bringing the meals is social **Lack of connections within hospital**
Connections in the hospital other than clinicians **Support – feeling supported**

Advocate in the hospital system (*me: medical social worker: SAGE: GEMS Team*) **Support & Power - Vulnerability**
Don't Tick Boxes **Listening to the patient – Communication**

AT DISCHARGE

Can't do anything more medically for him/her – **Communication/Language Used/Lack of Power (patient)**
(translated as) Need the bed - **Vulnerability**
Fear of Voicing concerns – **Lack of Power - Vulnerability**
No Time to listen (Mike) – **Time constrains- Communication – Support – Power - Vulnerability**
Joined up Roles – **Organisation – Holistic Treatment**
Team Meetings – **Communication – Holistic Treatment**
Community Medical Team – interdisciplinary **Communication – Holistic Treatment**
Not being able to make feelings known - with family **Communication – Power – Vulnerability**
Fit packages to people – Packages don't fit the people - **Lack of Correct Supports - Communication**
Family not included - **Communication**
More information on stages - **Communication**
Easier to use Nursing Home rather than home - **Vulnerability**
Family Conflict – **Lack of Support for both Family & Older Person**
The need to ask Questions – **Communication – Support - Knowledge**
Older Person afraid to ask questions – **Communication & Vulnerability- Lack of Power**
Personal Advocate - **Support**
Sent Home without anybody - **Support - - Communication - Vulnerability**
Support and Advice after discharge – **Communication- Support - Listening** (i.e. best)
Discharge – Families have problems preparing home – economic – family support **Communication- Support – Listening- Vulnerability**
Need Knowledge – **Communication – Power -**
House set up for Older Person? Organising home for discharge **Support**
Plan in place in Hospital but not at discharge (Sheila) *me: true or her truth?* – **Organisation - Communication**
A Voice for YOU **Power – Communication**
Don't Tick Boxes **Listening to the patient – Communication**
Continuity of carers – dignity – respect for both **Support – Organisation**

AFTER DISCHARGE

Liaison Officers – **Communication, Support**
Discharge – Families have problems preparing home – economic – family support **Communication- Support – Listening- Vulnerability**
Self Care for Carers – family and professional – **Support – Information (Communication)**
Directory of Integrated services **Information (Communication) – Knowledge - Support**
Services 'First Aid Box' **Information (Communication) – Knowledge - Support**
Training on equipment – safety and dignity of person being cared for – training for both family and professional carer - Trained in use of equipment **Support – Information/Knowledge - Power**
Training – longer periods shadowing experienced staff **Support – Information/Knowledge - Power**
Not enough carers **Support – Dignity at work and for older person**
Carers not paid enough **Support – Dignity at work**
Staff need a good wage **Support – Dignity at work**
Continuity of carers – dignity – respect for both **Support – Dignity at work and for older person -**
Staff need good training **Support – Dignity at work and for older person -**
Skill shortage in carers **Support – Dignity at work and for older person -**
Social Enterprise **Solution that is focused on social rather than economic (servant leadership)**
Community Health Nurse for Older People **Important**
A way to measure how you are doing **Support – Vulnerable – Knowledge – Holistic Measurement**
Measurement of progress **Support - Vulnerable – Knowledge – Holistic Measurement**
Dedicated Social Prescribing team – **Support – Holistic Tool**
Don't Tick Boxes **Listening – Communication**
Huge toll on families **Support**
Funding a huge burden on families - **Support**
Causes conflict in a family - **Support**
Very few families ~~don't~~ get pulled apart - **Support**
Felt alone in family support – **Support – lack of Power**
Dignity – Disempowered **Support – lack of Power**
Pressure on families **Support – lack of Power**
Saps the energy from you **Support – lack of Power**
Community nurse 'elusive' **Listening – Communication/Language**
Social Prescribing important – KLP Social Prescriber – Social Prescriber – **Holistic Solution - Support**

Peer Support Helpful – **Solution – Holistic – Support - Knowledge**
Volunteers in the Community **Support - Knowledge**
Personal Recovery versus Medical – Personal Recovery **Holistic**
Someone Statutory Stuff – NOT just medical **Holistic**
Transport to Community Centre – **Holistic – Solution in the Community**
"Interesting lecture that I got" (Sheila re communication style of CHN) – **Communication - Language**
Peer Support Hub for over 65's – Chronic Illness – Ceart (under 65's) **Holistic – Solution in the Community**
Neighbourhood Watch – Who's in Need? **Holistic – Solution in the Community**
Encouraging Community Gatherings **Holistic – Solution in the Community**
Once a month Community Nights **Holistic – Solution in the Community**
Not Just Pub or Pope **Holistic – Solution in the Community**
Local Pub – New Rituals to support community **Holistic – Solution in the Community**
Library Gatherings **Holistic – Solution in the Community**

@ end of
Social – dignity in [illegible]

Figure 19 Axial Coding of Data from the Co-Design Session with Older People

A peer debrief session took place at this stage to articulate the methods used to analyse the data thus far and to discuss the findings to date (Lincoln and Guba, 1985; Amankwaa, 2016). This was particularly important for validation of the preliminary findings as qualitative methods were being used and in particular design methods where it is suggested no 'developed criteria' for methods to be used or for evaluating the 'quality of contributions' has been achieved to date (Zimmerman, 2010; p. 310). The researcher took two colleagues through her process of analysis explaining how the coding was undertaken, what themes had emerged from the open coding and subsequent axial coding – the first two stages of analysis in a grounded theory process (Strauss and Corbin, 1998; Charmaz, 2006) (see figure 20)

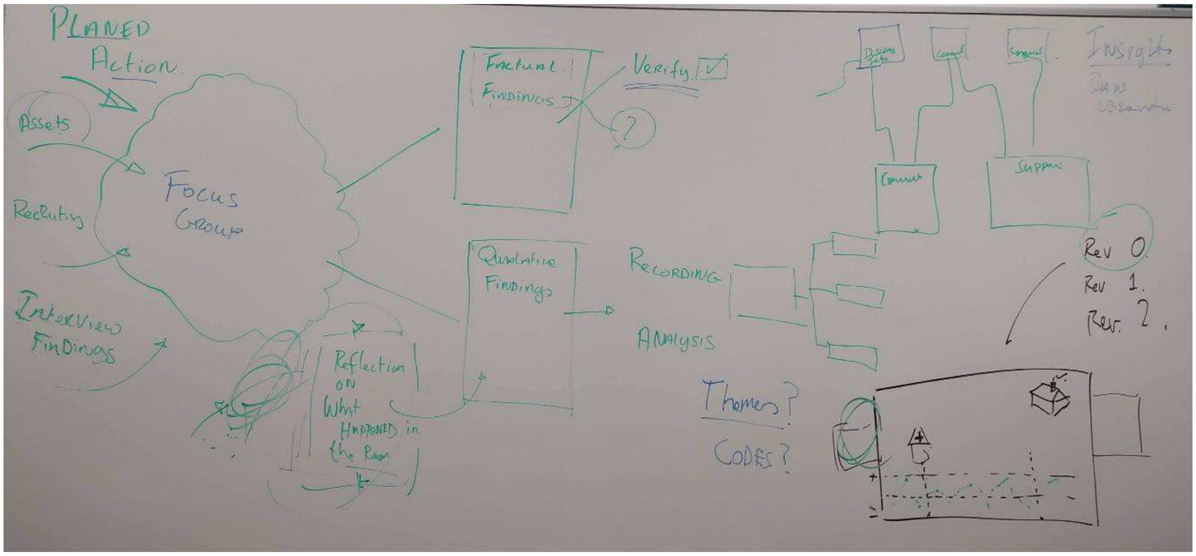


Figure 20 Peer De-brief Session after the Co-Design Session with Older People

. The colleagues asked questions of the process and thinking, argued points raised around the emerging themes and through the process validated the preliminary findings. Subsequently the data was manually compared in Miro^{TM} (a digital whiteboard) to the data from the interviews and uploaded to Nvivo^{TM} (a qualitative data analysis computer software package that helps organize and analyse qualitative data) for further comparison. Similar themes that emerged informed the third stage of the field research.

3.7.3 Stakeholders' Co-production Workshop and Feedback Session

The stakeholders' co-production workshop was the third stage of the primary research process. It was held to facilitate a discussion amongst all the stakeholders on the findings from the interview and co-design session with older people. A particular emphasis was placed on community and how working with the community in which one resides and, the community and voluntary sector would establish a consensus on what is important to enabling older people to age well in place. This phase of the research was important to validate the findings of the previous two stages.

3.7.3.1 Recruitment

All those who had engaged in the interview and co-design session were invited to attend. In addition, invitations were issued to GPs, community development organisations, and managers of supported living accommodation for older people within Kilkenny. As the community element of the Living Well at Home piece of ICPOP was seen as important in the findings from the two previous engagements it was deemed important to hear the voice of those involved in community development in Kilkenny. Furthermore, the stakeholders workshop needed to be balanced in terms of participants from each cohort so that existing power imbalances were not unintentionally being reinforced (Osborne *et al,* 2016). There were nine participants on the day (see Table 2) and all were resident in or working in County Kilkenny. Despite numerous attempts to get the participation of GPs and consultant geriatricians we were unsuccessful. This was a limitation to the process as both GPs and geriatricians are an important aspect to the roll out of ICPOP. The preliminary findings were emailed to GP representatives and a geriatrician who had engaged with the interview process to ask for feedback in order to include their voices.

Clinicians	two participants 3 participants in the feedback session	four participants	Older People
Community Development Worker & Supported Accommodation Management	two participants	one participant	Advocacy Agency

Table 2 Participants in the Stakeholders' Co-Production Workshop

The preliminary findings were also sent to a member of the Health Promotion Unit with responsibility for older people and to the research lead for health and wellbeing in Kilkenny, who had expressed an interest in feeding back as they couldn't attend the workshop. A feedback session was held with three of those who had expressed an interest in contributing to the process – a member of the health promotion unit in Kilkenny with a particular interest in older people, a lead on the role out of ICPOP in Kilkenny/Carlow and the research lead for health and wellbeing in Kilkenny. This was conducted over Microsoft Teams^{TM}, manually transcribed, themes exacted and compared to the themes that emerged from co-design session. This process expanded on and validated the findings not just from the workshop but also the interviews and co-design session.

3.7.3.2 Rationale

The stakeholders' co-production workshop had been organised to take place in November 2021 a week after the co-design session with older people, however, due to Covid-19 restrictions it was postponed until March 2022. It was felt that participants would be more comfortable with a face-to-face meeting and a more robust discussion would take place if it was held in person rather than online via white board software (Smithson, 2000). The same rationale underpinning the decision to hold a co-design session with older people also underpinned the stakeholders' co-production workshop.

3.7.3.3 Venue, Layout and Tools Used

The venue was in Kilkenny City with easy access by all stakeholders. Tea and coffee was available as participants arrived. With restrictions lifted participants were able to chat with one another prior to formal introductions and an explanation of the workshop itself. It was important to make sure participants were comfortable and at ease with the set up so a short discussion took place as to whether masks should be worn. The room was spacious and well ventilated. The participants were split into two groups with a balance achieved between disciplines. Butcher paper was used for the participants to hang their post it comments on as it is made from recycled paper and can itself be recycled. It is lightweight and on a roll that can be easily attached to the wall with masking tape enabling trouble free removal. Having the post-its at eye level and in sequence assisted in feedback to the room allowing all participants to easily hear and engage in the discussion. Post-its and pens were on each table along with a copy of the ICPOP service pathway with emphasis placed on the 'Living Well at Home' piece. It was important to acknowledge that everyone's contribution was important and valid -there was no right or wrong answer to the questions being posed, the discussion process and listening to everyone's opinion was what was important.

3.7.3.4 Questions to be Answered

1. What does community mean to you – professionally and personally?
2. What is needed in Kilkenny to enable older people to live well at home?

Working in groups the first part of the workshop was a discussion on what community meant to the participants both from a professional and personal perspective. Community is a contested concept (Cohen, 1985) with communities being variously described as geographical, of interest, of practice and professional, amongst others (Smith, 2001; Wenger, 2006). Community had been mentioned in both the interviews and co-design session with older people as important to enabling people to age well at home. However, community to a healthcare professional may mean how they work in a community healthcare setting whereas to the older person it is where they live. Language and the standardisation of words used and their meaning across and between healthcare disciplines and in conversation with older people was a finding from the previous research processes. It was important, therefore, for the stakeholders' co-production workshop to have a common understanding of what is meant by community.

The second part of the workshop was a discussion guided by the 'Living Well at Home' piece of ICPOP of which community-based supports and services are a part of. The discussion was on what is needed in Kilkenny to enable older people to age well at home and alleviate pressure on the acute system. Each group was asked to nominate a scribe who undertook to record on post-its what was being said and attach them to the butchers paper. However, each group stayed at their table and didn't gather at the butcher paper as was envisaged by the facilitators. To accommodate easy feedback and engagement in the discussion, the facilitator gathered the post-its and attached them to the butchers paper (see figure 21).

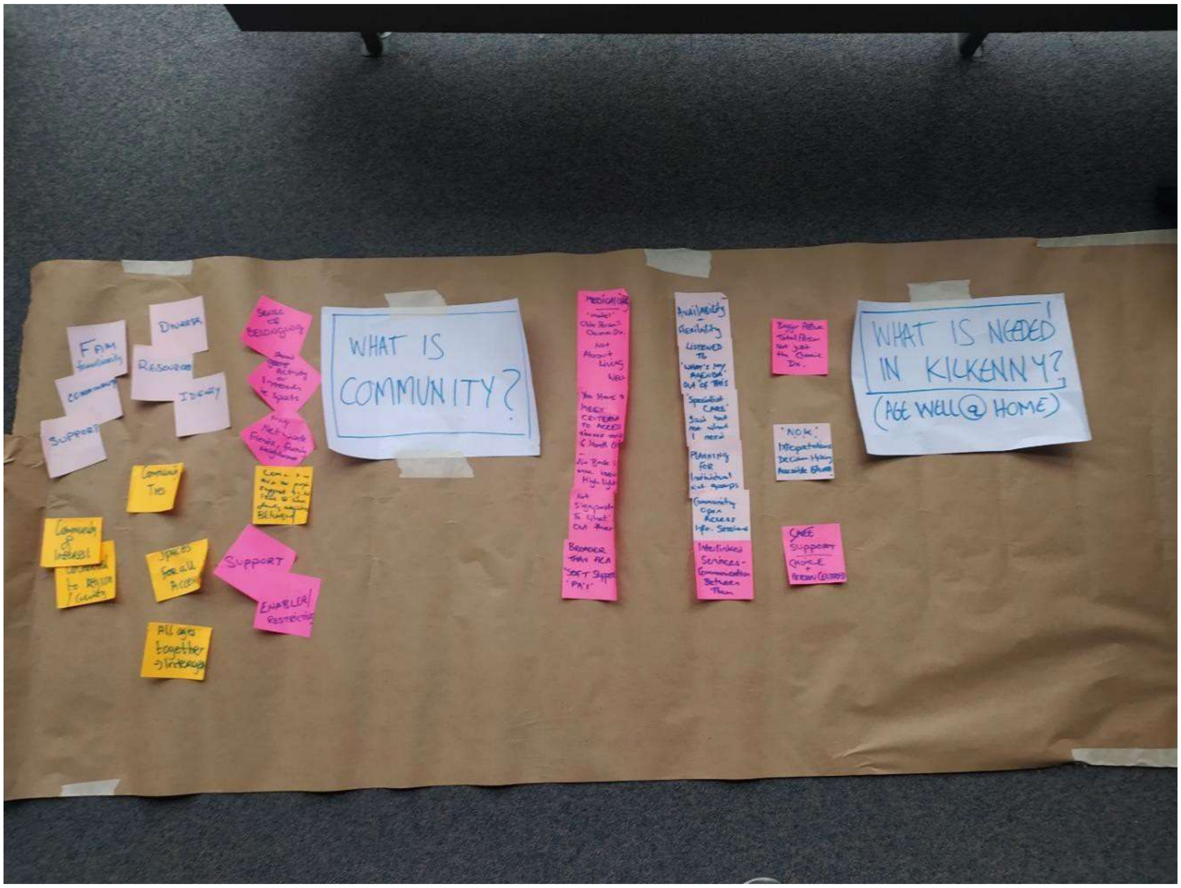
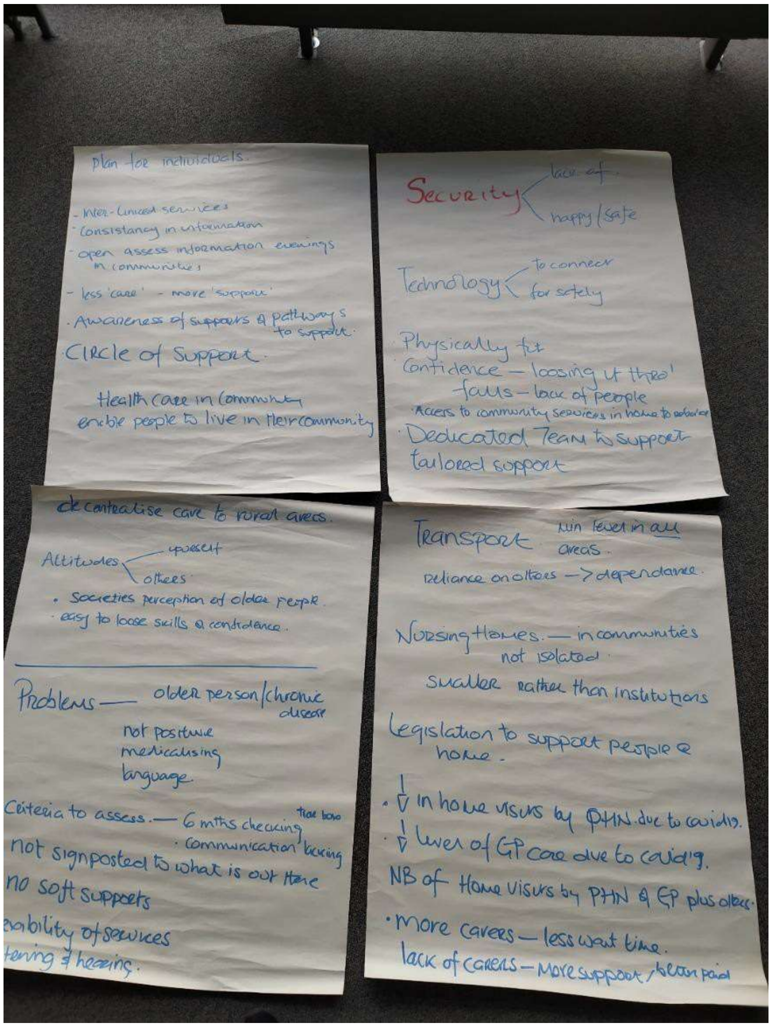


Figure 21 Data from the Stakeholders' Co-Production Workshop

As with the older persons co-design session it was important that the researcher is prepared to change how the workshop is delivered by allowing the participants to lead the discussion and use the props given to them as they wish (Fitzpatrick, 2016). Participants fed back after the first question on community so that there was a consensus on how community was perceived. This was important for the second question as the Living Well at Home piece of ICPOP (see figure 16) mentions community supports and services in enabling people to age well in place. The appointed scribe fed back to the main group summing up in succinct phrases what the group believed was important to enabling people to age well in place. The penultimate stage of the stakeholders' co-production workshop was a discussion with all participants on what had emerged from the process, coming to an agreed consensus on what was most important. For the final part each participant summed up in one sentence what they had taken from the afternoon. All feedback was recorded by the facilitator on a flipchart. (see figures 22 and23)



plan for individuals.

- inter-linked services
- consistancy in information
- open assess information evenings
in communities
- less 'care' - more 'support'
. Awareness of supports & pathways
to support.
. Circle of Support.

Health care in community
enable people to live in their community

de centralise care to rural areas.

Attitudes — upsetf
— others.
• Societies perception of older people.
· easy to loose skills & confidence.

Problems — older person/chronic
disease
not positive
medicalising
language.

Criteria to assess. — 6 mths checking
· communication
time box
lacking
not signposted to what is out there
no soft supports
ability of services
tening & hearing.

Security — lack of.
— happy / safe

Technology — to connect
— for safety

Physically fit
Confidence — loosing it thro'
falls — lack of people
· Access to community services in home to avoid or
· Dedicated Team to support
tailored support

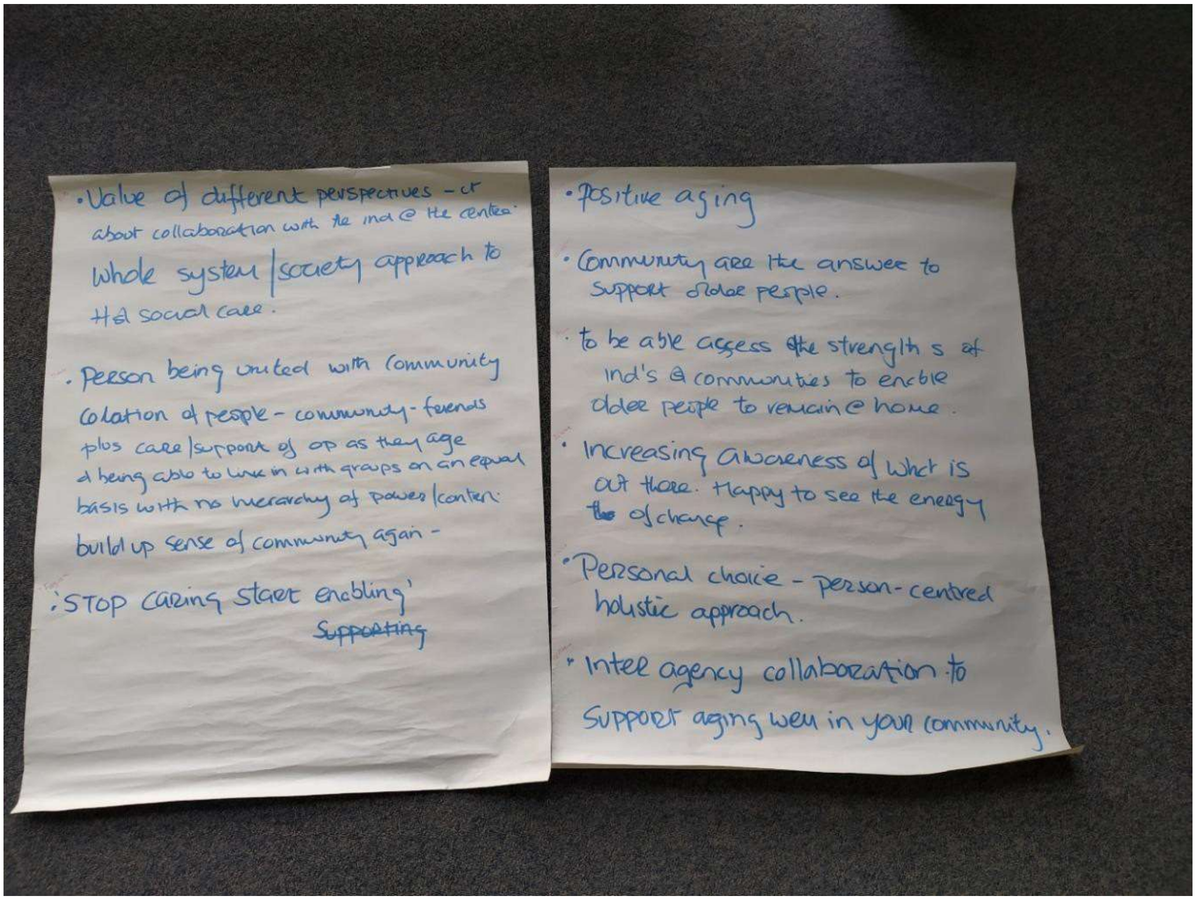
Transport — min level in all
areas.
reliance on others -> dependance.

Nursing Homes. — in communities
not isolated.
smaller rather than institutions

Legislation to support people @
home.

• ↓ in home visits by PHN. due to covid19.
· ↓ level of GP care due to covid'19.
NB of Home visits by PHN & GP plus others.
• More carers — less wait time.
lack of carers — More support / better paid

Figure 22 Consensus on what was most important by participants at the Stakeholders' Co-Production Workshop



- Value of different perspectives – it about collaboration with the ind @ the centre.
Whole system | society approach to H&social care.
- Person being united with community
Isolation of people – community – friends plus care | support of op as they age & being able to link in with groups on an equal basis with no hierarchy of power | control.
build up sense of community again –
- 'STOP caring start enabling'
~~Supporting~~

- Positive aging
- Community are the answer to support older people.
- to be able assess ~~the~~ strengths of ind's & communities to enable older people to remain @ home.
- Increasing awareness of what is out there. Happy to see the energy ~~the~~ of change.
- Personal choice – person-centred holistic approach.
- Inter agency collaboration to support aging well in your community.

Figure 23 Take Home Message from each participant at the Stakeholders' Co-Production Workshop

In addition, during both parts of the workshop the facilitators listened carefully to the groups and documented what was being said on post-its, adding to the data gathered. After an initial first analysis of the data from the workshop, preliminary findings were extracted, and a feedback session was held online through video conferencing software with three clinicians. The session was recorded with participants permission and five minutes discussion was given for each preliminary finding. It was uploaded to Nvivo^{TM} and manually transcribed providing further validation of the themes that had emerged from the field research.

3.7.3.5 Methods of Analysis

A journal entry was made on the completion of the stakeholders' co-production workshop and again after the feedback session. These entries recorded the researchers immediate thoughts and feelings on how both had gone and what could have been done better while also documenting initial thoughts on the themes that may emerge from the data. Data from both groups in the workshop and the flipcharts were transcribed verbatim into a Word™ document. Using coloured pens the data were analysed for similarities and themes extracted. The feedback session was uploaded to Nvivo™ and transcribed manually to gain an insight into the context of what was said. The transcription was printed and using coloured pens analysed for themes and quotes extracted. The emerging themes from the workshop were compared to those emerging from the feedback session. Through theoretical sampling and comparison an in depth understanding of perspectives from both the workshop and feedback session emerged. A peer debrief session was held to clarify the methods used for data analysis and to compare themes over all stages of the research process (see figure 24)

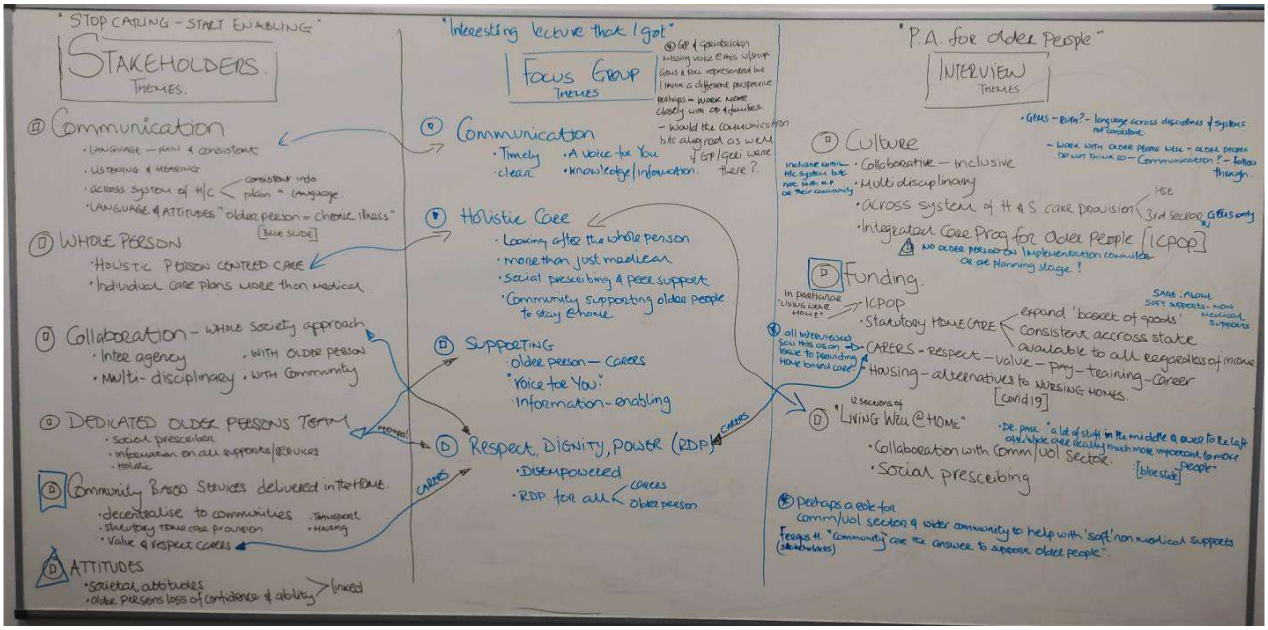


Figure 24 Peer Debrief Session on the Three Stages of Data Analysis

3.8 RtD Framework Development

Throughout the field research notes were made in the journal on the process of RtD. It was important to document what had gone well and what required re-working in order to extract findings from the process on how RtD uses co-design methods and develop a framework.

3.9 Ethical Considerations

An application to the ethics committee of The Institute of Technology Carlow was submitted prior to the commencement of the field research. As the research involved engaging with older people who are considered a vulnerable population consideration on how to keep them safe during the Covid-19 pandemic was paramount. This involved additional safety precautions to be in place for both the co-design session with the older people themselves and the stakeholders' co-production workshops. The interviews were conducted online through Teams^{TM}, recorded and uploaded to One Drive where they will remain in line with IT Carlow and GDPR guidelines for five years after the awarding of the degree and then destroyed. As participants can be identified the recordings cannot be used for any future research. However, due to the anonymised nature of the data from the co-design session and workshop these maybe used to inform future research with consent from the orginial participants. A copy of the ethics application, the consent forms for the interviews, the co-design session and stakeholders' co-production workshop are in Appendix One.

3.10 Conclusion

The researcher takes the view that as relational connected beings humans actively construct their reality from interaction with others. A RtD approach to the field research fitted well with this view engaging with and listening to stakeholders through a co-design session and a stakeholders' co-production workshop. The research took place in three stages – stage one through interviews with clinicians and advocates of older people to gain an understanding of how healthcare is being delivered to older people both nationally and at a local level. This informed a co-design session with older people and a co-production workshop with all stakeholders. Grounded Theory was used to explore and examine the data gathered.

The next chapter will discuss the process engaged with over the three stages of the field research and outline the findings that emerged from the process.

4.0 Chapter Four – Discussion and Findings

4.1 Introduction

The previous chapter discussed the methodologies underpinning the analysis of the data and the methods used to analyse the data gathered from the field research. This chapter discusses the themes that emerged from each stage and how it informed the process in the following stage. In addition, it compares the findings from all stages and extracts common themes which are then discussed to find the 'collective voice' that emerges from the research data (Smithson, 2000).

The field research was organised into three stages.

1. Semi structured interviews with clinicians involved in healthcare delivery for older people and representatives of third sector advocacy agencies. This initial stage was conducted to gain an understanding of how healthcare is delivered for older people at all levels, primary, community and acute, nationally and locally, and to ascertain if or how ICPOP will change that delivery from a clinician's perspective.
2. A co-design session with older people themselves to listen to their experience of healthcare delivery both from a personal perspective and that of an informal carer for a loved one and how it addresses their needs and concerns.
3. A stakeholders' co-production workshop involving all those engaged with the previous stages plus representatives from other cohorts pertinent to the process. Due to the absence of participants from a clinical background an on-line feedback session was held with three people from a clinical background who were unable to attend and wished to contribute. The feedback session was held online and discussed the preliminary findings from the stakeholders' co-production workshop.

4.2 Interview - Discussion of Data Analysis

From the extensive analysis of the data as outlined in the methodology chapter (see page 52) the main concept that emerged from the analysis of the data was the lack of supports required to enable older people to age well at home. In addition, the data suggested that funding of the 'Living Well at Home' part of ICPOP which would facilitate the provision of those supports was missing. There were three main themes that emerged (see figure 25) which are explored in detail below.

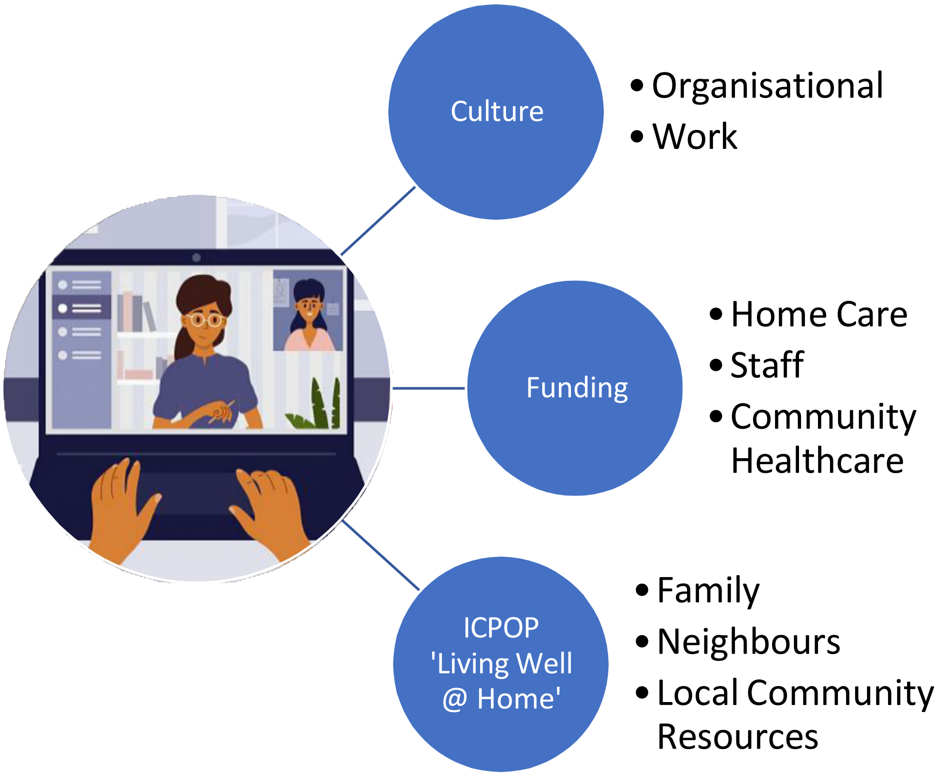


Figure 25 Themes from the Stage One of the Field Research - Interview Stage

4.2.1 Culture

Changing how healthcare is delivered in Ireland requires a change of culture within the system (HSE, 2018). ICPOP is built on a foundation of collaboration and inclusiveness (ICPOP Steering Group, 2017) which is a progressive step in changing how healthcare is delivered to older people. This culture of collaboration and inclusiveness has been evident in Carlow Kilkenny for over forty years. The Carlow Kilkenny Clinical Society (CKCS) established in the 1970s, started as a group of hospital consultants and General Practitioners (GPs). It has evolved over the years from an informal ad hoc group that *'used to meet each another over a sandwich in the hospital'* (George) to one of multi-disciplinary professionals in acute, primary and community healthcare provision in the catchment area of the local hospital St Luke's, collaborating on innovative practices to improve healthcare delivery and outcomes.

The ICPOP ten-step framework clearly sets out a model of care to be applied by each local implementation committee allowing the needs of the local population to be taken into account, enabling flexibility and innovation to be part of the process - *'we have a certain amount of freedom to work on what we already have, but there is a very clear end point'* (Patrick). An example of the HSE enabling innovation at local level was their funding of an original idea of assessment for the older person on presentation at St Luke's Emergency Department. The Geriatric Emergency Medicine Service (GEMS) has been facilitated by an organisational culture within St Luke's that encourages staff to be innovative and collaborative in their work. GEMS identifies, at admission, older people who are frail or pre-frail and puts in place a case manager to oversee their stay in hospital and their discharge. The collaborative process encompassing hospital staff and outside agencies relevant to the patients recovery and discharge required the GEMS team to build trust amongst the multi-disciplinary teams involved. Scaling up of this project to other hospitals by ICPOP is another example of the change of organisational culture within the HSE. Although not called GEMS but Frail Intervention Therapy Teams (FITT) the other pioneer sites have used the GEMS template to screen older people for frailty at admission and put in place case managers to oversee their stay and discharge. *'The GEMS service in Lukes is almost like the template that other frailty teams learnt from'* (Marie).

Co-production and co-design is based on trusting, reciprocal relationships (Adam and Donelson, 2020). It is clear from the data that, although not acknowledged or indeed understood by the interviewees themselves, co-production is practiced within the healthcare services in the Carlow Kilkenny catchment area. *'We don't feel or recognise it (the work) as that (co-production). But that is good to know'* (Patrick). As part of co-production in practice the involvement of all stakeholders is paramount. Including the voice of the older person and the general practitioner on the implementation committee of the ICPOP in each area is set out in the rules and regulations underpinning the programme. Patrick acknowledges that the older person has so far not been included and on reflection he admits that they should have been, *'I'm kind of listening to myself talking and thinking maybe we should have got them involved a bit earlier'.* While there are ongoing negotiations with the GPs to find a way to include them within their busy schedules, there is yet to be an engagement with older people and their organisations. Several interviewees have said that it is difficult to get the older person to engage at this level - *'I appreciate it can be hard to reach older people, get them to participate'* (Connie). However, the general consensus is that it is necessary for the implementation of ICPOP that a way is found to empower the older person to become involved.

4.2.2 Funding

The Health Service Executive through the National Clinical and Integrated Care Programme have put *'huge resources'* (Patrick) into rolling out ICPOP. Prior to the Covid-19 pandemic funding was provided for innovative pilot projects, and for the establishment of ambulatory hubs to assess and treat older patients in order to avoid hospital admission. Due to the disproportionate impact on our older population from Covid-19, in terms of the number of deaths, (Lima, 2021) and the understanding that as a society we need to put in place better care for our ageing population, the roll out of ICPOP and its funding has accelerated.

Covid-19 has also shown the inappropriateness and dangers of communal living for vulnerable populations (HIQA, 2020). One of the fundamental objectives of ICPOP is to keep the older person out of the acute hospital system and enable them to age well at home (ICPOP Steering Group, 2017). When discharged from hospital requiring support there are in general two options available to the older person - home with home care supports that are provided free, or long-term care in a nursing home funded through the Nursing Home Support Scheme known as the Fair Deal Scheme. A third option are community homes or supported care homes, however, if returning to live in a community home, the older person needs to be able to live independently. Should they require home care support they will need to be admitted to a nursing home – *'people in a supported living environment when they come to need a homecare package they now need to go into a nursing home'* (Connie). Implementation of Statutory Home Care provision has been delayed due to Covid-19 (Walsh and Lyons, 2021) and there is unease amongst the interviewees around how it will be delivered. A lack of carers in the system is pointed out by numerous participants as a barrier to implementation. Rachels contention that it seems to be an *'eircode lotto'* for homecare in some places is supported by Smith *et al* (2019). The level of pay, the career pathway and the education and training of carers needs to be examined so that there is standardisation of training and an understanding of the rights of the older person in directing their own care, such as the provisions made within the Decision-Making Capacity Act 2015 - *'there needs to be training for homecare providers probably across the board, including voluntary programmes'* (Anthony). At State level, there is a requirement for an appreciation of the work that carers provide to make it a valuable and well-paid career path for people to aspire too - *'it's probably not an attractive career for people to go into and stay in for any length of time'* (Connie).

It is clear from the data that there is no standardisation of care across the country, different supports and services are offered depending on where in the country an older person lives and even between providers. HSE staff are prohibited from providing support to their clients that requires handling money. However, some private suppliers provide this service. While Walsh and Lyons (2021, p.3) suggest that the aim of statutory homecare provision 'is to ensure that cost is not a barrier to accessing services', how it will be funded is still being researched by the Economic and Social Research Institute (ESRI) and some form of contribution may be necessary from the older person. The Home Care Coalition, of which ALONE is a member, suggests that

> *'it should only take some form of co-payment if it leaves the older person with an adequate level of income so that they are not at risk of poverty'* (Anthony).

The *'basket of goods'* (Anthony) provided by homecare support needs to be expanded to include softer supports and standardised across the country. Connie suggests a *'PA for Older People'* is required to provide supports such as help with shopping, cooking, socialising and finances, amongst others. It is the Community and Voluntary sector that provide many of those softer supports. It was very clear during the pandemic that they are an essential part of how services are delivered. The HSE acknowledge this through the inclusion of the community and voluntary sector as a partner in the 'Living Well at Home' piece of ICPOP. It is clear from the data that it is this part of the programme that all agree requires funding.

4.2.3 Living Well at Home

ICPOP outline twelve 'Living Well at Home' supports that they see as being required for the older person to age well at home (see figure 15). These twelve categories do not stand alone but are part of ICPOP along with primary care, the ambulatory hubs and acute hospital care. The data indicates that this piece is seen as vitally important in enabling the older person to remain healthy, out of the acute hospital system and at home for longer –

> *'a lot of the stuff in the middle and over to the left of the slide are really much more important to more people'* (Patrick).

This assumption is corroborated by the four goals of the National Positive Ageing Strategy (DOH, 2013) whose objective is to support people as they age 'enabling them to age with confidence, security and dignity in their own homes' (p.19). The strategy mentions some of the supports outlined in the living well at home piece of ICPOP including transport, housing and the promotion of physical and mental wellbeing through engagement with local community (DOH, 2013). These supports are being delivered by local community and voluntary organisations under the Healthy Ireland framework (DOH, 2013) and the local Age Friendly strategy (KKCC, 2017) and, supported by Kilkenny County Council and local community development enterprise, Kilkenny LEADER Partnership (KLP). It is the development of those supports not already in train and the integration of all twelve into ICPOP evenly across the county, that the data indicates is missing.

4.3 Co-Design Session with Older People - Discussion of Data Analysis

Four themes emerged from the process of analysing the data from the Co-Design Session with Older People (see figure 26)

Figure 26 Themes from the Co-Design Session with Older People

4.3.1 Communicating

Communication is more than just language used and words spoken (Harvey, 2006). It is, therefore, important for those in a position of authority or power to communicate effectively and respectfully to those in a vulnerable position (Shanahan, 2020). From the analysis of the data from the co-design session it is clear that for the participants communication is important at all stages of the journey from acute hospital care to home. For them how information is given, to whom and when are all important - *'timely communication'* – *'clear directions'* – *'more information on stages (of discharge)',* and *'need(ing) knowledge'* are mentioned. While Harvey (2006) attests that listening is a large part of communication the older person feels they are not listened too. *'The need to be heard'* – *'no time to listen'* – *''a voice for YOU'* – are statements that are repeated by the participants at all stages of the journey from hospital to home.

Power and trust are important in the delivery of healthcare (Tronto, 2013; Adam and Donselson, 2020). Regardless of their ability or status ill people feel vulnerable and less powerful than those delivering care (Joseph Williams *et al,* 2014). There is a perception that as a patient you do not ask questions or disagree with a clinician as by doing so you become 'difficult' (Frosch *et al,* 2012; Joseph Williams *et al,* 2014). Participants spoke of the *'need to ask questions'* but of being *'afraid to ask questions'*. Comparison with data from the practitioners' interviews shows that the clinicians see communication as good pre-discharge and at discharge. The GEMS team say that they *'link in with the patients, the families'* and that *'they work closely with the discharge planner, the public health nurse….the community'*. SAGE also speak of good communication and liaison between GEMS, the discharge planner and the older person. However, the data from the co-design session would suggest a disconnect between the older persons lived experience of the system and the practitioners' perspective that there is adequate communication pre and at discharge.

Participants also spoke of the lack of good communication post discharge. Clinicians were seen as *'elusive'*. One participant spoke of *'the good lecture'* she had received. Families have problems preparing home for discharge and did not seem to have any information on supports and funding that they could access to help. Those living alone were at a greater disadvantage as they may not have anyone to prepare their home for discharge. The older person feels that discharge planners need to understand that discharge is more than medical having *'a carton of milk in the house'* is as important as medication.

4.3.2 Supporting

The data shows that in hospital the older person feels they are not supported in any meaningful way to make decisions about their discharge and subsequent care which is at odds with the perception of the clinicians and SAGE. From the interview data we can see that GEMS provide support to the older person in hospital pre and at discharge, putting a plan in place with the input of the MDT, SAGE (if required), the older person and their family, and the discharge planner. However, data from the co-design session suggests that nursing home is considered first and foremost and that going home is secondary - *'easier to use (a) nursing home than home'*. 'An advocate in hospital' is considered essential to assist in putting forward the older persons wishes, a *'designated listener'*, perhaps *'someone other than next of kin'* nominated by themselves to ensure a *'voice for the patient'*. The data implies that supporting families in *'organising home for discharge'* is not in place - *'sent home without anybody', 'families have problems preparing home'*. However, the clinicians understand that it is –

> *'so it's case by case what you will need to get that person where they want to be with the support that they require.'* (Rachel)

The clinicians, the third sector organisations and the older people themselves agree that there are not enough carers in the system to provide adequate care to all those that need it and that those already in the system require support and training to do their jobs properly. Data from the co-design session suggest that support and training should also be extended to family carers- *'training for both family and professional carers - in (the) use of equipment'*. Furthermore, they suggest that as each patient is different a package of care suited to their needs is required - *'fit packages to people'* while remembering that *'discharge is more than just medical'*. This view is supported by SAGE and ALONE when they suggest that *'the basket of goods'* available is not broad enough to enable the older person to remain at home. Supports that are more than medical, what Connie from SAGE refers to as a *'PA for older persons'* enabling them to do everyday chores such as shopping and banking and also socialising *'that would actually allow someone to live very independently at home'* (Connie).

A *'services first aid box'* and /or a *'directory of integrated services'* for use by both the older person themselves and those that care for them were also suggested. *'Social prescribing'* and *'peer support'* is important for the older person to enable them to live with a chronic illness or come to terms with a diagnosis. *'Personal recovery'* is as important as physical and that *'a way to measure how you are doing'* or *'a measurement of progress'* through a *'dedicated social prescribing team'* for older people or/and a *'peer support hub'* was suggested. Community supports such as a *'neighbourhood watch'* for older residents, *'transport to the community centre', 'encouraging community gatherings'* that are neither *'pub not pope'* and creating *'new rituals to support community'* post-Covid-19 should be considered. The idea that community supports are important reflects the 'Living Well at Home' piece of ICPOP that Patrick suggests *'are really much more important to more people'* than the medical side of ICPOP.

4.3.3 Dignity, Respect, Power

Person-centred care is a core commitment in HSE policy documents and in Sláintecare itself (HSE, 2018; 2021; Committee on the Future of Healthcare, 2017; DOH, 2018; HIQA, 2021). McCormack and McCance (2017) include the family and those delivering care in their definition of person-centredness which the HSE envisage being part of how ICPOP is delivered (DOH, 2018). This affords dignity and respect to all through shared power and decision-making (McCormack and McCance, 2017).

The participants spoke of being *'disempowered', 'afraid to ask questions',* affording *'deference to medical staff'*. They had a *'fear of voicing concerns'* and *'fear around discharge'*. They mentioned *'needing knowledge'* and *'timely communication'* and *'involving families'* or a *'designated person'* in discussions. All these quotes speak to a lack of dignity and respect for the older person. They also articulate the unacknowledged power that healthcare practitioners have over those requiring their care (Frosch *et al,* 2012; Tronto, 2013). It is clear from the data that older people feel disrespected and disempowered in their illness. While the clinicians recognise that the older persons voice needs to be more involved in the design of service delivery through ICPOP the data suggests that the voice of the older person is not adequately heard or listened in the delivery of healthcare.

Moreover, the data indicates that dignity and respect is not afforded to professional carers either. The participants indicate that training is inadequate - *'skill shortages in carers'*, *'staff need good training'* and that carers are not paid sufficiently - *'staff need a good wage', 'carers are not paid enough'*. Continuity of carers is also mentioned as a lack of dignity and respect towards professional and family carers and the older person – *'continuity of carers, dignity and respect for both'– 'felt alone in family support', 'training on equipment'* for *'the safety and dignity of the person being cared for'.* Osbourne *et al*, (2015, p. 4) say that reducing staff costs through a reduction in numbers or qualification of the employee, 'can reduce the quality of the service which ultimately undermines its sustainability'. It is clear from the data that professional carers are in short supply and are not adequately trained. While Osbourne *et al* (2015) speak of a planned reduction in numbers to reduce costs, the data here suggests it is an absence of career development, wages commensurate with the work being undertaken and a lack of value placed on caring in the home that is at the heart of a shortage of staff.

4.3.4 Holistic Person-centred Care

'We are not just physical beings' speaks to the concept of human beings as relational, connected and interdependent (Buetow *et al* 2016; Larson *et al* 2019). The participants were clear that healthcare is more than just medical – *'discharge is more than medical', 'personal recovery versus medical', 'looking after the whole person', 'social prescribing (is) important'.* SAGE and ALONE along with the GEMS team agree that supports other than medical are important to enable the older person to remain and be cared for at home. Holistic care also looks beyond supporting the person at the centre of care to supporting family carers to alleviate the financial and emotional stress that comes with caring for a loved one – *'felt alone in family support', 'pressure on families', 'causes conflict in families', 'saps the energy from you'.* It is clear from the data that care must be viewed as holistic, caring for the whole person medically, emotionally, spiritually and personally.

4.4 Stakeholders' Co-production Workshop and Feedback Session – Discussion of Data Analysis

In this workshop two questions were asked of the participants. The first question 'what is community?' was important to the second question - what is required in Kilkenny to enable older people to age well in place? A collective understanding on the meaning of community was essential to get a consensus on what supports and services would enable people to age well at home. Using the emerging themes from the preliminary analysis of the data a feedback session was convened with three people who wished to be involved in the process but were unable to attend the workshop. This session validated the findings not just from the stakeholders' co-production workshop but also from the other stages of the field research. The themes that emerged from both processes are discussed and compared to the findings from the previous stages of research (see figure 28).

Figure 27 Themes from the Stakeholders' Co-Production Workshop

4.4.1 Question 1: What is Community?

The discussion on what community meant to the participants centred on community in a personal capacity - *'a sense of belonging'* - *'my network – family, friends, neighbours'* – *'familiarity'* - *'community as a choice'*. Community was seen as being *'connected to others'* and *'volunteering' with 'all ages together'* along with the cultural diversity of *'new communities of immigrants'*. The participants also felt that communities had *'declined'* and that this had led to *'isolation'* with the loss of local, easily accessible amenities and *'young* *people leaving'* particularly rural areas. However, the onset of the Covid-19 pandemic and the subsequent restrictions rekindled *'community spirit'* and an increase in *'volunteerism'*.

4.4.2 Question 2: What Kilkenny Needs?

4.4.2.1 Communicating and Collaborating

Older people see how information is communicated to them as problematic (HSE and Age Friendly Ireland, 2015). The data from the co-design session is supported by the stakeholders' co-production workshop data that suggests a lack of communication with older people and their family/informal carers of supports tailored specific to their needs and requirements. As in the co-design session an older persons *'dedicated team'* was suggested to signpost what is available particularly from a social aspect to *'support (the) independence of older people'* and encourage a *'positive mindset'* so that they can *'stay interested in life'*. The *'medicalised'* model of care is outdated and a more *'social model'* is necessary to enable people to age well at home.

A *'directory of services'* was suggested by participants in the co-design session, the stakeholders' co-production workshop and in the feedback session as a means for both the clinicians and older person to be informed of what is available to support and enable people to stay living in their communities from both a medical and social perspective. However, funding to resource the compiling and *'continuous updating'* of such a directory was important to keep it relevant and useful (stakeholders' co-production workshop). As with the co-design session there was an understanding that advocates to accompany older people to appointments was important –

> *'you know there is a signficant piece of understanding in terms of the role of advocates for older people, and the importance of them being part of their care journey'.*

Ageism attitudes in the language used to describe older people and societal attitudes towards them as dependent are seen as *'a barrier'* to older people's engagement in community and as self-fulfilling through a *'loss of confidence'* in ability particular after a fall or bereavement. Post Covid research has also shown a decline in older people's confidence and in their physical and mental health due to the restrictions in place during the pandemic, in particular the effects of 'cocooning' due to the isolation and a lack of connections to others (HIQA, 2020; Oireachtas Committee on Covid-19 Response, 2020; 2020a; Age Alliance, 2021). An example of how language can be ageist, whether intentional or not, is situating the service model for ICPOP and the Integrated Care Programme of those living with Chronic Disease on the same illustration (see figure 16). Equating older people with chronic disease is how this was perceived by participants – *'the medicalisation of old age'*. This led to the question as to whether co-designed with older people or those living with chronic disease was undertaken at the outset which is in line with the model of co-production espoused by the HSE (HSE, 2018; 2019). This lack of consultation and collaboration with those who will use the service seemed not to be considered nor their contribution valued – it was *'not positive towards older people'* - *'I am not a chronic disease'*.

The data from this stage of the process underpins that of the co-design session by indicating that consistency in the information provided and language used across the systems of care was a barrier to communicating effectively with the older person. In addition, this was further validated by data from the feedback session where a *'one pager'* outlining in *'bullet points'* and *'very simple NALA (National Adult Literacy Agency) approved'* language '*what are you going to do for me next'* and where - was suggested as good practice after a clinical consultation. Furthermore, it validates the findings from the service improvement workshops in CHO5 (ICPOP, 2018), examined in the literature review, where effective communication was found to be of vital importance but lacking between the older person and their clinicians.

4.4.2.2 Supporting

Implementing ICPOP will see older people being cared for in their communities and out of the acute hospital system where outcomes for older people are poor (ICPOP, 2018). What the workshop participants would like to see is

> *'care close to home' decentralised 'to rural areas out of the City' where 'healthcare in the community (will) enable people to live in their community'.*

At the feedback session 'M' spoke about ICPOP Kilkenny's vision of a *'hub and spoke style service'* - an older persons hub in Kilkenny City with *'outreach clinics'* across the counties of Carlow and Kilkenny. The main hub with clinical and non-clinical supports is envisaged to be co-located with services accessed by all ages

> *'because if …if we put people into buckets and boxes… then they will stay in them and they won't integrate with people in their community.'*

Participants in both the stakeholders' co-production workshop and feedback session suggest that while integrated care is necessary, the integration and availability of non-medical services are also essential to enable people to age well at home. *'Specialised nonclinical services'* that support *'the person to live the life they want to'* rather than caring for them in a medical way is how the workshop participants envisaged enabling older people to age well at home. This was endorsed both by the feedback session and the co-design session with older people where working collaboratively with other disciplines and, the community and voluntary sector is deemed essential for older person health and social care.

Providing *'a minimum level of transport regardless of where you live in Kilkenny'* is essential to maintaining self-confidence and independence. Building nursing homes in *'communities, not isolated'* on the outskirts of a town or village will 'support older people's continued independence by bringing amenities and transport within reach' (Age Alliance, 2021, p.43). Language around older people 'going into' nursing homes rather than 'going to live' in nursing homes is problematic and reinforces the attitudes towards older people as dependant and non-contributors to society (Age Alliance, 2021, p. 44). The devastating effects of Covid19 on those living within congregated settings are well documented – older people need to be enabled to live independently in their own homes (McGarrigle *et al*, 2020; Age Alliance, 2021; Lima, 2021).

Participants from all stages of the field research suggest that in order to age well at home formal and informal caring that provides for both the clinical needs of the older person and the basic day to day tasks that some may have trouble with is necessary –

> *'so I think that personal care, that basic personal care is the corner stone of supporting people at home' – 'like if I had a disability, I would get a PA but because I'm over 65 I don't'.* (Feedback Session)

The participants see third sector organisations and the community itself as important in providing essential non-medical supports such as social prescribing and that *'community are the answer to supporting people to live in their community.'* Being

> *'able to access the strengths of individuals and communities'* will *'enable older people to remain at home'* however, *'inter-agency collaboration'* is essential *'to support (you) ageing well in your community',* a *'whole system/society approach to health and social care'* is required.

There was a clear understanding from the feedback session that ICPOP is *'still very much in the development stage' and* older people being seen by the ICPOP team are *'getting a different, a more cohesive service'*. The ICPOP team are *'building links'* across all disciplines involved with the care of the older person and links with community and voluntary organisations to deliver non-medical supports are being commenced –

> *'an example of a piece of work collaborating between voluntary and clinical side is that the social prescriber in Kilkenny is going to have a clinical space to see clients in Newpark Primary Care Centre once a week'*.

4.4.2.3 Respect, Dignity, Power

The lack of respect for formal and informal carers and the lack of value placed on caring in general was to the fore in this workshop as it was in both the interview process and the co-design session. Funding to increase the numbers of those providing homecare support, sufficient training, good career development and pay commensurate with the work were all raised and discussed again. Home care support services were seen as *'antiquated'* and in need of *'huge money'* and *'huge time put into developing'* them. The requirement from State sources to *'value'* carers and put in place a *'progression route for them – so they don't come into a dead-end job'* supported the consensus from the co-design focus group and interview process. 'M' suggests that there has been *'no workforce planning in relation to home support'* services. In line will findings from the earlier stages of the research process they argue that there needs to be more carers as

> *'the time allocated to each person is so short it puts carers under pressure'* and *'they're on the road constantly trying to get to the next call'*.(Feedback Session)

In addition, training carers to *'promote independence'* so that there is a *'reablement element to home support'* is important so that older people can live at home. However, it is also suggested that *'a more sophisticated system'* to assess needs and allocate services according to those needs is required.

Valuing, respecting and supporting the informal or family carers is as important and reenforced the findings from co-design focus group. As we have seen ageism and how older people are viewed and treated are seen by participants as problematic and goes to a lack of respect. The lack of good, timely information and communication with older people and a lack of collaboration in the planning and development stages of ICPOP or other services can also be viewed as power over rather than power with older people (Labonte, 2010; ICPOP, 2018). Co-produced person-centred care is embedded in HSE policy (HSE, 2018; 2019) and as the data suggests should be incorporated into all levels of healthcare and across all organisations involved in the delivery of health and social care. Not to do so indicates a lack of respect.

4.4.2.4 Holistic Person-centred Care

It is clear from the data that holistic person-centred care as envisaged by McCormack and McCance (2017) is required to enable older people to age well in place – *'total person - not just the chronic disease – the bigger picture'*. *'A circle of support'* is suggested for the older person themselves, their family/carers, those that provide clinical care, third sector organisations that advocate for older people and the wider community itself to support, care and enable older people to age well in place.

4.5 Universal Understanding of Person-Centred Care

Person-centred care is embedded in HSE policy (DOH, 2019; HSE, 2021) and ICPOP (ICPOP, 2018), however, the data indicates that there is no universal understanding of what is meant by person centred care. As person-centred integrated care is being implemented across the health and social care systems in Ireland (DOH, 2019; HSE, 2021) it is imperative that this is addressed. A brief look at the modules delivered to nursing undergraduates would suggest that person-centred care is not taught as a standalone module at any stage of the course (University College Dublin, 2022; Waterford Institute of Technology, 2022). As Tresolini and Pew-Fetzer, (1994) suggest person-centred care should be included for all undergraduate education across all medical and social care disciplines in order to have a universal definition and understanding of what is required.

4.6 Conclusion

The 'collective voice' that emerged from the data gathered over three stages of primary research indicate that communication, support, respect, dignity and power, and holistic person-centred care are the important aspects to enabling older people to age well in place (see figure 27). However, it is also clear from the data that an organisational culture that values innovation and collaboration is required to facilitate the implementation of ICPOP . Furthermore, while the data indicates that ICPOP has been well resourced in the pioneer sites before and subsequent to Covid-19(ICPOP, 2022; Lima, 2021, HSE, 2022) there is a need for further funding for homecare supports and the Living Well at Home piece of ICPOP.

4.6.1 Communicating:

Communication is vitally important to the provision of good health and social care. However, while clinicians feel that communication is good within the acute system the observation of the older person and clinicians at community level is that relevant, timely information in accessible, easily understood language is lacking. Furthermore, advocates, appointed by the older person themselves, are important for communication and for shared decision-making around their treatment and care.

4.6.2 Supporting

Involving third sector organisations and the community itself in the delivery of non-medical supports is included in the Living Well at Home piece of ICPOP and emerges from the data as an important aspect to enabling people to age well in place.

4.6.3 Respect, Dignity and Power

The data suggests that respect is lacking towards those receiving and delivering care and that power relations at play disempower both the older person and their carers. Viewing those receiving care holistically, requiring supports and services that are more than just medical, is a mainstay of person-centred care. As important is shared decision making with all those involved in the delivery and receipt of health and social care. The lack of formal carers stems, the data suggests, from poor workforce management and the lack of value and respect for the job of caring through poor pay, poor training and poor career progression. This lack of respect and dignity extends to informal or family carers who undertake the job of caring without adequate training, pay or support from the State.

4.6.4 Holistic, Person-centred, Integrated Care

It is clear from the comparison of data from across the field research process that continually viewing and treating the older person holistically with needs beyond purely medical is necessary to enable the older person to age well at home. The data indicates that supporting older people to age well in place requires both integrated health care and integration between the healthcare services, infrastructure in terms of housing and transport and supports delivered by the community and voluntary and third sector organisations. In addition, the delivery of healthcare in the community and homes of older people is important to enable people to age well in place. This is strengthened through the *'hub and spoke'* vision of healthcare delivery to older people mentioned in the feedback session. Finally, while person-centred care is mentioned within HSE policy documents (HSE, 2021) and ICPOP (ICPOP, 2018) the data would suggest that there is no universal understanding of what is meant by person-centredness.

4.6.5 Contribution made by the research

This research project has contributed to the understanding that the social dimension to healthcare delivery is as important as the medical aspect. Our social connectedness and relationship to others in the community in which we reside impacts on our mental and physical wellbeing. This research confirms that the community in which one resides, and the community and voluntary sector are an important part of an integrated health and social care system. It is through collaborative practice which involves all stakeholders – most importantly older adults themselves – that people will be enabled to age well in their community reducing the need for acute care. This, in turn, will decrease the cost of healthcare and improve outcomes for all. An additional contribution that this research makes is its finding that in order for the ICPOP programme to deliver on its vision of better health and social care for older people – a universal understanding of what is meant by person-centred care is essential and that whatever concept is used in public policy it is taught as part of all health and social care courses in all institutions across the state.

The following chapter discusses the findings from the RtD design methodology and design methods used to undertake this research.

Clinicians & 3rd Sector Organisations
Link with patients, their families- liaison with the older person
Co-Design Session with Older People
Clear Direction -More Information -The Need to ask Questions - Afraid to ask Questions
Co-Design Stakeholders Workshop & Feedback Session
Awareness of Supports -Signposting & Tailored Supports

Clinicians & 3rd Sector Organisations
Living Well at Home Supports are really much more important to more people
Co-Design Session with Older People
Designated Listener- Someone other than Next of Kin- A Voice for the Patient -Social Prescribing important
Co-Design Stakeholders Workshop & Feedback Session
Stop 'caring': Start 'enabling' - Circle of Support

Clinicians & 3rd Sector Organisations
Person-Centred Holistic Care - Accepting the Older Persons Lived Experience as Knowledge
Co-Design Session with Older People
Continuity of Carers - Dignity & Respect for Both
Co-Design Stakeholders Workshop & Feedback Session
Informal and Formal Carers Respected & Valued. Less Wait time for Home Care Supports

Clinicians & 3rd Sector Organisations
A 'PA for Older People' - Expanding the 'Basket of Goods' available for Home Support
Co-Design Session with Older People
Personal Recovery versus Medical - Looking after the Whole Person
Co-Design Stakeholders Workshop & Feedback Session
Person-Centred Holistic Care in Your Community

Figure 28 The 'Collective Voice' from across All Stages of Field Research (Smithson, 2000, p. 109)

5.0 Chapter 5 – Findings from Co-Design Process

5.1 Introduction

From the research presented in this study a framework incorporating the five stages of co-design is created. Firstly, I will consider what is meant by the co-design process discussing perspectives from the Design Councils Double Diamond (2004; 2019), Hartung and Rottenburg's (2019) reimagining of Don Norman's HCD concept, as well as .the Hasso Plattner Institute of Design (2010) model. In addition, using this research project I will analyse the researchers role in the RtD process. Furthermore, I will compare the principles of RtD with those of community development and finally, I will summarise my findings in a framework.

5.2 What is meant by the Co-design Process?

Sanders and Stappers (2014) contend that until the 1990s design was a specialist domain in areas such as craft, interior design and architecture where designers designed *for*[4] people. They suggest that things changed in the 1990s, with the advent of personal computer devices. End users were then consulted through market research to test the user ability of devices, but that designers still, in the main, designed *for* people. They indicate that a 'mindset shift' took place in 2014 where designers shifted from designing *for* people to designing *with* people (Sanders and Stappers, 2014, p. 28). The first stage of the process of designing with people is research with the end user. Ehn (2008, p. 1) refers to this as 'use before actual use' and Frayling (1993, p. 1) as research through design (RtD) that is 'directed towards the innovation, introduction and improvement of objects or process'. This method for improving a process is not new. Zamenopoulos and Alexiou (2018, p. 5) argue that in education it has been advocated for and used by numerous scholars including John Dewey and Paolo Friere who 'provide powerful and philosophical resources for thinking with'. Wakefield and Sanchez Rodriguez (2018) suggest that co-design methods have previously been used by social movements worldwide in what Columbian sociologist and activist Orlando Fals Borda called participatory action research. The techniques used by Fals Borda, who built on the ideas of Friere, are similar to the methods used in the co-design process. Zamenopoulos and

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[4] Italics are for emphasis and are the authors own.

Alexiou (2018, p. 10) argue that ‘co-design is a practice where people collaborate or connect their knowledge, skills and resources in order to carry out a design task’.

Co-design can be then said to be the first stage in the process of RtD. It involves the end user from stage one – understanding from their perspective what their needs are. The Hasso Plattner Institute of Design (2010) founded by David Kelley and Bernard Roth at Standford University in 2004 and now called d.school outline five stages of the co-design process (see figure 29)

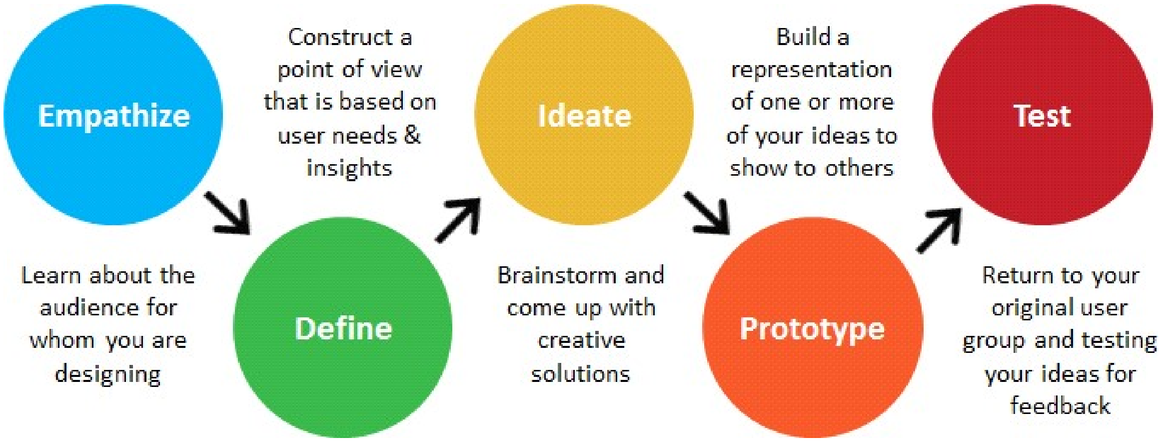

Figure 29 The Hasso Plattner Institute of Design (2010) Five Stages of Design ©

The Double Diamond for design was created by The Design Council of Great Britain in 2004 (see Figure 30) incorporating concepts derived from Pughs Controlled Convergence.

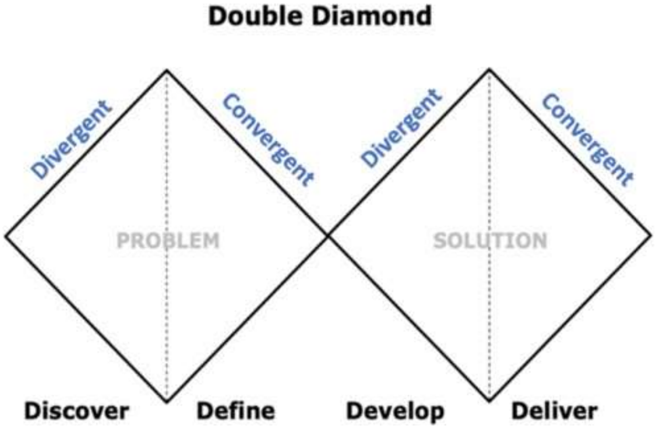

Figure 30 The Design Council of Great Britain (2004) Double Diamond ©

The first diamond concentrated on the problem to be solved using input from stakeholders including the end users of the product/service under design. The second diamond concentrated on solutions to the problem using the concepts derived from the first process of engagement and understanding of the problem itself. It is a simple expression of the design process that is easily explained to non-designers and emerged when service design was new as a practice (Drew, 2019). In 2019 the Double Diamond concept was improved upon through a collaborative process where users of the Double Diamond were asked to share with The Design Council how they used the original design and what innovative techniques they had added themselves. (Drew, 2019).The 2019 iteration of the Double Diamond is a framework (see figure 31) and includes four core design principles that designers should adopt so that they can work as effectively as possible (Design Council, 2022). In addition, it includes a methods bank that can be used to address challenges and design successful solutions. Furthermore, by the inclusion of concepts such as engagement and leadership, the framework suggests that engagement with other stakeholders and building an organisational culture and leadership style that allows and builds on innovative practices is an important part of design practice and process (Design Council, 2022).

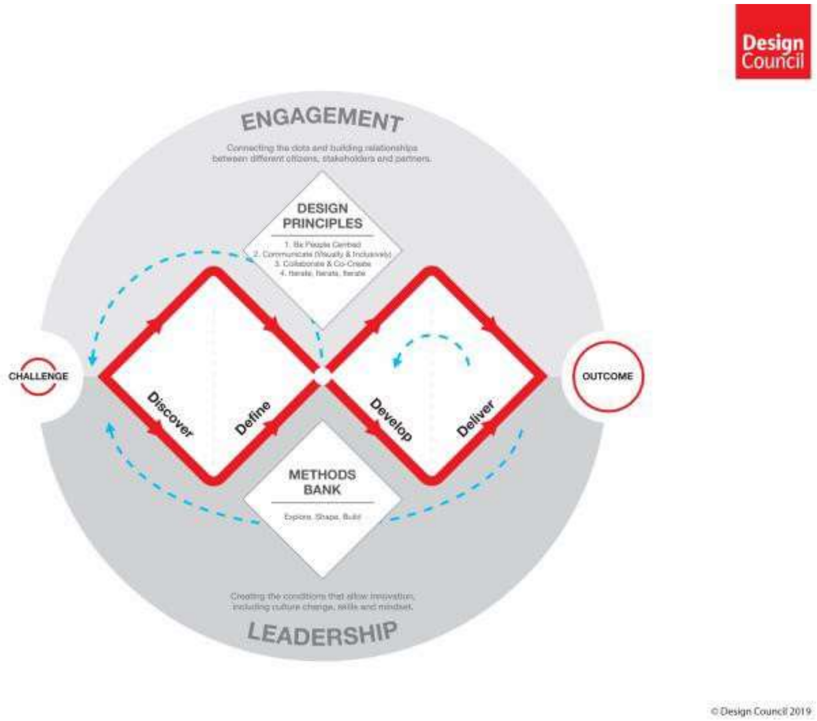

Figure 31 The Design Council of Great Britain (2019) Double Diamond ©

Hartung and Rottenberg (2019) use Don Norman’s Human Centred Design concept in suggesting four stages in the design thinking process (see figure 32). It is an iterative process across and between each stage – investigate, ideate, iterate and implement.

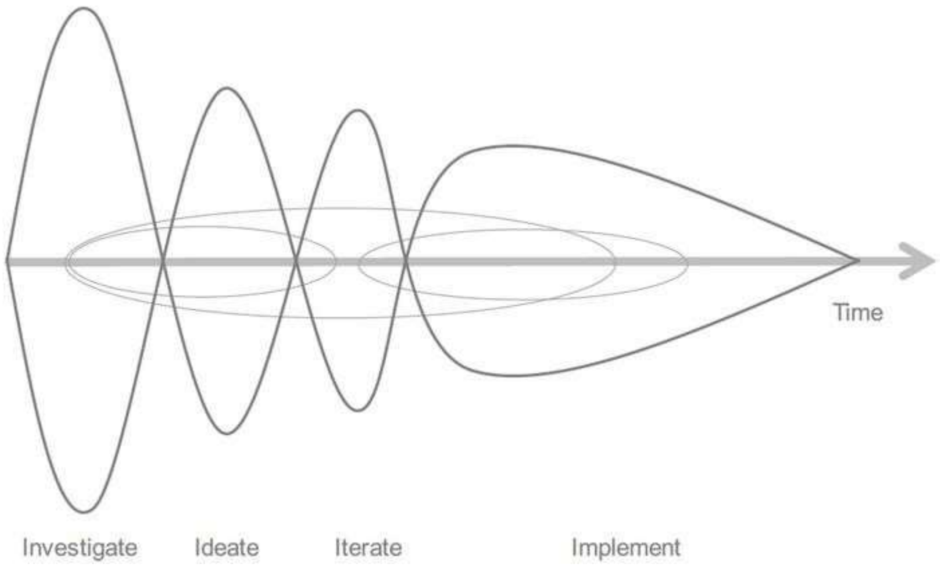

Figure 32 Hartung and Rottenberg (20191) Four Stages of HCD ©

Whichever approach is used to co-design with people the process is clear, stage one is empathising with and investigating how stakeholders will use the product or service. In this research project stage one was achieved in two parts. Part one was the literature review investigating how health and social care services were being delivered to older people at an international, national and local level. Part two involved a series of ‘conversations’ or semi-structured interviews (Hasso Plattner, 2010, p. 3) with those delivering health and social care, and those advocating for older people receiving that care.

<u>5.2.1</u> <u>Define</u>

The data gathered from this process led to stage two of the process as outlined by Hasso Plattner (2010) and the ‘define’ side of the first diamond in the Design Councils Double Diamond (Drew, 2019). This stage is not apparent in the HCD approach but is important for RtD that a ‘point of view’ should be defined in order to narrow the focus of the research

(Hasso Plattner, 2010, p. 4). Hasso Plattner (2010) go on to suggest that this 'point of view' is an 'explicit expression of the problem' that the research is trying to address. As with all research projects the area to be investigated is narrowed down by the process, discovering gaps in knowledge that require answering (Dawson, 2002; Gray, 2004; Bryman, 2015). It is, as Norman (2002) suggests, finding the right problem to solve – looking beyond the symptoms to the root cause. RtD seeks to outline a solution to the problem under investigation. This is unlike many other research methods that only seek to uncover and explain the challenge and its implications (Zamenopoulos and Alexiou, 2018).

5.2.2 Ideate and Iterate/Prototype through Co-Production

Ideation is the third stage of the co-design process as envisaged by Hasso Plattner (2010), the second diamond in the Double Diamond (Drew, 2019) and the second stage as outlined by Hartung and Rottenberg (2018). Ideation is accomplished through co-production, which this writer views as the second stage of the RtD process. Bovaird (2007) suggests that only services are co-produced[5] and that the resources of all stakeholders are used equally in the process. This stage of the co-design process involves co-producing a solution to the problem ascertained by the Hasso Plattner (2010) stage two 'define'. As discussed in the methodology chapter its methods are creative, engaging stakeholders in interactive workshops to elicit potential solutions. The researchers job during these workshops is neither as a facilitator nor a participant but as an observer gathering data through observation and note taking. The co-production workshop should enable participants to converse, discuss and argue freely in a non-judgemental environment. This allows for what is referred to as 'infrastructuring' (Karasti, 2014; Ehn *et al*, 2014; Zamenopoulos and Alexiou, 2018). It suggests that connections between people and the building of social networks is an important aspect to designing with people. It builds trust, enabling power-sharing which in turn leads to shared knowledge and decision-making and therefore to better design outcomes. It does not presuppose consensus but aims to finds ways to turn conflicting positions into 'productive and more democratic interventions and outcomes' (Ehn *et al,* 2014, p. 9). The literature review indicates that trust building enables the sharing of knowledge and decision-making

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[5] 'the provision of services through regular, long-term relationships between professionalised service providers (in any sector) and service users or other members of the community, where all parties make substantial resource contributions' (Bovaird, 2006)

and is important in the co-production process. In design-thinking they accept this premise through the concept of infrastructuring. Zamenopoulos and Alexiou (2018, p. 18) contend that the addition of ‘ing’ to infrastructure makes it a continuous action. Infrastructuring, therefore, infers designs ‘made in use’ that focuses on the working relations between participants thus creating ‘conditions for common learning’(2018, p. 18). Infrastructuring is seen in the iterate - implement stages of Hartung and Rottenberg (2018) process, the develop - deliver stage of the second diamond in the Design Councils Double Diamond (Drew, 2019) and the prototype - tests stages of the Hasso Plattner (2010) process. All three envisage a cyclical process until a design solution is agreed by all stakeholders. This writer contends that RtD uses infrastructuring making it a cyclical and reflective process.

5.2.3 Co-Creation

The third and final stage of RtD as envisaged by this writer is co-creation. This stage is the evaluation of the process and its outcomes. As circumstances at societal level change and technological advances are made continuous evaluation on the service design are required – it is a never ending continuous reflective cycle. If RtD is to be an inclusive process, then the evaluation stage must also include all stakeholders. (See figure 33) for the researchers concept of RtD

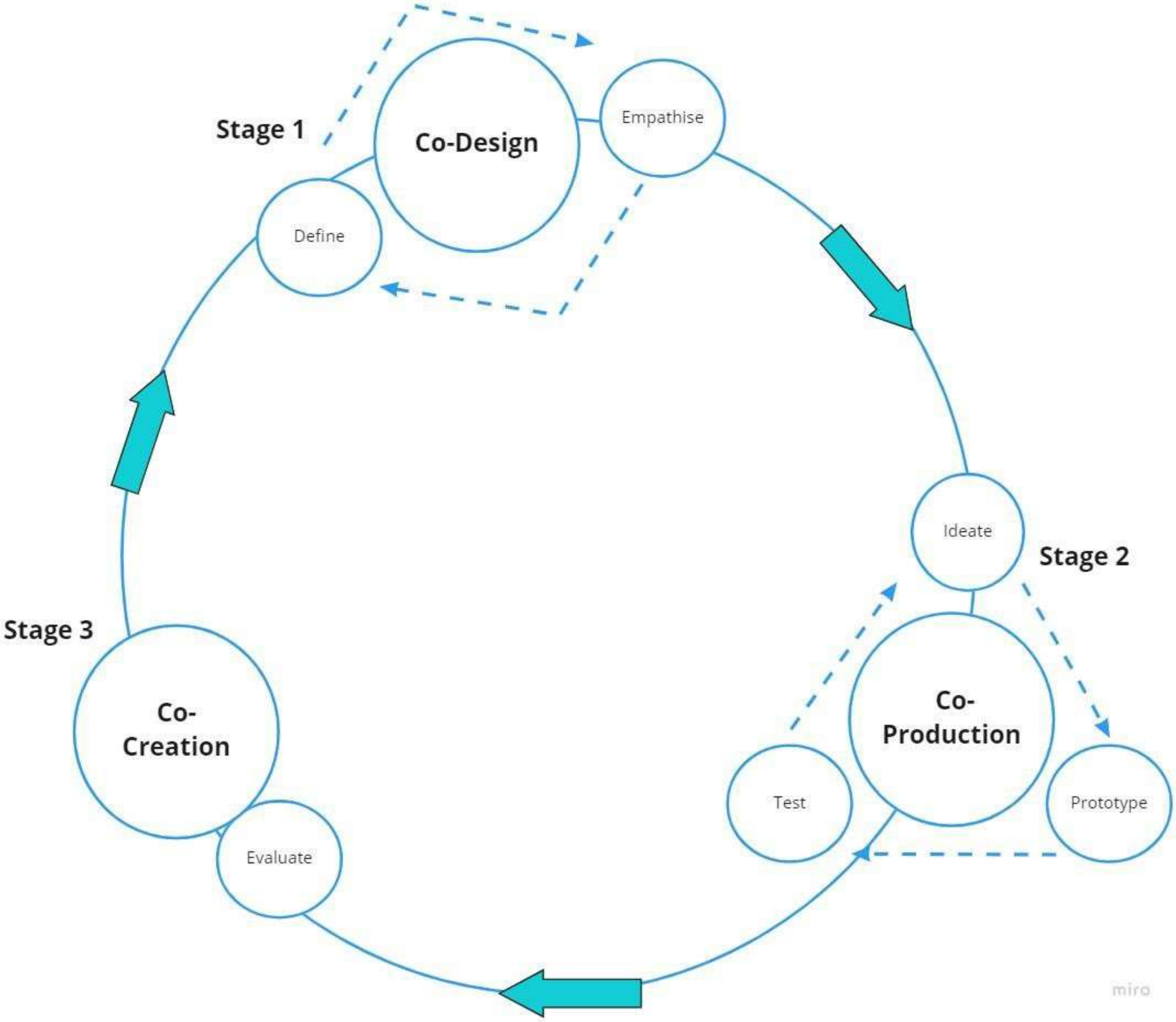

Figure 33 The RtD Process as envisaged by the Researcher

5.3 What is the Researcher's role in Research through Design?

In RtD it is necessary for the researcher to engage in reflective practice at all stages of the process (Bon Ku and Lupton, 2020). In stage one it includes a critical analysis and reflection on the literature around healthcare design and delivery, and the purposeful sampling of interview candidates. As interviews are conducted and data analysed the researcher should reflect on whether other perspectives also need to be explored before the second stage of co-production. Careful purposeful recruitment of participants for this stage is also important to be sure that all voices and perspectives are listened too. Pre-planning is an important and essential task associated with co-production workshops. The whole experience should seem unstructured and led by the participants themselves. This free-flowing process is only made possible by thoroughly pre-planning sessions. This should be done in conjunction with peers who will be co-observers at the workshop. In addition, there is a requirement for the researcher to pre-empt the co-production workshop process – what this researcher calls a 'just in case' (JIC) scenario. What is meant by a JIC scenario is anticipating what could go askew in a workshop before it happens and having in place a solution just in case it does. In this research project a considerable amount of pre-planning went into how the co-produced stakeholders workshop would evolve using the Miro^{TM} whiteboard (see figures 34 to 36)

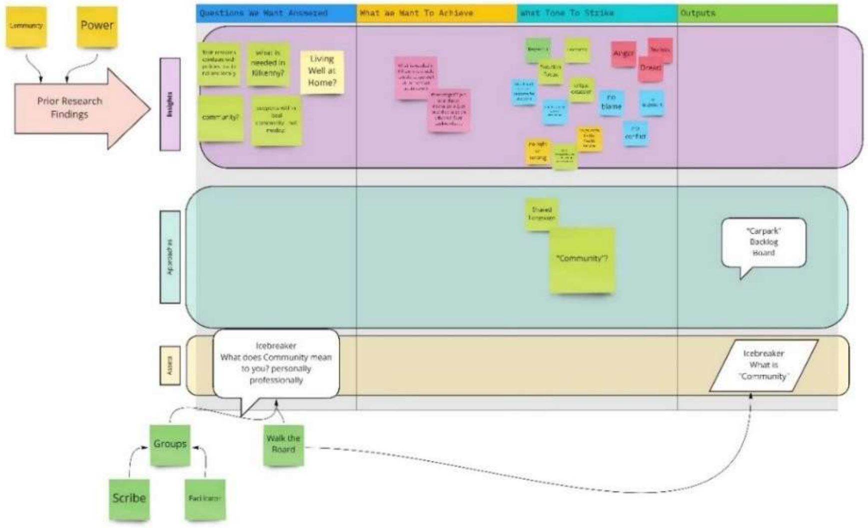

Figure 34 Pre-Planning for the Stakeholders' Co-Production Workshop Whiteboard 1

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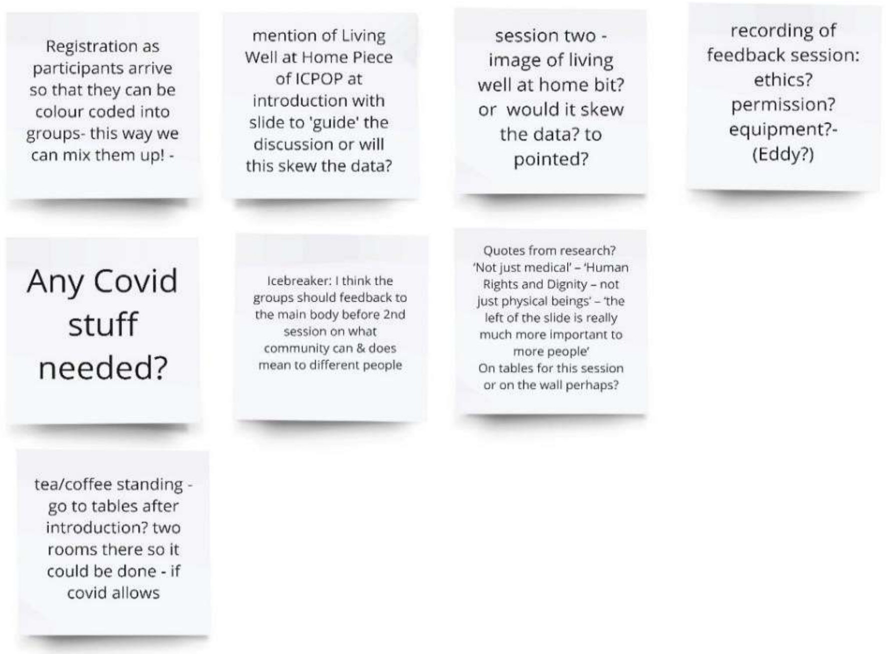
Having in place a contingency (a JIC) in case what is planned does not happen is important. This will occur regularly as the whole premise of a co-produced workshop is for the participants to take the lead. The researcher and assistants are there as observers, note takers and occasional guides. Validation of the data gathered is an important aspect of any research methodology. For RtD it is particularly challenging, and some would suggest a limitation to the veracity of any research undertaken in this way (Zimmerman *et al,* 2010; Graver, 2012;

Dudau *et al,* 2019). Therefore, it is the researchers task at the end of the workshop to verify with participants their perceptions of the consensus or collective voice that has emerged. In the co-production workshop this can be done through a feedback session where the researcher engages as a facilitator, documenting the outputs, the potential barriers to design and the potential, but hopefully, numerous solutions in plain clear unambiguous language. This data can then be further verified through thematic analysis and a peer review session with the co-observers.



Registration as participants arrive so that they can be colour coded into groups- this way we can mix them up! -

mention of Living Well at Home Piece of ICPOP at introduction with slide to 'guide' the discussion or will this skew the data?

session two - image of living well at home bit? or would it skew the data? to pointed?

recording of feedback session: ethics? permission? equipment?- (Eddy?)

Any Covid stuff needed?

Icebreaker: I think the groups should feedback to the main body before 2nd session on what community can & does mean to different people

Quotes from research? 'Not just medical' – 'Human Rights and Dignity – not just physical beings' – 'the left of the slide is really much more important to more people'
On tables for this session or on the wall perhaps?

tea/coffee standing - go to tables after introduction? two rooms there so it could be done - if covid allows

Figure 35 Pre-Planning for the Stakeholders' Co-Production Workshop Whiteboard 2

While the example given here is in the co-production part of the RtD process, it is important that a researcher should be self-aware throughout the process. RtD requires that a researcher is reflective at all stages.

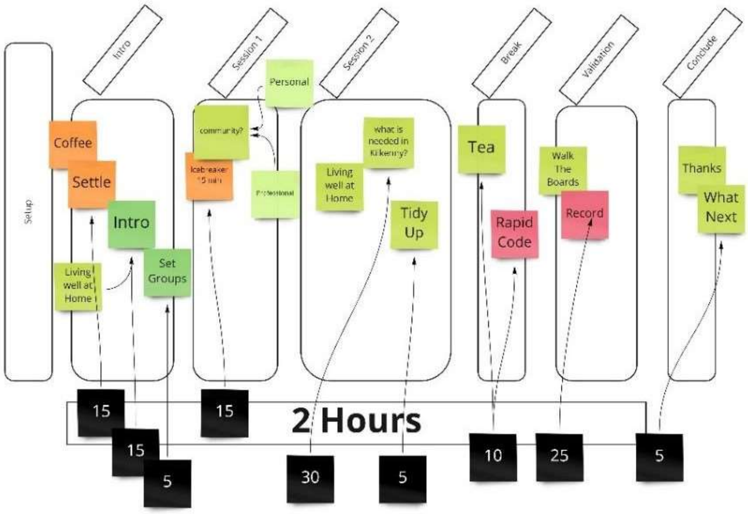


Figure 36 Pre-Planning for the Stakeholders' Co-Production Workshop Whiteboard 2

5.4 Research through Design and Community Development

The principles underlying community development are collaboration, participation and empowerment all based on a social justice and human rights approach (AIEB, 2016). RtD also includes the principles of collaboration, participation and empowerment. Furthermore, as RtD seeks to be inclusive of all those the research impacts, particularly in health care design, a human rights and social justice perspective must be at its core. Both seek to ascertain and build on the strengths of those involved in the process. In community development parlance the equivalent to Normans (2002) concept of looking for the right problem to solve is Russells (2011, p. 96) suggestion that rather than 'providing better ambulances at the bottom of the cliff' we need instead 'fences at the top'. This requires involving all those that are impacted by the research question from the beginning of the process which both RtD and community development practices seek to do. In addition, both are reflective and reflexive practices and processes, and both require the practitioner or researcher to be reflective through continuous self-development. Furthermore, both require a hands-off approach at the co-design and co-production stages of the process. The researcher guides rather than facilitates, building trusting relationships and allowing the participants through power sharing to come to a negotiated consensual solution. Finally, both are a continuous cyclical process and practice as peoples' needs change, technological advances are made and different perspectives and voices are required.

5.5 Findings and Conclusion

This research project used RtD as its methodology incorporating co-design and some co-production. However, the process for this research was not completed – it stopped short. While solutions to healthcare design for older people were identified it was not the remit of this particular research project to prototype, test or evaluate potential solutions. Through the RtD process the following findings were determined:

- RtD is a practice and a process based on the philosophies of Friere and Fals Borda. It involves hearing all voices and using the resources of all stakeholders in ascertaining the right problem and designing a solution.
- Community development principles are the same of those that underpin RtD including a human rights and social justice approach.
- As with community development RtD is also a cyclical and reflective cycle - as circumstances at societal level change, technological advances are made and different voices need to be heard.
- It is also a reflective practice for the researcher building their personal and professional development.
- The creation of social networks through forming trusting relationships between different stakeholders enables consensus building and shared decision-making.
- And while it is a protracted, sometimes messy process, its solution focussed perspective should ensure that outcomes for all stakeholders are enduring.

6.0 Chapter Six – Conclusion

The dissertation set out to answer the following questions

Question 1:	Investigate through co-design what is important to all stakeholders in the design and delivery of healthcare for older people?
Question 2:	What role can the community in which an older person resides, and the community and voluntary sector play in the delivery of healthcare, enabling people to age well in place?
Question 3:	Incorporating the concepts of co-design, co-production and co-creation - what does a Research through Design (RtD) framework look like?

A RtD methodology was used to listen to all perspectives, allowing the authentic voice of participants to emerge from the data through a GT method of analysis. This afforded a consensual 'collective voice'; on potential solutions to be identified for healthcare design for older people (Smithson, 200, p. 109)

6.1 Question One

What emerged as important to all stakeholders was

- Clear, unambiguous communication at all stages of healthcare delivery and between all stakeholders including the family and/or informal carers of the older person.
- Soft supports or non-medical supports for the older person and their informal carers are essential to enabling people to age well at home.
- Respect, dignity and power with all stakeholders through a McCormack and McCance (2017) model of person-centred care that is cognisant of the needs of all those in receipt and delivery of healthcare is required.
- An organisational culture of collaboration, innovation and power-sharing is important to the delivery of co-produced, person-centred, integrated care

6.1 Future Research Areas

Further areas for research that have been identified through this project include the following

- This research project was narrow geographically in its focus future research could expand the scope to verify the findings across the country. It should enable the roll out of the Living Well at Home supports based on evidence of their importance to all cohorts involved in the delivery and receipt of healthcare for older people.

- In addition, research needs to be undertaken around the concepts of co-produced, person-centred care within healthcare delivery. While the concept of co-production has been used in mental health provision (Government of Ireland, 2006) and is at the core of healthcare reform (DOH, 2012; 2019) this research has found no universal understanding of either in an Irish context.
- Furthermore, RtD, requires further study through the co-design process and using the framework developed by the researcher to put in place a comprehensive understanding of the practice and process. Doing so would add credibility in academic circles of RtD as an important, verifiable and useful method of field research.
- Finally, power and trust have been found to be important in the co-design process. Further research in this area could identify where power lies and how to alleviate it leading to a better co-design process.

6.2 Question Two

During the pandemic the importance of the community in which one resides and the community and voluntary sector in delivering supports to those isolated and cocooning was apparent. The service model for ICPOP has a twelve point Living Well at Home section which includes the soft supports required to enable people to age well in place. The research indicates that this piece of ICPOP is as important, if not more so, than its medical aspect. One of the takeaway messages at the stakeholders co-production workshop was that ‘community are the answer to supporting older people’. There is some evidence of collaboration in Kilkenny between community organisations and primary care centres, and between the hospital and community systems of healthcare delivery. However, while funding for ICPOP has accelerated post Covid-19, this part of the programme remains under funded leading to a slow implementation of the Living Well at Home section which is seen as vital in enabling people to age well at home.

6.3 Question Three

A framework was developed for the RtD process to aid future researchers using a RtD methodology. An analysis of the RtD process concluded that it is a reflective, iterative practice and process. In addition, it is based on the same principles as community development – empowerment, inclusive participation and collaboration and, social justice and human rights. It uses and develops social capital networks building trust and reciprocal relationships that are based on power with others and shared decision-making. Finally, it can be a protracted and sometimes chaotic practice and process but is a democratic method of research that is solution focussed.

6.4 Additional Finding

While person-centred care is a mainstay of the Sláintecare programme of healthcare reform and ICPOP there is no universal understanding of what person-centred care is .

6.5 Future Research Areas

Further areas for research that have been identified through this project include the following:

- This research project shows a narrow but deep analysis of a specific setting. Using the same methodology and methods it could be replicated across the country . Doing so should enable the roll out of the Living Well at Home supports based on evidence of their importance to all cohorts involved in the delivery and receipt of healthcare for older people.
- In addition, research needs to be undertaken around the concept of person-centred care within healthcare delivery. .Although an important part of Sláintecare's policy of healthcare reform this research has found no universal understanding of the concept
- • Using the framework developed through this project further study of the RtD process is warranted to put in place a comprehensive understanding of the practice and process. Doing so would add credibility in academic circles of RtD as an important, verifiable, and useful method of field research.
- • Finally, co-design without considering the power imbalance found within it is of limited value. Further research in this area identifying where power lies and how to alleviate it would lead to a co-design process based on equity.

In conclusion, the findings of this research project would indicate that a Research through Design methodology and co-design methods offer an opportunity to improve healthcare delivery to older people in the community in which they reside.

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8.0 Appendix One

8.1 Ethics Application

Application to the IT Carlow Research Ethics Committee for

Ethical Approval of a Research Project involving Human Participants or samples donated by Human Participants (e.g. tissue or blood samples)

(FORM REC2-L9(R)/ L10)

Applicants are advised to submit any supporting documentation they may feel is relevant to their research proposal (e.g. sample interview schedules, consent forms, third party licenses or ethical approvals).

A. Applicant Details

A.1 Researcher Details:

Name: Trish Finegan

Email: C00265252@itcarlow.ie

Telephone: 087 7565376

A.2 Principal Investigator / Research Supervisor(s):

Name: Dr. PJ White

Email: pj.white@itcarlow.ie

Telephone: 087 6637940

A.3 Additional Expertise (if applicable)

Name: Dr. Brian Casey

Email: brian.casey@itcarlow.ie

Telephone: 083 1188017

A.4 Does this research form part of a programme of study? ☒ Yes ☐ No

If yes – please give details

This research is being conducted as part of a two-year Presidents Research Fellowship Scholarship leading to a Masters degree by research

A.5 I confirm that I have read and understood the following IT Carlow Policies:

Ethics Policy ☒ Yes ☐ No

Ethics Procedures and Guidance notes

On completing this form ☒ Yes ☐ No

Data Protection Policy ☒ Yes ☐ No

Anti-Plagiarism Policy ☒ Yes ☐ No

B. Research Proposal

B.1 Title of the proposed research project

Health Service Design for Older People in the South East of Ireland

B.2 To what extent has this topic already been researched and written about (e.g. is there a significant body of existing published work)?

Co-design and co-production of health services is not a new phenomenon in other jurisdictions (Batalden *et al*, 2015; Osborne *et al,* 2015). In Ireland they have been used in the provision of Mental Health recovery programmes (DOH, 2006; DOH, 2020). They have been embedded in how recovery focused programmes have been delivered in recent years but has not gained as much traction in the design and delivery of physical health and wellbeing. It has been said that co-design and co-production improve health outcomes for patients, and efficiencies in delivery (Batalden *et al*, 2015; Osborne *et al,* 2015). In order for this to happen, however, co-design and co-production in practice must include all stakeholders (Ramirez, 1999; Joshi and Moore, 2003; Bovaird, 2007; Bovaird and Loeffler, 2013). Co-production of services is broader than self-help programmes such as Stop Smoking or Cancer Screening. Patients, their families and carers are stakeholders in how all health services are designed and delivered. While the Health Service Executive (HSE) speak of person-centred care, integrated care and co-design of services, rarely do they explicitly include the patient in their narrative (Delaney *et al,* 2004; DOH, 1999; HSE, 2018; HSE, 2020). The lived experience of the patient, used so effectively in the design and delivery of mental health services, can be replicated in design and delivery of other health services.

This research will look at how health services for older people in the South East of Ireland, can be delivered more effectively and efficiently through co-design and co-production methods involving expert semi-structured interviews and, workshops and focus groups with all stakeholders. In particular, it will look the benefits and barriers to co-designing and co-producing a service pathway from acute hospital care to home based care for older people with chronic illnesses.

B.3 From that, describe how this proposed research is contributing to what is known about the topic

This research will investigate how co-design and co-production methods can enhance the quality and efficiency of care for the transition of older people with chronic illness, from an acute setting to home based care. Its purpose is to show how with co-design and co-production, improved outcomes for all stakeholders, but most importantly the patients, can be made.

B.4 Provide a brief description of research *(not more than 200 words in any section)*

a) The aims and objectives

The aim of the research is to understand the needs of the older patient in the transfer from an acute hospital setting to their own home. The goal of the research is to envision a service pathway which assists in the transfer of an older person with chronic illness from a hospital setting to their own home in collaboration with other stakeholders.

Project Objectives:

Conduct semi-structured expert interviews with clinicians involved in the delivery of service pathways for the transition of patients from acute care to homebased care, to ascertain the knowledge gaps that exist.

Develop an understanding of the patient experience of the transition from acute care to homebased care in the Irish healthcare system.

Visually map the patient journey from the perspective of all stakeholders.

Highlight key points in the process where change would positively impact on wellness and clinical outcome and efficiency of the service.

Investigate the development of a service pathway that empowers the patient in provision of their healthcare through co-design and co-production methods of collaboration with other stakeholders.

b) The research design

(Note: This section can include an overview of methodology research design proposals regarding for example, evaluation and data gathering. In describing the research design, applicants are required to explain the reasoning behind their choice of method)

1. Expert semi-structured interviews to ascertain knowledge gaps for the research

2. Focus Groups: initially with groups of individual stakeholders to learn the needs of each group, their experiences of the process and the positive outcomes they see for co-design and co-production

3. Workshop: with all stakeholders to discuss the learnings from the individual focus groups and collaborate on a way forward.

Qualitative methods will be used in this research project. The initial semi-structured interviews with clinicians will ascertain the gaps in knowledge that will guide the questions to be answered in the subsequent focus groups and workshop.

Involving all stakeholders in the focus groups, starting with conversations amongst themselves, will allow the teasing out of the challenges perceived by each group and establish their needs around the design of a service pathway. It is envisioned that three focus groups comprising of individuals from each stakeholder group, will be facilitated by the researcher and research assistants.

Through a facilitated discussion of all the stakeholders challenges and needs, the workshop will design an agreed potential pathway for service delivery.

Iterative design methods as outlined by Norman and Spencer (2019) in his concept of Community Based Human Centred Design will be used in the focus groups. These will be underpinned by Community Development Principles of empowerment, participation, connectivity, social justice and equality. Undertaking research by these methods must be supported by good ethical considerations. Using contacts formed by DesignCORE with the HSE geriatric services and older peoples advocacy groups, participants will be contacted by lead researcher Trish Finegan, to engage with the research process. All participants will give informed consent prior to participation.

c) The size and composition of sample

Practice based researchers within DesignCORE have established relationships with the HSE geriatric services and older peoples advocacy groups. It is the intent of this research project to utilise these existing contact networks to recruit participants for both the expert interviews and the focus groups and workshop.

Individual expert semi-structured interviews with four to five participants.

There will be three focus groups. Each group will consist of four to six participants. It is envisaged that the focus group sessions and workshop will be conducted within Institute of Technology Carlow over half a day. We will endeavour to have a gender balance in each of the focus groups. All engagement will be with voluntary participants over the age of eighteen.

d) The method of how participants are expected to be selected, approached and recruited in conducting this proposed research?

(Note: The process of participant selection is required to be outlined clearly. If for example, participants are being contacted through an organisation, e.g. Faculty/Campus, an initial step would be to seek permission from the organisation to approach the participants. Any inclusion or exclusion criteria must also be specified.

It is envisaged that older persons, their carers and family members, and older people's advocacy organisations that have been engaged in previous research with the HSE geriatric services and older peoples advocacy groups will be contacted to be involved with this research. Participants will then be selected by meeting the inclusion/ exclusion criteria, age demographic, gender and availability and willingness to participate in the study. Contact with the participants will be made directly by lead researcher Trish Finegan.

As older people will be engaged in this research we must be cognisant of the fact that some may be vulnerable. Consent forms will outline in clear language what the research is about, how the data will be collected, and how the data will be stored, used, and disposed of.

e) Describe the procedures that will be adopted to maintain the confidentiality of research subject(s).

Participants will be required to discuss within the group setting their thoughts and feelings on what is most important to them in the transition process and care at home.

The participants will be directed to not disclose specific health conditions but rather focus on their interactions with the healthcare system and other stakeholders.

All data collected will be stored and disposed of in accordance with the guidelines as laid down by IT Carlow and in line with GDPR.

f) Will any member of the intended group of research subjects, to your knowledge, be involved in other research projects or activities? If so, please give details and explain the nature of the engagement with other projects.

As we hope to liaise with older persons advocacy groups and with HSE geriatric research participants, some of the research subjects may have been involved in other healthcare research projects.

g) Describe how the information is gathered, stored, handled and anonymised.

Information on the research being undertaken will be distributed to the participants in written form beforehand. Prior to the interviews and workshops, participants will be asked to fill in and sign consent forms on which it will be outlined how information will be collected, stored and disposed of. (see Appendix Two page 12)

Semi-structured interviews with healthcare experts will be conducted face to face if Covid19 guidelines allow or over a video conference call. They will be recorded on a password protected phone or computer and copied as soon as possible onto

OneDrive space on IT Carlow’s server. Recordings will then be deleted from the phone/computer. Recordings will be transcribed and held in a secure place while the research is being conducted. In keeping with principle five of the Data Protection Act 2003, data will be retained for five years after the award of the degree at which time it will be destroyed (September 2027)

During the focus groups/workshops data will be compiled through visual mapping on whiteboards or sticky notes. In this way immediate feedback is provided to the participants. Through feedback to the main body of participants and through discussion, the findings from the workshops will be approved by the participants. A record keeper will be on hand to document all feedback. The visual mapping will be the only record of the session. All information compiled will be anonymised, no names will be documented and no recordings either audio or visual will be made of the workshops.

More information on the methodology is in Appendix Three, page 17

h) Please state how long participant data is to be retained for before being destroyed and the proposed method of destruction.

In keeping with principle five of the Data Protection Act 2003, data will be retained for five years after the award of the degree after which time it will be destroyed (September 2027)

i) If your research involves the taking of samples (e.g. blood, tissue etc.), please state clearly exactly how this is to be performed, how those samples will be stored, how and when they will be disposed of.

N/A

j) Please state whether participants are to be given the opportunity to access the results of the research and how this will be achieved.

The participants in the semi-structured interviews will have an opportunity to view a draft of their contribution before its inclusion in the research document. All interviewees will be given a pseudonym. Participants can at all times before the research is submitted, withdraw their consent for the information to be used.

Those participating in the focus groups and workshops will approve the feedback through discussion and consensus on the day. The visual mapping of feedback will be recorded in written form. No names or personal details will be recorded in the feedback. No audio or video recording of the sessions will take place. Participants will be afforded the opportunity, by contacting the researcher, to access the findings before publication.

The researchers contact details will be on the information sheets and consent forms signed by participants before interviews and workshops take place. Participants will be encouraged to contact the researcher with questions at any time.

k) Please state the location(s) the proposed research is to be conducted

Interviews will be conducted at a place and time convenient to the interviewees or if Covid19 restrictions do not allow face to face interaction, through a secure video conferencing platform.

Workshops and focus groups will take place in the DesignCORE meeting rooms in IT Carlow, or if Covid19 restrictions do not allow face to face interaction, through a secure video conferencing platform with relevant features such as a whiteboard.

l) The proposed starting date of research/ study

Participant research proposed to begin January/February 2021

B.5 Has this research proposal received ethical approval from any other body? – if so please provide details.

No

B.6 Does this proposed research require licensing approval? – if so please provide details of licenses obtained.

No

B.7 Describe the research procedures as they affect the research subject and any other parties involved.

There is no foreseen impact on the participants for this research study. Their participation is entirely voluntary. They may withdraw from the interviews, focus groups or workshop at any time. Furthermore, those been interviewed may withdraw their consent for information gathered in the interview session to be used.

B.8 Describe (a) the ethical considerations of this proposal and (b) the steps to be taken to address these.

Participants in the interview process for this research are experts in their field, will have read and agreed the format of the interviews and, the storage and disposal of data gathered.

The majority of those engaged in the workshops will be from a clinician background where they will have read and agreed the format of the workshop sessions and how the data will be gathered and used. Some of the participants will be over 65 years of age and, therefore, considered to be in the vulnerable category of citizens.

However, in order for the findings to have any relevance on healthcare provision for older people through a co-designed and co-production process, they are an important stakeholder and must be included.

By working with older adults who have engaged before in research with the HSE geriatric services and advocacy groups, we will be confident of including those who are not vulnerable in the process. It will be particularly important to have information and consent forms in clear, plain, easily understood language and to be available by email and phone to answer queries. No older persons with a diagnosis of dementia or other cognitive impairment will be approached to take part. While it is acknowledged that the inclusion of people with a mental health difficulty would bring a unique perspective and be beneficial to the study, we are not in a position to determine if they would be able to give informed consent to participate. Furthermore, if informed consent could be ascertained, we do not have the skills required to facilitate inclusive participation of individuals with a mental health difficulty and/or a dementia diagnosis. Therefore, no older people with a diagnosis of dementia or other cognitive impairment will be approached to take part.

All participants will be made aware that their participation is entirely voluntary, and that consent can be withdrawn at any time, before the research is submitted. To make sure all participants understand what is involved an information sheet and a consent form will be issued to all. The information sheet will state the rationale for the research project and how the data will be gathered, stored, anonymised, used and disposed of. It will outline the voluntary nature of participation and how they can recuse themselves at any time before the research project is submitted.

All data collected and stored will be in accordance with statutory guidelines and the ethics of IT Carlow. They will be stored securely on a password protected device and backed up on a password protected hard drive.

The researcher has acknowledged that she is the lead author of this study, and all data collected can be used in relation to this project only.

B.9 Please list the investigators (including assistants) who will conduct the research. Please provide details of their qualifications and experience

Lead investigator- Trish Finegan (postgraduate research fellow)

Assistants- Dr PJ White and Dr Brian Casey

B.10 Are arrangements for the provision of clinical facilities to handle emergencies necessary? If so, briefly describe the arrangements made.

We are aware that participants may have had a difficult time in hospital or coming to terms with a diagnosis of an illness and may become upset/uncomfortable while participating in the study. The participants will be directed, in the consent forms and at the outset of the workshop/focus groups not to disclose specific health conditions. During the workshops/focus groups, it is envisioned that there will be a qualified partitioner available if a participant should become upset/uncomfortable. At the outset of the session his/her presence will be made known to the participants. If someone becomes upset they should raise their hand and the qualified practitioner will accompany them to a previously determined quiet space until such time they are able to return, should wish too.

B.11 Specify whether research subjects include learners or others in a dependent relationship.

Research participants are not in a dependent relationship with the researcher

B.12 Specify whether the research will include primary respondents such as children, individuals with mental health issues, individuals deemed to be of diminished responsibility, individuals with a physical or intellectual disability. If so, please explain the rational for accessing these subjects for the proposed research. Please indicate alternative measures investigated to avoid the necessity for direct access to these primary respondents.

All participants will be aged over eighteen. There is inclusion and exclusion criteria, if the participant does not meet the criteria they are not invited to participate in the study. Individuals with mental health issues, individuals deemed to be of diminished responsibility, individuals of intellectual disability have been explicitly excluded from this research.

B.13 Please confirm that no payment will be made to any research subject

I confirm no payment will be made to any research participant

B.14 Describe the procedures to be used in obtaining a valid consent from the subject. Please supply a copy of the information sheet provided to the individual subject(s).

A research participant information sheet will be provided to individual participants who are to engage in the research A separate consent form to be signed by the participant before the research is started is also included

See Appendix Two, page 12

B.15 Please indicate if there are any cultural, social, gender-based characteristics or sexual orientation, practices or behaviour of the subject(s) which have affected the design of the project or which may affect its outcomes.

None

Signed: ______________________________ **Date**:__________________

Researcher

Signed: ________________________ **Date** __________________

(Principal Investigator
Supervisor)

REVIEWER COMMENT IF APPLICABLE FROM HEAD OF DEPARTMENT/GROUP/ INSTITUTE/FACULTY/CAMPUS

Signed: ________________________ **Date** __________________

(Head of Department/Group/CORE/Institute/Faculty/Campus)

8.2 Information Sheet

Institiúid Teicneolaíochta Cheatharlach
INSTITUTE of TECHNOLOGY
CARLOW
At the Heart of South Leinster

designcore
humanising innovation

INFORMATION SHEET

You are invited to participate in a research study conducted by Trish Finegan, an MA Researcher in DesignCORE at the Institute of Technology Carlow.

Your participation in this study is entirely voluntary. Please read the information below and ask questions about anything you do not understand.

- **PURPOSE OF THE STUDY**

The aim of the research is to understand the needs of the older patient with a chronic illness transferring from an acute hospital setting to their own home. The goal of the research is to imagine how a service which assists in the transfer of an older person with chronic illness from a hospital setting to their own home would look like. This will be done in collaboration with all stakeholders, hospital clinicians, community health service providers and, older people, their carers, families and support organisations.

This research will investigate how co-design and co-production methods can enhance the quality and efficiency of care for the older people with chronic illness, moving from an acute setting to home based care. Its purpose is to show how with the collaborative principles of co-design and co-production, improved outcomes for all stakeholders, but most importantly the older person, can be made.

- **PROCEDURES**

If you volunteer to participate in this study, you will be asked to do the following:

a) Participate in a semi-structured interview to ascertain the knowledge gaps that exist.

And/Or

b) Participate in a focus group with a team of three researchers and up to five other participants. You will be asked to share your opinions and feelings in relation to the transition from acute hospital care to home based care.

And

c) Participate in a workshop with other focus groups consisting of up to fifteen other participants and three researchers. You will be asked to collaborate with the other stakeholders and discuss how changes can be made in the transition from acute care to home based care that would positively impact on the patient's wellbeing, the clinical outcome and the efficiency of the service.

Your feedback is of utmost importance.

We do NOT want you to discuss any specific medical conditions you have.
We do NOT want you to divulge any personal information.
You will NOT be asked to describe any information about your health and wellbeing.

- **POTENTIAL RISKS AND DISCOMFORTS**

There are no known risks for participating in this research study, nor are there any costs for participating in the study. The information provided will help only the researcher with this project. Participating in this study may benefit future practice.

- **POTENTIAL BENEFITS TO SUBJECTS AND/ OR TO SOCIETY**

The outcome of this research is unlikely to benefit you directly. It is hoped that it will make a contribution to the overall health and wellbeing of the older person within the healthcare system by aiding in the design of a service to address the real issues older people, and the healthcare providers face, in the safe transition and continued care of the older person with a chronic illness from an acute hospital setting to their own home.

- **COMPENSATION FOR PARTICIPATION**

You will not receive any payment or other compensation for participation in this study. There is also no cost to you for participation.

You will not be referenced or credited for your participation in this research study, as your participation is entirely anonymous. A full report of findings will be offered on the completion of the research.

- **CONFIDENTIALITY**

Participant's privacy and confidentiality will be maintained by adhering to the guidelines as outlined by statutory legislation and the ethics of IT Carlow. Names or any other means of identification will not be used so individuals cannot be identified in any records of the interview process, focus group study, workshops or in any of the research reports. The information you provide will be used solely in this study and will not be used elsewhere. The information will not be provided to any third party. The reporting of the focus group and workshop will be gathered within the session and individual contributions will not be recorded or reported. No recording (audio or video), or transcript of the focus group session or workshop will be made.

Those participating in the interview process will be recorded on a password secured device. The audio will be uploaded to OneDrive as soon as possible after the interview and deleted from the device. All participants in the transcripts will be anonymised. The transcripts will be held in a secure, password protected place and deleted after use.

- **PARTICIPATION AND WITHDRAWAL**

You can choose whether you wish to take part in this research project. If you volunteer to be in this study, you may withdraw at any time without any consequences. During the interview and in the focus groups and workshop sessions you may refuse to answer any questions you do not want to answer.

- **RESULTS OF RESEARCH STUDY**

The results of the research study will be used as part of a master thesis. The results may also be presented at conferences or in journal articles. However, the data gathered will only be used by the members of the research team and at no point will your personal information or data be revealed.

If you wish to be given a copy of any findings from the research, please do not hesitate to contact me by phone or email. (See below)

- **IDENTIFICATION OF INVESTIGATORS**

If you have any questions or concerns about the research, please feel free to contact me

Trish Finegan
MA Design Researcher
DesignCORE
Institute of Technology Carlow
Kilkenny Road
Carlow R93 V960
trish.finegan@itcarlow.ie

Tel: 087 7565376

- **RIGHTS OF RESEARCH SUBJECTS**

If you have any concerns about your rights in this study, please contact Dr. PJ White, Design Lecturer and Researcher at DesignCORE, Institute of Technology Carlow by email on pj.white@itcarlow.ie

8.3 Interviews Consent Form

Institiúid Teicneolaíochta Cheatharlach
INSTITUTE *of* TECHNOLOGY CARLOW
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Interview Participant Consent Form

Title of Research: Health Service Design for Older People in the South East

☐ I……………………………………… voluntarily agree to participate in this research study.

☐ I understand that even if I agree to participate now, I can withdraw at any time during the process or refuse to answer any question without any consequences of any kind.

☐ I have had the purpose and nature of the study explained to me in writing and I have had the opportunity to ask questions about the study.

☐ I understand that participation involves a one to one interview undertaken at a time and place convenient to me.

☐ I agree to my interview being audio recorded,

☐ I understand that I will not benefit directly from participating in this research.

☐ I understand that all information I provide for this study will be treated within the limits of confidentially.

☐ I understand that a transcript of my interview in which all identifying information has been removed will be stored and deleted in line with It Carlow and statutory guidelines

☐ I understand that in the gathering of data for this research my identity will remain anonymous.

☐ I understand that quotes from the data gathered may be used in the report but that my identity will remain anonymous

☐ I understand that if I inform the researcher that myself or someone else is at risk of harm they may have to report this to the relevant authorities - they will discuss this with me first but may be required to report with or without my permission.

☐ I understand that signed consent forms and data gathered will be gathered, stored and deleted in line with IT Carlow and statutory guidelines.

☐ I understand that I am free to contact any of the people involved in the research to seek further clarification and information at any time.

Trish Finegan
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Tel: 087 7565376

Dr. PJ White,
Design Lecturer and Researcher at DesignCORE,
Institute of Technology Carlow,
Kilkenny Road,
Carlow R93 V960
pj.white@itcarlow.ie

I understand the procedures described above. My questions have been answered to my satisfaction, and I agree to participate in this study. I have been given a copy of this form.

________________________	________________________
Printed Name of Participant	Signature of Participant

Date ____________________

I believe the participant is giving informed consent to participate in this study

Signature of researcher: _________________________________

Date: _______________________________

8.4 Co-Design Session with Older People and Stakeholders Co-Production Workshop Consent Form

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At the Heart of South Leinster

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Focus Group and Workshop Participant Consent Form

Title of Research: Health Service Design for Older People in the South East – with particular emphasis on County Kilkenny

☐ I…………………………………… voluntarily agree to participate in this research study.

☐ I understand that even if I agree to participate now, I can withdraw at any time during the process or refuse to answer any question without any consequences of any kind.

☐ I have had the purpose and nature of the study explained to me in writing and I have had the opportunity to ask questions about the study.

☐ I understand that participation involves engaging in a half-day session comprising of one focus group and a workshop

☐ I understand that I will not benefit directly from participating in this research.

☐ I understand that all information I provide for this study will be treated within the limits of confidentially.

☐ I understand that in the gathering of data for this research my identity will remain anonymous.

☐ I understand that quotes from the data gathered may be used in the report but that my identity will remain anonymous

☐ I understand that if I inform the researcher that myself or someone else is at risk of harm they may have to report this to the relevant authorities - they will discuss this with me first but may be required to report with or without my permission.

☐ I understand that signed consent forms and data gathered will be gathered, stored and deleted in line with IT Carlow and statutory guidelines.

☐ I understand that I am free to contact any of the people involved in the research to seek further clarification and information at any time.

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I understand the procedures described above. My questions have been answered to my satisfaction, and I agree to participate in this study. I have been given a copy of this form.

______________________	______________________
Printed Name of Participant	Signature of Participant

Date ___________________

I believe the participant is giving informed consent to participate in this study

Signature of researcher: _______________________________

Date: _____________________________