

HUMAN-CENTRED DESIGN AND PERSON-CENTRED CARE: DEVELOPING DESIGN PERSONAS IN RESIDENTIAL AGED CARE

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ABSTRACT

Background

Personas are a human-centred design technique that employ a narrative style to present data and insights in a form that engages our social conscience, emotional intuition and empathy. Representing clusters of service users who display similar behaviours, attitudes or needs, personas can help shift our focus away from the needs of the organisation or system and onto the needs of the service user.

Method

First, the concept of personas and human-centred design in aged care was explored through a literature review and examination of persona methodology. Next, the persona methodology was implemented in a residential aged care facility in Sydney, Australia. Data was collected through observation and interviews to understand residents' needs, behaviours and attitudes. A variable mapping process was used to identify clusters of similar residents. Insights were presented in the form of personas which were reviewed with key staff to obtain feedback on their usefulness for informing future service improvement initiatives.

Results

The literature review revealed few studies using human-centred participatory design techniques to enhance person-centred care in aged care. One human-centred design technique not previously utilised in aged care was personas. A methodology to develop ethnographic research-based personas in a residential aged care setting was developed.

Four key behavioural and attitudinal variables were identified that distinguished between residents: tendency to interact/isolate; likes to help out/does not help out (insular); strong/weak family bond; and, feeling unsettled in care. These four factors were manifest in three personas. Each persona has a unique identity but draws on the anecdotes, life stories and experiences of all residents involved in the study.

Conclusions

This proof of concept study has demonstrated the potential of personas to assist in the design and delivery of more person-centred care: to drive person-centred decision-

making; turn resident data into actionable insights; and, encourage aged-care facilities to look at how to deliver person-centred care more effectively and in new ways. For residents, the technique could allow a vulnerable, often marginalised, group to express their experience, needs, and expectations in their own voice. For service delivery, personas could be used to great advantage in residential aged care to overcome the challenge of operationalising person-centred care.

STATEMENT OF ORIGINALITY

This thesis is presented to fulfil the requirements for the degree of Master of Research. This thesis is an original piece of research and has been written by me. Any help and assistance I have received in my research or in the preparation of this thesis has been appropriately acknowledged. All information sources and literature used are indicated in the thesis.

This work has not previously been submitted for a higher degree to any other university or institution.

The research presented in this thesis was approved by the Macquarie University Human Research Ethics Committee (HREC (Medical Sciences)). Reference No: 5201800108.

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1. PART 1: CONCEPT DEVELOPMENT

1.1. INTRODUCTION

1.1.1. Increasing demand for aged care

The good news is that Australians are living longer and healthier lives than ever before. The impact of this on a public scale, however, is more complex: increased lifespans bring about an increase in the prevalence of health issues and impairments. While many older Australians consider themselves to be in good health, conditions such as arthritis, dementia, and hearing loss become more common as people get older (Australian Institute of Health and Welfare, 2016).

People 65 years and older currently make up around 15% of the Australian population, (Australian Bureau of Statistics, 2014). By 2061, the proportion is projected to rise to more than 25% (Australian Bureau of Statistics, 2013). As the number of elderly Australians increases, so too does government expenditure on aged care services. Australian Government expenditure on aged care, expressed as a proportion of GDP (gross domestic product), is projected to nearly double by 2055 (Commonwealth Treasury, 2015). The aging of Australia's population also has significant implications for infrastructure, the labour market and economic growth (Productivity Commission, 2013).

Of those Australians aged 65 and over, nearly 8%, or around 270,000 people, live in residential care facilities (Australian Institute of Health and Welfare, 2014). Residential aged care provides permanent and respite care for people who can no longer live independently, or with home care support, in their own homes.

1.1.2. Quality of life in residential aged care

In addition to the challenge of increasing demand, there is also pressure to improve the experience of residential aged care for service consumers. Previously, the emphasis of public policy, external regulation and monitoring was on safety and prevention of poor quality care. Now there is a greater focus on resident *quality of life*. It is no longer assumed that service quality will automatically lead to desired quality of life (Australian Aged Care Quality Agency, 2015).

Residential care providers' ideas concerning *quality of care* had a clinical emphasis, focusing on medical treatments and physical care routines. Regulatory processes reinforced the medical model by putting greater focus on reporting of issues such as weight loss, falls and other clinical metrics, rather than residents' overall well-being and satisfaction (Australian Aged Care Quality Agency, 2015). While *quality of care* is highly important for residents, and inseparably linked to *quality of life*, it is not the same thing (Koren, 2010). For example, the key issues arising in residential care settings include: lack of autonomy and difficulty forming relationships (Bradshaw et al., 2012); and loneliness, helplessness and boredom (Li and Porock, 2014).

Four principles have been identified that have positive impact on quality of life for individuals in residential care (Bradshaw et al., 2012):

1. ***Acceptance and adaptation*** – supporting acceptance of living situation and adaption to the new shared environment;
2. ***Connectedness with others*** – facilitating relationships with peers, staff and family;
3. ***Homelike environment*** – as well as allowing for more personalisation of the physical environment, this also includes establishing routines that are not overly regimented or restrictive, allowing for resident control, autonomy and independence; and,
4. ***Caring practices*** – while carer competence is important, an attitude of considerate care is equally important to promote quality of life.

1.1.3. Person-centred care

1.1.3.1. What is person-centred care?

A concept frequently discussed in parallel with quality is person-, or patient-, centred care. It is an approach that advocates for the individual to be considered as more than the object of disease; care should also address the individual's emotional and spiritual well-being and physical comfort. Patient-centred care, the term frequently used in medical environments, is respectful of patients' needs, wants, values and preferences (Luxford et al., 2011). It provides communication and transparency that enables shared decision-making between patients and professionals, and supports the involvement of family and carers (Hogden et al., 2015).

One perspective sees patient-centred care as a means to improving quality of care (Rathert et al., 2012). On the other hand, Berwick, an early champion of patient-centred care, proclaims a radically consumerist definition of patient-centeredness where the patient's needs and wants come before those of the professional and the system. He argues that 'patient-centred' is a critical dimension of care in its own right, not just because of the effect it may have on the effectiveness, safety, or quality of care (Berwick, 2009).

Like health care more broadly, aged care, and in particular residential aged care, is also striving to become more person-centred (Rosemond et al., 2012). While the concept is similar to patient-centred care, the term 'person-centred' is typically used in aged care. Person-centred care is characterised as holistic, individualised, respectful and empowering (Morgan and Yoder, 2012). It emphasises personhood, respect for and knowing the person, maximising choice and autonomy, physical and emotional comfort, nurturing relationships, and a supportive physical environment (Jones, 2011). Person-centred care goes beyond the medical treatments and physical care routines that have traditionally been the focus of residential aged care, instead aiming to empower residents to be partners in their own care (Koren, 2010). This is particularly pertinent in residential aged care where the needs, wants and preferences of the residents go beyond the treatment of particular illnesses or impairments, but are also about the experience of day-to-day living. It is argued that 'person-centred' is a preferable term as it places the emphasis on the person, not the illness and avoids balance of power issues embedded in the concept of 'patient', which can be seen as more passive position (Morgan and Yoder, 2012).

1.1.3.2. What are the drivers of person-centred care?

The imperative to become more person-centred in the provision of services is not limited to aged care. There is a strong commercial motivation for service organisations to gain competitive advantage by being more person-centred, promoting customers from passive consumers to value co-creators (Mukhtar et al., 2012). This shift to a more consumerist-driven perspective is also evident in aged care. The next wave of consumers have higher expectations of quality, are more informed, and have greater awareness of their power as consumers than ever before (Australian Aged Care Quality Agency, 2015).

In residential aged care there is also a moral obligation to provide person-centred care (Li and Porock, 2014): every individual is seen to have a *right* to respect and self-determination (Morgan and Yoder, 2012), which must be especially defended for vulnerable or disadvantaged populations such as the young, elderly, disabled or mentally distressed (Australian Commission on Safety and Quality in Health Care, 2011). Residential aged care providers are expected to create an environment and culture where relationships are central, where people come before tasks (Jones, 2011). Expectations have moved beyond simply providing safe, *quality care*, to a desire for these services to support and nurture *quality of life* (Koren, 2010).

In addition to the moral obligation is the motive of self-interest. We are now designing the aged care services we may one day be using. To borrow from Berwick (2009):

“I fear to become a [resident]... the indignity... loss of influence... homogenized, anonymous, powerless... helpless before my time. To be made ignorant when I want to know, to be made to sit when I wish to stand, to be alone when I need to hold my wife's hand, to eat what I do not wish to eat, to be named what I do not wish to be named, to be told when I wish to be asked, to be awoken when I wish to sleep.” (Berwick, 2009, w564)

1.1.3.3. What are the barriers to person-centred care?

Despite the strong and genuine desire for more person-centred care in residential aged care, it is often more an ideal state than a reality. Residential care homes are often ‘homes’ in name only, retaining an overriding clinical character (Koren, 2010).

Providing a relationship-based approach to care, in a homelike environment, tailored to the preferences of individual residents, requires a deep understanding of residents’ attitudes, preferences and perceptions (Bradshaw et al., 2012). Changes are required at the public policy and regulation level and the organisational policy level (Koren, 2010). Physical environments must be transformed (Koren, 2010). Particular qualities and skills will be required of frontline staff: a personal belief in the person-centred philosophy, relationship building skills, and personal qualities such as kindness and

empathy (Australian Aged Care Quality Agency, 2015). In addition, organisational level leadership support (Li and Porock, 2014, Rokstad et al., 2015) and engagement and measurement tools to track progress towards quality of life outcomes (Van Haitsma et al., 2014) are critical to nurturing and sustaining the success of person-centred care interventions. Even information technology can play a role in supporting enhanced care delivery through monitoring and communicating resident's needs (Alexander et al., 2016).

1.1.4. Human-centred design

1.1.4.1. *What is human-centred design?*

Many service-based organisations are increasingly looking to human-centred design disciplines to help them better understand the needs of their service users and design services that better meet those needs. In *The Experience Economy* (Pine and Gilmore, 2011), Pine and Gilmore argue that we have moved beyond the industrial economy where the invention and production of new goods fuelled the economy, and are moving into a new era where value is created in the invention and construction of *experiences*. This transition from a manufacturing based economy to a service or experience-based economy has given rise to the emerging discipline of service science (Mukhtar et al., 2012). Service science advocates an interdisciplinary approach to the study, design and implementation of *service systems*, with service systems defined as one in which “specific arrangements of people and technologies take actions that provide value for others” (Ng et al., 2011, p14). Central to service science is the concept of value co-creation between the customer and the firm. There is no value until a service is used and experienced by the customer (Mukhtar et al., 2012). This idea of value-in-use replaces the industrial-age concept of value-in-exchange where a tangible product was created within the enterprise and exchanged with the customer (Ng et al., 2011). Success in this new experience economy requires a deep understanding the needs, wants, motivations, attitudes and behaviours of service users in order to design and deliver the most desirable experience (Bate and Robert, 2007).

The idea of customer participation in the design and creation of new products and services is not new. The term human-centred design was popularised by Donald Norman in the original 1990 release of his book *The Design of Everyday Things* (Norman, 2013). Human-centred design is a philosophy that places human needs, capabilities and

behaviours at the centre of the design problem-solving process and encompasses more focused areas of design such as industrial design, interaction design, experience design and service design (Norman, 2013). These design disciplines advocate a vast range of techniques for involving customers in the design process, including participatory method, empathetic design, co-designing, prototyping, personas and avatars, laddering interview techniques, living labs, lead user approach, ideas competition and community based innovation method (Mukhtar et al., 2012). This list is not exhaustive. It does, however, demonstrate the common purpose behind all human-centred design techniques: bringing the user of a product or service into the design process.

1.1.4.2. How can human-centred design help in aged care?

Overcoming the challenge of operationalising person-centred care requires understanding residents' attitudes, preferences and perceptions (Bradshaw et al., 2012). A human-centred design approach that places human needs, capabilities and behaviours at the centre of the design problem-solving process can transform services to be more person-centred (Norman, 2013). Human-centred design techniques have already been utilised in healthcare settings to transform services to be more person-centred or, in the case of healthcare, patient-centred. The creation of patient journeys using process mapping techniques and involving clinicians, managers, patients and carers was used to inform clinical process re-design in 60 NSW public hospitals (Ben-Tovim et al., 2008). User-centred design was used to identify opportunities for service and facility re-design in a number of United States hospitals and health centres in a process that included collecting data from staff and patients, empathising with patient experiences, and drawing on the expertise of architects, psychologists and sociologists (Altringer, 2010). Over 80 projects across seven countries have utilised the Experience-based Co-design approach advocated by England's National Health Service (NHS) which seeks to facilitate partnerships between patients and professionals in the design of health care services (Donetto et al., 2014).

In aged care, person-centred care models such as the culture change movement, person-centred dementia care, and person-centred nursing framework (Li and Porock, 2014) utilise similar principles and strategies to those advocated under the human-centred design banner.

1.1.5. Personas

A human-centred design technique yet to be trialled in aged care is 'personas'. Personas are a design tool that help 'bring users to life' so design efforts can focus on users and their needs, as opposed to the needs of systems, engineers, developers, or business managers (Cooper, 2004). They were originally conceived within the user experience design field by Cooper in the 1990s and are now successfully applied to service design. A persona represents a cluster of customers who display similar behaviour patterns, but it is written in the form of a detailed narrative about a specific, but fictitious, individual (Miaskiewicz et al., 2008). It is an archetype that stands in as a surrogate for a group of real people (Mulder and Yaar, 2006). However, while personas are created characters, Cooper stresses the importance of personas as being grounded in robust investigation and research, rather than 'made-up' (Cooper, 2004).

Personas may sound similar to customer profiling techniques used in marketing research and segmentation, but they go much further. Marketing research is concerned with potential customers and what they will buy. Personas, and the qualitative design-informing research that unpins them, seek out deeper insights into people's real needs, desires and motivations; examining what people actually do, not just what they say they will do (Norman, 2013).

Personas stand in for real people during the design process. They prevent us designing systems, processes, or experiences for ourselves. 'You are not your user' is a refrain often heard in design. Unless designers or decision makers have a clear alternative individual in mind, they will tend to make decisions that assume everyone else is just like them, with the same desires, goals and priorities (Mulder and Yaar, 2006). Personas are also useful in business because they are sharable, memorable and actionable. They turn data into knowledge that can be used by business to make better decisions about what works best for their customers and inspire superior product and service design (Cooper, 2004).

The persona methodology is examined in more detail in Section 1.3., Methodology.

1.1.6. Aims of this study

This research is a proof of concept study of the persona technique in a residential aged care setting. Insights about resident's needs, desires, motivations and behaviours, gathered through qualitative research, will be presented in a realistic and actionable way, in the form of personas. The personas will be reviewed with key staff to obtain feedback on their usefulness for informing future service improvement initiatives. If successful, the persona tool and methodology could be used by residential aged care providers to design improved resident experiences and assist to overcome the hurdle of operationalising person-centred care.

1.1.7. Thesis structure

This thesis is presented in 2 parts: (1) Concept development; and, (2) Proof of concept study. **Part 1: Section 1.1 (Introduction)** introduces the key concepts involved in the study and their relationship to each other: quality of life in aged care; person-centred care; human-centred design; and, personas; the literature review presented in **Section 1.2 (Literature review)** examines the published evidence of human-centred design in aged care; and, **Section 1.3 (Methodology Review)** examines the persona methodology, including benefits of the technique, different types and approaches, common criticisms and challenges, and outlines of how the methodology was applied in this study.

Part 2 examines the proof of concept study of the persona technique conducted at a residential aged care facility in Sydney, Australia: **Section 2.1 (Method)** outlines how the persona methodology was conducted for the study; **Section 2.2 (Findings)** reports the study findings, including a presentation of the final personas; the discussion in **Section 2.3 (Discussion)** reflects on both the insights uncovered into the behaviours, attitudes and motivations of residents, and analyses the application of the persona process itself; and **Section 2.4 (Conclusion)** considers the implications of this study for encouraging aged-care facilities to look at how to deliver person-centred care more effectively and in new ways and empowering residents to play a meaningful role in making valuable improvements to the quality of their experience.

1.2. LITERATURE REVIEW

1.2.1. Purpose

The purpose of this literature review is to identify published evidence of human-centred design being used within aged care. This review will assess how these studies have enabled the participation of older people in seeking to improve person-centred care and quality of life in aged care.

Within aged care, many person-centred models or frameworks are promoted. These include models specific to residential aged care such as person-centred dementia care and person-centred nursing framework (Li and Porock, 2014), and culture change models such as Regenerative Community, the Eden Alternative, the Wellspring Model, Green House, the Neighborhood Model, and the Pioneer Network (Brownie and Nancarrow, 2013, Jones, 2011). There are also patient-centred care models within healthcare that specifically focus on older people: Nurses Improving Care for Health System Elders, Integrated Depression Care Management Model, Authentic Consciousness and VIPS Practice Model (Constand et al., 2014). This prevalence of person-centred frameworks and models suggests that human-centred design techniques and strategies should be common practice in aged care. Through the use of these approaches older service users could be empowered to become partners in their own care, including the design of new and improved services and models of care.

1.2.2. Literature review approach

As there is no exhaustive list of techniques by which human-centred design can be judged (Mukhtar et al., 2012, Norman, 2013), this review takes a broader approach, evaluating studies according to the level of participation they afford the service user; in this context, older people. Both person-centred care and human-centred design place great importance on the centrality and empowerment of the individual, so the participation of individuals in service improvement efforts is a critical factor to be examined. This review considers participation in two areas: research and design. Full participation in research allows the older person to be both informant and co-researcher, giving them the opportunity to influence research agendas and priorities. The pinnacle of design participation, co-design, involves designers and users working collaboratively to identify problems and solutions, moving from a mindset of designing

for users, to one where services are designed *with* users (Borgstrom and Barclay, 2017, Sanders and Stappers, 2014). In aged care, this would involve older people working alongside others (care professionals, designers and decision makers) to conceive and shape new services and experiences.

The literature review contained in this section differs in scope to the study discussed in Part 2 of this thesis. This review looks at the use of human-centred design more broadly across the aged care sector. The study, however, implements a single technique, personas, within a specific residential aged care facility. Further, where this literature review assesses studies that have included service users in both research and design, the scope of the study conducted for this thesis is a proof of concept study to develop personas in a residential aged care environment; it does not extend to the application of the personas to designing improved resident experiences. This will be the subject of future research.

1.2.3. Review methods

A scoping review (Arksey and O'Malley, 2005) was selected as the most appropriate approach to determine the extent of research activity in this previously undocumented area. A scoping review takes a broad approach to identify all relevant literature in an area of interest, regardless of study design. It is useful for identifying gaps in the literature and generating a descriptive summary of research findings for consumption by policy makers, consumers and practitioners (Arksey and O'Malley, 2005). This approach is particularly relevant when working in an area of emerging evidence, where it is necessary to understand the breadth and depth of a field to help clarify new or complex concepts (Levac et al., 2010).

Database searches were conducted, followed by a process of review to identify studies that addressed the research aim. Relevant literature was then mapped and analysed to provide an assessment of the implementation of human-centred design in aged care.

1.2.3.1. Search strategy

Searches were conducted across six databases: MEDLINE Complete, Business Source Premier, CINAHL Complete, Health Source: Nursing/Academic Edition, Psychology and Behavioral Sciences Collection. Key search terms were variations for “human-centred design” and “aged care”. Following database searches, reference lists of pertinent articles were examined to identify further relevant studies.

1.2.3.2. Inclusion criteria

Searches were confined to articles written in English and published since 2000. Studies were eligible for inclusion if they utilised a research and design method that included older people who acted as co-creators with the research team in seeking to improve quality of care, quality of life or the person-centredness of care. This could range from studies that used older people as resources for ideas on how to improve a current service or experience, through to co-design or participatory design activities where older people were directly involved in formulating new services or solutions. By extension, studies that conducted participatory research with older people, but had no design element, were not eligible for inclusion. For example, studies involving older people in the evaluation of an intervention, but that did not include a design activity to address the issues or opportunities raised were not included. Additionally, to be eligible for inclusion, a study had to be seeking to improve quality of care, quality of life or the person-centeredness of care. Studies aimed at improving specific clinical outcomes or using only narrow measures – for example, financial measures, service utilisation or admission rates, nutrition status, mobility – were not eligible for inclusion.

1.2.4. Review process

Titles and abstracts of all articles were assessed for alignment with inclusion criteria. Articles that met the inclusion criteria, or where there was insufficient information in the title or abstract, were subject to a full-text review. Data extracted from included articles was captured in summary form in a spreadsheet. Articles were then assessed on two aspects of participation: participation in research and participation in design. Table 1 describes how different levels of participation have been defined for each aspect. Only those studies with a medium or high levels of participation in both research and design

have been included in this review as they will provide the greatest learning opportunity for the future application of human-centred design in aged care.

Table 1. Levels of participation

Levels	Research participation	Design participation	Eligibility
Nil	Nothing was researched.	Nothing was designed.	Not eligible for inclusion.
Low	Opportunity to provide general feedback within bounds set by the researcher.	User input provided areas for investigation in a future study or project.	Not eligible for inclusion.
Medium	Consulted on specific issue or service, with opportunity to provide open feedback and input. Trial new product or service.	Priorities and recommendations for improvement provided by users were actioned by experts.	Eligible for inclusion.
High	Involved as both informant and peer researcher. Opportunity to set or influence research agenda and priorities.	Co-design – work alongside designers and decision makers to shape a new or improved service, product, or experience.	Eligible for inclusion.

Only studies with a medium or high level of participation overall have been included in this study.

1.2.5. Scoping review results

The initial electronic database search returned 179 articles. On review, 145 articles were excluded based on their title and abstract. A further 28 articles were rejected as ineligible following a full-text assessment. Six articles were selected for inclusion from the database search. An additional five records were identified through the “snowballing” technique, where articles were discovered by searching through the footnotes and references of the articles already selected (Greenhalgh and Peacock, 2005). This resulted in 11 articles being included in the review, representing 10 unique studies. Figure 1 outlines the search process and outcomes. Table 2 summarises the data extracted from the articles selected for inclusion in this review.

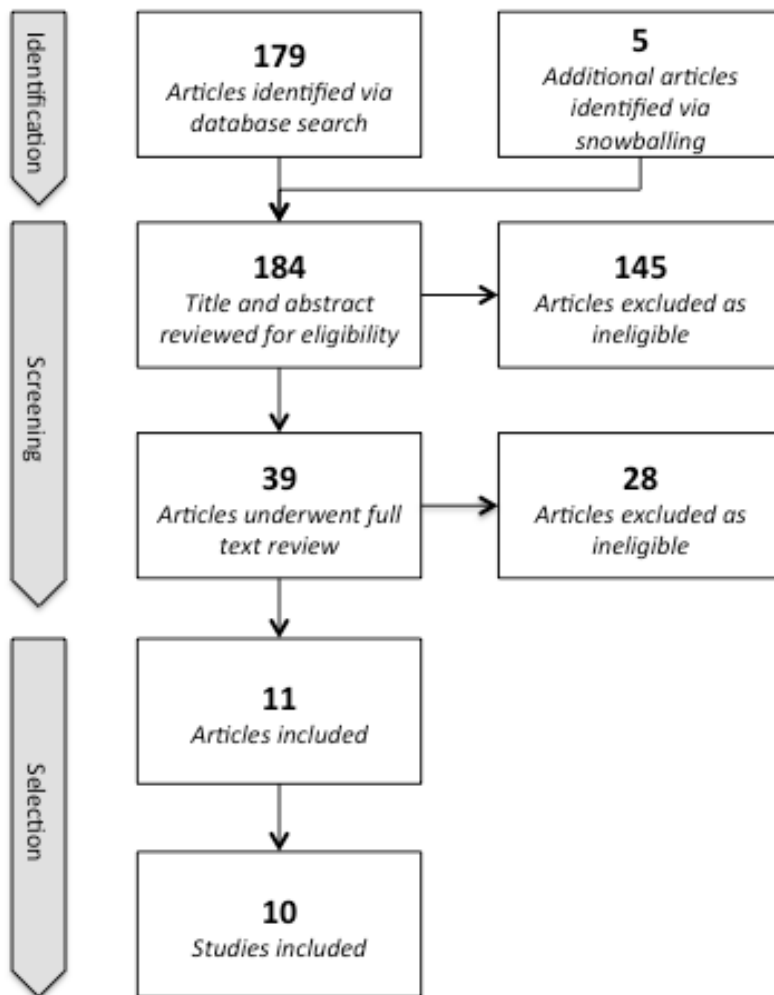


Figure 1. Flow diagram of search strategy and outcomes

Table 2. Articles included in this review

Author/s	Title	Topic / Objective	Setting	Population	Country	Methodology	Research and design activities	Outcomes
Jones et al. (2008)	Engaging service users in the development of stroke services: an action research study	(Re)Developing stroke services by involving those affected by stroke.	Acute care hospital and community	Elderly stroke service users, carers and health practitioners	UK	Participatory action research	Semi-structured interviews and focus groups with patients and carers to understand experiences. Facilitated workgroups with patients, carers and professionals to identify service development priorities and action plans.	Information pack for service users, socially integrated rehabilitation activities, enhanced caregiver involvement in discharge process.
Rota-Bartelink and Lipmann (2010)	Older people with alcohol-related brain injury and associated complex behaviours: a psychosocial model of residential care (The Wicking Project)	18month trial of residential care for older people with complex behavioural needs.	Residential aged care facility (1)	Older people, facility staff and other related health professionals	Australia	Participatory action research	Residents consented to be involved in the 18month trial, ongoing feedback and iteration of care model during the trial.	A specialist residential care model for older people with alcohol-related brain injury.
Uzor et al. (2012)	Senior designers: empowering seniors to design enjoyable falls rehabilitation tools	Co-design multimodal games with seniors to improve adherence to home exercise programs.	Community	Older adults (16)	UK	Participatory design	Two facilitated co-design workshops with elders and designers/ researchers. Design techniques used included personas, storyboarding, scenarios, and prototyping.	Conceptual designs for interactive rehabilitation games.

Author/s	Title	Topic / Objective	Setting	Population	Country	Methodology	Research and design activities	Outcomes
van Hoof et al. (2015)	Exploring Innovative Solutions for Quality of Life and Care of Bed-Ridden Nursing Home Residents through Co-design Sessions	Improving quality of life for bed-ridden nursing home residents.	Residential aged care facility (1)	Bed-ridden nursing home residents, design and aged care professionals	Netherlands	Participatory Action Research and User-Centred Design	Ethnographic immersion with patients informed personas, storyboards and scenarios that were used by design experts and care professionals in 'Design improvisation sessions' held on-site in-patient rooms within a teaching hospital. Other design techniques included performance, collaborative design and prototyping.	Design concepts for new products, product improvements (eg. technology and bed), service innovation and process improvements.
Baur and Abma (2012)	'The Taste Buddies': participation and empowerment in a residential home for older people	Enhancing resident participation in practice improvements and policy issues.	Residential aged care facility (1)	Residential aged care facility residents (7)	Netherlands	Participatory action research	Facilitated group activity. Exchange of experiences through narratives, democratic identification of issues and priorities, creative envisioning exercise, ownership development and participation in improvement designs/ recommendations.	Onsite kitchen and cooks, food prepared onsite, new menu and meal choices, themed dinners, process improvements to facilitate meal time as a social opportunity, resident involvement in staff recruitment.

Author/s	Title	Topic / Objective	Setting	Population	Country	Methodology	Research and design activities	Outcomes
Bowen et al. (2010)	Co-designing Better Outpatient Services for Older People: Inspiration stories for Participatory Design with Health and Social Care Institutions Workshop	Healthcare service improvement project: Better Outpatients Services for Older People (BOSOP).	Hospital outpatient clinic	Elderly users of outpatient service (21) and staff	UK	Experience based design	Followed experience-based design method advocated by the UK National Health Service. Techniques included interviews, patient journeys, emotional maps, experience events, and co-design teams.	New template for patient appointment letters, design proposals for new way-finding materials (signage and maps), proposed layout of roads surrounding outpatient building, patient stories video distributed to all staff, theatre training event to improve staff awareness of customer care.
Wolstenholme (2010)	Design-led service improvement for older people							
Carey-Smith et al. (2013)	A user-centred design process to develop technology to improve sleep quality in residential care homes	Exploration of the potential of technology to improve sleep quality in residential care homes.	Residential aged care facilities (4)	40 residents and staff	UK	User-centred design	Interviews and observation, prioritisation of concept ideas via group interviews and questionnaires, participant feedback, design iteration through sketching, models and prototyping, and physical trial.	Functional prototypes of potential solutions to address difficulties with nocturnal anxiety and relaxation.

Author/s	Title	Topic / Objective	Setting	Population	Country	Methodology	Research and design activities	Outcomes
Hewitt et al. (2007)	Improving food provision in a Guyanese home for the elderly: a participatory approach	Improving food provision and nutrition in a residential care home.	Residential aged care facility (1)	Residents and staff	Guyana (Caribbean)	Participatory design	Observation, interviews, focus groups and resident voting to understand needs and context and generate ideas for improvement, feedback and iteration during trial phase via interviews and focus groups.	Introduction of new meal plan including more nutrient-dense foods, changes to food sourcing and preparation. Resulted in improved nutrient profile of the facility diet.
Martin et al. (2013)	Participatory Research to Design a Novel Telehealth System to Support the Night-Time Needs of People with Dementia: NOCTURNAL	Designing a technology-based system to support people living with dementia.	Community	People with dementia (8) and their carers and family, plus public sector service provides and a commercial telehealth provider	Ireland	Participatory design: Translating Research and Innovation Living Lab	Participant and carer interviews and contextual enquiry and observation to gather requirements, 6month in-home trial involving iterative validation and evaluation.	Proof on concept: first generation functional prototype of new technology product for people with dementia.
Shura et al. (2011)	Culture change in long-term care: Participatory action research and the role of the resident	Advance the process of culture change and promote the active engagement and leadership of residents.	Residential aged care facility (1)	74 residents, staff, and family/friends	US	Participatory Action Research	Resident groups, facilitated by a researcher, conduct critical and collective reflection about ideas for community improvements.	Redesign of bulletin boards, dining room changes, resident newsletter.

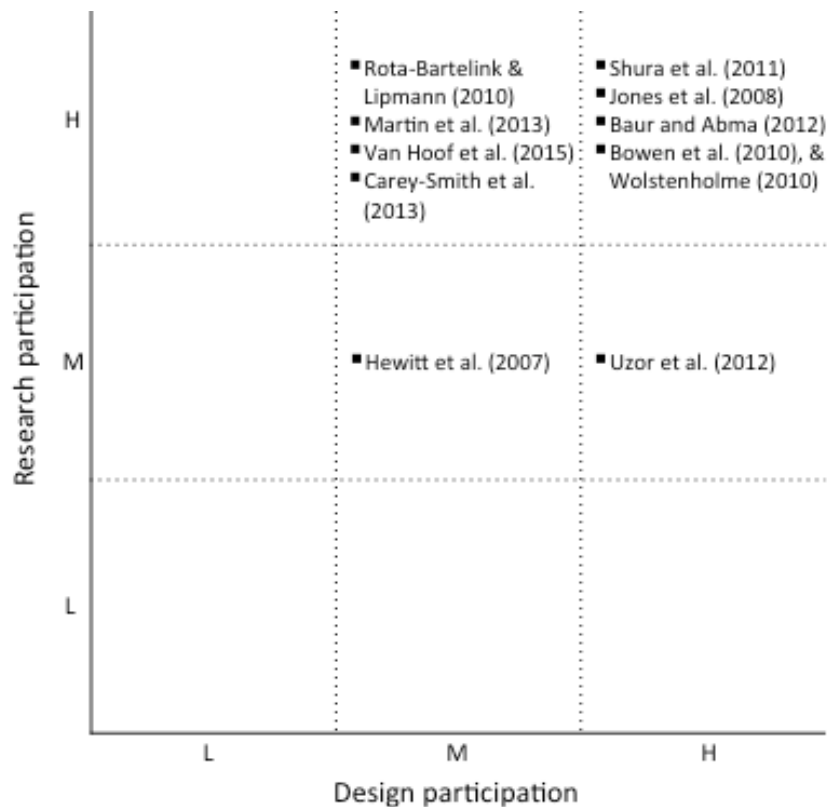


Figure 2. Participation matrix

The studies in this review have been assessed as having a medium or high level of participant involvement in both research and design activities. Figure 2 is a visualisation of how the studies compare. The types of participation and factors affecting participation are discussed below.

1.2.5.1. Types of participation

Of the studies included in this review, four had a high level of research and design participation by older people. That is, older people were involved as both informant and researcher, with the opportunity to influence the research agenda, *and* acted as co-designers in shaping solutions, new services or models for care.

Four studies had a high level of research participation by elders, but only a medium level of design participation. In these studies, initial research activities were thorough. Full immersion into the elders' world occurred through ethnographic style research methods: in-depth interviews, observations and contextual enquiry. The open-ended nature of this style of research leaves room for the subject to influence the direction and agenda of the study. However, when it came to design activities, older people were not included. Their

needs, expectations, feedback and ideas were fed into a solution design process that was taken forward by 'experts'. van Hoof et al. (2015) acknowledge the lack of participation in creative sessions as a weakness of their study, noting that the needs of the people being designed for may be misrepresented, potentially compromising the suitability of the solutions being designed. In the trial of a new model of residential care for people with complex behavioural needs, residents were immersed in the research experience and able to provide feedback. Nevertheless, it was experts, rather than residents, who created the model originally and made the decisions about how the model would be iterated during the trial (Rota-Bartelink and Lipmann, 2010). In two studies involving the design of technology assisted solutions, the complexity of the underlying technology was prohibitive to full co-design with the target users. However, both studies instead used comprehensive prototyping and trials to bring users as close as possible to the design process (Carey-Smith et al., 2013, Martin et al., 2013).

Two studies were rated only medium for research participation. In both these cases, older people were researched, but they had limited ability to influence the direction of the research. Uzor et al. (2013) relied heavily on personas and scenarios that were pre-produced then validated by participants during design sessions. Hewitt (2013, 2007) captured participants' perspectives, but in a tightly controlled manner that limited the opportunity for dialogue with residents that could influence the research.

For the studies rated high on design participation, this was achieved through expert facilitated face-to-face meetings with older people, carers and healthcare professionals or facility staff (Bowen et al., 2010, Jones et al., 2008, Wolstenholme et al., 2010), older people and designers (Uzor et al., 2013) or older people only (Baur and Abma, 2012, Shura et al., 2011).

1.2.5.2. Study setting

While all studies were aged care related, the specific setting differed: six studies were conducted in residential aged care facilities, two with users of community care services, one within a hospital setting and one study was set in both a hospital and the community. Further, the four studies with the highest level of research and design participation by older people also represented a variety of settings: residential aged care facility, hospital

and hospital and community. Based on this diversity, this review finds that study setting does not prevent or limit participation.

This is not to suggest that different settings do not present particular benefits or challenges. For example, residential aged care facilities provide access to a large number of potential participants in a single location, which could simplify participant recruitment. On the other hand, the more complex needs of people in residential care (Dupuis et al., 2016, Rota-Bartelink and Lipmann, 2010, van Hoof et al., 2015) may make participation more challenging than in a community setting.

1.2.5.3. *Design vs research methodologies*

The studies considered in this review utilise a variety of approaches. Half the studies describe their methodology as participatory action research. Six studies use design approaches, variously described as participatory design, user-centred design or experienced based design, including one study that used both participatory action research and user-centred design.

The choice of a research methodology versus a design methodology does not influence the level of participation achieved. Of the five studies rated high for design participation, three use a participatory action research approach and two use a design methodology. A similar pattern is evident for high levels of research participation: four studies use participatory action research, three use a design methodology and one uses both.

1.2.6. Discussion of scoping review

This scoping review provides an overview of studies using human-centred design in aged care to generate improvements in quality of care or enhance person-centred care. Studies were assessed to be following a human-centred design approach according to the level of participation they afforded the service user, in this context, older people. Participation has been considered along two aspects: participation in research and participation in design activities.

The requirement for older people to be included in research activity in an active and meaningful way lead to many studies being excluded from this review. Despite efforts to increase the participation of older people in research as collaborators or advisors, many

studies continue to prioritise stakeholders such as care-home staff, relatives or health professionals (Backhouse et al., 2016), or position older people as a passive entity to be tested and measured (Blair and Minkler, 2009). Participatory action research is one method being promoted as a means of reversing this situation. It is a collaborative approach to problem solving that involves a partnership between researchers and those with firsthand experience of the issue under investigation (Dupuis et al., 2016). The method was established for the purpose of effecting learning, social change and transformative action and involves a power shift where the participants become more than subjects of study (Blair and Minkler, 2009). The method is also promoted as a mechanism for delivering greater person-centred care (Fortune et al., 2015) and, from the evidence considered in this study, shares considerable common ground with human-centred design approaches. However, many of the participatory action research projects reviewed were focused on nurses, residential care workers, carers, or advocate organisations, rather than older people themselves. This is likely a reflection of the very real challenges involved in working directly with elderly people, particularly the frail or those with dementia (Carey-Smith et al., 2013, Martin et al., 2013, Shura et al., 2011, van Hoof et al., 2015).

Another issue encountered was that many of the participatory action research studies assessed for this review did not include a design component or produce an identifiable outcome beyond the intangible benefits that came through participation in the project. Like Blair and Minkler (2009), this review found that outcomes typically reported included: improved confidence and strengthened relationships; opportunities for elder feedback and communication; elder training in research and data collection; and improved understanding of a service or experience. While these are valuable contributions, they did not qualify as person-centred care improvements. In contrast, the design methodologies employed here all have 'inbuilt' research stages or activities that occur either prior to or concurrently with the design activities. For example, Carey-Smith et al. (2013) conducted needs analysis and prioritisation phases before commencing design activity. In the experienced based design approach capturing and understanding patients' and staff's experiences and identifying areas for service improvements are the first two phases of the process (Bowen et al., 2010, Wolstenholme et al., 2010). In a different approach, Uzor et al. (2012) conducted their research within co-design workshops, with research-oriented activities such as discussions of past experiences. This approach could be described as

“learning from those who know” (Shura et al., 2011, p213) or involving older people as “experts in their own experience” (Sanders and Stappers, 2014, p30).

The intent of human-centred design is to bring the user into the heart of the design problem-solving space. At its best, human-centred design should involve users and other stakeholders working in partnership with designers to create, prototype, test, implement and iterate new services or solutions. Experience based co-design is the methodology advocated by the United Kingdom’s National Health Service (Donetto et al., 2014).

Described as a form of participatory service design, it shares many of the same principles as participatory action research: the central role of the people who share the problems; the primacy of experiential knowledge; and, the co-creation of new knowledge and solutions. This methodology was used by one of the studies in this review (Bowen et al., 2010, Wolstenholme et al., 2010) and referenced as an influence by another (Jones et al., 2008). In both instances, it delivered high levels of both research and design participation. This evidence suggests that the use of participatory design methodologies is more mature in healthcare than aged care: a methodology endorsed by a national health service, the two case studies included in this review; and, numerous other design-lead service improvement projects (Altringer, 2010, Bate and Robert, 2007, Borgstrom and Barclay, 2017, Bowen et al., 2013, Ben-Tovim et al., 2008, Donetto et al., 2014).

In addition to borrowing participatory design methodologies from healthcare, aged care could also benefit from practices borrowed from other sectors. Four of the studies included here used design methodologies originating from outside healthcare: the use of participatory design by Uzor et al. (2013) and Martin et al. (2013) and user-centred design by van Hoof et al. (2015) and Carey-Smith et al. (2013). Although these approaches all share significant common ground with the research methodologies represented here, their origination in design practice means they provide a sharper focus on the design and implementation of service and experience improvements.

A challenge of any of these design- or research-lead participatory methodologies is that they are resource intensive and tend to involve immersion in a single community or experience. That means the results or outcomes may not be applicable or transferable to other settings without further investigation and validation. There is also no evidence of these participatory strategies being used to design overarching models of care.

Instead, many of the studies identified focus on smaller, incremental improvements within the overarching system. For example: improvements around meals and mealtimes (Baur and Abma, 2012, Hewitt et al., 2007); re-designs of bulletin board and dining room layouts (Shura et al., 2011); new patient letter templates, building signage and staff communication tools (Bowen et al., 2010); and, user information packs (Jones et al., 2008). These studies were all significant opportunities for older people to make meaningful and valuable improvements to the quality of their experience. However, the opportunity to extend this approach to empower older people to become partners in designing the underlying frameworks or models of care to which they are subject is yet to be explored.

The studies included in this review have utilised a wide range of techniques to understand the experience, attitudes and preferences of older people and make that insight central to the problem-solving and service improvement process. No evidence was found of the persona technique being utilised in the design of aged care services.

1.2.7. Literature review conclusion and implications

This scoping review provides an overview of the limited number of studies using human-centred participatory design techniques in aged care to enhance person-centred care. The studies included here illustrate, both in their substance and volume, the rewards and challenges of conducting participatory research and design activity with older people. These studies illuminate the transformative effect and potential of human-centred, participatory techniques and approaches. They also demonstrate that there are older people keen and willing to participate in activity to improve their experience.

This review highlights that further opportunities exist to extend the use of human-centred design in aged care. Future research could trial human-centred design techniques that have been beneficial in other service environments, like personas, in aged care to empower older people and enable their participation in service improvement initiatives. There is also the opportunity to extend these participatory strategies beyond incremental improvement projects to designing overarching models of care.

The following section examines the persona methodology, including its benefits, different types and approaches, common criticisms and challenges, and considers how the methodology should be applied in this study.

1.3. METHODOLOGY REVIEW

This section provides an examination of the persona methodology which informed the activities undertaken in this study. The topics covered are as follows: an explanation of personas (Section 1.3.1) and their benefits (Section 1.3.2); an overview of different types of personas and a summary of key persona development approaches (Section 1.3.3); an examination of common criticisms of the methodology (Section 1.3.4); a discussion of challenges expected during the persona creation phase (Section 1.3.5); and finally, an outline of the how the persona method will be applied in this study to maximise the advantages of the technique and address the criticisms and challenges (Section 1.3.6).

1.3.1. What are personas?

Originally conceived within the software design field by Cooper in the 1990s (Cooper, 1999), personas are a design tool that help ‘bring customers to life’. A persona represents a cluster of customers who display similar behaviour patterns and is written in the form of a narrative about a specific, fictitious individual that designers and decision-makers can relate to (Miaskiewicz et al., 2008). The persona is an archetype that stands in as a surrogate for a group of real people (Mulder and Yaar, 2006).

Personas use storytelling to engage our social conscience, emotional intuition and empathy, and to convey the insights behind complex data in a compelling and memorable way (Goodwin, 2011). Personas are made to feel real by being given a name, photo, demographic details and stories that give insight into their environment, behaviour, goals, frustrations and attitudes. While they are not real people, they are ‘composite archetypes’ based on behaviour patterns uncovered during ethnographic style research (Cooper et al., 2014). Key elements of a persona, adapted from Baxter and colleagues (2015), Mulder and Yaar (2006) and Idoughi and colleagues (2012), and abstracted to be more service design appropriate and less interaction design specific, are presented in Table 3.

Table 3. Key elements of personas

Element	Description
Identity and personal profile	Create a realistic identity including name, age, gender and other relevant demographic data. Include a photograph. Describe the individual, their personality, family life and hobbies.
Goals, motivators and pain points	Personal goals as well as those related to the product/service being designed. What are their motivations for achieving these goals and the barriers or pain points they are experiencing?
Tasks	Basic or critical tasks the user conducts, and the frequency, importance and duration of those tasks.
Relationships	Significant relationships relevant to the individual's tasks or goals.
Needs and requirements	What does the person need to be able to use the product/service: for example, knowledge, skills and abilities, as well as infrastructure or tools?
Expectations	How does the individual perceive the product/service to work, or expect it to work in the future?

Adapted from Baxter and colleagues (2015), Mulder and Yaar (2006) and Idoughi and colleagues (2012), and abstracted to be more service design appropriate and less interaction design specific.

Being a reasonably new and specialised technique having been in existence since the late 1990s, the seminal works, which are still commonly referred to, are textbooks and practical 'how to guides' written by design practitioners (Cooper, 1999, Cooper, 2004, Cooper et al., 2014, Goodwin, 2011, Mulder and Yaar, 2006, Pruitt and Grudin, 2003, Pruitt and Adlin, 2010). Since then, journal article authors and conference presenters have sought to extend the theory and practice through: application of the methodology in practice (Billestrup et al., 2014, Chang et al., 2008, Dotan et al., 2009, Matthews et al., 2012, Nielsen and Hansen, 2014); variations to method or practice (Faily and Flechais, 2011, McGinn and Kotamraju, 2008, Miaskiewicz et al., 2008); or, discussion of advantages and criticisms (Chapman and Milham, 2006, Floyd et al., 2008, Massanari, 2010, Miaskiewicz and Kozar, 2011). Personas are now applied in a range of different contexts: product development; marketing and communication; service design (Nielsen and Hansen, 2014); interior design; education course design; business process and organisational structure design; and, business strategy (Goodwin, 2011).

1.3.2. Benefits of personas

Personas stand in for real people during the design process when customers cannot be in the room, allowing stakeholders to 'meet' the target audience by proxy (Goodwin, 2011). A panel of 19 persona experts recognised three significant benefits of personas (Miaskiewicz and Kozar, 2011). The first was to focus designers and decision-makers on the needs and

goals of *target customers*, rather than the needs of the business, or a generic category of ‘all possible consumers’. The second benefit was the prevention of self-referential design. Without a clear alternative individual in mind, we tend to assume everyone else is just like us, with the same goals and priorities. Design decisions will reflect that bias, leading to products and services better suited to their designers than to customers. The third benefit was that personas surface and challenge (often incorrect) assumptions businesses hold about their customers, preventing them from acting on incorrect information.

In addition, a study of personas in practice identified their communication-related benefits: personas were found to provide a common language and understanding between team members, both designers and non-designers (Nielsen and Hansen, 2014). This makes personas useful in many business contexts. They are memorable and actionable, turning data into knowledge that can be used to make better decisions about what works best for customers, to inspire superior product and service design (Cooper, 2004) and avoid poor business decisions (Nielsen and Hansen, 2014).

As a manifestation of research data, personas provide an effective means of justifying and defending design decisions. Rather than arguing for a solution based on personal opinion, or by referring to reams of complex research data, team members can simply point to how a decision or idea will work effectively for a particular persona (Goodwin, 2011). Personas enable us to make predictions about how customers might behave because they give us a mental model of a type of customer – a sort of shorthand version of the models psychologists construct to understand human reasoning (Floyd et al., 2008). This means we can use personas to make complex cost-benefit evaluations and trade-off decisions quickly and efficiently.

1.3.3. Persona types and development approaches

Although a relatively new design concept, the term persona has been used to refer to a range of artefacts or methodologies. A key point of difference is the data source on which personas are based: ethnographic or mixed methods based personas, or non-empirical based (Floyd et al., 2008) – see Table 4. For the purpose of this study, I will be using personas to refer to the empirical evidence-based types.

Table 4. Types of personas by data source

Type	Description	Examples
Ethnographic research based	Includes methodologies that rely on, or place primary importance on, qualitative ethnographic research conducted specifically for the design task at hand.	Cooper (2004) Cooper and colleagues (2014) Goodwin (2011) Mulder and Yaar (2006)
Mixed methods based	These methodologies also have strong empirical emphasis, allowing for multiple data sources, both qualitative and quantitative.	Pruitt and Adlin (2010) Faily and Flechais (2011) McGinn and Kotamraju (2008) Miaskiewicz (2008) Mulder and Yaar (2006)
Non-empirical based	Fictitious personas based on stakeholder information, hypothesis or designer intuition. Sometimes used in conjunction with empirical personas, or stand-alone.	Pruitt and Adlin's assumption personas (2010) Norman's ad hoc empathic focus personas (2010) Goodwin's provisional personas (2011)

Based on Floyd and colleagues (2008).

Table 5. Persona development approaches compared

Author	Persona development stages			
Goodwin (2011)	1. Research planning: number of interviewees, site visits, scheduling	2. Conduct research: interview and observe	3. Data modelling: synthesise and analyse data, identify behaviour patterns, create 'proto-personas'	4. Create personas: turn behaviour patterns into useful characterisations
Mulder and Yaar (2006)		1. Conduct research: interviews, field studies and usability tests	2. Identify segments: uncover patterns that enable similar users to be grouped. Validate with quantitative data	3. Making personas real: transform segments into personas
Pruitt and Adlin (2010)	1. Family planning: identify existing data sources and conduct primary data collection		2. Conception and gestation: process and analyse data, identify and create 'persona skeletons', develop personas and validate	3. Birth and maturation: personas in use, communication, education

The persona development approaches of three leading practitioners are compared in Table 5. While terminology and details vary, a common sequence can be distinguished:

1. **Conduct research** – source data, chiefly through conducting primary research;
2. **Data analysis and pattern identification** – uncover patterns in data and identify groups that will become basis for personas; and,
3. **Create personas** – construct a detailed description for each persona.

1.3.4. Criticisms of persona methodology

One of the main areas of criticism is the veracity of the data source for personas. Personas based on qualitative data alone may be seen to be too subjective, lacking rigour (Miaskiewicz et al., 2008, Nielsen and Hansen, 2014) and being ‘unscientific’ (Billestrup et al., 2014, Chapman and Milham, 2006). There are two main responses to this criticism.

The first response is to improve communication and education around the persona methodology specifically and qualitative ethnographic research more generally. Criticism of the veracity of persona methodology often goes hand-in-hand with observations about lack of understanding of team members regarding development and use of personas (Billestrup et al., 2014). Proper training in personas can lead to greater benefits being realised (Matthews et al., 2012). This line of criticism of the methodology points to a misunderstanding of qualitative research and the purpose of personas. For example, disapproval of personas on the basis that they are not properly representational because they only represent a small portion of customers, with no way to say exactly how many people each persona describes (Chapman and Milham, 2006). Personas represent critical patterns in research. Their function is to promote empathy for customers and facilitate discussion and decision-making, not to be an exact statistical representation of the population (Goodwin, 2011).

Further criticism of the methodology is that personas cannot be validated or falsified through statistical means (Chapman and Milham, 2006). This demonstrates misunderstanding of the differences between quantitative and qualitative approaches. Qualitative research using an inductive approach, focuses on exploring the meaning individuals and groups assign to phenomena, seeking to understand context, and faithfully render the rich details and complexity of real life (Creswell, 2009). While quantitative research can tell us ‘*what*’ is happening, qualitative methods are essential for good design

as they enable us to understand the ‘*why*’ and ‘*how*’ of people’s behaviour (Mulder and Yaar, 2006).

While criticism concerning the lack of rigour of qualitative approaches may be ill informed, it points to a gap in understanding. Improvements could be made to the traceability of personas to their underlying research and the transparency of the persona creation methodology. Many practitioners recommend including stakeholders in the persona creation process to ensure they have exposure to both the methodology and the underlying raw data (Dotan et al., 2009, Goodwin, 2011, Pruitt and Adlin, 2010).

The second strategy for responding to criticism about the legitimacy and rigour of the persona methodology is to incorporate a validation step. A common approach uses qualitative research to identify the behaviour patterns on which different customer groups, or segments, can be based, followed by quantitative research to validate the model (Mulder and Yaar, 2006). A quantitative research tool such as a survey can be used to test the segmentation model against a larger sample size to confirm it reflects the broader study population. In this approach, the quantitative data is not intended to prove every aspect of the final persona, but to validate the segmentation that underpins the model, or key differences between personas.

An alternative approach is to reverse this process and use quantitative data to identify customer segments, followed by qualitative interviews to validate the segmentation and flesh out the final personas (McGinn and Kotamraju, 2008). In this approach, stakeholders were used to help design a survey that collected demographic and behavioural data. Factor analysis was used to generate segments based on the tasks people reported undertaking. Interviews were then conducted with representatives from each segment to explore people’s motivation and goals. Poor alignment between an interviewee and their segment prompted a re-examination the data and refinement the model. This approach claims to reduce time and cost compared to more traditional ‘qualitative first’ approaches (McGinn and Kotamraju, 2008). A disadvantage of the approach is its dependency on stakeholder input. Stakeholder’s existing knowledge and assumptions about their customers are implicitly assumed to be correct and drive the design of the primary data collection tool.

Other validation tactics focus on ensuring final personas do not ‘stray too far’ during the storytelling phase of persona creation. These tactics include: reviewing final personas against original data; expert or stakeholder review of final personas; final persona review by representatives of the persona segments; and, conducting ‘reality check’ site visits or interviews (Pruitt and Adlin, 2010). These tactics are not mutually exclusive. The approach will depend on the time and resources available, the complexity of the situation and the level of stakeholder support.

1.3.5. Challenges during the persona creation stage

In the persona creation stage, details from research are amalgamated, extended and shaped into a single realistic description for each persona. For personas to be an effective tool they must be believable, hence the practice of making personas specific, giving them names and describing each unique character (Cooper, 2004). Achieving the right level of detail and specificity presents a challenge for many practitioners. Common obstacles to persona adoption reflect this: descriptions are too sparse or abstract (Billestrup et al., 2014); personas are too impersonal; or, personas include distracting details (Matthews et al., 2012).

While persona experts warn of the pitfalls of too little or too much creative flourish, the specific guidelines provided often conflict. One recommendation is to avoid silly or alliterative names as it undermines the value of the persona and emphasises that it is not real (Goodwin, 2011). However, such advice contradicts the direction to provide personas with a name and tag line, using alliteration to make them memorable, for example ‘Toby the Typical Teenager’ or ‘Abe the Active Administrator’ (Adlin and Pruitt, 2010). Creating the level of detail and narrative appropriate for each context takes experience and practice (Cooper et al., 2014). The aim is to create useful descriptions and provide information that will inform design decisions (Goodwin, 2011). Meeting this challenge can be best achieved by applying the guidelines flexibly, according to industry context and specific setting.

1.3.6. How the persona methodology will be applied in this study

This study will follow the common stages of persona development outlined above (section 3.4), with the addition of a validation stage. Within each stage, aspects of various approaches will be incorporated to create a methodology most appropriate to this study and the residential aged-care environment. The four stages are:

1. **Implement data collection** – qualitative research to uncover insights into customer's goals, behaviours and attitudes;
2. **Pattern identification** – identify patterns in the data that enable similar customers to be grouped together in 'proto-personas';
3. **Create personas** – create a persona to reflect the behaviours, goals and attitudes of each proto-persona; and,
4. **Persona review** – validate personas with study participants by seeking feedback on their appropriateness and anticipated use.

1.3.6.1. Implement data collection

This study will develop ethnographic research-based personas. An ethnographic research strategy involves studying a cultural group in their natural setting, and collecting primarily observation and interview data through a flexible and emergent research process (Creswell, 2009). This immersive approach is appropriate when seeking insights into people's behaviours, needs, desires and motivations (Goodwin, 2011) and wanting to understand the meaning of an experience through the eyes of the participants (Creswell, 2009). The personas developed for this study will be based on the primary research conducted for this purpose, without the use of pre-existing data or stakeholder input. As the researcher does not have prior familiarity with the research site, and the research is taking place at the request of the researcher, not the facility, this is the most pragmatic approach. Observation will be the first research technique employed, followed by interviews with residents. The initial observation activity allows time for the researcher to immerse in the environment and identify potential behaviour patterns and dynamics that can then be explored further in the interviews. This approach is particularly helpful when working in an unfamiliar environment (Goodwin, 2011).

1.3.6.2. Pattern identification

Goodwin's (2011) variable mapping process, outlined in Table 6, will be used to identify the segmentation model or 'proto-persona' groupings that will become the basis of the final personas. This process focuses on drawing out the primary behavioural patterns from the data, is a natural extension of data collection and can be carried out iteratively. Additional advantages include being suitable for the anticipated size of the data pool, not relying on advanced data analysis tools and producing artefacts that provide traceability from data to proto-personas. In this study, the outputs of this process will be referred to as 'proto-

personas' (Goodwin, 2011). The term 'proto-persona' makes it clear that the output is one step in a process, not the end in itself.

Table 6. Variable mapping process to identify proto-personas

Step	Description
1. Identify variables	Inductively identify behavioural variables across interviewees.
2. Create continuums	Create continuum for each variable. For example, is something done frequently or infrequently, is someone motivated by cost or quality, is someone organised or disorganised.
3. Map interviewees	Map each interviewee to every variable.
4. Identify patterns	Look for interviewees who cluster together frequently across multiple variables. Proto-personas will be groupings that are defined by the correlation of multiple behavioural variables.

Based on Goodwin (2011)

1.3.6.3. Create personas

As this is, to the best of our knowledge, the first time personas have been used in a residential aged-care environment, some degree of trial and error is anticipated. Determining the right type of information and level of detail required in the final personas is predicted to necessitate iteration between stages. As in other fields, the right level of detail may vary according to context so this will need to be re-addressed each time the persona technique is applied (Nielsen and Hansen, 2014). In this study, consultation with stakeholders will be undertaken to determine the most appropriate level of detail for the personas.

1.3.6.4. Persona review

Two validation steps will be undertaken to ensure the personas appropriately capture the behaviours, perceptions, preferences and attitudes of residents. Following the recommendations of Pruitt and Adlin (2010): personas will be reviewed against original data and feedback on personas will be sought from residents involved in the initial data collection phase. The final test of the personas will focus on their appropriateness, or 'fit for use'. The personas will be reviewed with key stakeholders to gain feedback on their usefulness for identifying service improvement opportunities and designing new services.

The way in which personas are introduced to stakeholders, and the supporting education provided, is critical to the success of the technique in helping design enhanced customer-centred services (Billestrup et al., 2014, Dotan et al., 2009, Matthews et al., 2012, Nielsen

and Hansen, 2014). For this study, communication with stakeholders will include information about the methodology and purpose of personas, to ensure they are well informed.

1.3.7. Methodology review conclusion

This section has provided an examination of the persona methodology, including benefits, challenges, criticisms and alternate approaches, which has informed the way the technique will be applied in this study.

The persona approach outlined here draws on the experience of a number of leading persona practitioners. In keeping with the original persona concept expounded by Cooper (1999), this study will develop ethnographic research-based personas. Complimenting this approach, other, more recent, developments of the technique will also be utilised: the variable mapping process to develop proto-personas (Goodwin, 2011) and the ratification of final personas against source data and with residents (Pruitt and Adlin, 2010).

2. PART 2: PROOF OF CONCEPT

Part 2 of this thesis outlines a proof of concept study to apply the persona technique in a residential aged care facility in Sydney, Australia. As discussed in the literature review (section 1.2), a number of participatory methods from the broad field of human-centred design, have been used in aged care. There is no research evidence, however, of the persona technique being used in this setting. This study aimed to determine if the technique can be successfully applied to residential aged care. Insights about resident's behaviours, desires and motivations were gathered through qualitative research, then presented in a realistic and actionable way in the form of personas. The personas were reviewed with key staff to obtain feedback of their usefulness in informing future service improvement initiatives.

2.1. METHOD

The persona technique was examined in detail in the methodology review (Section 1.3). What follows here is an outline of how the technique was implemented for the purpose of this study. The study was conducted in four stages: (1) implement data collection, (2) pattern identification, (3) persona creation, and (4) persona review.

2.1.1. Implementing data collection

2.1.1.1. *Research approach*

Following an ethnographic research approach, residents were considered in their everyday setting and data collected through observation and interviews in a flexible and emergent research process (Creswell, 2009). This method was selected as the most appropriate for seeking insights into people's behaviours, needs, desires and motivations (Goodwin, 2011) and wanting to understand the meaning of an experience through the eyes of the participants (Creswell, 2009).

2.1.1.2. *Setting and participants*

Three residential aged care providers were approached to take part in this study. Two declined as they had patient-centred care service improvement initiatives already underway at that time. Presbyterian Aged Care (PAC) agreed to participate and the specific study site was selected following consultation with PAC management based on facility

accessibility, size and availability of staff. Access to the facility was planned and organised with the facility staff, in particular, the facility manager.

This study was conducted in a PAC residential aged care home in Sydney, Australia. It is a 125-bed facility providing basic, complex and dementia care. (The dementia care unit is excluded from this study.) Study participants included approximately 50 residents and 3 staff members.

Ethical and scientific approval for the study was granted by Macquarie University Human Research Ethics Committee (HREC (Medical Sciences)), reference number 5201800108. Written approval was also provided by Presbyterian Aged Care.

2.1.1.3. Data collection activities

Data collection activities undertaken were key informant (staff) interviews, participant observation and resident interviews.

Key informant interviews (Pelto, 2016) consisted of open, unstructured interviews with crucial staff to obtain information about the community, its behaviours, cultural 'rules' and common practices. Interviews were guided by topic areas rather than specific questions to support the discovery process. (Please refer to Key Informant Interview Guide in Appendix A.) Topic areas for both the key informant and resident interviews were developed with reference to a number of sources: social situation dimensions (Spradley, 2016); previous studies and reviews regarding quality of life in aged care (Australian Aged Care Quality Agency, 2015, Bradshaw et al., 2012, Li and Porock, 2014); key elements of personas (see Table 3, Section 1.3.1) and, discussion with other researchers. The key informants also acted as gatekeepers to the community and as a specialist reference when further explanation was required regarding people, events or processes.

Participant observation was undertaken to identify the community's normal routines, interactions and activities, and to inform the issues to be explored in greater depth in the resident interviews. It was conducted in communal areas through participation in group activities and social times. An observation checklist was used, based on Spradley's (2016) nine major dimensions of social situations: space, actor, activity, object, act, event, time, goal, and feeling. In addition to capturing condensed notes during observation and making

a more expanded account shortly after, the thick description technique (Geertz, 1973) was also used to help the researcher process and reflect on the situations being observed.

For resident interviews, an in-depth interview approach was used (Serry and Liamputtong, 2013) where interviewees were engaged in conversation through the use of broad, open-ended questions to extract their understanding and interpretation of events, activities and behaviours. (Please refer to Resident Interview Guide in Appendix B.)

An empathy map (Grey, 2017) was used to capture the outputs and reflections from each interview to help generate insights and understand the similarities and differences between interviewees, particularly in regard to behaviour, attitude and motivations. (Please refer to see Appendix C for an example empathy map).

2.1.2. Pattern identification

A variable mapping process was used to identify 'proto-persona' groupings (Goodwin, 2011). This involved inductively identifying variables arising from observation and interview data, creating semantic differentials, or continuums, for each variable, then mapping interviewees to each differential and identifying the patterns that emerged (i.e. interviewees who cluster together frequently across multiple variables). For example, participation in organised activities was a behaviour variable observed during observation. A semantic differential was created for this variable, with 'no participation' at one end of the continuum and 'frequent participation' at the other. Resident interviewees were then mapped on the continuum according to their observed and reported behaviour. The mapping of each interviewee on the semantic differentials produced artefacts that provide traceability from interview to proto-personas.

2.1.3. Create personas

The proto-personas were expanded using stories, anecdotes and details from the research to create a single description for each persona. Personas were made to feel real by being given a name, photo, demographic details and stories that give insight into their environment, behaviour, goals, frustrations and attitudes. The personas are presented as written documents incorporating words and stock photography images.

2.1.4. Persona review

To ensure the personas appropriately captured the behaviours, perceptions, preferences and attitudes of residents, personas were tested in two ways: (1) personas were reviewed against original data at both the proto-persona and final persona stages; and, (2) feedback was sought from residents and key informants involved in the data collection phase.

Additional validation involved testing whether the personas were ‘fit for purpose’. This involved examining the personas with key informants to assess their suitability for assisting staff to identify and design service improvements.

2.2. FINDINGS

Immersive ethnographic research, involving 30 hours of direct participant observation and 15 interviews with residents (12) and staff (three), was conducted over a two-week period to uncover insights into residents’ goals, needs, behaviours and attitudes. Table 7 provides a detailed breakdown of time spent on data collection and related activities during the two-week data collection stage.

Table 7. Time spent on data collection and related activities

Data collection activity	Time (hours)
Direct observation	30
Resident interviews	11.25
Key informant interviews	6.08
Onsite note taking	15.84
Journaling	40
Peer debrief and discussion	10
TOTAL	113.17

2.2.1. About the study setting

The residential aged care facility where this study was carried out has been operating for many years and is of an older style where different types of accommodation are used to provide different levels of care. Basic care is provided in hostel accommodation consisting of hotel-style rooms, typically set up with an adjustable single bed, small table and chair, a bedside table and small wardrobe, televisions and space for tea/coffee making facility and a private ensuite bathroom. Rooms also have space for some personal furniture items (bookshelf, small buffet, desk or chest of draws). All hostel rooms open onto one of two open-air courtyards, with covered walkways leading to the common areas of the facility. More complex needs are catered for in the nursing home wing of the facility which is more

of a hospital-style set up with large rooms shared by 2-3 residents with common bathroom facilities shared by a number of rooms. Privacy in shared rooms can be created by drawing a curtain around the resident's corner of the room – including their bed, bedside table, television, small wardrobe and high-backed single lounge chair. The space can be personalised through bed coverings, wall hangings or photos, but there is little space for additional personal furniture items.

The hostel and nursing home accommodation wings operate over two levels, connected by a number of sets of stairs, ramps and lifts. There are common areas on both levels of the facility open to residents from both the hostel and the nursing home. They include dining rooms (one on each level), lounge rooms (one on each level), outdoor courtyards (downstairs), and chapel (upstairs). The ground floor lounge is the largest indoor space and the most frequently used. It is set up with chairs and tables that are reconfigured according to need: chairs around a mix of different sized tables for bingo or trivia, a single large table with chairs for knitting or art. Smaller tables for Scrabble afternoons, chairs in rough semi-circular rows for concerts, or simply chairs around the perimeter of the room when it is being used as a lounge area. Most of the common areas are situated roughly centrally relative to the accommodation wings, however, because the various accommodation wings and central areas have been added or updated at different times, the facility layout is not straightforward.

2.2.2. Key informant interviews

Key informant (KI) interviews were conducted with three senior staff members: the facility manager, the care manager (nursing unit manager) and the head of the Leisure and Activities team. These interviews happened progressively over the course of the two-week data collection phase. Initial key informant interviews typically lasted 45 minutes and were conducted in the staff member's office or a local coffee shop. Follow-up discussions occurred more opportunistically, taking between 10-20 minutes and taking place in various parts of the facility, such as administration and office areas, hallways, courtyard or lounge.

Key informants provided clarification or alternate views on matters arising during observation or resident interviews, as well as contextual information about the facility's environment, history, policies and processes. In addition, one of the key informants

provided the researcher with a brief tour of the facility at the commencement of the data collection stage and assisted the preparation of an observation schedule, helping identify the times, locations and activities that would be both beneficial to observe and appropriate for the community. For example, the researcher assisted residents to attend prayer group and bible study but did not participate in these activities. There was a concern that the addition of an outsider in these more intimate gatherings would cause anxiety for some of the regular participants. The key informants also assisted the researcher to identify potential resident interviewees, helping ensure participants were: able to provide their own consent; likely to be open to participating; could participate in an English language interview; physically and cognitively able to participate; and, as much as possible, reflected a cross section of the resident community. The researcher then approached each resident individually to invite them to participate. A summary of the contribution made by key informants is provided in Table 8.

Table 8. A summary of key informants' (KI) contribution to the study

How	Examples
Introduction and familiarisation with the community	<ul style="list-style-type: none"> • Facility tour • Provision of resident activity calendar • Assistance to identify times, places and activities for observation • Identify potential resident interviewees
Providing additional context regarding areas of interest	<ul style="list-style-type: none"> • Large age discrepancy between residents: <ul style="list-style-type: none"> <i>"Some people choose to live in the hostel at a younger age. They might have no relatives so it's easier and safer here. Or single men. Wife dies. They don't know how to manage a household."</i> (KI1) <i>"Maybe 20% of residents here are younger. It's not happening anymore though. There's now different government policy. Now, people tend to be older... Mostly physical and cognitive decline. Or could be just cognitive."</i> (KI3) • Relationships between residents: <ul style="list-style-type: none"> <i>"... focused on their health. Particularly in nursing home. They're in the last stages so there's irritability, depression, low tolerance. They don't adapt. Strong habits, decreased communication ability which can be frustrating for them - so they stick to their room. They lose the ability to sense what's going on with others. Sick people don't have energy for making friends. It's tiring to be social."</i> (KI1) <i>"We have more mental health issues here - it's linked to social economic background."</i> (KI3) <i>"Residents are more likely to make friends in the hostel. Much harder in the nursing home. Many are bed bound. Or just not able to interact anymore."</i> (KI2)
Alternate views on topics of interest	<ul style="list-style-type: none"> • Drivers of tendency for interaction/ isolation: <ul style="list-style-type: none"> <i>"Some prefer to stay in their room. They're not social or extroverted. Usually different racial background."</i> (KI3) <i>"Physical layout is hard for staff and residents. Can be a barrier to maximising participation... long distances... stairs."</i> (KI2) • Adaption to new environment: <ul style="list-style-type: none"> <i>"Need to allow 3 months for people to adjust."</i> (KI2) <i>"Some people who don't want to be here. Often initially. But they see it as the best outcome after a few weeks. Only a few continue [to not want to be here]."</i> (KI3)
Suggest new topics to explore	<ul style="list-style-type: none"> • Expectations and contentment in care: <ul style="list-style-type: none"> <i>"We have happier residents than in other places. There are less complaints. Some, but not as much as other places. They have lower expectations so they're more grateful... I think it's the lower social economic background."</i> (KI3) <i>"Residents generally really appreciate what help they get. They came from poorer backgrounds."</i> (KI2)

2.2.3. Observation

A total of 30 hours of observation was conducted over a two-week period. Observation took place by spending time in the common areas of the facility (generally the dining and lounge rooms) and through involvement in group activities such as bingo, trivia, art therapy, music group, knitting group, exercises and concerts. A day's observation would typically extend over 5-6 hours where the researcher would alternate between attending group activities, sitting in the lounge and dining rooms and taking short breaks of 10-20 minutes to write notes and reflections. Observation sessions had staggered start times to provide exposure to different times of the day and, therefore, different types of activities and mealtimes.

An opt-out consent process was used for observation. Residents and their families were notified about the observation via: an announcement at a resident's meeting; resident newsletter and meeting minutes circulated to all residents following the meeting; and, posters displayed in common areas when observation was taking place (see Appendix K). Residents wanting to opt-out could either elect to use an alternate common area, or notify the researcher or staff member, and they would be excluded from the observation field notes.

Through observation, the researcher came in contact with approximately 50 residents from both the hostel and nursing home. Most of these residents became known by name to the researcher over the course of the study, either through the introduction of a key informant, or through the researcher introducing themselves and requesting the resident's name. This accounted for 45% of the facility population (excluding the dementia care unit) and 60% of the 'available population' (25 residents in the nursing home are bed-ridden and non-responsive and were therefore not accessible for observation). Two-thirds of residents observed were female; one-third male. Table 9 provides a breakdown of the study population.

Table 9. Study population

	Resident population	Residents observed	Proportions
Hostel	50	24	48%
Nursing home	60	17	28%
Dementia unit		Not included in study	
Unknown	0	9	
Total population	110	50	45%
Bed-ridden/ non-responsive	25		
Available population	85	50	59%
Female		33	66%
Male		17	34%

Most residents appeared initially to be aware but uninterested in the researcher's presence, as though they were used to unfamiliar people in their space: which would be a common experience given the fairly constant stream of staff, visitors and volunteers observed moving through the common areas of the facility on most days and the high levels of memory impairment among residents which would render even regular guests unfamiliar. By the second and third day of observation, some of the more regular common area attendees had started to acknowledge of the researcher's presence and show some curiosity. The researcher responded to this interest by introducing themselves and starting brief conversations with residents. By the end of the first week of observation, the researcher had become a more familiar presence for residents who spent any time in the facility common areas. This growing familiarity was apparent through responses to greetings and non-verbal responses such as smiles and nods, though only a small number of residents recalled the researchers name or reason for being there.

The vast majority of introductions and conversations with residents were initiated by the researcher: only three residents initiated conversation with the researcher and this occurred in the later-half of the project. The range of responses from residents reflected the variety of personalities in any community: some were keen to engage; others were polite but reluctant; some seemed accepting of the researcher's presence but uninterested; and, others wanted attention and were unwilling to share it or let it go. Only one resident displayed annoyance at the researcher's presence; they left the room, though it was unclear if they were leaving because of the researcher or where on their way out anyway.

2.2.4. Resident interviews

Interviews were conducted with 12 residents. 13 residents were initially approached. One person preferred to be included in the observation rather than an interview. Therefore, the final response rate for resident interviews was 92%. Written consent was obtained from all interviewees. (The consent form used can be found in Appendix J).

Most interviews were conducted in a single session of between 30-60 minutes, with others spread over multiple discussions when opportunity allowed. Six interviews were conducted in resident's rooms, the other six were conducted in one of the common areas. Interview location was chosen by the resident.

Interview data were recorded as field notes only: audio recordings were not taken. The original intention was to use a mobile phone to record the resident interviews, however, in practice, this felt awkward and intrusive. Additionally, the pace of the interview allowed sufficient time for note taking during the session, and the researcher was familiar with this approach from previous client interviews.

Two-thirds of interviewees were female; one-third male. The key informants report this being aligned with the facility population as a whole. Interviewees ranged in age from 65 to 97 years old (Figure 3). While most interviewees had been in the facility for less than five years, one third of interviewees had been the facility for an extended period of time, one as long as 26 years (Figure 4). This profile of resident age and time in care is seen by the key informants as being particular to this facility; they have a number of residents who came into care as the result of a complex health crisis in middle age, at a time when there was less support for people to stay in the community. In the words of one key informant: "Maybe 20% of people here are younger. It's not happening anymore though. There's now different government policy." (K13).

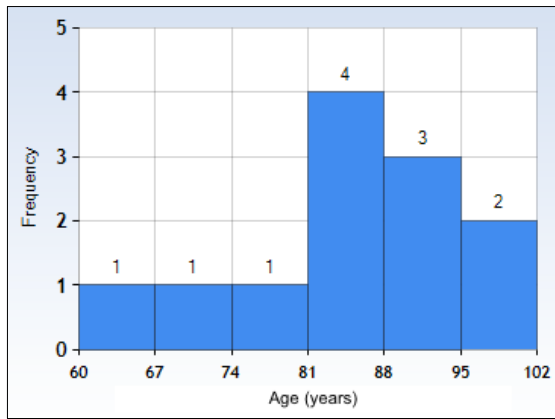


Figure 3: Age distribution

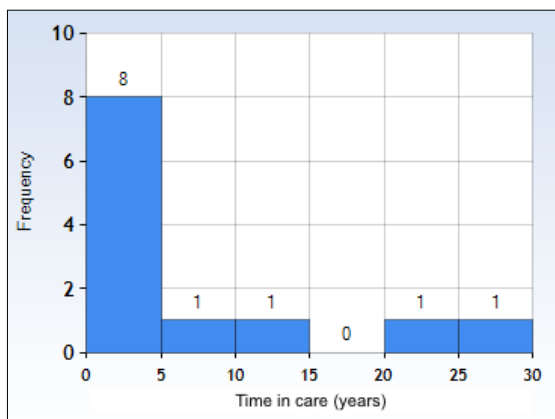


Figure 4: Time in care distribution

2.2.5. Identifying patterns

Three proto-persona groupings for the Ashfield PAC aged care home were identified using a variable mapping process (Goodwin, 2011). The following is a description of how that result was arrived at. A visual representation can be found in Figure 5. The Figure demonstrates how the process followed to generate variables, map interviewees, identify patterns and develop the proto-personas involved alternating between divergent and convergent thinking in a pattern similar to the UK Design Council's 'double diamond' design process model (Design Council, 2007).

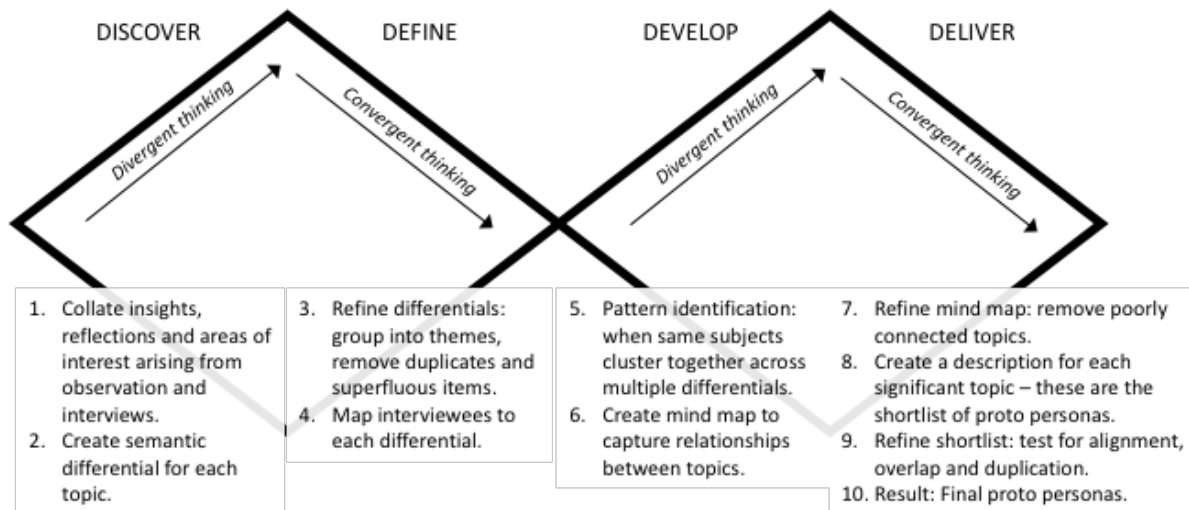


Figure 5. Flow chart of stage 2: pattern identification
'Double diamond' design model adapted from Design Council (2007)

Data collection tools from stage 1 – field notes, expanded notes, interview notes (resident and key informant), empathy maps and thick description – were reviewed to identify all areas of interest, reflections and insights. Each topic was then expressed as a semantic differential, or continuum. Examples of differentials developed include; resident finds it easy/hard to make friends; resident enjoys/avoids attention from staff; and, resident initiates conversation with others/responds to conversation efforts of others. The intent of this exercise was to generate as many differentials as possible to ensure the data collected had been exhausted. (See Figure 5, steps 1-2.)

A pool of 90 differentials were created initially; this was refined down to 40 which were taken forward in the analysis. Differentials were rejected for the following reasons: duplication; only relevant to a few interviewees; the issue was not observed or could not be inferred; or, the topic was too broad and was better represented by more specific, observable behaviours. For example: a differential concerning cognitive impairment was excluded in favour of a differential regarding 'functional memory'. 'Functional memory' was used to refer to the degree that the resident's memory impairment was apparent to the researcher during conversation or observation of the resident interacting with other people. 'Functional memory' was an observable characteristic for the researcher, whereas an assessment of cognitive impairment was beyond the researcher's training and expertise. (See Figure 5 step 3.)

Each of the 12 interviewees was then mapped to each differential. This activity was carried out manually, using paper and different coloured markers to code for each interviewee. (See Figure 5 step 4.) Interview data was de-identified prior to mapping.

The pattern identification activity was also conducted manually with all differentials displayed on a wall. Differentials were moved into groups or proximity to each other as patterns were discovered, that is, where the same interviewees were seen to cluster together across multiple topics. (Please refer to Appendix D for a picture of the design wall used for differential mapping and pattern identification.) At this stage, the mapped differentials were also reviewed to ensure there was an overall focus on behaviours, attitudes and needs, rather than demographic factors. Demographic factors were still included where relevant, but they were de-prioritised during the pattern identification activity and only added back in once the behavioural and attitudinal patterns had been established. A mind map was created to capture the relationships between topics. In addition to capturing positive relationships between factors, the initial mind map also captured 'negative' relationships, where an assumed connection between two factors had been tested and disproven. For example, a hypothesised relationship between a resident's tendency to interact or isolate, and whether or not they needed staff assistance to leave their room was tested, but no correlation was found. This 'negative' relationship is expressed on the initial mind map. (Please refer to Appendix E for an image of the initial mind map). (See Figure 5, steps 5-6.)

Moving back to a more convergent mode of thinking, the mind map was refined and simplified by removing 'negative' relationships and topics that had few connections, or were superfluous. The most connected topics in this mind map became the basis for the initial shortlist of possible proto-personas (Appendix F). Referencing both the refined mind map and the original differentials, a short description of each possible proto-persona was created. (See Figure 5 steps 7-8.)

An initial comparison of the 12 possible proto-personas identified five that could be removed: four were duplicates and one was removed because there was not a strong correlation between the differentials that made it up. The remaining seven proto-personas on the shortlist appeared to have some alignment or overlap (see Appendix G for an outline

of the seven proto-personas). The extent of the alignment was assessed by plotting the proto-persona elements against each other using 2x2 matrices, with one variable on the X axis, the other on the Y axis (see example in Appendix H). This analysis indicated the proto-personas could be further consolidated because there was a strong correlation between a number of groups. The final three proto-personas groupings are described in Table 10. (See Figure 5 steps 9-10.)

Table 10. Final proto-persona groupings: seven variables consolidated into three groups

Proto-persona group 1	Proto-persona group 2	Proto-persona group 3
Tendency to interact <ul style="list-style-type: none"> • Frequent participant in activities • Likes fuss/ attention from staff • Regularly in pain/ discomfort • Fears death/ loss of capacity • No interest in outside world • Does not leave facility • Tends to be older 	Tendency to isolate <ul style="list-style-type: none"> • Selective participation in activities • Prefers own interests to group activities • Avoids attention from staff • Positive about being in care • Shows interest in outside world • Leaves facility on their own • Tends to be younger 	Unsettled in care <ul style="list-style-type: none"> • In persistent pain/ discomfort • Rails against declining health • Discontent in general/ irritable • Desire to interact with others • Easily frustrated (by other residents, own limitations, by care) • Short time in care
Insular/ self-referenced (does not help out) <ul style="list-style-type: none"> • Desires interaction but does not initiate conversation with others • No contact with friends outside the facility • Does not leave the facility • Poor functional memory • Tends to be older 	Likes to help out <ul style="list-style-type: none"> • Good functional memory • Initiates conversation with others • Has regular contact with friends outside • Leaves the facility (with help or on own) • Settled about being in care • Tends to be younger • Has been in care longer 	
Strong family bond <ul style="list-style-type: none"> • Strong family bond • Frequent visitors • Shorter time in care • Made own decision to go into care 	Weak family bond <ul style="list-style-type: none"> • No family, or troubled and distant family contact • Infrequent or no visitors • Mental health issues (not dementia related) • Did not make their own decision to go into care • Long time in care 	

The same colour coding has been used across all relevant tables and figures for ease of tracking proto-persona groups through to final personas.

2.2.6. Key themes

Three overarching themes were identified that cut across all residents: the need to connect with others, difficulties making friendships and the need to fill time. Four additional factors were uncovered as the key behavioural and attitudinal variables that differentiated residents: tendency to interact/isolate; likes to help out/does not help out (insular/self-referenced); strong or weak family bond; and, feeling unsettled in care (Table 10).

The tendency to interact or isolate was foundational and drove many observed behaviours. The research found that this choice was primarily driven by resident preference. Other factors assumed by the researcher, or suggested by key informants were secondary considerations: physical limitations/impairments; dependence on staff for mobility; cognitive function and memory; declining ability to pursue interests and hobbies; or even actual (dis)interest in a given activity. For some resident interviewees (RI), the need to interact overrode all other considerations:

"You just want to be with the people. Anything not to sit here alone." (RI8);

"I like to talk to people. I'm so forgetful! But that doesn't stop me. Some people here don't make an effort" (RI12);

"I like doing things [the activities]. It's a good way to meet people" (RI7); and,

"I talk to everyone. I'm like the house detective around here. I know who's who and where they come from." (RI11).

For these people, being around others and keeping busy went hand in hand:

"I come to everything... exercises, then I go to whatever is on next." (RI12);

"I prefer to get out of my room... It's good to keep busy. Better than staring at the walls" (RI6);

"I go whatever is on. Even bingo. It's something to do" (RI9); and,

"Meals give structure to the day, then you fill in the gaps" (RI7).

Those with a tendency to isolate still had a need to connect with others and fill their time, but they were more selective about how they went about it:

"You have to choose the right ones. I wait and see what connection there is. Some of them talk about nothing. They have no personal interests. I have my own interests." (RI5);

"I'm not very comfortable with others. I go out on my own when there aren't activities I want to go to. I sit with [other resident] at bingo. It works quite well. We have a bit of a chat." (R12);

"I don't feel lonely. I've been single for a long time. But I do get a bit down sometimes. Then I call a friend." (R11); and,

"They're more acquaintances. Not friends... I like my own space. But I try to keep involved. Bingo – it's something to do" (R14).

As is demonstrated by these quotes from residents, the importance of connecting with others, the difficulty making friends in the aged care environment, and the desire to keep busy and hold boredom at bay were universal issues regardless of the tendency to isolate or interact.

Whether or not residents wanted to 'help out' was another key differentiator. Residents who helped out were satisfying a need to feel useful. Sometimes this manifested in very practical ways – helping set up for bingo, or hanging Christmas decorations. But more often, these residents spoke about kindness to other residents, and initiating conversation with people who couldn't, as their way of contributing:

"I like to be able to help out... I've got the gift of the gab and half a brain. I try to get to know people, remember their names, find something to talk about." (R13); and,

"It's important to feel useful.... My job here is to be patient and friendly, and speak to people." (R11)

Those who did not express this need tended to have greater memory impairment and were more 'insular' in that both their physical and psychological world had contracted around them: they no longer left the facility, expressed no interest in the world outside, and were typically unable to initiate conversation with others. They still desired interaction with others and were able to communicate, even engage in conversation, however, they did not have enough perception or awareness of others to be able to initiate an exchange.

The strength of a resident's family connection, or bond, was another key driver of attitude and behaviour variation and was more relevant than simply whether or not a resident had living family. Not surprisingly, the strength of the family bond correlated closely to the frequency of visitors a resident received. Very few residents interviewed had friends who

visited, as opposed to family members. Frequency of visitors was more significant for residents than the number of people who visited. This was because visitors were an activity and interaction that residents looked forward to: it satisfied both the need to connect with others and the need to fill time. How often residents received visitors was challenging to identify: key informants reported that this was an area where 'storytelling' was prevalent. It was also difficult for residents with memory issues to report definitively. However, residents were able to indicate how they felt about their (perceived) frequency of visitors. Residents who were happiest about the frequency of visitors they received reported a higher frequency of visitors.

Interestingly, a weak family bond (either no family, or a distant and/or strained family connection) was aligned with: mental health issues contributing to the resident moving into care; residents not making their own decision to go into care but having it thrust upon them by circumstance; and, having been in care for an extended period of time. This was the typical portrait of the resident who had to come into care comparatively early in life due to a complex health crisis which was compounded by mental health issues and a lack of family support.

The final factor that differentiated residents was whether they were unsettled in care. This factor did not correlate strongly with any of the others so it remained a stand-alone proto-persona. Typically in persistent pain or discomfort, these residents rail against their declining health. They're discontent and easily frustrated; by other residents, their own limitations or by being in care. They still have things that bring them joy, but they're unsettled, not yet accepting of, or adapted to, their new life situation.

The research identified other factors that created a clear distinction between residents, but were not foundational or defining characteristics. For example, there was significant variance within the group regarding whether a resident chose to eat their meals in their own room or the dining room. These different choices were reflected in the final personas, but they did not drive the creation of the underlying proto-persona, or cluster.

2.2.7. Creating personas

In this stage, the proto-personas were 'brought to life'; made to appear as real people. This was achieved by creating a rich story and unique identity for each persona, including giving

them a name, age, gender, backstory, hobbies and interests, impairments and use of mobility devices, likes and dislikes, and goals.

Many of these aspects were *specified* by the proto-persona description, such as whether or not they leave the facility, their frequency of participation in organised group activities, and whether or not they initiate conversation with others. Other elements were *guided* by the proto-persona description but not specified: age, time in care and degree of memory impairment (functional memory). Finally, many details of each persona were *open*; i.e. not specified or guided by the proto-persona description. Hobbies, sex, level of staff assistance required, mobility, personal history and where they ate meals (own room or common dining room) are all examples of persona elements that were not indicated by the proto-persona but were required to bring the characters to life. Table 11 provides a summary of items that were specific, guided or left open for each persona. It is interesting to note that Persona 3 has fewer elements that were specified or guided by the proto-persona. This was a result of the amalgamation of the proto-personas, where Persona 1 and 2 were a combination of multiple proto-personas.

Table 11: Elements of the final persona: specified (S), guided (G) by the proto-persona, or left open (O)

	Persona 1	Persona 2	Persona 3
Name	O	O	O
Age	G	G	G
Time in care	G	G	G
Accommodation type	O	O	O
Mobility	O	O	O
Functional memory	S	S	O
Staff assistance	O	O	O
Goals and motivations	S	S	S
Pain points and fears	S, G	S, G	S, G
Likes	S, G	S, G	S, G
Dislikes	S, G	S, G	S, G
Hobbies	O	O	O
Meal times	O	O	O
Background	O	O	O
Family	S	S	O
Visitors	S	S	O
Going into care	S	S	O
Leaves the facility	S	S	O
Other impairments	O	S	O

The same colour coding has been used across all relevant tables and figures for ease of tracking proto-persona groups through to final personas.

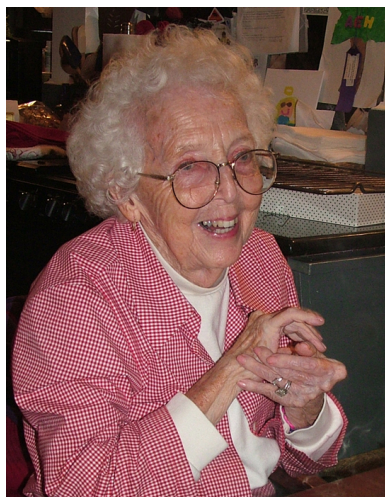
The addition of the 'open' elements of each persona was critical to making the character appear whole and believable. These elements were not arbitrarily 'made-up', but involved drawing on the anecdotes, life stories and experience of the interviewees and other residents observed in the care home. Priority was given to the experience of the interviewees most strongly aligned to the proto-persona group, but they were not used exclusively. This was partly to protect the privacy of the interviewees, but also to reflect the experience of the broader resident community.

The creation of 'open' elements, and adding the required specificity to 'guided' elements required the researcher to balance the following considerations: keeping true to the proto-persona description; creating a character with internal consistency; and reflecting the variety of behaviour observed in the community. The first two factors concerned each individual persona. The requirement to reflect the variety of behaviour observed across the community had to be considered across the three personas in combination. For example, whether the persona was in the hostel or nursing home accommodation wing was not specified, but it was important to ensure there was a persona to reflect each type of experience.

Before presenting the personas in their final form, the various elements of each persona were built in a simple table format to provide easy reference to the underlying proto-personas and easy comparison across personas (Appendix I). This table was reviewed with key informants and some residents before the personas were laid out in their final format. The final personas are shown in Figure 6, 7 and 8.

Enid

"I want to be with other people"



Age: 94

Time in care: 18 months

Accommodation type:
Nursing home

VISITORS

Never Multiple times a week

LEAVES FACILITY

Never Frequently

FUNCTIONAL MEMORY

Poor Good

MOBILITY ASSISTANCE

High Low

Mobility aids: walking frame

PERSONAL CARE ASSISTANCE

High Low

GOALS AND MOTIVATIONS

- I want to be around other people, to talk with them. Everyone I know is here now.
- I like having things to do. It fills the time and gets me out of my room.
- I'm comfortable and happy here. I have pretty simple tastes. I just take the day as it comes.

PAINPOINTS AND FEARS

- It's hard to make friends here - people don't talk to you. I did have some good friends, but they're in a better place now.
- My memory is no good any more. I'm always saying I don't have dementia, but may be I do. I'm so forgetful. And I get a bit confused sometimes. It's like my brain clogs up.
- I do struggle with pain sometimes. It can be hard at night. I wake up a lot.
- They say I'm doing OK, but I do worry. About dying. About getting worse. I see some of the people here... they've really lost it.

LIKES

- The activities are very good. I go to everything. Exercises in the morning, then morning tea, then whatever's on next.
- I like the opportunity to have a good chat. Residents or staff – anybody!
- The staff are very friendly. They look out for me. They collect me for exercise every morning. We chat on the way.
- My daughter visits a lot. I look forward to it. If it's sunny we sit in the courtyard. And my son calls me when he can.

DISLIKES

- Some residents don't make much of an effort to chat. I think they have dementia.
- I'd rather not stay in my room. Some people just watch TV all day - I don't want to do that.
- My room mate isn't good. She makes a lot of noise. Wanders at night. It's a bit frightening.

A BIT MORE ABOUT ME...

I'm comfortable here. I knew it was time. I told my daughter. I couldn't manage anymore. Even with getting help at home. It was too much.

I was married. But my husband passed away many years ago. I have a son and a daughter. My daughter is close by and visits all the time. My son calls and visits when he can – he lives on the other side of Sydney. I have five grandkids and now some great grandchildren too. I have their photos in my room. They visit sometimes too.

I mostly fill my time with group activities. Sometimes I just sit in the lounge and watch whatever's going on, people coming and going, chat to whoever is about. I used to enjoy reading but my eyes are too bad now for that. I do watch a little bit of TV in the afternoons, but I usually just fall asleep!

Figure 6. Final persona 1: Enid

Arthur *"I'm more comfortable in my own space, but I help out when I can"*



Age: 75

Time in care: 7 years

Accommodation type:
Hostel

VISITORS

Never Multiple times a week

☐ ☐

LEAVES FACILITY

Never Frequently

☐ ☐

FUNCTIONAL MEMORY

Poor Good

☐ ☐

MOBILITY ASSISTANCE

High Low

☐ ☐

Mobility aids: walking stick/ walking frame

PERSONAL CARE ASSISTANCE

High Low

☐ ☐

GOALS AND MOTIVATIONS

- I try to stay positive. You've got to be adaptive.
- I'm grateful I'm here. So I like to be useful and do things for others.
- It's important to keep doing things. You need to make an effort to fill your time.
- I'm most comfortable in my own space. I have my own interests.

PAINPOINTS AND FEARS

- It takes time to find people you can connect with. Find the right ones. I'm not always very comfortable with other people.
- I have my bad days. I can get pretty down sometimes and it takes me a while to get back to normal.
- I think it might be nice to have visitors sometimes. But it's not good to dwell on that.

LIKES

- I like to paint. I spend a lot of time on it. In my room, the light's pretty good.
- I go out on my own. To the library or the club. Sometimes I just sit and watch people go by.
- I try to be useful. Helpful. I'm lucky I can still go out and do things. I pick up library books for one of the ladies here. I think it's important to be kind to people. Learn names, make conversation. Not everyone can do that.
- I try to keep up with what's happening. I read the newspaper everyday and watch the news.
- **DISLIKES**
- I don't like to cause a fuss. I'd rather do things for myself than have to ask staff. I don't like the attention.
- Some people become real complainers when they get old. I think they should be more grateful.
- There are always people you can't stand. But I don't make a fuss. Just avoid them.

A BIT MORE ABOUT ME...

I came here after I got sick. I wasn't good on my own – I went through a really dark patch back then. I'm grateful to be here now. It's much better than where I could have ended up.

Painting is my main interest. I only learnt to paint after I got sick. It was a good outlet. And it keeps me busy. I also read a lot. Mostly the newspaper. And I play scrabble in the lounge with a small group of regulars a few times a week. They say you've got to exercise your brain!

Some people complain about the food, but I think the meals are fine. They're something to look forward to if there's not much else happening that day. I find the mealtimes give a structure to the day, then you fill in the gaps. I eat all my meals in the dining room. It's just what you do. I wouldn't like to trouble anyone to change that.

I've got two siblings – but we're not close. There was a lot of nastiness over my Mum's estate – I don't like to talk about it. You can't dwell on that sort of thing.

Figure 7. Final persona 2: Arthur

Bianca “I’m still getting used to it here”



Age: 89

Time in care: 2 years

Accommodation type:
Hostel

VISITORS

Never Multiple times a week

LEAVES FACILITY

Never Frequently

FUNCTIONAL MEMORY

Poor Good

MOBILITY ASSISTANCE

High Low

Mobility aids: walking frame, wheelchair

PERSONAL CARE ASSISTANCE

High Low

GOALS AND MOTIVATIONS

- I try to get on with it. Make the most of the situation. But it's hard sometimes to move on.
- I wish I could reduce my pain – it worries me.
- I try to fill my time as best I can. Any distraction is good.
- I try to make friends... find people like me.

PAINPOINTS AND FEARS

- Pain is always there. They give me pain killers. But they don't work.
- I don't like getting old. I know I shouldn't, but I think about the things I used to do.
- I don't have as many friends as I used to. There's a lot of dementia here. You can't make friends with them. I had more friends at home. But they stopped calling when I came here.
- Some of these people are off with the fairies. I worry I'll get like that. It's getting bad when they move you to the nursing home.

LIKES

- I go to lots of the activities. Even bingo. It's not really my thing, but it's something to do. It's good to keep busy. Better than staring at the walls.
- I really like the music group and concerts - anything musical is good.
- I've made a few friends here. I'm lucky about that. We sit together. It's good to have people who are like you.
- They organise outings sometimes - I really look forward to those.
- My son visits when he comes up from Melbourne. We usually go to the club for lunch. I like that.

DISLIKES

- I have to eat soft food. It's awful. Just seems like the same muck all the time.
- I'd rather do things in my own time. But you have to work to the schedule here.
- I used to be able to do more for myself. I've lost that since I got here. I used to be able to shower myself, but I couldn't do it now. You get used to the help.
- People with dementia, they can't do things properly. Like bingo. They always need someone to help them. You can't even communicate with them. It's frustrating.

A BIT MORE ABOUT ME...

Music is very important to me. It really helps me. I go to all the musical activities here. And I always have music on in my room. Usually jazz or classical on the radio. My son got me a new radio for Christmas that's very good. I used to sew: I made all my own clothes. But I can't do that any more.

I moved to Australia with my husband after we got married. We had 3 boys but one died young. The others are married now, and have their own children. They call me. Visit when they can. But I don't expect them here all the time. Life is busy and they don't live near here.

Sometimes I think, 'Why did I do it? Why did I leave my home?'. I know I had to, but it gets me down.

Figure 8. Final persona 3: Bianca

2.2.8. Reviewing developed personas

The purpose of reviewing personas was twofold: firstly, to ensure personas appropriately captured the behaviours, perceptions, attitudes and motivations of residents; and secondly, to gain feedback on their usefulness in informing future service improvement efforts. The first step is a pre-requisite for the second: if the personas are not believed to be an accurate or adequate representation of residents, then they are less likely to be used by staff or others in decision-making positions. Before reviewing the draft personas with stakeholders, they had already been tested against the original data during the proto-persona and persona creation stages. The amalgamation of 12 proto-personas down to the final three involved retesting relationships and correlations found within the data (see Section 2.2.5). During the creation of the final personas (Section 2.2.6), original data sources were referred to as a source of anecdotes, quotes and other evidence.

Once the personas had been constructed in table format (see Appendix I) they were reviewed with key informants (KI1 and KI2 only; KI3 was unavailable). The review meeting was conducted in person at the study site with KI1 and KI2. Following the advice of other persona studies (Billestrup et al., 2014, Dotan et al., 2009, Matthews et al., 2012, Nielsen and Hansen, 2014), careful attention was paid to the education provided to key informants regarding the methodology and purpose of the personas to ensure they were able to judge the personas from an informed perspective. Given the researcher was working face-to-face with a small number of people who were unfamiliar with human-centred design, this education information was kept simple and direct: the researcher provided the key informants with a verbal explanation of the data collection and analysis process, using some visual aids (an example of a final persona, as well as artefacts from the data analysis and pattern identification stage), rather than providing written materials or more technical documentation. The researcher took care to educate the key informants about the personas not representing particular individuals within the population but being an aggregation of the diversity of attitudes, behaviours and needs within the community. Following a read-through of the table containing the descriptions of the three personas, informants were asked *“Does this sound like the type of resident you have here?”*, *“Do these three personas capture the variety of attitudes and behaviours you see?”*, and *“What’s missing?”*.

Both key informants agreed that the personas represented the types of residents in the community and captured the variety of attitudes and behaviours they experienced in the facility. Specific aspects of the personas were discussed where the key informants offered suggestions on how elements could be more appropriately described, or better examples provided. The idea of reflecting *an example* of a type of behaviour, rather than the most extreme illustration, or all the possible manifestations of a behaviour was discussed, and it was agreed that a single, common, or moderate example was suitable. For example, mental health issues are prevalent within the care home community. The example used in one of the personas is of depression and anxiety, rather than choosing the equally valid, but less common, examples of schizophrenia or bipolar disorder.

One issue raised by key informants was the inadequacy of the personas in covering the more severely impaired residents; those who are bed-bound, unable to talk or interact. This led to discussion about whether or not these residents were simply a more extreme version of the three personas presented. Even so, key informants felt it would still be useful for this issue to be addressed. They understood why these residents hadn't been included at this time (i.e. the researcher having no access to those residents), and agreed further investigation into this part of the nursing home community was needed, before creating an additional persona.

Key informants were then asked if they could see a tool like this being useful, how and by whom. Both were enthusiastic about the personas being used for staff induction, training and education. They described how the personas could be used to familiarise new staff with the types of residents they would meet and the types of behaviours and issues that they would encounter. When training staff, particularly around issues such as behaviour management and exercising resident choice, they envisaged the personas being used in role play activities. One key informant considered the personas may even be used to develop and implement new behaviour management strategies, with a different strategy for each persona 'type'.

The key informants believed some categories of staff would particularly benefit from using the personas: those new to aged care; people new to the nursing environment; or, recent immigrants. Personas may assist new staff to develop empathy for residents, and help them see patient care needs within the broader context of the whole person. On

discussion, key informants extended their definition of staff to include allied health workers and volunteers. Neither of the key informants felt they could comment on whether the personas would be useful for people outside the facility, for example, organisation-based administrative staff or management.

In parallel to validating the draft personas with key informants, two resident interviewees also reviewed them. Other resident interviewees were not available to meet. The two residents were provided with similar education and explanation regarding personas as the key informants. There were three important differences between the resident and key informant reviews. First was the use of verbal descriptions for each persona, without the use of the summary table key informants had been able to review, as both residents were vision impaired. Second, the researcher met with each resident reviewer separately, not together. Third, residents were only asked whether the personas adequately captured the behaviours, attitudes and needs of residents, and not how the tools might be used.

One resident thought the proposed personas were too detailed and suggested they should be split up. This resident agreed that friendships were an important element of residents' experience but felt the person who wanted to interact frequently with others was probably different to the person who found it hard to talk to others or make friends. The second resident reviewer believed the personas were good descriptions of residents and identified strongly with one of the personas. The resident was keen to talk about how their experience was similar to this persona and offered suggestions for how the persona could be updated to better align to their personal experience. As a result of the resident reviews, the researcher was able to fine-tune the language and anecdotes used in the final personas.

2.3. DISCUSSION

This research aimed to determine if the persona technique could be applied in residential aged care to improve resident experiences and deliver more person-centred care. Through this proof of concept study, personas have been successfully developed for a single residential care home in Sydney, Australia. The findings and review of the derived personas indicate potential for this tool to assist in the design and delivery of more person-centred care.

This discussion reflects on the process undertaken to develop the personas, analyses the benefits and disadvantages of the approach and its suitability for the environment, and examines how personas might help residential aged care providers promote empathy and deep understanding of residents' attitudes, behaviours and perceptions to support the delivery of person-centred services.

Ethnography in the residential aged care environment

The immersive ethnographic research strategy utilised for this study was effective in gaining insights into resident's behaviour, attitudes and needs and helpful for a researcher entering an unfamiliar environment (Goodwin, 2011). The emergent nature of the approach (Creswell, 2009) allowed the researcher to identify broad topics of interest initially, and then increase focus on those issues through additional observation and interviews. In particular, the combination of participant observation and interviews was useful in the residential aged care environment where considerable communication challenges exist: physical impairments such as hearing and sight deterioration or loss; cognitive impairments, not solely dementia related; mental health issues such as depression, anxiety and paranoia; and, social impairments. The flexibility of the ethnographic approach also enabled the researcher to adapt to other challenges of the aged care environment. This included modifying the observation schedule to work around a suspected flu outbreak that prevented access to part of the facility for a time, and accommodating residents who were unable to schedule interviews due to memory impairments.

Specific research techniques that proved helpful in this study were thick description, in-depth interviews and empathy maps. Thick description of observations (Geertz, 1973) assisted the researcher practice reflexivity within the research project. That is, self-

examination within the research project; exploring assumptions, reactions, culture positioning and considering the researcher's influence on the people being researched (Probst, 2015). Thick description also provided a rich resource from which to draw anecdotes and direct quotes for the creation of the personas.

The in-depth interview approach (Serry and Liamputtong, 2013) used with residents enabled the researcher to learn about each resident's feelings, experiences, fears and hopes in their own words. Although the researcher had some prepared topic areas and conversation starters, residents were able to set the tempo and direction of the conversation, with the result that responses were more like natural conversation, and avoided the unequal power dynamic that could result from a more prescriptive and authoritative interviewing style (Gill and Liamputtong, 2009). Empathy maps (Grey, 2017) were then used to capture outputs and reflect on resident interviews. Given the wide-ranging conversations that resulted from the open and unstructured interview approach, it was helpful to use a common template to capture insights for each interviewee and allow for comparison across interviewees.

As participatory research (see Section 1.2 Literature review), this study gave residents the opportunity to influence the research agenda and priorities, allowing them to be the "experts in their own experience" (Sanders and Stappers, 2014, p30). However, like many other studies involving older people in research activity in active and meaningful ways, this research faced challenges due to the complex needs of people in residential in aged care (Backhouse et al., 2016, Dupuis et al., 2016, Shura et al., 2011, van Hoof et al., 2015). Communication difficulties, physical frailty, dementia, cognitive impairments and mental health issues were prevalent, and although they did not necessarily prevent participation in the study, more could be done to improve the participation of these residents. Some ways this could be achieved include: extending the duration of observation; increasing the amount of observation in the nursing home wing (i.e. where the more frail and impaired members of the community reside); involving carers or family in interviews for residents with communication difficulties; and, borrowing from design methodologies to invent more creative exercises to obtain input from residents who struggle with verbal communication.

The involvement of key informants in the study was both crucial and problematic. In their role as gate keepers, key informants were critical to the researcher gaining access to the community and identifying potential interviewees. They were also able to provide an alternate view on information reported directly by residents. While this different perspective was often informative and insightful, it was essential for the researcher to maintain an open and unbiased outlook and not to treat the key informant's information as more 'true', or of greater authority, than the resident's. This is similar to the challenge addressed by Lancaster (2017) in regard to researching 'elites' who desired control of what was to be reported. Ultimately, what is critical for the creation of personas is the resident's attitudes and needs and how that manifests in their behaviour – not whether their perception is correct or true. The small number of key informants compared to residents, and their limited availability, was a useful check to this risk.

The variable mapping process (Goodwin, 2011) used to identify the segmentation model that underpinned the proto-persona groupings was useful in helping the researcher move from the individual and specific, to the abstract and conceptual. Mapping each individual interviewee on the semantic differential continuums required the researcher to re-immerses in the data collection artefacts (Figure 5, step 4). The next step in the research process, identifying patterns where the same subjects clustered together across multiple differentials (Figure 5, step 5), required the researcher to employ abstract thinking. This was extended further into conceptual thinking with the creation of the mind map (Figure 5, step 6) and seeking to understand the relationships between topics.

Understanding commonalities and differences

Another benefit of the persona methodology was that it illuminated both the commonalities and differences within the community being studied. Previous studies regarding quality of life in residential age care found key issue to be lack of autonomy and difficulty forming relationships (Bradshaw et al., 2012), and loneliness, helplessness and boredom (Li and Porock, 2014). This study confirms these findings, identifying key themes common to all resident participants: the need to connect with others; difficulties making friendships; and, the need to fill time. This research also provides useful insight into the different ways residents respond to those challenges. The different personas reflect these different responses, but fundamental challenge of building meaningful connections with others and the need to fill time is manifested in all personas.

Key behavioural and attitudinal variables that distinguished between residents and became the basis for the personas are: tendency to interact/isolate; likes to help out/does not help out (insular); strong/weak family bond; and, feeling unsettled in care. These four factors (representing seven behavioural/attitudinal variations) were ultimately manifested in three personas (see Table 10). The decision to consolidate the possible seven proto-personas into three was a judgement made by the researcher after consideration of a number of factors specific to this study: the degree of correlation between the factors; the anticipated context of use of the personas; the maturity of the facility and broader organisation regarding the use of human-centred design tools and strategies; and, the purpose of this study as a proof of concept. While the decision made reflects the particular needs and context of this study, the necessary trade-off between simplicity (fewer personas) and sensitivity (more personas) will be common to all persona projects. If there was a service improvement initiative directly connected to the development of the personas, then the project team would be involved in the simplicity/sensitivity trade-off decision. Where key informants were used in this study to assess the usability of the personas, this assessment would fall to the project team as the end-users of the personas.

The decision about which elements to include in the final personas also needs to reflect the particular requirements and context of the persona's intended use. Table 3 (Section 1.3.1) outlines the typical key elements of a persona (Baxter et al., 2015, Idoughi et al., 2012, Mulder and Yaar, 2006). Reflecting the technique's beginnings in interaction design, many of the elements focus on information required to design a new product or service, such as use of a particular product/service, carrying out certain tasks, or the skills and abilities required to carry out tasks. These elements provided a good starting point, but needed to be modified to suit the context of residential aged care. For example, goals, motivators and pain points had to be considered not just in relation to a particular activity, but in relation to the resident's life more broadly. The language in the final personas (Figures 6,7 and 8) was modified to reflect this broader focus: 'Pain points' became 'Pain points and fears'. Rather than examining the tasks the resident conducted, the personas developed for this project considered a resident's activities and hobbies. Other elements were added to the personas that were unique to the aged care environment: the level of staff assistance required, mobility needs, frequency of visitors. These additional elements were selected for inclusion if: they existed in significant variation across the community; were closely

related to significant behaviours or attitudes; or, where key to the day-to-day operations of the facility, particularly the function and responsibilities of staff. This final consideration was the result of feedback from key informants about the usefulness of the personas for staff training.

Creating authentic personas

The ability for personas to promote empathy and greater understanding (Goodwin, 2011), and the desperate need for those qualities to help improve quality of life in aged care (Bradshaw et al., 2012), is a key motivation for conducting this proof of concept study. As a result, there was a strong temptation to make the personas overly likeable, at the expense of 'truthfulness'. Another temptation was to create overly simplistic 'good' and 'bad' personas: here's what well-adjusted happy residents look like; but don't be like these grumpy unhappy people. This is similar to the pitfall Goodwin (2011) warned against of making personas too 'silly' or caricature-like. The researcher used three strategies to combat these risks. The first was to keep focused on the data and the need for the personas to describe the observed community, not prescribe the solution. Personas help inspire better decisions, and avoid poor decisions, because they are a manifestation of research data, turning data into knowledge (Cooper et al., 2014, Nielsen and Hansen, 2014).

Secondly, it was helpful for the researcher to gain distance from the interviewees, both physically and emotionally. An important outcome of the intensity of the ethnographic approach was the researcher's emotional engagement with the community being studied, not just academic interest. However, this also meant the researcher had developed attachments to some residents, and a preference for certain residents over others. In order to create personas that represented the aggregation of diversity within the community, rather than telling the stories of a few favourites, or preferencing some experiences over others, the researcher needed to be removed from the emotional intensity of the initial data collection activity. This was achieved through the abstraction that comes as a result of the data analysis process, by withdrawing from the physical environment, and by allowing some time to elapse between data collection and creating the personas.

The final strategy employed by the researcher to create authentic personas was to adopt a first-person narrative style for the final persona presentation. Most personas employ a

narrative style to some extent. It is one of the reasons personas are able to create empathy and engage our intuition (Goodwin, 2011). Incorporating direct quotes from customers or users, or using some first-person language is also common. In this case, the decision was made to use first-person language for the entirety of the persona. This helped the researcher put themselves in the persona's place and create a well-rounded character with good days and bad days, things that make them happy and sad, likeable and less-likeable qualities. The first-person approach also avoided the possible criticism of the personas being too impersonal (Matthews et al., 2012). By drawing heavily on resident's direct quotes, the researcher was continually directed back to the data. It also prevented the researcher imposing an 'authoritative voice' over the persona – something to be particularly avoided in a situation where participatory qualitative research methods are being used to give a voice to those who are vulnerable, often marginalised and, as a result, denied a voice or the opportunity to express their experiences and needs in their own words (Liamputtong, 2010).

A challenge that arose as a result of choosing to write the personas in first-person was finding ways to demonstrate and describe dementia and mental health experiences from the participant's perspective. As well as referring to the expressions, behaviours, mannerisms of the residents in the study, it was also helpful to reflect on non-academic accounts of aging, dementia and mental health – autobiographies and fictional stories. These sources were not for collecting data but to explore how these experiences might be expressed. Some examples include *Still Alice* (Genova, 2014), *All of Me* (Noble, 2012), *Madness Made Me* (O'Hagan, 2015), and *The Insults of Age* (Garner, 2015).

When writing final personas, the researcher was required to weigh up three considerations: the integrity, or internal consistency, of the character being created; the specifications of the underlying proto-persona; and the need to create balance across the personas to reflect the broader community. As discussed, the use of first-person voice was key to ensuring the internal consistency and integrity of each persona. Staying true to the underlying proto-persona specifications was achieved through utilising processes and artefacts that created traceability across the research stages: data collection, data analysis and pattern identification, and the creation of the personas. Key artefacts providing traceability included: the semantic differentials against which interviewees had been mapped (Appendix D); the initial and refined mind maps showing the relationships

between topic (Appendices E and F); and the table connecting the proto-persona descriptions with the expanded persona elements (Appendix I).

The need to create balance across the three personas concerned ensuring the personas were an aggregate of the diversity observed in the community. This particularly affected how the 'open' elements of each persona were selected: that is, the persona details that were not specified or guided by the proto-persona description, such as staff assistance and mobility needs, hobbies and accommodation type. The final suite of personas needed to reflect the diversity of needs, attitudes and behaviours that existed within the community. As a result, the personas were allocated different levels of staff assistance and mobility requirements, different hobbies and were split between the hostel and nursing accommodation types. The decision about what aspect to assign to a persona had to achieve both internal integrity and portfolio balance.

Strengthening persona credibility

Persona practitioners have recommended a range of strategies to address criticisms concerning a perceived lack of rigour regarding the persona technique (Billestrup et al., 2014, Chapman and Milham, 2006, Miaskiewicz et al., 2008, Nielsen and Hansen, 2014) including: using a mix of qualitative and quantitative research methods; reviewing final personas against original data, stakeholder or expert reviews; reviewing personas with representatives from the community being researched; and reality checks via site visits or interviews (Pruitt and Adlin, 2010). These are similar to strategies recommended to ensure rigor in qualitative studies more broadly (summarised in Barusch et al., 2011).

This study employed seven strategies adopted from persona theory and qualitative research theory to strengthen the credibility of the personas. (1) Personas were assessed against original data at a number of points throughout the process: relationships between factors and correlations were reviewed and retested when amalgamating the short-list of proto-personas (see Section 2.2.5); and, original data sources were used extensively during the final persona creations stage as a source of quotes and anecdotes (see Section 2.2.7). (2) Stakeholder reviews were conducted with key informants (who are also likely end-users of the personas) to assess whether the personas adequately reflected the diversity of needs, behaviours and attitudes within the aged care community. (3) Member-checking occurred through the review of draft personas with resident interviewees. (4)

Triangulation was demonstrated through the use of multiple data sources: observation; resident interviews; and, key informant interviews. (5) Peer review was conducted through regular discussion and debriefing with a research colleague during all stages of data collection, analysis and interpretation; a researcher working in a different industry, familiar with persona methodology but with no professional interest in aged care or the production of this thesis. (6) Thick description was employed to capture data and reflections from the resident observation activity, helping the researcher connect the behaviour being observed with the context of observation, including the researcher's existing theoretical models and assumptions. (7) Reflexivity (that is, self-examination within the research project; exploring assumptions, reactions, culture positioning and considering the researcher's influence on the people being researched (Probst, 2015)), was achieved through the use of thick description and peer and supervisor debriefing. Many of the resulting reflections are captured in this discussion: this study is as much as examination of the persona implementation, as it is of the researcher conducting it.

2.3.1. Limitations

Like any participatory research methodology (participatory action research, participatory design, user-centred design, and experienced-based design are discussed in Section 1.2 Literature review) a challenge of ethnographic-based personas is that it is a resource intensive and site-specific methodology, the result of immersion in a single community. As a result, the personas generated are not applicable or transferable to other residential aged care settings without further investigation and validation.

The focus of this proof of concept study was to determine if the persona technique could be implemented in a residential aged care environment. The application of the resultant personas to a specific service improvement initiative is outside the scope of this study. As a result, the personas have not been tested in use. Feedback from stakeholders is a positive indicator for the future applicability, but the personas remain untested in this regard. Should these personas be used in a future service improvement initiative, it would be beneficial to conduct a workshop with stakeholders to: explain the purpose of the personas and how they might be used; educate about the methodology followed to construct the personas; review the personas to ensure they are effective communication tools (i.e. ensure layout and language confirms with any technical or industry-specific requirements or expectation of the group); and assess the applicability of the personas to the project

being conducted. Using the artefacts from the data analysis stage that create traceability between the original data and the final personas, the personas could be adapted to suit the particular focus of the project, for example, providing more or less detail or sensitivity regarding the particular area of interest.

Many practitioners advocate for stakeholder involvement *during* persona development (Goodwin, 2011, Mulder and Yaar, 2006, Pruitt and Adlin, 2010). To best work within the constraints of this study environment (that is, a research project with limited access to facility staff and management, not a commercial consulting engagement), stakeholder involvement was limited and occurred following persona development. It is anticipated that the validation tactics employed in the study will assist to gain *post-development* stakeholder acceptance and endorsement of the personas.

The insufficient inclusion of the more frail members of the resident community occurred because observation took place primarily in common areas, so that residents who were bed-ridden were not exposed or available to the researcher. Key informants estimated there were about 25 bed-ridden and non-communicative residents at the time of the study – a little under a quarter of the community. Observation involving shadowing nursing staff, or involving family and care staff in interviews may help close this gap in future studies. The emphasis of observation on common areas may also have meant that more reclusive residents were less visible. The researcher sought to address this concern by seeking out interviewees who were not often seen in the common areas or in group activities.

Another factor that influenced the findings was the communication ability of the resident interviewees. Although around half the interviewees had some level of memory or cognitive impairment that was evident in their conversation, all were verbal. While numerous residents included in the observation appeared to be non-verbal, this wasn't an area that could be explored further via interview. Again, the involvement of family and carers in interviews and more extensive observation could assist future research.

This study employed numerous validation strategies to strengthen the credibility of the final personas. One strategy not adopted, however, was to incorporate quantitative data into the methodology. This was due to the practical limitations of the proof of concept study. A validation activity using quantitative data could be carried out once the proto-

personas had been identified to confirm the underpinning segmentation model. Following the process outlined by Mulder and Yaar (2006), quantitative data relevant to the segmentation model could be gathered via access to facility level databases or via resident or staff survey. Data analysis could be conducted to confirm if the identified attributes cover the resident population at the facility and provide sufficient differentiation between proto-personas. This validation activity could further strengthen the perception of robustness and rigour of the persons.

2.4. CONCLUSION

Residential aged-care, like other service-based sectors, is striving to become more person-centred. There are a number of drivers behind the imperative to make aged care more person-centred, including commercial, moral and self-interest considerations. However, despite genuine desire for improvement, residential aged care homes are often 'homes' in name only and fail to deliver a desirable quality of life. Transforming services to be more person-centred requires design techniques that place the customer's needs, capabilities and behaviours at the centre of the design process. Human-centred design approaches can provide significant opportunities for older people to make meaningful and valuable improvements to the quality of their experience.

The application of a previously untested human-centred design technique in residential aged care successfully delivered a proof of concept study of personas in this setting. While the three personas delivered in this research project are site-specific and not directly transferable to other aged care facilities, the methodology outlined and tested here is transferable, credible and dependable. As this study has demonstrated, the persona methodology has strong potential in the residential aged care environment and can be used to allow a vulnerable, often marginalised, group to express their experience, needs, and expectations in their own voice.

Personas are a valuable tool for designing the culture, structure, policies and processes that support delivery of person-centred services, as has been demonstrated by their use beyond their original interaction design domain. The application of personas in the aged care field has capacity to: drive person-centred decision-making; turn resident data into actionable insights; and, encourage aged-care facilities to look at how to deliver person-centred care more effectively and in new ways.

A small number of studies identified in this thesis have used human-centred, participatory research and design methodologies to successfully deliver service improvements within the overarching system of aged care. However, there is no evidence of participatory strategies being used to design *overarching* models of aged care. This is surprising given the prevalence of person-centred frameworks and models in aged care that indicate that human-centred design techniques and strategies could be common practice. There is an opportunity to extend the use of human-centred participatory approaches to empower older people to become partners in designing the underlying frameworks or models of care to which they are subject. Without the support of human-centred participatory research and design approaches, we risk developing models of care that are at best considerate of, but ultimately patronising of, the older people living under them. If we want care of older people to be person-centred – holistic, respectful and empowering – then our research and design approaches should reflect that and be person-centred as well.

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4. APPENDIX

4.1. APPENDIX A: KET INFORMANT INTERVIEW GUIDE

Key Informant Interview Guide

Human-centred design and person-centred care: Trialling design personas in residential aged care

Date:

Time: Start:

Finish:

Location:

Interviewee:

Interviewer:

Consent Form provided: YES/NO

OK to record interview: YES/NO

Topics

Residents	<ul style="list-style-type: none">○ How many?○ Age○ Gender split○ Types of care○ Impairments○ Different personalities? What are typical 'types'? How is that managed?○ Cliques? Who are influencers?○ Resident-resident relationships○ Resident-staff relationships○ Family and friend visitors○ Other visitors?○ Typical duration in care○ Full time v respite care○ Induction process for new people
Routines:	<ul style="list-style-type: none">○ Typical day○ Week○ Month
Activities:	<ul style="list-style-type: none">○ Internal v external○ Solo v group activities○ Planned v spontaneous○ Mandatory v elective
Space:	<ul style="list-style-type: none">○ Shared or single room○ Personalised spaces?○ Quiet v busy spaces○ Inside v outside○ Offsite trips?

Resident interview guide

Human-centred design and person-centred care: Trialling design personas in residential aged care

Date:

Time: Start:Finish:

Location:

Interviewee:

Consent Form provided: YESNO

Interviewer:

OK to record interview: YESNO

Opening

- Introduce self
- Project overview: *We are interviewing residents to talk about their experience living in residential aged care. The insight we gain from you, and other residents, will be used to help us create resident profiles, or 'personas'. These personas will be presented to PAC staff to help them the development improved services and programs that we hope will lead to enhanced experience and quality of life of all residents.*
- Privacy: *The personas will be based on the information you share with us, but they won't be an exact copy of what you say or use any of your personal details.*
- Recording: *I'll be writing notes as we talk, but I'd also like to record our discussion in case I need to go back to check anything I've missed. Are you comfortable with that?*

Example questions:

- Can you tell me a bit about yourself?
- Can you describe for me what happens on a regular day here?
- What happens for special occasions – Christmas, Aust Day, Easter, birthdays?
- Can you tell me about some of the activities that are put on here each week?
- Can you describe to me how meal times work?
- What sorts of things do you do like to do during the week?
- What area of the home do you spend most time in and why?
- Do you tend to sit with/talk to the same group of friends or do you mix with lots of other residents?
- How would you describe yourself?
- What's the highlight of your week?
- What have you got planned for later today/next week?
- Can you tell me more about...?
- What happened last time you...?

Topics	
Personal	<ul style="list-style-type: none">○ Age○ Gender○ Family
Activities:	<ul style="list-style-type: none">○ Internal v external○ Solo v group activities○ Planned v spontaneous○ Mandatory v elective○ Lots v little○ Watch v participate
Personality:	<ul style="list-style-type: none">○ Proactive v passive○ Optimistic/pessimistic○ Extrovert / introvert○ Leader/ follower○ Thinker/feeler
Time in care home:	<ul style="list-style-type: none">○ Recent v long term○ Respite?
Impairments:	<ul style="list-style-type: none">○ Mobility?○ Hearing?○ Sight?○ Other?
Relationships:	<ul style="list-style-type: none">○ Other residents○ Staff○ Family○ Visitors○ Many v few
Space:	<ul style="list-style-type: none">○ Shared or single room○ Personalised space?○ Quiet v busy spaces○ Inside v outside○ Offsite trips?

Closing:

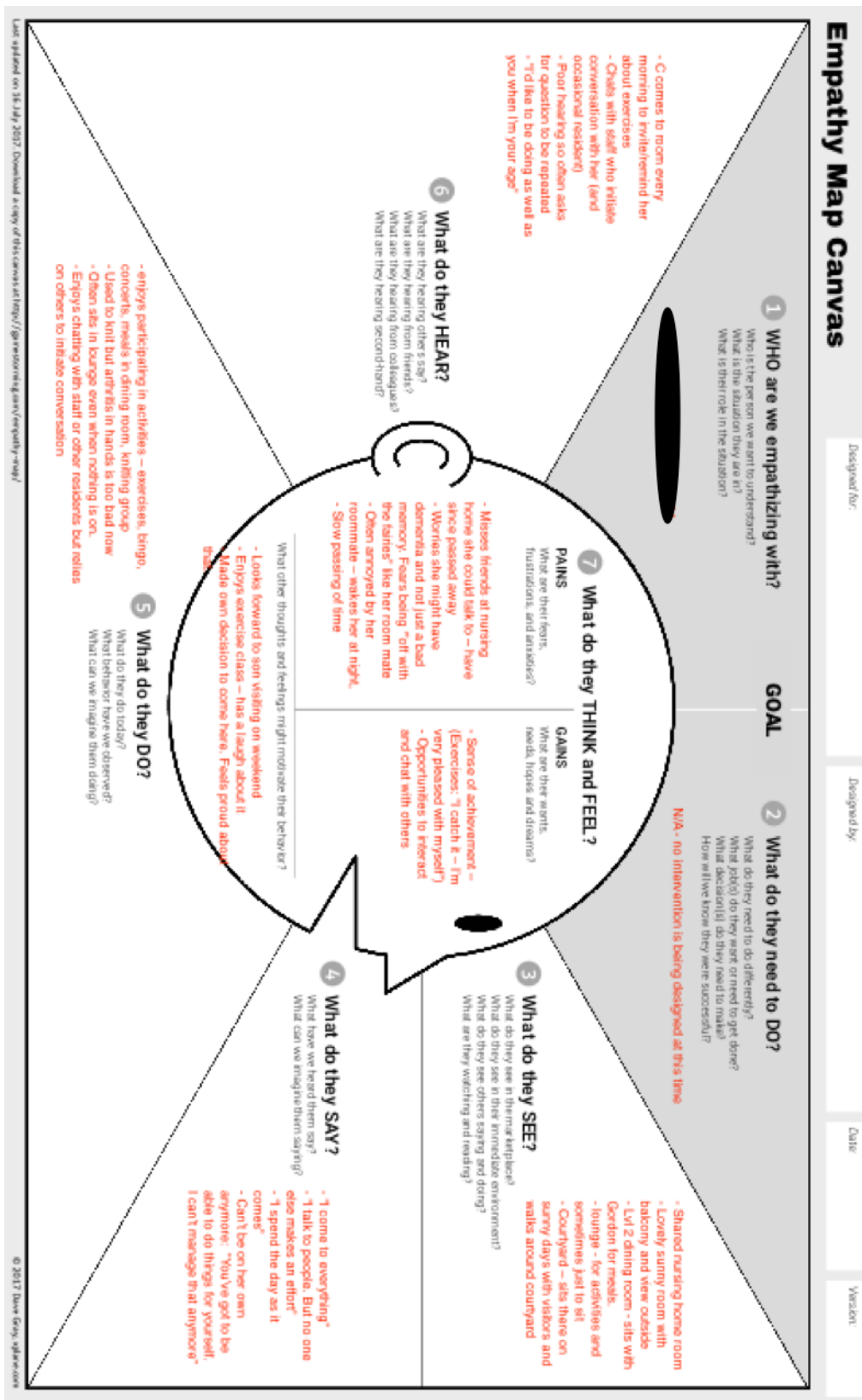
- Any questions or anything to add?
- I'd like to get your feedback on the draft personas once they're ready – is that OK?
- Would you like to receive a copy of the final personas? I'll also provide a 1 page summary of the study results.

Other notes:

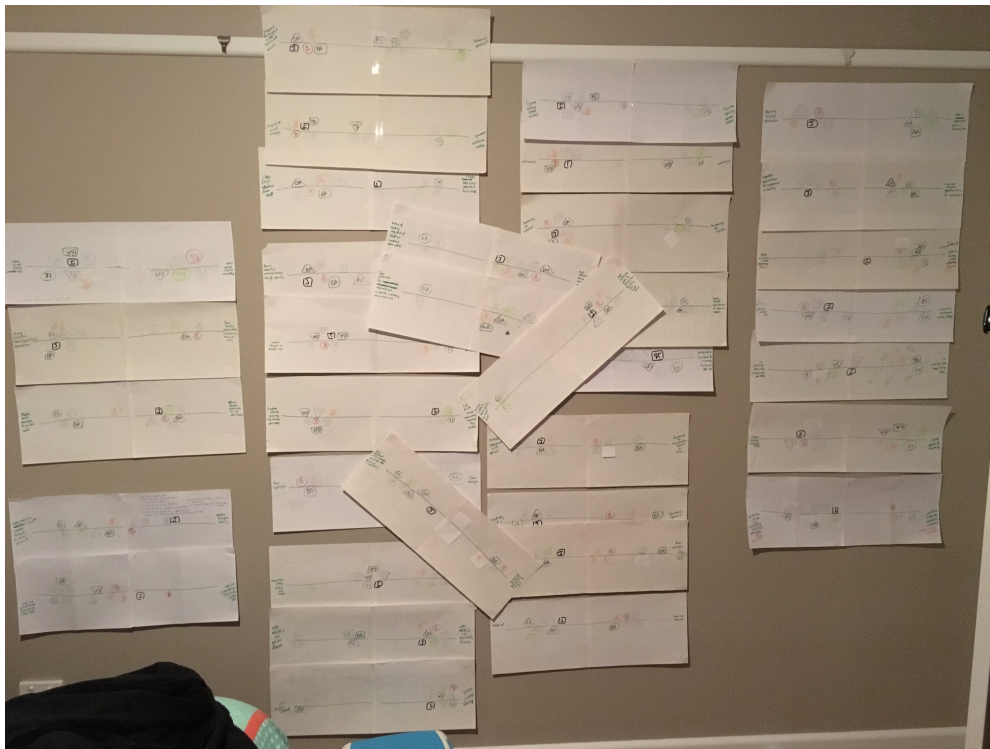
- How was interviewee recruited?
- Description of interview setting
- Description of interviewee – appearance, personal style/attitude
- Did the resident experience any distress during the interview? Did the interview need to be stopped/paused? Has manager/NUM been notified?
- Follow-up actions

4.3. APPENDIX C: EXAMPLE EMPATHY MAP

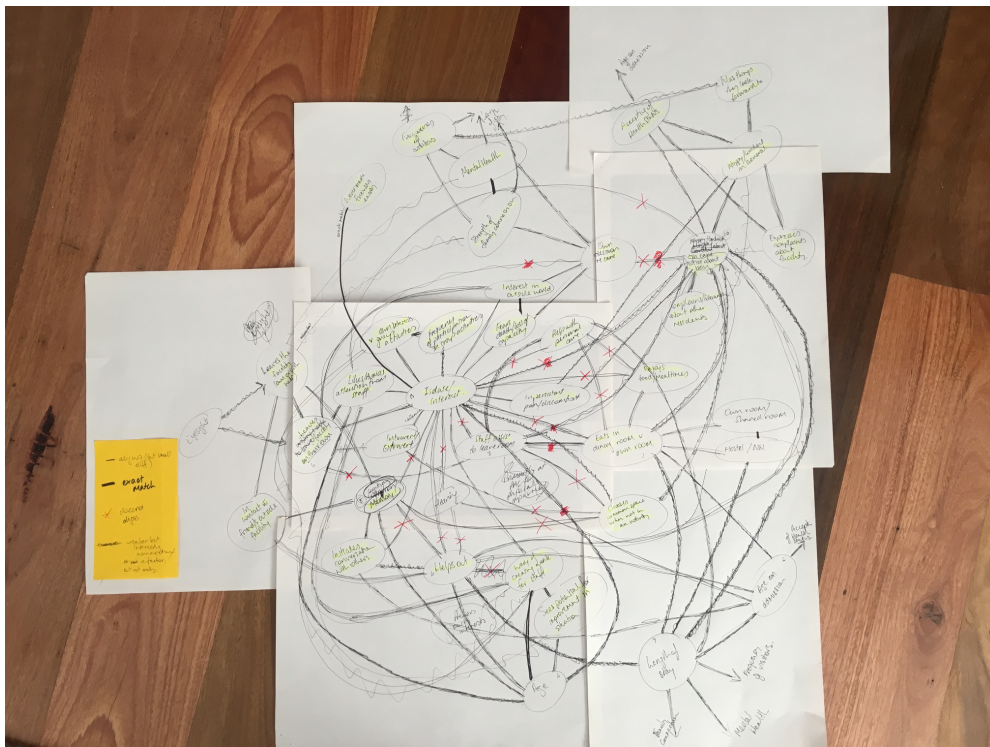
Template from Dave Grey (2017), Updated Empathy Map Canvas



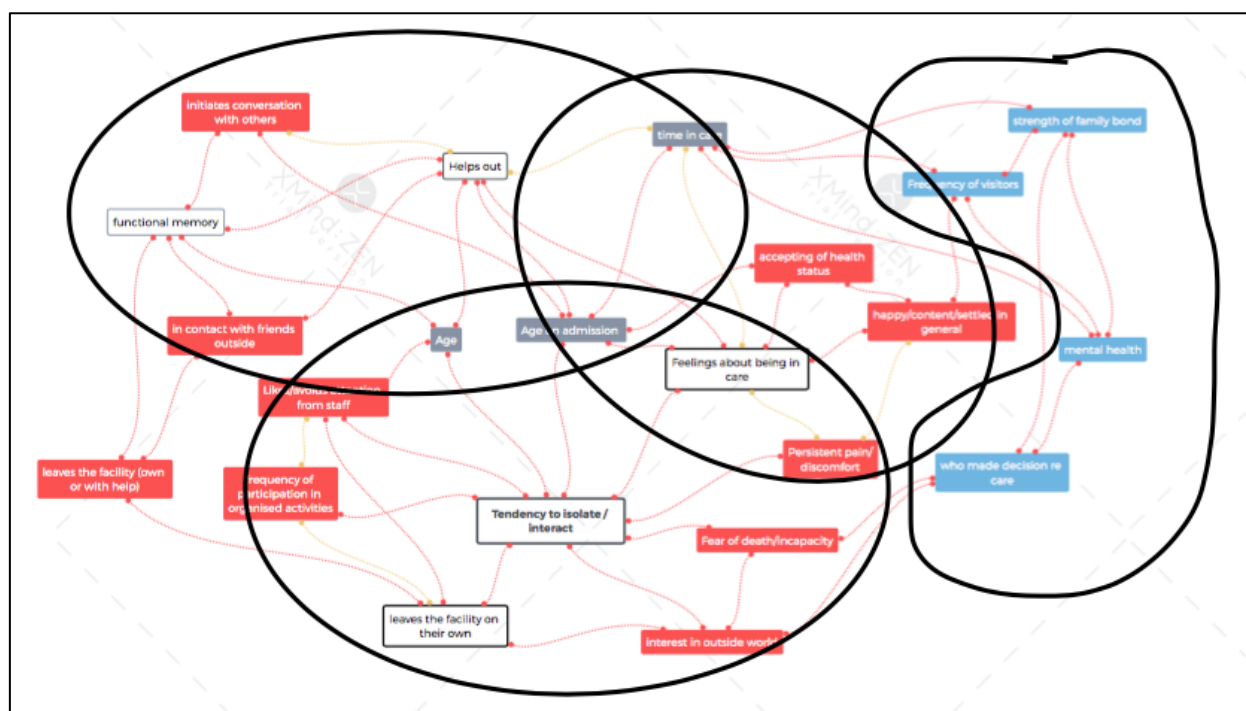
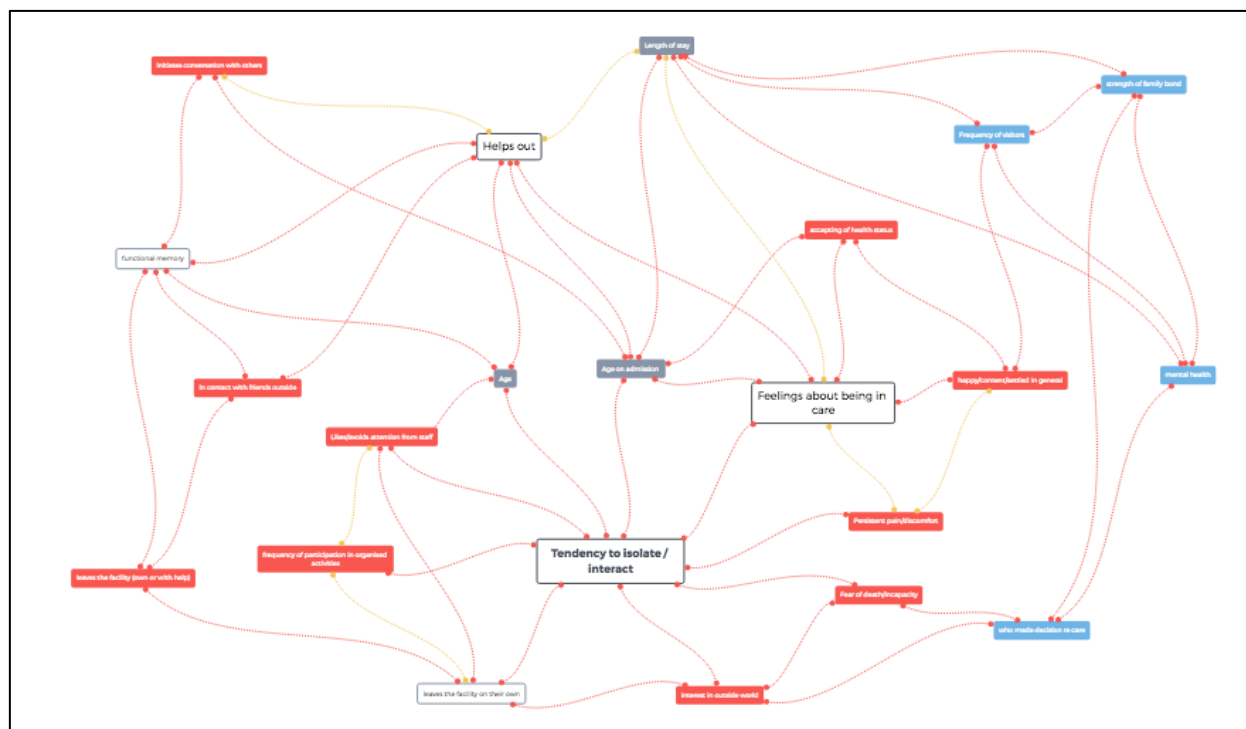
4.4. APPENDIX D: DESIGN WALL USED FOR DIFFERENTIAL MAPPING AND PATTERN IDENTIFICATION



4.5. APPENDIX E: INITIAL MIND MAP



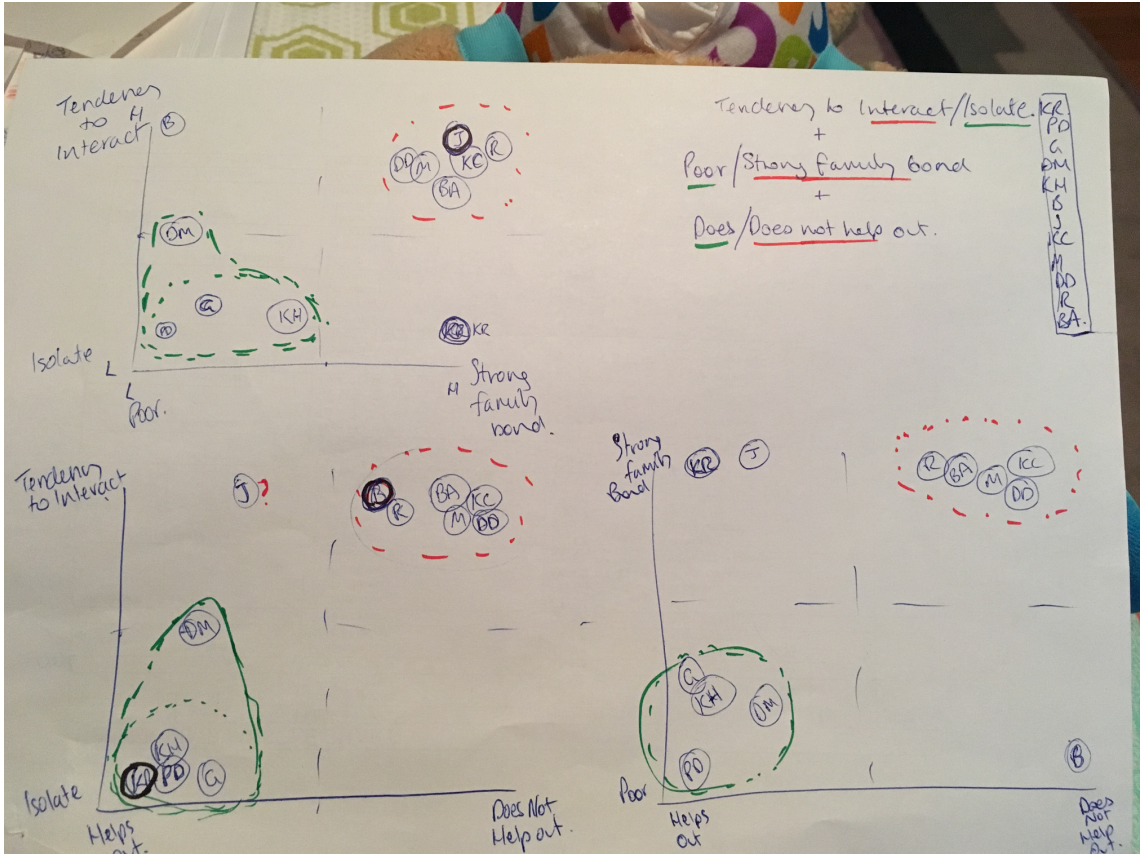
4.6. APPENDIX F: REFINED MIND MAP AND INITIAL PROTO-PERSONA GROUPS



4.7. APPENDIX G: PROTO-PERSONA SHORTLIST

possible proto personas						
subjects	tendency to interact	tendency to isolate	unsettled in care	likes to help out	insular	weak family bond
R11		X		X		
R12		X		X		X
R13		X		X		X
R14	X			X		X
R15		X		X		X
R16	X				X	
R17	X		X	X		
R18	X		X		X	
R19	X		X		X	
R110	X		X		X	
R111	X				X	
R112	X				X	
Description (other connected factors)	Includes: - Tendency to interact - Frequent participant in activities - Likes fuss/attention from staff	Includes: - tendency to isolate - selective participation in activities - prefers own interests to group activities - Avoids attention from staff	Includes: - unsettled in care - in persistent pain/discomfort - rails against declining health	Includes: - Likes to 'help out' - at the home or outside - good functional memory - initiates conversation with others - has regular contact with friends outside - gets out of the facility (with help or on own)	Includes: - desires interaction - but does not/cannot initiate conversation with others - no contact with friends outside the facility - Does not leave the facility - poor functional memory - tends to be older	Includes: - no family, or troubled and distant family relationships - infrequent or no visitors - mental health issues (not dementia related) - did not make their own decision to go into care - long time in care
	- Regularly in pain/discomfort due to health issues - fears death/loss of capacity - limited interest in outside world - does not leave facility - tends to be older	- has interest in outside world - leaves the facility on their own - tends to be younger	- discontent in general / irritable - desire to interact with others - easily frustrated (by other residents, own own limitations, by care) - short time in care (so far)	- settled about being in care - tends to be younger and has been in care longer		

4.8. APPENDIX H: ASSESSING PROTO-PERSONAS FOR FURTHER CONSOLIDATION



4.9. APPENDIX I: DRAFT PERSONAS

	PERSONA 1	PERSONA 2	PERSONA 3
proto-persona	Tendency to interact Includes: - Frequent participant in activities - Likes fuss/attention from staff - Often in discomfort due to health issues - fears death/loss of capacity - limited interest in outside world - does not leave facility - tends to be older	Tendency to isolate Includes: - selective participation in activities - prefers own interests to group activities - Avoids attention from staff - Positive about being in care - has interest in outside world - leaves the facility on their own - tends to be younger	Unsettled in care Includes: - in persistent pain/discomfort - rails against declining health - discontent in general / easily irritated - desire to interact with others - easily frustrated (by other residents, own limitations, by care) - short time in care (so far)
Plus	Insular Includes: - desires interaction but does not initiate conversation with others - no contact with friends outside the facility - Does not leave the facility - poor functional memory - tends to be older	Likes to help out Includes: - good functional memory - initiates conversation with others - has regular contact with friends outside - gets out of the facility (with help or on own) - settled about being in care - tends to be younger and has been in care longer	
Plus	Strong family bond Includes: - strong family bond - frequent visitors - shorter time in care - made own decision to go into care	Weak family bond Includes: - no family, or troubled and distant family relationships - Infrequent or no visitors - mental health issues (not dementia related) - did not make their own decision to go into care - longer time in care	
ration for combining	High correlation between these group - see matrices	High correlation between these groups - see matrices	Some overlap with other groups but not sufficient correlation
name	Enid	Arthur	Dominika / Bianca
age	94	75	89
time in care	18 mths	7 years	2 years
Accom type	Nursing home	Hostel	Hostel
mobility	Uses walking frame	Uses walking frame when out / walking stick in facility	Uses walking frame in room. Wheelchair when leaving room
functional memory	Poor functional memory. Repeats herself frequently in conversation. Often confused about who people are and what's happening around her.	no issues	declining but ok for conversation
staff assist	- Staff assist with personal care. - Able to leave room unassisted, but needs a reminder when activities are on	- Minimal staff assistance for personal care or mobility	- staff assist with personal care - staff assist with mobility when leaving room.
Goals and motivations	- I want to be around other people, to talk with them. Everyone I know is here now. - I like having things to do. It fills the time and gets me out of my room - I'm comfortable and happy here. I have pretty simple tastes. I just take the day as it comes.	- I try to stay positive - I'm grateful I'm here. So I like to be useful and do things for others. - It's important to avoid being bored. You need to make an effort to fill your time.	- I try to get on with it and make the most of the situation, but it's hard sometimes to move on. - I'd like to reduce my pain - it's a constant worry. - I try to fill my time as best I can. Any distraction is good.
Painpoints and fears	- It's hard to make friends here - people don't talk to you. I did have some good friends, but they're in a better place now. - My memory is no good any more. I say I don't have dementia - but I guess what I've got is damn near it! I'm so forgetful. And I do get a bit confused sometimes. I wonder how I got here. - I do struggle sometimes with pain. It can be hard at night. I wake up a lot. - They say I'm doing OK, but I do worry about dying, about how much worse I might get. I see some of the people here... they've really lost it.	- It takes time to find people you can connect to. Find the right ones. I'm not always very comfortable with other people. - I have my bad days. I can get pretty down sometimes and it takes me a while to get back to things. - I think it might be nice to have visitors sometimes. But it's not good to dwell on that.	- Sometimes my pain gets on tops of me. They give me pain killers. But they don't really work. - I don't like getting old. I think about the things I used to be able to do. But nothing works anymore. - I sometimes think, "Why did I do it? Why did I leave my own home?". I know I had to, but it gets me down. - I don't have as many friends as I used to. So many people here have dementia You can't make friends with those people. I had more friends when I was still at home. But they stop calling once you come somewhere like this. - Some of the people here with dementia are really off with the faeries. I worry I'm going to get like that. You know you're in trouble when they move you into the nursing home.
Likes	- The activities they run here are very good. I go to everything. I go to exercises in the morning, then morning tea, then I go to whatever is on next. - I like the opportunity to have a good chat. Other residents or staff - I don't mind. - The staff are very friendly here. They look out for me. Every morning they come to take me to exercises and we chat on the way. - My daughter visits often. I look forward to it. We used to go out but now we just stay here. It's nice. If it's sunny we sit in the courtyard.	- I have my own interests. I like to paint. I spend a lot of time on that. In my room, the light's pretty good. - I go out on my own. To the library or the club. Sometimes it's just nice to sit somewhere and watch people go by. - I try to be useful. Helpful to others. I'm lucky I can still go out and do things. I pick up library books sometimes for one of the other residents. And I think it's important to be kind to people. Get to know their names, make conversation. Not everyone can do that. - I think it's important to try and keep up with what's happening. I read the newspaper everyday. And I like the 7.30 report.	- I go to lots of the activities. Even bingo. It's not really my thing, but it's something to do. It's good to keep busy. Better than staring at the walls. - I really like music group and the concerts - anything musical is good. Music is very important to me. It really helps me. - I've made a few friends here. I'm lucky about that. We sit together at the activities. It's good to have people who are like you. - They organise outings sometimes - I really look forward to those. - My son visits when he comes up from Melbourne. We usually go to the club for lunch. I like going out.
Dislikes	- Some residents don't make much of an effort to chat. I think they have dementia. - I'd rather not stay in my room. Some people here just watch TV all day - I don't want to do that. - My room mate isn't good. She makes a lot of noise and wanders around at night. It can be a bit frightening.	- I don't like to cause a fuss. I'd rather do things for myself than have to ask staff. don't like the attention. - Some people become real complainers when they get old. I don't like that. I think they should be more grateful. - There are always some people you can't stand in a place like this. But you keep quite about it. Avoid them.	- I have to eat soft food. It's awful. Just seems like the same muck all the time. - I'd rather do things in my own time. But you have to work to the schedule here. - I'd like to be able to go out more. But I can't manage that on my own. - I used to be able to do more for myself. But I've lost that since I got here. They have rules about staff helping. I used to be able to shower myself, but I couldn't do it now. You get used to the help. - Some people here are really 'off with the faeries'. They can't do things properly. Like bingo. They always need someone to help them. You can't even communicate with them. It's frustrating.
Hobbies	- I mostly fill my time with group activities. - Sometimes I just sit in the lounge and watch whatever's going on, people coming and going, chat to whoever is about. - I used to enjoy reading but my eyes are too bad now for that. - I do watch a little bit of TV in the afternoons, but I usually just fall asleep!	- Painting is my main interest. I only learnt to paint after I got sick. It was a good outlet. And it keeps me busy. - I also read a lot. Mostly the newspaper. - I play scrabble in the lounge with a small group of regulars a few afternoons a week.	- I used to sew a lot and knit. I made all my own clothes. But my arthritis is too bad for that now. - If I'm in my room I always have music on. I like the radio. ABC Jazz or classical music. - Sometimes I read a bit. Or watch TV after dinner. I like those English murder mysteries.
Meal times	- I like eating in the dining room, but I can't all the time. - They started bringing me dinner in my room. I don't know why. I liked it better before.	- I eat all my meals in the dining room. It's just what you do. I wouldn't like to trouble anyone to change that. - Meals give structure to the day, then you fill in the gaps - Meals can be a highlight of the day. Something to look forward to if there's not much else happening that day.	- I eat my meals in the dining room. - I should be happy someone is doing the cooking and cleaning for me. But it's hard to get excited about the mush I have to eat. - And some people are terrible at the table. They get food everywhere. All other themselves.. Its not very nice to have to see it.
Quotes	- "You just want to be with other people" - "I don't really have any close friends to talk to anymore - they've gone to a better place." - "I keep saying that what I have isn't dementia but I worry it's damn near it! I'm so forgetful." - "I get a bit confused. My memory clogs up." - "All my friends are here now"	I have good days and bad days.... "You have to choose the right ones. I wait and see what connection there is. Some of them talk about nothing. They have no personal interests. I have my own interests." "I'm not very comfortable with others. I go out on my own when there aren't activities I want to go to. I sit with [other resident] at bingo. It works quite well. We have a bit of a chat." (PB); "I don't feel lonely. I've been single for a long time. But I do get a bit down sometimes. Then I call a friend." "They're more acquaintances. Not friends... I like my own space. But I try to keep involved. Bingo - it's something to do" "I like to be able to help out... I've got the gift of the gab and half a brain. I try to get to know people, remember their names, find something to talk about." (G); and,	- "There are a lot of people with dementia here. Some are really off with the faeries. I hope I don't get like that." "I go whatever is on. Even bingo. It's something to do" (M); and, "Meals give structure to the day, then you fill in the gaps" (J). "I like doing things [the activities]. It's a good way to meet people" "I prefer to get out of my room... it's good to keep busy. Better than staring at the walls" (I)
Background	Was married - husband passed away many yrs ago (she doesn't quite remember when). 2 kids. 5 grandkids. 1 great great grandkid. Used to work as a nurse - loved when.	never married. No children. Has 2 siblings.	Was married with 2 sons. One son has passed away. Husband died 8 years ago.
Family	yes - daughter lives very close by and visits twice a week. Son calls and visits. Grandkids visit from time to time.	Has family but relationship is tense. Doesn't like to talk about family. Sounds like there were arguments over money - the parents estate.	Has family - one son living, one passed away when a young adult, 2 grandkids. They visit when they can - they live some distance away and have busy work
Visitors	Typically has visitors 2-3 times/wk. Family are only visitors	Does not have visitors	Once a fortnight or so.
Going into care	I knew it was time. I told my daughter. I couldn't manage anymore. I'm comfortable here.	After I got sick I couldn't go back home.	I wish I was still at home. I know I can't be, but I was happy there.
Leaves the facility	I don't go out. People come here to see me. It's easier. I went to my granddaughters wedding - but that might have been before I came here. It was a lovely day! I can't remember when it was.	yes - can get out on their own. Goes to local library or mall	with help - occasionally
other impairments	poor hearing poor eyesight	anxiety, depression	poor hearing - often asks for thing to be repeated

7 What are the possible risks and disadvantages of taking part?
We do not anticipate any risks or disadvantages to taking part in this project. However, if you feel some of the topics we discuss are stressful or upsetting, you may skip them. We can also stop or pause the interview. You can speak to a staff member at any time about anything that concerns you. We will also let the Nursing Unit Manager know if you become distressed so they can ensure you receive appropriate support.

8 What if I withdraw from this research project?
If you consent to take part in this project, you may withdraw at any time. Withdrawal from the study will not affect your care or relationship with staff or other health professionals. Please notify Amanda Bryan-Fox if you decide to withdraw from the project.

If you decide to withdraw from the research project, we will not collect additional personal information from you, although data you have already provided will form part of the research project results. If you do not want your data to be included, you must tell us when you withdraw from the research project.

9 Could this research project be stopped unexpectedly?
It is unlikely that this research project would be stopped unexpectedly. But should an unanticipated event stop the project, you will be notified immediately.

10 What happens when the research project ends?
This project will be completed in mid-2018. Results of the project will be presented to Presbyterian Aged Care staff and Macquarie University Faculty of Medicine and Health Sciences staff and students. We will also seek to have the results published in relevant journals (such as *Aging and Aged Care*) and presented at health and aged care related conferences. Any data included in any presentation or publication of project results will be de-identified.

Part 2 How is the research project being conducted?

11 What will happen to information about me?

By signing the consent form you consent to the research team collecting and using personal information about you for the research project. Any information obtained in connection with this research project that can identify you will remain confidential. Your personal information will be non-identifiable. Information that you contribute to the project will be securely stored. Amanda Bryan-Fox will be the only member of the study team to access your personal information.

Your information will only be used for the purpose of this research project and it will only be disclosed with your permission, except as required by law. The personal information that the research team collect and use is information gathered during observation and interviews at the PAC Ashfield Residential Aged Care Home. This information will be stored at Macquarie University for five years following the completion of the project. Data will be destroyed at the end of this period. Your privacy and confidentiality will be maintained.

It is anticipated that the results of this research project will be published and presented in a variety of forums. In any publication or presentation, information will be provided in such a way that you cannot be identified.

In accordance with relevant Australian and NSW privacy and other relevant laws, you have the right to request access to the information about you that is collected and stored by the research team. You also have the right to request that any information with which you disagree be corrected. Please inform the research team member named at the end of this document if you would like to access your information.

Any information obtained for the purpose of this research project that can identify you will be treated as confidential and securely stored. It will be disclosed only with your permission, or as required by law.

12 Complaints and compensation
If you suffer any distress as a result of this research project, you should contact PAC staff as soon as possible. They will assist with arranging appropriate treatment and support. They will also notify the research team.

13 Who is organising and funding the research?
This research project is being conducted Amanda Bryan-Fox, with assistance and oversight from by Dr Arne Hodgden and Prof David Greenfield. The project is not funded by any commercial entity. You will not benefit financially from your involvement in this research project. No member of the research team will receive a personal financial benefit from your involvement in this research project (other than their ordinary wages).

14 Who has reviewed the research project?
All research in Australia involving humans is reviewed by an independent group of people called a Human Research Ethics Committee (HREC).

The ethical aspects of this research project have been approved by the HREC of Macquarie University.

This project will be carried out according to the *National Statement on Ethical Conduct in Human Research* (2007). This statement has been developed to protect the interests of people who agree to participate in human research studies.

15 Further information and who to contact
The person you may need to contact will depend on the nature of your query. If you want any further information concerning this project or if you have any problems which may be related to your involvement in the project, you can contact Amanda Bryan-Fox by email Amanda.bryan-fox@hdr.mq.edu.au or phone 0405 131 976.

If you have any complaints about any aspect of the project, the way it is being conducted or any questions about being a research participant in general, then you may contact:

Reviewing HREC approving this research and HREC Executive Officer details

Reviewing HREC name	Macquarie University HREC
Director of Ethics and Integrity	Dr Kandy White
Telephone	9850 7854
Email	karolyn.white@mq.edu.au

Consent Form - Adult providing own consent

Title **Developing personas for residential aged care.**

Coordinating Principal Investigator/ Principal Investigator Dr Anne Hogden
Associate Investigator(s) Ms Amanda Bryan-Fox,
Professor David Greenfield

Location Presbyterian Aged Care (PAC), Residential Aged Care Home, Asrfield

Declaration by Participant

I have read the Participant Information Sheet or someone has read it to me in a language that I understand.
I understand the purposes, procedures and risks of the research described in the project.
I have had an opportunity to ask questions and I am satisfied with the answers I have received.
I freely agree to participate in this research project as described and understand that I am free to withdraw at any time during the project without affecting my future care. I understand withdrawal will not impact my care or relationship with Presbyterian Aged Care.
I understand that I will be given a signed copy of this document to keep.

Name of Participant (please print) _____

Signature _____ Date _____

Declaration by Researcher[†]

I have given a verbal explanation of the research project, its procedures and risks and I believe that the participant has understood that explanation.

Name of Researcher[†] (please print) _____

Signature _____ Date _____

[†] An appropriately qualified member of the research team must provide the explanation of, and information concerning, the research project.

Note: All parties signing the consent section must date their own signature.



Research activity currently underway

What's happening?

A researcher from Macquarie University, Amanda Bryan-Fox, is currently conducting observation research in this common area.

What do I need to do?

You don't need to do anything. Just go about your usual routine and activities. You are welcome to speak with Amanda, but you don't have to. Taking part in this research is voluntary.

Prefer not to be involved?

There is no obligation for you to take part in this research.

You can:

- Tell Amanda, or a PAC staff member, you don't wish to participate, and you won't be included in the research notes.
- Use another common area while the research is taking place.

Why are we doing this?

PAC Ashfield is taking part in this research project with Macquarie University to help improve understanding of the experience of people living in residential aged care.

The information gathered in this research about our usual routines, activities and interactions with each other will contribute to the development of resident profiles, or 'personas'. We hope to use these personas in the future to help us design improved services and programs, and ultimately enhance the day to day experience and quality of life for all residents.

Your privacy

The information Amanda collects about you and other residents through her observation and discussions will be de-identified so that your privacy is maintained. Any personal information will remain confidential.

More information?

If you'd like more information or you have any concerns, please speak to:

- [REDACTED] Facility Manager: [REDACTED]
- Amanda Bryan-Fox, Macquarie University: 0405 131 976 or Amanda.bryanfox@gmail.com

Meet the researcher



Amanda Bryan-Fox
Student researcher
Macquarie University