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Older People and their Carers as Co-producers of Complex Care

A Study of Co-production in Caring for Ageing Populations in the Community

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ABSTRACT

Co-production is where citizens and clients actively contribute to the work of delivering public services and the production of publicly valuable outcomes. This thesis examines co-production in the care of ageing populations, as one of the greatest challenges facing 21st century governments. It comprises both theoretical and applied research at the point where two literatures, in co-production and in health and social care intersect, with important implications for policy and practice. A narrative review of the literature was conducted revealing gaps in the current analysis. From a top-down perspective, a systematic policy document analysis and key stakeholder interviews were performed, that illustrates the impact of emerging Australian health reforms on co-production. The main study of the thesis adopted a bottom-up perspective, that involved qualitative semi-structured interviews to capture the lived experiences of older people with complex needs and their carers as 'co-producers' of complex care in the community. This thesis provides frameworks for facilitating and sustaining the co-production of complex care that consider what influences people's propensity to co-produce in this context and how care tasks are distributed between clients, their informal carers and the service system.

DECLARATION

This is to certify that:

1. the thesis comprises only my original work;
2. due acknowledgement has been made in the text to all other material used;
3. the thesis is less than 100,000 words in length, exclusive of tables, maps, bibliographies, appendices and footnotes

_____

Louise M. Freijser

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INTRODUCTION

One of the greatest challenges facing 21st century governments is sustaining public health systems to meet demands associated with caring for ageing populations. Globally, populations are ageing, with the proportion aged 60 years and over expected to double, and those aged 80 years and older to more than triple by 2050 (UN, 2017). While there is great diversity among older people (with many remaining fit and well into later life), as we age the likelihood of developing chronic and degenerative conditions increases, as does the severity (WHO, 2015; UN 2019). As the need for care services continues to sharply rise in ageing populations, the nature of these demands is also shifting with technical advancements and specialisation and changing expectations. Meanwhile, the financial and human resources required to meet these needs are in diminishing supply (Muir, 2017). This burgeoning gap between supply and demand calls into question the future sustainability of public health systems (De La Maisonneuve & Martins 2013; UN, 2017). In formulating ways of addressing this looming crisis, governments have called on a variety of approaches. This thesis explores one of them, namely 'co-production' and other closely related approaches such as public participation in decision-making or 'co-design.'

In this thesis, co-production refers to active contributions of inputs, activities and behaviours by the public (as citizens and clients or third parties) to the delivery of public services and achievement of publicly valuable outcomes. The term was originally adopted in the context of public service delivery by Ostrom and Ostrom (1977) who stated that "co-production may be defined as the inputs and activities of citizens that affect the quality of services delivered" (p. 9). In the 1970s and early 1980s, co-production gained traction in the field of public management. However, it was largely overshadowed in subsequent decades by the pervasive movement towards marketisation of the public sector. Since the turn of the century there has been renewed interest in co-production, in the wake of the global financial crisis and as the shortcomings of market-based approaches have come to the fore. Co-production has evolved as an international and inter-disciplinary field of study, with a resurgence of interest particularly in health and social care. However, there are ongoing debates and disparities in how it has been defined and conceptualised in the literature (Verschuere, Brandsen, & Pestoff, 2012).

The analysis of co-production to date has been limited on two fronts. Firstly, it has been treated as an optional yet beneficial approach to service delivery, creating interest in the question of whether to co-produce. However, co-production is often not optional, as inter-dependencies exist in the delivery of many public services, where co-production is operationally embedded in the service or program. In other words, services cannot function without contributions by external actors. In this case, the question is not whether to co-produce, but rather how to make it function better. Secondly, co-

production has been treated as a generic phenomenon, however it is not necessarily directly applicable to health and long-term care of the elderly. The analysis to date has been largely concerned with co-production as an alternative approach to delivering care services associated with participation in service design and planning, as well as implementation. Academics and policy makers have enthusiastically embraced new approaches that engage clients in decision-making about service planning and design, without much consideration or examination of co-production as an operational element in the delivery of care services.

Co-production already exists in the delivery of complex care, although its antecedents and working mechanisms are only partially understood. There are complex inter-dependencies in the delivery of care services in the community, where co-production is necessary yet often beset by the very issues it seeks to address. The analysis thus far has also been largely top down, while the lived experiences of clients and carers has been afforded limited attention. This thesis addresses these gaps, providing a rich, diverse and nuanced context to examine the theoretical constructs of co-production, and how this resonates with health policy and practice in caring for ageing populations in the community.

Interest in the study of co-production has arisen as a way to improve the efficiency and effectiveness of providing services in the community. Co-production has also been credited with the potential to enhance local relationships and popular trust in government services. It is particularly germane as a field of study where services have no choice but to harness co-production, as a way to examine how these inter-dependences can be better managed. Co-production is a particularly pertinent frame for examining health and aged care for many of the aforementioned reasons. Health systems already represent some of the largest areas of government spending, which are set to face unprecedented increases in cost and demand in coming decades. As governments seek to decrease pressure on health systems, policy makers have sought to engage the public in efforts to decrease pressure on the health systems by avoiding or delaying costly admissions to hospital and residential care. However, health systems have had varying success in facilitating these approaches, as evidenced by the increasing prevalence and severity of chronic illness, high rates of preventable hospitalisations and health inequities (OECD, 2017). This thesis considers the benefits of co-production in the delivery of health and aged care, by exploring how and under what circumstances clients and their carers co-produce complex care in the community to inform how these processes can be better managed.

The following is an overview of the thesis. Chapter One charts the evolution of co-production theory and examines key debates and disparities in the literature, outlines the theoretical constructs and presents the working definition of co-production for this thesis. Chapter Two provides background on how co-production has been shaped by the changing landscape of health systems policy and practice. Chapter Three details the research rationale, design and methodology for this thesis. This research comprises both theoretical and applied policy research, by applying the theoretical constructs of co-

production to health policy and practice. A narrative review of the current analysis of co-production in the care services literature is presented in Chapter Four. Adopting a top-down perspective, Chapter Five examines the potential impact of recent health systems reforms in Australia on co-production and Chapter Six presents key stakeholder perspectives on the systemic challenges to the co-production of care service in the Australian context. Chapters Seven to Eleven adopt a bottom-up perspective, presenting the main study in the thesis that explores the lived experiences of older people with complex needs and their carers as co-producers. Frameworks for facilitating and sustaining the co-production of complex care in the community are presented in Chapter Twelve, followed by a concluding chapter providing a summary of the key theoretical and practical implications of the thesis.

CHAPTER 1

The Theory of Co-production

INTRODUCTION

Since it emerged in the US in the late 1970s, co-production has evolved as a multi-disciplinary and international field of study. This chapter charts how co-production has fared as a policy and program idea in the changing landscape of public administration and management. The key divergences in the literature on how co-production has been conceptualised are then discussed to provide a theoretical framework and definition for the purposes of this thesis. Other key aspects of the co-production literature are then examined including when and how co-production should be elicited and facilitated. This chapter sets up the foundation for examining co-production in health systems policy and practice, which is the central focus of this thesis.

1.1 THE DEVELOPMENT OF CO-PRODUCTION THEORY

The term 'co-production' first appeared in the services sector literature. In 1968, Victor Fuchs distinguished the 'new' services economy from the 'old' industrial economy, as representing a different relationship between the producer (i.e. paid employees of the service) and the consumer (i.e. clients of the service). In his study, 'The Service Economy', Fuchs (1968) noted that consumers and producers *work together to create value*. Gersuny and Rosengren (1973) first adopted the term in their formative book, 'The Service Society', in which the authors refer to consumers as 'co-producers' to describe their contribution to the production of services they consume, assigning them a role in the division of labour. In 1974, Gartner and Riessmann analysed the role of the consumer as a direct factor in the production of services. These, among other early contributions to the literature, provided a catalyst for the study of co-production.

The emergence of co-production as a field of study in public administration has been credited to the contributions of Nobel Laureate in Economics, Elinor Ostrom and her colleagues at Indiana University (Ostrom & Ostrom, 1977; Parks et al., 1981). These early commentators adopted a public choice perspective that applies economic tools to inform political decision-making (Tullock, 2008). In 1977, Elinor and her husband Vincent Ostrom introduced co-production as an alternative paradigm for considering the production process, which recognises the influence of citizens on the quality and cost effectiveness of public service delivery.

> The dominant model of the production process is a factory where input factors are combined to produce output. Only the production firm is involved in making goods. Hence, output

> occurs without efforts on the part of consumers. This model is appropriate for thinking about producing a wide variety of goods. However, it is not an appropriate model for thinking about the production of many services, particularly those in the public sector. Many services require high levels of co-production. Co-production may be defined as the inputs and activities of citizens that affect the quality of services delivered.
> (Ostrom & Ostrom, 1977, p. 9)

While studying urban reform in the US, Ostrom and her colleagues observed that citizens actively influenced the ability of police officers to produce outputs, such as an arrest, by giving evidence or reporting a victimisation in progress, and outcomes, such as decreased crime rates (Parks et al., 1981). These early authors observed that co-production is often inherent and instrumental in the delivery of public services (Brudney & England, 1983; Parks et al., 1981; Sharp, 1980; Whitaker, 1980).

> In many instances, consumer production is an essential complement to the efforts of regular producers; without the productive activities of consumers nothing of value will result. This appears to be characteristic of much public service production.
> (Parks et al., 1981, p. 1002)

Co-production resonated with the notion of citizen participation (Thomas, 2012). In the 1960s, citizen participation had gained momentum from civil rights movements in the US, emphasising the rights of the individual and popularising participatory ideals (Holmström & Röing, 2010). In her seminal work, 'A Ladder of Participation', Sherry Arnstein (1969) posited a spectrum from non-participation to citizen control. Citizen participation provided a way to enhance the role of the public as citizens, by providing them 'voice' and shared responsibility for determining the course of government (Thomas, 2012). Whitaker (1980), described co-production as taking citizen participation a step further, where "citizens might influence the execution of public policy as well as its formulation" (p. 241).

Citizen participation and co-production cast the public in different roles, namely, shaping and implementing public policy, respectively. These concepts stood in stark contrast to the traditional paternalistic approach in the public sector. Public involvement in Anglo-American democracies, as developed in the late 19th and early 20th century, was typically confined to the democratic process of electing government officials. Under this paradigm, the delivery of public services was the preserve of public servants, acting in the public interest, as stewards of limited government resources. This perspective casts the public in the role of passive recipients (Thomas, 2012).

The institutionalisation of citizen participation was first mandated in the US, as part of President Lyndon Johnson's 'Great Society' programs, with the push for "maximum feasible participation"

(Thomas, 2012; Cahn & Gray, 2012). By the end of the 1970s, government programs across America mandated citizen participation, a trend echoed in other democracies (Thomas, 2012). The citizen participation movement has also been influential for health systems policy, which is discussed further in Chapter Two. Despite gaining prominence in the public sector in the late 1970s and early 80s, the widespread adoption of market-orientated approaches largely overshadowed interest in co-production in the public administration discourse in subsequent decades (Verschuere, Brandsen, & Pestoff, 2012).

From the early 1980s, bureaucratic reform agendas of many OECD countries adopted private sector strategies, placing greater emphasis on efficiency and driving down resource demands on the public sector (Hood, 1991). Hood (1991) coined the phrase 'New Public Management' (NPM) to describe this trend. NPM represented a solution for the shortcomings of traditional public administration, that was seen to be overly concerned with processes, and consequently stymied manager's flexibility (Osborne, 2006). The promise of NPM was a greater focus on achieving results rather than following processes, providing managers greater autonomy and incentives to achieve them (Hood, 1991). NPM reforms have been enacted in health systems policy, with consequences for co-production in the delivery of health services.

Co-production was generally not a good fit under NPM, in part due to the primacy of performance management. For instance, it can be difficult to control or account for work performed by external actors and assign responsibility for performance. Co-production at times constitutes a 'complex exchange', where there is uncertainty about the features of the exchange, that includes a lack of clear specification of what co-producers are required to do (Brown et al., 2013). In addition, managers tend to require more subtle tools than rewards or punishments, featured under NPM, to elicit co-production efforts (Weaver, 2014).

The role of the public under NPM was largely that of 'quasi' customer (Thomas, 2012). Customer service, through quality assurance, customer satisfaction research and choice of provider under contractualism, was afforded greater emphasis under NPM (Bovaird, 2007). The public as 'customers' were given the right to exercise choice and voice (Osborne, 2010), while the formulation and implementation of public policy, for the most part, continued to be determined by managers and professionals (Bovaird, 2007). In response to rising dissatisfaction with managerial and contractualist approaches to service delivery and rising fiscal constraints, there has been renewed consideration of the active and productive role of the public in the delivery of public services (Alford, 2014; Osborne, 2006; Osborne & Gaebler, 1992).

A resurgence of interest co-production

Since the late 1990s, there has been a resurgence of interest in the public management discourse with ways to facilitate cooperation, as alternatives to: hierarchy and vertical line management of traditional public administration; and competition, price mechanisms and contracts under NPM (Alford & Hughes, 2008). A new paradigm has emerged where the mechanism of governance involves *collaboration*, based on trust and relational contracts, in the increasingly fragmented and inter-organisational context of public service delivery (Osborne, 2006; Osborne et al., 2013).

This new phase of public management focuses on the central theme of cooperation between organisations for achieving results (Alford & Hughes, 2008). The literature has brought up strategies for achieving inter-organisational cooperation such as partnerships, networks, coordination, and collaboration. In their influential book, 'Reinventing Government' Osborne and Gaebler (1992), while mostly expounding ideas from the NPM discourse, also recognised concepts from the emerging collaboration paradigm including co-production. Recent schemes such as 'joined-up governance' in the UK, 'whole of government' initiatives in Australia, and the emergence of 'interagency collaborations' in the US, reflect these approaches. The purpose being to create a seamless rather than a fragmented service system through horizontal and vertical coordination (Pollitt, 2003). Since the 1990s, health systems and services literature has been focused on how to better integrate and coordinate health services, as discussed further in Chapter Two.

Concepts such as 'network governance' referred to mechanisms of governance that are reliant on interpersonal and inter-organisational processes in the absence of authority (Kettl, 2002; Stoker, 2006). Stoker (2006) defines 'network governance' as "a particular framing of collective decision-making that is characterised by a trend for a wider range of participants to be legitimate members of the decision-making process in the context of considerable uncertainty and complexity" (p. 41). Network governance represents greater recognition of the legitimacy of a wide range of stakeholders, including citizens and clients (Stoker, 2006).

Ways of engaging citizens and clients in the provision and governance of public services, to meet the demographic, economic and political challenges facing welfare states in the 21st century, including co-production, have experienced a resurgence of interest in recent decades (Pestoff, 2009). Osborne (2006) uses the phrase 'New Public Governance' to describe "both a plural state where multiple interdependent actors contribute to the delivery of public services and a pluralist state, where multiple processes inform the public policy making system (p. 384). Bovaird (2007) refers to a 'radical reinterpretation' of public policy, marked by increased involvement of citizens and clients in the process of planning, designing, delivery and evaluation of public services. He observed that:

> Policy is now seen as the negotiated outcome of many interacting policy systems, not

> simply the preserve of policy planners and top decision-makers. Similarly, the delivery and management of service are no longer just the preserve of professionals and managers, users and other members of the community are playing a large role in shaping decisions and outcomes.
> (Bovaird 2007, p. 846)

Some of the recent co-production literature has drawn on 'service-dominant logic' (Osborne et al., 2013). Rather than conceiving (regular) producers as satisfying the needs and desires of the consumer, Norman (2001) refers to 'service logic' where "they together form a value-creating system" (p. 98). 'Service-dominant logic' posits that co-production is an intrinsic element of all services (Vargo & Lusch, 2008). Osborne and colleagues (2013) identified three key features to service-dominant logic. Firstly, in contrast to producing a tangible good, service delivery is an intangible process. Secondly, the value created by services is both produced and consumed at the same time, placing greater emphasis on not only outputs, but the *experience* of the service (Alford, 2016a). Thirdly, consumers are *obligate* co-producers of service outcomes (Norman 2001). Interest in (public) service-dominant logic has helped further interest in inherent forms of co-production.

> From a service-dominant approach, there is no way to avoid the co-production of public services because it is an inalienable element of such services. The question thus is not how to 'add-in' co-production to public services but rather how to manage and work with its implications for effective public service delivery.
> (Osborne & Strokosch, 2013, p. 146)

In recent years, co-production has widely influenced public service policy globally (Alford & Yates, 2015). However, there are different streams of thought on co-production and how it is operationalised between countries. In the UK, co-production has been fostered under the political ideology of localism, austerity measures, and the 'Big Society' agenda (Lowndes & Pratchett, 2011). To quote the British Prime Minister, David Cameron (2007), "the public become, not the passive recipients of state services, but the active agents of their own life. They are trusted to make the right choices for themselves and their families. They become doers, not the done-for" (cited in Boyle & Harris, 2009, p. 2). In Australia, co-production is increasingly embedded, albeit implicitly, in policies at the state and national level (Alford & Yates, 2015; Holmes, 2011), as illustrated in Chapter Five.

Co-production has been heralded as a mechanism for improving the quality and decreasing the cost of public service delivery (Parks et al., 1981; Verschuere, Brandsen, & Pestoff, 2012). However, others have cautioned that co-production is not a silver bullet and is not necessarily universally beneficial. Alford and Hughes (2008) are wary of 'one-size-fits-all' approaches, calling for "public value

pragmatism", whereby, "the best management approach to adopt depends on the circumstances, such as the value being produced, the context, or the nature of the task" (p. 130). It has also been suggested that the perceived "cure all potential" of co-production may reflect the elasticity of the term (Needham, 2008). Thus far, the study of co-production has been hindered by a lack of definitional and conceptual clarity (Verschuere, Brandsen, & Pestoff, 2012). The following explores key debates and divergences in the general co-production literature to provide a conceptual foundation and working definition for the purposes of this research.

1.2 DEFINING CO-PRODUCTION

Co-production has evolved from its origins in the US service sector, with increasing inter-disciplinary and international interest (Verschuere, Brandsen, & Pestoff, 2012). Despite renewed and sustained interest in co-production to date, most of the literature is theoretical, reflecting the ongoing quest for conceptual clarity. As noted by Verschuere and colleagues (2012), "we still lack a comprehensive theoretical and systematic empirically orientated understanding of what happens when citizens and/or the third sector are drawn into public service provision, and of the various aspects of co-production" (p. 1086). This chapter makes explicit how co-production is defined and conceptualised to provide a platform for examining co-production in delivery of health and social care services for older people with complex needs. The following discussion examines the varying dimensions of how co-production is conceived in the literature including: how we perceive who co-produces; what constitutes co-production efforts; whether co-production is voluntary; and whether co-production is inherent or optional.

Who constitutes a 'co-producer'?

The literature varies as to who constitutes a 'co-producer'. In its early years, the focus was on "the productive role of consumers as co-producers of the services they receive", or "consumer producers" (Parks et al., 1981, p. 1002: original emphasis). Ostrom (1996) later revised her definition to, "the process through which inputs used to produce a good or service are contributed by individuals who are not 'in' the same organisation" (p.1073: emphasis added). A range of different external actors have been seen to perform the role of 'co-producer', in varying and overlapping ways, which has added to the confusion.

"Co-producers", as used here, refers exclusively to the delivery of public services. As citizens, the public contribute to the production of value that is consumed collectively by the citizen (Alford, 2009). For example, placing rubbish in designated bins contributes to the creation of a healthier environment for the community as a whole. However, in many cases the public also act in other roles as co-producers to create value (Moore, 1995; Alford, 2009). As clients, the public contribute to the

production of value they consume privately as the main recipient of the service. For example, patients providing information to health professionals about their symptoms, to gain an accurate diagnosis and treatment plan to improve their own health outcomes. In addition to their role as clients, as citizens they also contribute to the creation of public value through creating a healthier and more productive society. Clients have varying types of relationships with public service organisations (PSOs), constituting a mixture of different roles including paying customer, obligatees (i.e. those compelled by legal obligation to comply), and beneficiaries (Alford, 2009; Moore, 1995). In the context of care services, clients are typically beneficiaries but may also be paying customers where they are required to make co-payments.

People close to clients often play a pivotal role in the co-production of public services, particularly in the delivery of highly salient and enduring services (which is indicative of many health and social care services) (Pestoff, 2012; Porter, 2012; Verschuere, Brandsen, & Pestoff, 2012). In recognising the efforts of people close to the clients of social services, Pestoff (2012) stated:

> It is important to realise that the participants in and beneficiaries of co-production are not necessarily the same person. If they are not, they need to ask whether they are family members, relatives, friends, neighbours? In publicly financed social services, particularly of the enduring type the participants in co-producing services are not always identical with the subject of the service or the beneficiaries. (p. 21)

In the health and aged care sectors, the term 'carer' (also referred to as informal or family caregivers in the literature) is here used in reference to people who contribute informal care and support to someone close to them (outside of paid employment, volunteering as part of an organisation, or for education or training purposes). The contribution of co-production efforts by carers is examined in this research, as a sub-set of volunteer co-production, who are not formally organised. They contribute to the delivery of services to people with whom they have a social relationship. Carers act as third parties, who as noted by Alford (2009) "can assist (or in some cases hinder) the organisation in various ways in its efforts to elicit co-production from its clients" (p. 201).

Volunteers as co-producers contribute to the production of value consumed privately by other citizens (as well as public value), who are unpaid yet formally organised as part of the NGOs or not-for profits that make up the 'third sector'. The phrase 'the third sector', coined by Etzioni in 1973, has been defined where "something is ruled neither primarily by market logic nor via a bureaucratic chain of command, it must be part of the 'third' sector" (Corry, 2010, p. 13).

Co-producers may act individually or collectively to contribute to the delivery of public services (Brudney & England, 1983; Alford, 2009). Brudney and England (1983) refer to "group co-

production" that involves "voluntary, active participation by a number of citizens and may require formal coordination mechanisms between service agents and citizen groups" (p. 63). Formally organised, volunteers differ from co-producers as they are analogous to the suppliers of the service, not its consumers (Alford, 2009). Third sector organisations (TSOs) have also been included under the banner of co-production. In limiting the use of co-production to citizen and client contributions at the operational level, Pestoff, Osborne and Brandsen (2006), use the terms 'co-governance' and 'co-management' to distinguish third sector involvement in planning and production of public services respectively. Whilst acknowledging the contributions of volunteers and TSOs in achieving government purposes, this research is primarily concerned with client and carers as co-producers whose contributions are not formally organised.

What constitutes co-production efforts?

Co-production has been used as a heterogeneous or umbrella term (Verschuere, Brandsen & Pestoff, 2012). In the literature, public involvement across a wide range of activities has been placed under the rubric of co-production, including commissioning, planning, designing, managing, delivering and evaluating public services (Bovaird, 2007; Loeffler et al., 2013). Co-production in this thesis refers exclusively to active contribution of time and effort by citizens and clients to the production process of delivering public goods or services.

The provision of public services encompasses two distinct, yet interrelated, processes. One is *decision-making* about whether and how to deliver a benefit or service. The other is *production* which involves active contributions of resources including time and effort to implementing these decisions to produce value. Some of the literature has included both, under the banner of co-production. There are typologies that distinguish between co-production with and without involvement in the decision-making role, including planning and/or design of services. Public involvement in production and design has been referred to as "enhanced co-production" (Osborne & Strokosch, 2013) and has been credited with the potential for more transformational change (Bovaird, 2007). According to Alford (2016a):

> Co-production must entail external actors performing some of the actual work instead of (or in addition to) deliberating about whether or how to do it. This is at odds with commentators who envisage co-production as a consultative arrangement; it is about production, rather than governance or deliberation. (p. 158)

An argument for distinguishing between decision-making and production roles is that different actors may perform different roles in each of these processes. The term co-production is used here in relation to the producing role, rather than the deciding role. However, involvement of the public in

both roles is examined in this research, particularly given the role of autonomy, and participation in decision-making in eliciting behaviour change (Weaver, 2014).

The core meaning of co-production is that it involves active contributions by external actors (i.e. citizens and clients). There have been differing views on the nature of the relationship between co-producer and government agent or 'regular producer'. Some commentators have given prominence to social or relational aspects of the relationship, in some cases wholly rejecting more transactional exchanges in the definition (Boyle & Harris, 2009). In his formative work, Bovaird (2007) specified the longitudinal aspect of interactions between internal and external providers, defining co-production as:

> The provision of services through *regular, long-term relationships* between professionalized service providers (in any sector) and service users or other members of the community, where all parties make substantial resource contributions. (p. 847: emphasis added)

The emphasis on relational aspects reflects co-production that is reliant on 'collaboration'. Collaboration draws on social bonds that are shaped by the frequency of their dealings, information sharing, the fostering of trust, and agreed purposes between co-producers and government agents (Alford, 2009; Bovaird, 2007). However, the focal feature of co-production is the *operational relationship*, where the public and PSOs are involved in the production process of achieving government purposes, that may occur on a spectrum from purely transactional to highly relational.

The literature offers varying understandings of the nature of the interaction between co-producers and PSOs. Some commentators have suggested that the scope of co-production be confined to direct interactions with government agents in the same production process (Bovaird, 2007; Brandsen & Honingh, 2015; 2018). Brandsen and Honingh (2015) specified co-production as:

> A relationship between a paid employee of an organisation and (groups of) individual citizens that requires a direct and active contribution from these citizens to the work of the organisation. (Brandsen & Honingh, 2015, p. 5)

A distinction is also made between core and complementary co-production based on "the proximity of the tasks that citizens perform to the core services of the organization" (Brandsen & Honginh, 2015). However, the authors concede that what is considered 'core' work of the organisation is open to interpretation and may need to be defined on a case by case basis. The word 'direct' is also used, which may relate to whether tasks are performed conjointly during direct service interactions or directly related to the core work of the organisation.

In the early literature, co-production was defined as encompassing both direct and indirect contributions. In their seminal work, Parks and colleagues (1981) defined co-production as:

> A mixing of productive efforts of regular and consumer producers. This mixing may occur directly, involving coordinated efforts in the same production process, or indirectly through independent, yet related efforts of regular and consumer producers. (p. 1002)

In keeping with its original usage, Alford (2009) defined co-production as an active contribution that is, "conjoint with agency production, or is independent of it but prompted by some action of the agency" (p. 23). He provides examples where the public contribute to the production process without contributing directly or conjointly with government agents. There is a spectrum between complete external production (self-service or self-help) and complete internal production. Co-production occurs in the space between these poles, where *both* parties contribute to the production process in varying ways and extents. On this spectrum is the phenomenon of 'nudge', where policy outcomes are produced by shaping people's contexts, by subtly reminding or warning them to behave in a certain way, rather than coercing them to do so (Thaler & Sunstein, 2008).

For the purpose of this thesis, co-production includes both contributions performed directly with or independently yet prompted by the relevant government agency towards the achievement of service outputs as well as outcomes. As Alford and Yates (2015) put it:

> We see co-production as including not only conjoint activity by both government personnel and citizens/service-users, but also *any activity by one which adds value ('produces') and is at least partly prompted by some action or behaviour of the other* – particularly where the citizen co-producer's behaviours contribute in some way to achieving publicly valuable purposes (e.g. reduced health spending, or better environmental outcomes). (p. 161: original emphasis)

This is an important distinction where the achievement of service objectives typically involves coordination across different services, organisations and sectors, as well as formal and informal providers, as in the case of caring for ageing populations in the community.

Is co-production voluntary?

Another divergence in the literature has been whether co-production only applies where it is voluntary. In arguing that co-production is voluntary, Whitaker (1980) ruled out compliance, as acting out of fear of reprisal or acting out a habituated set of behaviours. In contrast, 'cooperation' is *intentional and voluntary*. However, this may be an issue of semantics, as noted by Alford (2009):

> The consensus is flawed in ruling compliance out of the domain of co-production. The reason is that it confuses compliance with compulsion. Strictly speaking, compliance is where people *act in accordance with* agency requirements. They do so either voluntarily or because of compulsion. (p. 22: original emphasis)

Alford (2016b) observed that even compliance has an element of voluntarism, thus co-production can be "at least partly voluntary" (Alford, 2009, p. 23). Although voluntary, it has been noted that rational choice or free will does not necessarily factor into the equation where services are dependent on co-productive efforts for the service to achieve its desired purposes (Brandsen & Honingh, 2015). Whitaker (1980) referred to "soft service activities" where co-production is an operational element of service delivery. Meanwhile, Sharp (1980), coined the phrase "captured co-production" in reference to clients having little choice but to participate if they are to gain value from the service. In other words, the 'option' to co-produce is often part of a 'choice set' where other options do not represent an opportunity to have their needs met, where co-production is necessity.

The key distinction here is between voluntary and coerced or non-voluntary compliance. Co-production is at least partly voluntary. The question of whether mundane compliance constitutes co-production, touches on another question about the nature of co-production, whether co-production is an inherent part of the production process or an optional extra.

Co-production, inherent or optional?

There are variations in the literature on whether co-production is inherent in the delivery of services, an optional design element, or both. Parks and colleagues (1981) took the latter stance. They identified two "ideal-types" of co-production. In the first "ideal-type", contributions by 'regular producers' (i.e. 'professional providers' of the service) can be substituted by 'consumer producers' (i.e. citizens and clients who contribute to the delivery of the service or 'co-producers'). In this case, co-production is not structurally required, but responsibility for certain inputs or activities can be transferred onto citizens or clients. Thus, co-production can be utilised as a *substitute* for the work of government agency and is therefore optional.

In the second "ideal-type", there is an *interdependent* relationship (Parks et al., 1981). In this case, the delivery of the service is dependent on inputs from the citizen or client. Here, co-production is inherent, as it is *structurally embedded* as an operational element that is necessary for achieving service objectives.

> In many instances, consumer production is an essential complement to the efforts of regular producers; without the productive activities of consumers nothing of value will result. This appears to be characteristic of much public service production. (Parks et al., 1981, p. 1002)

In reality, the production of public services often combines interdependent and substitutionary types of co-production (Parks et al., 1981). The view that co-production is often an inherent part of the production process has long been held in the literature (Alford, 2016b; Verschuere, Brandsen & Pestoff, 2012; Loeffler et al., 2008; Parks et al., 1981; Sharp, 1980; Whitaker, 1980). There has been a tendency by some commentators to treat co-production as an optional extra (Boyle & Harris, 2009), while others have claimed that co-production is inherent in the delivery of *all* services (Vargo & Lusch, 2004; Osborne & Strokosch, 2013).

In examining the inherence of co-production, Alford (201b) refers to the *degree of dependence* on co-production, where government purposes can only be achieved with the contribution of an action, behaviour, capability or resource provided by a co-producer. This is influenced by a range of factors including: the extent that the co-producer (citizen or client) has a monopoly of skills and resources required; the significance of the co-producer's capabilities to the production process; the degree of integration between the work of the organisation and the co-producer; and the extent to which co-producers are required to change themselves (Alford, 2016b). The practical implications of interdependent and substitutional forms of co-production are discussed below.

1.3 TO CO-PRODUCE OR NOT TO CO-PRODUCE, IS THAT THE QUESTION?

How to determine whether to enlist co-production has been debated in the literature. Initially, whether to co-produce was considered on economic terms, drawing on Public Choice Theory (Ostrom & Ostrom, 1977; Parks et al., 1981). However, reducing the decision of whether to utilise co-production to an analysis of marginal costs, (weighing up of relative *monetary* costs in wages of internal actors against opportunity costs for external actors), has since been challenged (Verschuere et al., 2012). Alford (2016a) proffered criteria to consider when determining whether to utilise co-production, including *service*, *strategic*, and *relationship* costs.

Service costs and benefits refer to the relative capabilities of internal and external actors (Alford, 2016). Based on the given circumstances, internal or external actors may have a greater capacity to perform the task. Thus, the choice of whether to utilise co-production can have implications for the quality of the service.

> In some situations, citizen co-producers may constitute well-meaning but bumbling amateurs, whereas in others they may have a real edge in knowledge of or legitimacy with a particular community or constituency. (Alford, 2016a, p. 163)

Relationship costs are those "concerning dealings with the other party to make the arrangement work", which might entail: specifying the task to be performed and by whom; encouraging or incentivising; facilitating the process; and determining whether it has been done (Alford, 2016a, p.

163). There are also strategic costs and benefits to consider, where co-production has an impact on the organisation beyond the delivery of the service such as influencing the reputation or legitimacy, the distribution of risk, or the mission or values of the organisation (Alford, 2016a).

1.4 ELICITING AND FACILITATING CO-PRODUCTION

Whether to co-produce may not be the question, given co-production is often structurally required due to dependency on contributions from external actors for the achievement of service objectives. Where services are inter-dependent or necessary, the question is not whether to co-produce but rather how to elicit and facilitate it. Whether co-production occurs is influenced by the propensity to co-produce. Theorising on people's propensity to co-produce has been the central focus in much of the co-production literature and is said to be the combination of their *motivations* and *ability* that influence the *willingness* to co-produce (Alford, 2009). According to Alford (2009) government agencies may seek to increase clients co-productive behaviours using motivators and facilitators.

Willingness to co-produce is induced by a complex range of *motivators.* The public administration and social science literature identifies a variety of drivers motivating people to co-produce (Verschuere, Brandsen, & Pestoff, 2012). Drawing on public choice theory, an assumption popular among some economists is that people co-produce when the benefits of doing so outweigh the costs, that people are 'rational utility-maximisers' motivated by self-interest (Verschuere, Brandsen, & Pestoff, 2012). However, the limitations of self-interest as the *sole* motivator of co-production have been widely documented (Alford, 2009; Thomas, 2012; Rosentraub & Sharp, 1980; Verschuere, Brandsen & Pestoff, 2012). Some writers have demonstrated that intrinsic rewards, social connection and moral values also factor into people's motivations to co-produce (Alford, 2009; Thomas, 2012; Rosentraub & Sharp, 1981; Verschuere, Brandsen, & Pestoff, 2012). For instance, instilling a sense of self-efficacy has featured in chronic disease management that is reliant on behaviour change to improve health outcomes (Bodenheimer et al., 2002). Particular attention is given to the influence of intrinsic rewards on health behaviours in Chapter Two.

The propensity to co-produce is also considered to be a product of the *ability* to co-produce (Alford, 2009; Pestoff, 2012; Verschuere, Brandsen, & Pestoff, 2012). The willingness to co-produce may be influenced by the perceived ability to do so. The propensity to co-produce can be influenced by two types of facilitators (Alford, 2009). First, making the task easier, such as decreasing the 'transaction cost' or the time and effort required to perform the task. Second, is to increase their capacity to co-produce, such as providing information, education and training (Alford, 2009; Verschuere, Brandsen, & Pestoff, 2012). Technology may influence the proclivity to co-produce based on the capabilities and resources required. Technologies can be instrumental to some forms of co-production, and to influence the inclination to co-produce given varying willingness, skills and resources to utilise

technology for co-production (Meijer, 2012; Paletti, 2016; Verschuere, Brandsen, & Pestoff, 2012). This is an important consideration given the increased utilization of Information and Communication Technology (ICT) in the health system.

The propensity to co-produce is also influenced by access to the requisite material resources, although the analysis has been largely concerned with motivations and abilities. Porter (2012) observed the need for organisations to account for resource contributions of time, money and intangible efforts, required from co-producers. In addition, whether co-production occurs may also be dependent on inputs from other external actors or third parties (i.e. those not acting as professional/paid public service providers or private for-profit providers). Public services and systems of service delivery tend to involve "networks of actors" in the "task environment" (Porter, 2012; Verschuere, Brandsen, & Pestoff, 2012). In education, Porter (2012) identified "polycentric networks of actors" that have supportive or inhibitive influence on co-production. However, limited attention has been afforded to the study of co-production by people in clients' social networks acting as third parties. In the health and social care sector, informal care providers or 'carers' may contribute significantly to the achievement of government purposes as further explored in this thesis.

The compliance literature, being concerned with behaviours, can also inform co-production. In his significant paper 'Compliance Regimes and Barriers to Behavioural Change', Weaver (2014) provides a useful overview, detailing barriers to behaviour change across three categories. The first, is external issues to 'perceived incentives' including sanction, monitoring and enforcement problems. The second, relates to the 'willingness' to comply, including information and cognition shortfalls, attitude and beliefs problems, and peer effects. The behavioural economics literature provides insights into cognitive and decision-making limitations that may skew decisions away from rational choices (Kahneman, 2003; Thaler & Sunstein, 2008). The third, is about 'capacity', which Weaver (2014) sees as autonomy and resource problems. In compliance, resources can be critical, and encompass not only financial assets but other resources such as health, human capital, social networks and proximity to public infrastructure. As Weaver (2014) says, "targets who have multiple resource disadvantages are likely to have particularly severe problems complying with some policies" (p. 249). Weaver (2014) also highlights autonomy as influential to compliance, "when individuals' behaviour depends on conditions and decisions by others over which they have limited control, and compliance is blocked by others not due to active hostility to that behaviour, but because they have conflicting priorities" (p. 250). This provides a holistic consideration of the barriers to compliance, and consequently the propensity to co-produce where behaviour change is required. There are parallels in the health policy discourse and the compliance and co-production literature relating to how to encourage citizens and clients to actively contribute to the achievement of better health outcomes, as explored in Chapter Two, and throughout the thesis.

CONCLUSION

Co-production has undergone a renaissance as governments grapple with the demographic, economic and political challenges in the 21st century, in increasingly fragmented and silo-bound service systems. Co-production holds the promise of improving the effectiveness and efficiency of public service delivery. However, it is not universally beneficial. Where it is necessary, public servants are tasked with eliciting and facilitating co-production and mitigating potential distributional consequences caused by disparities in people's propensity to co-produce.

The literature is divided on how co-production is conceptualised. The following definition has been devised for the purposes of this research into the role of co-production in the delivery of services for older people with complex and ongoing care needs. Co-production is defined as:

> *Active contributions of inputs, activities and behaviors by the public (as citizens and clients or third parties) to the delivery of public services and achievement of publicly valuable outcomes.*

In this definition co-production is:

- Active contributions by the public as co-producers in the form of *inputs, activities* and *behaviours* to the *delivery* of public services;
- The public making co-productive contributions as *citizens* and *clients* or *third parties* including *volunteers* and *carers* (i.e. representing a sub-set of volunteering that is performed informally by people in the clients' social network);
- Co-producers working conjointly with professional providers during direct interactions or performed *independently* (yet prompted in some way by the relevant government agency);
- An *operational relationship* between the co-producer and PSO that may occur on a spectrum from purely *transactional* to highly *relational*;
- Contributions made directly to the achievement of program or services *outputs*, and indirectly yet contributing to the achievement of service objectives and publicly valuable *outcomes*; and
- Inter-related yet *separate* from public participation in decision-making about service planning and design (i.e. co-design)

The focus of this thesis is the phenomenon of co-production of government purposes of caring for ageing populations, specifically the delivery of health and social care services for older people with complex needs. The next chapter provides background on health policy and considers the changing role of the public as co-producers of care services.

CHAPTER 2

Health Policy: From Paternalism to Partnerships

INTRODUCTION

This thesis examines co-production in caring for ageing populations in policy and practice. Health policy, as nested in public policy more generally, has implications for co-production. The shifting landscape of health and social care has shaped the nature of contributions required from clients and their carers to achieve service objectives. Put another way, it shapes how co-production (as defined in the previous chapter) has been employed as an operational element in the delivery of care services. Historically, the dominant biomedical model adopted a paternalistic perspective of 'patients' as passive recipients of care provided by health professionals. However, transitions towards ageing populations and increasing proportions of the populations with complex needs requiring long-term care have called for different approaches. As governments seek to address people's complex care needs in the community, policy makers have turned their attention to integration and partnership approaches to care. This chapter charts key trends in health system policy and practice, drawing inferences on the implications for co-production. This provides context and foreshadows an analysis of the potential impact of recent health system reforms on co-production later in this thesis.

2.1 MODELS OF CARE

The delivery of care services has changed over time as models that shape ways of thinking about health that are held by society have shifted. Many models of health and cultural beliefs about health exist and influence the way health system resources are shaped and used, including the role of the public in addressing health through health policies. Health policies are "decisions, plans, and actions that are undertaken to achieve specific health care goals within a society" (WHO, 2019a, p. 1). The following is a brief overview of the most prevailing models of health and their implications for health policies and the contributions of clients and their carers as co-producers of these services.

The Biomedical Model

The prevailing model of western health systems since the mid-19th century has been the biomedical model, which is concerned with physical and biological aspects of disease, illness or disability (Wade & Halligan, 2004). In this tradition, health is defined as the absence of disease, and care services are concerned with the diagnosis, cure and treatment of established conditions. The biomedical model of care is provider-centric as it is concerned with the provision of medical services by specialised health professionals. Based on this paradigm, Western health systems were originally designed to treat

disease and injury through medical or surgical interventions by health professionals in institutional settings. Historically, health systems were characterised by large public hospitals and single practitioner general practices (Gröne & Garcia-Barbero, 2001).

As new technologies and treatments have been developed over the 20th century, there has been increasing pressure on hospitals and health professionals to diagnose, treat and cure disease. Dependency on specialised knowledge of health professionals and technology to address existing health issues has become increasingly costly. It also creates a knowledge and power imbalance between professional providers and their clients as 'patients'. These clients tend to be confined to a *passive* role, acting in compliance with services in the form they are bestowed on them by professional providers. According to Wade and Halligan (2004) the biomedical model is based on the belief that, "the patient is a victim of circumstance with little or no responsibility for the presence or cause of the illness – the patient is a passive recipient of treatment, although cooperation with treatment is expected" (p. 1398). The biomedical model was not concerned with the role of patients and the public as co-producers in delivery of care or improving health outcomes.

The biomedical model approach to health services continues to make significant contributions to improving health outcomes, with many common causes of death of previous generations now being treated or cured by medical interventions in the acute sector. However, gains in life expectancies, along with the rise in chronic illness and multi-morbidity, has contributed to the emergence of new challenges faced by governments to meet the health care needs of their populations, along with critiques of the biomedical model to address them (Powles, 1973).

The Behavioural Model

Since the 1970s, alternative perspectives on health and approaches for addressing the health of populations have emerged, with the proliferation of non-communicable diseases (i.e. chronic conditions linked to lifestyle factors). Recognition of the influence of people's lifestyles on their health, sparked the widespread adoption of health policies and community programs aimed at changing individual's health-related behaviours. In Australia, the stance advocated was, "a positive philosophy of personal responsibility for health is required in the community at large – stimulated by health professionals at all levels and also by mass media" (Hetzel, 1976, p. 290). This included the 'Life - Be in it' mass media campaign promoting healthy behaviours in Australia in 1975. In 1976, the 'Prevention and Health: Everybody's Business' report was published in the UK (Great Britain Department of Health and Social Security, 1976), followed in 1979, by the 'Healthy People Report' in the USA, both advocating behavioural approaches to health promotion (Richmond 1979). In 1974, the 'Lalonde Report' was published in Canada which proposed four determinants of health including biology, health services, lifestyles and environment. The Lalonde Report foreshadowed the later

inclusion of broader determinants of health, rather than focusing solely on behavioural change to address lifestyle factors (Lalonde, 1974).

In the 1970s and '80s, behaviour modification programs proliferated drawing on psychological theories including: the Health Belief Model (Becker, 1974); Social Learning Theory (Bandura, 1977); the Theory of Reasoned Action (Ajzen & Fishbein, 1980); and the Stages of Change Model (Prochaska & DiClemente, 1984). The emphasis was placed on the individual to take responsibility for changing behaviours to prevent health problems and improve health outcomes. While not adopting the terminology, the behavioural model is concerned with engaging the public to co-produce better health outcomes. However, these lifestyle approaches focusing on behaviour modification failed to address the broader influences on health. This failure was acknowledged in 'The Black Report' published by the UK Department of Health and Social Security (1980), which illustrated that health inequities had continued since the establishment of the National Health Service (NHS) in 1948, not due to the failings of acute services, but *social inequalities*. It was argued that while behaviours play a part in influencing health, social and economic factors including disparities in income, education, housing, employment and condition of work, were the primary cause of inequalities in health. Proponents of lifestyle interventions were criticised for "promoting a victim-blaming ideology by neglecting the importance of social influences on health and disease" (McLeroy et al., 1988, p. 351). In addressing these shortcomings, the socio-ecological model of health emerged.

The Social-ecological Model of Health

A key turning point for re-thinking health systems occurred in 1978, at the International Conference on Primary Health Care of Alma Ata organised by the World Health Organization (WHO). The goal of 'Health for All by the Year 2000' set out in the conference's 'Alma Ata Declaration' affirmed basic health care as a fundamental human right and called for the re-orientation of health systems towards health promotion and primary health care (PHC). The Declaration was critical of the predominance of elitism and medical over-specialization and top-down health campaigns that were characteristic of many health systems. It called for a change in perspective on the role of the public in the health systems and service delivery, avowing that "people have the right and duty to participate individually and collectively in the planning and implementation of their health care" (WHO, 1978, p. 1: Emphasis added). This statement set the foundation in the policy discourse for greater participation and partnership approaches to care.

However, 'comprehensive' PHC as set out in the Declaration was swiftly set aside as too idealistic and expensive, in its place there was a widespread adoption across western countries of 'selective' PHC. This selective model, proposed by Walsh and Warren (1979), focused on new technological breakthroughs and espoused a package of cost-effective interventions to address specific diseases that

were seen as 'best-buys' (i.e. having the best cost-effectiveness ratio for improving overall population health). However, the adoption of this selective approach has since been lamented for placing too much emphasis on specialists to address specific diseases rather than addressing the root causes of disease (Werner, Sanders, & Weston, 1997). In response to poor uptake of comprehensive PHC in industrialised countries, the shortcomings of individualised approaches to behavioural change, and bourgeoning health budgets the WHO reconvened in 1986 with the First International Conference on Health Promotion.

At this conference, the 'Ottawa Charter on Health Promotion' agreement was signed (WHO, 1986). The Charter did not reject behavioural and lifestyle approaches, instead included them as part of five key principles for health promotion as described in Table 2.1.

Table 2.1

Principles for health promotion

Principles	Description
Building Healthy Public Policy	Inter-sectoral approaches that recognise the need for healthy public policies outside the health sector that influence health.
Creating Supportive Environments	Addressing the broader determinants of health including social, economic and physical environment factors that influence behavioural determinants of health, linking people and their environment as the basis for a socio-ecological approach to health.
Strengthening Community Actions	Increase the ability for communities to perform health promotion works through community action in setting priorities, designing and planning strategies and implementing them to achieve better health, which is "at the heart of the empowerment of communities."
Developing Personal Skills	Acknowledge the role that lifestyle and behaviours have on health, and the need to support personal and social development through the provision of information and education and skills to enable people by increasing their ability to exercise more control over their own health and environments, and to make healthy choices.
Reorienting Health Services	Where the responsibility for health promotion is shared across informal and formal actors, who must work together, to refocus health services on the total needs of the individual as a whole person. The reorientation of health services beyond clinical and curative services, focused on hospital-based care and extensive technological diagnostic and interventions to a community-based system that is focused on individual needs: on health, rather than disease.

Note. WHO, 1986, p. 2-3.

Since the 1970s, other models of health gained some prominence alongside the predominant biomedical model, that acknowledge the broader determinants of health (see Table 2.2). The social model draws heavily on the principles set out in the Ottawa Charter, focusing on the broader determinants of health, inter-sectoral collaboration, the reduction of health inequities, access to health care, and the empowerment of individuals and communities. The ecological model is concerned with

the reciprocal relationship between individuals' health-related behaviours and the environments in which they live. Drawing on these models, the socio-ecological model of health takes the view that health is determined by influences at multiple levels including public policy, community, institutional, interpersonal and intrapersonal factors or determinants of health (McLeroy, et al., 1988). Co-production is reflected in this model of health, which acknowledges the role of the public in achieving better health outcomes and the need for formal and informal actors to "work together".

Table 2.2

The socio-ecological model, determinants of health

Determinants of health	Definition
Intrapersonal factors	Characteristics of the individual, such as knowledge, attitudes, behaviour, self-concept, skills etc.
Interpersonal factors and primary groups	Formal and informal social networks and social support systems, including the family, work group, friendship networks.
Institutional factors	Social institutions with organizational characteristics, and formal (and informal) rules and regulations for operation.
Community factors	Relationships among organisations, institutions, and informal networks within defined boundaries.
Public policy	Local, state, and national laws and policies

Note. McLeroy, et al., 1998, p. 255.

The Alma Ata Declaration re-defined health as: "a state of complete physical, mental and social wellbeing, and not merely the absence of disease or infirmity" (p. 1). In turn, it expanded the scope of the health system beyond reactive clinical and curative care to include prevention. There are three levels of prevention: primary, secondary and tertiary prevention. Primary prevention is focused on eliminating or reducing risk factors and promoting and protecting health before a condition has developed; Secondary prevention involves preventing the progression of disease through early detection and intervention; and Tertiary prevention is concerned with reducing the impact of established diseases, by reducing further progression and improving quality of life for people with diagnosed illness and disease, including chronic disease management (WHO, 2019b).

Both the Alma Ata Declaration and the Ottawa Charter re-cast the role of citizens and clients of health services in the health system and delivery of health services, making explicit references to their right and responsibility to participate and be involved in the planning and implementation of services. They called for a reorientation away from reliance on provider-centric, expert-driven care focused on treating and curing disease, to community-based care that empowers communities and individuals to involvement in health promotion and prevention. These models of health call for clients and people in their social networks to make active contributions to the delivery of care, whist acknowledging the impact of broader determinants of health on their capacity to make these contributions.

2.2 CARING FOR AGEING POPULATIONS

Globally, there have been demographic and epidemiological transitions, characterised by ageing populations and increasing prevalence of chronic conditions, multi-morbidity and functional decline (Coleman, 2003; Fabbri et al., 2015). Caring for older people in the community often extends beyond the primary and acute health care sectors to overcome functional decline to maintain living independently in the community, often referred to as 'long-term', 'social' or 'aged' care. The WHO defined long-term care as "the system of activities undertaken by informal caregivers (family, friends and/or neighbours) and/or professionals (health and social services) to ensure that a person who is not fully capable of self-care can maintain the highest possible quality of life, according to his or her individual preferences, with the greatest possible degree of independence, autonomy, participation, personal fulfilment and human dignity" (WHO, 2019c, p. 1). This definition has two particularly salient implications for the co-production of care. Firstly, it recognises the role of informal carers (or third party co-producers) contributing to the delivery of care for older people in the community. Secondly, it orientates care to focus on enabling older people to maintain their independence and participate in the delivery of care.

As populations age, governments have been grappling with how to provide and fund long-term care. According to the United Nations (UN): "in the coming decades many countries are likely to face fiscal and political pressures in relation to public systems of health care, pensions and social protections for a growing older population" (2019, p. 1). The 'old-age dependency ratio' represents the number of people aged 65 years and over to those of average working age (aged 15-64) (OECD, 2017). This ratio is used to identify areas of social and economic challenges due to population ageing. In 2015, there are 28 older people for every 100 persons of working age on average across OECD countries, representing a ratio of 15 (OECD, 2017). By 2050, this ratio is expected to double and reaching 58 by 2075.

> Reducing severe disability from disease and health conditions is one key to holding down health and social costs. The health and economic burden of disability also can be reinforced or alleviated by environmental characteristics that can determine whether an older person can remain independent despite physical limitations. The longer people can remain mobile and care for themselves, the lower are the costs for long-term care to families and society. (WHO 2011, p. 3)

Long-term care tends to involve support with 'personal care' or 'Basic' Activities of Daily Living (ADLs), defined as "the fundamental skills typically needed to manage basic physical needs" (Mlinac & Feng, 2016, p. 506). There are variations in what is included under the banner of ADL, however it often includes: bathing/personal hygiene, dressing/grooming, toileting/continence, mobility

(transferring/ambulating), and eating (Mlinac & Feng, 2016). People requiring long-term care may also be based on addressing the need for support to perform Instrumental Activities of Daily Living (IADLs), which "include more complex activities related to independent living in the community" (Mlinac & Feng, 2016, p. 506). Assessment of the older people's need for support tends to be measured using Lawton IADL scale, which includes activities such as ability to use telephone, shopping, food preparation, housekeeping, laundry, mode of transportation; responsibilities for own medications, and able to handle finances (Lawton & Broady, 1969).

Long-term care systems provide care in older people's homes rather than in institutional or residential care settings. In addition to support with ADLS and IADLS, long-term care may also include medical care in the home and support for informal care providers.

> Long-term care systems enable older people, who experience significant declines in capacity, to receive the care and support of other consistent with their basic rights, fundamental freedoms and human dignity – these services help reduce inappropriate use of acute health-care services, help families avoid catastrophic care expenditures and free women – usually the main caregivers – to have broader social roles.
> (WHO 2019c, p. 1)

Long-term care is often part of governments' social care sectors, creating a divide between service delivered by the health and social care sectors, which are both involved in providing continuing care in the community for older people. However, the vast majority of the care provided in the community is informal, provided by people in the clients' social networks acting as carers. In fact, not all countries provide formal public support and the level of social protection varies widely (Roberts, 2017). As noted by Muir (2017):

> Coverage for home care for moderate or severe needs is often insufficient, leaving people with large out-of-pocket costs. In contrast, all countries studied ensure that institutional care is affordable. Unless family and friends can provide informal care, many people will be unable to afford LTC in their own home, leaving them with unmet needs or at risk of early institutionalisation. Benefits are usually means-tested to provide more support to those less able to afford to contribute, but it is still those with lowest incomes that are most likely to face unaffordable costs. (p. 4)

The long-term care needs of ageing populations, "can be met by formal or informal care, or can go unmet, all of which have a cost" (Muir, 2017, p. 9).

2.3 INFORMAL CARE

Informal care represents unpaid and unregulated care provided on the basis of a social relationship with the clients. Along with people contributing to the delivery of their own care and improvement of their health outcomes, carers make the most significant contributions of time and effort to the delivery of care in the community. As discussed in Chapter Six, the vast majority of care provided in the community can be attributed to co-production by carers. From an operational perspective, carers are said to contribute as a 'quasi-patient' (i.e. supporting clients to make co-productive contributions) and 'quasi-provider' (i.e. providing care as a substitute for formal care) (Weinberg et al., 2007). The term and concept of 'informal care' can be traced to the mid-1970s, relating to interrelated developments in the conceptualisation of care including "political and economic change; the move to community care; feminist discussion of the role of women; and the scale and hardship of unpaid familial 'caring' in the community" (Beresford, 2008, p. 4). At this time, international recessions that triggered fiscal constraints and imposed restrictions on public expenditure, along with globalisation and political shift to the right, provided the context for increased interest in informal care (Beresford, 2008). According to Beresford (2008): "the new political right was hostile to state intervention and expenditure and strongly supportive of the market and individual responsibility" (p. 4).

Globally, there have been shifts away from institutional services providing residential care for people with mental health issues or disability including the elderly. The phrase 'ageing in place' was adopted in the political discourse, defined by Davey and colleagues (2004) as "remaining living in the community, with some level of independence, rather than residential care" (p.133). According to Wiles et al. (2012), 'ageing in place' was seen to provide "a sense of attachment or connection and feelings of security and familiarity in relation to both homes and communities. Ageing in place related to a sense of identity both through independence and autonomy and through caring relationships and roles in the places people live" (2012, p. 357). Wiles and colleagues (2012) identified two key drivers to deinstitutionalisation of aged care from residential to community care settings. One is rights based, in response to the need to respond to preference for 'ageing in place', and to greater support independence and autonomy; the other reflects economic pressure to address the fiscal sustainability of long-term care systems, and the cost to governments of providing institutional care, rather than home care, where care is shared between formal and informal care providers.

Informal care has been described as a "burning policy issue in almost every society" (Kröger, 2009, p. 399). As populations age, there are growing concerns of a 'caring deficit' as the number of informal care providers becomes insufficient to meet the needs of the growing number of dependent older people (Tronto, 2013). Over the last half century, dramatic changes in longevity, declining fertility, demographic dispersion of family and social networks, and increased employment among women have contributed to this deficit (Tomassini et al., 2004; Evandrou & Glaser, 2003; WHO, 2019d). A

‘care crisis’ has been predicted as people face multiple role commitments, combining paid employment and informal caregiving resulting in a ‘time bind’ (Hoschschild, 1997). According to the WHO:

> With the group aged ≥80 growing faster than any other and the average age of caregivers for the elderly rising, a better balance is needed between informal care and public support. Putting an appropriate and coordinated mix of services in place (including health and social services; technical aids; support to informal care) is key to making health and long-term care systems sustainable in the future. (2019d, p. 1)

The terminology for informal care providers varies between countries. In the USA and Canada, the term ‘caregivers’ is favoured as opposed to ‘carers’ in the UK and Australia. References to care providers who are not employed to perform the role, are often prefaced by terms such as ‘informal’, ‘family’ or ‘primary’, with differing connotations. These terms are used to make a distinction from paid care workers (given that the term carer is sometimes also used to describe paid care workers). However, these terms may be limiting or exclusionary therefore the term ‘carer’ was chosen for this study. Despite a lack of definitional consistency in the use of the term ‘carer,’ common themes between the definitions were identified. These included people providing care who are not employed in paid or voluntary work. Carers are defined here as “people who provide personal care, support and assistance to people with a disability, medical condition (including terminal or chronic illness) mental illness or frailty due to age” (Australian Government Department of Social Services [DSS], 2011, p. 13). People’s perceptions of themselves as carers have been found to suggest that “self-identification with the role and label of carer can (also) be nuanced, shifting and variable and related to apparent expectations about whether one should assume a caring role” (Hughes, Locock, & Ziebland, 2013, p78).

The literature on the nature of care provided by carers highlights the increasing complexity and multifaceted nature of informal care giving. The term ‘shadow workforce’ has been used to describe the extent of the contributions that untrained and often under-supported carers give to the health system (Bookman & Harrington, 2007). International studies exploring the nature of care delivered by carers highlight the multi-faceted nature of the role that encompasses physical, material, social and emotional aspects of care (Wiles, 2003). The role of carers varies over time due to factors including: the stage of the care recipient’s condition: the presence of co-morbidity for the recipient and the carer; and the relational and material context (Thomas et al., 2002). The conceptualisations of contributions by carers often fails to capture its complexity and the diverse and extensive manner in which they contribute to supporting people with care needs in the community. The care provided by carers

extends beyond the home to the broader health care system (Bookman & Harrington, 2007), as will be further illustrated by this thesis.

Professional provider perceptions of the carer role

There are variations in professional provider perceptions of the care role. Twigg (1989) first explored how social care agencies conceptualise their relationship with carers. The way formal services view their relationship with carers was divided into three models including identifying carers as 'resources', 'co-workers', and 'co-clients' (Twigg, 1989). A study on the ambiguity of the carer role also identified that conflict arises from carers' needs as 'recipients' (or co-client) and their status as an 'expert' carer. Therefore, clarity about the status of carers as perceived by healthcare professionals is required to support carers in their multifaceted role (Gillies, 2000).

A study by Guberman and colleagues (2006) found that practitioners tended to ignore family relations, focusing on their role as instrumental and clinical. In addition, practitioners were found to have high expectations of the role that family caregivers can have in treatment plans and acting as quasi-nurse aides (Guberman et al., 2006). In a study of carer and professional provider perceptions of each other's roles, Ward-Griffin (2002) found that the nurses' professional knowledge and higher status designation impacted on the relationship between professionals and family carers. Role ambiguity has implications for the way carer are treated in the health system including the support they are provided with and expectations about their capacity to provide care. Despite the fundamental contribution made by carers, their unique role as third party co-producers has been afforded limited attention in the literature (as discussed in Chapter One and Four).

Policies to support informal care

The achievement of government purposes to provide care in the community is often dependent on significant contributions by external actors in the form of carers. Internationally there is an increasing recognition of the pivotal role that carers play in providing care in the community, with governments providing support for carers to perform this role. In 1999, in the UK, 'Caring About Carers' a national strategy for carers was launched to provide access to information and support for carers, followed by the Carers and Disabled Children Act 2000, and the Carers (Equal Opportunities) 2004 (UK Department of Health 1999; UK Parliament 1999; 2004). In 2010, Australia passed the Carer Recognition Act, and the first National Carer Strategy the following year (Australian Government, 2010; DSS, 2011a). The Australian Government's Charter of Rights and Responsibilities for Community Care also highlights the need for services to be delivered in a way that respects people who need care, their families and carers (Australian Government, 2011a). In the USA, the Recognise, Assist, Include, Support and Engage (RAISE) family Caregivers Act was passed in 2017 (U.S.

Congress, 2017). The bill called for a national strategy to support informal carers. Carer strategies outline policies to assist carers in the role in providing care in the community. As co-producers they represent a unique yet diverse workforce.

The shift towards caring for ageing populations involves clients contributing behaviours and actions to improve their health outcomes and a mix of care from the health (acute and primary health care), social (long-term or aged care) and informal care (care by people in the clients' social networks) sectors. Consequently, a growing proportion of populations have 'complex care needs'; they require care from different providers across service, organisation and sector boundaries (Coleman, 2003). Older people with complex needs often experience fragmented care, which can lead to avoidable hospitalisations (Calver, et al., 2006; Downing & Wilson, 2005; WHO, 2013). Addressing older people's health and long-term care needs requires coordination between clients, their informal care providers and the formal service system. However, the formal service sector has become increasingly fragmented, siloed and differentiated. Overcoming these challenges has led to policy makers focusing on health systems policy and integrated care, to make it easier for clients and their carers to navigate and increase the responsiveness of the service system.

2.4 HEALTH SYSTEMS POLICY

Health system policies are largely shaped by broader public administration and management trends, as described in Chapter One. The WHO defines health systems as "all the activities whose primary purpose is to promote, restore and/or maintain health; the people, institutions and resources, arranged together in accordance with established policies, to improve the health of the population they serve" (WHO, 2019e, p. 1). Health systems were originally designed to address acute conditions to patients as passive recipients for professional care services. In the 1960s, health care was provided through public hospitals and single practitioner general practices (Gröne & Garcia-Barbero, 2001). From the 1970s there have been increasing technological and medical advances, sub-specialisation of health care provision, and a notable reduction in the number of hospital beds, with the shift to primary and secondary care in the community (Gröne & Garcia-Barbero, 2001). Since the 1990s, acute hospital beds have been decreasing in favour of health care provided by day care facilities, transitional care, ambulant clinics, specialist outpatient care, multi-disciplinary health care centres, multi-provider general practices, and home care in private residences. The provision of care transitioned towards increasing specialisation and differentiation, and a move away from institutional to community-based care settings including long-term care of the elderly (Kodner, 2009). The move towards community-based care requires greater contributions by clients and people in their social networks to the delivery of care and a greater need to coordinate care between formal and informal actors.

In the 1980s and 1990s, traditional bureaucratic approaches were subjected to health system reforms, with the widespread adoption of market-based approaches in an attempt to increase efficiency, cost-effectiveness and customer satisfaction, provide greater transparency, and empower managers (Newman & Lawler, 2009). These strategies aimed to open up competition and improve organisational performance by placing greater emphasis on outcomes measurements to increasing accountability, decentralising decision-making, contracting-out of public services, and partnering with the private sector (Simonet, 2008). Organisational structures were adopted, where bureaucracies were transformed into 'funders' and 'purchasers', creating a purchaser/provider split where service provision is privatised or corporatised (Baum, 2008; Podger & Hagan, 1999). The public also had a new role, as *customers* engaging in market activities, in an attempt to use user-based mechanisms of choice, voice and exit to drive public service performance and accountability. However, as the shortcomings of these approaches have come to the fore, policy makers have been increasingly concerned with more collaborative approaches to integrate care, including casting clients and their carers as *partners* in their care.

Integrated care

Over the last few decades, the concept of integrated care has influenced major policy and practice level changes across the world (Kodner, 2009). In response to the changing landscape of care provision, a wide range of tools and interventions has been developed, under the banner of integrated care. In the 1980s, trends in approaches to integrated care included coordinated working; shared care planning; coordinated care; and case/care management (Shaw, Rosen, & Rumbold, 2011). The 1990s saw additional approaches to integrated care including inter-agency working; intermediate care; shared protocols; managed care; and disease management (Shaw, Rosen, & Rumbold, 2011). Since 2000, there has been a focus on inter-professional working, whole systems working, integrated delivery networks, integrated care pathways that address issues at the systems level, as well as shared decision-making; and patient-centred care at the individual level (Shaw, Rosen, & Rumbold, 2011). Mounting interest in the integration of care has provided a forum for reconsidering the role of the clients and citizens in the design and delivery of care.

It has been suggested that many failings of the modern health and social care systems can be attributed to fragmentation of these systems, which tend towards silos and specialised approaches to care (Gröne & Garcia-Barbero, 2001; Kodner, 2009). Strategies to address fragmentation, such as system integration of care have been a major focus of health policies globally (Gröne & Garcia-Barbero, 2001). The word 'integration' originates from the Latin verb, 'integer' or 'to complete' (Kodner & Spreeuwenberg, 2002). The concept of integration of care is underpinned by 'systems theory', which is central to organisational design and performance (Kodner & Spreeuwenberg, 2002). Organisations and systems have structures comprised of separate yet interconnected components, that

are required to perform complementary roles to achieve shared goals (Kodner & Spreeuwenberg, 2002).

The WHO defines integrated care as "a concept bringing together inputs, delivery, management and organization of services related to diagnosis, treatment, care, rehabilitation and health promotion - as a means to improve the services in relation to access, quality, user satisfaction and efficiency" (Gröne & Garcia-Barbero, 2001, p. 7). However, there is a plethora of definitions for integration of care and integrated care (Armitage et al., 2009). To date, no standard definition of integration exists and there are multiple concepts and models of integration that reflect differing perspectives and are tailored to specific contexts. The terms 'integration' and 'coordination' are often used interchangeably. Coordination may be defined as "the deliberate organization of patient care activities between two or more participants (including the patient) involved in a patient's care to facilitate the appropriate delivery of health care services." (McDonald, 2014, p. 13). Care coordination is often used in reference to integration at the clinical level.

A widely used framework developed by Leutz (1999) is based on the 'Degree of Integration' which is to be determined by the complexity of care required by the client. Linkage refers to an explicit understanding across the system about what services are available, for whom, and who provides them, to avoid cost and responsibility shifting (Leutz, 1999). Coordination is the next level of integration for people with more complex needs, which involves identifying areas of discontinuity between service and system interfaces and the development of structures and processes for addressing them (Leutz, 1999). Full integration is the ultimate level, which involves the creation of entirely new models of care, pooling resources and funding from multiple services and systems (Leutz, 1999).

The 'Kaiser Pyramid of Care' has been used to illustrate different levels of care required for people receiving complex care. This model was later extended to include a fourth level representing health promotion and prevention in the general population (See Figure 2.1). The level of formal support is determined by the level of need and dictates the distribution of tasks between formal service providers, and informal actors as co-producers.

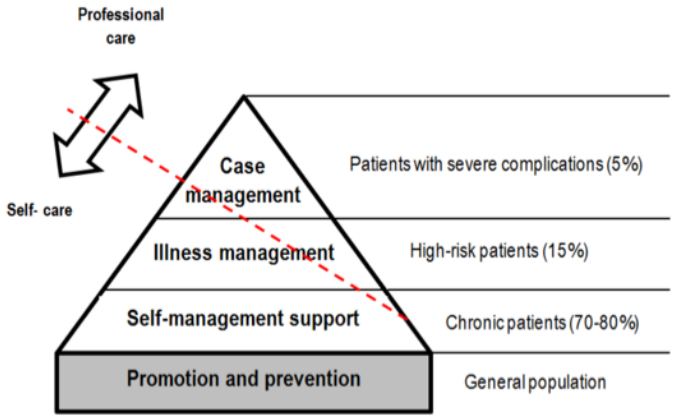

Figure 2.1. The (extended) Kaiser pyramid of care. (WHO, 2016, p. 15)

Integration is a multi-level, multi-modal concept that accesses a range of tools and interventions to address the fragmentation of care. Models of integrated care may focus on entire populations or specific at-risk populations. Under that umbrella of integrated care, a continuum of strategies acts at different system levels. The 'Levels of Integration' framework was developed by Kodner and Spreeuwenberg (2002), providing a continuum of strategies to foster integrated care from the macro to the micro level. The five interlocking domains include the clinical, services delivery, organisational, administrative and funding domains (See Table 2.3). These different types highlight the need for a whole of system approach, based on the belief that clinical level integration efforts are not sufficient to achieving integrated care, without the support of integrating strategies at other levels of the system.

Table 2.3

Domains of integration

Domain	Description
Funding	More often than not, form follows financing. This means that the division, structure and flow of funds for health and social care and related services can affect virtually all aspects of integrated care.
Administrative	The manner in which government regulatory and administrative functions are structured and devolved can help eliminate program complexities, streamline eligibility and access, and better manage system resources.
Organisational	Networking, both vertically and horizontally and through formal or informal means, is a major method to improve how organisations work together. Collaboration is another important strategy. Joint working relationships within and between agencies in the health and social care sectors can optimise resources, facilitate overall efficiency, and enhance the capacity for 'seamless care,' that is, the smooth and uninterrupted provision of necessary care.
Services delivery	The mode of service delivery and management—how staff are trained, perform their responsibilities and tasks, work together, and relate to patients and family carers and

	their needs—have a major impact on a number of critical variables in integrated care. Such variables include service access, availability and flexibility, continuity and co-ordination of care, consumer satisfaction, and quality and cost outcomes.
Clinical	Shared understanding of patient needs, common professional language and criteria, the use of specific, agreed-upon practices and standards throughout the lifecycle of a particular disease or condition, and the maintenance of ongoing patient-provider communication and feedback are essential quality ingredients in integrated care.

Note. Kodner and Spreeuwenberg, 2002, p. 4.

The Chronic Care Model (CCM) was developed in 1998 in the USA and has become one of the most widely known and applied models of integrated care globally (Bodenheimer, Wagner, & Grumbach, 2002; Wagner et al., 2001; WHO, 2016). The CCM "suggests a shift from acute, episodic and reactive care towards care that embraces longitudinal, preventive, community-based and integrated approaches" (WHO, 2016, p. 10). The CCM is based on the view that improved outcomes are the result of productive interactions between informed, activated patient, and prepared, proactive practice team (See Figure 2.2). There are six components including: health system and organisation of healthcare; self-management support; decision-support; delivery system design; clinical information systems; community resources and policies. Self-management support focuses on empowering and preparing clients to manage their health and health care, including strategies such as assessment, goal setting, action planning, problem-solving and follow-up ICIC 2019). The CCM explicitly assigns clients or patients in the central role in managing their own care and producing better health outcomes. Co-production of care in CCM has been evaluated in the literature as discussed in Chapter Four.

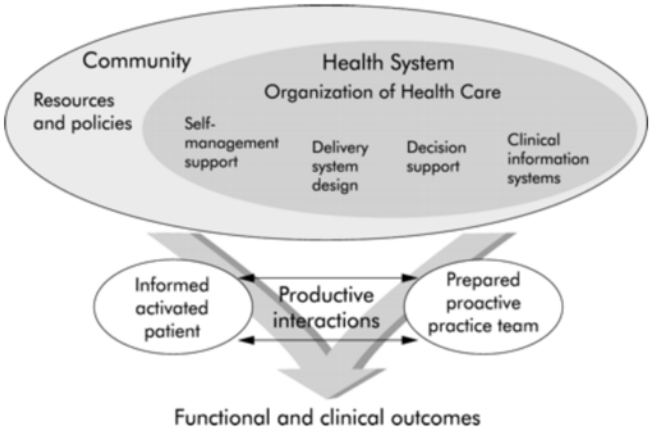

Figure 2.2. The chronic care model. (Epping-Jordan et. al, 2004, p. 300)

The CCM represents a systems approach to integrated care. There are also individual models of integrated care that are discussed below in relation to services designed to integrate care for older people with complex care needs.

Individual models of integrated care for older people

At the clinical level, one of the first and most widely used individual models of integrated care for older people with complex needs was case management (Low, Yap, & Brodaty, 2011). You et al. (2012) define key distinguishing features of case management for community based care including: being based in the aged care sector; spanning across community and medical care services; for people with chronic, ongoing and complex medical conditions, and age related disability; on a long-term basis or for intense short term periods (prior to admission to residential care); using a planned approach; in collaboration with family and carers; to achieve client outcomes and cost-efficiency. Case management is a generic term, which is operationalised based on the specific context (You et al., 2012).

In their review of models of home and community care services for older persons, Low and colleagues (2012) found that some studies demonstrated that case management might improve function, medication management and clinical outcomes; increase the use of community services; and decrease residential aged care and hospital admissions. However, the findings were not consistent across all studies (Low, Yap, & Brodaty, 2011). You and colleagues (2012) reviewed the effects of case management in community-based aged care on client and carer outcomes. Their review found evidence that case management may improve physiological health and wellbeing and address unmet service needs (You et al., 2012). However, the authors highlight that further research was required to determine the specific components of case management that improve outcomes (You et al., 2012).

Other approaches were developed to address fragmentation at points of transition. The term 'transitional care' may be defined as "a set of actions designed to ensure the coordination and continuity of health care as patients transfer between different locations or different levels of care within the same location." (Coleman, 2003, p. 549). In a review of transitional care, Naylor et al. (2011) identified twenty-one interventions under the banner of transitional care including: comprehensive discharge planning and follow up (with or without home visits); disease or case management; coaching; education or psychoeducation; peer support; tele-health facilitation; mobile crisis; post-discharge geriatric assessment and intensive primary care. Despite the heterogeneous nature of both the models and their interventions; and their outcome measures,[1] the authors maintain that there is a robust body of evidence of the benefits of transitional care, particularly in regard to reducing unnecessary admissions (Naylor et al., 2011).

Despite widespread adoption of interventions to coordinate care, there has been criticism that interventions and models of care targeted at the clinical level alone, are too limiting to overcome the

[1] The studies identified in the review included range of different outcomes including health outcomes; quality of life; patient satisfaction or perception of care; resource use including re-admissions and costs.

fragmentation of the system as a whole (Kodner, 2009). Internationally, a wide range of models of integrated care for older people have been developed which act across different levels of the system (Leichsenring, 2004). Beland and Hollander (2011) identified key characteristics common to integrated models of care for the frail elderly including: an underlying belief of the benefits of a 'coordinated continuum of care'; a single point of entry into the care system; care planning and coordination over a wide range of services which are seen to be part of the continuum of care; client assessment and classification; independent case management; an integrated information system; system level policies and procedures outlining how the continuum of care works, including who is eligible for care, how care is provided by multiple services over the same period of time and how clients transition between services.

In 2009, a review of coordinated and integrated interventions targeting frail elderly was performed (Eklund & Wihelmson, 2009). The authors found mixed results, however they concluded that some evidence suggests integrated and coordinated care is beneficial. However, the authors questioned the quality of the current evidence (Eklund & Wihelmson, 2009). The prevailing outcome measures were focused on decreased utilisation, with a stark lack of evidence on how these models affect carers (Eklund & Wihelmson, 2009). In 2011, Beland and Hollander also performed a review of integrated systems of care for the frail elderly. Beland and Hollander (2011) found that it is unclear from the current level of evidence, to what specific elements of a model make it successful. The authors concluded that regardless of which specific model is adopted, it is fundamental to consider how all care required across the care continuum can be coordinated to ensure continuity of care for frail elderly persons (Beland & Hollander, 2011).

Over several decades, there has been mounting advocacy for increased flexibility and choice in the context of long-term community-based care through personalised budgets or 'consumer-directed care'. Consumer-directed care places control and responsibility of health and social care spending onto consumers rather than government agencies with the aim of fostering marketization of care, to control costs and increase competition and quality through market forces (Ottmann, Allen, & Feldman, 2013). Initially, consumer-directed care was seen as the "antithesis" of integrated care approaches (Kodner, 2009). However, there has been increasing recognition of the role that consumer-directed care can play in integrated models of care (Kodner, 2009; Leichsenring, 2004).

There are significant variations in how consumer-directed care is operationalised within and between countries, including the level and type of control afforded to the consumer. In a review of consumer-directed care for older people, Low and colleagues (2011) found some evidence that it improved satisfaction with care and increased community service use, although there was limited effect on clinical outcomes. One study in the review found consumer-directed care might increase psychological morbidity (Low, Yap, & Brodaty, 2011). There have been concerns that it may fail to

increase choice in the context of limited information and system restraints and may result in a shift of cost onto the consumer (Low, Yap, & Brodaty, 2011).

In 2012, Ottmann and colleagues conducted a systematic narrative review of consumer-directed care for older people. Their review aimed to establish an evidence base for older people's preferences and satisfaction with consumer-directed care programs of home-based care in the US and UK (Ottmann, Allen, & Feldman, 2013). The authors found consumer-directed schemes were linked to greater choice, sense of control and satisfaction, and may relieve carer burden, although older people were found to be less interested in consumer-directed care (Ottmann, Allen, & Feldman, 2013). It was also noted that there has been limited attention afforded to comparisons of user preferences between different schemes or the ecological factors that influenced user preference (Ottmann, Allen, & Feldman, 2013). The authors concluded that further investigation into the diverse contexts, needs and preferences of older people in regard to consumer-directed care to community-based aged care is required (Ottmann, Allen, & Feldman, 2013).

Low and colleagues (2011) compared evidence on the three prevailing models of integrated care for home and community services for older people including case management, consumer-directed care and integrated models of care. The authors found that our understanding of the impacts of each model is based on the specific focus of the model. For instance, case management focuses on the provision of care, integrated care on the efficiency of the system and consumer-directed care on giving more control to the consumer through the provision of a personal budget. According to the authors, an ideal model may incorporate key elements of each of these models based on a clear understanding of the focus or goal and the prioritisation of outcomes (Low, Yap, & Brodaty, 2011). Furthermore, to determine the best approach, there needs to be an understanding of what elements of different models work, in order to maximise outcomes within a given context (Low, Yap, & Brodaty, 2011).

In response to criticism that interventions and models of care targeted at the clinical level alone are too limiting to overcome fragmentation, a wide range of integrated care models have been developed (Kodner, 2009; Leichsenring, 2004). Beland and Hollander (2011) identified the following key characteristics regarding integrated care models for older people with complex care needs: a single point of entry into the care system; care planning and coordination over a wide range of services; client assessment and classification; independent case management; an integrated information system; system level policies and procedures outlining how the continuum of care works, including who is eligible for care, how care is provided by multiple services over the same period of time and how clients transition between services. Internationally, clinical and whole of system approaches to integrated care have been widely implemented.

Despite decades of research and evaluation of integrated models of care, there remains a lack of evidence to support these approaches (Beland & Hollander, 2011; Eklund & Wilhelmsen, 2009; Leichsenring, 2004; Low, Yap, & Brodaty, 2011; Ottmann, Allen, & Feldman, 2013; You et al., 2012). The ability to synthesise findings to gain a strong evidence base on how to best integrate care is hampered by divergences between models of integrated care and research methods used to evaluate these models. Evaluations of models of integrated care tend to be 'black-box', this is, they are concerned with measuring the outcomes, rather than understanding what aspects of the models work for whom and under what circumstances. In addition, these evaluations tend to preference a provider perspective, limiting our understanding of how these models influence the experiences of clients (Kodner & Spreeuwenberg, 2002).

The way care is conceptualised, operationalized and measured, differs based on the perspective of different stakeholders (Kodner, 2009; Lloyd & Wait, 2005; McDonald et al., 2014; Shaw, Rosen, & Rumbold, 2011). It has been suggested that there are two prevailing perspectives on integrated care. One perspective is 'top-down', which is largely concerned with improving the cost-effectiveness and appropriate use of resources that can be achieved through coordination and managerial approaches to care. The other is a 'bottom-up' patient-centred perspective, providing a mechanism for focusing on the specific needs of consumer groups being met by existing systems of care and determines the what, how and where of integration (Kodner & Spreeuwenberg, 2002). A patient-centred or humanistic perspective provides a frame of reference that may endow integrated care with a greater relevance to the complex needs of consumers (Armitage, 2009; Kodner & Spreeuwenberg, 2002). The shift towards a bottom-up perspective on integrated care is reflected in the resurgence of interest in the co-production of care services.

Patient-centred care and partnership approaches

Traditionally, a paternalistic model dominated the delivery of care, whereby health professionals act as stewards in decision making for the 'patients' who acted as the passive recipient of care (Longtin et al., 2010). Since the 1960s and '70s there has been a groundswell towards increasing citizen or public participation in their healthcare. In 1969, Arnstein's seminal 'Ladder of Citizen Participation' was published. It describes the degree of participation from non-participation, through varying degrees of 'tokenism,' to citizen power. But it has been lamented that the role of consumers often falls short of Arnstein's vision of inclusive and empowering health care (Ottmann, Allen, & Feldman, 2013). However, over recent decades there has been a global shift in health policy discourse towards participation and partnership approaches under the banner of 'patient-centred care.'

The contemporary conceptualisation of patient-centred care is often credited to the seminal book 'Through the Patient's Eyes: Understanding and Promoting Patient-Centred Care,' based on a study

conducted on behalf of the Picker Institute and the Commonwealth Fund (Gerteis et al., 1993). The research identified eight dimensions of patient-centred care including:

- Respect for patients' values, preferences and expressed needs;
- Coordination and integration of care;
- Information, communication and education;
- Shared decision-making and support for self-care;
- Physical comfort;
- Emotional support and alleviation of fear and anxiety;
- Involvement of family and friends; and
- Continuity of care and smooth transition across service boundaries (Gerteis et al.,1993)

Patient-centred care marks a shift in thinking from a focus on the disease, to a focus on the person as a whole. This shift reflects a change in ontological perspectives, from the conventional positivistic approach of the biomedical model, to an approach which is underpinned by a humanistic, holistic and biopsychosocial model (Taylor, 2009). There has also been increasing recognition of the need to address how health and social care services will manage the needs of people with multiple conditions, calling for a move away from the delivery of care built around single diseases (Smith et al., 2012). In the literature, there has been a shift in focus from 'co-morbidity' (the presence of additional disease in relation to an index disease) to 'multi-morbidity' (the presence of multiple diseases), (Valdaras et al., 2009). This may seem like a subtle distinction; however, it requires a paradigm shift from a siloed single-disease focus to a more holistic view of patients (Fortin et al., 2012).

There has been a shift in health policy with the widespread mandate for patient-centred care in Australia and internationally. A major catalyst for recent global attention on the concept of patient-centred care was the report by the American Institute of Medicine, 'Crossing the Quality Chasm: A New Health System for the 21st Century' (IOM, 2001). The report defined high-quality health care as being safe, effective, 'patient-centred,' timely, efficient and equitable. Patient-centred care is defined as "health care that establishes a partnership among practitioners, patients, and their families (when appropriate) to ensure that decisions respect patients' wants, needs, and preferences and that patients have the education and support to make decisions and participate in their own care" (IOM, 2001, cited in Shaller, 2007, p.1).

Patient-centred care has become a blanket term as its meaning is often assumed rather than defined, reflecting a philosophy and an approach to care delivery (De Silva, 2014). Patient-centeredness has been seen to mark a shift in thinking from paternalism to partnership through shared understanding and empowerment, emphasising the rights and abilities of the individual (Aujoulat, d'Hoore, &

Deccache, 2006; Taylor, 2009). However, like many of these blanket terms, there is a lack of definitional and conceptual consensus on patient-centred care (Kitson et al., 2013; De Silva, 2014). In a review of definitions performed by Kitson and colleagues (2013), the authors found that patient involvement and participation, and the relationship between the patients and the care providers were the most common elements across definitions (Kitson et al., 2013). De Silva (2014) also found, 'partnership' and 'mutual respect,' to be common features among definitions of patient-centred care.

The traditional role of health systems was to provide care to the majority, with service users being required to fit within the existing service system as determined for them by service providers (De Silva, 2014). The transition towards partnership approaches to care represents a significant paradigm shift, where services are required to be flexible and responsive to the needs and preferences of clients (Berwick, 2009; De Silva, 2014).

A wide range of factors has been identified that influence the capability of clients to participate in the delivery of their care (Longtin et al., 2010). The movement towards a partnership approach has implications relating to responsibility, power and control, recognition of expertise, respect, autonomy and independence (Lawn et al., 2013; Thille & Russell, 2010). It has been observed that partnership approaches to care raise tensions, particularly relating to the radical shifts in control and power that are required (Berwick, 2009; Longtin et al., 2010). Factors that may influence providers' participation in facilitating partnership forms of co-production identified in the literature include: maintaining control, time constraints, the type of condition, personal beliefs, disciplinary background and training in facilitating consumer participation (Longtin et al., 2010).

'Patient empowerment' refers to the notion that "patients accept responsibility to manage their own conditions and are encouraged to solve their own problems with information - rather than orders from professionals" (Bodenheimer, Wagner, & Grumbach, 2002, p. 2470). In this context, the concept of empowerment is underpinned by the theory that internal or intrinsic motivation is more effective than external motivation to making life-style changes required for the management of chronic conditions (Aujoulat, d'Hoore, & Deccache, 2006). The emphasis is therefore placed on empowerment rather than compliance (Aujoulat, d'Hoore, & Deccache, 2006). In the literature, there has been a focus on enabling clients by increasing their capacity and motivation or self-efficacy (Lawn & Battersby, 2009; Lawn et al., 2013; Lorig & Holman, 2003).

In contrast to traditional paternalistic approaches, the patient-professional partnership involves a collaborative care approach (Bodenheimer, Wagner, & Grumbach, 2002), whereby consumers are framed as 'active partners' in their care, and frontline care providers responsible for engaging them in shared decision-making and empowering them as effective self-care managers (Burt et al., 2012; Lawn et al., 2013; Lorig et al., 1999; Wagner et al., 2001). In practice, this shift involves a move

away from providing information and technical skills, towards the facilitation of 'self-efficacy' (i.e. the belief in one's ability to perform a task) through self-management education focusing on fostering problem-solving skills (Bodenheimer, Wagner, & Grumbach, 2002; Lawn et al., 2013; Lorig et al., 1999; Wagner et al., 2001). However, partnership approaches are dependent on the motivation and capabilities of clients and frontline care providers (Longtin et al., 2010). The trend towards partnership approaches reflects a shift in health policy from perceiving the public as passive recipients to active participants in the delivery of care and achievement of better outcomes. This shift laid the foundation for increasing interest in the co-production of care which is the central concern of this thesis.

CONCLUSION

As an operational element of service delivery that involves active contributions to production processes of achieving service objectives, co-production is unavoidable in the delivery of care for ageing populations in the community. These care services seek to engage older people as clients with complex needs to contribute to performing health promoting behaviours and activities involved in the self-management of chronic illnesses. The deinstitutionalisation of long-term care where possible, also shaped the role of informal carer as people in clients' social networks provide the majority of care.

However, clients and carers often experience a fragmented system resulting in avoidable hospitalisations as they fall through the gaps in the service system. As a response, over the last three decades policy makers have largely been concerned with the integration of health system. Increasingly participation has been espoused to increase the responsiveness of the system and as a way to enlist and facilitate clients and their carers as partners in the delivery of their care. This trend dovetails with the emerging co-production of care services literature as discussed in Chapter Four. However, this thesis challenges some of the existing assumptions about what determines whether people co-produce, and provide new insights into how these processes can be better facilitated. The following chapter provides the research rationale, design and methodology.

CHAPTER 3

Research Rationale, Design and Methodology

INTRODUCTION

This thesis explores co-production in the delivery of complex care for an ageing population in the community by clients and their carers. A pragmatic approach was adopted, placing the research question at the forefront rather than aligning with a particular philosophical stance (Patton, 2002; Ritchie & Lewis, 2003). The exploratory and descriptive nature of the topic lent itself to naturalist inquiry. The research encompasses multiple methods and perspectives to seek convergence and corroboration between different sources of data (Mays & Pope, 2000). This chapter presents the rationale, aim, and research questions, followed by an overview of the philosophical and methodological orientation for the thesis, and research methods.

3.1 RATIONALE FOR THE RESEARCH

This research serves two mutually beneficial purposes. Caring for older people with complex needs in the community provides a rich and nuanced context for examining co-production; just as co-production provides a useful lens for examining how governments care for ageing populations and how these processes can be better managed. Australia, like many countries, faces significant challenges in coming decades as the baby boomer generation reaches old age. Consistent with global trends, Australia's population is rapidly ageing, with the proportion of the population of people 65 years and over set to double (from 13.4% to 25.3%), and those 85 years and over to triple (from 1.7% to 5.6%) between 2007 and 2047 (Australian Government, 2007). While there is great diversity among older people, the likelihood of developing chronic conditions leading to physical and cognitive disability increases with age, as does the severity. In 2015, 37.8% of Australians 65-69y.o. has a disability, rising steadily to 75.4% of those between the ages of 85 and 89 (ABS, 2018). One in three Australians aged 65 years and over require assistance in the community with their daily activities (ABS, 2018). Chronic illness is the major contributor to the burden of disease and injury in Australia. Meanwhile, many of the most prevalent conditions are progressive, resulting in increased demands for care over time, as a growing proportion of the population have complex health and long-term care needs (i.e. complex need) across health and social care sectors.

Australia's health system is already struggling to keep up with growing demand and with already stretched budgets and workforce shortages. By comparison with other OECD countries, Australia has high hospital admission rates, largely as a result of unnecessary admissions or re-admission, and a lack of sub-acute service and other gaps in the service system such as access to after-hours general

practice services (OECD, 2015). In 2013-2014, more than one in three (39%) of all hospitalisations were for potentially preventable chronic diseases (AIHW, 2018). Australia has also experienced workforce shortages that are insufficient to meet current demands, particularly outside major cities (Mason, 2013). There is also fragmentation across the health and aged sectors, providing personal and community care for older people with a disability or 'aged care.'

> Patients often experience: a fragmented system, with providers and services working in isolation from each other rather than as a team; uncoordinated care; difficulty finding services they need; at times, service duplication and at other times, absent or delayed services; a low uptake of eHealth and other health technology by providers to overcome these barriers; difficulty in accessing services due to lack of mobility, transport, language, financial barriers and remoteness; and feelings of disempowerment, frustration and disengagement.
> (PHCAG, 2015, p. 11)

The cost of providing Australian's universal coverage under the national health insurance scheme 'Medicare' is estimated to almost double by 2050, from 4.2% in 2014-2015 to 7.1% of GDP (Australian Government, 2015). In addition to costs associated with increased demand, there are also higher costs associated with new treatments and technologies (Marci, 2016). This increase is set to occur as the number of Australians of working age contributing to tax revenue declines. It has been said: "Australia, like many developed countries, will face serious policy challenges that it will need to address over the next decade; in particular, an increasing ageing population, increased medical technology costs, the public-private mix of health expenditure, structural research issues within the medical sector, equity considerations across groups and rapid urbanisation" (Marci, 2016, p. 1).

In many countries, including Australia, the policy agenda is to decrease pressure on the acute sector by avoiding or delaying costly admissions to hospital and residential care. The Australian Government's policy agenda is to support older people to remain in their own residence where possible (Productivity Commission, 2008). The expansion of community-based care has been seen as a "win-win" situation that suits the preferences of older people to stay functioning independently in their home, and as a cheaper option for the Government (Bruen, 2005). In formulating ways of achieving caring for ageing populations, there has been renewed interest in the study of co-production. Co-production has been operationalised in various ways, often occurring at a subterranean level or embedded in various guises in health policy discourse. This is the central concern of this thesis as governments seek to involve older people in actively preventing and managing their health, and maintain independence living in the community with the informal support from people in their social network as informal carers.

This research contributes to both co-production theory and health policy and practice, specifically the delivery of care to people with complex needs in the community. To date, the study of co-production has been limited on several fronts. Firstly, as an emergent field of study, "its nature, antecedents, working mechanisms, and consequences are only patchily understood. In each of these aspects, partial understandings – some of them in contention with each other – have taken root somewhat haphazardly" (Alford & Yates, 2015, p. 159). Secondly, co-production treated as a generic phenomenon, may not be directly applicable to the delivery of care services. Thirdly, the analysis of the co-production of care services has been largely concerned with optional or alternative approaches that involve public participation in planning and design, as well as delivery of services. However, co-production is often not optional, particularly in the delivery of care services that involve complex inter-dependencies between providers, clients and their carers. To date, there has been limited examination of co-production as an operational element in the delivery of care services. Fourthly, these existing forms have been afforded limited attention from the perspective of clients and their carers as co-producers. This research addresses these gaps. It applies the theoretical constructs of co-production theory to policy and practice of caring for ageing populations in the Australian context. It also provides a better understanding of the contributions of different external actors to the delivery of complex care, and under what circumstances, to inform how these processes can be better managed, capturing the lived experiences of older people and their carers.

3.2 RESEARCH AIM, QUESTION AND DESIGN

Research aim

This thesis comprises theoretical and applied research with the aim of improving our understanding of co-production in health and long-term care of ageing populations in the community. The theoretical constructs of co-production are applied in the context of complex care, to determine how this resonates with policy and practice. Specifically, the research examines the nature, antecedents and circumstances in which different external actors make co-productive contributions to complex care for older people in Australia, to inform governments to better facilitate and sustain the care of ageing population in the community.

Overarching research question

What role does co-production play in the delivery of health and social care services for older people with complex needs, to improve health outcomes and maintain independence living in the community?

Co-production is defined for the purposes of this thesis as:

Active contributions of inputs, activities and behaviors by the public (as citizens and clients or third parties) to the delivery of public services and achievement of publicly valuable outcomes.

This overarching research question is addressed from three perspectives including a review of the literature and from a top-down and bottom-up perspective. The research design including questions for each perspective and corresponding methods are detailed in Table 3.1.

Table 3.1

Research design

Research questions	Sub-questions	Methods
According to the literature, what role does co-production play in health and social care services?	What types of actors are involved in co-producing care services? What constitutes co-productive efforts in the delivery of care services? How is co-production of care services elicited and facilitated?	Narrative review of the literature (Chapter Four)
What is the potential impact of emerging changes to health system policies in Australia on co-production?	How is the term co-production used on the policy discourse? How is co-production operationalised in recent Australian reforms? How do polices in recent Australian reforms potentially enlist or facilitate co-production? What are the systemic challenges for co-producing care services?	Systematic policy document analysis and semi-structured interviews with policy makers and other key stakeholders (Chapters Five and Six)
How do older Victorians with complex care needs and their carers experience the co-production of their health and social care services?	Who contributes to the delivery of complex care? What contributions do they make to addressing health outcomes and maintaining independence living in the community? What influences peoples' capacity to co-produce complex care in the community? Why do people co-produce complex care in the community?	Qualitative semi-structured interview study with older people with complex care needs and their carers (Chapters Seven to Eleven)

	What are the benefits and unintended consequences of co-producing complex care in the community?	

The methods for answering these sub-questions are detailed below, after a discussion of the philosophical and methodological orientation of the research.

3.3 PHILOSOPHICAL AND METHODOLOGICAL ORIENTATION

This thesis comprises social research that is underpinned by a range of factors, including philosophical orientation, the purpose and audience of the research, the phenomenon being studied, and the position of the researchers themselves (Ritchie & Lewis, 2003). The following briefly examines these factors to make explicit the philosophical and methodological orientation of this research.

Research paradigms, as defined by Thomas Kuhn in his book (1962) 'The Nature of Scientific Revolutions,' are the "underlying assumptions and intellectual structure upon which research and development in a field of inquiry is based" (in Dill & Romiszowski, 1997, p. 10). Positivism has been the dominant paradigm within social research, based on the school of thought that social sciences can follow on from the research traditions of natural sciences. August Comte (1789-1857) argued that the social world, like the natural world, can be studied in terms of invariant laws, consistent with the positivist school of thought (Ritchie & Lewis, 2003). This position shaped the widespread use of quantitative methodology modelled on methods used in the natural sciences (Ritchie & Lewis, 2003). Qualitative research has been heavily criticised as 'soft' and 'unscientific' (Ritchie & Lewis, 2003). In response, qualitative researchers began to formalise their methods – accentuating the importance of rigour in data collection and analysis (Denzin & Lincoln, 2000). In the 1970s, "positivism itself and the legitimacy of social research based on the 'scientific methods' began to be debated" (Ritchie & Lewis, 2003, p. 8).

In contrast to positivism, the interpretivist paradigm rejects the use of methods from the natural sciences, with the view that the social world is not governed by law-like regularities, rather it is mediated through meaning, the purpose being "to explore and understand the social world using the participant's and the researcher's understanding" (Ritchie & Lewis, 2003, p. 17). In 1781, Emmanuel Kant published his 'Critic of Pure Reason,' in which he argued that there are ways of knowing the world beyond the process of direct observation (in Ritchie & Lewis, 2003). Kant argued that perception relates not only through direct observation through the senses but also in how we interpret these observations. Kant distinguished between 'scientific reason' or causal determinism and 'practical reason,' which is based on interpretivist thought (Ritchie & Lewis, 2003). Wilhelm Dithey

(1860s-70s) also contributed to interpretivist thought, asserting the importance of understanding or 'verstehen' that involves studying lived experiences that occur within specific historical and social contexts (Ritchie & Lewis, 2003). The interpretivist paradigm is aligned with qualitative research.

'Qualitative research' is a blanket term that is used across a range of different methods, approaches and disciplinary perspectives (Ritchie & Lewis, 2003). Strauss and Corbin (1988) broadly delineate qualitative research in contrast to quantitative research, stating that "by the term 'qualitative research' we mean any type of research that produces findings not arrived at by statistical procedures or other means of quantification" (p. 11). Denzin and Lincoln (2000) describe qualitative research as involving "an interpretive, naturalistic approach to the world. This means that qualitative researchers study things in their natural settings, attempting to make sense of, or interpret, phenomena in terms of the meanings people bring to them" (p. 3).

An alternative paradigm emerged that criticised the eminence of philosophical positions as undermining pragmatic consideration, suggesting a finer balance can be made between pragmatism and philosophy (Bryman, 1988; Ritchie et al., 2013; Silverman, 2000). According to this view, "qualitative and quantitative research should not be seen as competing and contradictory but should instead be viewed as complementary strategies appropriate to different types of research questions or issues" (Ritchie & Lewis, 2003, p. 15). This thesis takes a pragmatic approach, placing the research questions at the forefront of considerations about methodology. The exploratory and descriptive nature of the research into the phenomenon of co-production in the delivery of care services lends itself to naturalist inquiry using qualitative methods. The strength of qualitative research is the ability to understand a phenomenon holistically and in context (Al-Busaidi, 2008). This thesis adopts a systems or 'holistic' approach, which "assumes that the whole is greater than the sum of its parts" (Patton, 1980, p. 40). From this perspective, complex inter-dependences and system dynamics cannot be reduced to linear cause and effort relationships.

Social research is often distinguished as being either theoretical (also called pure or basic research) or applied research (Ritchie & Lewis, 2003). According to Patton (2002), "basic researchers work to generate new theories or test existing theories" (p. 215). Ritchie and Lewis (2003) state that theoretical research is concerned with "the aim of testing, generating or enhancing thinking within a particular discipline" (p. 24). On the other hand, "applied social research is often equated with social policy research, which has the objectives of developing, monitoring, or evaluating policy and its related practice" (Ritchie & Lewis, 2003, p. 45). Applied policy research is aimed at finding actionable information to inform policy (Huberman & Miles, 2002; Patton, 2002). There has been debate in social research as to whether it is useful to distinguish between theoretical or applied research (Ritchie & Lewis, 2003, p. 25). In the words of Silverman (2000), "without theory, research

is impossibly narrow. Without research, theory is mere armchair contemplation" (p. 86). This research comprises both theoretical and applied research.

3.4 CO-PRODUCTION OF CARE LITERATURE REVIEW METHODS

Chapters One and Two provide broad historical overviews to situate the topic in relation to other aspects of the relevant intellectual and practical fields. In contrast, Chapter Four is a systematic narrative review of care services literature on co-production was performed to examine the analysis to date and identify gaps to be addressed in this thesis.

Key review question:

> *According to the literature, what role does co-production play in health and social care services?*

Sub-questions:

- What types of actors are involved in co-producing care services?
- What constitutes co-productive efforts in the delivery of care services?
- How is co-production of care services elicited and facilitated?

A systematic search of the literature was performed in January 2016. The search terms of co-production and co-creation (i.e. co-produc* OR coproduc* OR co-creat* OR cocreat*) were used. The information sources included health and social care literature databases: Medline (Web of Science), SCOPUS, CINAHL, and PsycINFO. The inclusion criteria included: all time periods, English language, co-production/co-creation in the context of health or social care services, peer-reviewed and grey literature, empirical and theoretical papers. The screening process included scanning titles and abstracts for relevance according to inclusion and exclusion criteria. The search results for each database included Medline 2,738 (257 exported), CINAHL 2,253 (152 exported), Scopus 2,466 (671 exported). A total of 1,080 papers were exported to EndNote based on their titles. After removing duplicates and reading abstracts, a total of 187 including 102 empirical papers were identified. Since 2016, further snowballing and searches have been conducted, including the Google Scholar, and scanning bibliographies of relevant articles. The empirical papers were placed into a database based on the year of publication, country, methods, specific topic area. This database provided an overview of the contexts and conceptual approaches that have been used to examine co-production in the delivery of health services. However, given how broadly and loosely the term co-production has been applied, the scope of the review was narrowed to key theoretical and empirical

papers that provided insights into the main review questions. This review is presented in Chapter Four.

3.5 HEALTH POLICY AND CO-PRODUCTION STUDY METHODS

This part of the research adopts a top-down perspective on the potential impact of health policies on co-production, by examining recent system-wide reforms in Australia. It involves a systematic policy documents review to identify trends in health systems policies that have potential impacts for co-production in the delivery of care services, thus providing a link between co-production as an operational element in the delivery of services and health policy. A series of targeted semi-structured interviews were conducted with senior policy makers, consumers and carer advocates, health professionals and aged care services providers for further context and insights into systemic challenges to co-producing care services. The findings from this study provide insights into how co-production is operationalised in health system reforms and the potential impact of health policies on co-production.

Key research question:

> *What is the potential impact of emerging changes to health system policies in Australia on co-production?*

Sub-questions:

- How is the term co-production used on the policy discourse?
- How is co-production operationalised in recent Australian reforms?
- How do polices in recent Australian reforms potentially enlist or facilitate co-production?
- What are the systemic challenges for co-producing care services?

Systematic policy document analysis methods

A systematic analysis of health system reform documents was conducted to identify trends in Australian health system reforms that potentially impact operational contributions required from the public to the delivery of care in the community. Documents, as sources of data, can be used to provide an understanding of the research context and uncover insights to inform the research (Merriam, 1988). Documents can also be used to corroborate or refute findings from other sources of data, by providing evidence to clarify or challenge other findings (Yanow, 2006).

Document analysis provides a systematic approach for reviewing and evaluating textual data (Yanow, 2006). The analysis of documentary data benefits from being both unobtrusive and non-reactive. In

contrast to interview studies or other methods that involve direct human interaction, the process of investigation does not alter the form of the data (Merriam, 1988). The method for analysing textual data in the form of documents (in contrast to transcripts of direct human to human interactions) is often referred to as 'content analysis' (Bowen, 2009).

Content analysis is the process of grouping together words, phases or other units of text that are presumed to have similar meanings, to classify large amounts of data into an efficient number of categories (Weber, 1990; Stemler, 2001). The similarity of the words may be judged based on the precise meanings of the words (synonyms), those with similar connotations, or concerned with a specific concept (Weber, 1990). Content analysis can be performed quantitatively or qualitatively (Hsieh & Shannon, 2005).

Quantitative content analysis involves deductively assigning textual data into pre-defined categories and then counting the number of units in each category (Rourke & Anderson, 2004). A quantitative approach is concerned with providing a universal account of the data, which is dependent on the validity and transferability of the findings. In comparison to other quantitative research methods, content analysis has been criticised as being highly susceptible to subjectivity and interpretive bias in the process of categorisation (Mower, 1996; Kippendorff, 1980).

In contrast, qualitative content analysis involves identifying similarities and developing categories grounded in the data. Hsieh and Shannon (2005) defined qualitative content analysis as "the subjective interpretation of the content of text data through the systematic classification process of coding and identifying themes or patterns" (p. 1278). The development of themes involves "the systematic search for patterns to generate full descriptions capable of shedding light on the phenomenon under investigation" (Gale et al., 2013, p. 3).

Rather than counting the occurrences of words, the qualitative approach involves examining the language intensely for explicit and inferred communication (Weber, 1990). From a pragmatic standpoint, a qualitative approach was used for this review, given its aim to identify how public contributions can be inferred from by the reforms, based on understanding of health systems policies presented in Chapter Two. This is an exploratory topic, which did not lend itself solely to deductively quantifying pre-identified terms or concepts, although it is informed by a priori knowledge of global trends in health systems policy and practice.

Document Sampling Approach

A qualitative approach to sampling was used for selecting the health system reform documents. Purposive sampling is a technique for selecting units of analysis, based on a specific purpose (Tashakkori & Teddlie, 2003). This approach involves making transparent choices that will stand up

to independent scrutiny (Ritchie & Lewis, 2003). The intention of the sampling approach was to select policy documents that would capture the most recent national health system reforms in Australia. The documents include national system-wide reforms under the National Health and Hospital Network (NHHN) agreement, and subsequent reform documents detailing reforms to primary health care, aged care and mental health, that all have impacted services for older Australians receiving care in the community (see Table 3.2).

Table 3.2

Policy documents analysed

Australian Policy Documents
• A National Health and Hospitals Network for Australia's Future: Delivering Better Health and Better Hospitals (Australian Government Department of Health and Ageing [DHA], 2010a) • Building a 21st Century Primary Health Care System: Australia's First National Primary Health Care Strategy (DHA, 2010b) • Living Longer Living Better: Aged Care Reform Package (DHA, 2012) • Australian Government Response to Contributing Lives, Thriving Communities: Review of Mental Health Programs and Services (Australian Government Department of Health [DH], 2015a)

Data Analysis

The 'Framework Approach' to qualitative data analysis was used for this review (Huberman & Miles, 2002; Pope, Ziebland, & Mays, 2000). This approach has been increasingly used in the context of health care and applied policy research, which allows the objectives of the research to be set in advance (Gale et al., 2013; Huberman & Miles, 2002; Pope, Ziebland, & Mays, 2000; Ritchie & Lewis, 1993). The Framework Approach "is not aligned with a particular epistemological, philosophical, or theoretical approach. Rather, it is a flexible tool that can be adapted for use with many qualitative approaches that aim to generate themes" (Gale et al., 2013, p. 3). It involves deduction to provide an initial structure for coding while allowing new insights to emerge inductively through the process of line-by-line coding, preventing data from being pigeonholed into existing codes (Pope, Ziebland, & Mays, 2000). This process allows new findings to both benefit from and build on existing insights in the field (Miles & Huberman, 1994). In contrast to other qualitative data analysis, this approach aims to be informed by a priori issues (Pope, Ziebland, & Mays, 2000).

The Framework Approach comprises of five interconnected stages as described in Table 3.3. This was not a linear process and involved many iterations. Types of policies that potentially impact co-production were identified and labelled. Through the process of interpreting relationships between these policies, four overarching trends were identified across the policies that represent key aspects of health systems (i.e. re-orienting, re-locating, re-balancing and re-align as defined and discussed in Chapter Five).

Table 3.3

Five stages of the Framework Approach policy

Stage	Description
Familiarisation	Become immersed in the raw data to identify key ideas or recurrent themes.
Developing a thematic framework	Develop a framework based on the key concepts or themes (drawing on the review questions, a priori knowledge, as well as those emerging from the data).
Indexing the data	Systematically highlighting sections of the text with corresponding meaning to a category.
Charting	Charting all the indexed data into a matrix.
Mapping and interpretation	The data charted in the matrix is used to identify explanations for the findings by mapping the nature and range of phenomena and identifying typologies and associations between them.

Note. Sources: Huberman & Miles, 2002; Pope, Ziebland, & Mays, 2000.

In the tradition of qualitative research, the quality of research is judged by the concept of 'trustworthiness,' based on the 'confirmability' of the interpretation, drawing on the interpretivist view that knowledge is socially constructed and thus inherently subjective (Boyd & Richardson, 2004). Qualitative content analysis embraces the subjectivity of the findings, acknowledging that different researchers may derive differing findings from the data (Wesley, 2010). The intent is to achieve 'confirmability' by making explicit how inferences drawn can be traced back to the data (Ritchie et al., 2013). During the process of analysing the data using the Framework Approach, the matrix developed to chart the raw data into corresponding categories provides a direct link between the findings and the underpinning data. This matrix provides thick description to allow the reader to verify and make judgements about the trustworthiness and transferability of the findings. The matrix for this review is attached, linking the four overarching themes and associated policies in the policy documents to provide a link to data (Appendix 3.A).

Key Stakeholder Interview Methods

Semi-structured interviews with system representatives were conducted to identify systemic challenges to co-production in delivering care services, to guide a discussion of how the system has sought to address these challenges, subsequent to recent system-wide reforms. Ethics approval was attained for this study from the Human Research Ethics Committee (HREC), at the University of Melbourne (Ethics ID 1443382.1).

Sampling and Recruitment Strategy

Study participants were purposively sampled to represent a diverse range of perspectives. Participants were contacted via email, which included a request for their assistance with the research and attached with an information sheet (plain language statement) and consent form (Appendix 3.B & 3.C). Participants were selected purposefully to identify information rich cases (Patton, 2002). The selection of participants was based on key stakeholders with contextual insights including senior policy-makers (i.e. Department of Health, Department of Social Services), peak body representatives (i.e. Carers Australia, Consumer Health Forum, Dementia Australia, National Seniors Australia) and senior managers of service organisations and professional providers. A total of 12 participants were interviewed representing a broad range of perspectives to provide additional insights into the themes identified from the policy document review.

Data Collection

The study participants were engaged in semi-structured individual telephone interviews, (ranging from 45-90 min). With their permission, the interviews were digitally recorded. The interview questions would only relate to the participants' professional opinions and experiences. All participants were reminded immediately prior to the collection of data that no identifiable personal information about the participant and pseudonyms will be used for the report. The participants would also be reminded that they were free to withdraw from the study at any time.

Data Analysis

The interview data collected provided contextual insights into trends in health system policies, and the practical challenges and implications of co-production in care services. The data was analysed by listing references to systemic challenges for co-producing care services raised in the interviews, that were used to frame the discussion presented in Chapter Six.

3.6 CLIENTS AND CARERS AS CO-PRODUCERS STUDY METHODS

The main study in this thesis is concerned with the lived experiences of co-producing care in community which comprises a qualitative semi-structured interview study with older people with complex needs and their carers. This study is concerned with the experience of co-production in the delivery of complex care in the community from a co-producer's perspective. The purpose was to identify both the explicit and more subterranean contributions made by external actors, to the achievement of government purposes of improving health outcomes and keeping people living independently in the community. Ethics approval was attained for this study from the Human Research Ethics Committee (HREC), at the University of Melbourne (Ethics ID 1545855.1).

The key research question is:

> *How do older people with complex and ongoing care needs and their carers experience the co-production of their health and community care services?*

Sub questions:

- Who contributes to the delivery of complex care?
- What contributions do they make to addressing health outcomes and maintaining independence living in the community?
- What influences peoples' capacity to co-produce complex care in the community?
- Why do people co-produce complex care in the community?
- What are the benefits and unintended consequences of co-producing complex care in the community?

These questions correspond with the aim of understanding co-production in the delivery of complex care in the community. In contributing to our understanding of the nature of this phenomenon, the study also increases our understanding of how this process is facilitated from the co-producer's perspective. Thus, findings of the study can inform policy and practice on the pivotal role of co-production in achieving program objectives. The following are methods and ethical considerations detailed in relation to the sampling and recruitment strategies, interview content and structure, and analysis of the data.

Sampling and recruitment

A purposive sampling approach was used to capture the experiences of older people with complex and continuing health and social care needs as clients and their carers. The aim was not to recruit a representative or random sample. Random sampling is used to generalise from the sample studies to

the population of interest. In contrast, purposive sampling is a qualitative technique for selecting units of analysis, based on a specific purpose, to capture rich descriptive data that provides the context of people's experiences. (Tashakkori & Teddlie, 2003). This approach involves making transparent choices that will stand up to independent scrutiny (Ritchie & Lewis, 2003).

In order to capture a diverse sample of clients and carers, recruitment involved identifying eligible clients receiving services from local government under the Commonwealth Home Support Programme (CHSP), formally the Home and Community Care (HACC) programme in the Australian state of Victoria. By nature, CHSP clients tend to have complex needs, characterised by the need for ongoing and episodic health and community care from multiple providers across different care settings and sectors (Coleman, 2003; Goodwin et al., 2014). In Victoria, community care services provided under the CHSP are available to all Victorians aged 65 years and over, that have been assessed as eligible based on their needs. Recruitment through this programme provided the opportunity to identify study participants from LGAs with diverse geographic, cultural and socio-economic profiles.

This research was not an evaluation of CHSP services but to explore the nature of the phenomenon of co-production by capturing the experiences of clients and their carers in the delivery of their health and community care services in general. Clients were recruited to capture older people with complex needs who can consent and participate in the study, based on the following criteria:

- Aged 65 years or over;
- Living with three or more chronic conditions (defined as lasting 6 months of more);
- Living in the residence within the community (not in residential nursing care);
- Receiving ongoing care by two or more care providers in more than one sector (i.e. primary, secondary, acute and community care sector) over the previous 12 months; and
- Able to participate in terms of verbal communication and lucidity

A heterogeneous sampling approach was used to capture a diverse range of perspectives among people that met these criteria (Patton, 2002). Two strategies were used to capture diversity of experiences. The first was to recruit from different geographical locations based on Victorian local government areas (LGAs). The Australian state of Victoria comprises 79 LGAs. Five LGAs, representing different geographic, socio-economic, and culturally and linguistically diverse (CALD) populations, were used to facilitated recruitment of participants. The second strategy was to recruit a diverse sample from each of these LGAs, based on factors identified in the literature and consultation with Municipal Association of Victoria (MAV). These factors included age, gender, level of complexity of health conditions, length of service use and mix of conditions, and those on waiting lists for high level care packages, and the amount of access to informal support.

Carers of CHSP clients were also invited into the study, and clients were given the option of nominating a carer to be interviewed, either on their behalf or with them. Carers are defined in the study in accordance with the National Carers Strategy as "people who provide personal care, support and assistance to people with a disability, medical condition (including terminal or chronic illness) mental illness or frailty due to age" (Australian Government Department of Social Services [DSS], 2011, p. 13). The inclusion criteria for carers to be recruited into the study were:

- Providing informal care, support or assistance to someone close to them, specifically an older person with complex and ongoing care needs (as characterised above);
- Care provided is outside of paid employment, volunteering as part of an organisation, or for education or training purposes; and
- Aged 18 years or older (to meet restrictions set as part of the ethical approval gained for this study)

Initial assistance for recruitment was sought from the MAV to identify and elicit support from regional managers from local councils, to identify suitable CHSP clients to be recruited into the study. The aim was to identify regional managers from six local councils, representing a range of different socio-demographic and geographic locations. This was a time-consuming process and was hindered by a preoccupation of local councils with the transition of community care services from the HACC model to CHSP. Only two willing managers were identified through this approach. These managers provided contact details for relevant CHSP coordinators, who were contacted by the researcher to organise the recruitment of study participants. One of these coordinators provided details of their counterpart at a different council who also agreed to participate in the recruitment process. A further two local councils were cold-called directly to capture further socio-economic, cultural and geographic diversity, in north-western metro and regional Victoria.

CHSP coordinators from each LGA were contacted and provided with an information sheet (Appendix 3.D). This information included the purpose of the study and the recruitment approach, detailing the inclusion criteria for the study and criteria for selecting a diverse sample. Programme coordinators (or their staff) contracted CHSP clients and/or their carers directly to gain consent for their contact details being forwarded to the researcher. Given the dependent relationship between CHSP staff and their clients, potential participants were assured by the CHSP coordinators that whether they participate will have no bearing on their current or future service provision. They were also reassured that their participation was completely voluntary, that they can withdraw at any time and that their confidentiality would be strictly maintained. Only clients deemed by the CHSP staff to be cognitively able to provide informed consent were invited into the study. However, carers of

people who were unable to either consent or participate due to their level of lucidity or ability to verbally communicate, identified by CHSP staff were included.

Potential participants identified by CHSP staff were contacted over the telephone and asked if they would be interested in participating in an interview. They were informed of the purpose of the research and the questions they would be asked. It was important to avoid any anxiety or coercion resulting from concerns that there may be negative implications as a result of their decision whether to participate in the study. Participants were reassured that their decision to participate will have no bearing on current or future service provision and that their participation is completely voluntary, that they can withdraw at any time, and their anonymity and confidentiality of their responses will be strictly maintained. Only one potential participant identified by a CHSP coordinator, and who had agreed to be contacted by researcher, did not respond after being called twice and messages left without response.

Study participants were able to choose an interview time, date and location of their preference, to minimise inconvenience to them. All interviewees chose to be interviewed face-to-face in their homes. That was the method of choice as, "in-person contact helps to build rapport with the person and draw on non-verbal ques when interpreting their words" (Jensen & Laurie, 2016, p. 179). For pragmatic reasons, participants were given the option of being interviewed in the presence of a carer or care recipient depending on their preference. For carers, this allowed them to participate without accessing respite. Participants were given a copy of the plain language statement (PLS), which was also verbally explained to ensure they were able to make an informed decision about whether to participate (Appendix 3.E). Formal consent was obtained from participants at the time of the interview, with the signing of the consent form (Appendix 3.F).

Data collection

Qualitative semi-structured interviews were used to collect data for this study. A holistic perspective was adopted that focuses on capturing contextual influences, whereby "the whole is understood as a complex system that is greater than the sum of its parts" (Patton, 2002, p. 59). An interview schedule was used to guide the interview and facilitate a more focused exploration of the topic. The schedule was developed as a guide, as the interviews were not formally structured around the questions but followed a conversational approach. "Semi-structured qualitative interviewing is the most appropriate method of data collection when you are looking to understand individuals' perspectives on a specific topic in depth while maintaining the flexibility of exploring interesting threads in the interview as it unfolds" (Jensen & Laurie, 2016, p. 173). This allowed for participants to elaborate on the issues of most interest or concerning to them. Reciprocity is important for developing rapport and trust. Interviews can provide "a positive experience for participants to be intently listened to in an affirming

manner for a significant period of time" (Laurie & Jensen, 2016, p. 174). A conversational approach was taken to provide participants with the opportunity for sharing one's story and reflecting on one's resilience, expertise and ingenuity in participating in the provision of their health services or the care of someone close to them.

Some participants became teary as they discussed their experiences, particularly around loss and grief associated with caring for a loved one. Participants who began to show signs of distress were encouraged to take a break and then asked whether they wished to continue. Three participants decided to take a break and this time was spent discussing their hobbies, looking at photographs and having a tour of their garden. All three were happy to return to the interview afterwards and expressed that it was helpful to have someone to talk to. As found by Corbin and Morse (2003), "when research is conducted with sensitivity and guided by ethics, it becomes a process with benefits to both participants and researchers" (p. 335). During other interviews, there were times when there was prolonged discussion of highly sensitive topics. In these instances, the conversation was steered into more general conversation to reduce some of the emotional tension, before guiding them gently back to the areas of interest for the research. The participants were supported by the researcher through active listening and being present (Jensen & Laurie, 2016). Participants were reminded at the close of the interview that if they experience any distress afterwards to contact the researcher or a support service. The contact details for these options were provided on the PLS.

Some interviewees required more prompting and guiding to remain on topic than others. These participants tended to be more closed in their answers than others, requiring more use of questioning. The richest data came from interviews that involved extended narratives. Webster (1966) defined a narrative as "discourse, or an example of it designed to represent a connected succession of happenings" (p. 1503). Narratives have an organisational aspect, as noted by Sarbin (1986), "the narrative is a way of organizing episodes, actions, and accounts of actions; it is an achievement that brings together mundane facts and fantastic creations; time and place are incorporated. The narrative allows for the inclusion of actors' reasons for their acts, as well as the causes of happening" (p. 9). In many cases, it was difficult to directly answer questions, particularly around motivations, but these themes emerged through story telling. This early finding guided subsequent interviews towards a more narrative approach.

This researcher's personal influences on knowledge construction were considered throughout the research process. The researcher, in addition to qualitative interviewing performed as part of a mini-thesis for achievement of a Master of Public Health, had experience in semi-structured interviewing as a research assistant for the Australian Health Workforce Institute, including interviewing carers on their caring role. As a woman, with a clinical background and having cared for her grand-mother including her end-of-life care in the home, this researcher had personal understanding of the topic.

Reflexivity is "a consideration of the practice of research, our place within it and the construction of our fields of inquiry themselves" (May, 2011, p.44). This process of reflexivity included reflecting on the interview style and the influence of the researcher on the interview. An empathic neutrality and mindfulness approach were used during the interviews, where the interviewer takes an empathic stance to vicariously understand without making judgments (empathic neutrality) and shows openness, respect, awareness, sensitivity and responsiveness during the observation by being fully present (mindfulness), (Patton, 2002). Directly prior to each interview, a list of interviewing techniques for avoiding bias was read. Notes were also taken after the interviews and during analysis, exploring new insights as they emerged, and provided an opportunity to reflect on the researcher's interpretations.

The interviews were audio-recorded and transcribed verbatim by the researcher. On return from the interview the audio file was exported into an encrypted file, and the original recording was deleted from the recording device. Once transcribed, all identifying information including names and locations were removed, and pseudonyms were applied to the redacted transcripts. A spreadsheet with the participants names and pseudonyms and scanned copies of signed consent forms along with the audio files, were saved in a secure and encrypted folder to ensure confidentiality.

CHSP coordinators were asked to provide a de-identified data on participant's age, gender, types of health conditions, length of service use and mix of conditions, and those on waiting lists for high level care packages. This data was used to provide an overview of the participants profiles.

Analysis of the data

The Framework Approach was used to analyse the interview data, as used for the policy document review. Firstly, as part of the 'familiarisation' stage, the interview transcripts were read and re-read to become immersed in the raw data to start identifying key ideas or recurrent themes. This stage was aided by the process of transcribing the interviews and reading of the transcripts to remove any identifiable information. The next stage was the development of a 'thematic framework', which involved identifying key concepts and themes, drawing on both a priori issues and the objectives of the study and the raw data. The purpose was to develop a framework by which data can be examined and referenced, including those identified through inductive reasoning grounded in the data. The key analysis was performed focusing on the objectives of the study, including the following topics: (1) the actors involved in improving health outcomes and maintaining living independently in the community; (2) the types of contributions they made towards the achievement of these government purposes; (3) what influenced their capacity to make these contributions; and (4) the reasons why they decided to make (or not make) these contributions. A fifth topic was added during the analysis as a recurring theme that emerged from the data, relating to (5) the implications of the caring role.

After the first 10 interviews were transcribed, line-by-line coding was performed based on the study objectives. Codes that were conceptually related were then grouped together under umbrella categories for each topic area detailed above. These categories were used to develop the thematic framework using Microsoft Excel spreadsheets. As further interviews were transcribed, line-by-line coding was performed to expand and refine the 'thematic framework.' As different iterations of the framework and the initial categories for each topic were developed, they were tested against codes emerging from line-by-line analysis of the data. This allowed the categories to be further developed and refined to be both specific and inclusive of themes emerging for the data. Any codes that did not fit into existing categories were placed in "other" category and were used to guide further development of the framework. In accordance with the framework approach, two researchers should independently code the first few transcripts (Gale et al. 2013). A post-graduate student was engaged to code three transcripts into the coding framework (as it was developed and further refined by the PhD researcher), to gauge whether an independent party would consistently code the data into the framework. This was to ensure the specificity and inclusivity of the categories or themes in the framework, while not contributing to the analysis or the content of the thesis, but rather provided insights on the clarity of the terminology and categories used in the coding framework. The most important aspect from a qualitative methods perspective, is to be transparent about how and by whom the analysis was performed, to allow the reader to gauge the trustworthiness and transferability of the findings (Gale et al., 2013).

Once the testing of the framework did not yield further refinement, stages three and four, indexing and charting of the data, were commenced. A template was used to index and chart the data in the matrix for each of the interview transcripts. These matrices are used to "define concepts, map the range and nature of phenomena, create typologies and find associations between themes with a view to providing explanations of the findings" (Mays & Pope, 2000, p. 116). Indexing involved systematically going through each transcript, and 'coding' which involves identifying sections of the text with corresponding meaning to the relevant category from the framework. Codes that did not fit into existing categories were placed in the "other" category to allow for new or discrepant findings. The data was then abstracted from the transcripts, whereby the coded sections were summarised and charted into the corresponding cell in the spreadsheet matrix along, with the line and page number to provide a direct link to the raw data (Appendix 3.G). The final stage of the analysis involved mapping and interpretation, influenced by the research objectives of the study as topics of analysis, and themes that emerged from the data. The data charted in the matrix was used to identify explanations for the findings, by mapping the nature and range of phenomena and identifying typologies and associations between themes.

In the qualitative research tradition, the quality of research is judged by the concept of 'trustworthiness,' based on the 'confirmability' of the interpretation, drawing on the interpretivist view that knowledge is socially constructed as thus inherently subjective (Ritchie & Lewis, 2003). Qualitative content analysis embraces the subjectivity of the findings, acknowledging that different researchers may derive differing findings from the data (Al-Busaidi, 2008). The intent was to achieve 'confirmability' by making explicit how inferences drawn can be traced back to the data (Ritchie & Lewis, 2003). Thick description is a technique used to establish trustworthiness, which involves meticulous reporting of the findings and providing links to the underpinning evidence on which they are based (Berg, 2004). Establishing the 'transferability' of the findings also requires detailed accounts of the processes by which the findings were reached (Platt, 2006). During the process of analysing the data using the Framework Approach, the matrix developed to chart the raw data into corresponding categories provides a direct link between the findings and the data on which they were based. These matrices allow the reader to verify and make judgements about the trustworthiness and transferability of the findings.

Limitations of the study

This study has potential limitations. Despite efforts to the contrary, the number of people interviewed from culturally diverse backgrounds was limited to three, all of whom spoke English. It would be valuable to capture insights from CALD backgrounds and Indigenous Australians, who likely experience unique challenges in co-producing their care and have different social dynamics relating to the provision of informal care. The people interviewed may not be representative of the full extent of difficulties faced by older people and their carers who, in the midst of these challenges, presumably would be less likely to have the capacity or inclination to participate. It is unclear whether having the resources to offer respite for carers to participate in the study would influence the willingness of carers to participate in the study. Three carers who were interviewed elected to do so in the presence of the person they care for, and several couples were interviewed together who were acting as carers for each other to varying extents. It is possible that this may have affected the nature of experiences they disclosed. As an exploratory and descriptive study, it was limited to qualitative self-reported interview data based on people's narratives and life stories which may be subject to bias (for example, selective memory, telescoping, attribution and exaggeration). In addition, despite maintaining a neutral stance and asking indirect questions, the presence of the researcher during data collection might affect participants' responses. This research would be strengthened by triangulating the findings using mixed methods to measure associations between factors that influence co-productive contributions made by the public in their unique roles as client or carer co-producers.

CONCLUSION

Rather than engaging in the 'paradigm wars' between qualitative and quantitative methods of researching the social sciences, this thesis takes a pragmatic approach that places the research question at the centre of considerations about study design. Given the exploratory nature of the topic, qualitative methodology was used to examine the phenomenon of co-production in delivering services for older people with complex care needs. This research explores how the theoretical constructs of co-production apply to the delivery of complex care in the community, while informing health policy and practice on how co-production of care services can be better managed. This research examines co-production from three perspectives. The first is a review of the co-production in health and social care service literature, presented in Chapter Four. The second is top-down, examining the potential impact of health system reforms on co-production in the delivery of care services, presented in Chapters Five and Six. The third is bottom-up, exploring the experiences of older people and their carers as co-producers of complex care in the community, as presented in Chapters Seven through to Eleven, followed by a discussion in Chapter Twelve.

CHAPTER 4

Co-production of Care: An Emergent Literature

INTRODUCTION

There has been mounting interest in co-production of health and social care as a means of addressing the challenges facing 21st century welfare states, including rising demands and expenditure associated with ageing populations, changing expectations and fiscal constraints in the wake of the global financial crisis (Bovaird et al., 2015; Dunston et al., 2009; Pestoff, 2008). In recent decades, interest in the study of co-production has gained increasing traction in the UK, Europe, Scandinavia, the USA and Australia in various ways (Alford & Yates, 2015; Bovaird et al., 2015; Kunzel, 2012). It has been credited with a range of benefits including the potential to increase the efficacy and efficiency of services and creating democratic value and social capacity (Dunston et al., 2009; Evans, Hills & Orme, 2012; Hibbard, 2003; Isett & Miranda, 2015; Palumbo, 2016). However, as noted by Needham (2008) its "cure-all" potential, in part reflects the "excessive elasticity" of the term.

As an emerging field of study, the lack of definitional and conceptual clarity and consensus has hindered efforts to understand its benefits, antecedents and working mechanisms (Brandsen & Honingh, 2015; Verschuere, Brandsen, & Pestoff, 2012). For the purpose of this thesis, co-production refers to *active contributions of inputs, activities and behaviours by the public (as citizens and clients or third parties) to the delivery of public services and achievement of publicly valuable outcomes.* From this perspective, co-production is not necessarily novel in the delivery of care services (acting as an operational element in the delivery of care), as it often occurs at a subterranean level or under different guises in the policy discourse. This chapter provides a narrative review to explore what the health and social care services literature tells us about co-production. Key trends in the literature are presented, highlighting gaps in our understanding of the who, how and under what circumstances care is co-produced.

4.1 THE PUBLIC AS CO-PRODUCERS OF CARE

The public contribute as co-producers of care in different roles as citizens and as clients or third parties, including as carers or volunteers (as discussed in Chapter One). There are important distinctions between these co-producer roles, that warrant investigation to discern their motivations and contributions.

Client co-producers

Clients as co-producers, as defined in this thesis, actively contribute inputs, behaviours or activities to the delivery of their care services as the main recipient of the service. In the health and social care sector, a range of terms are used in relation to service recipients including patient, service user, consumer and customer. However, these terms are used in divergent ways and conjure differing identities and subtexts for the relationship to the service and perceptions of their role (McLaughlin, 2008). For lack of a more suitable alternative, the term 'client' is used here in reference to the main recipient or beneficiary of the service, who as co-producers contribute to the creation of value they consume privately.

Perceptions of the role of clients in the delivery of their care varies and has shifted over time as discussed in Chapter Two. Historically, clients or 'patients' were cast in the role of passive recipients of professionally directed and provided care (Longtin et al., 2010). Since the 1980s, market-based approaches have been variously adopted in the delivery of health services, where clients are placed in the role of 'consumer' exercising choice of providers and services (Thomas, 2012). However, since the turn of the century, policy makers have increasingly turned their attention towards collaborative approaches where clients are seen as 'partners' in the delivery of their care (Berwick, 2009; De Silva, 2014; Kodner & Spreeuwenberg, 2002; Lawn et al., 2013; Thille & Russell, 2010). The care services literature has used the term co-production to describe a partnership approaches to care (Batalden et al., 2015). As noted by McMullin and Needham (2018), "co-production has been promoted as a way of organising services and restructuring relationships between service users and professionals" (p. 151).

According to Ewert and Evers (2014), "the identity of the co-producers is a patchwork, the defining characteristics of which depend on a combination of individual dispositions, patterns of healthcare provision, service arrangements, and different healthcare contexts" (p. 433). Clients perform various roles in the delivery of their care. Ewert (2016) describes different facets to client identities including patient, co-producer, consumer, community member or citizen (defined in Table 4.1) that gain or lose relevance depending on the context.

Table 4.1

Client identities in health services

Client identities	Description
Patient	Passive user of health care services.
Co-producer	Involved in the production of health care services.
Consumer	Requested to choose health care providers and service features individually.

Community member	Seeks support through being engaged in informal ties and networks.
Citizen	Enjoying entitlements and participating in health care governance.

Note. Source: Ewert, 2016, p. 165.

Co-production is often contrasted in the literature with other types of client behaviours. Hirschman (1970) identified three types of responses clients may adopt if they perceive a decrease in quality or benefit from an organisation. These behaviours include: a) *exit* by withdrawing from the relationship; b) *voice* by expressing complaint or providing proposals for change in an attempt to improve the relationship; or c) *loyalty* where they remain acquiescent to the organisation. Loyalty was said to occur where clients feel the probability of influencing decisions is minimal, but the cost of exit is high (Hirschman, 1970). However, this typology does not account for obligatees, who are compelled to comply.

Building on Hirschman's typology, Dent and Pahor (2015) classified clients of health services behaviours as: (a) *choice* (similar to exit); (b) *voice*; and (c) *co-production*. In this typology *co-production* is defined as a form of "active loyalty" that involves patients expressing trust in the system by actively participating in the design *and* implementation of services. The authors distinguish co-production from "loyalty by default" or "proto-professionalism" where patients passively express their acquiescence (Dent & Pahor, 2015). The care service literature is largely concerned with participatory approaches, in contrast to passive compliance and consumerist approaches that involve shifting choice and control to clients (Boyle & Harris, 2009; Dunston et al., 2009).

It has been said that co-production rejects binary provider-centric or consumer-centric approaches and has greater transformational potential than traditional forms of participation, through exercising choice or providing commentary (Dunston et al., 2009). According to Dunston et al. (2009), rather than shifting power and control away from professional providers towards clients (leaving their respective roles unchanged), co-production moves clients "inside" the domain of service production.

> Co-production argues the need for an extended and distinctly different form of consumer participation, a participation that locates – co-locates – consumers with health professionals (and other stakeholders) as co-participants, co-designers and co-producers as part of the process of service production.
> (Dunston et al., 2009, p. 45)

Co-production is often framed as a way to shift the perception of clients to that of 'co-producer.' As stated by Ostrom (1996), "co-production implies that citizens can play an active role in producing public goods and services of consequences to them" (p. 1073). As is discussed further in this chapter,

co-production as recently applied to health and social care often marks a significant departure from its usage as an operational role. Increasingly, the research on co-production has been concerned with *new* collaborative or partnership approaches to care, that involve clients actively participating in *both* service design or planning (i.e. 'deciding role') and delivery (i.e. the 'doing role'). This stance is central to how the co-production of care has been conceptualised and defined in the care service literature. However, there are other forms of co-production that exist in the delivery of care services.

Volunteer co-producers

Volunteers as third-party co-producers contribute to the care of others, without receiving service from the organisation (Alford and Yates 2015). They may act with others in the form of 'group co-production,' defined as "voluntary, active participation by a number of citizens and may require formal coordination mechanisms between service agents and citizen groups" (Brudney & England, 1983, p. 63). In contrast to individual and group forms, Brudney and England (1983) also identified a third type, namely 'collective co-production,' where "co-productive activities result in collective goods whose benefits may be enjoyed by the entire community" (p. 64). According to Pestoff (2012) "collective action and, even more, collective interaction have the ability to transform the pursuit of self-interest into something more than the sum of individual self-interest, particularly promoting 'the development of social capital, mutualism and reciprocity'" (p. 30). In recent decades there has been mounting interest in eliciting collective action through initiatives such as time banking, peer support, and lay-led self-management programs, in areas of social care, mental health and chronic disease management (Glynos & Speed, 2012; Pavolini & Spina, 2015; Realpe, et al., 2015; Sharma et al., 2013; Wallace et al., 2012). Although formally organised group co-production by volunteers and the third sector also contributes to the co-production of care (Pestoff, 2012; Verschuere, Brandsen. & Pestoff, 2012), this thesis is primarily concerned with individual co-production by clients and their informal care providers.

Carer co-producers

Carers as 'third party' co-producers, represent a sub-set of volunteers, who provide *informal* care to others, with whom they have a *social relationship*. The term 'carer' represents a homogenous group, in part, differentiated by the nature of their social relationship to the client, such as spouse, parent, child, friend, neighbour and community members. Through their relationship with the client, carers may receive value from the service by extension in exchange for their co-productive contributions (Alford, 2009). There is also potentially a form of reciprocity, not only between formal providers and clients, but between clients and carers, as will be further explored in this thesis.

In their frequently cited definition in the care services literature, Boyle and Harris (2009) refer to co-production as a "relationship between professionals, people using services, their families and their neighbours" (p.11). The WHO (2016) in defining co-production also refer to the relationship between "professionals, people using care services, their families and the communities to which they belong" (p. 4). Citizens acting as carers often engaged in the delivery of care services on behalf of others. As noted by Bovaird and Löffler (2012) "most social care in the UK is not provided by the public sector but by family members looking after their elderly parents or children with care needs" (p. 23).

Despite the scale of contributions made by carers to health and social care, they have been afforded little attention in the literature as co-producers in their own right, with a few noteworthy exceptions. Weinberg and et al. (2007) examined coordination between carers and professional providers. They observed that there has been increasing 'outsourcing' of care-related tasks not only to clients but their informal carers. Carers were described as performing both a "quasi-patient" and "quasi-provider" role, that was critical to successful co-production but required better coordination with professional providers to perform this role effectively (Weinberg et al., 2007).

The role of carers as co-producers has been mostly explored in the delivery of mental health services. In the UK, The Carers Trust developed the "triangle of care" where clients, carers and healthcare professionals are involved in decision-making and establishing a therapeutic alliance, as a guide to best practice in mental healthcare (Worthington et al., 2013). In contrast to a disconnected model (A) where carers can be excluded at important points, (B) the triangle of care involves collaborating between professional providers, clients and carers as active partners in the delivery of care (see Figure 4.1).

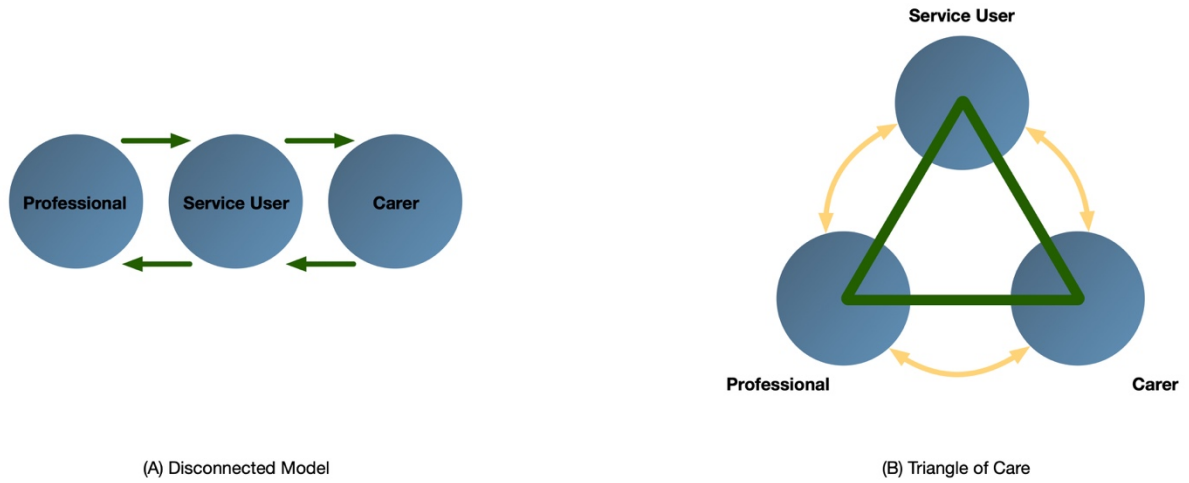

Figure 4.1. Models of relationships with carers. (Worthington et al. 2013, p. 6)

In 2015, a review on the role of carers in mental healthcare was conducted. Its author concluded that "informal carers are recognised as a fundamental resource for mental health service provision, as well

as a rich source of expertise through experience" (Bradley, 2015, p. 232). Despite the pivotal contributions in the care of older people, the research has paid limited attention to the contributions of carers including what influences their propensity to co-produce and inter-dependences between clients, carers and the service system.

4.2 THE NATURE OF CO-PRODUCTIVE CONTRIBUTIONS TO CARE

Public participation and the co-production of care

Co-production has become a ubiquitous umbrella term for a wide range of public participation and involvement in health system and service activities. Increasingly, it has been conceived as re-defining the role of citizens and clients in the health system to one that is *active and participatory* rather than *dependent and passive* (Dunston et al., 2009; Palumbo, 2016). This reflects trends in public policy more generally, emphasising active citizenship, deliberative democracy, and participation of the public as in all areas of public service sector functioning and development (Dunston et al., 2009). Since the 1960s and '70s there have been calls for increased public participation, from tokenistic towards citizen empowerment, that challenge traditional relationships of power, control and expertise (Arnstein, 1969; WHO, 1978; WHO, 1986; Durose & Richardson, 2016). However, as noted by Bovaird (2007), Arnstein's 'ladder of participation' fails to capture the complexity of the provider-user relationship.

It has been suggested that co-production provides a way for welfare states to "emancipate" citizens from "dependency culture" (Palumbo, 2016). The governance and performance of health systems has become highly political and scrutinized (Dunston et al., 2009). In response, health system reforms have adopted a greater focus on public participation marking a shift from managerial to more collaborative approaches (Gillgren, 2005; Dunston et al., 2009; van Eijk & Steen, 2013). These concepts have gained prominence in the health policy discourse in reference to the participation of the citizens and clients in innovation processes and quality improvement, such as the emerging field of experience-based co-design (Bate & Robert, 2006; Tsianakas et al., 2012).

In their vision for co-production of health and social care in the UK, Löffler and colleagues (2013) referred to the four *co's* of co-production including: *co-commissioning*, (including co-planning of health and social policy, co-prioritisation and co-financing of services); *co-design*; *co-delivery* (including co-managing and co-performing services), and *co-assessment* (including co-monitoring and co-evaluation of services). Bovaird (2007) also conceives co-production as applicable across the "full value chain of service planning, design, commissioning, managing, delivering, monitoring and evaluation activities" (p. 846–847).

As discussed in Chapter One, early commentators did not treat co-production as an optional choice made by public bureaucracies but rather an inherent (and not necessarily conscious) element of many public services (Parks et al., 1981; Brudney & England, 1983; Ostrom, 1996). However, as it has been more recently applied to health and social care, co-production has been seen to represent a "radical" departure from traditional approaches to public service provision, where it involves participation in service planning or design. The literature describes co-production as 'enhanced' or 'transformational' where the public participate in the design and planning, as well as delivery of public services (Bovaird, 2007; Dunston et al., 2009; Needham & Carr, 2009, Boyle & Harris, 2009).

Needham and Carr (2009) distinguish between different *levels* of co-production. These levels range from descriptive to ultimate or 'transformative' co-production, achieved through empowerment of both clients and professional providers (see Table 4.2). According to the authors, the descriptive level restates existing forms of co-production, rather than acknowledging productive capabilities or creating social capital (Needham & Carr, 2009). At the transformational level, co-production involves "new structures of delivery to entrench co-production, rather than simply ad hoc opportunities for collaboration." "It repositions the service user as one of the experts and asks what assets they can contribute to collaborative relationships which will transform provision" (Needham & Carr, 2009, p. 6).

Table 4.2.

Levels of co-production in adult social care

Level of co-production	Process
Descriptive level	The focus is on addressing compliance issues by negotiating shared problem definition and solutions.
Intermediate or 'recognisable' level	Engaging in problem-solving tasks and agreeing on outcomes, with structures for supporting user contribution and flexibility to accommodate for individual needs.
Transformative or 'ultimate' level	Involving a shift in power from service providers to empowering consumers to determine how the service is delivered through user led mechanisms of planning, delivery and management AND the empowerment of frontline staff, who are crucial to the process of co-production and the quality of service delivery.

Note. Source: Needham & Carr 2009, p. 9.

As discussed in Chapter One, this thesis distinguishes between *participation* (i.e. *deciding what to do)* and *co-production* (i.e. *doing it)* as inter-related yet distinct types of contributions. Bovaird (2007) developed a typology to demonstrate potential variations in professional provider and client *relationships* (see Table 4.3). In this scheme, *'full co-production'* is client involvement in *both* planning and delivery.

Table 4.3.

Types of professional provider and client relationships

	Professional provider as sole service planner	Client as co-planners	No professional provider input into service planning
Professional provider as sole service deliverer	Traditional service professional service provision	Traditional service provision with client involvement in planning and design	Formal provider delivery of client designed or planned service (N/A)
Professional provider and client as co-deliverers	Client co-delivery of professionally designed services	Full co-production	Client co-delivery of service with professionals, with little formal planning or design
Client as sole service deliverer	Client delivery of professionally planned services	Client delivery of co-planned or co-designed services	Self service

Note. Source: adapted from Bovaird 2007, p. 848.

Co-production as conceived in the care services literature overlaps with other concepts in the health policy discourse including patient-centred care and personalisation (McMullin & Needham, 2018). Increasingly, co-production is described in the literature as a partnership approach that involves dialogue between providers and client, drawing on the expertise of both parties, to achieve shared decision-making (i.e. patient-centred care) and providing choice to increase service responsiveness to clients' individual needs and preferences (i.e. personalisation). These approaches relate to the type of relationship clients have with providers in decision-making about their care services, in addition to their operational role as co-producers.

Involving clients in making decisions about their services has been linked to the achievement of better outcomes (Hibbard, 2003). The conventional wisdom is that participation in decision-making is: (a) always an option; (b) universally beneficial; and (c) will result in increased compliance. However, despite public participation often being treated as an unquestionable good, some commentators have noted that there are circumstances where it is not possible or preferable in the provision of health and social care (Batalden et al., 2015). In addition, there are other influencing factors and types of relationships that exist, which have been given limited consideration in the analysis (Parrado et al., 2013).

The analysis in this area has focused on forms of co-production associated with clients' participation in decision-making about their care, largely from a top-down perspective. However, there are

existing forms of co-production in the delivery of care services that have been largely overlooked despite being instrumental to the delivery of care services. In this thesis, participative service planning or design is recognised and explored as a potential antecedent or working mechanism. In addition, other factors that influence the propensity to co-produce are also explored from both top-down and bottom-up perspectives based on the lived experiences of clients and carers as co-producers of care in the community.

Co-production as a relational element of care service delivery

The care services literature on co-production is largely concerned with the nature of the relationship between clients and professional providers. In this way, co-production is linked with other concepts in the health policy discourse, including shared decision-making, patient engagement, patient activation and relationship or patient-centred care, and other *partnership* models including chronic disease management and self-management (Batalden et al., 2015; Palumbo, 2016). A conceptual model of healthcare service co-production was developed by Batalden and colleagues (2015), which centres on the *partnership* between "patients" and "professionals." The authors stated that:

> Our central tenet is that healthcare services are always co-produced by patients and professionals in systems that support and constrain effective partnerships. We do not improve healthcare services by adding co-production. Rather, as we come to recognise this essential co-productive character of healthcare services, we see new opportunities for innovation and improvement.
> (Batalden et. al., 2015, p. 4)

This model includes three levels of the "co-creative relationship" between patients and professionals. The most basic level, *civil discourse*, involves good communication and respectful interaction. The next level, *co-planning*, requires a deeper understanding of the expertise and value of the other. While, the ultimate level, *co-execution*, involves trust, shared goals and greater mutuality of responsibility and accountability for performance (Batalden et al., 2015). Batalden and colleagues (2015) state that:

> Even in the most traditional model of medical practice - patient comes to clinician for help, clinician listens to and examines the patient, clinician formulates a plan and instructs the patient, patient follows (or does not follow) suggestions - health outcomes (good and bad) are co-produced. Good outcomes, most recognise, are more likely if the patient can and does seek and receive help in a timely way, if the clinician and patient communicate effectively, develop a shared understanding of the problem and generate a mutually acceptable evaluation and management plan. (p. 1)

Co-production as "a dialogic and dialectical partnership approach," has been described in relation to care services as "the very mechanism and process through which health systems and services become co-productive" (Dunston et al., 2009, p. 46). Farrelly (2014) described co-production as "a process of active dialogue and engagement between people who use services and those who provide them - it aims to draw on the knowledge and resources of both parties to develop solutions to problems and improve the overall interaction between citizens and those who serve them" (p 763). There is a common trend in the literature, where co-production is considered to be a deliberative process that occurs during direct service interactions (Dunston et al., 2009; Farr & Cressey, 2015; Farrelly, 2014).

> Through the lens of co-production, the provision of health care is ultimately conceived as a human encounter, during which the patients and the health care professionals share mutual information and define a joint strategy to deal with the illness - it recognises patients are the key players in provision of health care, where they perform as co-creators of value. (Palumbo 2016, p. 73)

The relationship between formal providers and clients is often portrayed as the most important element of co-production in health and social care, with relational aspects of service interactions as a key theme across the literature (Dunston et al., 2009; Batalden et al., 2015). The term *relational practices* has been employed in reference to dialogue, understanding, empathy and intimacy in client and professional provider relationships. Parker and Heapy (2006) state that "learning to understand and map how people experience the point of delivery, the interface between the service and their lives, is essential for creating the conditions for co-production" (p. 15).

There is a tendency in the literature to define co-production based on the relational aspects of the relationship with professional providers that provide favourable conditions for collaboration. However, there is evidence to suggest that there are other factors that have not been examined in the literature that influence whether co-production happens beyond service satisfaction and being involved in decision-making about services (Parrado et al., 2013; Alford & Yates, 2015). To date, the literature has been concentrated on new collaborative and participatory approaches to care, however co-production can be used as a lens to better understand public contributions to the delivery of existing care services to achieve government purposes.

Direct and indirect co-production of care

Co-production has been conceived by some commentators as a characteristic or *intrinsic* element of *all* services as consumption and production are inseparable, and the quality of the service is produced during *direct* interactions between professional providers and the clients (Osborne et al. 2013). This

‘service-dominant logic’ may have contributed to the focus in the literature on co-production that occurs during direct service interactions. According to Dunston and colleagues (2009):

> The site of the *relationship*, the interface between health consumers and health professionals, is identified as the location of ‘production’ - where services, outcomes and the experience of the various participants are shaped. The process of the relationship, its formation, use and development are identified as the mechanism and process, through which production becomes either more or less co-productive, more or less effective, more or less sustainable, more or less satisfying. (p. 48)

In this vein, Bovaird and Löffler (2012) state that “the creation of value and quality often occurs usually during the interaction between the client and the formal provider,” whereby “clients do not evaluate quality of the service based on the achievement of improved health outcomes, but also the process of service delivery - their experience of the service” (Bovaird & Löffler, 2012, p. 7). However, there are divergences on whether co-production involves activities performed conjointly during direct service interactions (as previously discussed in Chapter One).

Co-production can be conceived as a reciprocal process provides a way of understanding the “joint” nature of co-production between formal providers and clients or citizens. Alford and Yates (2015) employed a definition for considering client contributions to health service delivery, in which “not only conjoint activity by both government personnel and citizens/service-users, but also *any activity by one which adds value (‘produces’) and is at least partly prompted by some action or behaviour of the other* - particularly where the citizen co-producer’s behaviours contribute in some way to achieving publicly valuable purposes (e.g. reduced health spending)” (p. 161:original emphasis). This is a broader definition than is commonly used in the literature, extending the scope of co-production efforts beyond direct interactions with formal providers, which is arguably more managerially useful (Alford & Yates, 2015).

> Co-production involves a mixing of the productive efforts of regular and consumer producers. This mixing may occur directly, involving coordinated efforts in the same production process, or indirectly through independent, yet related efforts of regular and consumer producers.
> (Parks et al. 1982, p, 1002)

In their typology of co-production, Brandsen and Honingh (2015), distinguished between the extent of involvement in the design as well as the implementation of the services; and “the proximity of the tasks that citizens perform to the core services of the organisation” (p. 432). In addition to direct contributions to the ‘core’ production process involved in the delivery of a service; the author also

acknowledged 'complementary' that indirectly contribute to achievement of the organisation's goals (Brandsen & Honingh, 2015). This typology is useful in examining care services, as demonstrated by the movement towards user involvement in health care (McMullin & Needham, 2018). Achieving service objectives in caring for people with complex needs in the community typically involves inputs from formal and informal third parties outside direct service interaction (in the highly specialised, differentiated and siloed health and social care sectors), however these complexities have yet to be considered in the literature.

There has been limited interest in or empirical evidence on behaviours outside direct interactions from a policy and practice perspective (Parrado et al., 2013). This thesis addresses this gap, examining existing forms of direct (i.e. performed conjointly with providers during direct service interactions and contributing directly to 'core' production processes of the service); and indirect co-production (i.e. performed independently and tasks performed outside the core production process of the service that contribute to the achievement outputs and outcomes).

4.3 ELICITING AND FACILITATING CO-PRODUCTION OF CARE

Enabling and Relieving Logics

The work of Richard Normann (1984) has been particularly influential in the way of framing the co-production of care services (Bovaird et al., 2015; Batalden et al., 2015: Edgren & Barnard, 2012). Normann distinguished between two philosophies that can be used to reconfigure services, namely "relieving" and "enabling" service logic (Normann, 1984; Normann, 2001). "Relieving" refers to formal providers doing something for the consumer or client that the professional can do better, or so that the consumer can focus on their "core business", save costs and time and reduce complexity (Normann, 2001). In contrast, "enabling" is aimed at "*expanding the scope of what a customer can do* (as opposed to just liberating him from having to do something he did before). It visibly changes what value the customer can create in his business, or his value-creating process in general. It endows him with new competences and market opportunities" (Normann, 2001, p. 101). In describing these logics, Normann (2001) uses the example of healthcare, that will "typically both relieve customers (as in the case of acute illness) and try to enable them (such as by informing them about what is a healthy lifestyle, about preventive care, about self-care, about post-surgery rehabilitation)" (p. 101).

> A healthcare system applying an enabling logic would ask itself what it could do to support the customer's processes to create health rather than what it can do to cure illness. Of course, such a system would still contain large elements and islands of relieving, but my guess is that it would mean a revolution to rethink healthcare systems with an enabling point of view (focusing on the citizen's health-creation process) framing elements of relieving

> (such as when the citizen becomes a patient lying on the operating table), rather than the other way around. By creatively designing a system so that the customer is provided with capabilities, time, or vision the slumbering potential of a customer can be realized. (Normann 2001, p. 102-103)

This perspective recognises that whether to adopt a relieving or enabling logic depends on the circumstances. The enabling logic aligns with preventive approaches to health care, including self-management and patient empowerment that involve people actively contributing to improving health outcomes. It also aligns with strengths or asset-based approaches to care (SCIE 2015). In adult social care, Bovaird and Löffler (2012) define co-production as "professionals and citizens making better use of each other's assets, resources and contributions to achieve better outcomes or improved efficiency" (p. 23). The authors refer to "core principles" of co-production based on perceptions of the client or 'customer' role and identity (see Table 4.4).

Table 4.4.

Core principles of co-production

Core Principles	Description
Customers as innovators	Citizens have knowledge that formal providers don't have.
Customers as critical success factors	Citizens can make service more effective through compliance and evaluation.
Customers and resources	Citizens have time, information, and financial resources they are willing to invest to improve their outcomes or help others.
Customers as asset-holders	Citizens have diverse capabilities and talents to share with professionals and other citizens.
Customers as community-developers	Citizens can engage in collaborative rather than paternalistic relationships with staff and other service users and members of the public to bring out the best in them.

Note. Source: Bovaird & Löffler, 2012, p. 23.

The concept of co-production has also been influenced by Cahn (2000) through the acknowledgement of clients' resources and expertise. In his book titled 'No more throw-away people: The co-production imperative', Cahn (2000) details core values of co-production including taking an *asset perspective*, along with redefining work, reciprocity, and social capital. In the UK, Boyle and colleagues (2006) describe "an emerging co-production sector – where service users are regarded as assets, involved in mutual support and the delivery of services" (p. xiii). Russell (2011) called for a shift from the omnipotent, medicalised, "sickness" model of healthcare to an "asset-based approach" where citizens with the assistance of professional providers "co-produce" healthy lifestyles and improve their health outcomes in their communities. Although the concept suggests clients have latent potential that can be "activated", people may face barriers that preclude them from co-producing.

Facilitating co-production is more complex than it may first appear, particularly for older people with complex needs as illustrated in this thesis.

Self-efficacy and the propensity to co-produce

What motivates people to co-produce is an oft studied aspect of co-production and is particularly pertinent to care services where "barriers and challenges exist that may not exist in other sectors" (McMullin & Needham, 2018, p. 153). The willingness to co-produce has been found to extend beyond self-interest (i.e. where people are motivated to co-produce their care services to gain value from the service (Alford, 2002; Alford, 2009; Thomas, 2012; Sharp, 1980; van Eijk & Steen, 2014). Other motivating factors include intrinsic motivations, sociality or social affiliation, and normative values (Alford, 2009). The weight of these motivations is also influenced by how they are framed and whether they are direct or oblique (Alford & O'Flynn, 2012). Alford and Yates (2015) note that "given this complexity, motivations are difficult to investigate, prone as they are to conscious and sub-conscious bias, interdependencies, and feedback loops" (p. 162). As discussed in Chapter One, another aspect that influences the propensity to co-produce is *ability*. Alford (2009) found that people may be willing but not able to co-produce, meaning that organisations are required to either simplify the task or increase the persons' capacity to perform it.

One frequently researched concept of what influences co-production captures elements of both *motivation* and *ability* is *self-efficacy*, where "the greater the sense of self-efficacy, the greater it resonates with citizens' intrinsic motivations. At the same time, the more the citizens' capacity relative to the task is enhanced, the more their sense of self-efficacy is boosted. In short, we focus on willingness to do more and self-efficacy as indicators of motivation and ability to co-produce" (Alford & Yates, 2015, p.162). The concept of self-efficacy stems from Bandura's (1977) Social Learning Theory, that seeks to explain and predict behaviour based on incentives, outcome expectations and self-efficacy. According to his theoretical framework, behaviour change and maintenance are the function of: (a) expectations about the outcomes that will be achieved by engaging in the behaviour; and (b) expectations or belief about one's ability to successfully engage in the behaviour, or their level of "self-efficacy."

Co-production has been examined in the management of chronic or long-term conditions, specifically involving group co-production in the form of ley-led Self-Management Program (SMP) (Turner et al., 2015). Recent government policies have been underpinned by the theory that supporting patient participation is a mechanism for improving self-management, embedding patient centeredness and patient involvement as well as self-management in quality improvement initiatives (Turner et al., 2015). In the UK, self-management programs emerged such as the "Expert Patient Program' (EPP) that are led by patients (Barlow, Edwards, & Turner, 2009; Turner et al., 2015). EPP is based on the

Chronic Care Model that promotes five core areas of self-management of long-term health conditions including: problem solving, decision-making, resource utilisation, developing effective partnerships with healthcare providers, and taking action in order to make behavioural changes (Wilson, 2001).

The concept of patient activation has been linked to co-production as a marker of self-efficacy. Patient activation is defined as "the extent that patients have the knowledge, skills, and confidence, to use self-management support skills in their lives" (Turner et al., 2015, p. 214; see also Hibbard et al., 2004). In the UK, a group-based SMP co-delivered by health professionals and patients, was evaluated to determine whether participation resulted in improved patient activation (Barlow, Edwards, & Turner, 2009; Turner et al., 2015). In addition, whether the SMP influenced health related quality of life, health status, mental health and self-management skills were also evaluated. The pre-post intervention survey found significant improvement in self-reported patient activation for 54% of those who attended the program, along with improvement in self-management skills (Turner et al., 2015). Increased patient activation is thought to increase the likelihood of performing self-care (Turner et al., 2015).

Building on these EPP initiatives, an independent charity for the quality improvement (QI) of health care in the UK, The Health Foundation, developed a national QI demonstration program called 'Co-Creating Health' (CCH). Drawing on Wagner's Chronic Care Model, support for self-management is a main objective of health services that create knowledgeable and confident patients and clinicians supported by a responsive and flexible administrative structure (Turner et al., 2015). CCH aimed to "transform the traditional interaction between clinicians and patients to a more collaborative relationship" (Sharma et al., 2013, p. 39). An evaluation of CCH self-management programs for people with type 2 diabetes mellitus found "improvement in patient activation is an important finding because activated patients participate in collaborative decision-making with their clinicians, report improved health-related behaviours and clinical outcomes, and better adhere to treatment" (Kosmala-Anderson et al., 2014, p. 773). People's level of self-efficacy (as measured by patient activation) has been demonstrated as influencing co-production (Parrado et al., 2013).

The majority of co-production of healthcare literature is theoretical or based on qualitative case study research. A notable exception was a large quantitative survey study on the role of citizens in delivering public services performed across five European countries including the UK, Germany, France, Denmark, and the Czech Republic (Löffler et al., 2008; Parrado et. al., 2013; Bovaird et al., 2015), and later replicated in Australia (Alford & Yates, 2015). A random sample of approximately 1,000 people aged 18 and over was recruited for each country with quotas for age, gender and region. The European study also included 15 focus groups (n = 98) with policy makers and key stakeholders for each country. The countries were chosen to represent different administrative traditions Anglo-

Saxon, Prussian, Scandinavian, Napoleonic, and ex-communist, with the expectation that different administrative traditions may influence co-production.

The survey explored correlates of co-production including "demographic factors (age, gender, education, and employment status), community characteristics (urban, non-urban), performance perceptions (how good a job government is doing), government outreach (providing information and seeking consultation), and self-efficacy (how much of a difference citizens believe they can make)" (Parrado et al., 2013, p. 85). The survey covered three different sectors and government functions including community safety (coercive action), local environment (regulatory function), and public health (welfare improvement). In relation to public health, participants were asked to rate the frequency of performing co-production behaviours including: (1) changing to a more healthy diet; (2) trying to exercise; (3) seeing a doctor for a health check and blood tests; (4) taking care of a sick family member or friend; and (5) participating in a group or organization that deals with health issues" (Parrado et al., 2013, p. 94).

The indicators focused on preventative and service delivery behaviours, rather than consultative behaviours which have often been the focus of previous studies and given the importance of behaviours outside direct consultation from a policy perspective (Parrado et al., 2013). The survey also aimed to capture a mix of co-productive behaviours that were likely the function of different motivations. Participants were also asked how much time they would be willing to contribute to improvements in public health generally. In order to measure levels of self-efficacy participants were also asked "how much of a difference do you think ordinary citizens can make to the quality of their own health and health care?" (Parrado et al., 2013, p. 95).

The European study found that self-efficacy was an especially important determinant of co-production across sectors, that women and the elderly engage more often in co-production, and good outcomes (i.e. good health) seemed to discourage co-production somewhat with the authors concluding that "co-production appears to depend in part on awareness of a shortfall in public performance on outcomes" (Parrado et al., 2013, p. 85). The study found some evidence that co-production is enhanced through the provision of information or engaging citizens in consultation, however "the specific determinants vary, however, not only by sector but across national contexts" (Parrado et al., 2013, p. 85). In considering the findings Löffler and colleagues (2008) stated that "increased levels of co-production in the future will require appropriate mechanisms and initiatives, which are sufficiently easy and straightforward to encourage individuals and their families to get involved. Ideally, these should be initiatives that individuals can pursue on their own, if they want to do so - many individuals are reluctant 'joiners'" (p. 7).

The Australian study also found higher levels of co-production in activities performed individually, and closely reciprocal activities that yield high levels of private value as opposed to group activities (Alford & Yates, 2015). Contrary to the European study, there was no evidence to suggest a relationship between service satisfaction and co-production, or the provision of information and inclusion/consultation (i.e. whether health care providers ask the participant's opinion about issues affecting their health) and co-production (Alford & Yates, 2015). This finding was surprising given that it challenges key assumptions in the literature about what motivates co-production of health and social care. People demonstrated high levels of self-efficacy for improving their health and the health of others, with 70% feeling they can make a big difference, and 23% some difference. However, there was modest evidence of a positive relationship between self-efficacy and co-production levels (Alford & Yates, 2015). As demonstrated in this thesis there are other inter-related and complex factors that also influence clients and carers to co-produce their care in the community.

4.4 CHALLENGES TO CO-PRODUCING CARE

Co-production is an operational element in the delivery of care services in the community, but it does not necessarily happen or achieve desired outcomes. As noted by McMullin and Needham (2018), despite impetus for co-production in the care sector "it is also a setting in which barriers to co-production may be particularly prohibitive (p. 151). The literature has been largely concerned with challenges to engaging the public in decision-making processes, in which co-production involving a collaborative relationship with providers is said to challenge existing provider-centric, expert-based practice requiring substantial socio-cultural and organisational change. According to Dunston et al. (2009), all forms of co-production "profoundly disturb many fundamental constructs that have long informed professional identity, defined and differentiated expert knowledge from lay knowledge and shaped the roles and rules that typically govern the ways in which health professionals and health consumers interact" (p. 42).

A qualitative study looking at 'pro-social organisational behaviour of health care workers' (PSOB) as the "the willingness of workers to both fulfil and go beyond formal job requirements, which has long been recognised as a valuable contributor to organisational performance" (Hyde, Harris, & Boaden, 2013, p. 3115). The authors found that PSOB to be "particularly important in health organisations where service provision involves high levels of task interdependence, task complexity and uncertainty, and delivery often depends on the spontaneous actions of employees as they co-produce services with the patient" (p. 3115). This approach calls for human resource management that builds shared values that service both clients' needs and the needs of health organisations (Hyde, Harris, & Boaden, 2013). Four types of organisational capabilities for increased client participation in health services were identified by Sharma et al. (2014) including *customer activation*, *organisational activation*, *interaction capabilities*, and *learning agility*. The authors found that "health care

organisations perceive they lack the capabilities required to effectively manage increased customer participation" (Sharma, Conduit, & Rao Hill, 2014, p. 186).

Partnership approaches have implications relating to responsibility, power and control, recognition of expertise, respect, autonomy and independence (Lawn et al., 2013; Thille & Russell, 2010; Alakeson, Bunnin, & Miller, 2013). It has been observed that shared decision-making in the delivery of health services may raise tensions, particularly relating to the radical shifts in control and power that are required (Berwick, 2009; Longtin et al., 2010). Factors that may influence providers participation in facilitating partnership approaches identified in the literature include: maintaining control, time constraints, the type of condition, personal beliefs, disciplinary background and training in facilitating consumer participation (Longtin et al., 2010). Resistance to shared decision-making by providers has been framed by arguments such as the need to prioritise evidence-based medicine in decision-making over the needs and wants defined by the consumer, and the responsibility of providers to steward limited social resources (Berwick, 2009). According to Ewert and Evers (2014) "role-expectations such as the ''expert-patient'' or the ''citizen-consumer'' have a liberating potential but may likewise marginalize issues such as trust and the need for protection" (p. 425).

There is a trend in the care service literature that defines co-production as changing the balance of power and control (Boyle & Harris, 2009; Fairlie, 2015; WHO, 2016), although the notion of co-production as the delivery of care in an *equal* relationship with professional providers is debatable. As stated by Batalden and colleagues (2015) "it is neither possible or desirable to share power and responsibility equitably between patients and professionals in all situations - the healthcare system cannot abandon patients who do not have the resources or expertise to partner effectively in co-producing good health outcomes for themselves" (p. 6).

> Not all patients have the desire or capacity to be active participants in co-producing their healthcare service - the character of the partnership between professionals and patients is dynamic and degrees of agency shift across time and setting and circumstance. People from every background and social location become patients with widely disparate co-production dispositions and capacities.
> (Batalden et al., 2015, p. 6)

Health professionals and clients are different types of actors that have their own perspectives and conceptualisations of health care provision, for instance the former having a third person while the latter have a first-person perspective of health issues (Owens & Cribb, 2012). As a result, they may have different or conflicting priorities and beliefs that may hinder value co-creation (Palumbo, 2016). Another issue raised in the literature is information asymmetry. According to Palumbo (2016) "it prevents information exchange and undermines mutual understandings between the health care

professionals and the patients, thus discouraging the engagement of the latter" (Barile, Savino, & Polese, 2014; Palumbo, 2016, p. 79).

It has been suggested information asymmetry is particularly problematic, for instance, services mediated by Information Communication Technology (ICT). Robertson and colleagues (2014) found online self-diagnosis to result in "co-destruction", where clients' resources are deficient or misused, or e-health provider's resources are of a poor quality. People who are unable to comprehend or apply health information fail to comply with e-health service instructions and destroy value rather than co-producing it.

It has also been suggested that "there is a danger that any co-production that occurs will be individualised, transactional and substitutive, particularly where users lack individual and social capital" (Miller & Stirling, 2004, p. 5). Reliance on co-production by consumers for the delivery of health services may lead to people 'falling through the gaps', given clients have different capabilities and willingness to engage in co-production. Although it tends to be treated as a panacea of unquestionable good in literature; there are some commentators who raised concerns about the possible negative consequences of co-producing health services (Batalden et. al., 2015; Bovaird, 2007) and who have called for a contingent approach (Alford, 2009).

CONCLUSION

The current literature of co-production of care blurs the line between participation in decision-making processes and co-production as an operational element of service delivery (i.e. active contributions of time and effort to the production of publicly valuable outcomes). The literature is largely concerned with the transformational potential of co-production, where it involves new collaborative approaches to service delivery. This has often narrowed the focus in the literature on processes that occur during direct service interactions, particularly relational aspects of these interactions, as the central mechanisms that influence clients to make necessary contributions to their care. As it is used in the care services literature, 'co-production' has overlapping conceptual boundaries with other approaches in the health policy discourse. This thesis differentiates and draws links between co-production and trends in health system policy and examines the impact of health system reforms on co-production in the delivery of care services (see Chapters Five and Six). To date, there is a paucity of evidence based on client and carer perspectives as co-producers, to provide a human face to the analysis of co-production. This thesis also addresses this gap by exploring the lived experiences of older people and their carers to inform our understanding of the nature of co-productive contributions to the delivery of complex care in the community, and what influences these processes (see Chapters Seven to Eleven). It applies generic co-production theory to caring for ageing populations to inform health systems policy and practice on how existing forms of co-production can be better facilitated and sustained.

CHAPTER 5

The Impact of Health System Reforms on Co-production

INTRODUCTION

This chapter examines how health system reforms potentially impact co-production in the delivery of health and social care, as it is necessary for the achievement of service objectives and government purposes. Australia's health system is facing significant and mounting challenges associated with increasing prevalence of chronic illness, multi-morbidity and frailty due to age. As demands on the health system continue to burgeon, financial and human resources are in diminishing supply. In seeking solutions to this looming crisis, Australia has undergone a series of national system-wide reforms (see Table 5.1 for corresponding policy documents analysed in this study). Some of these solutions seek to improve internal efficiencies (i.e. integration and responsiveness), while others involve enlisting the public to contribute to the work of delivering care and improving health outcomes through prevention and community-based care. This usually amounted to some form of co-production, although not always explicitly framed or acknowledged as such. Co-production, while inherent in many of the reforms, tends to occur at a subterranean level and has yet to be adopted in a policy vernacular.

Table 5.1

Key Australian reforms and corresponding policy documents

Reforms	Policy documents
The National Health and Hospital Network (NHHN) or system-wide reforms	A National Health and Hospitals Network for Australia's Future: Delivering Better Health and Better Hospitals (DHA 2010a)
Primary health care (PHC) reforms	Building a 21st Century Primary Health Care System: Australia's First National Primary Health Care Strategy (DHA 2010b)
Aged care reforms	Living Longer Living Better: Aged Care Reform Package (DHA 2012)
Mental health reforms	Australian Government Response to Contributing Lives, Thriving Communities: Review of Mental Health Programs and Services (DH 2015)

Since the central concern of this study is the impact of the system level changes on co-production, it is important to understand what those changes are, and how they might affect the system. This study involved a systematic document analysis of recent system-wide Australian health system reform documents (methods detailed in Chapter Three), and targeted key stakeholder interviews discussed in

the following chapter. Four major trends were identified through the analysis that potentially impinge on co-production (or in turn be affected by it) including:

- Re-orienting the system towards *prevention*
- Re-locating care in the *community*
- Re-balancing control through *participation*
- Re-aligning services to be *more responsive* and *better integrated* across the service system

This chapter describes each of these in turn, identifying the organisational and operational points where co-production and the reforms might potentially impact each other.

5.1 RE-ORIENTING THE SYSTEM TOWARDS PREVENTION

A cornerstone of Australian health system reforms was reorienting the system towards prevention. This involves engaging or enabling people to behave or act in ways that improve their health, rather than reactively responding to established conditions. As the Department of Health and Ageing put it:

> A greater focus on prevention and a more systematic approach to preventive care will help to ensure that Australians are supported to maintain optimum health.
> (DHA 2010b, p. 35)

Overall, this reorienting involves diverting attention and resources from the costly acute care sector, where health outcomes are achieved largely through clinical interventions performed by health professionals using specialised skills and equipment. This shift involves strengthening the provision of primary health care (PHC) in the community to encourage clients to perform preventive activities to improve their own health outcomes. Preventive care is dependent on people changing their health-related behaviours (such as diet, physical activities and substance use) and performing activities to manage and minimise the impact of existing conditions on a day-to-day basis (as discussed in Chapter Two). Thus, prevention represents a shift in the nature and scope of time and effort required from clients (i.e. co-production) necessary to improve health outcomes. This approach raises challenges for health systems to better enlist and facilitate clients in making necessary contributions to achieve service objectives. It calls for a shift of organisational responsibilities, both at the differing levels (vertically) and across the system (horizontally).

A number of organisations and programmes were either created, amended or expanded to meet this call. The system-wide *National Health and Hospital Network* (NHHN) was established in response to the *National Health and Hospitals Network: Delivering Better Health and Better Hospitals* report (DHA, 2010a). Central to this reform was placing greater emphasis on prevention across the health

sector, which evidence and practice had shown to reduce costs overall. These efforts could have been hamstrung by one of the risks of hampering health funding authorities, where actors in the sector take advantage of Australia's multi-jurisdictional structure to shift costs. The system reforms were designed to make it harder for them to do this. The NHHN reforms provided new incentives to invest in prevention by making the Commonwealth Government the majority funder for *both* costly acute hospital services and primary health care including prevention, to prevent cost shifting between sectors and levels of government.

At the local operational level, the NHHN reforms were also important to driving prevention through the establishment of a regional network of independent *Primary Health Care Organisations* (PHCOs), initially as '*Medicare Locals*', later reformed as '*Primary Health Networks*' in 2015[2]. Medicare Locals were responsible for providing a platform to improve the planning and delivery of health promotion and preventive health programs, targeting risk factors in the local community. The NHHN and PHC reforms included holding these PHCOs to account based on performance measures published in 'Healthy Community Reports' that include preventive health risk factors and other measures of community health and wellbeing. This provides new incentives for PHCOs to provide support services in the community to engage and facilitate local populations to perform health promoting behaviours and self-management activities, by holding providers to account for improving health outcomes.

The reforms also include incentives for prevention in general practice, providing PHC as the first point of contact with the service system in the community. The PHC reforms included new arrangements for chronic disease management, providing people with the option of enrolling with a General Practitioner (GP) responsible for managing their conditions over time. This "comprehensive national approach to chronic disease management" was said to benefit patients by "ensuring that: their GP is supported to manage their condition and keep them healthy over time, rather than just treating the presenting symptoms" (DHA, 2010b, p. 32). This approach included, "a performance framework, under which practices are rewarded if their patients' health improves" (DHA, 2010b, p. 32). This move from pay-for-service towards outcomes-based funding provides financial incentives for GPs to enlist clients in making necessary contributions to improving their health outcomes (that are largely performed independently). However, despite inter-dependence on co-production, the PHC reforms did not explicitly acknowledge the instrumental role of clients and carers in achieving service objectives. This is in stark contrast with the policy discourse on more recent developments in chronic

[2] In 2015, the incoming Coalition government called for a review of Medicare Locals, 'the Horvath review'. Based on this review the 62 Medicare Locals, were replaced by 31 'Primary Health Networks' (PHNs), to perform more of a commissioning rather than service delivery role.

disease management that refer to a 'partnership approach', as discussed further in the following chapter.

Two other mechanisms played roles in 'authorising' purposes and standards with other actors. One was relevant to the different levels in the federal system of government: The National Agreement on Preventive Health as part of the NHHN. Its role was to underpin the allocation of significant funding to developing a range of health promotion and population health programs, to motivate the public to change their health-related behaviours targeting lifestyle risk factors for chronic disease (DHA, 2010a).

The other was a statutory agency, the Australian National Preventive Health Agency (ANPHA), which sought to increase the capacity of the service system to provide preventive services. ANPHA was to be responsible for: policy leadership and national capacity to drive evidence-based preventive health policies and programs; strengthening investment and infrastructure in preventive health; and providing leadership in research and surveillance. It was also to be responsible for interventions, such as social marketing to increase people's capacity to engage in preventive behaviours and activities at a population level (DHA, 2010a).

The NHHN and PHC reforms also encompassed other efforts to increase the capacity of prevention activities, including providing inducements to expand and enhance the role of practice nurses in general practice under the Practice Nurse Incentive Programme. This initiative includes employing nurses to provide health assessments, health promotion education and advice on lifestyle issues and manage recall and reminder systems. These services involve motivating and enabling clients to change their health-related behaviours and to manage their conditions in the community to decrease acute exacerbation, resulting in the need for acute care through primary, secondary and tertiary prevention.

The mental health reforms also sought to re-orient the system by, adopting a 'stepped-care approach' to, "shift the focus upstream, away from acute and crisis intervention over time and towards an early intervention approach" (DH, 2015a, p. 8). In contrast, the aged care reforms did not explicitly reference prevention, with the exception of activities to increase early diagnosis for dementia (i.e. secondary prevention). However, as discussed in the following chapter, the aged care sector has adopted a 'wellness' and 'reablement' approach that focus on building people's functional capacity to maintain their independence.

Prevention is dependent on client co-production to improve health outcomes and decrease demand on costly acute hospital and residential care services. The recent Australian reforms analysed here involve re-orienting the system towards prevention through various strategies. They do this largely

by putting in place policies, mechanisms and processes that providers and clients (and their carers) must adapt to if they are to function successfully including: policy and programs for prevention; local planning and accountability for prevention related health outcomes in local communities; funding mechanisms and accountability for improving health outcomes in general practice; and increasing workforce capacity building for delivering preventive health. Preventive care is dependent on the public contributing to improving their health outcomes, often on a day-to-day basis through behaviour change and activities to manage existing conditions. Health care providers are required to enlist and enable people in making these contributions.

5.2 RE-LOCATING CARE INTO THE COMMUNITY

Another significant trend across all the reforms was re-locating care in the community where possible, to decrease demand on costly emergency department presentations and avoidable admissions to hospitals and residential care. In addition to the aforementioned orientation towards prevention, other strategies were adopted to shift care into the community as discussed here. The reforms analysed each included strategies to provide intermittent care in the community or people's homes rather than hospital or residential care settings. In this way, clients and their carers, are required to contribute to the work of addressing health issues and need for support to maintain living independently in the community between the provision of formal care services.

The NHHN reforms sought to increase the use and provision of services in the community. One key strategy was the use of funding and accountability mechanisms. The NHHN centralised policy and funding of *both* hospital and health services to provide financial incentives to avoid the used use of costly hospital services. A new hospital funding mechanism was adopted to provide further incentive to re-locate care in the community. This approach, termed 'activity-based funding', involves funding hospitals for each service they provide based on a national *efficient price* as set by an Independent Hospital Pricing Authority (IHPA). This places financial pressure on hospitals to avoid prolonged hospital stays and provide services in less costly non-acute settings where possible. Any residual funds from Commonwealth top-up funding to the States to finance growth in hospital costs, was also stipulated to be spent on: "any health service that will assist in ameliorating the growth in demand for hospital services, including programs for chronic disease management, preventive health, mental health, hospital admission programs and hospital early discharge programs" (DHA, 2010a, p. 54).[3]

The NHHN reforms also include investments in the provision of 'sub-acute care', providing medical care, outside hospital settings such as rehabilitation, palliative care, mental health and geriatric services. The IHPA was also tasked with classifying which hospital outpatient services could be

[3] The level of commitment to top up funding under the NHHN agreement in 2011 was later in withdrawn in 2014 budget by the Coalition Government.

provided more efficiently in the community. The increased acuity of care to be provided in the community likely represents an increase in the complexity and scale of informal care required, by people in clients' social networks acting as carers, to support people in the community.

> By improving the capacity of the public hospital system to provide appropriate care for people with sub-acute needs, health outcomes and quality of life will improve for many vulnerable patients. Without this care, these patients could otherwise be inappropriately cared for in an acute care facility or discharged prematurely to residential care or into the community.
> (DHA, 2010a, p. 77)

Strategies to re-locate included devolving responsibility for improving access to care in the community through the establishment of a regional network under the NHHN reforms. These institutions were to perform population needs assessments, service planning, and delivery or commissioning of services, specifically targeting at risk or under-serviced population sub-groups. The 'Medical Locals' were to improve transitions between PHC, aged care and hospitals to increase access to after-hours general practice and enhance the capacity of GPs to manage the care of people with chronic conditions (by providing a complementary array of services to support people to manage their care in the community). Reformed in 2015 as 'Primary Health Networks' these organisations were to provide a commissioning rather than provider role, whilst remaining accountable for preventing avoidable hospital admissions by strengthening PHC.

At the individual level, the NHHN and PHC reforms included new arrangements for chronic disease management, including 'coordinated care' by GPs. This model involves GPs developing personalised care plans and improving access and coordinating care with other providers involved in addressing clients' needs (such as diabetes educators and podiatrists) to: "reduce the costs associated with managing complications of diabetes and of unnecessary hospital admissions" (DHA, 2010b, p. 32). The mental health reform document also made reference to "innovative funding and delivery models" in primary care to better support coordinated services for people with complex needs, as informed by the Primary Health Care Advisory Group (PHCAG). Since the PHC reforms, the PHCAG provided a report in December 2015 on chronic disease management that espoused a 'Health Care Home' model, adopted under the 'Healthier Medicare' package in 2016, which is discussed further in following chapter. These new arrangements for chronic disease management include funding and accountability mechanisms, where providers are part funded based on reporting on improvement health outcomes and rates of avoidable hospital admissions. Providers are thus dependent on clients (and their carers) acting as co-producers by making necessary contributions of time and effort required to achieve these objectives, as will be demonstrated later in this thesis.

The trend towards providing care in the community was also central to the aged care reforms, as an alternative to costly residential care. This included increasing access to long-term care in the community by the number of Home Care Packages for people eligible for high level care in the community from 40,000 to 100,000, (through a phased increase in the 'aged care provision ratio' and increased proportion of home care places compared with residential care places). In addition, low-level aged care services provided across different levels of government was centralised under the Commonwealth Government funded program (CHSP). A review of this program was commissioned to inform more consistent and equitable service delivery and arrangements, and national consistency on clients' financial contributions to these services. Providing intermittent aged care services in the community, in contrast to residential settings, is typically dependent on a mix of formal and informal care by carers as discussed in Chapter Two. The impact of increasing dependence on carers acting as co-producers, providing informal care, is a key concern in this thesis.

Another key approach across the reforms to re-locate services was expanding e-health, using information communication technologies (ICT) in the form of telehealth and internet websites. These platforms were to provide access to remote services and referrals or linkages to other community-based services to address gaps in the system and increase people's ability to manage their care in the community. The PHC reforms included the establishment of a local after-hours primary care service. This service used a telephone line to provide a diagnostic, advice to facilitate self-care/management or referral to a service in the community where appropriate to prevent avoidable presentations to hospital emergency departments. The aged care reforms included establishing an aged care 'Gateway' comprising a website and national call centre to provide the main entry point to the aged care system. This digital Gateway includes a linking service to facilitate access to services in local communities such as referrals to health, housing, disability services and financial advice as well as aged care services.

The mental health reforms adopted a 'Stepped Care Model' to prevent under and over-servicing through referrals to low intensity services to digital mental health services where appropriate. A mental health 'Gateway' was to provide digital mental health treatment and linkages to community-based services through a centralised web and telephone portal. Digital services provide an alternative to face-to-face services including information, self-help, crisis support, assessment and treatment and peer support, encompassing both self-help and clinician moderated services. The mental health reforms noted that, "digital mental health will be only one element of the stepped care approach, recognising that it will not be suitable for all consumers, for a range of reasons including access to technology, literacy and clinical needs" (DH, 2015a, p. 13). These services may facilitate access to services in the community and increase people's capacity to contribute to improving their health

outcomes (although people vary in their ability and access to utilise these ICT platforms and e-health services).

A range of initiatives were adopted to address internal workforce shortages to improve access to care in the community. Under the NHHN and PHC reforms this included: establishing a planning agency (Health Workforce Australia) and national registration and accreditation agency (Australian National Health Professional Regulation Agency); increasing the number of doctors, nurses and allied health professionals working in the community; and providing incentives to increase recruitment and retention in rural and remote areas and in aged care. One significant initiative was expanding the roles of practice nurses and nurse practitioners in PHC. This provided nurses with a degree of access to the Medicare Benefits Scheme (MBS) and Pharmaceutical Benefits Scheme (PBS) to utilise their skills to benefit the community and provide a more flexible use of the health workforce.

Of particular interest for co-production, the reforms also consider the role of external actors in providing care as third parties. Each of the reform documents make reference to carers including family, friends and neighbours, that provide informal, unpaid care in the community.

> The Gillard Government understands the pivotal role that carers play in providing quality support to older Australians. Carers provide most of the care received by older Australians. Like any member of the workforce, these carers sometimes need to take a break and need to take care of themselves.
> (DHA, 2012, p. 7)

In the aged care reforms, there is explicit acknowledgement of carers and commitment to increasing access to support services such as respite and counselling. These services were consolidated under a national program, the Commonwealth Home Support Programme or CHSP, as well as establishing a network of carer support centres. In the aged care reforms, there were also references to better supporting carers through existing legislation under the National Carer Recognition Act (2010) and National Carers Strategy (2011), as discussed in the next chapter.

The mental health reforms also explicitly acknowledge carers, stating "carers should also be recognised as key partners in achieving better outcomes for people with mental illness" (DH, 2015a, p. 7). In addition, the reforms included the development of a 'consumer and carer participation framework' to establish mechanisms for participation in policy and practice. However, overall references to carers or family across the policy documents tended to be in conjunction with patients or consumers (i.e. clients), rather than distinct actors in the provision of care.

Despite the significant and well documented contributions of carers to the provision of care in the community, there are no references to carers in the PHC reform document. This suggests a lack of

concern for the operational role of carers as third parties in the delivery of PHC and improvement of health outcomes in the community. The NHHN reform document made a few references to carers in relation to the provision of aged care and mental health, and included the establishment of a national network of one stop shops to assist access to carer support services and a National Carers Strategy. However, on the whole, the NHHN reform document paid limited attention to the role of carers in the health system, despite the instrumental role carers play in the achievement of government purposes. This may in part reflect that carers were under the Department of Social Services (DSS), not the Department of Health and Ageing (DHA).[4]

In addition to carers, the reforms included some measures to elicit and enable other external actors to provide unpaid care. This included funding for volunteer schemes, such as the Community Visitor Scheme, and a review of legislation to ensure liability protections. Volunteering was also encouraged as part of the Government's 'Positive Ageing Agenda' in the aged care reforms, where it was also encouraged as a means to improve health outcomes (with older people gaining value through the act of volunteering). The mental health reforms also included measures to engage volunteers in the form of unpaid 'peer support.' It was defined as "social and emotional support, frequently coupled with practical support, provided by people who have experienced mental health problems to others sharing a similar mental health condition. Peer support aims to bring about a desired social or personal change and may be provided on a financial or unpaid basis" (DH, 2015a, p. 24). These mechanisms to facilitate volunteering, in both a formal and informal capacity, represent forms of co-production, where people external to the organisation contribute to the work of delivering services.

A significant aspect of Australia's health system reforms is to locate the provision of care in the community to decrease demand on costly hospital and residential care. This included measures to move sub-acute and aged care in the community where possible, and to bolster the provision of primary health care through a network of PHCOs. In general practice, new arrangements to support people with chronic illness were adopted to better support people to manage their conditions in the community. There was also a shift towards the use of ICT to improve access and provide service remotely that facilitate people to manage their conditions independently. The provision of care in the community represents a shift in some of the costs and responsibility for providing care onto clients and their carers. In acknowledging this, the reforms included strategies to increase access to carers support services. There were also strategies to capitalise care by external actors through expanding volunteering schemes.

[4] In 2013 the DHA was dissolved under the newly elected Coalition Government and superseded by the Department of Health (DH), and the responsibility for aged care services was transferred to the Department of Social Services (DSS).

5.3 RE-BALANCING THROUGH PUBLIC PARTICIPATION

A central focus in the reforms was concerned with public participation in decision making regarding their services and the service system. This re-balancing of control through participation was often linked to the concept of making the system more 'patient-centred' and responsive to people's needs and preferences. Across the policy documents, there are references to public engagement and participation in decision-making processes at different levels of government about policy, design, commissioning and implementation. The phrases 'engagement', 'participation', consultation' or 'working with' were often used when referring to client involvement in decision-making about policy, planning and the design of services. However, the nature and extent of these contributions is often not explicit, although there are some exceptions with strategies to formalise these processes.

These strategies to institutionalise participation included public or 'consumer' representation on various advisory panels as part of implementing the reforms. The mental health reforms included the development of national client and carer participation framework.

> The Government will develop with consumers and carers a participation framework to guide future national reform efforts by governments and services and will explore means to strengthen communication with consumers and carers in national policy.
> (DH 2015a, p. 7)

Under the NHHN reforms, decision-making about local services was devolved to the local level, including community and clinical engagement requirements. PHCOs as Primary Health Networks (PHN) were required to establish 'Consumer Advisory Committees', to provide formal public engagement in the governance and commissioning of local services. In addition, they were to provide frontline providers with greater autonomy through flexible funding pools to facilitate the delivery of more responsive services to local needs, as noted in the mental health reform document.

The phrase 'patient-centred care' is often used in the policy documents, although its meaning and application is not always clear or explicitly stated and it is variously applied throughout the reform documents. The mental health reforms also refer to person or patient-centred care, defined as "treatment and care provided by health services that places the person at the centre of their own care and considers the needs of carer/s" (DH, 2015a, p. 24). The NHHN reform document states the aim of providing "integrated care that is centred around patients' needs" (DHA, 2010a, p. 44), suggesting the system be integrated based on people's individual need to provide a more responsive service system.

In the health sector, personalised care planning was adopted as part of the PHC reforms, suggesting client participation in decision-making about their care (although this is not explicitly described in the

policy document, rather it focuses on improved coordination by professional providers). However, since the PHC reforms, the discourse around chronic disease management has shifted, as illustrated by the 'Healthier Medicare' package announced in March 2016, which demonstrate a move (at least rhetorically) towards 'partnership' approaches through *shared-decision making* with clients and their carers, as discussed further in the next chapter (where public involvement in the health system is largely considered in the form of participation rather than co-production).

The aged care reforms adopted an alternative method of re-balancing services through public participation through the adoption of market-based approaches. This 'Consumer-directed Care' (CDC) approach aimed to provide 'choice and control' through the provision of personal budgets for people receiving home care packages, "placing the individual at the centre of care decisions, fully engaging them in determining what and how their care needs are provided" (DHA, 2012, p. 4). This CDC approach is in contrast to other approaches adopted in the health sector that seek to involve people in decision-making such as personalised care plans in general practice that espouse involving clients in shared-decisions-making rather than having greater choice and flexibility over decision-making about their services.

All the reforms analysed included strategies to provide the public with information about health issues and the service system, to increase their capacity to manage their care in the community through informed decision-making. These strategies included individual models of care that encourage health professionals to provide information and education, providing information on websites and via telephone lines, and social media campaigns. The aged care reforms also included the provision of comparative data to inform client decision-making about their choice of services (based on national aged care quality indicators and a rating system). Initiatives to improve feedback and complaint systems were also included in the reforms, as a mechanism to provide recourse for clients and their input into strategies to improve client satisfaction with services and quality improvement. In addition, funding was increased for national advocacy programs as part of the aged care reforms to provide support and education for clients to understand and exercise their rights and have a greater say in the way their care is provided.

Australia's recent health reforms represent a shift, at least rhetorically, towards greater public participation in service planning, design and delivery. At the frontline, the health sector espouses a patient-centred approach, including involving people in their care planning. The aged care sector has adopted a CDC approach including providing individual budgets to increase choice and control of care planning, improved feedback and complaints mechanisms, and consumer advocacy. However, these approaches are contingent on people's level of health literacy. The reforms also included strategies to facilitate people to engage in decision-making through the provision of education and information about health and navigating the service system by providers directly or via online

platforms. Involving people in decision-making about their care services has been adopted as a strategy for increasing internal efficiencies by making services more responsive to clients' needs and preferences, and increasing people's willingness to adhere with care planning. However, as illustrated later in this thesis, co-production is influenced by a range of complex and inter-related factors that extend beyond client involvement in decision-making processes about their care.

5.4 RE-ALIGNING TO INTEGRATE CARE

A significant focus across recent Australian reforms was to improve internal efficiencies by re-aligning to better integrate the service system. Integration, as stated above, tended to be framed as making the system more efficient by providing coordinated services that are more responsive or centred around client needs, often under the banner of 'patient-centred care.' How responsive services are has implications for contributions required by clients and their carers as co-producers to coordinate their care and fill gaps in a fragmented service system.

Under the catchcry "ending the blame game", the NHHN reforms aimed to facilitate integration across the system. The Commonwealth Government assumed full funding and policy responsibility for primary health care (including general practice) and aged care, and majority funding of public hospitals based largely on 'activity-based funding', where hospitals are paid for the number and mix of patients they treat. This positioned the States as system managers for public hospitals, responsible for planning, regulation and governance. The States were also to fund a percentage of the 'national efficient price' for hospital services, as set by the Independent Hospital Pricing Authority, and pay costs above the efficient price. Partnership agreements between the Commonwealth and the States and commitment to inter-sectoral action was to facilitate coordination across levels of government or portfolios to improve system integration of service planning.

At the organisational level, responsibility for improving the integration of local services was devolved to networks of regional institutions under the NHHN reforms. This included establishing Local Hospital Networks (LHNs) responsible for local hospital management and performance; independent PHCOs to improve access and integration of primary health care; and 'one stop shops' to assist access to aged care services. To ensure the system is 'joined up' at the local level, these institutions were mandated to identify pathways between services and develop linkages between providers. As PHNs, these PHCOs were assigned responsibility for integrated service planning (i.e. performing needs assessments and service mapping to identify gaps) and commissioning of services through flexible funding pools to address local needs. As stated in the mental health reform document in reference to PHNs:

> Integration of services will occur 'on the ground' at the regional level because this is the level of the system where direct communication and practical steps can be taken to drive integration of currently disconnected services and to optimally address local needs. (DH 2015a p. 8)

Local service planning by PHCOs was to make services more responsive through clinical engagement and 'close links with the community,' formalised through consumer advisory committees. As discussed in the previous section, engaging the public in decision making about services aims to increase the responsiveness to better integrate services. Increasing the responsiveness of the system can have implications for enlisting co-production.

Another strategy to integrate the service system, adopted in the aged care and mental health reforms, was providing nationally consistent main entry points through digital 'Gateways.' These telephone and online portals included centralised assessment of needs and linking of services, providing a 'joined up' assessment and referral pathway. This approach makes it easier for clients to navigate the service system.

Efforts to coordinate services also included co-locating (i.e. providing a range of services in a single location). Initiatives to co-locate services in the reforms included 'GP Super Clinics,' 'Headspace' (providing a range of youth mental health services), and aged care 'One Stop Shops' to "assist older Australians and their carers to more easily access the services available to them in their community" (DHA, 2010a, p. 131). Co-locating services aims to facilitate and encourage people to access services in the community by making them more convenient, and decreasing the time and effort required to access services in different locations.

The NHHN also sought to better integrate care by enabling compatibility between information systems and establishing personal electronic health records to enhance communication between providers and provide a 'patient-centred health care' system. Electronic health records can decrease reliance on patients to recall and repeat health information to the different providers and prevent duplication and time spent chasing information or requiring patients to recount their health and medical history.

At the clinical level, initiatives to integrate care included new arrangements for chronic disease management, such as GPs providing 'coordinated care' for people with complex needs. This allows people with a chronic illness to enrol with a GP, responsible for performing personalised care planning and providing access to allied health services. Under this scheme, GPs are given financial incentives for managing and coordinating clients' health over time to decrease reliance on clients and their carers to perform this role.

The mental health reforms included the Stepped Care Model, providing a continuum of care based on increasing clients' needs to avoid gaps in the system. The aged care sector consolidated entry level aged care service under a national CHSP and adopted an alternative model of individual integrated care or higher-level home care packages under CDC, whereby care is integrated based on clients exercising choice and control through the provision of personal budgets.

> Increasingly, the level and mix of services will be driven more by the people using the system and less by Government regulation. The role of Government will be more focused on ensuring fairness of access to aged care services and enhancing the quality. Aged care providers will have new opportunities to extend the services they provide to ensure a more consumer focused approach to business.
> (DHA 2012 p. 29)

Each of the reforms included strategies to re-align the fragmented and siloed service system through mechanisms to better integrate the services system. These included: structural changes to policy, funding and adoption of inter-sectoral policies; regional integration through hospital and PHC networks; online and telephone Gateways to provide a main entry point and referral pathways; co-location of services; integrated information systems; and care coordination by GPs and personalised budgets and care plans for home care packages in aged care. These reforms aimed to make it easier for the public to navigate the service system with smoother transitions and coordination between providers. Integrated care potentially decreases transaction costs for clients and their carers coordinating care and increasing the responsiveness to individual needs and preferences to make it easier to manage their health issues and need for support in the community.

CONCLUSION

Australia has undergone a series of system-wide reforms in recent years. These reforms represent significant dependence on contribution of time and efforts by the public (as clients and carers) for the achievement of service objectives and government purposes, as 'co-producers,' re-orienting the system towards prevention to decrease demand on costly hospital and residential care. Prevention is dependent on clients proactively contributing to the work of improving their health outcomes through changing their health-related behaviours and activities as co-producers of their care.

The government has incentivised providers to enlist clients and their carers to make necessary contributions to address health issues, through outcomes-based performance measurement and funding mechanisms. There have been measures to relieve carers through improved access to formal aged care and carer support services. However, the re-location of care into the community including sub-acute and aged care, along with demographic and epidemiological changes towards increasing

longevity and prevalence of chronic and degenerative conditions, poses a need for increasingly complex and continuing care by informal carers.

The reforms aimed to relieve clients and carers by re-aligning the system through participation in decision-making processes. In health care, this includes shared decision-making that is thought to increase people's willingness to adhere to care planning. In aged care, a consumer-directed approach has been adopted to provide clients with choice and control through market-based approaches (including individualised budgets, competition, complaints systems and consumer advocacy). To enable their involvement in decision-making about their care, the reforms also include services to provide information about health issues and the service system, often through online platforms.

The reforms included measures to re-align the service system to improve internal efficiencies by integrating and coordinating care, to increase responsiveness of the services and make it easier for clients and their carers to navigate the system. However, enlisting and assisting people to improve their health outcomes and maintain independence in the community is often more complicated than it may first appear, particularly for older people with complex needs as illustrated in this thesis. The next chapter examines the potential implications of recent reforms on co-production drawing on targeted interviews with senior policy makers and other key stakeholders.

CHAPTER 6

Systemic Challenges to Co-producing Care

INTRODUCTION

As discussed in the previous chapter, recent Australian health reforms include co-production as a means of handling demands on the formal service system. However, these approaches call for a sustained, multi-faceted set of activities that in some cases are in friction with the challenges they seek to address. This chapter draws on insights from targeted interviews with senior policy makers, service providers, and consumer and carer representatives regarding how the Australian government has sought to elicit and facilitate the public to contribute to the delivery of care in the community (methods detailed in Chapter Three). The term 'co-production' was not familiar to many of the interviewees or was used inter-changeably with 'co-design' or to describe specific models of care. In parallel with the care services literature on co-production, policy makers and other stakeholders focused on challenges to participation in decision making (as an assumed antecedent of co-production). Variations in clients' capacity to make informed decisions and co-produce their care were also identified, along with implications of reliance on carers to provide care in the community. This chapter reports on the key systemic challenges for co-producing care from a top-down perspective as raised by interviewees, providing further context for the policy analysis in Chapter Five.

6.1 PUBLIC PARTICIPATION IN PRACTICE

Consideration of public involvement in the health system by interviewees was largely confined to participation in decision-making about services and the service system. This has been framed as a way to increase internal efficiencies by making services more responsive. It also reflects the idea that involving clients in decision-making is an antecedent of co-productive efforts; an assumption debated in the literature. The term 'co-design' was used in relation to public involvement in decision-making processes in the planning, design, commissioning and delivery of services.

At the systems level, there has been a commitment by the Australian Government to engage the public as stakeholders, "based on best practice to design and deliver high quality and innovative policy, programmes and regulations to achieve better health and wellbeing for all Australians" (DH, 2015b, p. 1). A review of the Department of Health reported active stakeholder engagement as an area for improvement and advised the development of a framework for policy development, service design and program delivery (DH, 2015b). Since the 2010 NHHN reforms, consumer engagement has progressed in Australia and internationally. Policy developments in consumer engagement and

shared decision-making have been led by the Australian Committee on Safety and Quality Health Care (ACSQHC). Health services are accredited against the ACSQHC 'National Safety and Quality Health Services Standards' (2nd Edition), including Standard 2: Partnering with Consumers, which "requires the involvement of consumers in the organisational and strategic processes that guide the planning, design and evaluation of health services" (2017, p. 1).

At the local level, Primary Health Networks (PHNs) were established in 2015 to perform a commissioning role. One interviewee reported that this commissioning role provides "greater flexibility and responsiveness to the needs of the community, and really the argument for that is as much about effectiveness and efficiency of service delivery." They went on to say, that PHNs were to establish 'Community Advisory Committees' to provide "an ongoing way of liaising and talking to the community so that they understand the needs of the particular region" (Interview 2: Policy maker, DH).

> *"We tend to fund in programs rather than funding for a population - do a proper assessment of the needs of the people they are supposed to be servicing and come up with services that meet some of those needs, I mean they are not going to have enough money to meet all of them, so it is about prioritising need. If you talk to the consumer, the population that you are supposed to be providing the service to, you will often find quite common themes of what are the need[s] and the solution[s] to meeting those needs, I mean talking to the consumer, co-design - is not just about people identifying their needs it is about them coming up with a solution too"* (Interview 1: Consumer Representative)

Although it was noted that there is "variability in the capacity of the organisations to do that work, some will be able to engage readily in stakeholder engagement - others that aren't might just do perfunctory engagement to tick the box, but it is not going to be adequate" (Interview 2: Policy maker: DH). PHNs were to adopt a 'co-design' approach to commissioning context that "goes beyond consultation - and ensures that patient experience and needs are central to the design process - which builds capacity and creates collective leadership and ownership in achieving the intended outcomes" (DH, 2018a, p. 1-2). At the individual level, the health and social care sectors have approached involving people in decision making about their care in different ways as discussed below.

Partnership approach and shared care planning

In the health sector, a patient-centred or partnership approach that involves 'shared decision-making' has been widely espoused in the policy discourse in recent decades. According to Hoffman and colleagues (2014), shared decision-making "enables a clinician and patient to participate jointly in

making a health decision, having discussed the options and their benefits and harms, and having considered the patients' values, preferences and circumstances" (p. 35). The ACSQHC's Safety and Quality Framework for Care, states that safe, high-quality health is always: (1) consumer centred; (2) driven by information; and (3) organised safely. In this framework, patient or 'consumer-centred' care is defined as:

> Providing care that is easy for patients to get when they need it. Making sure that healthcare staff respect and respond to patient choices, needs and values. Forming partnerships between patients, their family carers and health professionals.
> (ACSQHC, 2010, p. 2)

The ACSQHC also developed the Australian Charter of Healthcare Rights, which includes 'participation,' stating "I have a right to be included in decisions and choices about my care' (2008, p. 1). It was noted by a policy maker that the Royal Australian College of General Practitioners (RACGP) has practice standards and guidelines so we don't really control that, we don't tell doctors how they should do their work" (Interview 2: Policy maker, DH). The RACGP Standards for General Practice (5th Edition) includes as 'Core Standard 1: Communication and Patient Participation' which states:

> Communication must be patient-centred. This means that the practice team considers the patient's values, needs and preferences, and gives the patient time to provide input and participate actively in decisions regarding their healthcare. Patients must be provided with the appropriate information they need to manage their condition. The practice must also consider the communication needs of carers and other relevant parties.
> (2017, p. 10)

Practice in accordance with this Core Standard advocates a 'patient-centred approach' that requires GPs to engage clients in the contribution of *inputs* and *participate in shared decision-making*. It also stipulates GPs provide time and information to facilitate clients to engage in these processes, and recognition of the need to communicate with carers as informal care providers.

In Australia, there has been increasing interest in training and skills development in health communication and shared decision-making for health professionals, although these approaches have not been systematised or standardised (Trevena et al., 2017). According to Trevena and colleagues (2017), "undergraduate health students' exposure to shared decision-making teaching and learning is patchy and largely reliant on local champions with expertise to derive this into local curricula" (p. 20).

Shared care planning has been a critical element of recent changes to chronic disease management since the 2010 PHC reforms. In 2015, under the Coalition Government, a Primary Health Care Advisory Group (PHCAG) was established to develop options to improve care and health outcomes for people with complex and chronic conditions. In response to the PHCAG's final report, the Government announced a Health Care Home (HCH) model, where eligible clients can voluntarily enrol with a participating GP, that will be their 'home base' for ongoing coordination, management and support for their condition (Turnbull & Ley, 2016). In a stark contrast to the earlier policy discourse, this new 'Healthier Medicare' package including the HCH model, refers to a partnership approach with "tailored patient care plans developed in partnership with patients and their families" (Turnbull & Ley, 2016, p. 2-3). According to the Department of Health's HCH model program guidelines:

> High functioning team-based care requires a shift away from a GP-centric model and includes explicit efforts to build trust, respect, and value for any new roles that are included in the team, and for including patients as partners in their care. Building collaborative partnerships with patients allows them to take a more active role in decisions about their care and helps them develop the skills and confidence necessary to manage their health. An effective partnership recognises the expertise that patients bring to the medical encounter as well as the evidence base and medical judgment of all health care providers who are included in the patient's care team. Patients are not told what to do but are engaged in shared decision making that respects their personal goals, encourages patients to work towards and achieve those goals, regardless of how simple they may seem to the care provider. For patients with chronic conditions, the focus of the team broadens to provide a framework for self-management support.
> (DH 2018b, p. 7-8)

The reforms to chronic disease management in general practice included funding mechanisms and accountability for performance on achieving improved health outcomes. It has been suggested by one interviewee that "one of the challenges is that at the moment we pay for activity, so we pay fees on a for service basis, what you encourage is activity rather than outcomes" (Interview 2: Policy maker, DH). The achievement of these performance measures based on outcomes is dependent on clients changing their behaviours and performing health-related activities outside direct service activities that are necessary for achieving those outcomes, as illustrated later in this thesis. Thus, outcomes-based funding may provide incentives for providers to consider how to elicit these co-productive contributions. However, providing these incentives does not increase GPs competence and capacity to enlist and facilitate their clients to overcome barriers to adhering to their care plans. There has been some resistance to outcomes-based funding as described by an interviewee, "some doctors say,

how can you make a doctor accountable for a glucose level in a patient that continues to choose to eat donuts every day" (Interview 2: Policy maker, DH). Other challenges to involve clients in decisions about the delivery of health services included arguments about the need to steward limited resources and the need for evidenced-based practice.

> *"The first thing that needs to be made clear to them (clients) is that the delivery of health services is not really a passive process - understanding that there are some things you will need to do like adhere to whatever has been suggested to you, whether it's performing exercises, taking medications, developing best practice health behaviours - and realising that the provision of health services are finite"* (Interview 9: Health Professional)

There are different skills sets required to foster co-production, and governments do not control how health professionals provide services beyond funding mechanisms tied to performance measures and standards. Although new arrangements for chronic disease management provide funding and accountability arrangements as an incentive for providers, the transition to participatory approaches requires shifts in organisational structures and culture, and professional development.

Personalisation and assets-based approaches

In contrast to the partnership approach adopted by the health sector, the social services sector opted for personalisation through the provision of individual budgets to increase client's choice and control over their services. The term Consumer-Directed Care (CDC) was adopted in Australia in reference to individual budgets for Aged Care Packages to support older people to maintain living in the community. CDC has been described as a shift away from patient-centred care, where the clients have control over decision-making about their services.

> *"The modus operandi is from a patient centred approach to aged care to a consumer centric form of aged care delivery - before it was a very didactic patient-centred approach, where they said you need this, and you need that. This is about the consumer identifying what they feel they need so it is a complete paradigm shift"* (Interview 7: Policy maker, DSS)

Service providers and clients are both signatories on Home Care Agreements about how their budget will be allocated. This has been described as a collaborative process focused on meeting goals associated with improving health and wellbeing and maintaining living independently in the community.

> *"Home care agreements - that the provider and the home care consumer sit and negotiate and there is a conversation that happens about the goals for the consumer, then the provider*

and the consumer collaboratively agree about the range of services they want to meet those goals" (Interview 7: Policy maker DSS)

Programme guidelines for these packages call for services to be delivered on a 'wellness' and 'reablement' basis (DH, 2018b). These 'assets-based' approaches focus on identifying goals and building on people's strengths and regaining functional capacity to improve independence, that is said to represent a shift from "doing for" to "doing with" that actively involves clients in the delivery of their care (CommunityWest, 2016).

The term 'co-production' was first employed in the Australian health and social care policy discourse as part of research funded by the Department of Health in 2012. This research was to examine how the aged care services sector could incorporate 'co-production' into organisational service design, where co-production was defined as:

> Individuals, communities and organisations, working together as equals to improve experiences for people who access services. It requires a commitment to working collectively, where each person is involved in the process from beginning to end, exchanging information and power for mutual benefit.
> (CommunityWest, 2016, p. 16)

This use of the term 'co-production' in the policy discourse, as a new model of care, reflects how it has been generally conceptualised in the health and social care service literature. It is used to describe a collaborative model of care that has been imbued with a set of principles guiding the nature of interactions between service providers, and clients and their carers. However, from an analysis perspective, confining co-production to a relational rather than an operational role is limiting as discussed in Chapters One and Four.

'Co-production trials' were conducted by Community West Inc and the Council on the Ageing (COTA) Australia, across 10 providers in the Australian aged care sector testing "co-production processes, approaches and methodologies with older consumers as part of the Step Forward - Together™ project" (CommunityWest, 2016, p. 3). These trials used a 'wellness philosophy' that "supports a move towards developing and implementing service delivery models which have the potential to build a person's capacity by actively supporting them to maintain their independence and autonomy" (CommunityWest, 2016, p. 7). The term 'enablement" refers to "focusing resources on regaining and maintaining independence" (CommunityWest, 2016, p. 8). A service provider described their experience working on a 'co-production trial':

> *"We are working together in an equal partnership, there is no hierarchy, we are all the same, and it is about everybody being involved in decision-making, having input, working as peers irrespective of what position you hold or your stance in the community - So it is part of the culture change"* (Interview 5: Aged care service provider)

At the time of this thesis, entry level aged care services provided through the Commonwealth Home Support Programme (CHSP) were not provided on the basis of individual or personal budgets. In January 2017, the DH commissioned a review of wellness and reablement in the community care sector, demonstrating increasing interest in the role of older people as actively involved in the delivery of their care. In the most recent CHSP program manual it is stated that "a fundamental objective of the CHSP is to maximise clients' independence and to emphasise an increased focus on ways of working, aimed at maximising client autonomy" (DH, 2017, p. 13). Despite efforts to institutionalise participation in the delivery of health and social care, other factors influence clients' ability to engage in decision-making and co-production of their care.

6.2 HEALTH LITERACY

A key factor which was frequently raised by interviewees was people's level of health literacy to effectively engage in improving their health outcomes. Health literacy is also influenced by language, cultural beliefs, education, income, disability and health status (Sørensen et al., 2012). The WHO defines health literacy as, "the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health" (2019f, p. 1). The most recent survey of Australian health literacy was conducted in 2006 by the Australian Bureau of Statistics (ABS). Participants in the survey were tested on their understanding of health promotion, health protection, disease prevention and management, and navigation of the system. The health literacy scale ranges from the lowest (level 1) to the highest (level 5), with level 3 regarded as the minimum requirement. According to the 2006 survey, 83% of Australians aged 65-75 years of age did not have level 3 or above on the health literacy scale, indicating that they have inadequate skills to meaningfully engage and participate in their health care and navigate the system (ABS 2006).

> *"Understanding the health and social care system and how they interact with each other - we do have a very complex health system - and I think it is pretty impossible for patients to understand it, they need to have some sort of guidance, and I'm not really sure that guidance is always given. It's really difficult given the time constraints they have when they are interviewing patients to be able to give them any information at all, and written stuff is often contradictory, and I think patients particularly in the older population are probably*

reticent to ask or push conversations with their health practitioners too much because they don't feel their really being supported by their docs" (Interview 9, Health professional)

A study by Adams and colleagues (2009) measured risk associated with low levels of functional health literacy. The authors concluded that "many Australians are likely to have limited health literacy, and this is a risk to effective health care delivery and health improvement across the community" (Adams et al., 2009, p. 530). Low levels of health literacy among people aged 65 years and over, has implications for their ability to participate in shared decision-making outcomes (Adams et al., 2009; Trevena et al., 2017).

In Australia, there have been strategies to improve health literacy, although these approaches tend to be limited to the provision of information, often through using online platforms. However, it was noted that clients, particularly older people, may not have the skills or access to the necessary resources required to utilise these services:

"We have online and portals like Health Direct, My Aged Care, the Better Health Channel for people, but people need to actually be able to find and use these services" (Interview 1: Consumer representative)

The phrase 'digital divide' refers to the gap between people who can and cannot access information and communication technology (ICT), which refers to their level of 'digital inclusion' (Thomas et al., 2018). Access and affordability can present barriers to digital inclusion, but an individual's digital engagement and confidence is also affected by digital literacy, perceptions of relevance, motivation and concerns about safety (Thomas et al., 2018).

"What is the digital literacy out there? Probably better than we think but I tell you what, there is a big divide, there are people that are pretty savvy and there are a lot of people that aren't and it is often related to education status and financial status, so you have got a double whammy, you've got no money, education, access to the internet - again it's the haves and the have nots" (Interview 9, Health professional)

The Australian Digital Inclusion Index (ADII) looks at three areas including access, affordability and digital ability. Data from 2018 survey on digital inclusion found an age gap with people aged 65 years and over having an ADII of 46.0, some 14.2 points below the national average (and lower for those with low household incomes or in rural areas with poor digital infrastructure), representing low digital inclusion. 'The Good Things Foundation' is a digital inclusion strategy from the UK, which is being set up in Australia with funding from the DSS, as part of the Digital Literacy for Older Australians programme. Other initiatives include the Commonwealth Government run 'Be Connected

Program', and the 'GoDigi Program' delivered through Australia Post and Infoxchange, and the Australian Seniors Computer Clubs Association. The capacity for people to engage in improving their health outcomes is influenced by a range of factors such as their level of education, economic status, and geographic location. These barriers may be overcome by support from people in the clients' social networks.

> *"Some people are intimidated by having to ring up or go online, again another sort of cultural shift, and for people who have an advocate, a son, daughter, or friend, that is not so bad but if you are completely on your own, and we have lots of people who are completely on their own, they have no one, it can be very daunting"* (Interview 5: Aged care service provider)

Older people, particularly those with complex needs and functional decline are often dependent on people in their social networks to provide informal support to interact with the health system and address their health issues and care needs.

6.3 RELIANCE ON INFORMAL CARE

The provision of care into the community has implications for clients and people in their social network who provide informal care as carers. In Australia, there has been approaches to better support carers including legislation under the National Carer Recognition Act (2010), (Australian Government 2010), the National Disability Strategy (DSS 2011b), and the broader social inclusion agenda, the act forms part of the National Carer Recognition Framework. In 2011, the National Carer Support Strategy was released with six priority areas including: recognition and respect; information and access; economic security; services for carers; education and training; and health and wellbeing (DSS 2011a). The government also launched the 'Carer Gateway' in December 2015 and has since announced the development of an 'Integrated Plan for Carer Support Services,' to "reflect the Australian Government's priorities for carers, and outlines actions to recognise, support and sustain the vital work of unpaid carers" (DSS, 2018, p. 1). Despite these efforts, there have been ongoing concerns raised about the feasibility and sustainability, based on the magnitude of care required from informal providers and the current level of support they are receiving to perform these roles.

In Australia, the vast majority of care provided in the community is by informal carers (ABS, 2018). Government policy to support care in the community represents increasing demands on informal care providers. Over the next three decades the demand for care in the community is expected to increase markedly (Productivity Commission, 2008; Deloitte Access Economics, 2015). Carers are already heavily relied upon to bridge gaps in formal care necessary to achieve government purposes of improving health outcomes and decreasing demand on costly hospital and residential care (ABS,

2018). However, the availability of carers (along with paid care workers) is expected to significantly decline during this time period (Productivity Commission, 2008; Deloitte Access Economics, 2015).

> *"We have to challenge that shift to community care and actually reframe it, it is actually a shift to individual, family and informal carer care. The one or two hours a day or week that you are going to get of formal service, compared to the rest of the hours in the day"*
> (Interview 12: Carer representative)

The Survey of Disability, Ageing and Carers (SDAC) is a national survey performed by the Australian Bureau of Statistics (ABS) to provide information on the prevalence of disability, the need for support for older people and people with a disability, and the information about those who provide informal care. In this survey, a carer is defined as "a person who provides any informal assistance, in terms of help or supervision, to older people (aged 65 years and over) and those with disability. Assistance must be ongoing, or likely to be ongoing, for at least six months. A primary carer is the person who provides the most informal assistance to a person with disability with one or more of the core activities of mobility, self-care and communication" (ABS, 2018, p. 1). The SDAC distinguishes 'core activities' from 'non-core activities' including health care, cognitive and emotional tasks, household chores, property maintenance, meal preparation, reading or writing and transport (ABS, 2018).

The most recent SDAC found that in 2015 over one in eight Australians provided informal care, 31.7% of carers were primary carers (ABS, 2018). The majority of primary carers were female (68.1%), although primary carers aged 75 years and over represented an equal distribution between male and female carers (ABS, 2018). The proportion of Australians who provide informal care increased with age (ABS, 2018). The average age of primary carers is 55 years, and the vast majority of primary carers are family members (96%), (ABS, 2018). Primary carers were more likely to be the partner of the main recipient of care (40.0%) and reside in the same household (79.3%), (ABS, 2018). Primary carers themselves were more likely to be living with a disability, 37.8%, than the rest of the population (15.7%), (ABS, 2018). Carers often have dual roles, as clients with their own health issues and need for support, and as carers for others. In some cases, clients may choose between addressing their own needs and performing their role as a carer.

> *"We have also seen some really gross outcomes of carers neglecting their own health in favour of the person they care for. So, we have seen some women with extremely advanced breast cancer that is rarely seen these days because they are like, I can't do anything about it because I can't leave the person. I was talking to a physiotherapist one time about a carer who had chosen to have a bilateral hip replacement, and I asked why, usually you do one then the other so you can mobilise in between, and they said, because she wanted to*

minimise the amount of time she was in hospital, she had organised respite for the person, so she could get both hips done at the same time so she could be out looking after the person, not to mention her own rehab and recovery" (Interview 12: Carer representative)

In addition, the caring role itself may have an impact on people's health particularly if they do not have adequate support to respite and other support services.

> *"That's why we are not seeing the preventive approach for carers because they will sacrifice their own needs to a certain extent in order to attend to the needs of another person, and the health and wellbeing impacts of that is sort of collateral damage"* (Interview 12: Carer representative)

It is estimated that Australians provided 1.9 million hours of informal care in 2015, which is equivalent to each carer providing 13 hours a week (Deloitte Access Economics, 2015). The economic cost of replacing this care would be $60.3 billion or 3.8% of GDP (Deloitte Access Economics, 2015). The vast majority of care provided in Australia is unpaid. It is performed informally by people in the client's social networks. Along with demographic and epidemiological shifts resulting in a higher proportion of the population in older age living with disability, reforms aimed at increasing the provision of care in the community represents increasing complexity and dependence on informal care.

As demand is expected to sharply increase, the supply of informal care is in decline (Productivity Commission, 2008; Deloitte Access Economics, 2015). Over the next decade, the demand for informal support is expected to increasingly outstrip supply as represented by the 'carer ratio' (Deloitte Access Economics, 2015). This ratio is based on the supply of informal carers divided by that number of people with profound or severe disability (Deloitte Access Economics, 2015). Based on the 2015 data, the carer ratio is expected to fall substantially, with an estimated deficit of 20% by 2025 (Deloitte Access Economics, 2015). In addition to increasing the deficit in informal care, there is also a diminishing supply of paid care workforce, which represents one of the most difficult to fill occupations in the health care and social assistance industry (Harrington & Jolly, 2019). This is alarming given the impact that carer shortages would have on the ability of the system to provide care in the community.

> *"You can get some gains from technology but at the end of the day aged and disability care is still going to be labour intensive and I think the workforce for that is one of the highest demands because families are much more mobile now, people don't want to move and leave their family home, and nor should they in some regards because that is where there support networks are, that is where there health care providers are that they know, that is where*

they feel comfortable, the fact that people are living longer means that they are living longer at home in a more frail state so how we facilitate that in a safe way is becoming more of a challenge for service providers" (Interview 2: Policy Maker, DH)

A multitude of factors are thought to contribute to the diminishing supply of carers including: demographic transition towards an ageing population; changing social structures with smaller families, higher rates of divorces and childlessness, and increasingly single-person households; increased rates of female and older people participating in the labour force; access to Government subsidised care in the home and changing average age of entry to residential care; changes in intergenerational attitudes and perceptions of caregiving; and longer durations and complexity of care required as a result of extended life expectancy, placing increasing demand on informal carers (Deloitte Access Economics, 2015). How governments elicit, facilitate and sustain people to make contributions to the care of others poses a challenge for policy makers.

The most common reasons for taking on the caring role as reported by primary carers: a sense of family responsibility (66.9%); feeling they could provide better care (50.3%), feeling an emotional obligation (44.2%), and having no other family or friends available (31.0%); having no other choice (21.7%); alternative care too costly (20.4%); no other friends or family willing (19.7%); no other care arrangements available (15.9%); and other reason (8.3%), (ABS 2018).[5]

"The predominant way carers are viewed in the system is free resources, so they are the unpaid part of the system, they do about 75% of all the care, and the other 25% is done by formal care systems, and it's just assumed. So you discharge a person from hospital and you just assume that there is someone there to take over, but we won't actually do a handover of care as we would to another health professional, we will just sent them home and then you will be on your own to manage their health, and that continues to be the predominate way, they are assumed to be willing and capable until proved otherwise" (Interview 12: Carer representative)

Concerns have been raised about the capacity in terms of knowledge and skills of people to provide informal care, and the potentially deleterious consequences of informal care for clients as well as carers themselves. The National Carers' Strategy identified education and training as a priority area for supporting carers. The strategy states that training may be required to ensure carers have the skill and knowledge to undertake the caring role (DSS, 2011a). Skills identified in the strategy include

[5] Respondents choose from fixed options and were able to provide more than one reason for performing the caring role.

practical skills (i.e. administering medications and safe manual handling) and an array of advocacy skills in order to effectively negotiate with clinicians, service providers and support workers.

> *"As you discharge people with more and more complex needs into home care then you have to train that person, you have to ensure they know how to do basically a whole range of nursing tasks and make sure they are reasonably competent to so that so they will keep your patient safe - most of the carers we speak to say they never got any of that training they needed from the health system, they are supposed to just pick it up along the way, on the job"* (Interview 12: Carer representative)

Carers Australia has called for "improvements in access to, and awareness of, carer support services such as respite care to encourage service utilisation and alleviate the impact of caring" and "further investigation of carer perceptions of the costs and quality of formal care to encourage an optimal mix of formal and informal care provision" (Deloitte Access Economics, 2015, p. iv).

> *"One of the things you have to look at is what sort of informal supports are there, and what is sustainable, and what additional support do they need, also incorporating the family into the overall plan, and of course you have to do that with consent, but making sure everyone is one the same page and that we are all working together"* (Interview 5, Aged care service provider)

In March 2018, there were more than 108,000 people on the waiting list for their appropriate level of home care, representing a 3.7% increase from the previous quarter (DH, 2018c). People assessed and eligible for high level home care packages are waiting for over a 12-month period (DH, 2018c). Of those waiting for high level packages, 55,000 were on lower level packages, while 33,000 had not been assigned any care (DH, 2018c). Despite an increased allocation of $1.6billion into 14,000 additional aged care packages, the Shadow Minister for Ageing and Mental Health, Ms Collins MP referred to these measures as a "cruel hoax," "with the waiting list growing by almost 4,000 older Australians in just three months, the 3,500 new home care packages a year committed in the Budget won't come close to keeping pace with demand" (Skatssoon, 2018).

> *"There is insufficient support in place to actually prevent those negative things from occurring, most of the services are targeting people who are already very stressed, burdened and overwhelmed, rather than actually preventing them getting that way in the first place"* (Interview 12: Carer representative)

CONCLUSION

Co-production is already happening, as it is inherent in the delivery of care in the community. Recent government reforms represent increasing dependence on clients and their carers to contribute time, effort and resources to their care. The conventional wisdom among those interviewed was that public participation provides a mechanism to increase efficiency and responsiveness of the service system and to elicit co-productive contributions. However, involving the public in decision-making is more complicated than might first appear and does not address all the challenges in enlisting and fostering co-production. The current system is heavily reliant on informal support by carers, which is also in diminishing supply. Failure to provide support to sustain people as carers, will have significant implications on the ability for the government to achieve its purposes. Co-production is instrumental to many solutions for achieving better health outcomes and allowing people to maintain living independently in the community, decreasing costs and demands on the formal system. However, a better understanding of client and carer contributions to the provision of complex care in the community is required to inform how these processes can be better managed. This is the central concern of this thesis, which is explored across the next five chapters, based on the experiences of older people with complex needs and their carers.

CHAPTER 7

Co-productive Contributions to the Delivery of Complex Care

INTRODUCTION

The following chapters draw insights from the main study of the thesis exploring clients' and carers' lived experiences as co-producers of complex care in the community. This study explores co-production in caring for older people with complex health and social care needs as they navigate the services system. It provides insights into the types of contributions clients and people in their social networks, acting as informal carers, make to the delivery of their care and how these processes are facilitated. This chapter provides a description of the study participants, who were purposively recruited to capture commonalities across a diverse range of client and carer experiences. The types of actors involved in the care workforce are then introduced, followed by an overview of the client and carer contributions to the delivery of care for older people with complex needs. This overview provides a roadmap for the subsequent chapters on how and under what circumstances clients and carers act as co-producers of complex care in the community.

7.1 STUDY PARTICIPANT PROFILES

Participants in the study provided historical accounts of their experiences of navigating the formal service system and addressing health issues and needs for support in the community. Older people with complex needs are defined as those aged 65 years and over, living with multiple chronic conditions and functional decline, that require ongoing and episodic care from multiple providers across different disciplines, services across the health and social care sectors (or complex care). As detailed in Chapter Three, heterogenous sampling was used to capture the diverse experiences. Participants were recruited based on a range of factors including age, gender, level of complexity of health conditions, and complexity of care needs, based on the length and type of service use and eligibility for higher level care packages.

A total of thirty-eight people were interviewed in the study (four interviews were performed with two participants present). Thirty of these participants were clients of the Commonwealth Home Support Programme (CHSP). Carers of CHSP clients were invited into the study, and clients were also given the option of nominating a carer to be interviewed, either on their behalf or with them. Eight participants described their roles solely as carers, including two male spouses, five female spouses and one daughter. However, in most cases participants shared their experiences of acting in multiple

roles, both giving and receiving care from a range of formal and informal actors, to varying extents at different times in their lives (n = 31).

Table 7.1

Number of client and carer perspectives represented in the study

Interviewee experienced captured as client and/or carer	No. of interviewees
Client only	7
Carer only	8
Client and carer	23
Total no. of client experiences	30
Total no. of carer experiences	31

Age and gender

CHSP clients interviewed included twenty-one females and nine males. These participants represent a range of ages from 66 to 98 years old, as represented in Figure 7.1.

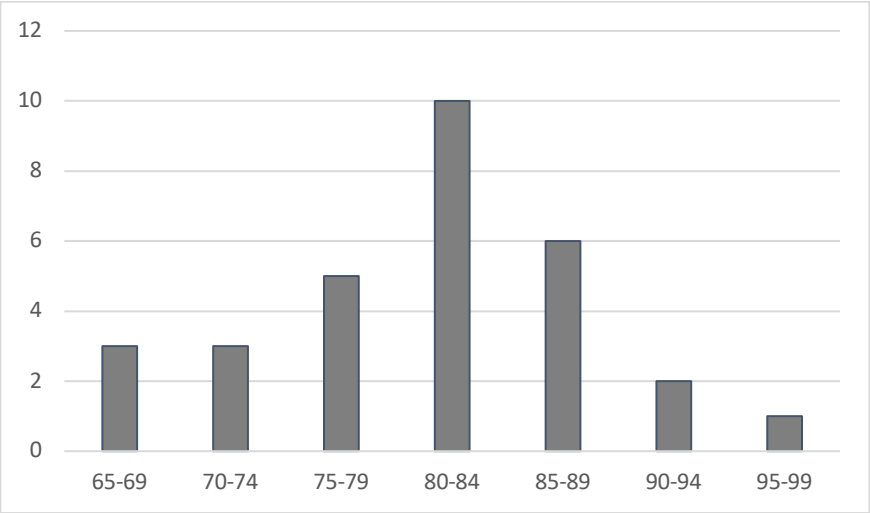

Figure 7.1. Number of client participants per age group.

Diversity of health issues represented

Clients as participants in the study had three or more chronic conditions representing a wide range of conditions as presented in Table 7.2.

Table 7.2

Range of health issues represented in the study

Disease categories	Types of diseases represented in the study
Cardiovascular diseases	Hyper/hypotension, deep vein thrombosis (DVT), angina, Reynaud's disease, high cholesterol, atrial fibrillation (AF), oedema, cardio-vascular accidents (CVA/stroke), transient ischemic attacks (TIAs/mini-strokes)
Respiratory diseases	Pneumonia, asthma, chronic obstructive respiratory disorder (COPD), emphysema
Gastrointestinal diseases	Bowel obstruction/incontinence, oesophagitis, diverticulitis
Neurological conditions	Parkinson's, multi-systems atrophy (MSA), PCP, MS, Dementia, Migraines, post-polio syndrome, polymyalgia
Musculoskeletal disorders and injuries	Rheumatoid and osteoarthritis, stenosis, sciatica, bursitis, falls and other injuries and other conditions requiring surgical intervention including joint replacements, impaired mobility and pain
Cancer and other neoplasms	Cervical cancer, lymphoma, skin cancer, breast cancer, bowel cancer
Kidney and Urinary diseases	Urinary incontinence, chronic kidney disease
Mental disorders or mental health issues	Anxiety, depression, memory loss, stress, grief and loss
Blood and metabolic disorders	Anaemia
Endocrine disorders	Diabetes
Skin disorders	Psoriasis, leg ulcers, cellulitis
Sense organ disorders	Cornea transplant, hearing impairment, macular degeneration, cataracts, glaucoma
Oral disorders	Teeth infection, edentate
Sleep disorders	Sleep disturbance

Participant CHSP service use

The length of time participants had been receiving CHSP services ranged from under one year to twenty years, as presented in Figure 7.2. Almost 30% (9 of 30) of client participants were eligible for higher level Aged Care Packages.

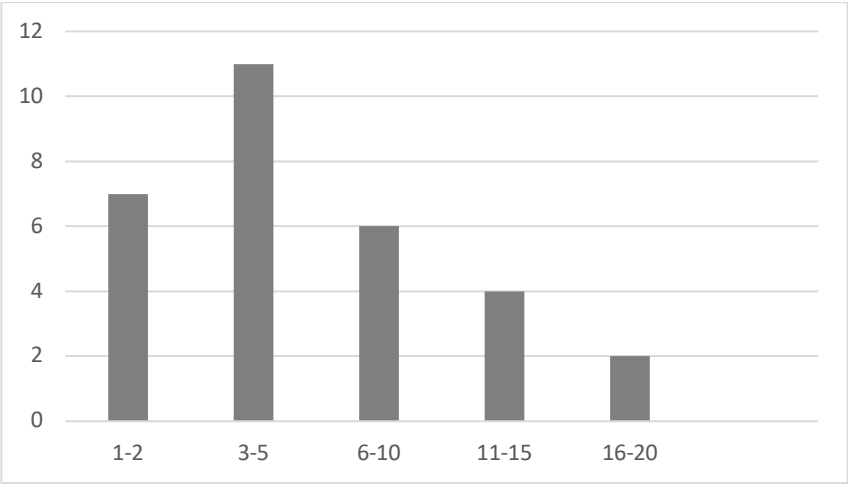

Figure 7.2. Number of years participants have been accessing CHSP services.

CHSP clients interviewed in the study received a range of services. The percentage of clients interviewed receiving services included: domestic assistance (i.e. cleaning, washing etc) (80%), meal delivery/shopping and meal preparation (47%), home maintenance and modifications (36%), personal care (i.e. bathing, grooming, dressing etc) (27%), social support (i.e. planned group activities) (10%) and transport (10%).

Geographic and cultural diversity

Participants were selected from five local government areas (LGAs) including Bayside, Maribyrnong, Knox, Monash and Mansfield. These five LGAs are situated across four different Victorian Government Regions including Northern and Western, Eastern and Southern Metropolitan, and Hume, (see Appendix 7.A & 7.B). Each area represents a different geographic, socio-economic, and culturally and linguistically diverse (CALD) populations. Despite multiple strategies to increase the recruitment of people from CALD backgrounds, only four participants had non-English-speaking backgrounds, two from Asian and two from European countries.

7.2 ACTORS IN THE COMMUNITY CARE WORKFORCE

Overall, the research revealed that the workforce is disaggregated into three broad categories: professional providers, clients and carers (see Figure 7.3). However, variations exist between and within these types that have implications for co-production as discussed here.

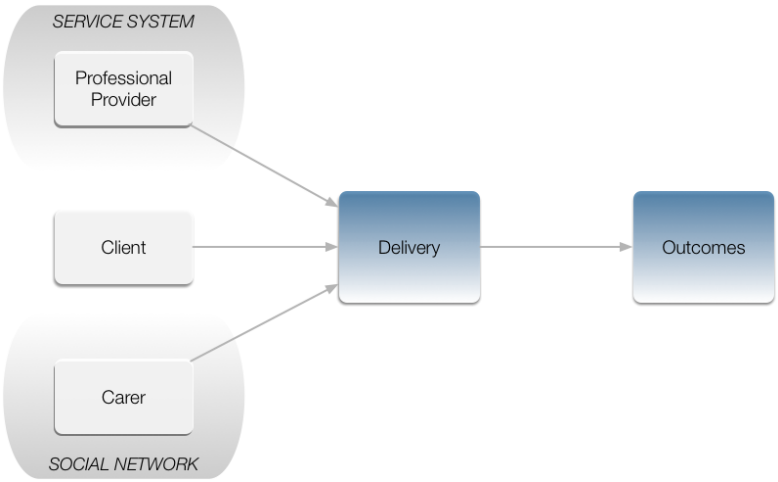

Figure 7.3. Types of actors in the complex care workforce.

The formal service system

The community care workforce comprises employees from health and social care in the public, private and third sectors. The phrase *'professional provider'* is used here as a general term for employees of the service system that are publicly or privately funded, or a mix of both with clients incurring out-of-pocket costs for some public services. In Australia, primary health care is largely provided by general practitioners (GPs) as the first point of contact with the health system and act as a gateway to other health care services (i.e. services specialists, allied health and diagnostic services), covered or subsidised by the universal health insurance scheme 'Medicare.' Meanwhile, social care for older Australians involves clients to be assessed to determine their eligibility for age care services provided under the Commonwealth Home Support Programme (CHSP), although CHSP clients can be eligible for higher level care packages (i.e. approximately 30% of clients interviewed). Clients may also have access to private and third sector care services through non-governmental organisations (NGOs) including volunteers as part of the formal service system.

Clients as co-producers

Clients as co-producers make contributions to the delivery of their care and achievement of service objectives, as the main beneficiary of the service. They vary in the level of health literacy and abilities to contribute to their care. Clients have different health issues and functional capacity that influence the type of care they require and their need for support to maintain living independently in the community, as opposed to residential care. They have different social, cultural and economic backgrounds that influence their capacity to contribute to their care. Older people with complex needs as clients often face barriers to making these necessary contributions and are reliant on support from third parties.

Informal care system, carers as co-producers

People in clients' social network acting as *carers* contribute to the care of others based on their social relationship and proximity to client. Carers represent a heterogenous group, and the nature and extent of the care they provide is largely determined by their social relationship to the client, as family, friends, neighbours or community members. Carers, as co-producers, may derive value by extension due to their social relationship to the clients or from the act of caring. People often act in multiple roles as both clients addressing their own issues and needs, and as carers, providing care to others. There may also be reciprocity between clients and carers, as they make various contributions to caring for each other.

Carer contributions may be planned or routine, although others may be ad hoc or happenstance. People with high levels of disability tend to require carers that reside with them. The term 'primary' carer refers to the person who provides the majority of the care, with or without additional support from other carers, who often have responsibility for coordinating the clients care over time. However, there are people who do not have a primary carer, instead they may receive care from multiple people (particularly those who live alone and who do not have family carers). Variations in the nature of carers role are illustrated further in the following cases.

7.3 ILLUSTRATIVE CASES

The following are illustrative cases that are presented under the pseudonyms Shirley, Joseph and Henry. These cases highlight variations in older peoples' issues and needs, and the varying roles of carers in supporting clients.

Shirley's story

Shirley is in her mid 70s. She lives alone and has been widowed twice. She moved to an inner Melbourne suburb five years ago to be closer to her daughter who was experiencing health issues. Shirley has a busy schedule attending poetry and art appreciation classes and works one day a week at a charity. Shirley has type 2 diabetes which she manages with diet, exercise and for many years avoided having to take medication.

> *"I have learned what to eat, and what not to eat. I am a diabetes 2, so it is controlled by medication, diet, and exercise, but I might mention that for years and years and years, I didn't have to have any medication at all because I managed it well - I have always learned about my condition to get the best health activity that I can. I will give you an example. My daughter was doing a paper round, the local paper, and she said, "mum you can do this" and I said, "right I will", so I walked for 2 hours on a Wednesday, 2 hours on a Thursday -*

> *that is how I am as healthy as I am now, because I can walk quite quickly when I have got a reason to do something"* (Shirley: Interview 32)

A decade ago Shirley felt a lump in her breast and had been treated for breast cancer. Since then she had routine mammograms. Last year another tumour was detected. It was in the very early stages, so she avoided chemotherapy after having surgery to remove the tumour. During her recovery, Shirley found some house work a bit difficult, so she organised an assessment for public services under the CHSP and was able to access cleaning once a fortnight.

Joseph's story

Joseph is in his early 80s, and like Shirley, also lives alone and has been widowed twice. He has two children that he doesn't see, he used to go and see his brother once a week, but the drive is too far for him now, so he hasn't seen him in years. However, he does have an adopted son Garry who comes to visit with his wife every now and then. Joseph also has neighbours that he talks to as they walk past, and a couple of neighbours help him to maintain his garden, while another takes his dog Bess for walks and washes her. Every morning Joseph walks down the street to get the paper. One morning, a friend who runs a local shop, Matt, noticed that Joseph seemed confused and didn't look too well so he called his son Garry. In turn, Garry visited Joseph and took him to the hospital where he was admitted with pneumonia. When he was discharged from hospital, Garry made it easier for him to manage his medications.

> *"I had all this medication to take, that I didn't know what pills I had to take, and I said to Garry, "I don't know what pills I need to take," and he said, "I will fix it," and brought one of those things, Monday to Sunday you know"* (Joseph: Interview 2)

Henry's story

Henry shared his experiences caring for his wife Pat. Henry and Pat are in their late 70s. Pat had been diagnosed with depression ten years earlier. However, Henry did not think this diagnosis accounted for all of her symptoms and changes in her behaviour. Eventually Pat was referred for a CT scan and was diagnosed with dementia. Pat's dementia progressed, and she lost her appetite resulting in dramatic weight loss, and had become very frail. Henry ended up taking her to the hospital where she was diagnosed with malnutrition and kidney failure. When Pat's health improved and she was discharged home with a referral for a nutritionist, Henry learned how to improve her nutrition and encourages her to drink protein shakes. Henry helps Pat to shower and perform other core personal care activities. Henry stopped getting CHSP services to do some of Pat's showering and cleaning because he can do those activities himself and Pat prefers him to do it. He asked if he could get some extra respite to go to the gym but was told it was not available.

> *"It's hard, I don't let it get me down you know, but when Pat came out (of hospital), my brain was whizzing all night, I was thinking how am I going to get out of that, how am I going to get through this, and you've got to, I've got to snap out of it - if I can keep active and keep positive, and stop worrying too much, then you know I can get through it a bit longer. We have no relations, we have no brothers, sisters, there's just me and Pat, so it's bloody hard work. You know what they say about necessity - if you have to do it you have to find a way around it, so it's changing all the time, and it gets more and more demanding"* (Henry: Interview 20)

Shirley, Joseph and Henry's stories highlight variations in the extent and nature of support provided by carers, and variations in their relationships to the clients. The cases highlight the scope of informal care from Shirley who requires minimal support to Henry who as a primary carer for Pat, provides significant assistance with personal care and responsibility for coordinating her care. These are just three of 38 participant stories captured in this study. The experiences of all the participants were used to identify the types of contributions clients and carer make to the delivery of complex care in the community and how these processes are facilitated. These contributions are overviewed below and detailed in the following four chapters.

7.4 CLIENT AND CARER CONTRIBUTIONS ACROSS THE SYSTEM

Older people with complex needs and their carers make a vast and diverse range of contributions to improve health outcomes and maintain living independently in the community. Clients as co-producers contribute *inputs*, *behaviours* or *activities* to the achievement of service objectives. These contributions are performed with professional providers during *direct* service interactions or *independently* yet prompted in some way by the relevant government agency. Clients make vast and significant contributions to the delivery of their health and social care in the community, and the *coordination* of their care as they navigate the service system. Some contributions represent inter-dependent co-production as they involve clients providing information based on their unique knowledge of their health and lived experiences (i.e. their *experiential expertise*) or changing their health-related activities and behaviours. In contrast to clients contributing to their own care, carers tend to perform a dual role in making co-productive contributions to the care of others with whom they have a social relationship by: (a) encourage, enabling or facilitating clients to make contributions to their own care; and (b) providing inputs and activities to the delivery of the client's care. Carers also make unique contributions due to their relationship and proximity to the client.

The production process for addressing health issues in the community is depicted in Figure 7.4. The delivery of health care services in the community, typically requires clients to *monitor* their health and *access* services as health issues arise or for formal input into the ongoing management of existing

conditions. Clients provide *inputs* and variously participate in professional provider assessments to inform formal diagnosis and care planning. Professional providers may perform clinical interventions that require client co-operation and referrals to other services for further diagnostic testing or assessment by other health professionals (i.e. specialists, allied health, diagnostic services etc). However, care in the community largely involves clients performing *behaviours* and *activities* to prevent, treat or manage their conditions, *independently* addressing their health issues outside direct service interactions to achieve better health outcomes. As circumstances change, clients may identify the need for further formal assessment and planning. Clients are often supported by their informal carers in making these necessary contributions to address their health issues in the community.

The care of older people with complex needs also includes clients contributing to social care to address their needs for support. The production process for addressing clients' needs for support is depicted in Figure 7.5. This includes *accessing* and providing *inputs* to inform formal eligibility/needs assessments for aged care services, and varying participation in care planning to address clients' need for support. Professional providers address clients' needs during the delivery of intermittent care services subject to their eligibility and the availability of public social care services (in addition, clients may also have access to formal long-term or aged care services from the private or third sector). Carers provide informal care to address clients' needs not addressed by the formal service system, or as an alternative. As circumstances change, clients and their carers are required to adapt or access services to ensure clients' issues and needs are addressed.

Insights gained from this research into the contributions of clients and people in their social networks to the delivery of complex care in the community, and what influences these processes, are presented in the subsequent chapters as follows: monitoring, identifying and appropriately *accessing* health and social care services (Chapter Eight); providing inputs and participating in formal assessment and care planning and cooperating with formal care interventions during direct service interactions (Chapter Nine); clients independently performing behaviours and activities to address their health issues outside direct service interactions, with support from their carers (Chapter Ten); and carer contributions to addressing clients' needs for support to maintain independent living in the community (Chapter Eleven).

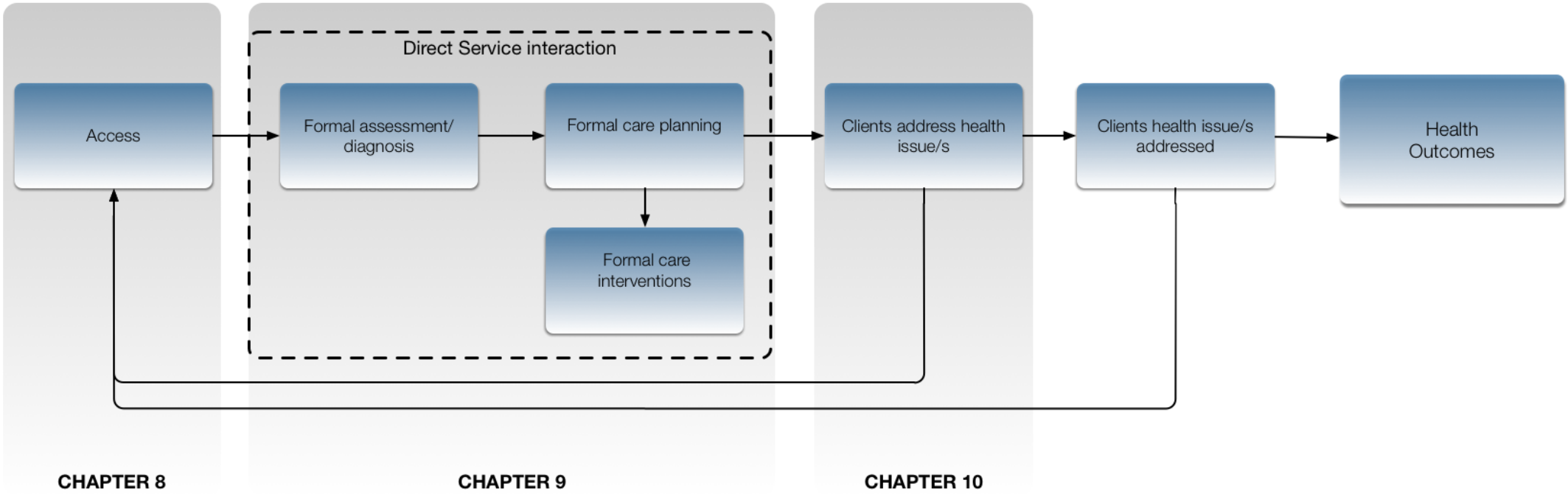

Figure 7.4. Production process for addressing health issues in the community.

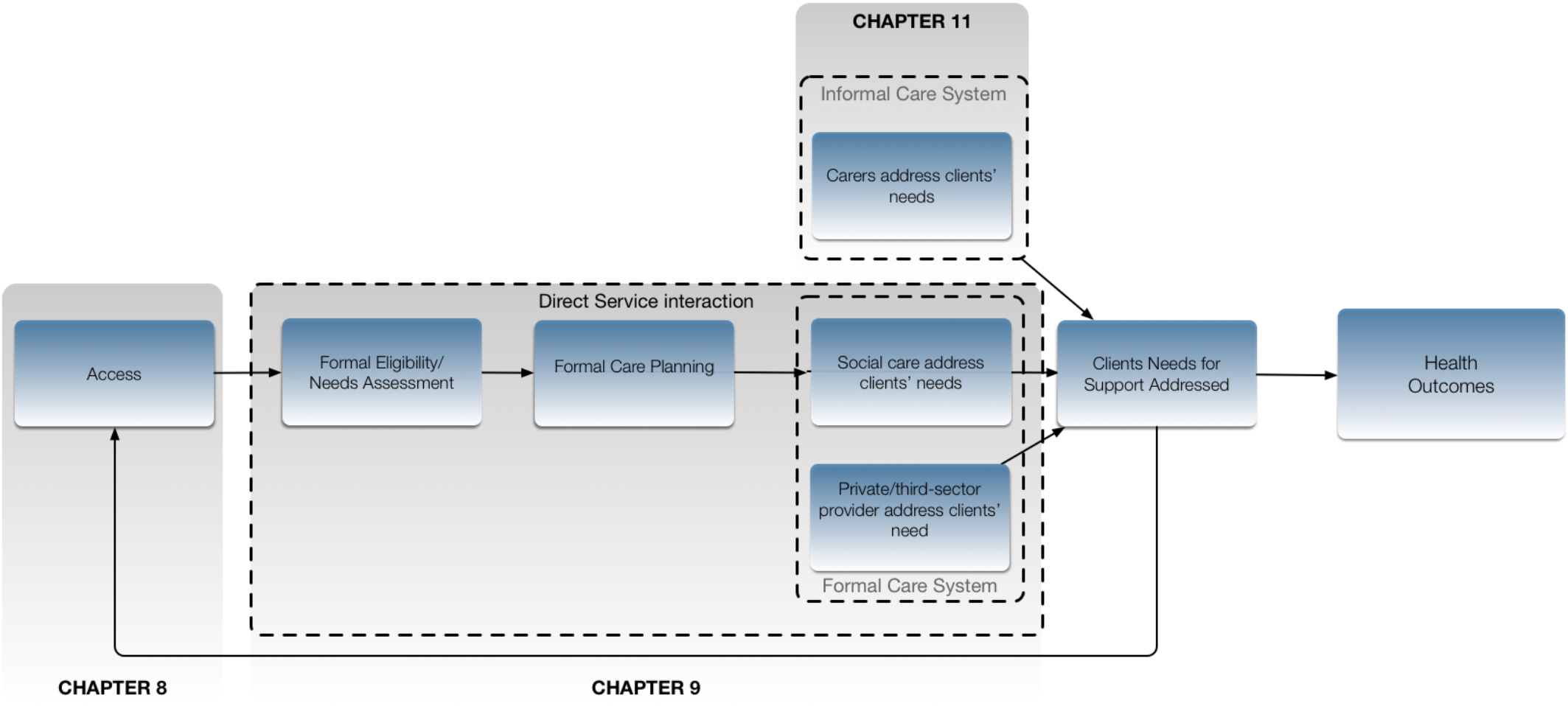

Figure 7.5. Production process for addressing clients' needs for support.

CONCLUSION

This qualitative interview study with older people with complex needs and their carers performed for this thesis highlights the vast and diverse contributions they make to the delivery of complex health and social care in the community. Services are dependent on clients to make these contributions including inputs and activities required to interact with the service system and improve their health outcomes. Older people with complex needs may be reliant on carers to facilitate them to make these contributions, particularly those made outside direct service interactions. The following chapters provide insights into what influences clients and carers in making these necessary contributions to the delivery of complex care in the community, to inform how these processes can be facilitated and sustained.

CHAPTER 8

Independent Contributions Prior to Direct Service Interactions

INTRODUCTION

Clients and carers contribute to the delivery of complex care in the community by accessing service to address health issues and needs for support to improve health outcomes and maintain living independently in the community. This process typically includes monitoring and recognising health issues and needs for support, determining when and which services to access, and performing activities involved in accessing services. Drawing on their lived experiences, this chapter also details what influences older people with complex needs and their carers to make necessary contributions to appropriately accessing services, providing insights into how these processes are facilitated.

8.1 MONITORING AND IDENTIFYING ISSUES AND NEEDS

Accessing services in the community involves clients or carers monitoring and identifying risk factors or signs and symptoms of health issues or the need for support to overcome functional declines to maintain living independently in their home environment. This often acts as the catalyst for clients' issues and needs being addressed by the formal service system. Monitoring clients in the community also provides an opportunity to identify emergency situations to ensure client safety living independently.

Clients are often best placed to identify their issues and needs because of their intimate knowledge of their own health and detecting changes in their condition as they arise. Consequently, clients can facilitate early intervention resulting in better health outcomes and decreased reliance on emergency or acute services. This is illustrated by Shirley who through performing a self-check identified a lump in her breast, prompting her to seek treatment in the early stage of the disease. Shirley was also aware of her risk of developing diabetes and was able to identify the early signs and symptoms of the condition, which also resulted in early intervention (Interview 32).

However, clients do not always have the ability to identify health issues or needs. Clients may not have the expertise including the knowledge or skills required to recognise or be aware of the significance of the issues or needs. In some cases, declines in their health and functional capacity due to existing conditions, or the presenting issue precludes them from having the capacity to self-identify, as was the case with Margery. Margery had advanced lung disease and was slipping out of consciousness. It was a chance visit from her neighbour, who took one look at her and decided to take her straight to a GP clinic.

> *"I would have been gone if it hadn't had been for my neighbour coming to my door"* (Margery: Interview 26)

There are also instances where clients are aware of issues and needs, but who are not *willing* to address them, or actively conceal them from people in their social network and professional providers. In some cases, this was articulated as a way of maintaining their autonomy, particularly if they anticipated it would affect their independence or result in interventions and outcomes that did not align with their personal preferences, such as being taken to hospital. This was the case with Edith. She lives alone and had fallen in the bathroom but decided not to call an ambulance because she did not want to be taken to hospital.

> *"I don't know what happened, I don't know if I might have had a bit of a black out, I don't know, there was nothing for me (to trip on). It is hard for me to get up when I fall. I could have called an ambulance, but you know what, I hate hospitals"* (Edith: Interview 31)

On another occasion Edith had fallen and called the ambulance as she was in severe pain.

> *"The (paramedic) said, I think you have broken your nose. I think we should take you to the hospital, and I said, please just leave me stay here, I'll be right, and he said, well we can't force you to go, we will ring your son and I said, please don't ring my son, because I said, he is a bit of a panic merchant, and he would have come flying out here, and he could have had an accident or something"* (Edith: Interview 31)

In the end the paramedics conceded that they could not force Edith to go and resolved to call to check in on her in the morning. When Edith's son came to visit the next day, he convinced her to allow him to call the district nurse to come and assess her at home. There can be tensions between clients and people in their social networks, acting as carers, where they have differing perspectives on how issues are addressed. Carers can also face barriers in providing care, based on the extent to which clients will accept their support.

Carers provided examples of monitoring and identifying clients' health issues and needs, through their social proximity to the clients as family friends or neighbours, or incidentally such as passers-by who happened across the clients (i.e. witnessing an accident or emergency). In Joseph's case, although he was aware that it was harder to get his breath, he did not address the issue. As his illness progressed, he did not identify the urgency or significance of the issue. However, in following his daily routine of going to the local shop, his friend Matt (the shop keeper) identified that Joseph was not himself and telephoned his son to check in on him. In turn, Joseph's son visited him, and although Joseph was initially reluctant his son took him to hospital.

> *"They did tell me I was pretty bad - if you get pneumonia and you don't do anything about it, by the time you do get found and you are taken to hospital it is too late, so that is the way I was going, so I wouldn't have been here if it wasn't for Matt up the street"* (Joseph: Interview 2)

Carers are often well placed to identify clients' issues and needs as they are able to detect changes based on their physical proximity or frequency of their contact with the clients and their intimate knowledge of the clients' health. Carers often have the ability to recognise changes over time and were privy to risk factors, signs and symptoms that may not be apparent or identified during service interactions. For example, Nancy identified changes in her husband Peter that may not have seemed concerning in of themselves but were unusual for him, which prompted her to encourage him to seek further formal assessment, resulting in a formal diagnosis of dementia.

> *"We had started to suspect there was something more going on, we couldn't figure out what it was, it didn't enter our head because he was so young. He was standing out the back and he couldn't think of the word fence, now that wouldn't worry me because I lose words very easily, they will eventually come back. I could be talking and lose track of my words, but Frank wasn't used to that, he hadn't done that before"* (Nancy: Interview 18)

Carers' proximity to the client and the knowledge gained from their ongoing caring role, can provide carers with the opportunity to identify issues and needs. Carers who do not reside with the client often institute mechanisms to routinely monitor the clients' condition, increasing their ability to identify issues or needs. This was demonstrated in Jim's case, whose children devised ways to observe him remotely by calling him routinely and using a mobile telephone pedometer application that collects real-time data.

> *'My other son rings me at least 5 times a week, might be more sometimes. They both ring and check on me and make sure I'm still ok and they know what I'm doing by my steps. He says, dad what have you been doing today, you haven't done many steps, are you alright. We watch one another's steps, he knows when I'm out of bed. He knows if I'm not out of bed, he says, you're not dressed yet, what's the matter"* (Jim: Interview 1)

In other situations, carers identify issues by happenstance rather than routine observation or monitoring, for instance by chance passing by and identifying the clients' need for help as a neighbour or community member. For example, Pat was in the backyard hanging out the washing and had fallen, unbeknownst to Henry who was inside. A neighbour happened to be walking past and found Pat, and alerted Henry (Interview 20).

There are also clients who use formal services to provide external monitoring, such as personal alarms systems (e.g. MePACS), that utilise the 'daily wellbeing check' function. This involves clients pressing a button on the alarm unit at a specified time each day. If this button is not pressed, the service verifies the client's wellbeing by calling them or their nominated contact (i.e. family, friend or neighbour) to go and check in on the client. For example, Bob is 98 and lives alone. He has a MePACS and uses the 'daily wellbeing check' function. At times this has been problematic as he has trouble remembering to press the button, much to his neighbour's frustration at being called frequently to check in on him and remind him.

> *"They keep having to remind me, I haven't done my MePACS, time and time again, by the time they were done I have notices printed all over the house, don't forget to press your button"* (Bob: Interview 12)

Carers who are aware of the client's issues have the opportunity to influence how these issues and needs are addressed. In some cases, carers identify clients' issues and needs that may not otherwise be identified, or before they reached crisis. Monitoring by carers allows them to identify client's issues and needs for support, provides a prompt for carers to potentially perform activities to address gaps in the service system, as described in Chapter Eleven.

There are situations where professional providers identify clients' health issues or the need for support through outreach or screening, or incidentally during consultations (such as routine monthly home visits, six-month follow-up with specialists). However, these approaches are still dependent on the clients or carers' ability and willingness to make necessary contributions to the delivery of these services. For instance, Shirley adhered with routine mammograms (to screen for breast cancer) after treatment for her first breast cancer (which she identified through a self-examination), resulting in the second breast cancer being diagnosed in an earlier stage requiring less intensive treatment (Interview 32). However, services are often dependent on clients and carers to identify clients' issues and needs to increase the chances for prevention and early intervention, decrease demand on the costly hospital sector and achieve better health outcomes. Further, clients and their carers may not have the capacity or willingness to identify or address issues until conditions have progressed resulting in potentially avoidable hospitalisation.

Clients and people in their social networks often perform a vital role in monitoring and identification, as a catalyst for addressing clients' issues and needs. However, not everyone has the same expertise or capacity to self-identify issues or needs. Clients are often aided by people in their social networks to provide monitoring and facilitating them to identify issues and needs. However, there can be situations where carers identify issues, yet they are unable to influence clients in how these issues are addressed. In some cases, clients may actively conceal their issues to maintain their autonomy.

Formal services can enable or relieve clients and carers with monitoring and identification, although some inputs or activities by clients or carers are typically still required.

8.2 DETERMINING WHETHER TO ACCESS SERVICES

Clients are often required to independently make decisions about when and which service to access to address their issues and needs. For example, when Joan felt a crushing sensation in her chest, she had little doubt, and she immediately told Harold her husband, "I'm having a heart attack."

> *"I'm sitting there one night, and I knew what it was, I could feel it, and I said, you better call an ambulance, and Harold said, I will make you a cup of tea and you will feel better, and I said, no I'm not going to feel better. I knew what it was, it is like an elephant sitting on your chest. The ambulance came, and the paramedic said, yeah we will take you up to the private hospital, and I knew who I wanted to see, and I saw that specialist"* (Joan: Interview 14)

However, clients may not have the requisite knowledge of health issues and the services system to be aware of the necessity to access a service or what services are available, and when they should access them. In addition, clients may be unwilling or unable to access a service, in which case they may access an alternative service, delay accessing or not access a formal service, resulting in under or over servicing.

Carers who are aware of the clients' issues and needs often influence clients' decision-making about accessing services, and in some instances access services on the clients' behalf. As was the case with Henry, who went to the GP as Pat would no longer agree to go to the GP clinic. Carers gave examples of situations where they influenced clients' decisions about accessing a service for several reasons including their proximity to the client, their social relationship and making access to the services feasible (Interview 20). For example, Joseph's son determined the need for him to go to the hospital, and despite Joseph's initial resistance, he was able to convince Joseph of the urgency of the situation and facilitate access by providing transportation. Similarly, Joseph may have been aware of his need for support with cleaning, but the catalyst for accessing aged care service was advice from his daughter-in-law to get social care services from the local council (Interview 2). Although there were also situations where carers are not able to influence when clients access services, an issue that was often raised in relation to clients refusing to go to respite.

Carers' involvement in determining access to formal services often acts as a catalyst for them to address client's issues and needs themselves to fill gaps in the service system. In some cases, carers performed first aid prior to accessing a service or instead of accessing a formal service. As described by Teresa.

> *"Falls were shocking, because I couldn't lift him when he fell, he was just straight out, and last time I had to ring my daughter, because we had our MePAC alarm (i.e. a monitored personal alarm service), but it was just easier for me to ring my daughter, and she dressed his leg"* (Teresa: Interview 27)

Clients and carers often spend time seeking information and learning how to navigate the system to find appropriate services. For example, Nina is a carer for her husband who has a rare neurodegenerative disease called progressive supranuclear palsy (PSP). Nina described her efforts to meet her husband's needs.

> *"Some I find are not competent enough to deal with his condition which is quite rare, and I feel like I'm wasting my time with some of the services. He used to go to another rehab, they are used to dealing with stroke victims, people that have other conditions to what he has, so I was searching for a while, and now I am told that a movement disorder clinic will be able to help him because they do PSP. I mean this is like two years down the track, why wasn't I told about this? I don't know. Anyway, so a referral letter has been sent to them, and they have come back, it will take three months, it is a three month wait, here we go again"* (Nina: Interview 22)

Professional providers can enable or relieve clients and carers in their decision-making regarding accessing services. These mechanisms include: scheduling regular follow-ups; sending reminders; referrals; providing home-visits/ambulant services or access to transport services; and providing information including as triage services over the phone.

8.3 PERFORMING ACTIVITIES TO ACCESS SERVICES

Clients are required to perform various activities to access services. In particular, activities involved in accessing services in the community can have high transaction costs including time and effort, resources required to schedule appointments (i.e. telephone/internet), access to a mode of transport, and out-of-pocket costs associated with some services. These costs are often significant for people with multiple issues and needs, requiring services from many different providers at different locations, particularly during initial diagnosis and during transitions (such as before and after hospitalisations).

Older people with complex needs, depending on their level of functional capacity are often reliant on support from others to overcome barriers to accessing services. Carers often facilitate clients accessing service for example by scheduling appointments, providing transport and assisting client mobility. For example, Deirdre taking her husband Harry to appointments.

> *"I took him into the hospital when they were re-building it, it was a nightmare, anyway I did it, because I drive him to the door everywhere we go. He is very frail on his legs, in fact, I put him into a wheel chair"* (Deirdre: Interview 13)

Accessing services often includes scheduling services over the telephone or online websites, which required clients to have the *functional capacity*, *expertise* (i.e. digital literacy) and access to *resources*. Carers may perform these tasks for clients, as in the case of Samantha who is a carer for her husband George who has dementia. Samantha described her experiences of organising for social care services over the phone and internet.

> *"My experiences with the phone was, of course you keep getting different people, and they would have to refer you to talk to someone else, so you would go through the story and you could be here all morning trying to sort things out, and you would actually lose your thread about who you had talked to about what. How people of advanced age cope with that, who does it for them? I don't know I don't know who does things on the computers for them? George's children who are 48 and 46 they will grow old with the skills required, but we have still got the remainders of this generation, my generation, baby boomers and George's generation, he was born in 1932, who are bewildered by computers"* (Interview 11: Samantha)

Additionally, access to the internet may be not affordable or readily available, particularly in rural and remote areas. As described by Enid who lives in a rural area, who didn't have (consistent) mobile reception or internet connection.

> *"I don't know about the NBN, I don't know if that is here, I don't understand, I've been living back in the eighteenth century since ever, and it is very difficult for me to sort of, my son, he used to get very frustrated, he used to get very disgruntled because he couldn't get any reception"* (Enid: Interview 29)

Accessing services in the community, in most cases, involves transportation to services, and time, effort and financial costs associated. Older people with complex needs, have regular consultations with multiple providers and then to diagnostic services which usually in separate geographic locations. Many participants had several consultations with various providers each week. The time involved in attending consultations is not limited to transport, but also time in waiting rooms prior to their consultations, incurred by clients and often their carers. These costs were very high for people interviewed who live in rural areas, where travel to specialist consultations can be in excess of 2 or 3 hours each way.

Clients' geographic location (i.e. urban/regional/rural) influences the distance to services, and often choice and availability of services, including access to bulk billed services. These access issues create significant variations in transaction costs incurred by clients in accessing services and increased reliance on informal support. Margery moved to a rural area to be closer to her daughter Gemma for informal support. They described some of the challenges they face.

> *"All those other specialty services, we've all got to go out of town, 2 hours to another regional centre, or 2 ½ hours to the city drive, there's no buses, which really, if you're sick anyway, you don't want to sit on a bus, that is probably the biggest issue"* (Interview 26: Gemma)

> *"In the city, when I was on a care plan for the podiatrist, I didn't have to pay there. Up here you have got to pay, now going for the diabetic educator, that you have got to pay for, the dietician, for the diabetes, that you have got to pay for, you have got to pay for everything when you are in the rural, because the facilities are just not there"* (Interview 26: Margery)

Transportation to services was often raised as an issue for older people with complex needs. Carers often make it feasible for clients to access services by providing transportation. The transaction costs associated with facilitating clients to access services can be high for carers, particularly for people who have frequent appointments with professional providers and those who live in regional and rural areas where they are required to travel long distances. This can be challenging for carers with competing obligations and responsibilities such as employment or other caring roles. For example, in Margery's case, her daughter Gemma drives her to the closest regional town for her specialist visits.

Some health services relieve clients or carers of the need to physically access services by providing services in home however it is uncommon, while social care services are typically provided in the home. Providers in some instances facilitate or simplify access to services to decrease dependence on client or carer contributions. For example, subsidised taxi vouchers to facilitate transportation to health services in the community, although clients frequently described having difficulty utilising these services. For instance, Edith lives alone and doesn't drive.

> *"I haven't been to physio in a while, I used to go just up the corner there, but I can't get a taxi because it's too short a distance. Pauline on the desk (at the physiotherapy clinic), she is very nice, because I'm a very independent person, and she always says, I can pop round and get you, and you know, I get very worked up about that, I think to myself, she shouldn't have to do it"* (Edith: Interview 31)

Clients may be eligible for (subsidised) transport services, however in many cases they were reliant on carers to overcome gaps in these services, to make it feasible to access formal services in the community.

CONCLUSION

Complex care in the community is dependent on clients' initiating access to services in the community to inform the ongoing management of chronic conditions and address issues and needs as circumstances change. These contributions influence the effectiveness of the system through the appropriate use of services and potential for prevention, early intervention and the management of health issues in the community. People with complex care needs are required to make significant contributions of time, effort and resources to access services to improve their health outcomes and maintain living in the community. Older people often face challenges making these contributions due to their level of expertise, functional capacity, resources and willingness. They are often reliant on carers to overcome these barriers to make necessary contributions to monitoring and accessing services for their issues and needs to be addressed. Co-production is embedded in the delivery of complex care in the community, as clients, and often their carers, are required to contribute time and effort for services to achieve their objectives.

CHAPTER 9

Contributions During Direct Service Interactions

INTRODUCTION

Clients and carers make contributions during *direct* service interactions with professional providers, necessary for the delivery of complex care in the community. These contributions include providing *inputs* to formal *assessment* and *care planning*. Clients and carers, as distinct actors, also variously participate in decision-making about health and social care planning. In addition, providers may perform clinical intervention during service interactions which involves *cooperation*. However, the majority of care in the community is performed by clients and their carers *independent* of professional providers as detailed in the following chapters (Chapters Ten and Eleven). This chapter details these contributions and insights into what facilitates these processes, as described by older people with complex needs and their carers.

9.1 PROVIDING INPUTS TO FORMAL ASSESSMENT AND PLANNING

Clients provide *inputs* to facilitate formal assessment and health and social care planning processes. Clients provide information about their needs for support during formal social care needs assessments, to determine their eligibility for aged care services. During consultations with health care providers in the community, clients provide information to inform formal diagnoses and care planning. As discussed in the previous chapter, clients require the requisite *expertise* to identify or recognise issues and gather pertinent information. The clients' ability to recall and communicate this information has implications for formal assessment and planning.

Clients possess historical information about the management of their health issues, such as previous responses to interventions, and inputs from other providers involved in their care. They also have unique knowledge or *experiential expertise*, based on the lived experience of their conditions and ability to identify changes over time. For example, Shirley was aware of her risk for developing diabetes and was able to recognise early signs and symptoms, which promoted her to access her GP and provide this information, resulting in early intervention.

> *"My mother was a diabetic, but hers wasn't diagnosed early enough, so I learned what the signs were, so I went to the doctor and said, I've got this kind of symptoms, right, and then they tested me for diabetes, and I had it"* (Shirley: Interview 32)

During the health assessment process, in addition to verbal information, clients may provide inputs by cooperating with physical examinations and referrals to other services for diagnostic testing or further assessment by specialists and other health professionals. Clients and carers often coordinate between different health professionals including transferring information between different providers and services. As illustrated by Henry, who described discussing the dieticians care plan with his wife's GP to ensure they had aligned purposes.

> *"It was a lot of work for me to get her back on to some sort of even keel and since then we have seen a dietician and doctors and health care workers. I've just seen the GP today actually, because the dietician is a bit concerned, although Pat's weight is going up she was a bit concerned that it's a bit high in sugar and high in cholesterol, but the doctor this morning, I knew what he would say, he says don't worry about it, it's quality of life"* (Henry: Interview 20)

There are some circumstances where clients face challenges communicating information due to their *functional capacity*, for example their ability to gather, recall and communicate information. For example, Anne had a friend Ron who suffers from memory loss. Ron went to his GP with a cough and was given a referral for a chest x-ray. When Anne asked Ron about it, she learned that he had forgotten to go for the x-ray. Anne, not being the next of kin, wrote to Ron's children to inform them that he needed assistance with attending medical appointments.

> *"I had to write to the son and daughter. They're in their 40s, one lives with him. I told them, so look you're the next of kin, you need to come to this appointment with this doctor because he'll need to know what's happening at home because I don't know what's happening there, I only know him outside, so they did come which was good and the doctor gave the son the responsibility of accepting the call from the hospital when he was due for his X-rays and things"* (Anne: Interview 5)

In some situations, carers attend consultations to provide information on the clients' behalf, acting as an *advocate,* or provide their own unique insights based on their *experiential expertise* of caring for the client. Carers also demonstrated having information about the clients' health history and their issues and needs, based on their unique insights as carers. Carers provided examples where they fulfilled the role of gathering and communicating information to assist formal assessments. For example, Joan is a carer for her husband Harold who has a kidney condition. The specialist requested that Harold measure his fluid intake and output. On his behalf, Joan kept a detailed written account which she provided to the specialist on their next appointment.

> *"Harold has a bladder and prostate problem, so he is under a urologist. I have to, I don't allow him to get out to the toilet at night. I brought him a urinal like they use in the hospitals and he uses that, I have to measure his urine and keep a diary for the urologist"* (Joan: Interview 14)

There are often significant costs of time. effort and resources involved in gathering information, particularly when it involves facilitating clients to access diagnostic services or specialists, including transportation and other tasks involved with accessing these services. In addition to having the knowledge to know what and how to gather information, and the *capacity* and *resources* to obtain the information, carers need to gather information and be present during consultations to communicate this information to providers.

In a few instances, carers described situations where they were excluded from formal processes by professional providers for reasons such as patient confidentially. For example, Gemma described being told she could not have information about her mother's condition to plan how to support her post-discharge from hospital, due to confidentiality.

> *"When mum was in ICU, the doctors and nurses and all that were really sus on me, which as a child whose caring for an elderly parent was really frustrating and annoying, but I can understand why they did it because a lot of people that don't care like they say they do, because at that stage we had talked about it several times, about doing a power of attorney medical and everything, and we never got around to it. So I found it particularly frustrating trying to get any information, trying to work out what I'm going to do with mum once she is off life support, I know you are all doing your job right here and now, but she has got to come home, she's going home to be on her own, so that was particularly frustrating for me, and then it was going to be, well it up to me to see what her needs will be. Because she is my mum I like to try and attend all of her medicals now, so we did get that power of attorney thing all sorted out when she came off the life support, and just to make sure she is getting the best care possible, I try to attend to all those things"* (Gemma: Interview 26)

Carers demonstrated how they provide unique insights based on their knowledge of the clients and their experience of providing care for clients. Carers in some instances influence the quality and safety of clients' care by *advocating* on clients' behalf if they disagreed with the formal diagnosis. In Henry's case, he advocated on several occasions to consider alternative diagnosis to describe changes he had observed in Pat's behaviour that were not consistent with the professional providers diagnosis of depression. Henry persisted during several consultations until Pat was referred for CT scan, which confirmed a diagnosis of dementia (Henry: Interview 20).

> *"I kept saying to him (the specialist), Pat's memory is not as good as it was, and she would do little things that she wouldn't normally do, and he kept saying, no, no, she is alright, and he did a test, he said, no, she is scoring 19 out of 21. I kept saying, that's not right, and eventually he had Pat have a scan at the hospital and they said, yeah it is dementia"* (Henry: Interview 20)

In addition to health services, carers provide information to inform social care assessments to determine clients' needs for formal support, that is shaped by the clients' functional capacity as well as access to informal supports. This information influences the accuracy of these assessment to identify what services clients require and the distribution of care between formal and informal providers to ensure clients' issues and needs are addressed.

How clients and carers were engaged in providing inputs to inform the assessment process varied between providers. In particular, carers are not always included in the assessment process, and their expertise and perspective are not always recognised, despite being involved in caring for the client. The extent that formal needs assessments or formal decision making resonated with clients' and carers' lived experiences, influenced their trust in the formal diagnosis and care planning. Professional providers may relieve clients of the responsibility to proactively provide inputs, by performing holistic assessment to identify client's issues and needs and inform clients and their carers on information to gather to assist future assessments.

Relational aspects of the interactions and continuity

Client and carer contributions to formal assessment and planning are also influenced by their inter-personal interactions with professional providers. In describing their experiences, participants in the study often focused on relational aspects of these exchanges and how they were engaged in the process by providers. For instance, whether they were asked questions and felt listened to; whether their concerns were dismissed or considered, investigated or followed up on; and if the professional provider demonstrated concern or empathy for them personally. As described by Ron:

> *"We did have a damn good Doctor until he moved out to a different suburb. We used to drive out to there, but as I was getting older, I just said to him, I'm afraid I can't come out here anymore. You would go in and he would say, how are you? what's the football score? or something else, he sort of settles you down, then he's oh, what's your trouble. You always felt like he cared"* (Ron: Interview 33)

A key aspect of their interactions was continuity in terms of having an ongoing or long-term relationship with the provider. Participants described building trust with their providers based on

their relational experiences (i.e. how they felt they were treated during service interaction), but also, whether previous experiences resulted in positive outcomes (i.e. building trust in their provider and the efficacy of the service). Having the same provider also had practical benefits such not having to repeat information. However, there were instances where seeing a new or different provider resulted in new issues being identified, because different providers have different expertise or can see the clients with fresh eyes. As illustrated in Patrick describing his wife Irma's being diagnosed by a different GP that had been missed by their usual doctor.

> *"Our GP was on leave, so in the group practice another GP took over the case, she saw Irma and she said, you have Parkinson's. We got a shock, what do you mean? Sorry but you have Parkinson's. So she said, let me refer you to the specialist on this matter, but I'll do that with your regular GP when he comes back from leave, so when my regular GP came back he said sorry, sorry, I have been seeing you so much that I don't see the change in you, that needs a fresh eye to look at it"* (Patrick: Interview 21)

Many of the participants shared the experience of having had the same GP for long periods in the past, who had since retired or moved location, and they had since found it difficult to replace or replicate, because of issues seeing the same provider (particularly at short notice) and the changing nature of their interactions. Enid described changes in her interactions with GPs.

> *"I might have to wait three weeks or a month even to get to see my own GP, it's sort of, this has been going for quite a while, you don't actually get to see your own GP, unless you are prepared to wait. Unless I ask the question, they hardly ask any questions at all. They seem to spend 90% of their time on the computer, which they probably have to in today's age you know, whereas before they would just sit there and ask you question after question after question, they don't do that anymore. Unless you ask the question, off they go, they don't ask me a question unless I actually ask something, but before they would ask, well how's this going and how are you doing with that, and how's you know, or have you had any problems with such and such, but they don't do that anymore"* (Enid: Interview 29)

Many participants felt there was often not enough time to discuss their issues and concerns, with the focus being on the single presenting issue. Variations between providers were described by Margery,

> *"They listen to their patients, and if your appointment time is there and you happen to run over that time, he doesn't rush you to get you out to get the next patient in, he listens to you, that's why I like the older doctors, a lot of the younger ones should take note actually"* (Interview 26: Margery)

Participants frequently described interactions with professional providers as feeling more transactional, with shorter consultation times and being less engaged in providing information, and professional providers largely working on the computer rather than directly facing and interacting with them.

9.2 PARTICIPATION IN CARE PLANNING

During direct service interactions, participants described various forms of participation in formal decision making in health and social care planning. In social care, a care plan details the formal public home care services to be delivered to assist clients with personal care and provide support with addressing health issues and maintaining living independently in the community. In primary health care, a care plan details interventions or tasks to be performed to address their health issues. For chronic conditions, this may include coordination with other professional providers across service and disciplinary boundaries involved in managing their conditions. However, tasks performed to address health issues detailed in care plans are largely performed independently by clients, often with support from their carers, outside direct service interactions.

Client-driven relationship

There are situations where clients had a *'client-driven relationship'* with providers, where participation involves exercising choice in their care planning. Clients decision-making about social care services, typically involved expressing preferences and choice of social care services based on their eligibility and the availability of these services. These choices were between set options as dictated by program guidelines, where clients had limited influence in how the service would be provided. However, some providers used their discretion to work outside these guidelines to make services more responsive to client's needs. As described by Teresa:

> *"When they come, because they are not allowed to lift anything, I have to lift the shower thing out, take it out, when someone comes a fortnight to clean the bath. They are very strict on what they are allowed to do and what they are not allowed to do, and I, I know some of them will do a bit more than what they are supposed to do. I had a talk to one of them the other day, that we really, we really like a lot of them, and he said, I do things they say I shouldn't do, he said, but what they don't know, don't hurt them, I said, I wondered what, I knew they weren't allowed to dust, and no lifting, some of them do move the chairs, I don't ask them to lift the chair but I mean move the chair out, you know what I mean, little things like that"* (Teresa: Interview 27)

In planning social care, primary carers are often involved to some extent in choices about aged care services. However, clients as the main beneficiaries are given the choice of services (based on their

right to self-determination). These choices influence the contributions that carers are required to make by default to ensure clients' issues and needs are addressed. Thus, carers perspectives or preferences may not be included in decisions about services, despite the impact of these choices on their caring responsibilities. Carers involved in this process may disagree with clients' preferences which can lead to conflicts. This issue was often raised in relation to respite. Cath as a carer for her husband in the decision to access respite services:

> *"I totally shut down about two years ago, I couldn't breathe, it's just ongoing stress really, you are always worrying about what's happening, you don't sleep, because you're always listening for his chain to rattle to see what's happening to him. He certainly doesn't like going to respite, it has made a real difference to us. He really hates it and doesn't see why he should have to, it's a problem, it's a shame, you don't want to see someone, put someone in that position that they get so upset, and so distressed that they don't want to be there, it's a hard choice to make"* (Cath: Interview 24)

There are also situations in the delivery of health care in the community where clients make choices about how to treat or manage their condition, depending on evidence-based practice that dictates how health issues are treated by health professionals. Shirley described traveling a significant distance to see the same GP because she felt she was included in decision-making by having choices about her care.

> *"There is another doctor who I have attended ever since I have returned back from the country since 1990. I return to every now and again because I really trust his advice, and he - gives me the choices, recommendations, if he is unsure of anything over the years he has always referred me to a specialist in the area that I might have the problem, yes, an excellent doctor, really good with people and a lovely family man. I've got a high regard for him"* (Shirley: Interview 32)

Participation in making choices extends beyond a client-driven process where it is a *collaborative process* that involves sharing information to overcome knowledge imbalances to enable clients to make informed decisions to about their care.

Provider-driven relationship

There are instances where clients and their carers have a *'provider-driven relationship'* where they are not engaged in participating in their care planning, where care plans were directed by professional providers. In these situations, clients often described their involvement in decision making based on the extent the professional providers asked them questions, listened ('feeling heard') and considered

individual circumstances and preferences during assessment processes. Whether clients acquiesced with formal care planning was often based on whether they felt engaged in providing inputs to formal assessments and their trust in the providers professional expertise to make decisions about their care. Bob described his interactions with his general practitioner (GP).

> *"He is like an old-time doctor, what we called in our day, the old-time doctor, he will sit there, and he will listen, he will listen to your troubles and he was always, he gives you his advice, I have got no complaints about that doctor"* (Bob: interview 12)

The extent to which clients and carers were engaged in providing inputs into formal assessments and care planning varied between professional providers and services. Participants in the study described situations where decisions were made about their care without their input, as they were not asked questions or included in decision-making to determine how issues and needs would be addressed. Enid told of her experience with a GP changing her medications where she felt she should have been consulted.

> *"That blood pressure tablet, they should have discussed that with me, but they just put me directly on that, which that was wrong - he just said, we will do this"* (Enid: Interview 29)

Participants often expressed the importance of being included in decision-making, and that their input had implications for the safety and quality of care. Where clients or carers did not trust or agree with professional providers' diagnoses or care plans, participants described responding in various ways. For example, participants providing examples of voicing their concerns, seeking an alternative opinion, or finding workarounds to *circumvent* or influence formal decision-making. Alternatively, clients may simply not adhere with care plans. For example, Bob was referred to an out-patient physiotherapy class, where he was given a booklet with exercises for him to do at home to improve his balance. Bob said he does not do them as he could not see the sense in it.

> *"Sometimes I have to ask, I can't see the sense in this, and they have to explain it to me, and I come out still not fully satisfied. You stand with your back to the wall, about that distance, and then you keep your feet still and lean back. I said I don't see the sense in this, and they said it is for balance, I said it is alright you have a wall behind you, say you are out in the open, I didn't get, I couldn't get an answer for that one." Well I'm doing enough exercise, even when I walk down these steps, that I'm doing my exercises really, I know it is misleading, they say are you doing your exercises? and I say, oh yeah I am"* (Bob: Interview 12)

Meanwhile, Myra described telling the hospital staff she had informal support so that she could be discharged home.

> *"I didn't have anyone at home, I don't have anyone to easily accompany me for same day operations, it is very difficult, I just lied about it, I just came home by myself"* (Myra: Interview 8)

There are variations in client and carer expectations regarding their involvement in clinical decision-making. This influences whether they initiate, or purse attempts to influence formal decisions about their care. There are clients who *passively comply*, while others do *not adhere* with provider-driven care plans because their concerns or circumstances have not been taken into account or addressed. As illustrated by Kelly, who may have been more willing to comply if her pain had been identified as a barrier and better managed.

> *"I admit I didn't do everything like I should have done. Because it still hurts so much. It was a thing of sort of pushing my knees too. You don't feel like you can say anything. You just kind of have to do what you're told"* (Kelly: Interview 4)

Where there are knowledge imbalances, clients and carers may rely on their trust to determine whether to adhere with a provider-driven care plan. Participants tended to describe building trust over time based on their relational interactions with providers and previous experiences. Some participants independently sought to educate themselves about conditions and treatments to influence care planning, allowing them to exercise *voice*, rather than trust or rely on professional providers in making decisions about the safety or quality of care. This was articulated by Patrick who was a carer for his wife, Irma.

> *"I do a lot of reading, I go to the internet and see about the progression. Before I see the specialist, I would look up and see whether there are new developments with drugs for Irma's condition, I would volunteer to say to the specialist, have you heard of this? Yeah, yeah, yeah, yeah, I know, he says. In other words, are you trying to tell me what I know"* (Patrick: Interview 21)

In some cases, clients or carers attempted to *circumvent* providers, for example tailoring their inputs based on what information would influence provider decision making in a preferable way. For example, Bob explained how if he had have told them he had greater disability they might have performed an operation rather than referred him for physiotherapy.

> *"It is a bit my own fault really. They said, how are you getting on with your walking? Oh, not too bad, I have to use a stick every now and then but ok, how about steps and stairs? Yeah, I will go upstairs, I've got steps in the garden and I get up them ok. They said, oh so you're not managing too bad, then are you? Oh no, no, no, I'm ok, I said. If I had of turned around and said I have a struggle getting up the steps, I have a struggle doing this, struggle doing that, then they might have done my knee, done something about it"* (Bob: Interview 12)

Nancy cares for her husband Paul who has dementia. Nancy hired a private cleaner and then uses the cleaner provided by the local council to provide additional respite rather than cleaning.

> *"She comes on Thursday morning is supposed to do some of the cleaning, but it wasn't enough really to ease my workload, so I thought I would rather get an independent cleaner, so she still comes supposedly as a cleaner, but he comes the day before she comes so it is not really working, but it is more important that there is just someone here with Paul"* (Nancy: Interview 18)

Clients may also seek to influence provider care plans through *exit*, where they are able to access alternative providers or services when they do not agree with a formal provider's care plan. The option of seeking alternative providers is not always possible. Although, people with private health insurance or who can afford to pay for private care services have greater choice. Joan described disagreeing with the care plan and seeking a second opinion.

> *"The doctor wanted to amputate and I said, no, not yet, I said, I would like a second opinion, and he said, that is your prerogative and I don't blame you, and he said have you got anyone in mind and I said yes, which I did and he was a younger man and he had different thoughts, so being in a private health cover gives you this freedom. If you have the money you can do that but if you don't you're not able to, and there's a lot of people I know in that position, but as I said, fortunately we are in the position to be able to do that, but it is one of the biggest outlays that we have"* (Joan: Interview 14)

Clients and carers often make their own judgements on the nature of the issue or need and may actively seek to influence formal decision where they do align with their experiences or they do not feel heard. Carers may *advocate* on clients' behalf where they do not agree with formal diagnosis or care planning by *voicing* their concerns. For example, Teresa's daughter, Lauren, attended her specialist consultation to act as an advocate for a different approach.

> *"All the years I have had infections on and off, at least now I don't have the pain in the eye or the headaches, we have had to fight for this one, we had to fight to get this, they didn't want to do it. Just keep up with the treatment, they said. So, we asked can we see somebody who is more…, because in the public hospital you can't choose who you see so I've gone through this for years and years with them. Lauren has finally taken me because she was upset with them, that they weren't really getting anywhere, and that last one was the last straw. We went over to another hospital and we went and saw a different specialist and he said, I think the only answer is to have the eye removed, and Lauren said, thank you very much for listening to us"* (Teresa: Interview 27)

However, there are situations where, particularly in the public sector, it is not possible to access alterative providers. In some cases, clients and carers make formal complaints, where *exit* is not an option.

Carers may not have the same priorities as the client, and there may be conflict between different actors. This was demonstrated in Samantha's case. Samantha cares for her husband, Greg, who has dementia.

> *"He (Greg) is very stubborn, like he is absolutely fixated on ice-cream now his doctor who we are seeing on Friday about his diabetes he is happy for Greg to have one scoop of ice-cream, but Greg doesn't stop at one scoop, and it is a battlefield if I keep trying to keep him to one scoop. Recently in one of the dementia classes I found that this is a common element with dementia sufferers that they will get fixated on a food and they will just want to keep eating it and eating it. Now unfortunately for Greg's diabetes, his fixation is ice-cream, and so I think I can't do this, this is killing me, trying to get him to keep to one scoop of ice-cream. Is this how I want my life to end, I have a stroke over a scoop of ice-cream, and that is awful - I think, this is just another thing to try and be hypervigilant about"* (Samantha: Interview 11)

There is a more complex dynamic in decision-making processes that include carers as well between providers and clients, as well as carers. Carers, who are not the main beneficiary of the service, described how their participation in decision-making about clients' formal care planning varied. In some instances, carers described being asked about their knowledge of the clients' issues and needs to inform assessment and planning, based on their unique insights from caring for the clients, as well as the person performing the work of implementing the care plan as the clients' carer. However, there were other examples where carers felt excluded, due to a lack of engagement or recognition from professional providers, and in some cases, based on the provider's concerns relating to confidentiality.

In the health sector, there is a tendency for professional providers to direct clients with a set of instruction on how to address their health issues. However, there are also instances where care planning processes are not client or provider-directed, where providers engage clients and their carers in dialogue and deliberations in the decision-making process.

Collaborative relationship

There are situations where decision-making was shared between clients, carers and professional providers, as described by Dorothy in the management of her chronic leg ulcers.

> *"Sometimes they will say, we can put you on, try this medication, and they'll ask what I think, and especially my husband, because he has got to be there with me anyway, as they said to him, are they looking any better, because he sees them every day, well he can tell them if, he'll say, yeah they definitely do, they look as though they went backwards or something like that, but other than that, yeah, it's just a general how I'm feeling, how I, how do I feel in myself, do I have any pain or anything like that"* (Dorothy: Interview 28)

Care planning can provide an opportunity for *collaboration* between providers, clients and carers to increase *willingness* to adhere by *negotiating shared purposes*. Dialogue around care planning also provides an important window of opportunity to *find solutions to barriers* to client and carers to make necessary contributions to addressing their issues and needs independently as they manage their condition day to day. For people with complex needs, this process tends to require coordination with other service providers that are required to make contributions to achieving service objectives. As illustrated by Betty, in describing her participating in care planning with her GP.

> *"It was to keep me out of hospital because every winter I would be in hospital once or twice for 10 days at a time with chest infections, and I said right, we need to do something about this, it is ridiculous, and so he said, right, we will do a management plan. We did the standard chronic disease management plan which you know, gives you your podiatry, physio and all that sort of stuff, and I opted for podiatry because it is the most expensive, because physio I get at the hospital for $9 a visit so it is fine, and my OT I think costs me $12 a visit, physio costs me $9 with the subsidy, so that is good, so I did that, and then added to that, for the surgeries purpose we worked out a plan, alright I'll have antibiotics at home at all times"* (Betty: Interview 23)

There are services or clinics in the community to facilitate clients to address specific conditions or symptoms, providing information and education to manage conditions day-to-day. For example, Gregory was a carer for his wife Edwina, which included supporting her to manage incontinence.

After having trouble managing the issue and ending up being hospitalised, Edwina was referred to a continence clinic. Gregory described how the incontinence clinic enabled him to better manage his wife's condition.

> *"This whole management of bowel control, it is bowel management, just realising that what she (the GP) was concerned about - so we now know what the things to do, what the Movicol does and what the fiber does and when, and the continence nurse was very good, the continence nurse was very good at explaining, to drink pear juice every morning, prunes, and all of this stuff, and logging it, keeping records, I'm keeping better records than the hospital did"* (Gregory: Interview 9)

Carers included in care planning are better positioned to facilitate clients in addressing their health issues, independent of professional providers as they manage their conditions. For example, Patrick attends physiotherapy appointments with his wife Irma to learn how to do the exercises that she was directed to do at home.

> *"I go with her, I'm always present with her, although it is once a week, but daily I do the exercise that are supposed to be done, where I would spend with her 5 to 10 minutes doing all those exercise with her"* (Patrick: Interview 21)

Carers can also have collaborative relationships with providers, including having influence of the way care is provided as described by Nancy,

> *"Yes, they have been quite cooperative. I was talking to the women and she, said oh they'll change it if it is not suitable, they don't want it to not be working for you. So she said, I'll ring them up if you like, well that was enough to make me feel guilty so I did then ring the council and they increased it to four hours, and one stays till 12:30, so it works quite well, and they are talking to me about what they will do once the bad weather comes because what they do now is basically walk him, but they will have to plan other things if the weather won't let them walk, so talking to me about what is possible to do so that's good"* (Nancy: Interview 18)

Although, there are services that provided ongoing education and monitoring to better manage certain conditions in the community, access to these services was patchy, sometimes only after clients had already been admitted for a potentially avoidable exacerbation of their symptoms. There are some services designed to create more supportive task environments to promote independence, such as facilitating access to aids and equipment, and making home adaptions.

Participants, in their distinct roles as clients or carers, described varying degrees of involvement in formal decision-making about what and how issues and needs would be addressed. Noting that there can also be conflicts to be negotiated where carers are involved in the decision-making process. In some instances, care planning involves a *client-directed relationship*, where clients have control of making choices about their services (although these choices are limited by their eligibility, program guidelines and availability of aged care services, and in health by evidence-based practice that dictates how health issues by health professionals). This may exclude carer preferences where they conflict with the clients' right to self-determination. In *provider-directed relationships*, clients respond in various ways, including seeking to influence formal decision-making (i.e. *exit*, *voice*, *or circumvent*), or just deciding to either *passively comply* or to *not adhere* with the care plan. There were also situations where clients and carers were engaged in a *collaborative relationship* with providers that involves a shared decision-making process. This can also provide an opportunity to find solutions to barriers to clients and carers adhering with care planning, to achieve service objectives.

9.3 COOPERATION WITH FORMAL CARE

During direct interactions in the delivery of health care services in the community, health professionals perform clinical interventions as indicated to address health issues, such as giving injections or dressing wounds. In these situations, clients are required to cooperate with these formal interventions. However, as discussed in the following chapter, the vast majority of the work of addressing health issues in the community is performed by clients and their carers independent of professional providers. Meanwhile, social care often involves personal care that also requires client cooperation. However, the majority of care is provided informally by carers as detailed in Chapter Eleven.

It is worth noting that clients and carers make contributions during direct service delivery through cooperation with professional interventions to address health issues and needs for support. Carers described their ongoing caring role in advocating for clients and facilitating during in-patient care, to improve the quality or safety of their care in clinical settings. Carers often continued to support clients with some of their core personal care activities (i.e. as a communication aid, feeding the patient, etc.) when they were hospitalised or moved into residential care. Carers also described instances where they perform tasks to maintain the home and living environment while clients were in in-patient care and during periods of recovery and rehabilitation.

CONCLUSION

Clients and their carers described making contributions to inform formal assessments and care planning. As distinct actors, they also describe different ways they are engaged in these processes and

participated in decision-making about what and how their issues and needs were addressed. In sharing their experiences, participants concentrated on relational aspects of their interactions with professional providers, which influenced not only their satisfaction with the services, but fostering trust in formal advice. Participants tended to make their own judgements on the nature of the issue or need and may not agree with formal judgements. If they did not trust or agree with professional providers' diagnosis or care plans, they sometimes found alternative ways to influence formal care planning. There is increased complexity involving carers in decision about care services such as negotiating conflicts between different actors. The level of collaboration in shared decision-making provides an opportunity to address barriers to increase clients' and carers' willingness and ability to contribute to achieving service objectives (i.e. performing the work of addressing clients' issues and needs outside direct service interactions). However, other factors influence the propensity to co-produce are explored further in the following chapters.

CHAPTER 10

Independent Contributions to Address Health Issues

INTRODUCTION

Clients with complex needs make significant contributions to addressing their health issues in the community, outside direct consultations with professional providers. Clients, often with support from carers, perform activities and behaviours to prevent, treat or manage illness, injury and disease. These tasks are dictated by clients' specific health issues, but also reflect their perspectives on the nature of contributions they perform to improve their health and wellbeing. In describing their contributions to these tasks, participants in their roles as clients and carers reveal not only their co-productive efforts to achieve service objectives, but insights on what influences their propensity to co-produce.

10.1. ACTIVITIES AND BEHAVIOURS TO ADDRESS HEALTH ISSUES

Older people with complex needs who have multiple health issues performed most of these interventions for each of their chronic and often progressive conditions on an ongoing basis, as well as having acute exacerbations of chronic conditions that involved additional short-term interventions. Study participants described spending a significant amount of time and other resources performing these tasks often on a day-to-day basis (in addition to contributions to accessing services in the ongoing management of their conditions, as described in Chapter Eight). These tasks included adopting general health promoting *behaviours* including healthy eating, physical activity, and smoking cessation, as well as keeping socially and mentally active. Clients also perform *activities* to treat or manage specific conditions, including: medication management, physical therapy, specialised nutrition, mental health and cognitive activities, and skin care and wound management.

Tasks performed independently by clients to address their health issues are inherently dependent on co-production as they involve clients' changing themselves (i.e. by behaving or acting in ways that influence their health outcomes). Care in the community is dependent on clients making these contributions and performing these tasks to achieve service objectives of managing their health in the community. However, these tasks often involve other elements that can be performed by others to make it easier for clients to perform these behaviours and activities. Tasks performed by clients to address health issues exhibit characteristics that have implications for co-production, where they intersect with variations in people's propensity to independently contribute to addressing health issues (see Table 10.1).

Table 10.1

Key task characteristics and implications for client co-production

Characteristic	Description	Implications
Specialisation	Tasks that require specialised knowledge and skills	Clients require expertise to effectively and safely perform the task
Specification	Tasks require re-specification in response to changing circumstances	Clients require the expertise and capacity to independently make judgments to re-specify tasks as conditions change
Resources	Tasks involve material, environmental or human resources	Client require access to resources to perform the task (which may include enlisting support from other formal and informal actors)
Motivators	Incentives for clients to perform the task	Clients' willingness to perform the task (e.g. the prominence, urgency or severity of the issue, or tasks that provide multiple incentives)

These characteristics have implications for clients' willingness and ability to feasibly and effectively perform tasks to improve their health outcomes and manage their care in the community. Tasks may require clients to have specialised information or training to be performed effectively. There are pre-specified tasks that can be performed routinely, and others that require specification (i.e. learning how to perform specific exercises for effective physical therapy). Tasks that involve specification require clients to have the knowledge and capacity to adapt tasks according to specific circumstances that influence the quality and safety of the intervention (i.e. titrating medications such as insulin based on blood sugar levels to manage the condition and prevent hyper or hypoglycaemic emergencies). There are also tasks that involve material resources or consumables required to perform the task, or specialised equipment. Some tasks may also require human resources (i.e. social or emotional care activities). Tasks also vary in the motivations they provide to clients. For example, tasks that address salient issues such as providing immediate relief from symptoms provide different incentives than changing behaviours to potential prevent conditions from occurring (where the benefit or efficacy of the tasks in not directly evident). There are also tasks that provide additional incentives as they serve more than one purpose, such as group exercise that provides both physical activity and social interactions, which provides additional motivation for clients to perform the task. Just as tasks have varying characteristics that influence co-production, clients also vary in their propensity to perform these tasks.

Whether clients can perform these tasks independently is in part influenced by the care planning process, to the extent that this process involves identifying and addressing barriers: including increasing client's ability to perform the task independently (*enabling*); changing the design of the tasks to make it more feasible for clients to perform necessary behaviours or activities (*relieving*);

providing motivation to align purposes (*motivating*); facilitating access to material resources required (*equipping*) and coordinate with other actors required to perform the task (*coordination*), as discussed in Chapter Nine.

The following are illustrative examples of the lived experiences of older people with complex needs and their carers addressing health issues after and between direct service interactions. The different types of tasks are discussed in relation to the intersections between task characteristics, client propensity and the mitigating role of carers.

Exercise and physical therapy

Exercise and physical therapy were commonly raised by clients as contributions they make to improve their health outcomes. This included general exercise, such as walking, going to the gym and playing sports, to increase their level of physical activity to promote health; and more specialised physical therapy to treat or manage specific health issues, for example, balance exercises aimed at strengthening specific muscles to prevent falls. This is the case for Enid, who had a hip-replacement and was advised to do specific exercises during post-operative rehabilitation.

> *"I do every day. I don't really need it as far as movement and walking goes, because I'm one of those people who has got to be constantly do, physically doing, not just sitting - you can't be as efficient as you used to be, but you've just got to slowly adjust yourself to your situation"* (Enid: Interview 29)

However, there are situations where clients face barriers to completing such activities, that relates to their *ability* and *willingness* to comply. For example, Bob described why he does not perform exercises prescribed by the physiotherapist.

> *"Sometimes I have to ask, I can't see the sense in this, and they have to explain it to me, and I come out, still not fully satisfied. When you're at home they give you a little booklet with little exercises in it. I thought to myself, well I'm doing enough exercise, even when I walk down these steps"* (Bob: Interview 12)

Meanwhile, Margery, who has advanced lung disease and is reliant on oxygen therapy, described difficulty owing to her *functional capacity*.

> *"I'm supposed to exercise, but it is very hard to exercise - well apart from the lungs, I mean I can go walking, I've got a crook knee, I've had both hips replaced, and they had to replace this one twice, and when they replaced this a second time, they broke my femur, so that had*

to put a plate and screws in that went passed the knee, so it hurts when I walk" (Margery: Interview 26)

Clients provided examples of ways that carers *facilitated* them to exercise or perform physical therapy, including activities involved in creating a supportive environment as discussed in further detail in Chapter Eleven. For example, Nina facilitates her husband Timothy who was diagnosed with a neuro-degenerative condition:

> *"They have always said to step up his activity to keep him active, and at that stage he used to drive himself to the gym and do some workouts and things, nothing intense, sit on the bike machine sort of thing, and then now the situation we are in, I have to go and take him"* (Nina: Interview 22)

In some situations, carers had attended consultations with professional providers, to learn the specialised exercises so that they could *direct* clients or perform the exercises with clients to facilitate them to comply. As illustrated by Patrick,

> *"Irma used to do a gym work out with me together until she fell and broke her hip, and of course, went for a hip replacement, since that time she has stopped going to the gym. Then we went to a movement disorder clinic, that does exercises more on falls management for balance. I go with her, I'm always present with her, although it is once a week, daily I do the exercise that are supposed to be done. I spend with her 5 to 10 minutes doing all those exercise with her"* (Patrick: Interview 21)

Although the vast majority of tasks required clients to actively contribute to behaviours or activities to the tasks, there were a few instances where carers performed tasks for clients. For example, Harold's wife Joan was taught by the specialist how to use a machine to stimulate his muscles and massaged as part of rehabilitation therapy after his operation.

> *"He has to do a bit of physio before he gets out of bed. So, I put on a Transcutaneous Electrical Nerve Stimulation (TENS) machine to stimulate the muscles, which he could do but it takes him so long. I don't do it every morning, some mornings I just massage the muscle"* (Joan: Interview 14)

There are also situations where physical activities were performed with others, providing social interactions as an *added incentive*. This was the case with Henry who described attending a group gym class.

> *"I like going to the gym because it's a good group, there are about 40 of us, we go to the group exercise and then we sit down and have a cup of tea, I enjoy that"* (Henry: Interview 20)

Meanwhile, as previously illustrated in the case of Shirley, she found an alternative way to *motivate* herself to increase her physical activity after being diagnosed with diabetes.

> *"My daughter was doing a paper round, and she said, "mum, you can do this", and I said, "right I will", so I walked for 2 hours on a Wednesday, 2 hours on a Thursday, I did other walking as well, I did that for three years since I lived out here, that is how I am as healthy as I am now, because I can walk quite quickly when I have got a reason to do something"* (Shirley: Interview 32)

As illustrated above, participants provided examples of performing exercises and physical therapy. Depending on the circumstance, clients were facilitated by carers such as *encouraging*, *directing*, *supervising*, *facilitating access to resources or equipment*, *and performing exercises with the clients to provide guidance or solidarity*.

Diet and nutrition

Participants often described changing their diet and nutrition intake to address health issues. For example, Dorothy described adapting her diet to consume less sugar, as advised by her doctor.

> *"The doctors will tell me, because of this thing I have got this autoimmune disease disorder, sugar believe it or not helps it going worse, that is where I can get into a lot of trouble, so I've just got to watch what I eat"* (Dorothy: Interview 28)

There were instances where some clients are supported by carers to change their diet or adapt their food and fluid intake as their condition required. For example, Harold was advised by his urologist to drink 2 litres of water. His wife, Joan, facilitates Harold's in performing this task:

> *"Harold was having a lot of trouble and he used to have to pass sediment and I had to measure the sediment, I have to keep an eye that he goes to the toilet regularly, I have to make sure he drinks enough water, 2 litres a day, it's babying him along, but I try to do it in an unobtrusive way"* (Joan: Interview 14)

Carers may be precluded from supporting clients who resistant to accepting help, although participants provided examples of innovative solutions they had devised overcome these barriers. For instance, Gemma found ways to improve her father-in-law, Don's nutrition by improving access to

healthy food. As with Joan, Gemma had to do this in an unobtrusive or discreet way so as not undermine Don's independence.

> *"Don is 83, he's got diabetes really bad, he doesn't care for himself very well, and you cannot even try to make him a cup of coffee because of his independence. He didn't even have teeth in his head for a long time, he would say, it costs too much. He wasn't cooking for himself because he couldn't eat properly so we worked out a way to make him think he was helping out by giving him food. I would just say, oh I ordered too much, and I can't fit it in my freezer, because if I said, "oh I'll help you out and give you some food", he would be offended"* (Gemma: Interview 26)

There were instances where clients and carers are required to *specify* tasks by changing their diet and fluid intake depending on their changing signs and symptoms as part of managing their conditions. Gregory, in caring for his wife Edwina, described managing her medication and dietary intake to manage her incontinence issue and try to ensure she has adequate and appropriate nutrition.

Clients and carers had varying levels of professional support to increase their expertise in managing conditions, often after a crisis. For example, as noted in the previous chapter, it was only after Pat was hospitalised with malnutrition and kidney failure, that services were accessed to inform Henry, her husband and primary carer, on how to ensure Pat has adequate nutrition and fluid intake.

> *"She started losing her appetite. She weighed about 60, but she got that bad that in March she got down to 42 kilos, and she just couldn't support herself, she kept falling, not falling, collapsing, so she finished up having to go to emergency department at the hospital - since then we have seen a dietician and doctors and health care workers"* (Henry: Interview 20)

Some participants accessed professional services such as subsidised prepared meals (e.g. Meals on Wheels) that tailor food and fluid intake based on their health issues. These services relieve clients of the need to have *specialised* knowledge to make dietary change to address their health issues. This was the case with Sam and Martha,

> *"It's only been under 12 months and he has reduced my diabetic medication because I don't need as much, it means that I stick to Meals on Wheels, although they don't supply breakfast, there is rolled oats there. There was a check by as to your health condition and what your requirements are before you start getting meals - Martha doesn't get soup because she is on a liquid restriction"* (Sam: Interview 19)

However, these services are dependent on clients consuming meals as provided, not eating additional foods that are not compliant with the prescribed diet and are not tailored to address acute changes in condition. There may be a gap between, assistance provided by the services, and the clients' need for support to perform the task.

Participants described changing diet to improve their health outcomes, in some cases, adjusting their nutritional intake to manage their conditions or symptoms, with varying support from carers. Carers also provide support to facilitate clients to change their diet and nutrition, as discussed in the following chapter, such as assistance with feeding or shopping and preparing meals.

Medication management

Clients described taking medications as part of addressing their health issues including access and taking medications as prescribed. There were medications that were taken *routinely*, and others taken in response to changing signs and symptoms, and often required *specification* through titrating the dose with other medications and dietary intake. In these cases, clients required *specialised* knowledge to determine how and when to use medication in the daily management of their conditions. For example, Rose has had rheumatoid arthritis since her early 30s and has had to learn a lot about the different medications over the years.

> *"I take about four every night, four tablets, then there is another one that I take on Friday, but before that I have to take two tablets, one before, and one the day after, to not get any nasty things in my stomach, like ulcers or things like that, and then I have got morphine patches that release every hour, so it's a lot. You get used to it through the years"* (Rose: Interview 25)

In some cases, clients faced practical barriers to managing their medications such as obtaining medication as a material *resource* required for the task. For example, Teresa takes strong pain killers for back pain but obtaining these medications was at times difficult.

> *"I have to ring Friday morning to see if they can get me in, otherwise I have got no pain killers left, so it's very hard - you feel like everything is crowding on you, especially when you have to rely on other people to take you to appointments and other things, it is very hard"* (Teresa: Interview 27)

Clients who faced barriers to managing their medications, may be supported by carers, such as prompting, reminding, supervising or directing them to *motivate* and *enable* them to manage their own medication or *relieving/equipping* them by performing parts of the task for them, such as collecting prescriptions or organising medications into dosette boxes to simplify the task. For

example, Moraine keeps her prescriptions at the local chemist, so her daughter can pick up her medications on her behalf (Interview 30). While, in Joseph's case, his son Gary simplified the task of taking his antibiotics by putting them in a dosette box (Interview 2).

There are also situations where carers facilitate clients' medication management by making decisions about when medications are needed, drawing on *experiential knowledge* from previous responses or the client's current condition and their *expertise* or specialised knowledge of medications. For example, Cath cares for her husband Jim and has learned how to manage his incontinence over time, learning about medications and how he responds to different combinations of medications and diet.

> *"He had a lot of trouble with bowel blockages. He was in and out of hospital a bit like two or three years ago till we learned how to manage it with a certain tablets and certain amount of fiber he takes. Before that he would get a bowel blockage, and we would manage it at home but after 24 hours you have to get him in because he hasn't taken any meds and he is so dehydrated"* (Cath: Interview 24)

Some participants accessed professional services to *facilitate* with their medication management such as employing the pharmacy to prepare their medications in a dosette box called "Webster Pak", that can be delivered weekly at an extra cost, as described by Robert:

> *"We have our tablets provided by the local pharmacist who has them all set out so that we take them in these capsules and hopefully one of us will remember for her to take them"* (Robert: Interview 15)

Although, these services *relieve* clients from performing parts of the tasks, clients are still required to remember and comply with taking their medications, and may take additional tablets that are not required routinely. This also illustrates gaps between support by formal services and clients' need for support, where clients require reminding or prompting from others to take medication or to determine which and when to take additional medications.

Social, mental and cognitive health activities

In describing their daily routines and caring for themselves and others, many people interviewed described performing cognitive activities and keeping socially and mentally active. In some instances, carers encouraged and *facilitated* clients with these activities. For example, Patrick, who is a carer for his wife Irma, stated that:

> *"I'm very conscious in her case, and in my case, to be mentally, socially, and physically active, that has helped a lot, and I think this has in fact, not only helped her, but helped me"* (Patrick: Interview 21)

In keeping his mind active, Patrick facilitates a weekly study group and includes Irma in this activity. Patrick also encourages Irma to play computer games that are both mentally stimulating but also involve fine motor skills thus doubling as a physical therapy. Nina, like Patrick, also explicitly referred to her role in keeping her husband mentally as well as physically active.

> *"I know that all he needs to do is to be kept active, mentally and physically. He does brain HQ which is a game on the computer, we try and do Sudoku as well, and he's got a diary for himself, to write what he is going to do for himself tomorrow, today, because his daughter in London wants to know what Dad's doing on a day to day basis. Other mental activities he has, he talks to his daughter because he needs to talk, and we have friends coming and going as well"* (Nina: Interview 22)

Some participants described instituting routines with family or friends to check in on each other, providing both social interaction and emotional support, and importantly for those living alone, a form of external observation and monitoring. Edith was widowed many years ago and lives alone.

> *"My son lives in another suburb see, they come out, but they are not near to me, and I haven't got any neighbours. I had Leon over the road, he was a lovely friend, but he committed suicide. Mostly I think they rent that places, they come and go. Most of my friends have passed away, but I seem to battle on, I have to. I've got a younger brother, he lives interstate, but we ring one another, I ring him on a Wednesday afternoon, and he rings me Sunday"* (Edith: Interview 31)

In the past, Edith would walk to town but was recently knocked down and robbed on the street so no-longer felt safe to walk alone so she started staying home more. Edith said she is not lonely, just depressed sometimes, but finds solace in her garden. As Edith continued to share her story, she confided, if I just had one nice friend who would "pop in" (Interview 31). Kelly also described feeling isolated.

> *"Nobody has time for you these days. You know, I had a friend down the road that I had for 50 odd years that we've been here but now she's got dementia. When you get older, you're left with nobody, I think. People come and go. I think these days everybody is too busy with their own lives. And I don't get outside a lot so that's another thing"* (Kelly: Interview 4)

Some participants accessed formal services organised by local councils, NGOs and religious organisations. As was the case for Moraine. Since her youngest son moved out, she started going to seniors' clubs several times a week for a social interaction (Interview 30). There were some participants who volunteered, such as Joyce, who would go with others from the church to visit elderly people (Interview 3). Some participants, like Joseph (Interview 2) and Enid (Interview 29), found companionship from their pets.

Skin care and wound management

Some participants described skin care and wound management as part of addressing health issues and improving their health outcomes. In some instances, carers facilitated clients with these tasks or performed these tasks for clients on their behalf. For example, Joan described keeping her husband Larry's legs moisturised to prevent skin tears or ulcers. Joan was a nurse, and said she is very conscious of maintaining Larry's skin integrity to prevent wounds and infections.

> *"It is important to moisturise the skin, because he has got dry skin because as you get older it's the ulcers that was what I was always terrified of, so every morning when he has his shower I slather it on from head to toe, ears the lot, and then when he goes to bed at night I just rub his legs, his arms, I suppose some people don't bother because they don't know, but I suppose having worked as a nurse you try to keep that up"* (Joan: Interview 14)

Cigarette smoking cessation and substance use

Two of the participants, Joseph (Interview 2) and Margery (Interview 26), included giving up smoking as actions they had taken to improve their health outcomes, both after having hospitalisations related to cigarette smoking. These tasks involve changing addictive behaviours, which influences the types of motivations and support clients may require. For example, Joseph described giving up cigarette smoking, including being held to account by his son Garry:

> *"I decided, I'm not smoking anymore. I took the ash trays out that were on that table or wherever and put them away, so they are out of sight and out of mind. I haven't even got any in my pocket, but I was eating mints and now even that is disappearing. I'm not sucking on those mint lollies all day everyday either and I don't even think about having a smoke now. At night I have a beer and I would like to have a smoke, but I know I can't. I said to Garry, if I want to smoke I've got some cigarettes at home, and he said, yeah I know, you have two packets in the cupboard and there is 14 in one packet and 17 in the other packet, and each time I come over I'm going to count them to make sure you have not snuck one. Well I haven't and I feel a lot better, and this morning I walked up the street, not running*

but walking quite well for what I was, and I thought to myself when I got up by the lights I feel much better now, I'm glad I gave up them cigarettes" (Joseph: Interview 2)

It is possible that drugs, alcohol and smoking cessation were not raised by other participants as they did not arise in this sample or given perceptions of stigma.

10.2 FACTORS INFLUENCING CLIENT PROPENSITY TO CO-PRODUCE

This research identified four critical factors that influence clients' propensity to coproduce. Whether clients perform activities to address their health issues is contingent on clients' *expertise*, *functional capacity*, *resources* and *willingness*. These factors are shaped by the people's broader social, economic, geographic and environmental circumstances. For example, people living in rural areas have greater challenges accessing services. Whether clients co-produce is determined by having the requisite *expertise* or specialised knowledge and skills to perform the tasks. Clients also require the *functional capacity* including both physical and cognitive ability to perform the task. Depending on the type of task, clients may also require material (i.e. consumables or equipment) or human *resources* to increase clients' ability to feasibly perform the task. In addition, other factors may influence their *willingness* to co-produce. In telling their stories, most participants described barriers in relation to their expertise, functional capacity and resources, rather than a lack of willingness or motivation to contribute. However, there were recurring themes in the interview data that influenced whether older people with complex needs were willing to make contributions to their care. Maintaining their autonomy and independence was a common thread across the interviews. Sam, who cares for his wife, Martha who has dementia stated that:

> *"To me the carer is one that looks after their partner, safety wise, food wise, whatever around the house, but they are independent, you make sure the independency is working the right way and not counteracting. If you are a minder, you are crucifying the particular person because you are undermining them and decrying them that little bit of independence they have, and they become completely dependent on you, and that is no life for anybody"* (Sam: Interview 19)

In some cases, clients were influenced by having people in their social networks perform a supervisory or monitoring role, holding them to account. Having a carer present can provide enablement and relief by reminding, directing and simplifying tasks. The presence of a carer can also provide motivation by holding clients to account for their actions through supervision and monitoring. There was also value derived from activities performed with others from the social benefit. Joan described caring for her husband, but also noted that they supported each other.

I have to keep an eye that he goes to the toilet regularly, I have to make sure he drinks enough water, 2 litres a day, it's babying him along, but I try to do it in an unobtrusive way, look hey, we are both the same age, that is it, support, a crutch for one, a crutch for the other. When we used to do the shopping, he used to bring the shopping in, I carry the shopping in now, and he puts it away, it is reversed roles" (Joan: Interview 14)

However, clients vary in their willingness to ask for or accept support from others, which can also influence their propensity to co-produce.

The willingness of clients to co-produce is not only motivated by self-interest. Participants in the study were often both clients and carers, as in the case of older spouses that care for each other in various ways. There were often situations where these participants, were forced to choose between their caring responsibilities and addressing their own health issues. Often, those responsible for caring for others neglected their own health issues, although, there were a few participants who were motivated to address their issues to ensure they can maintain their health in order to continue in their caring role.

Adding to the complexity, these factors are not constant, they are dynamic and inter-related. For instance, clients' propensity may increase as they learn how to manage their conditions, however, changing in the health or access to resources may decrease their propensity to co-produce. This may happen gradually over time or rapidly. In addition, to the above factors, clients' *adaptability to* changing circumstances is also critical to clients' propensity over time.

10.3 CARERS' ROLE IN FACILITATING CLIENT CO-PRODUCTION

Clients with complex needs are often supported by carers to overcome barriers for clients to co-produce and bridge gaps in the formal service system.

Table 10.2

Carer contributions to facilitating client co-production

Carer Role	Description
Enable	Increase clients' ability to perform the task
Relieve	Increase the feasibility of clients by performing substitutionary parts of the task on the clients' behalf
Equip	Provide access to resources required to perform the task
Motivate	Influence clients' willingness the clients to perform the task
Coordinate	Manage inter-dependencies with other actors and adapt to changing circumstances

As detailed in Table 10.2, carers may increase clients' ability by enabling clients to perform tasks such as instructing or directing them in how to perform the task. They may also relieve clients by contributing efforts that make it more feasible for clients to perform dependent behaviours or activities or perform tasks on the clients' behalf as discussed in the following chapter on carer contributions to addressing clients' needs for support. Carers may also equip clients by facilitating access to resources necessary to feasibly perform the tasks (i.e. consumables of equipment). In addition, carers may influence clients' willingness to perform tasks including supervising and holding clients to account. Clients are reliant on carers to act as third parties to facilitate them to address their health issues independently of the service provider. There are also barriers that can only be addressed by carers due to their social relationship and geographic proximity to the clients, as well as the flexibility of their informal role. However, carers also vary in their motivations and capacity to co-produce. Their role is defined by their relationship to the client, which dictates the nature of care tasks they are likely to provide, and that the client is likely to accept.

CONCLUSION

Older people with complex needs make significant contributions to tasks involving their health issues in the community, outside direct service interactions. The types of tasks clients perform are dictated by their health issues, which in turn impact on their ability to make these contributions. Various characteristics of these tasks have implications for co-production where they intersect with variations in people's propensity to independently co-produce better health outcomes. In addition, clients vary in their propensity to co-produce based on their expertise, functional capacity, resources and willingness to perform these tasks. Carers often support clients by enabling, relieving, equipping and motivating clients to co-produce, as well as coordinating their care over time as circumstances change. Carers, in addition to facilitating clients to make contributions to addressing their health issues, also often provide assistance with performing personal care activities and maintaining a supportive environment, as discussed in further detail in Chapter Eleven.

CHAPTER 11

Independent Contributions to Address Clients' Needs for Support

INTRODUCTION

People in the clients' social network acting as informal care providers or *'carers'*, make independent contributions to address clients' needs for support to maintain living in the community (in addition to facilitating clients to contribute to addressing their health issues as detailed in Chapter Ten). These contributions include supporting clients with functional decline to perform *personal care activities* and *maintaining a supportive environment* for clients to address their health issues in the community. This study found that the delivery of care in the community for older people with complex needs is often reliant on informal care to ensure their issues and needs are addressed. However, there are variations in clients' access to informal support and carers propensity to provide care. This chapter details the types of support people in the clients' social network are likely to make to maintain clients' living in the community, and what influences these processes.

11.1 SUPPORTING CLIENTS WITH PERSONAL CARE ACTIVITIES

Clients with functional decline are often reliant on carers to provide support with performing personal care activities including: mobility; bathing, dressing and grooming; toileting: feeding; communication and managing challenging behaviours. These tasks have various characteristics that have implications for who in the clients' social network is likely to perform the tasks, and the potential implications on the quality and safety of the client and carer (See Table 11.1).

Table 11.1

Key characteristics of tasks to assist clients with personal care activities

Characteristic	Description	Implications
Constancy	Tasks that involve providing assistance unpredictably and urgently	Clients require carers to be in close physical proximity on a continual basis, usually a primary carer who resides with the clients (i.e. spouse, child)
Intimacy	Tasks that involve activities that are usually performed privately by clients	Likely to be performed by carers with an intimate social relationship with the client
Specialisation	Tasks that require specialised knowledge or skills	Carers require expertise to effectively and safely perform the task.
Manual handling	Tasks that involve activities requiring the use of force to move the client	Carers at risk of physical injury if they lack the requisite skills and equipment to perform the task safely

Resources	Resources required from carers to perform the task, in addition to time and effort	Carers required to have access to material resources, (i.e. consumables or equipment)

Depending on the clients' functional capacity, they may require carers to be in *constant* close physical proximity to respond to urgent and unpredictable needs, in contrast to tasks that can be pre-scheduled and required intermittently. People with these types of needs require carers that co-reside with the client, which tends to be a spouse or child acting as a primary carer. There are care needs that involve *intimate* tasks that tend to dictate who performs these tasks based on the social relationship to the clients (i.e. spouses, female relatives). There are tasks that may be considered self-evident but require *specialised* knowledge or skills to be performed effectively to ensure the quality and safety of the client's care (for example skills in performing tasks to prevent falls, pressure sores, infections, etc). In addition, tasks that involve *manual handing* require carers to have the functional capacity and skills to perform these tasks without causing physical injury to themselves. Tasks also vary in the *resources* they require carers to contribute, including materials and equipment, in addition to the extent of time and effort required to perform the tasks. These characteristics influence who in the clients' social network may perform the tasks to support clients with their core personal care activities, and the potential consequences for the clients and carers.

The following are illustrative examples of various contributions of carers to assist clients with core personal care activities. Drawing on clients and carers lived experiences, this provides insights into the complex interplay between the nature of tasks to address clients need for support, the service system, and role of carers in facilitating clients to perform their personal care activities. It also illustrates the tensions or conflicts that can arise where carers, and the people they care for have differing perspectives or preferences.

Mobility

Clients with functional decline that affects their mobility can require assistance ambulating. Depending on the clients' need for support this may include carers *influencing and enabling them to mobilise independently*. In which case, carers can assist clients to obtain and use assistive devices or aids and adapt their living environment to increase their ability to mobilise independently and decrease the risk of falls. Although, carers were often met with resistance from clients about the use of assistive devices. For example, Boyd has an intellectual disability and lives alone. His sister who lives an hour away has been his primary carer since their parents passed away 12 years ago. She encourages and holds Boyd to account for using a walking frame or "walker".

> *"I didn't want to get the walker, my sister made me because I was on a walking stick, and she said, if you fall over and do your hip and end up in the hospital or something, so that's mainly why I got that"* (Boyd: Interview 34)

In caring for people at high risk of falls, carers often *supervise* or accompany clients while they ambulate to encourage or prompt them or provide physical assistance where necessary. In these cases, carers need to be in *close physical proximity*, and their role involves *constancy and vigilance*. As in the case of Dorothy, she was reliant on support from her husband Thomas when mobilising.

> *"Thomas is with me all the time because I have got to have somebody, because with the walking stick after walking for a little while, I start get the shakes a little bit, I get a little bit unsteady. I've got my walker there, but he has got to be there with me just in case I happen to overbalance"* (Dorothy: Interview 28)

Participants who did not have private health insurance often described periods of disability due to waiting lists for elective surgeries, which influenced their mobility. Dorothy described waiting to have her hip replaced.

> *"It hurts. Not so much with the one that have been done. Occasionally I'll get a twinge of pain, when I put too much pressure on it to save my left hip, it's the left hip that I can really notice now, since I've had the right one done. I've got six to nine months wait to have that one done. Especially at this time of year so we've just got to wait"* (Dorothy: Interview 28)

Like Thomas, Nina accompanies her husband Timothy when he is ambulating to provide supervision and remind him to use strategies to prevent falling.

> *"I do everything in terms of supporting and supervising him. I can't leave him alone because his condition is that he can fall if he doesn't do the right things and sometimes, he forgets. He can't be left alone. It is terribly difficult, because if he needs to go to the toilet, I have to walk with him, make sure he is doing the right thing and remind him, back to the wall when you are pulling up your pants, that sort of thing, just supervise him. So, I can only rest if he is sitting somewhere, otherwise I can't leave him and go away without knowing where he is, so it is quite difficult"* (Nina: Interview 22)

Carers support clients to overcome declines in their functional capacity to perform tasks independently. However, there were instances where carers provided assistance or performed part of tasks on clients' behalf, despite the client having the functional capacity to perform the task, to

improve the effectiveness or efficiency of the task. For example, Robert would wheel his wife to the bathroom as it was quicker.

> *"Well, she (Marie) finds it very difficult to get her out of bed, so I get her out of bed, which is getting her legs off the side of the bed and then getting her up to a sitting position and then a standing position, and walk her around to the walker which is at the end of the bed, and then it is quicker if I get her to sit on it and then wheel her into the bathroom"* (Robert: Interview 15)

Some carers raised challenges or tensions in relation to providing assistance that was seen to affect the clients' sense of *independence or autonomy*. As described by Joan, in caring for her husband Harold.

> *"You have to be careful not to take his independence away, not to let him feel he is not wanted anymore, I mean there is lots of things he can do, it is just with his day to day things, going down the steps, and I say to him, be careful. We have got rails everywhere, and he says, I'm alright, and I must be careful not to say, I'll come and help you, I've got to be very careful in that sort of aspect, that I don't take it away from him"* (Joan: Interview 14)

In some cases, carers were restricted by the type of assistance clients will accept. Clients' resistance to certain types of support impacts the carers role. As described by Elizabeth in caring for her husband Barry. As his Multiple Sclerosis (MS) progressed, Barry became disabled except for the use of his right arm. Elizabeth described having to find money to buy a hoist to go over the bed, so she could physically transfer him from the bed to chair. However, Barry did not want to be hoisted and would resist.

> *"Barry rejected everything, any aids he didn't want, he didn't want a walking stick, it was a cripple stick, and he hated the hoist, he would fight me on the hoist, a wheelchair, he didn't want a wheel chair"* (Elizabeth: Interview 17)

Carers of clients with severely limited mobility provide *manual assistance* to support them to mobilise. In some cases, carers require equipment such as a lifting machine to facilitate them to transfer clients, prevent injuring themselves. Carers were also required to learn techniques to mobilise the client and prevent health issues occurring as a result of decreased mobility, such as preventing pressure sores. Clients with mobility issues require continuing assistance with mobility from carers, between support provided by professional providers through intermittent formal services, in order to maintain independence living in the community.

Bathing, grooming and dressing

Clients with functional decline may require assistance with their personal hygiene including bathing and grooming (e.g. brushing hair and teeth, shaving, cutting nails etc), and dressing. As described by Joan:

> *"Harold gets up and goes to the toilet, then he has his shower, but I have to help him in the shower, help him shower, dry him, and there are parts he can dry himself like his back, and things like that, but his legs, he can't get down, right down like he used to, right down in between his toes, because you have to be so careful of ulcers and things like that and then I help him get dressed, then if we are going out, I put his shoes on, help him get ready generally"* (Joan: Interview 14)

Depending on their level of functional capacity, clients may be supported to perform tasks independently with the use of assistive devices or making adaptions to their environment, or require prompting or supervision from carers, while others require more physical assistance. Elizabeth described caring for her husband, who required high levels of assistance.

> *"Eventually he got a ceiling hoist, it was a help, but you've still got to manipulate the patient you know, he would be on the bed and he was, he was not able to help me at all and being right handed I constantly worked from one side of the bed to the other. I would get up at five thirty in morning and it took me over two hours to get him toileted and showered and everything"* (Elizabeth: Interview 17)

Clients may have access to formal services to provide assistance with bathing or showering in addition to formal services. However, there are other cases where carers chose as an *alternative* to formal services for convivence or due to *clients' preference* for carers to perform these *intimate* tasks, by someone they are not familiar with. As described by Joyce, in relation to caring for her mother:

> *"Mom was a very private person, if they'd sent one lady every time the same one it might not have been so bad, but it was three different ones, so I rang up and I said look don't send anyone else, I said, I'll shower her myself"* (Joyce: Interview 3)

Clients' choices about the nature of care they will accept from service providers, has implications for care required from carers, who through their ambiguous role may not have been included in decision-making processes, where service providers are bound by the clients' right to self-determination. There are also situations where carers provide support with personal hygiene, grooming and dressing *out of necessity* due to a lack of access to formal services.

Toileting

Clients in some cases required assistance with toileting including prompting but also use of the toilet, commode or urinal, and in some cases changing continence aids or associated hygiene. For example, Henry described his role in supporting his wife with toileting, from prompting her to helping with her related hygiene.

> *"She lost control of her bowels and she made some real messes in the hospital and when they cleaned her up it took three blokes to clean her up, but when they came home, she was still the same, and it's only me, there's not three people"* (Henry: Interview 20)

People who require assistance with toileting need someone to be in close proximity at all times given the urgency and frequency of their needs throughout the day and night.

Feeding

Clients who were unable to independently feed themselves or had with difficulty swallowing required assistance eating such as changing their positioning and physically feeding and assessing for signs of choking. Some clients were assisted with eating independently by having access to aids such as specialised cutlery and plates. For example, as Barry's MS progressed, he only had movement in his right arm. Elizabeth, his wife and carer, bought plates with a rim and specialised cutlery so he could feed himself (Interview 17). Although, as noted earlier Barry was resistant to using aids. In Edith's case, she assisted her husband with feeding and preventing him from aspirating by preparing specialised meals.

> *"I had to do everything really. I used to have to, because he couldn't swallow properly, I used to put all his meals into a vitamiser"* (Edith: Interview 31)

In maintaining clients with these issues to remain living independently, carers provided them with assistance to ensure they have adequate nutrition. In some cases, this involved carers performing supportive tasks other such as preparing specialised meals to assist with eating.

Managing sensory deficits and cognitive impairment

Clients with sensory deficits, such as hearing or vision loss, require assistance to overcome communication difficulties. In some cases, these deficits could be overcome with the use of assistive devices or aids and adapting the living environment. For example, Alice is legally blind, her husband designed their home to make it easier to overcome her visual impairment, and she has carers with her to help navigate her environment outside the house.

> *"My husband built this house, because my eye sight was going, and it has been wonderful because I can potter around, you see it is very simple for me to walk. Yesterday I was out with my son, he is very good, he will take me by the hand, and I will say, I'm not that helpless, just walk in front of me and watch where you put your feet, and I see him lifting his feet and I know I have to do that"* (Alice: Interview 6)

Clients with cognitive impairment may have difficulty with perception, memory, concentration and reasoning skills, and require assistance including specialised communication. As illustrated by Deidre, as she described caring for her husband with hearing and memory impairment.

> *"He is deaf, that is a big, big thing, and enormous problem, and very isolating, it is a horrible thing for anyone to have. I have learned to live with it, but we don't have long conversations. It is only when we are seated, and he is looking at me and I can speak directly to him, one-on-one that he will hear"* (Deidre: Interview 13)

When Deidre had to go for an operation, Harry did not want to go into respite, he preferred to stay at home. Deidre found ways to support him with his communication barriers while she was away.

> *"Harry wants to stay home, look I can understand it, I understand where he is coming from, but in a way, it would have been much easier for me, if he had gone to respite, you know it's organising him here. I brought an exercise book and I wrote a page up for every day and the times they were coming, the names, and he likes to know who is coming to shower him and that sort of thing. You have got to explain a lot, you know, his mind is not as good as it was"* (Deidre: Interview 13)

The use of respite was often raised as a source of tension between clients and carers, which can make it difficult for carers to address their own health issues where solutions cannot be negotiated.

Clients with cognitive impairment may also experience symptoms like wandering or "challenging behaviours"[6], such as agitation or aggression. Carers provided examples that are required to assist clients with wandering, decreased inhibition, and managing challenging behaviours, such as providing supervision, and learning their triggers and how to minimise these stressors. It is their social relationship and familiarity with the client that often dictates carers assuming responsibility for certain tasks over service providers. For example, Edith found that her husband with advanced dementia behaved differently with professional providers and in some cases decided to perform the task herself because he became agitated.

[6] Challenging behaviours is a term for maladaptive responses to unmet need that tend to manifest in agitation and aggression.

> *"He loved Rosa (the district nurse), but I don't know why, but he didn't like red headed people. They sent this red headed nurse here, he would not go, and she said, come on, and she got a bit pushy, Rosa never did that, and you know he went to hit her, and I said, leave him and I will try to wash him after"* (Edith: Interview 31)

Clients with cognitive impairment may require constant supervision, where carers need to be in close proximity, and need to find alternatives if they are not present with the clients to ensure their safety.

11.2 PERFORMING ACTIVITIES TO MAINTAIN A SUPPORTIVE ENVIRONMENT

For older people with complex needs to remain living independently in the community, they tended to require some level of assistance in maintaining a supportive environment. In some instances, people with the financial means also employed private services (not subsidised by the government). However, often clients were often reliant on support from carers to provide care not covered by the formal service system, to ensure their needs are addressed. These tasks may be routine, where carers make an ongoing commitment to supporting clients, as opposed to being happenstance. Participants described contributions made by people in clients' social networks, acting as carers, to enable them to maintain living independently in their homes including cleaning; meal preparation and shopping; gardening, and home adaptions and maintenance; transportation and shopping; financial and legal obligations; and caring for pets.

The following are illustrative examples of various contributions of carers to assist clients with maintaining a supportive environment. Drawing on clients and carers lived experiences, this provides insights into the distribution of tasks between the formal and informal providers, and who in the client's social network are likely to make various contributions.

Home cleaning

There are clients who require assistance with cleaning inside their home to maintain a hygienic living environment. Clients may have access to formal cleaning services through the social sector that cover some cleaning tasks. Those with the financial resources may be able to access private cleaning services as a substitute or in addition to publicly funded services. Despite whether they had access to formal services, clients with functional decline often required assistance from carers to also perform cleaning tasks not covered by professional services, as illustrated by Margery and her daughter Gemma.

> Margery: *"Well when Gemma came this morning, I said, how much time can you give me, I need my bed changed, I mean, I'm prepared to help, but I need help with it, and she'd rather do it all on her own."*

> Gemma: *"Things like that, in mum's case in particular, you know, that is a big exertion, I was unaware, I thought the home help she was getting recently was doing a lot more than they do, but it's not, mum with her health issue has real trouble and now can't get down to low levels and things so she gets the home help in to basically clean her toilet and shower."* (Margery and Gemma: Interview 26)

Meanwhile, Teresa described variations in the flexibility of providers in relation to the cleaning tasks they would provide.

> *"I've pulled a ligament in the arm, and I've got a crushed vertebra, so I am in pain. When they (professional provider) come because they are not allowed to lift anything, I have to lift the shower thing out, take it out. They are not allowed to lift, not allowed to bend, not allowed to go near your bed, not allowed to dust or move furniture, they are very strict on what they are allowed to do and what they are not allowed to do, and I, I know some of them will do a bit more than what they are supposed to do"* (Teresa: Interview 27)

Carers' support with home cleaning was often required in addition to tasks performed by public services.

Shopping and meal preparation

Supporting older people to remain living in the community in some cases included shopping and meal preparation, to ensure they have access to adequate and appropriate nutrition. For example, when Joseph was discharged from hospital, his sister-in-law provided meals during his recovery (Interview 2).

Some clients accessed formal services to provide meals. However, often carers prepared meals for clients in addition to these services or as a substitute. As described by Robert who cares for his wife Marie.

> *"Marie usually wakes between 5 and 6, and I take her to the toilet and return her to bed, and then make her a cup of tea with a biscuit, and then we go back to sleep and get up about 8am and I prepare breakfast for the two of us. We get meals on wheels delivered and you pay for them, I don't know if all meals on wheels are the same but ours are pretty strange, and so luckily we have a son and his wife who we have a dinner on a Thursday night, and Jody our daughter sometimes comes to that dinner or she'll come through the week and provide us with another meal"* (Robert: Interview 15)

Some clients were able to access professional services to facilitate them to go shopping where required. However, often carers facilitated clients to go shopping or did shopping on the client's behalf, in addition to formal services or as a substitute where these services were unavailable.

Transport

Older people with complex needs often required assistance with transportation. Issues of accessing transport was frequently raised as a barrier to addressing health issues and performing other tasks involved in maintaining a supportive environment. For example, Betty and her husband Noel live in regional town. Betty described issues she faces organising transport to attend specialist appointments three hours away in the city.

> *"I am in the situation now, Noel is 80, he can't drive to Melbourne and back in the one day, he did it for me in April and no, it is beyond him now, so I am stuck you know, I don't have transport options, the shire car will only take you to local appointments, and I'm thinking to myself, what the bloody hell do I do"* (Betty: Interview 23)

Some clients had access to subsidised taxi fares. However, most expressed difficulty accessing taxis for short distances, and gaps between the services that were provided and their needs. As described by Mae:

> *"I hate the taxi's they are too quick, you get in and they whiz off and you're not even in your seatbelt and things, and if they are putting all your groceries in as well, they seem to resent helping you even, you know, and you've got your walker, or used to have, and my husband would have a trolley, but they wouldn't take two, and then when it came to emptying out they would just empty them out onto the footpath, they wouldn't help you"* (Mae: Interview 10)

Although there are formal transport services, those eligible for these services also expressed with the availability or appropriateness of these services. Clients are often reliant on people in their social network, which creates uncertainty about whether they would be able to get transport support when they need it, as was the case for Teresa.

> *"Jay our grandson is 20, he takes me shopping on a Friday, he takes me shopping. So, Jay goes to the Navy on the 21st of August, so I don't know what I will do once that happens. You feel like everything is crowding on you, especially when you have to rely on other people to take you to appointment and other things, it is very hard. We don't have any services, we are not entitled to taxi tickets, we are not bad enough, you've got to be really bad to get them. My friend is blind in one eye, but because she has got nothing else wrong*

with her, she keeps getting knocked back, which is a bit sad really, because she is like us, she is dependent on someone picking her up, taking her shopping and all that sort of stuff" (Teresa: Interview 27)

Clients are often dependent on people in their social network for transportation. In some instances, clients do not access services or attend to other tasks due to a lack of transportation.

Gardening and home maintenance

In describing how they maintained living independently in the community, some clients described getting support from carers with gardening, taking out bins and maintenance and repairs of the house. For example, Joseph couldn't push the lawn mower anymore. Joseph said he couldn't access a public service to do gardening, so he started paying for a private service. Joseph's neighbours also provide support to help him maintain his garden.

> *"I can't cut the grass anymore, and when the leaves fall the guy who I pay to cut the grass, he won't mow over because there is too many of them, so I just let them all fall and then when the trees are bare, and they are all on the ground I get my neighbour Jim with his blower to come over. He comes over and blows all the leaves into piles, couple of people around the corner, they come with him with bags and take them home to put in the garden. Jim over the road over the last few years has been very good to me and he was cleaned the spouts, he'll come over and do it if I ask him, but I don't really like to ask him, because he has got his own job and his own life to lead, so I don't like to ask him to do things for me"* (Joseph: Interview 2)

Meanwhile, Dorothy was supported by her daughter to maintain her garden, however, now her daughter finds it difficult as she is on a waiting list for a hip replacement.

> *"Well my daughter will come down, a few months ago she came down and helped my husband cut back all my roses, or she will come down and give the house a good clean through and all that for me, but it's a bit hard for her at the moment because she needs a hip replacement as well, but she does it, she will pull herself around, and limp, but she'll come down and help me with it, whatever I need"* (Dorothy: Interview 28)

Bob is a widower and lives alone. He described the support from his neighbours to help him maintain his living environment.

> *"I went over to my neighbour Ben and said is there any way that I can have this sorted, and he got a mate of his who is a plumber who told him what to do and he came immediately*

and altered it, so that is how things are, and my other neighbour Arron, if I wanted anything done, he would come and do it. Ben, he will take the bins out and bring them in for me, as I say, I have got bloody good neighbours" (Bob: Interview 12)

Accessing aids and making home adaptions

Maintaining living in the community often involves adapting the home environment to make it easier for the clients to perform tasks independently. For example, Sam described how he had experienced the difficulties in helping neighbours who had become trapped in bathrooms, and how this encouraged him to renovate his bathroom to ensure easy access.

> *"The bathroom you are going to see here, it very similar to a hospital bathroom. That was done many moons before it was needed but I was capable of doing it. it struck me as the way to go, mainly because being a sparky (electrician) in the area, I had the steps and the ladders and so forth to rescue people, two on this street, a male was on the toilet and they couldn't get him out, he had had a heart attack, and what was her name, she collapsed in the shower, and of course, the shower door wasn't a sliding door, it moved inside, the body is in the way and all the rest of it"* (Sam: Interview 19)

Carers often provide support to logistically or financially acquire these resources. As described by Joan, as she prepared for her husband Harold to come home after being hospitalised with complications post-hip surgery.

> *"When Harold came home and he had a walker, I bought all the mechanical aids, I bought a 4 wheel walker, a Zimmer frame for in-doors, a toilet over thing, elbow crutches, we have got walking sticks everywhere, because I didn't know what the scenario was going to be, so to lift, he couldn't help me, by the time I got him in the car, he couldn't help me and I think it was just lifting the walker that was heavy"* (Joan: Interview 14)

Dorothy also described aids and home adaptions she has to facilitate her to maintain living independently.

> *"I yeah, well, we had to have a ramp, I had to have a ramp because I couldn't walk up and down the stairs. For two and a half years, I slept in the recliner because I couldn't get in and out of our bed, in the end, we had to get rid of our double bed, I've got a um, it's like a hospital bed, a special bed with a ROHO mattress on it and so I can get in and out of bed, so I can lift myself up and get out of bed, so there's all those types of things, and my husband put rails up in the toilet and different other places, although the shower, he can't put one there because it is not big enough. I had to buy a shower chair, I had to buy*

different things in the house, and then also with my feet, because I can't wear shoes I've had to go to buy, go to buy special shoes" (Dorothy: Interview 28)

There are costs associated with materials and equipment, and home adaptions required to provide care in their clients' home. As described by Gregory.

> *"While she was in hospital, we had the bathroom modified, because I was aware, if this was the condition, there was an oncoming need that we thought was a year or many, many months down the track, but after the fall, it was going to be necessary right now. There is a program, which you can get up to $10,000 if you wait at least 12 months and there is some other low, well supposedly low interest rate loan, but once you find out about it, it is about 1% higher than the deeming interest rate, or you can just do it yourself, which is what we did"* (Gregory: Interview 9)

Some clients have down-sized to decrease the amount of work required to maintain their home. In some cases, they had moved to retirement villages to down-size and increase access to private support services, and to have a more supportive environment to compensate for functional decline. Some people moved closer to people in their social network to increase their access to informal support. Moving locations had implications for clients' social networks and support, and often meant they had to access new services, also making it difficult to maintain continuity with the same provider, as experienced by Robert, who is a carer for his wife Marie.

> *"The children decided that it would be a good idea for us to come here because we lived in a nearby suburb and had lived there for 56 years since we were married, and it was getting difficult with, Marie because of her inability to walk unassisted, well I've been used to get up and looking after her through the night and so, it made it a bit easier here. We used to see the GP pretty regularly, because it was so convenient and at that stage we were on a part pension and so it didn't cost us anything and we had a very good working relationship with him for the last 40 or 50 years, and so now, we don't have such close medical attention because it is awkward the new GP"* (Robert: Interview 15)

Participants also described having their home assessed and adaptions made by professional providers. However, in some cases they had family or friends make adaptions to avoid costs associated with formal services.

Financial and legal obligations

Some participants also included financial and legal obligations in their descriptions of maintaining clients living in the community such as paying bills. Often there were shifts within households, as changing in one's capacity meant that carers needed to take on new additional roles, as described by Nancy.

> *"Things have changed quite a lot, like most women, or like most married couples, you separate all the various jobs that have to be done, so hubby does that garden and puts out the rubbish and you do the cooking and so on, and so we had very divided work situations and Peter (Nancy's husband) had always run all the finances for the family, very well to, so I've had, and it involved a self-managed super fund which he was doing himself, so I have had to learn very quickly to do all those things, there is a lot to learn"* (Nancy: Interview 18)

Clients sometimes relied on neighbours to help them perform tasks such as going to the bank and paying bills. As was the case with Henry, when he could not drive after an injury.

> *"I damaged my femur, my hamstring, I couldn't walk, I was on crutches, then I was on a walking stick, and I was trying to look after Pat, I couldn't get out and drive for 8 weeks, and the lady across the road, Joyce. She would come every day to see if we could manage, went to the bank for us, paid all the bills for us at the post office, and she would even come, for no reason, come and sit for an hour talking to us, she did a terrific job. Unfortunately, they are leaving, all the other neighbours say, if you want any help you know come and see us, the neighbours, all the neighbours around here are getting the same as me, there not in a position to help too many people"* (Henry: Interview 20)

However, participants did not tend to include their financial or legal obligations in describing how they maintain living in the community or in caring for others. This may be because participants in the study were able to do this independently and did not warrant mention, they did not consider these tasks as applying to the question or may have felt that these were private matters that should not be discussed in the forum of being interviewed.

Caring for pets

Caring for pets, whilst not technically requisite for maintaining living independently, was described by participants as part of support they received. As was the case with Enid, who was sometimes supported by her neighbours.

> *"I do have a couple, they live on the settlement near the end, lovely people, if I'm in dire straits, and they hear, they will come straight down and see if they can help, so I'm lucky in*

that respect. Just like the other day I wanted medication for the dogs, I wanted some food for the dogs, so I just rang the vet and they called in and picked up all the, things like that you know, or if I'm out of milk and they happen to be going into town, so that is really handy, that is really good" (Enid: interview 29)

In another example, while Joseph was in hospital, his neighbour Rose noticed he wasn't around so she came to feed and walk the dog while he was away.

"Rose said he is starting to smell, and I said, yeah, well I'll have to get someone to wash him, so off she went, she came back with this plastic bath thing and said, I'll wash him" (Joseph: Interview 2)

Participants described carers' contributions to performing activities to maintain a supportive environment to allow clients to maintain living independently in the community. These tasks are not reliant on client involvement, and can potentially be performed by clients, carers or formal care providers individually. These tasks tended to be performed by carers, where formal services were not accessible or affordable. The nature of the task seemed to influence the type of carers involved. Family members, tended to perform tasks inside the home such as cleaning or financial activities, while those with less intimate relationships such as neighbours and volunteers performed tasks outside the home. A broader range of actors were found to engage in activities outside the home, such as friends, neighbours and volunteers, possibly because these tasks are less intrusive. Neighbours often provided support during times of need, however, many participants described that the neighbours were also getting elderly or moved away, and they did not have the relationships with their neighbours and sense of community they once had.

11.3 FACTORS INFLUENCING CARER CO-PRODUCTION

This research identified six key factors that influence the propensity of people in the client's social network to co-produce care to support clients to maintain living independently in the community as presented in Table 11.2.

Table 11.2

Factors influencing the carer propensity to co-produce

Influencing Factor	Description
Expertise	Knowledge and skills relative to those required to perform the task
Functional Capacity	Physical and cognitive capacity to perform the task
Resources	Access to the resources required to perform the task

Social relationship	Social or interpersonal relationship with the to the client
Proximity to the client	Geographic closeness to the client
Willingness	Priorities and motivation to perform the task

The ability for carers to address clients' need for support is influenced by having the requisite expertise in term of knowledge or skills to perform the task. Carers also require the physical and cognitive capacity to perform the task. The ability for carers to perform the task is contingent on their access to the requisite resources, including the extent of time and effort involved in performing the task. Carers social relationship to the client often dictates the types of task they perform, as family, friends, neighbours and community members. The nature of their relationship to the client tends to dictate not only the type of tasks they perform, but also the way their support is requested, offered and received. Carers can face barriers to providing care, due to resistance from clients, who may conceal the need for support or resist care particularly if they feel it undermines their sense of autonomy and independence. Carers contributions are also influenced by their geographic proximity to the clients. Social and geographic proximity to the clients also influences who is aware of client needs and likely to offer support, and the likelihood of clients to ask for and accept support.

Family members, particularly spouses and children, tend to perform the role of primary carer. Clients with functional decline are reliant on carers who reside with them to ensure their needs for support are addressed. As noted by Ron, who lives with his wife Mary:

> *"Probably our biggest worry is, it's something I don't like to talk about, if one of us go, how is the other one going to carry on? I mean 63 years, that's a hell of a big gap in the, if I go, I would worry how Mary is going to go, or vice versa"* (Ron: Interview 33)

There were clients that lived alone whose neighbours and friends provided support which made it feasible for them to maintain living independently in their homes. Support from neighbours was often based on providing social interaction, and practical support with tasks outside the home such as gardening, caring for pets, putting out bins, picking up shopping, and help in emergency situations that they witnessed. There were a few participants who had accessed formal support from volunteers, providing social visits, and a couple who accessed help with gardening or visiting to provide social and emotional support.

Neighbours and friends are often able to provide support based on their geographic proximity, as well as their social relationship with the clients. Many people interviewed who live alone and had limited or no family support, were only able to stay because of support from their neighbours, both routine and in an emergency. However, participants described changes in their neighbourhoods and the

nature of their interactions, where people tend to have less time or interest in interacting with their neighbours. As noted by Mary:

> *"When we first came, we had lovely neighbours who would be in and out like their own homes and that, but not anymore, everybody sort of works or keeps to themselves, it's not the same"* (Mary: Interview 33)

11.4 THE DISTRIBUTION OF CARE TASKS

The assistance carers provide is largely shaped by clients' level of functional capacity to perform tasks independently and their access to formal services to address their needs for support. Clients may be enabled to perform tasks and only require assistance in the form of supervision, while others require physical assistance. Care in the community is typically distributed between formal services including social care and private and third sector services. However, the feasibility of caring for older people with complex needs is dependent on their access to informal support. As detailed in this chapter carers often perform a wide range of activities to address clients' needs for support.

Carer contributions were largely performed out of necessity due to a lack of access to formal services. Although clients are eligible for social care services, these services are not always accessible. This was often the case for social care due to lack of availability for public services including waiting lists and program guidelines that dictate what support they can access. Some clients may have access to private or third sector services including volunteering to provide some services. However, tasks performed by these formal services may not address all the clients' needs to maintain living independently in the community. As described by Rose, whose husband is her carer, but was recently diagnosed to a degenerative condition.

> *"I cannot do much, and my husband is the one that is taking care of everything, but now we are running into another problem, he's been diagnosed with a degenerative condition, so it is a little bit complicated now. He still can do everything, but we don't know down the track what is going to happen"* (Rose: Interview 25)

Clients may be eligible for higher levels of care through the social care system, however carers are required to provide care (or where accessible pay for private services) to ensure clients' needs for support are addressed until these services are available. In addition to providing care to address gaps in access to formal care (i.e. access gaps), carers also contribute gaps between needs addressed by formal services and clients need for assistance to benefit from these services (i.e. *responsiveness gap*). For example, clients may have a service that delivers pre-prepared meals. There may still be a gap in the margin between the meals delivered and the clients' need for support to access adequate nutrition (i.e. a responsiveness gap). Carers may fill this responsiveness gap by bringing delivered meals inside

and storing them in the fridge, preparing and serving them to the client at appropriate times and providing assistance with feeding depending on the clients' functional capacity.

Carers may enable clients to make contributions rather than relieving them by doing things for them. This was important in increasing clients' willingness by increasing their sense of independence. As described by Patrick in caring for his wife Irma.

> *"Previously she (Irma) had been the one doing the cooking, but now she is not able to do it, but she wants to continue to do, but as a result she falls. So, Karen says, oh mum don't do it anymore I will do it. There is this physical limitation on her part, to want to do and she doesn't know that limit is now there, and on the other hand there are some parts that she can contribute on the cooking process. For example, the other day, sweet potatoes for baking, Irma can strip the skin off, it is quite ok, but when it comes to getting a knife and chopping it is physically challenging, I would then help her. I say, is this the right size? Give her credit because she knows, I don't know. These are small things that are challenging and must be realised, there this adjustment that needs to be done, where she does not feel that she is no longer of any value, or a person you know, that she is part of the whole process. That has helped, at least Irma feels she is contributing something, the self-esteem should not be taken away, you must allow the person to feel that way, so that's kind of a constant battle"* (Patrick: Interview 21)

Carers may also make contributions to clients' care not out of necessity to fill *gaps* in *access* to service or the *responsiveness* of services, but as an *alternative* to formal services to improve the quality and safety of care or in responsive to clients' preferences. As illustrated by Henry.

> *"We used to get showers from the council, but we gave that away because a women would come, and Pat would say, oh she is a nice lady, but we'd never get her again, and they would never say they'd say anytime between 9 o'clock and half past 11, it chews into your day, you never know, you lose control of the day, you feel you have to be on standby waiting for them to turn up, you didn't know when they would turn up, you didn't know who would turn up. So me and Pat decided oh bugger it, I will do it, I help Pat have a shower, at least I can do it in my own time, so I give that away, I give the house cleaning away, because they don't do any dusting, all they do is vacuuming, which is alright, they do a good job, vacuuming, do the tile area, the bit where you live, just where you live, and they don't do anymore, and I thought I can bloody do that myself, so the only thing we are getting is meals on wheels and respite for the gym. I need more, so I'm waiting for the government, I'm waiting for them, could be 6 months, could be 9 months, I don't know, no idea"* (Henry: Interview 20)

Carers may choose to provide care as an alternative for formal service for convenience or to work around their schedules. The most frequently cited tasks that carers choose to perform were intimate or private tasks, particularly where there is a lack of continuity with formal providers.

The contributions of carers may be dictated by clients' preference, rather than the lack of access to formal care. Carers can provide additional value based on their social connection with client, that increases their expertise or capacity to perform certain tasks. For example, to manage clients with challenging behaviours because of their familiarity and relationship with the client. Although the converse can also be true as carers may not have specialised skills to safely manage these behaviours, or face resistance from clients who prefer formal providers to perform certain tasks.

Carers often perform tasks to ensure client's needs for support are addressed, largely out of necessity to address gaps in access or responsiveness of formal services. However, there are also situations where carers performed tasks as an *alternative* for formal providers due to concerns about the quality or safety of formal services or client preferences. Services were not always accessible available, appropriate or adequate to meet clients' needs, which often results in heavy burden on carers, which impacts their ability to sustain living in the community.

11.5 CONSEQUENCES OF THE CARING ROLE

Sharing their experiences of their caring role, carers often described consequences that had implications for whether they could sustain it. Being a carer often has significant financial, emotional, social and health ramifications, particularly for primary carers. Carers described the impact of their caring role on their health and wellbeing. Carers' skills in supporting clients with their personal care activities has implications for health outcomes, such as preventing falls and pressure sores, as well as their own health and safety in performing tasks, particularly manual handling. Activities performed by carers to assist clients with their core personal care activities, in particular for clients with severe disability, requires not only constancy and vigilance but were also physically taxing and in some cases caused injuries.

There were examples where carers delayed or forewent addressing their own health issues, because they had to choose between meeting clients' needs and their own care. There were also instances where carers attributed declines in the physical health including injuries caused by their caring role, particularly where they are required to perform manual handling. For example, Samantha attributed her back injury to her caring role.

> *"My spine just went, I think lifting him, for many, many years, at the end he was completely paralysed, and he was blind, I nursed him at home for 26 years and then he went into a*

nursing home for 13 because I could no longer lift him, you know my back was going" (Samantha: Interview 17)

Carers can become increasingly isolated, often because as they are not able to maintain their own social activities. As described by Nancy:

> *"I think you feel, you do feel very alone, not from the people at the council, those who are familiar with this disease, but your friends, I think they think they are trying to lift you and they say, oh doesn't Peter look good, he is managing very well, and I'm sort of thinking, he is not really, but you are not allowed to grieve, when someone is walking around saying "I'm fit", you're not allowed grieve for someone who can still do that, so I find that understanding, I suppose, from people, not the medical people, the friends. I have tried to keep up as much of my own involvement that I used to have so on a Thursday morning, which is why I get the carer in, I go off to a women's discussion group, but I have found most other things, my world is collapsing down quite a bit as the disease progresses"* (Nancy: Interview 18)

The length of time and constancy of the role has implications, particularly where they do not have adequate support or respite. In addition, there are clients who are resistant to formal care services, in particular respite or in-patient care was raised by several carers as creating a difficult situation of having to choose between addressing their own needs and the clients wishes. For example, Cath's husband Jim requires high levels of care and for a long time refused to go to in-patient respite. He had fallen and broken his ribs, so he could not assist Cath to transfer but was resistant to go to hospital.

> *"I think we have only succumbed this year to having respite, because he just wouldn't go, he hates, he absolutely hates it, but he is 24 hour care now, so it has got harder, he is a 130kg, he is a big guy you know, a big man, and while he can transfer and get in and out of bed himself it's ok, but when he can't it's, like this year he is having more trouble, and since he had that fall, it is just impossible to get him to be able to do anything, like getting him in and out of the car or like I got him the other day, I got him sideways across the bed, we made a monkey bar thing, one of his mates made it for him, but unless he has got the strength to get up, and get it, and pull himself around, because I can't lift him, we were stuck there"* (Cath: Interview 24)

In contrast to paid care workers, with defined working hours and scope of practice, carers often described of the 'constancy of vigilance' required when providing essentially 24-hour care, often with minimal or no support. Carers are often just coping day to day and may not anticipate the changing

care needs resulting in crisis situations. As described by Gregory, who is the primary carer for his wife Edwina who has a progressive neuromuscular disorder.

> *"The condition has progressed to the point where she can't look sideways, the stiffening up of the spine has meant she needs prompting, particularly when turning with the four-wheel frame, to just where to put her feet, how to manoeuvre, so there is being aware of mostly what she is wanting to do, and therefore being able to guide with prompts, so she can do it. Again, I guess, I do all the cooking, shopping, washing, ironing, and bed changing and stuff. We have help five days a week for showering and dressing, and on the other two days I help her with that"* (Gregory: Interview 9)

The impact of being a carer financially and on employment was also raised by some participants in the study. They described financial costs associated with caring role and the stress associated with managing their finances. In addition to potential loss of paid income, providing care in the home has a financial burden in providing the required resources, and the time and effort required to access formal supports. Cath has been borrowing money against their house to pay for her husband's care.

> *"We are about $17,000 in debt to the house now, for borrowing off the house, for things like, like respite. I just hope that money doesn't run out from the house before one of us carks it, because I don't know what we will do then"* (Cath: Interview 24)

Carers experience loss on a range of levels. The participants of the study described how as carers they often had to make the choice of giving up their paid profession or personal/social activities, with implications that are not just financially but can also impact on their sense of identity and wellbeing. There may also be a sense of loss or distorting of the relationship with the care recipient, that is impacted by the changing dynamic as they encompass a care provider role. As described by Samantha,

> *"It is a living grief apart from anything else, apart from any of the mechanics of it, the emotional impact and the living grief is just awful because the person that you choose to be your life partner and or who choose you, is here in body but everything else is slipping away"* (Samantha: Interview 11)

Carers often expressed guilt when they are unable to provide care themselves (in the short and long term). Carers also expressed significant concerns about the quality of care provided in formal care environments such as hospitals or aged care facilities. Bob described his decision to take his wife to the hospital.

"Well, between you had me, we had to keep it a bit quiet, about the bowel part of it. One of the carers happened to be at the time that it happened, and she said, she is bleeding a hell of a lot, so I thought to myself, right so it's hospital. No, I don't want to go to hospital, she said, and I said, sorry love but you have got to, the carers can't go on with what they are doing anymore, even they can't do it, I said I will do it as much as I can but there is a limitation to how far I can go. I said, it is for your own good, not realising that taking her to the hospital was her last day in a way, because she never came back, she never came out of hospital, it is where she died, and I regret it, I regret it to say, could I have done better?" (Bob: Interview 12)

CONCLUSION

Carers supported clients to allow those with disability or functional declines to remain living independently in the community. In some cases, carers support clients to perform activities independently, such as providing guidance and supervision to ensure safety, facilitating the use of assistive devices and aids, or making changes to the environment to increase their capacity to perform these tasks or make the task easier. Where clients did not have the functional capacity to perform these activities independently, carers provided support with performing personal care activities and maintaining a supportive environment. Carers may provide support instead of accessing a service in response to clients' preferences about who performs these activities and concerns about the quality or safety of formal care. Care is often provided out of necessity to fill gaps in the system to ensure clients' needs for support are addressed due to a lack of access (i.e. access gap) or the responsiveness of services (i.e. responsiveness gap). The caring role can create tensions that impact on the nature of care that carers provide, and changing dynamics in their relationship with the clients. The complexity and magnitude of care required by older people with complex needs tends to increase over time, further complicating and compounding the burden on carers, particularly where access to formal support services does not increase with clients' needs. Carers often face their own health issues along with the cumulative consequences of the caring role which impinge on their ability to continue to provide care.

CHAPTER 12

Facilitating and Sustaining Client and Carer Co-production

INTRODUCTION

Co-production is fundamental to government policies aimed at sustaining public health systems in caring for ageing populations. These policies centre on people actively improving their health outcomes and the provision of care in the community with the support of informal care, to reduce pressure on the acute sectors and costly in-patient and residential care. However, despite being necessary co-production is not always feasible, and the cost of failure is greater than the economic costs to the health system, but that of the health and safety of both clients and their carers. Given the extremely high stakes, the question is how co-production in caring for older people in the community can be better managed. One way this can be achieved is by examining its existing role in achieving government purposes as illustrated by this thesis. This research found that co-production exists in various forms in the delivery of complex care in the community, and various inter-related factors influence whether people can effectively co-produce their care. Adding to the complexity, there are inter-dependences between formal service providers, clients as the main beneficiary of the service, and carers in their ambiguous role as third party co-producers. Co-production is often unavoidable in the delivery of care services, raising the question of how to best enlist and facilitate it. Care in the community also involves contributions that can be performed by either internal or external actors, raising the question of when it is beneficial to outsource these tasks. This chapter provides frameworks for considering these questions, to inform how co-production can be facilitated and sustained in caring for older people with complex needs in the community.

12.1 CLIENT AND CARER CO-PRODUCTION OF COMPLEX CARE

There are different schools of thought on what constitutes co-production, with increasing weight given to co-production as a new or optional approach to service delivery. As a result, less attention has been paid to co-production that already exists in the delivery of public services, that are nevertheless fundamental to achieving government purposes. The analysis has also tended to adopt a narrow focus on co-production that occurs during direct service interactions, failing to capture other forms of co-production that are also instrumental to achieving service objectives, in particular, contributions by third parties. Using the case of delivering complex care of older people in the community, this thesis mapped the production processes to illustrate the contributions of both clients and carers.

Clients and carers, in their distinct roles, make instrumental contributions to the delivery of complex care to improve health outcomes and maintain living independently in the community. Care in the community typically involves people *monitoring* and *identifying* health issues and needs for support, and *determining* whether to access services, and performing activities involved in *accessing* those services. These contributions influence the effectiveness of services to manage people's health in the community. The earlier clients are able to identify or recognise issues and needs, the greater potential for prevention and early intervention to achieve better health outcomes (Bodenheimer et al., 2002). During service interactions, clients provide *inputs* to formal assessments and care planning processes, including their unique knowledge based on the lived experience of their health and individual circumstances (although as discussed later in this chapter their engagement and participation in providing inputs and care planning varies). Clients are required to *co-operate* with conjoint activities with professional providers as indicated to address their issues and needs. However, care in the community is largely dependent on clients making significant contributions of time, effort and resources to achieving service objectives independently outside service interactions. These contributions include a mix of both substitutionary and inter-dependent forms of co-production (the latter being unavoidable or non-optional as they involve clients *behaving* and *acting* in ways that change their health outcomes). Paradoxically, the capacity of people with complex needs to make necessary contributions to the delivery of their care is often hindered by the very issues and needs they seek to address. A range of inter-related factors influence whether clients co-produce. In handling these contingencies, *enabling* or *relieving* logics can often be adopted to better elicit or facilitate clients to make co-productive contributions to their care (see Figure 12.1). Carers often play a crucial role in supporting clients to co-produce and overcome gaps in the service system.

Carers, in their unique role as informal third parties, contribute in two key ways to the co-production of care in the community. Firstly, as *quasi-clients* they enable or relieve clients in making necessary co-productive contributions to the delivery of their care. Secondly, as *quasi-providers,* they provide informal care to clients (Twigg, 1989; Weinberg et al., 2007). In addition to substitutionary (i.e. zero-sum) contributions to the delivery of care, they can create additional value (i.e. positive-sum) by contributing to the delivery of formal services and due to their unique expertise and resources. In some instances, they have the capacity to be more responsive to clients' needs due to the flexibility of their role as informal providers. However, reliance on informal care is not universally beneficial. Care by informal providers has potential risks to the health and safety for both the client and carer (as is further discussed later in this chapter). There can also be tensions between different actors as care in the community for people with complex needs typically involves pooled efforts and thus complex inter-dependencies between clients, carers and the service system. Therefore, it is worthwhile considering what influences co-productive contributions outside direct service interactions, including

the contributions of formal and informal third parties, that are also instrumental to achieving government purposes of providing complex care in the community.

12.2 CO-PRODUCTION AND PARTICPATION

Co-production can exist in different decision-making relationships with professional providers (Bovaird, 2007). This thesis distinguished between *co-production*, where clients and carers contribute inputs, behaviours and activities to the production of service outputs and outcomes; and *participation*, that involves the public in formal decision-making processes about the planning or design of care services, providing an opportunity to examine the relationship between these processes. Three types of decision-making relationships were found to exist in the delivery of complex care. These relationships and the nature of client, carer, and professional provider interactions have implications for co-production. The involvement of carers (with their individual perspective and preferences) in decision making about the clients' care, can also create a complex three way dynamic, given their role as both quasi-clients and quasi-provider.

One type was a *provider-driven* relationship, where clients and carers do not participate in deliberations with frontline providers about how issues and needs will be addressed. In these situations, clients and carers respond in various ways to influence care planning. In the paternalistic tradition, they may passively acquiesce with directives from professional providers, consistent with the concepts of *loyalty* (Hirschman, 1970) or *loyalty by default* (Dent & Pahor, 2015). Alternatively, they may seek to influence formal decision-making by exercising *voice* (including carers acting as *advocates* on the clients' behalf) or *exit* by seeking out an alternative provider (Hirschman, 1970). However, in the context of health care, people may be reticent to question professional providers (Joseph-Williams, Edwards, & Elwin, 2014), and exit is often not an option in the public care sector. In addition, to existing typologies (Hirschman, 1970; Dent & Pahor, 2015), this research found that people may respond by *circumventing*. This is where they tailor their inputs to formal assessment processes in an effort to influence formal care planning to better align with their preferences.

Another type was a *consumer-driven* relationship, where clients exercise choice in decision-making about their care. In aged care service planning, clients were often given a choice of set options (subject to eligibility program guidelines). Similarly, in health care planning, there are instances where clients are given a choice of treatment or management options as dictated by evidence-based practice. However, there are other factors that influence whether people co-produce, (in addition to service availability and responsiveness of services to their individual needs and preferences). Carers can be in an ambiguous position regarding their involvement in making choices about services and there may be conflict between respecting clients' right to self-determination and the rights of carers as providers of care.

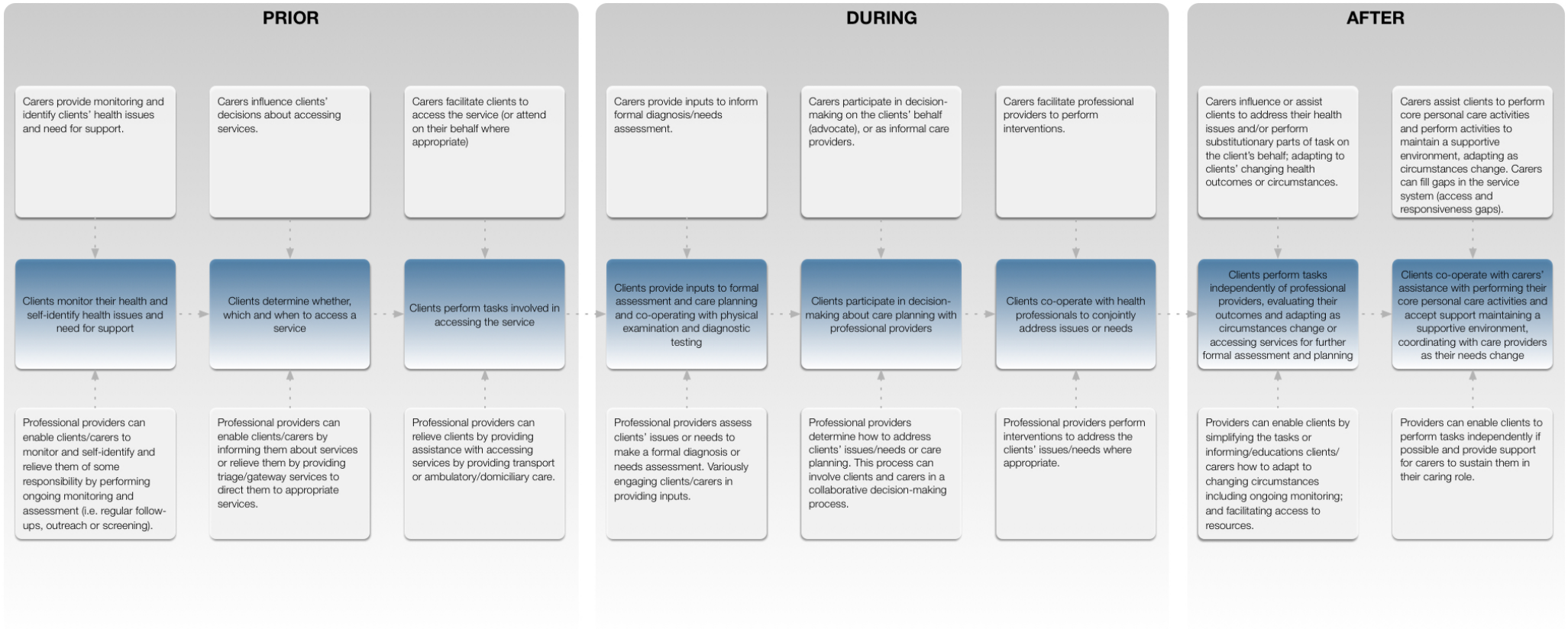

Figure 12.1. Potential co-productive contributions to complex care in the community.

The third type was a *collaborative* relationship, where clients, (their carers) and providers participate in deliberative process of decision-making. At the individual level, this involves a *dialogue* about care options (i.e. *co-planning*) or determining how issues and needs will be addressed by the service (i.e. *co-design*). This provides a mechanism for *aligning purposes* drawing on professional expertise and clients' individual needs and preferences. Joint care planning can also provide a forum for *identifying barriers* to clients adhering with the care plan and involve *coordination* with other relevant formal and informal third parties. This includes involving people's carers in the planning processes, consistent with 'triangle of care' approach (Worthington et al., 2013). Decisions informed by inputs from clients *and* carers, benefit from their expertise based on their unique experiences, increasing the feasibility of producing outcomes, although there can a lack of recognition of carers by professional providers despite their fundamental role in implementing care planning. A collaborative relationship is shaped by *relational* aspects of interactions with professional providers (i.e. empathy, active listening, showing personal interest) that influence people's experience and trust in the service. Interestingly, participants often described being engaged in providing inputs to assessment processes (or "feeling heard" and other relational aspects of the interaction) as representing involvement in their care planning (rather than participating in deliberative processes or exercising choice).

Collaborative approaches to the co-production of care have been widely espoused in the care service literature, as discussed in Chapter Four. Continuity through *long-term* relationships with providers and the benefits of involving people in decision-making about their care services is well documented (Gertis et al., 1993; Heaton, Corden, & Parker, 2012). However, partnership approaches have been met with resistance due to the implications for responsibility, power and control, recognition of expertise and independence (Lawn et al., 2013; Thille & Russell, 2010). Collaborative approaches are often undermined by organisational structure as well as culture, such as time constraints and difficulty accessing the same provider. There are also other factors to consider that influence whether people co-produce as illustrated in this thesis.

12.3 FACTORS INFLUENCING THE CLIENTS' PROPENSITY TO CO-PRODUCE

Traditionally, whether clients co-produce has been framed as a product of their willingness and ability (Alford 2009). As such, the analysis to date has focused on motivations and facilitating people to co-produce by making tasks easier or increasing people's capacity to perform tasks. There is a tendency to focus on how to better enlist or motivate people to co-produce, yet other factors can also influence whether it is feasible, such as access to resources and support from third parties. A more nuanced framework is put forth here, that makes an important distinction between ability, based on having the requisite *expertise* (i.e. knowing how to perform the task); and *functional capacity* (i.e. having the physical and cognitive functioning to able to perform the task). In addition, whether people co-produce is also influenced by people's access to the necessary *resources* required to *feasibly* make co-

productive contributions to the delivery of their care (see Figure 12.2). Whether people can effectively co-produce their care, expressed here as their "*propensity* to co-produce", is influenced by these dynamic and inter-related factors, as determined by people's health and broader social, cultural, economic and environmental circumstances (Marmot & Wilkinson, 2003). This framework provides insights into how we can more carefully think about how what influences whether it is feasible for people to co-produce, particularly those with complex needs.

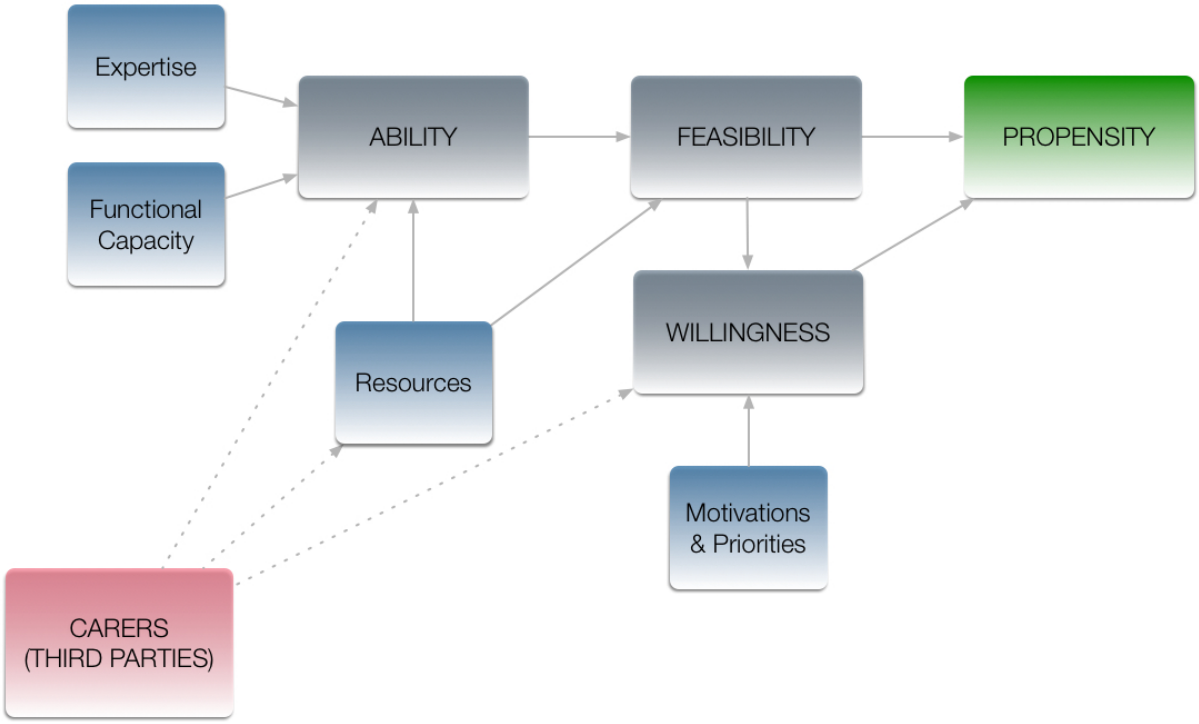

Figure 12.2. Factors influencing the propensity to co-produce.

The willingness to co-produce

Motivations to co-produce is one of the key factors studied in the literature (as discussed in Chapter One and Four). In the context of care services, this can include complex behavioural psychologies, which are beyond the scope of this thesis. However, there were recurring themes in the interview data that provide insights into the willingness to co-produce complex care, including competing priorities and motivations beyond self-interest.

People's health beliefs and belief in their ability to effectively perform tasks can influence whether people co-produce, consistent with the literature linking co-production with the level of self-efficacy (Parrado et al., 2013). However, adherence with care planning can also be based on trust in the provider, particularly where there is a knowledge imbalance (which is in turn influenced by the nature of their relational aspects of interactions with the providers). There are some co-productive activities that provide addition motivation for clients by serving more than one purpose, for example where exercise is performed in a group (such as a neighbourhood walking group) that provides both physical

exercise as well as social interaction. Clients may also be motivated by people in their social networks performing a supervisory or monitoring role to hold them to account.

Whether people are willing to co-produce can also be determined by competing priorities. For example, people may not co-produce where it involves having to ask for or accept support from others. They may conceal their need for support or reject help from others to maintain their autonomy, at the expense of addressing their issues and needs. There are often complex relationships between clients and carers that impact co-production by both parties. Whether clients accept support is often influenced by whether it is performed in a way that does not undermine their independence. This research found that carers often consciously considered how they negotiate and provide support in ways that maintains the clients' autonomy, dignity and sense of independence. There has also been a trend in the policy discourse towards adopting strengths or asset-based approaches, that aim to increase functional capacity and independence, underpinned by the notion of "do with" rather "than for" (Boyle & Harris, 2009).

People can also have competing obligations, where their willingness of clients to co-produce is not motivated by self-interest. Older people with complex needs often perform dual roles, as both client and carer (i.e. spouses that care for each other in various ways). There can be situations where people may have to choose between their caring responsibilities and addressing their own health issues. For example, where Alford (2009) refers to *expressive values,* where "people's beliefs about what is normatively right or about what principles should guide our society, which may differ from their views of what is in their own self-interest" (p. 66). There are also circumstances, where people are motivated and have the scope to proactively address their own health to ensure they can remain healthy enough to continue in their caring role. In addition, there is often reciprocity between clients and their informal carers, as both give and receive informal care to people in their social networks.

Although voluntary, co-production is necessary for clients to address their health issues and needs. The phrase *captured co-production* has been used (Whitaker, 1980), where clients are required to co-produce to gain value from the services. Co-production of care is part of a 'choice set' where co-production is *necessary* for clients to having their needs met. Often it is not simply a question of motivating people to co-produce, but addressing other factors that influence whether they can it is feasible for them to effectively do so, in order to ensure the safety and quality of their care.

The ability to co-produce

The *ability* to co-produce effectively involves having the requisite *expertise* to perform the task. Clients have *experiential knowledge* based on their unique experiences and knowledge of their own health and past history. However, they also require *specialised knowledge and skills* to make

effective co-productive contributions to improving their health outcomes. Clients' level of health literacy, including their proclivity to actively seek out information, and their capacity to apply information to their own circumstances, influences the safety and quality of their care (Adams et al., 2009; Trevena et al., 2017). Clients may have access to information communication technologies (ICT) to increase their *expertise* to perform tasks. However, people have differing levels of *digital literacy*, which has implications given the move towards online formats for accessing information and services. To effectively co-produce complex care in the community requires clients to have specialised skills and knowledge however, older generations, people from lower-social economic backgrounds, and culturally and linguistically diverse backgrounds (CALD) tend to have lower levels of health and digital literacy (Adams et al., 2009; Sørensen et al., 2012; Trevena et al., 2017).

In addition to needing to know how to co-produce, clients also require the physical and cognitive functioning or *functional capacity*. Many of the most common conditions among older people are progressively manifest in functional decline and disability (WHO, 2011). Health is not static and clients' functional capacity to perform certain tasks can change suddenly. Functional declines might be for a limited period (i.e. whilst on waiting lists for elective surgeries and during recovery or rehabilitation), while other prominent conditions are progressive, manifesting in increased disability and need for support over time. Whether people co-produce their care in the community is often contingent on carers to identify and rapidly respond to clients' changing needs to ensure their issues and needs are met (i.e. where access formal support does not increase along with their increased needs for support). While a lack of specialised expertise can be addressed through the provision of information and education, people with functional decline often require practical support or assistance to enable them to perform tasks independently or to relieve by performing substitutionary elements of tasks on their behalf.

The feasibility of co-production

In addition to having the willingness and ability to co-produce, clients require access to requisite *resources* for co-production to be *feasible*. Care in the community typically requires access to *material resources* such as those associated with accessing services (i.e. transport, out-of-pocket costs); consumables (i.e. medications, continence aids, wound dressings etc); and aids and equipment; and home adaptations required to provide care in the community. In addition, access to *human resources* may be required to perform group activities (i.e. social activities to promote wellbeing) or provide support as formal or informal third party care providers. Depending on their functional capacity, clients can be enabled to co-produce independently with the use of specialised equipment such as assistive devices and aids, and by adapting the physical environment to overcome disability. However, third parties may be required to overcome barriers for people co-producing outside direct interactions with the service provider, that are necessary for achieving service objectives.

The role of third parties

Delivering care in the community often involves coordination with other formal and informal third parties and making adjustments as circumstances change. Older people with complex care needs are often reliant on support from people in their social networks to overcome barriers to co-production outside direct service interaction with service providers. Carers can increase clients' propensity by motivating and enabling clients to perform tasks independently, relieving them by providing assistance, equipping them with material and human resources required to make co-productive contributions, and assist in coordinating their care across other actors. Often these tasks fall to carers by default, where the service system is not responsive to the clients' individual needs, with the implicit assumption that carers are willing, able and have the resources to bridge these gaps to ensure the clients' needs are met.

12.4 THE INHERENCY- PROPENSITY GAP

Co-production is *inherent* in the delivery of care services in the community as it is necessary for clients to make contributions to the production of service objectives. As discussed above, whether people with complex care needs can effectively co-produce is contingent on whether they are not only willing but have the requisite expertise, functional capacity and resources. However, people vary in their *propensity* to make these contributions, particularly clients with complex needs. The provision of care in the community is determined by how well these contingencies are handled by the service system, clients, and their carers. Adding to the complexity, these factors are not constant, they are dynamic and inter-related. For instance, clients' propensity may increase as they learn how to manage their conditions, however, changing in the health or access to resources may decrease their propensity to co-produce. This may happen gradually over time or rapidly. This research introduces the *'Inherency-Propensity Gap'* (I-P Gap) as a framework for considering how to elicit and facilitate co-production (see Figure 12.3). Rather than a 'one-size-fits-all' approach, a tailored method is required to identify and address barriers through enabling and relieving logics. This provides opportunity to address distributional consequences caused by variations in people's ability to benefit from services based on their own capacity to co-produce.

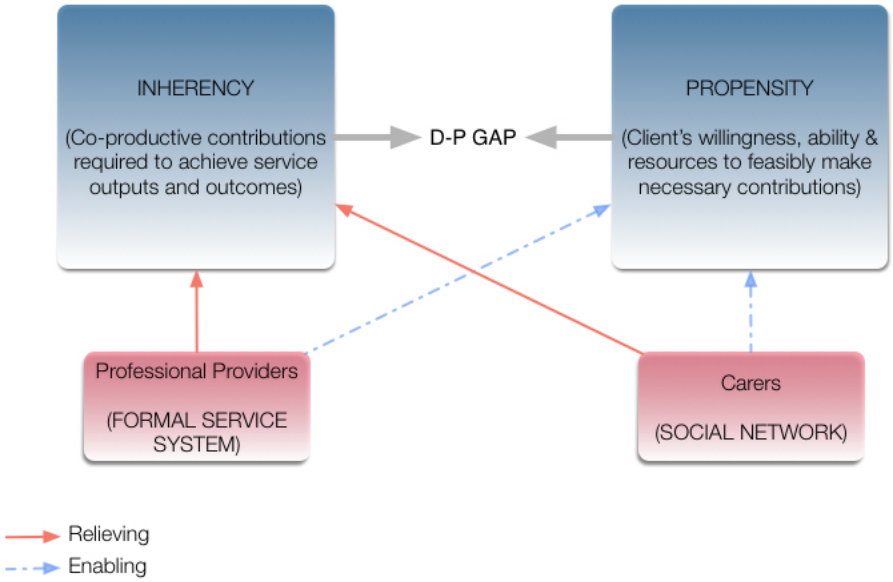

Figure 12.3. The Inherency-Propensity Gap.

The adaptability of the service system, clients and their carers to bridge I-P Gaps as circumstances change is critical to sustain clients in co-producing their care in the community. According to Thompson (1967), coordinating task inter-dependencies is best through ongoing *mutual adjustments*. This involves ongoing monitoring and communication to coordinate care over time, as required to overcome barriers to clients making necessary contributions to addressing their health issues in the community. This is where decision-making intersects with co-production, where collaboration provides an opportunity to find shared solutions to overcome barriers to co-production that include carers who both support clients to co-produce and make contributions to their care across the care continuum.

The design of a service influences the nature of co-productive contributions necessary for achieving service outputs and outcomes. Service orientation and culture also influences co-production to the extent that services are concerned with enlisting people to co-produce. Alford and O'Flynn (2012) refer to *client focus* as a way of framing service delivery. In addition to providing a sense of *helpfulness* in terms of both the providers' competence and positive intentions, factors that shape this approach include: *bilateralism* which involves frontline providers ascertaining their needs; and 'individualisation' that involves tailoring services to meet these needs (Alford & O'Flynn, 2012). This is in part dictated by the organisational structure or flexibility to tailor services to clients' individual circumstances, that requires a degree of discretion as the frontline (Lipsky, 1969). In addressing complex issues, there are also inter-dependencies with formal and informal third parties that require coordination to facilitate clients to make contributions outside direct service interactions.

This requires coordination with clients' informal networks and across organisational and sector boundaries.

At the frontline, providers have the opportunity to address the I-P Gap during direct service interactions. The prevailing wisdom is that co-production of health and social care services is enhanced through collaborative relationships to align purposes and increase clients' willingness to adhere with care planning. These processes involve clients participating in service planning or design informed by both clients' and professional expertise to increase the responsiveness of services. The care services literature on co-production is largely concerned with these collaborative forms of co-production (Bovaird, 2007; Dunston et al., 2009; Needham & Carr, 2009; Boyle & Harris, 2009). However, in practice, enlisting and facilitating co-production is often more complex than it first appears.

Services may adopt an *enabling logic* to increase clients' ability to make contributions, a *relieving logic* by performing substitutionary elements of the tasks to make it more feasible, or a mix of both (Normann, 1984; Normann, 2001). Facilitating co-production in the literature is largely concerned with *enabling* clients by increasing their self-efficacy, thus drawing on clients' internal motivations to increase their willingness to adhere with making independent contributions to their care. However, despite having the willingness and the expertise to know how to perform the task, there are often practical barriers that need to be addressed, particularly with complex care needs that preclude them from making contributions independently. For clients with functional decline, providers may be required to identify and overcome cognitive and physical disability. This may require a *relieving* approach by simplifying tasks or coordinating with third parties to facilitate clients to perform tasks outside direct service interactions. Clients may also require support to access the material resources necessary to feasibly perform tasks.

Clients' propensity to co-produce is influenced by complex inter-related factors that are not static and may change rapidly. As many co-productive contributions are made outside direct service interactions, and services do not necessarily adapt along with clients' changing circumstances, the responsibility for bridging the I-P Gap often falls to clients and their carers. There are often gaps between what we are asking people to do to benefit from the service and their propensity to make these contributions. Carers often perform a pivotal role in facilitating clients to make necessary contributions to their care including: motivating (i.e. encouraging, supervising or monitoring, holding them to account, influencing them based on their social relationship to the client), enabling (i.e. reminding or directing them how to perform the task), relieving (i.e. performing substitutionary parts of the task for them); equipping them (i.e. providing resources required to perform the task); coordinating (i.e. making adjustments and managing care across different actors as circumstances

change). Whether co-production is feasible is often contingent on clients or their carers to overcome I-G gaps as circumstances change.

It has been suggested that co-production can perpetuate inequities in the system, given disadvantaged citizens may not have the same opportunities to contribute (Porter, 2012; Rosentraub & Sharp 1981; Warren, Rosentraub, & Harlow, 1984). Co-production can be seen to have distributional consequences given disparities in people's willingness, motivation or resources to co-produce (Jakobsen & Anderson, 2013). Rosentraub and Sharp (1981) found that "wealthier, better-educated, or non-minority citizens may be more willing or able to engage in co-production activities" (p. 517). Conversely, co-production can be managed in ways that decrease inequities (Jakobsen & Anderson, 2013). Jakobsen and Anderson (2013) found that services can be designed and implemented in ways that benefit from co-production and overcome disadvantage rather than perpetuate it. This is particularly pertinent to the delivery of health and social care that aims to improve "health for all" by addressing inequities in the system.

Despite co-production being necessary for service delivery, it still may or may not occur. Whether co-production transpires is the culmination of a wide range of factors that influence the propensity to co-produce and organisational conditions. While it has been cautioned that co-production may further exacerbate disparities in the system, the inverse is also possible; where co-production is designed and implemented in ways that elicit and facilitate co-production to overcome I-P Gaps, it can address inequities in the system.

12.5 THE SERVICE-NEEDS GAP

Caring for older people with complex needs involves a mix of formal and informal contributions to facilitate clients to address their health issues and need for support. One critical aspect in the co-production of care in the community is how tasks are distributed between these actors. There is often a gap between clients' *needs* for support and those addressed by the *formal service system* i.e. a Service-Needs Gap (S-N Gap), (see Figure 12.4). Short of increasing formal care provision to be more responsive to clients' needs, one approach that has been gaining traction is enabling approaches to increase people's ability to care for themselves. Nonetheless, in the case of people with complex needs, there are limitations to the extent that this can address gaps in the system. In which case, the default is a reliance on care by third parties (Figure, 12.4, third parties shown in red). While there has been growing interest in ways to increase social capital through formalised approaches to volunteering, the majority of care in the community is provided by informal carers based on their social connection to the client. Clients are reliant on support from people in their social network, acting as informal carers, to fill gaps in the system for their issues and needs to be addressed. The S-N Gap provides a framework for considering the distribution of tasks between formal and informal

actors to inform how co-production in the delivery of complex care in the community can be better facilitated and sustained.

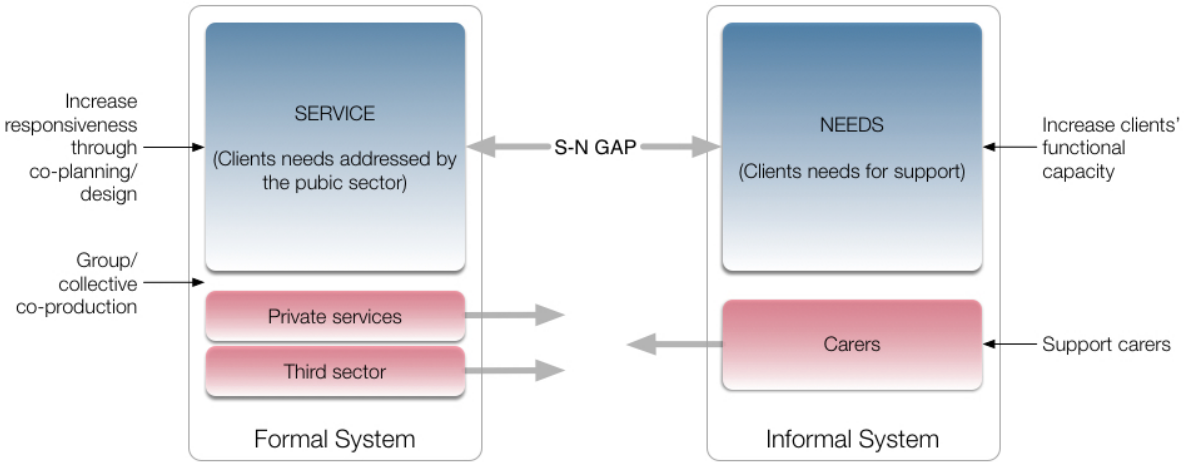

Figure 12.4. The Service-Needs Gap.

As noted earlier, S-N Gaps may be in part addressed by decreasing clients' need for support by adopting asset or strengths-based approaches to care, that focus on increasing clients' functional capacity to increase their ability to perform tasks independently where possible (SCIE, 2015; DH, 2018b). The care services literature on co-production has adopted this assets-based perspective (Bovaird & Löffler, 2012; Boyle et al., 2006; Russell, 2011). For example, in Australia, the aged care sector under the Commonwealth Home Support Program (CHSP) has adopted a wellness and re-ablement approach to the delivery of home care.

Volunteers, acting as third party co-producers, can also contribute to addressing the S-N Gap by providing care in the community that is formally organised (e.g. peer support, visiting schemes, timebanking). However, these approaches cannot replace the role of primary carers but can assist in a more sustainable distribution of care responsibilities. They may provide additional resources, rather than a substitute for professional care provision, where they provide expertise based on experiential knowledge. There is an emphasis in the literature on benefits of group and collective over individual forms of co-production (Pestoff, 2012), although it has been found that people may be "reluctant joiners" (Löffler et al., 2007). There are also limits in the nature of care that can be appropriately provided by the public (such as issues around safety, privacy and liability). These S-N Gaps can also be influenced by associated concepts such as co-planning and co-design, to the extent that they can better align the service system to people's individual needs.

People's needs for support to maintain independence in the community or long-term care "can be met by formal or informal care, or can go unmet, all of which have a cost" (OECD, 2017, p. 9). The

distribution of care responsibilities is often dictated by access to formal care. By default, informal care is required to bridge gaps in access to formal services to ensure clients' needs for support are addressed. For example, in Australia availability of public long-term aged care services is subject to planning ratios. In addition, access to formal services does not adjust automatically as clients' needs and circumstances change (which may happen unexpectedly and suddenly). There are often waiting lists for clients to be reassessed for higher level packages, and then further waiting lists for these packages to become available (Skatssoon, 2018). There can also be access issues for private and third sector services, such as affordability and availability of these services.

In bridging the S-N Gaps, carers contribute to two types of service gaps. One is the *access gap* where carers provide care that could be performed by formal services they were accessible. The other is the *responsiveness gap* which represents a gap between needs addressed by formal services and clients' need for support. Responsiveness gaps necessitate third parties to contribute to the delivery of these services to achieve its objectives. Informal care is typically required to bridge these gaps to ensure clients' needs for support are addressed. There are also situations where carers performed tasks as an *alternative* to formal care, due to concerns about the quality or safety of formal services or to align with client preferences on who performs certain tasks (particularly in relation to intimate tasks). In addition to addressing access gaps (i.e. substitutionary or zero-sum co-production), carers also improve the effectiveness of formal services by contributing to the production process of delivering formal services and creating additional value due to their social and physical proximity to the client (positive-sum co-production).

The term 'carer' represents a heterogenous group of informal and unpaid providers, whose role is uniquely shaped by the specific circumstances including their relationship and proximity to the clients, which has implications for the nature of contributions they are likely to provide. The nature of informal care provided by carers is largely determined by their social and geographic proximity to the client. Carers have different social relationships with the clients as family, friends, neighbours or community members. In addition there is often reciprocity, as with people who provide care for each other.

Carers, often as family members, who are emotionally or otherwise invested in the clients' outcomes, may derive value from contributing to the care of the clients by extension. People may be motivated to co-produce based on their *expressive values* (Alford, 2009). These values may be shaped by cultural norms, including gender roles, which seemed to inform beliefs and attitudes about the nature of contributions they make, as demonstrated by the tendency for personal care to be performed by female relations and spouses. In contrast to clients who may co-produce out of self-interest, there are other motivators which may influence why carers provide informal care. Alford (2009) found that in

addition to expressive values, intrinsic rewards and solidary incentives are also motivators to co-produce (p. 66).

Neighbours and friends may provide support due to their close geographic proximity, as well as their social relationship to the client. There are older people with complex needs that live alone, where it is only feasible for them to maintain living in the community through support they receive from neighbours and friends. Support from neighbours typically included providing social interaction, and practical support with tasks outside the home such as gardening, caring for pets, putting out bins, picking up shopping, monitoring and responding to emergency situations. Friends may also provide social and emotional support, external monitoring and practical assistance.

Family members, particularly spouses and children, tend to perform the role of primary carer, and are more likely to attend consultations, and be aware of gaps in the system and perform a monitoring and coordinating role to ensure clients' issues and needs are addressed. Carers may feel responsible to provide care to clients in the community out of concern regarding the quality and safety of residential care services, as well as client preference. Older people's need for informal support tends to increase over time. Services are not always accessible and those available were not always appropriate or adequate to meet clients' needs, resulting in a heavy burden on carers.

12.6 SUBSTITUTABILITY AND SUSTAINABILITY

The significant financial, emotional, social and health ramifications of providing informal care, particularly for primary carers are well documented (Bremer et al., 2015; Doran, Drever, & Whitehead, 2003; Hiel et al., 2015; Kaschowitz & Brandt, 2017; OECD, 2011; van den Berg, Fiebig, & Hall, 2014). Carers in the study described their caring role as having implications for their own health and wellbeing. Carers often described not being able to maintain their own social activities and becoming socially isolated. There were often instances where clients delayed or forewent addressing their own health issues, because they had to choose between meeting clients' needs and their own care. The impact of being a carer financially and on employment was also raised by some participants in the study. For carers, there are financial costs associated with the caring role and the stress associated with managing finances. In addition to potential loss of paid income, there are also financial costs of caring such as paying for consumables, equipment and other necessary resources.

The length of time and constancy of the role has implications, particularly where they do not have access to other informal support or formal respite. In contrast to paid care workers, with defined working hours and scope of practice, primary carers of people with significant functional decline describe the 'constancy of vigilance' as they provide essentially 24-hour care, with limited or minimal support. The complexity and magnitude of care provided by carers often increases over time, as the

social and economic implications of caring further complicate and compound the burden on carers (Brereton & Nolan, 2000). In addition, implications on their health and wellbeing also impinges on their ability to sustain their caring role.

Carers may require education and training where tasks require specialised knowledge and skills, to ensure the safety and quality of clients' care (Atkinson, 1992; Farran et al., 2003; Given & Sherwood, 2008; Schumacher et al., 1998; Smith et al., 2004; Wrubel & Folman, 1997). Even activities such as providing personal care that may seem rudimentary, if not performed correctly can result in poor health outcomes (Davis, 2010; Shumacher et al., 2000). Tasks that involve manual labour require clients to have skills (and often specialised equipment) to prevent causing injury. As informal providers, carers do not have occupational health and safety training or competency standards to ensure safety for the clients and themselves. Carers vary in their expertise and capacity that influences the quality of care they can provide, and their own health outcomes.

Ensuring clients' needs for support are addressed is instrumental for the achievement of primary health service objectives, to facilitate clients to make necessary contributions to improve health outcomes in the community. However, carers may require education and training to ensure the safety and quality of care (Greenwood et al., 2009; Innes, Morgan, & Kostenik, 2011; Levine et al., 2010; Wilkins, Bruce, & Sirey, 2009). The distribution of tasks to informal carers should not be by default or assumed to be universally beneficial, particularly where the cumulative burden has implications for the sustainability of the caring role for primary carers.

CONCLUSION

Co-production exists in the delivery of complex care, where clients and their carers make significant contributions of inputs, behaviours and activities before, during and after direct service interactions. These contributions are operationally necessary for the achievement of government purposes of caring for ageing populations in the community. Client co-production is beneficial to decrease costs and demands on health and social care systems. In some respects, it is unavoidable as providers are dependent on inputs, behaviours and activities that only clients can provide. However, it is not always feasible. Facilitating client co-production involves bridging 'Inherency-Propensity Gaps' by ensuring clients have the relative expertise, functional capacity, resources and motivations to make necessary contributions to the delivery of the care. However, for people with complex needs, these contributions may be in friction with the issues and needs they seek to address. There are often inter-dependencies on formal and informal third parties to support client co-production. Carer co-production can be beneficial to facilitating clients to co-produce better health outcomes and address their needs for support, decreasing costs and demands on the formal service system by bridging the 'Service-Needs Gap'. However, outsourcing care to informal carers requires further consideration

than their willingness to make contributions, as it has implications on the quality of care for clients and the safety and sustainability of the caring role.

CONCLUSION

Over the last half a century, the epidemiological and demographic profiles of populations have dramatically changed, giving rise to growing proportions with chronic illness. Governments have sought ways to adapt health systems designed around the acute treatment of curable conditions in hospital settings, to address the complex and ongoing care needs of ageing populations. Policy makers, as demonstrated in recent Australian health system reforms, have sought to re-orient services towards prevention, and re-locate health and aged care in the community where possible. These reforms are dependent on clients and their carers making significant contributions of time, effort and resources to the delivery of care. To better enlist and facilitate people in making these contributions, the reforms include strategies to re-balance and re-align the system through participatory approaches and integration to be more responsive and easier to navigate. In practice, facilitating co-production by older people with complex needs requires a more nuanced and sustained approach, to address the complex and inter-related factors that influence their propensity to co-produce. The delivery of complex care in the community calls for clients to make significant and sustained contributions before, during and after direct service interactions, that are in some cases in friction with the challenges they seek to address. Carers are often in an ambiguous role as both quasi-client and quasi-provider.

Co-production is inherent as an operational element of delivering of complex care in the community. However, it is not always feasible. Clients vary in their propensity to co-produce depending on their health and health literacy as shaped by their social, cultural and economic backgrounds. This thesis presents the 'Inherency-Propensity Gap' (I-P Gap) as a framework for considering how co-production is facilitated. Clients' propensity to co-produce is contingent on a variety of interrelated factors that influence their relative expertise, functional capacity, resources and motivations, that influence whether they are willing and able, but also if it is feasible. In addition, the sustainability of people co-producing is determined by how these factors influence the clients' capacity to adapt. Coordinating co-production involves ongoing mutual adjustments to bridge the I-P Gap. In some instances, an enabling approach is required to increase client's ability to perform task independently, while in others a relieving approach involving third parties may be required to make it feasible for clients to co-produce. There may be other practical barriers to overcome such as access to requisite resources. In addition, there are also complex dynamics between clients, carers and service providers.

The main focus in the care service literature is concerned with how to elicit co-production through collaborative partnership approaches, that involve clients in shared decision-making and increasing their self-efficacy. However, these processes do not guarantee co-production will be feasible. Clients and carers can be engaged in providing inputs about their individual circumstances and dialogue with

providers about service planning and design options. However, there are often organisational structures and cultures that undermine these processes. The flexibility of services is confined by program guidelines and evidence-based practice, which may not align with client's individual needs and preferences. Meanwhile, relational aspects such as empathy, active listening and continuity foster trust in providers that can be influential to aligning purposes. Consistent with the main focus of co-production of care service literature, service interactions provide an opportunity for service providers to identify and address barriers to client propensity. However, there are often other practical barriers that preclude clients from making necessary co-production contributions outside service interactions. Adding to the complexity, clients are often dependent on formal and informal third parties to overcome these barriers.

The 'Service-Needs Gap' (S-N Gap) was also coined in this thesis to describe the gap between services covered by the formal care system and clients' need for support to maintain living independently in the community. Clients are reliant on people in their social networks to fill this gap for their needs to be addressed out of necessity, although in some cases as an alternative to formal services to improve the quality of care. Whether care is outsourced to carers is often by default, however there are factors that should be considered relating to the implications for both clients' and carers' health and safety. Characteristics of the tasks, including whether they involve specialised skills or knowledge; manual handling, intimacy and constancy, should be considered in how carers are supported in their role. The S-N Gap provides a framework for considering the balance between formal and informal care. Sustaining informal care is an economic imperative, that calls for proactive approaches to getting the right balance and supporting carers rather than reacting to crisis resulting in hospitalisations or early admission to residential care.

Co-production offers a solution to achieving better health outcomes and allowing people to maintain living independently in the community, decreasing costs and demands for the formal system. Often older people with complex needs are reliant on people in their social networks to interact with the service system and ensure issues and needs are addressed. The scale of informal care is staggering, representing three-quarters of care provided in Australia. However, reliance on informal carers without providing adequate support is counter intuitive. Forcing carers into situations where they have to choose between addressing their own health issues and continuing their caring role, not only results in poor health outcomes, but an inability to sustain providing care.

The public are often viewed in the academic discourse as representing dormant or latent resources to be activated - failing to see the human face of co-production, particularly for people with complex needs. The assumption that the barrier facing co-production is the need to increase the sense of self-efficacy through the provision of information and education falls far short of the reality of what is required to facilitate the co-production of their care in the community. Addressing these gaps

involves mutual adjustments on both the supply and demand side, and involves complex inter-dependences between providers, clients, their carers and other third parties. While co-planning and co-design hold the promise of bridging I-P and S-N Gaps, in practice they are often not supported by organisational structures and culture.

In Australia, there have been attempts to better integrate the health and social care sector, yet lack of access to formal care significantly undermines the feasibility of people with complex needs making necessary contributions to addressing their health issues in the community. Facilitating and sustaining the care of ageing populations in the community is largely contingent on the contributions of clients and carers as co-producers. This requires considerations not just of how to better manage these processes at the individual level but broader social, cultural, economic and environmental factors that influence disadvantage, in particular levels of health literacy, social connectedness and real recognition and support for carers.

AFTERWORD

It has been a humbling experience to share in people's stories about how they manage their care in the community, and the resilience and ingenuity they portray. As was the generosity of people in varying relationships to clients, providing care and support for the older people to maintain living independently in the community as family, friends and neighbours.

These stories remain crystallised in my memory and provided intensely vivid and rich insights into the lived experiences of people making vast and significant contributions to the delivery of complex care in the community. These stories often also revealed the harrowing realities faced by carers particularly as older people's needs for support increases. Primary carers were often forced to choose between their caring role and maintaining their own health, due to lack of alternative options (with over 100,000 Australians on waiting lists of up to two years for higher level aged care packages at the time of writing) and concerns often founded through poor past experiences, about the quality and safety of formal care services (a service system under review by a Royal Commission for failing to provide the most basic level of care and safety for the most vulnerable in our society).

When faced with this Sophie's Choice carers' instincts are often to prioritise the care of others at the expense their own health. Too often carers are the 'collateral damage' of a system where the default is to outsource care to people in the clients' social network until this approach fails. In addition, these stories do not necessarily capture those most disadvantaged in the system that are often hard to reach and underrepresented in research.

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APPENDIX 3.A

Policy Document Analysis, Coding Framework Matrix.

Sub-category	Key initiatives and illustrative quotes	Links to data
Re-orienting towards prevention		
National policy and funding for prevention	Centralisation of health and hospital funding with the Commonwealth as majority funder, creates incentive to invest in prevention to decrease demands on other parts of the system by keeping people healthy. The Commonwealth also assumed full funding and policy responsibility for primary health care including prevention (under the National Health Hospital Network agreement). "A greater focus on prevention and a more systematic approach to preventive care will help to ensure that Australians are supported to maintain optimum health" (DHA 2010b, p. 35). A National Partnership Agreement on Preventive Health with the states and territories was established, including funding commitment to develop a range of health promotion and population health programs including preventive health focusing on lifestyle risk factors for chronic disease. A key element of the nation agreement on preventive health was establishing a statutory agency (the Australian National Preventive Health Agency or ANPHA) responsible for policy leadership and national capacity to drive preventive health policies and programs, strengthen investment and infrastructure in preventive health, managing social marketing activities (targeting lifestyle factors), and providing leadership in research and surveillance.	NHHN reforms: p. 2, 4, 9, 10, 13, 19, 21, 22, 26, 40, 54, 61, 64, 77, 78, 79, 80, 81, 82, 83, 110, 112 PHC reforms: p. 29, 33, 34, 35 Aged care reforms: p. 19, 34 -36 (Active ageing) Mental health reforms: p. 7, 10, 18, 20, 21
Local planning and accountability for prevention	Structural changes in the reforms included the establishment of a regional network of Primary Health Care Organisations or PHCOs (initially as Medicare Locals and reformed as Primary Health Networks in 2015). These organisations aim to provide a platform for better planning and delivery of health promotion and preventive health programs targeted at risk factors in the local community (with support from ANPHA). To increase accountability for prevention, performance reporting for PHCOs (through 'Healthy Communities Reports') includes preventive health risk factors and other measures of community health and wellbeing. The mental health reforms focused on prevention in PHC for people with mental health issues, as part of the stepped-care approach to "shift the focus upstream, away from acute and crisis intervention over time and towards an early intervention approach" (DH 2015 p. 8).	NHHN reforms: p. 6, 11, 25, 40, 43, 46, 47, 64, 82, 83 PHC reforms: p. 34, 37 Mental health reforms: p. 8, 9, 11, 12, 13, 14, 17, 22
Prevention in GP and outcomes-based funding	Prevention in PHC included new models of care involving a range of preventive activities. These included providing GPs incentives to expand and enhance the role of practice nurses "to undertake a broad range of prevention activities such as health	NHHN reforms: p. 6,10, 59, 64, 65, 67, 68

	assessments, health promotion and advice, educating patients on lifestyle issues and managing recall and reminder systems" (DHA 2010b p. 36). In general practice, new arrangements for chronic disease management (starting with diabetes), were included to provide people with the option to enrol with a GP responsible for managing their condition and "keep them healthy over time, rather than just treating the presenting symptoms" (DHA 2010b p. 32). There was a shift towards outcomes-based funding with including new funding arrangements and incentives for prevention in GP through a mixture of flexible funding to manage peoples' chronic conditions and rewarding GPs for achieving health outcomes.	PHC reforms: p. 29, 33, 34 Aged care reforms: p. 19, 22 Mental health reforms: p. 13, 14, 17, 18
Workforce capacity building for delivering preventive health	As the frontline of the health system, GP and other PHC providers were said to provide a key environment for delivering preventive care. The reforms included increasing the capacity of the PHC workforce to undertake preventive health in the community, focusing new funding models to incentivise prevention in GP, and expanding the role of practice nurses to perform prevention activities.	NHHN reforms: p. 9, 65, 68, 120 PHC reforms: p. 34 Mental health reforms: 7, 13, 15, 20, 21
Re-locating care into the community		
Centralisation and funding to drive the provision of care in community	Centralisation of funding across the health and hospital system aimed to create incentives to decrease demand for costly hospital services by improving access to primary health care (PHC) and other community-based services and supporting a healthier community. The reforms also included a shift from block funding for hospital services to activity-based funding, where payment is based on a national efficient price for each hospital service (set by the Independent Hospital Pricing Authority or IHPA). Funding based on the efficient price for each service creates incentive to avoid prolonged hospital stays or services they could be provided in less costly non-acute settings while still receiving funding for that service. The Commonwealth was to provide the States with 'top up funding' to finance growth in hospital costs whereby the "states will be required to spend the residual on any health service that will assist in ameliorating the growth in demand for hospital services, including programs for chronic disease management, preventive health, mental health, hospital admission programs and hospital early discharge programs" (DHA 2010a, p. 54). The Government is committed to sustainable, high quality aged care and to providing funding for more services to older Australians. Since November 2007, more than 10,000 new aged care places have become operational and the Government is making more than 12,000 new aged care places available this year, with a strong focus on community care" (DHA 2010a p. 22). "This reform will help improve integration between the acute and primary health care sectors, and help patients access more	NHHN reforms: p. 5, 8, 9, 10, 11, 12, 13, 17, 18, 22, 27, 31, 34, 57, 58, 59, 60, 61, 62, 71, 73, 75, 76, 77, 103, 108, 111, 114, 117, PHC reforms: p. 7, 8 Mental health reforms: p. 7, 10, 21, 22

	appropriate and cost-effective care in the community" (DHA 2010a p. 31).	
Moving sub-acute and outpatient services into the community	Investments in sub-acute care to ensure patients who still require medical care but could be better treated outside the hospital setting to have access the services they need including rehabilitation, palliative care, mental health and geriatric services. "By improving the capacity of the public hospital system to provide appropriate care for people with sub-acute need, health outcomes and quality of like will improve for many vulnerable patients. Without this care, these patients could otherwise be inapparently care for in an acute care facility or discharged prematurely to residential care or into the community" (DHS 2010b, p. 77). The reforms also included the Independent Hospital Pricing Authority (IHPA) to classify which outpatient services could be provided as effectively and more efficiently in the community as PHC services, to be provided outside hospitals. This reform will help improve integration between the acute and primary health care sectors, and help patients access more appropriate and cost-effective care in the community. Some outpatient services are more closely associated with admitted services, whereas others can be more appropriately associated with primary health care. With the assistance of the states, and the increased data that will become available as a result of these reforms, the Government aims to distinguish between these different types of outpatient services, and over time, move to funding them in a manner that better reflects the character of the service. In doing this, the Government will ensure patients continue to receive public hospital services free of charge (DHA 2010a, p. 31)	NHHN reforms: p. 5, 9, 11, 12, 17, 20, 27, 31 44, 57, 58, 62, 69, 75,76, 77, 90, 92, 93, 108, 114, 115, 116 Mental health reforms: 10
Local service planning and accountability to address service gaps in the community	At the regional level, devolving responsibility for population needs assessment and service planning and delivering or commissioning of services to address local needs, including services targeted at risk or under-serviced population sub-groups. PHCOs were also to improve links between health and aged care by identifying and addressing gaps in primary care for older people and ensuring access to a GP after discharging from hospital for follow-up care and after-hours GP services. PHCOs were also to enhance the capacity of GPs to manage the care of people with chronic conditions, by providing them with a complementary array of services, including allied health care services, identified in personalised care plans prepared by GPs. Regional mental health plans were designed to perform comprehensive needs assessment and service mapping to identify gaps and remove inefficiencies, with the commissioning of service through flexible funding pools by PHCOs. PHOCs to be held to account for reporting on measuring performance including access to community-based services and rates of avoidable hospital admissions, as part of	NHHN reforms: p. 5, 10, 11, 25, 28, 34, 35, 40, 41, 43, 44, 45, 46, 67, 57, 58, 63, 64, 111, 118, 121 PHC reforms: p. 8, 13, 14 Mental health reforms: p. 8, 9, 11, 12, 13, 14, 21

	new performance and accountability framework (under the National Performance Authority).	
Better chronic disease management in the community	New arrangements for chronic disease management were included in the reforms to improve access to community-based services and better manage conditions in the community. This included voluntary enrolment with a GP, starting with diabetes, responsible for managing their condition over time. GP would develop personalised care plans to improve access and coordinate care with other providers to address the client's need such as diabetes educators and podiatrist, to "reduce the costs associated with managing complications of diabetes and of unnecessary hospital admissions" (DHA 2010b p. 32). The 'Stepped Care Model' also referred to "innovative funding and delivery models" in primary care to better support coordinated services for people with complex needs (as informed by the Primary Health Care Advisory Group).	NHHN reforms: p. 10, 16, 17, 20, 25, 54, 59, 60, 61, 64, 65, 66 PHC reforms: p. 31, 32 Aged care reforms: p. 19 Mental health reforms: p. 17, 18
New infrastructure for community-based care	Increasing and improving access to community-based services included funding for physical infrastructure such as building new and expanding existing services that provide a range of services in a single location, targeted to the needs of local communities open for extended hours (including PHC 'GP Super Clinics' and youth mental health services 'Headspace'. There was also funding allocated to establishing a national network of 'One Stop Shops' to, "assist older Australians and their carers to more easily access the services available to them in their community" (DHA 2010a, p. 131).	NHHN reforms: p. 4, 15, 20, 21, 60, 67, 113 PHC reforms: p. 21, 22, 23 Mental health reforms: p. 11
Use of e-health to provide remote services	The reforms included e-health (using information communication technologies (ICT) including tele-health and internet websites) as a means of providing access to remote services and to provide referrals/linkages to other community-based services. This included an after-hours primary care through a telephone-based medical diagnostic service and advice or ensure access to a local after-hour GP service, to prevent avoidable presentations to hospital emergency departments. The aged care reforms included establishing a gateway comprising a website and national call centre to provide the main entry point for accessing the aged care system and provide a linking service to facilitate access to services in local communities such as referrals to health, housing, disability services and financial advice as well as aged care services. The 'Stepped Care Model', in the mental health reforms aimed to prevent under and over-servicing, by referring people requiring low intensity services to digital mental health services (as an alternative for GP referral to physiological services). This approach included the establishment of a 'gateway' providing access to information, advice, and digital mental health treatment and connecting people to community-based services through a centralised web and telephone portal. Alternatives to face-to-face services offered as part of community care included information, self-help, crisis support, assessment and	NHHN reforms: p. 10, 12, 13, 82, 86, 87, 111, 112 PHC reforms: p. 15, 16, 17 Mental health reforms: p. 7, 9, 10, 11, 12 Aged care: p. 29, 31, 32 (access not virtual service)

	treatment and peer support, encompassing both self-help and clinician moderated services, online and by telephone.	
Addressing professional workforce shortages for community-based care	Increasing the provision of care in the community included addressing professional workforce shortages. This included initiatives such as: establishing a planning agency (Health Workforce Australia) and national registration and accreditation (Australian National Health Professional Regulation Agency); increasing the number doctors, nurses and allied health professionals working in the community; and providing incentives to increase recruitment and retention in rural and remote areas. There were also initiatives to expand the roles of nurse practitioners and practice nurses (Practice Nurse Incentive Programme), to decrease pressure on general practitioners.	NHHN Reforms: p. 13, 15, 16, 20, 21, 25, 58, 60, 68, 69, 76, 90, 100, 101, 102, 103, 104, 105, 106, 107, 116, 117, 118, 123 PHC reforms: p. 10, 12, 18, 19, 20, 21, 27, 34, 35 Aged care reforms: p. 1, 15, 16, 20, 29, 30 Mental health reforms: 7, 11, 12, 13, 15, 19, 20, 21
Increased access to aged care for older people	The shift towards community-based care included increasing access to aged care services to assist older people to maintain living independently in the community. This included increasing the number of Home Care Packages for people eligible for high level care in the community from 40,000 to 100,000, (based on a phased increase in the 'aged care provision ratio' and increased proportion of home care places compared with residential care places). The aged care reforms also included centralising low-level aged care services under one Commonwealth Government funded program (CHSP) and included a future review of the newly formed CHSP, to inform the more consistent and equitable service delivery and arrangements, and more national consistency on what consumers contribute to the cost of these services.	NHHN reforms: p. 4, 5, 8, 9, 10, 11, 18, 19, 22, 25, 26, 28, 34, 35, 41, 43, 44, 57, 73, 74, 76, 91, 115-118 PHC reforms: p. 13, 28, 30 Aged care reforms: p. 15, 1, 2, 3, 4, 5, 6, 21, 22, 23, 25, 26, 28, 29, 34, 35 Mental health reforms: p. (NDIS – 17, 18, 20, 21)
Supporting informal or	Carers	NHHN reforms: p.

unpaid care providers in the community	The reforms included support for carers or family that provide informal care in the community. The aged care reforms included increasing access to support services (such as respite and counselling), consolidating carer services under a national home support program (Commonwealth Home Support Programme or CHSP), establishing a network of carer support centres, legislation under the National Carer Recognition Act, and a national carers strategy. "The Gillard Government understands the pivotal role that carers play in providing quality support to older Australians. Carers provide most of the care received by older Australians. Like any member of the workforce, these carers sometimes need to take a break and need to take care of themselves" (DHA 2012, p. 7). The mental health reforms document noted that, "carers should also be recognised as key partners in achieving better outcomes for people with mental illness" and made reference to the development of a national consumer and carer participation framework (DH 2015, p. 7). However, references to carers or family tended to be in conjunction with references to patients or consumers, rather than distinct actors in the provision of care. Volunteers There were also measures to facilitate other unpaid care providers acting formally as volunteers. This included funding for volunteer schemes (Community Visitor Scheme) and a review legislation to ensure liability protections. Volunteering was also encouraged as part of the Government's 'Positive Ageing Agenda'. Peer support The concept of 'peer support' was raised in the mental health reforms. Peer support was defined as "social and emotional support, frequently coupled with practical support, provided by people who have experienced mental health problems to others sharing a similar mental health condition. Peer support aims to bring about a desired social or personal change and may be provided on a financial or unpaid basis" (DH 2015, p. 24). Peer support involves people with lived experience of a condition providing support in informal/formally organised and paid/unpaid capacities. This included developing mechanisms for consumer and carer participation service delivery through a consumer and carer participation framework.	18, 43 (respite) 72, (111 mentor services ?) Aged care reforms: p. carers – 1, 3, 7, 8, 18, 24, 31; volunteers – 17, 34, 35, 36) Mental health reforms: p. carers: 3, 4, 7, 14, 18, 19, 20, 21; peer support: 7, 10, 23
Re-balancing decision-making towards public participation		
Public engagement and participation	Re-balancing power included various references to public engagement and participation in decision-making processes at different levels of government about policy, design, commissioning and implementation. However, the nature and extent of these contributions was often not explicit.	NHHN reforms: p. 5, 19, 23, 24, 28, 36, 40, 88,

	The reform documents used phrases such as, 'engagement', 'participation', consultation' or 'working with' in referring to client involvement in decision-making about policy, planning and the design of services. These references included some formal processes including consumer representation on advisory panels at the systems level, and the establishment of a national participation framework, and at the regional level through PHCOs were required to establish 'Community Advisory Committees' to formalise public participation in local governance, and engagement with local providers including clinical engagement. Devolving decision-making closer to the clients and providing frontline providers greater autonomy and (funding) flexibility to provide more responsive services. "The Government will develop with consumers and carers a participation framework to guide future national reform efforts by governments and services and will explore means to strengthen communication with consumers and carers in national policy (DH 2015, p. 7).	PHC reforms: p. 39 Aged care reforms: p. 3, 20, 35 Mental health reforms: p. 3, 4, 7, 18, 20, 21
Client participation in decision-making about their care	At the individual level, client participation in decision-making about their care may be (inferred) in reference to personalised care planning as part of 'coordinated care' for people with chronic conditions. Care planning was referred to as providing personal choice and control in relation to advanced care planning. The phrase 'choice and control' was also used in relation to the provision of personalised budgets for people and social care packages was part of the reforms to give clients control over decision-making about their choice of services. The aged care reforms focused on providing 'choice and control' by providing Home Care Packages on a 'Consumer Directed Care' (CDC) basis through the provision of personal budgets, "placing the individual at the centre of care decisions, fully engaging them in determining what and how their care needs are provided" (DHA 2012, p. 4). CDC was also said to provide carers with more choices and flexibility in the services they use (however it is unclear who has control of personalised budget, clients, carers or negotiated between them). The mental health reform document referred to the Government's commitment to the National Disability Insurance Scheme (NDIS) to provide support on a CDC basis to provide choice and control. "Increasingly, the level and mix of services will be driven more by the people using the system and less by Government regulation. The role of Government will be more focused on ensuring fairness of access to aged care services and enhancing the quality. Aged care providers will have new opportunities to extend the services they provide to ensure a more consumer focused approach to business" (DHA 2012 p. 29). "A consumer focused approach to care must be underpinned by consumer centred funding arrangements. Essentially, funding for primary mental health care services	NHHN reforms: p. 65, 66, 122 PHC reforms: p. 9, 32 Aged care reforms: p. 4, 17, 31 (choice and control – 1, 4, 7, 8, 10, 11, 19, 29, 30) Mental health reforms: p. 3, 7, 18, 20

	should be targeted at, and support, the choices of the individual consumer based on the level and type of need" (DH 2015, 7).	
Providing information to increase health literacy and competition	The reforms included initiatives to inform decision-making about their health and services. These initiatives included individual models of care encouraging health professionals to provide information and education and providing information on website and telephone platforms to improve health literacy. The aged care reforms also included providing comparative data to inform choice of service (based on national aged care quality indicators and a rating system). Nationally comparable performance data through Local Hospital Networks and Medicare Locals/Primary Health Networks. Personally controlled electronic health record also provide clients access to their own health information.	NHHN reforms: p. 5, 6, 7, 12, 18, 26, 28, 35, 41, 45, 47, 51, 57, 71, 72, 74, 84, 85, 86, 87, 99 PHC reforms: p. 2, 7, 20, 25, 30, 31, 32, 33 Aged care reforms: p. 2, 7, 17, 20, 25, 30, 31, 32 Mental health reforms: p. 13, 2, 6, 7, 10, 11, 12, 13, 14, 15, 18, 19, 21
Improving feedback and complaints	The aged care reforms also included initiatives to improve feedback and complaints systems, as a mechanism for provide recourse for client satisfaction and to influence quality improvement by improving feedback or complaints systems.	PHC reforms: p. 12, 36, Aged care reforms: p. 2, 17, 18, 32, 36
Advocacy	Increased funding for the national advocacy programs was also part of the aged care reforms to provide support and education to clients/consumers to understand and exercise their rights and have a greater say in the way their care is provided.	Aged care reforms: p. 1,17
Re-aligning to integrate care		
Centralised policy and funding to better integrate the system	Centralisation of funding for health and hospital service under the NHHN was said to provide incentive to better integrate services across the systems to improve the efficiency. Commonwealth commitment to partnership agreements with the States, and inter-sectoral action, also strategies used in the reforms where coordination was required across levels of government or portfolios which required improve system integration or service planning. The Commonwealth will be responsible for setting national standards and policy. As a result of taking full funding responsibility for all primary health care and aged care services, the Commonwealth will be able to draw services together so they are better integrated, better coordinated, and more responsive to the needs of patients (DHA 2010a p. 34).	NHHN reforms: p. 4, 5, 9, 11, 26, 27, 31, 34, 41, 43, 44, 57, 58, 60, 61, 71, 72, 73, 74, 76, 89, 108, 109, 111, PHC reforms: p. 7, 8, 24, 25, 26

	"A vital element of a person-centred mental health system is ensuring providers at a national and regional level understand that, from the consumer's perspective, a failure in one part of the system will reduce outcomes in another and increase their demands on services and benefits" (DH 2015 p. 7).	Aged care reforms: p. 1, 19 Mental health reforms: 2, 4, 5, 6, 7, 11, 16, 18, 21
Regional integration	At the regional level, responsibility for service integration was devolved to local institutions including PHCOs and LHNs working with aged care 'one stop shops' to ensure service cooperate and collaborate. These local institutions have responsibility to work together to identify pathways between services, including transitions from hospital, and develop linkages between aged care providers, the private sector, and Aboriginal Health Services, to ensure the system is joined up at the local level. A regional approach to integrated service planning and delivery across the spectrum of services, in partnership with LHN and other key stakeholders including NGOs, clinicians and consumers, to make the service system responsive to local needs. Integrated service planning including needs assessment and service mapping to identify gaps and commissioning of service through flexible funding pools with PHCOs to address local needs. "Integration of services will occur 'on the ground' at the regional level because this is the level of the system where direct communication and practical steps can be taken to drive integration of currently disconnected services and to optimally address local needs" (DH 2015 p. 8).	NHHN reforms: p. 5, 10, 11, 13, 25, 28, 34, 35, 36, 40, 41, 42, 43, 44, 57, 58, 61, 63, 64, 74, 111 PHC reforms: p. 13, 14 Aged care reforms: p. 1, 19 Mental health reforms: p. 2, 3, 5, 6, 7, 8, 9, 11, 14, 15, 16, 17, 18
Gateways at main entry points and referral pathways	The aged care and mental health reforms included establish 'gateways' to provide a single portal or main entry point to services by establishing a website and telephone portal. These gateways included centralised assessment of care needs, advice and information, and linking services for accessing local services, in the aged care and mental health sector, providing joined up assessment and referral pathways. Another approach to facilitate coordination between services was co-location to provide a range of services in a single location. Stepped care approach in mental health	NHHN reforms: p. 37, 43, 67, 82, 109, 112 Aged care reforms: p. 2, 31, 108 Mental health reforms: p. 2, 3, 6, 7, 8, 9, 10, 11, 12, 13, 14, 15, 18, 19
Co-location and multi-disciplinary team-based care	Co-location was another approach to facilitate integration through the provision of a range of services in a single location. This included funding to establish new and expand existing 'GP Super Clinics'. The mental health reforms also included co-location with the expansion of 'Headspaces' that provides a range of services in a single location to ease access for younger	NHHN reforms: 11, 20, 58, 6 p. 0, 67, 108, 109, 112

	people to mental health services in the community. GP Super Clinics provide the facilities for multi-disciplinary teams to work together and enable better coordinated referrals to ensure patients receive care centred around their needs. Practice nurses also play a role in team-based care in GP.	PHC reforms: p. 15, 21, 22 Aged care reforms: p. 1, 19, 20 Mental health reforms: p. 6, 13, 15, 16, 17
Individual level care coordination	Individual models of integrated care included "coordinated care" for people with complex needs through enrolment with a GP responsible for the continuity of their care over time, personalised care planning to facilitate access to a range of providers to address their needs and coordination of care across a range of providers. Another individual model of integrated care included the use of personalised budgets for aged care home care packages, to provide greater choice and control, "placing the individual at the centre of care decisions" (DHA 2012 p. 1). "Provide wrap-around coordinated care or people with complex needs" (DH 2015, p. 9).	NHHN reforms: p. 10, 11, 16, 17, 25, 57, 58, 65, 66, 72, 83, 91, 111, 113, 114 PHC reforms: p. 31, 32, 34 Aged care reforms: p. 2, 4 Mental health reforms: p. 3, 6, 9, 14, 17, 18, 19
Integrated information systems	The reforms also included the electronic exchange of patient/consumer information to improve integration, including e-Health and other technologies and enabling compatibility between information systems. Shared use of a single e-health record or (the 'Personally Controlled Electronic Health Record' or PCEHR) was to be implemented to enhance communication between providers and patients, with information attached to patients to support a 'patient-centred health care system. The electronic health record aimed to decrease reliance on patients to recall and repeat health information and prevent duplication and time spent chasing information or requiring patients to recount their health and medical history. "patients will no longer need to recall and repeat their health information to different health care providers, or carry their medication lists with them when they travel or see new providers. They will not need to rely on their memory of test results and procedures" (DHA 2010a p. 85)	NHHN reforms: p. 9, 24, 57, 84, 85, 87 PHC reforms: p. 15, Mental health reforms: p. 8, 11 17, 18,

APPENDIX 3.D

CHSP coordinator recruitment information sheet.

Project Title: Older people and their carers as co-producers of complex community-based care

Information Sheet for CHSP Coordinators

We are conducting a study to explore how older Victorians and their carers experience participating in their own care or the care of someone close to them, in order to understand how they use their resilience, expertise and resourcefulness to participate in the delivery of care in the community.

This study will seek to provide insights into how older people with complex needs and their carers participate in the delivery of care to improve health outcomes and maintain living independently in the community.

The study will be performed by Louise Freijser (PhD Candidate), Dr Helen Jordan at the Centre for Health Policy, and Prof. John Alford at the School of Government, at The University of Melbourne.

What We Are Asking You To Do?

We are seeking your assistance in the recruitment of 8 Commonwealth Home Support Programme (CHSP) clients (and their carers). This would involve identifying clients who meet the inclusion criteria and then extending an invitation for them to participate in a 30-45 minute interview (at a location of their choosing).

The invitation will be in the form of letter detailing what would be required if they choose to participate in the study and a consent form to be contacted by a researcher. Potential participants would be required to fill in the consent form, including details on how and when they would like to be contacted.

Potential participants will be assured that they are under no obligation to participate and are free to withdraw at any time. Confidentiality will be strictly maintained. Participants will also be assured that their participation will have no bearing on their service provision.

Inclusion Criteria for Participation in the Study

Inclusion criteria for older Victorians includes:

1. Aged 65 years and over
2. Living with three or more chronic conditions
3. Living in private residences (not assisted living/residential care)
4. Receiving ongoing care by two or more care providers in more than one sector (i.e. primary, secondary, acute and community and home care sector) over the previous 12 months

Secondary criteria to capture a diverse mix of participants:

- Gender
- Cultural background
- Age
- Types of conditions
- New clients/post discharge from hospital and long term clients with a high degree of complexity
- Level of support provided by informal carers

Key Research Questions

1. How do you manage your health on a day to day basis? (Or, if you are a carer of someone with complex care needs, how do you provide support to this person?)
2. What helps and hinders managing your health on a day to day basis? (Or, if you are a carer of someone with complex care needs, what helps or hinders the management of their health?)
3. What activities are required in managing your health on a day to day basis? (Or, if you are a carer of someone with complex care needs, what activities are required to perform in the management of their health?)
4. What might make this easier?

Ethics Approval

This research project has been subject to rigorous ethics committee review has been approved by the Human Research Ethics Committee at The University of Melbourne (Ethics id: HREC 1545855).

Data Collection

Participants will be asked to attend an interview (either face-to-face or via the telephone, based on their preference). With their permission, the interview will be recorded. The total time commitment required of participants would not exceed 45 minutes.

The interview questions will only relate to the participants' experiences and expectations of participating in the production of health and social care services. The interview questions will be provided to potential participants prior to their recruitment into the study.

All participants will be reminded immediately prior to the collection of data that no identifiable personal information about the participant will be made available to any person except the researchers. Pseudonyms will be used for the report. The participants will also be reminded that they are free to withdraw from the study at any time.

The Purpose of the Study

The findings of this study will provide strategies for enhancing the capabilities of older people and their carers to participate in their care, in order to empower and support them to continue living independently in the community. In addition, the study will also identify systemic issues that create barriers to people effectively co-producing care.

Where Can I Get Further Information?

Should you require any further information, or have any concerns, please do not hesitate to contact Louise Freijser at louise.freijser@unimelb.edu.au or 0410 879 519.

Thank you for your support

APPENDIX 3.E

Policy maker and other key stakeholder interview plain language statement.

Ms. Louise Freijser (PhD Student)
Melbourne School of Population and Global Health
The University of Melbourne
Level 4/207 Bouverie St,
VIC 3010
Australia
louise.freijser@unimelb.edu.au
0410879519

PLAIN LANGUAGE STATEMENT

Project title:

Older people and their carers as co-producers of complex community-based care

Introduction

I would like to invite you to participate in a research project led by Professor John Alford and conducted by myself, a PhD student at the University of Melbourne, Centre for Health Policy. We are interested in capturing your experiences of participating in your own care or providing care to a person with complex care needs who is close to you.

Your story will help us to understand how people use their resilience, expertise and resourcefulness to participate in the delivery of care. It will also help us understand how people with complex care needs may be facilitated and supported, in ways that promote independence, health equity and the wellbeing of carers.

The project has been approved by the Human Research Ethics Committee (HREC Ethics Number 1545855).

What will I be asked to do?

If you would like to participate in the study you would be asked to take part in a face-to-face interview. You will be able to decide a date, time and place that suits you. The interview can be as long or short as you like and we can stop for breaks at any time. However, it is anticipated that it would take approximately 45 minutes in total.

With your permission, the interview would be tape-recorded, to ensure that we make an accurate record of what you say. If you wish, you can also participate in a follow up telephone call/visit to check the researchers understanding of your responses.
The key questions sought to be answered by the project overall are:

1. How do you manage your health on a day to day basis? (Or, if you are a carer of someone with complex care needs, how do you provide support to this person?)
2. What helps and hinders managing your health on a day to day basis? (Or, if you are a carer of someone with complex care needs, what helps or hinders the management of their health?)
3. What activities are required in managing your health on a day to day basis? (Or, if you are a carer of someone with complex care needs, what activities are required to perform in the management of their health?)
4. What might make this easier?

How will my confidentiality be protected?

Your privacy and the confidentiality of your responses will be protected to the fullest possible extent. Your name and contact details will be kept in a separate, password-encrypted computer file from any data that you supply. In the final report, you will be referred to by a different name.

Any references to personal information that might allow someone to guess your identity will be removed; however, you should note that as the number of people we seek to interview is small, it is possible that someone may still be able to identify you. The data will be kept securely at The University of Melbourne for five years from the date of publication, before being destroyed.

How will I receive feedback?

You will be provided with a report of the study findings, via email or post (based on your preference).

Will participation prejudice me in any way?

Your participation in this study is completely voluntary. Whether you do or do not decide to participate in the study, will have no bearing on your current or future Home and Community Care or other services. Should you wish to withdraw at any stage, or to withdraw any unprocessed data you have supplied, you are free to do so without prejudice.

Where can I get further information?

Should you require any further information or you have any concerns at any time, please do not hesitate to contact one of the researchers, Louise Freijser by telephone on 0410 879 519 or via email on louise.freijser@unimelb.edu.au or Professor John Alford on 8344 1975 or via email on j.alford@anzsog.edu.au

For advice regarding support services you can also contact the My Aged Care on 1800 200 422 or the website myagedcare.com or Carers Victoria on 1800 242 636.

If you have any concerns or complaints about the conduct of this research project, you can contact the Manager, Human Research Ethics, Office for Research Ethics and Integrity, The University of Melbourne by phone 8344 2073 or email humanethics-complaints@unimelb.edu.au quoting HREC 1545855.

How do I agree to participate?

If you are willing to participate, please complete the attached consent form and you will be contacted by the researchers to arrange an interview. Thank you for your consideration.

APPENDIX 3.F

Client and carer interview consent form.

CENTRE FOR HEALTH POLICY
MELBOURNE SCHOOL OF POPULATION AND GLOBAL HEALTH

Consent form for persons participating in a research project

PROJECT TITLE:

Older people and their carers as co-producers of complex community-based care

Name of participant:

Name of investigators:

Ms. Louise Freijser (PhD Student)
Centre for Health Policy
School of Population and Global Health
The University of Melbourne
Level 4/207 Bourverie St,
VIC 3010
Australia
louise.freijser@unimelb.edu.au
0410879519

Prof. John Alford (Primary supervisor)
jalford@unimelb.edu.au

Dr. Helen Jordan (Supervisor)
h.jordan@unimelb.edu.au

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1. I consent to participating in this project, the details of which have been explained to me, and I have been provided with a written plain language statement to keep.

2. I understand that after I sign and return this consent form the researcher will retain it.

3. I understand that my participation will involve an ***interview*** and I agree that the researcher may use the results as described in the plain language statement.

4. I acknowledge that:

(a) the possible effects of participating in the ***interview*** have been explained to my satisfaction;

(b) I have been informed that I am free to withdraw from the project at any time without explanation or prejudice and to withdraw any unprocessed data I have provided;

(c) the project is for the purpose of research;

(d) I have been informed that the confidentiality of the information I provide will be safeguarded subject to any legal requirements;

(e) I have been informed that with my consent the ***interview will be audiotaped and I understand that audiotapes*** will be stored at University of Melbourne and will be destroyed after five years;

(f) my name will be referred to by a pseudonym in any publications arising from the research

(g) I have been informed that a copy of the research findings will be forwarded to me, should I agree to this.

. I consent to having the following contact details provided to the researchers and to be contacted to arrange an interview.

Contact Details: _____

Telephone number: _____

Best times to call: _____

Address: _____

_____

Participant signature: _____

Date: _____

APPENDIX 3.G

Client and carer interview study, sample coding framework matrix.

Interview 20, Henry (primary carer for wife with advanced dementia).

1. Contributions to the production process

Emergent Themes from the Data	Link to the Raw Data and Notes
Monitoring and identifying health issue or need for support	20:7 (i.e. interview and transcript line number) - identified wife doing things she wouldn't normally do 20:16 - fall in garden - neighbour happened by and found she had fallen 20:131 - GP advised to return in 6 weeks - follow-up 20:424 - routine specialist appointment - regular follow-up 20:199/332 - Henry identified his own need for counselling
Determining whether to access a service	20:16 - wife in pain after fall/can't get up - decide to call ambulance (broken femur) 20:131 - Provider (GP) advises to return in 6 weeks 20:424 - Provider (specialist) referral/routine appointment 20:255 - Provider (cardiologist) 6-month check up 20:332 - internet - found number to call for counselling
Perform activities to access a service	20:16 - call ambulance for wife after fall 20:388 - takes a lot of time/planning to get to appointments - getting wife 20:403 - wife does not want to go to the doctor - husband goes on her behalf
Provide inputs to inform formal assessment and care planning	20:7 - Wife diagnosed with depression - kept saying that's not right - eventually sent for a scan and she was diagnosed with dementia 20: 39/96 - visit GP on wife behalf - coordinate between dietician and GP on diet. Tell GP about his wife's diet as requested by dietician who was concerned about high sugar/cholesterol - GP says don't worry it is quality of life
Participate in care planning	
Provider-driven	20:7 - Wife diagnosed with depression - told the specialist that's not right - memory not as good is it was/behaviour change (advocacy/voice) - told she was scoring well on MMSE (eventually had scan and was diagnosed with dementia) 20:211 - was told wife to be discharged that day - asked if she could stay until the next day so he could prepare - was told no
Client-driven	20:210 - asked if Henry wanted wife to come home or enter residential care

Collaborative/relational	20:100/122/131 - GP is a very good doctor - he is familiar with people with dementia - he seems to be understanding - he reckons I'm going a good job
Activities to address health issues	
Co-operate with conjoint activities with professional provider	20:113 - wife refuses to have blood test
Exercise and physical therapy	20:58 - Henry goes to gym to do group exercise 20: 286 - Walk around shop with wife
Diet and nutrition	20:34 - encouraging food and fluids to increase weight range recommended by dietician 20:98 - gives protein drink (in addition to meals on wheels)
Medication management	20:115 - Henry had flu injection 20:185 -- Henry stand and watch - wife puts next day's tablets in a little box - prompting her a couple of times 20:220 - get her bowels steady - liquid paraffin - as long as I don't go over or under 20:255 - Henry - take medication
Social, mental and cognitive health activities	20:58/360 - Henry goes to gym to do group exercise - have cup of tea after (combines both fitness and social interaction). 20:199/332/414 - Henry rang Carers NGO because couldn't sleep, really worried, referred to a councillor 20:267 - gets magazines sent form England that wife likes to read - does reading and watch TV shows and both try to answer trivia questions 20: 311 - when Henry injured - neighbour come and visit (but now that neighbour is moving, and other neighbours are also elderly - not in position to help others) 20:372 - friends as the gym - can talk to them about problems - some are widowed or are carers - have same issues 20:375 - attend NGO social events - once a month with wife - for people with dementia and their carers
Skin care and wound management	
Cigarette smoking cessation and substance use	
Other	
Supporting with personal care activities	
Mobility	
Bathing, grooming and dressing	20:66 - showering wife - council used to do showering but send someone different every time and on standby waiting for them to come so decided to give it up

	20:178 - get her up and dressed 20:50 clean her teeth
Toileting	20:217 - lost control of bowel on anti-biotics - (noted that in hospital - had three blokes to clean her up but at home just him) 20:220 - wife has not bladder control - change continence pads 2-3 times a day
Feeding	
Other	
Maintain a supportive home and living environment	
Home cleaning	20:66 - cleaning house (used to get home cleaning form counsel but don't do dusting only vacuum which he can do and have to be home which chews into the day so cancelled it 20:178 - do washing, cleaning the house, making bed 20: 235 - got washable mat for bed that can wash rather washing sheets everyday - made a sting with clips to hold napkins to save changing wife's clothes after each meal
Shopping and meal preparation	20:178 - get her breakfast, and prepare meals from service
Transport	20:302 - injury - couldn't drive for 8 weeks - neighbour went to post office
Gardening, and home maintenance	20:179 - gardening (hoping to access gardening service when receives higher level package)
Accessing aids and making home adaptions	20:84 - council came to assess - told need overhead shower - got the plumber across the road to come put one in 20:86 - council put in rails in bathroom, got slip proof mats and chair for the shower
Financial and legal obligations	20: 178 - do the finances 20:439 - budgeting (wife used to do it) 20:453 - health insurance - price going up - rang complained - so decreased price
Caring for pets	
Other	

2. Factors influencing the propensity to co-produce

Specialised knowledge/specification	20:220 - learn how to titrate medication and diet/fluids to improve continence
Cognitive/physical capacity	

Resources	20:43 - after wife discharged from hospital -no relations to provide informal support other than husband 20:229 - get $600 funding for incontinence pads - use more than that and other aids. 20: 311 - when Henry injured - neighbour come and visit (but now that neighbour is moving, and other neighbours are also elderly - not in position to help others)
Independence	20:185 -- prompting her a couple of times (assisting not doing for - maintain wife's independence)
Monitoring/being held to account	20:185 -- Henry stand and watch - wife puts next day's tablets in a little box - prompting her a couple of times
Other Motivations/priorities	20:58/360 - go to gym to do group exercise - have cup of tea after (combines both fitness and social interaction). 20:260 - Henry - got to stay fit physically, mentally - because just the two of us - nobody else to care for wife 20:292 - of I can keep active and keep positive - I can keep going a bit longer
Access to formal service	20:50 - asked for more respite but council won't give me more - waiting for higher care package 20: 50 - get 4 hours of respite - told can't access anymore from council (waiting list) 20:78 - waiting for government higher level care package - could be 6 months, 9 months I don't know 20:453 - health insurance - did not have to wait for surgery
Tasks not covered by formal services	20:66 - council don't do dusting, just vacuuming 20:98 - nutrition/meal preparation in addition to meals on wheels
Client preference	20:66 - stopped showering service from council because different people coming
Improve quality/safety/convivence	20:66 - council services between 9-11 - chew into the day
Other	20:135 - privacy laws - can't have access to wife's records without power of attorney (has finance but not medial) - too late - need to get guardianship

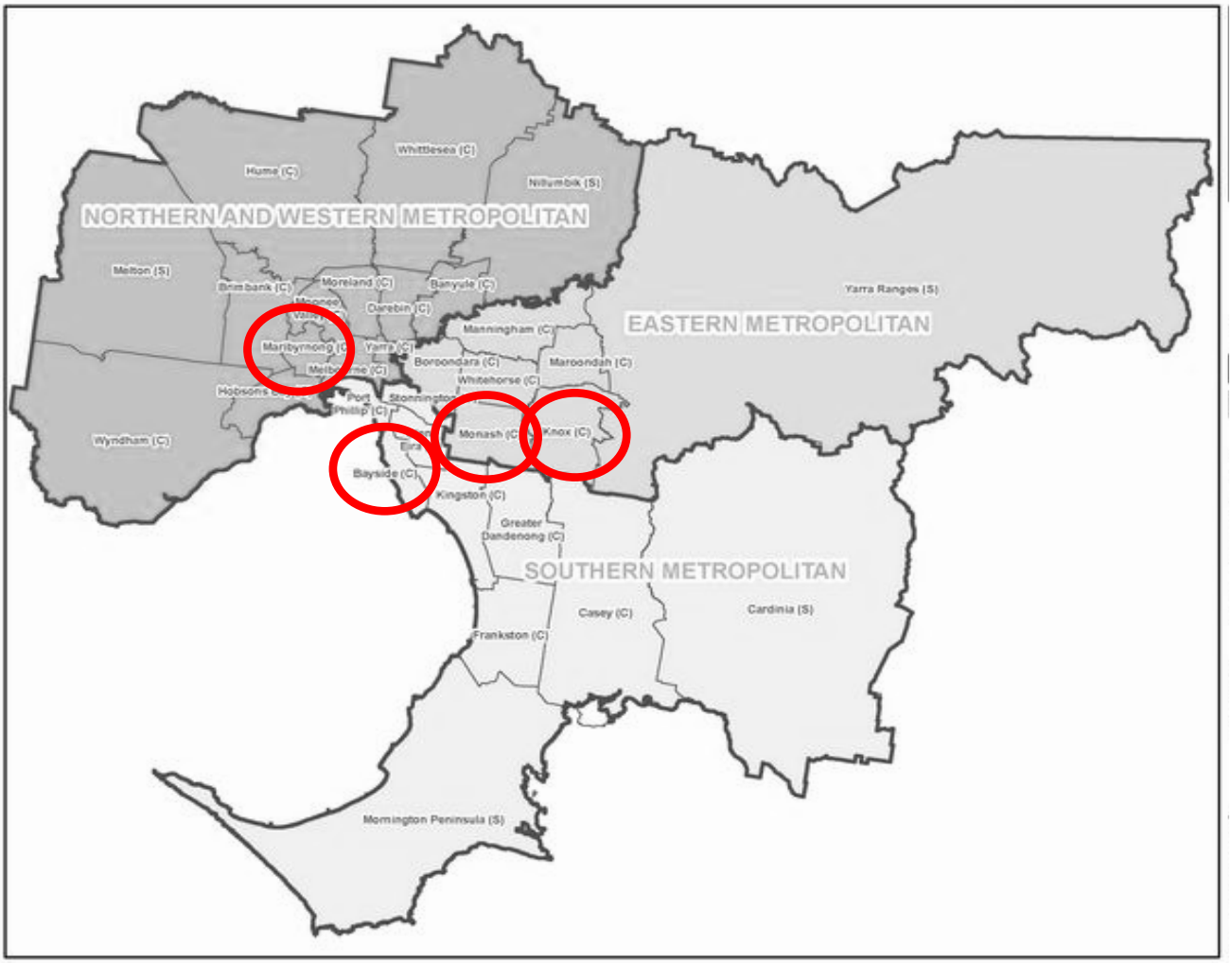
3. Consequences of the caring role

Social isolation	20:345 - Henry wants to play lawn bowls - waiting to get respite so can go
Stress and anxiety	20:199 - Henry rang Carers NGO because couldn't sleep, really worried, finished having a councillor - worried how will cope caring for wife when she was discharged from hospital

	20:292 - when wife came out of hospital - brain whizzing all night - thinking how I am going to get through this
Physical injury	
Neglect own health	EXCEPTION - 20:260 - Henry - got to stay fit physically, mentally - because just the two of us - nobody else to care for wife; 20:292 - of I can keep active and keep positive - I can keep going a bit longer
Other health and wellbeing issues	20: 43 - after wife discharged from hospital - knocked around - constancy - 24hours - get 4 hours of respite - told can't access anymore from council 20:163 - caring for 13 years - big job - no relatives 20:243 - gets more and more demanding
Financial/employment	20:229 - cost of paying for consumables such as continence aids 20:453 - health insurance - price going up - rang complained - so decreased price - did not have to wait for surgery
Other	

APPENDIX 7.A

Local government areas in metropolitan Melbourne represented in the study.



APPENDIX 7.B

Victorian government region in rural Victoria represented in the study.