



# Putting the consumer in the driver's seat: A visual journey through the Australian health-care system as experienced by people living with dementia and their carers

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## Abstract

**Objective:** To better understand the individual journeys of people living with dementia and their carers through the Australian health-care system.

**Methods:** Stories were collected from 25 participants, through five face-to-face workshops, across Australia. This produced 18 visual storyboards and a range of opportunities for improvement, which were then synthesised into an aggregated “ideal-journey” model.

**Results:** Several issues were identified: long lead times to diagnosis; diverse experiences of treatment and support; and little coordination of care or thought for its impact on the consumer. Information about services, their purpose and eligibility criteria was difficult to obtain, and potential care pathways were largely unexplained. Much of the carer support received was reactive rather than proactive.

**Conclusions:** A better understanding of the current health-care pathway of dementia is essential for the design and delivery of future health-care services. It is vital to include the consumer voice in future research and allocation of health-care resources.

## KEYWORDS

caregivers, critical pathways, delivery of health care, dementia, health services accessibility

## 1 | INTRODUCTION

The Australian health-care system, including the aged care system, endeavours to meet the needs of all Australians. However, navigating the overall system is difficult. People living with dementia and their carers are challenged because, even though a variety of services are available, these services are across disparate organisations and locations and access is not always easy. To understand the effects of the health-care system on its users more deeply, it is important to examine the real-life experiences of consumers. This examination

must include a close investigation of the care pathway from beginning to end.

Care pathways for people living with dementia have been established in several countries, including Australia.<sup>1</sup> In addition, recently published *Clinical Practice Guidelines and Principles of Care for People with Dementia*<sup>2</sup> have been developed to improve care delivered to people living with dementia and their carers.<sup>2,3</sup> However, to date, little research has focused on how people living with dementia and their carers navigate care pathways from a personal perspective. Open dialogue between people living with dementia and their carers,

policymakers and health-care providers is needed to identify the problem areas that require care path redesign.

End-user involvement in health-care research can enhance the quality of research findings and improve their dissemination and implementation.<sup>4,5</sup> This study provides a snapshot of the current quality of the consumer journey of people living with dementia and their carers through the Australian health-care system. The voice of consumers and accounts of their experiences were used to map participants' unique personal pathways through the health-care system. This provided the researchers with a better understanding of current barriers and potential solutions from the consumer's perspective. Specifically, this study aimed to demonstrate how consumers experienced the journey (current state) and how they would like to see the journey redesigned (ideal state).

## 2 | METHODS

Five, two-day participatory workshops were held in Brisbane, Adelaide, Sydney and Kiama (regional NSW). Data were collected from group discussions and analysed using a health-care-specific transformational change methodology: DXC's Essomenic™<sup>6</sup> and its consumer journey-modelling component. The software was used to map participants' journeys through the Australian health-care system. Essomenic™ creates easy-to-understand visual storyboards of consumer journeys and assists in clearly identifying barriers and inefficiencies.<sup>3</sup> Storyboards allow for a greater understanding of consumer needs and highlight opportunities for improvement.<sup>7,8</sup>

This research was reviewed by the Griffith University ethics committee (IBA/12/15/HREC) and was conducted in accordance with ethical standards. All participants involved in this research gave informed consent prior to the commencement of the study. Participants were self-selected, responding to a call for participation via an email distributed by the leader of a dementia consumer group. Specific geographic areas were targeted to ensure metropolitan and rural areas were covered. Data were collected at independent sites, including a local bowling club and community centre.

Data were collected during the five, two-day focus groups. The total sample consisted of 25 participants and comprised of 40% men ( $n = 10$ ) and 60% women ( $n = 15$ ) between the ages of 48 and 73 years. The sample was made up of the following:

- people diagnosed with younger onset dementia (YOD) ( $n = 2$ );
- people diagnosed with dementia after the age of 65 ( $n = 5$ );
- carers of people living with dementia who were still living at home ( $n = 11$ );
- carers of people living with dementia who lived in residential aged care ( $n = 2$ ); and
- carers of people who had been diagnosed with dementia and who are now deceased ( $n = 5$ ).

### Policy Impact

We investigated what improvements to the current dementia care journey are needed. To maximise research impact, we listened to people living with dementia and their carers and, using their voices, created an 'ideal' journey. This ideal can be used to underpin improvements to national health and aged care policy, including the justification for a nation-wide program to make life changing improvements.

Some participants knew the researchers from previous interactions. This was important as it assisted with the development of rapport and trust. The 2-day workshops used an interactive consumer-centric approach to examine participants' individual journeys. The first day of each workshop focused on listening to participants' personal stories. Sample questions included the following:

- When did you first realise something had changed in your loved one's health status?
- What sort of assistance or investigation did you seek?
- What was your experience with your general practitioner (GP) and other specialists?
- What services have you accessed throughout this journey?
- How did you find out about service availability and access?
- What specific events caused stress and/or anxiety?
- What were the best and worst things you have experienced?

For those who were currently living with dementia, or currently caring for someone living with dementia, additional questions such as "what is happening now?" and "what do you see the future holding?" were also asked. Participants' responses directly contributed to the creation of personal visual storyboards. The research team created software versions of the models overnight, between Day 1 and Day 2 of the workshops. On the second day of the workshops, each participant was presented with their personal storyboard (an individual consumer journey model) for validation purposes.

Each storyboard model was amended as required until participants felt their experiences had been accurately visualised. The workshops then focused on using consumers' voices to determine what an ideal dementia journey should look like. The key goal was to design a journey that retained the positive aspects of people's experiences and eliminated or redesigned the negative experiences that participants felt others "should never go through." In addition, participants were asked how they thought this ideal state could be achieved.

At the conclusion of the five workshops, ideas were synthesised into a single visual “ideal state” model. Participants were then asked to validate the synthesised “ideal state” model through an email-based feedback process.

This method gave a voice to people living with dementia and their carers and allowed participants to direct the research. Our method included two comparative processes to improve the trustworthiness of results: (a) participants compared their stories with others’ accounts within each workshop, and (b) the researchers compared results across workshops. This constant comparison minimised bias and allowed for continuous reflection on participant input.

### 3 | RESULTS

Eighteen individual consumer journey models were created. The models provided evidence of experiences along the dementia journey that consistently caused stress and anxiety for consumers and their carers. Five major areas for improvement were identified:

1. Poor recognition of the early symptoms—particularly in YOD;
2. Variable assessment processes;
3. Time to and un-empathetic delivery of a diagnosis;
4. Difficulty navigating the service system; and
5. Development of a “wellness plan.”

Although the processes identified in themes 1, 2 and 3 overlapped, participants identified them as distinct issues requiring attention.

#### 3.1 | Poor recognition of early symptoms

Participants’ experiences indicated that GPs did not recognise the early symptoms of dementia very well. The perception of consumers was that GPs lacked general education and knowledge about dementia, especially YOD.

The majority of the participants had negative experiences with their GP when presenting with their initial symptoms. Some consumers were told to go home, with comments from their GP such as: “*you are probably too stressed*” and “*you are too young to have dementia.*”

One participant, a care partner, stated:

I asked for tests for my partner to investigate concerns about epilepsy, auditory process et cetera. The diagnosis was stress. (Participant 1)

Notwithstanding this, some participants did provide positive feedback about the support they received from their GP when presenting with initial symptoms:

He [the GP] was also from South Africa, so they [GP and Dad with dementia] connected well. We had good contact and lots of support. (Participant 2)

Participants had a particular concern about the lack of recognition of YOD. Two participants who were eventually diagnosed with YOD recounted many doctor visits that resulted in a range of diagnoses over time, including stress, psychosis and marital problems.

#### 3.1.1 | Suggestions from Participants

As a suggested solution to this issue, there was general agreement that there was a need to:

Improve the education of GPs around recognising symptoms regarding dementia-related illnesses and create more awareness of younger onset dementia. (Participants’ group discussion 1,2,3,4)

Participants were informed that Alzheimer’s Australia already provides libraries and practice education to professionals, including GPs, and that Dementia Training Australia has also been established to provide training to professionals and paid carer/s, free-of-charge. In general, the groups had not experienced any benefits from this education/training, but hoped that in time it would deliver better experiences for consumers in the early stages of dementia and their carer/s.

#### 3.2 | Variable assessment processes

Some participants stated that the assessment and diagnostic processes went well and were quite quick. However, the majority of participants indicated they were not satisfied with the diagnostic process. Individual journey models indicated little consistency across the assessment and diagnostic process. Some participants received referrals to a geriatrician, whilst others were provided with referrals to a neurologist or psychiatrist.

Participant stories varied considerably around assessments conducted, indicating that standard guidelines for evidence-based best practice referral and assessment processes were not being followed. Some consumers and carers felt confused because they were referred to several different types of doctors. The lack of adherence to guidelines led to individuals being left feeling stressed and anxious.

One carer stated:

I [carer] couldn’t do anything more. I needed some help myself. (Participant 3)

### 3.2.1 | Suggestions from participants

An option supported by all focus groups was to “centralise access to dementia information and services.” This way of dealing with the problem of practice inconsistency prompted the idea of establishing a dementia wellness centre, which would provide a holistic multi-disciplinary centre staffed with specialists and could be similar in concept to the Chris O'Brien Lifehouse for cancer in Sydney, Australia. Ideally, the centre would be able to provide the latest evidence-based best practice education about standard assessment processes and referral pathways to GPs and professionals from a variety of disciplines. Such a centre would act as a community base where consumers and their carers interact with people in similar situations to their own and receive peer support.

Another focus group also suggested that there was potential to refer all individuals over a certain age to a clinic for standard screening for dementia (similar to the National Bowel Cancer Screening Program). The benefits of standard screening would include earlier diagnosis leading to earlier commencement of appropriate care and treatment. An additional benefit would be improved capacity to collect research data on disease progression patterns.

### 3.3 | Time to and un-empathetic delivery of a diagnosis

This issue is twofold with the first concern being the time between the initial presentation of symptoms to a GP and receipt of a confirmed diagnosis, and the second relating to the way in which a diagnosis is delivered to the consumer and their carer/s.

On average, it took more than four years for participants to receive a diagnosis of dementia and one participant stated it took ten years to get a diagnosis of YOD at the age of 59. This finding indicates that dementia, especially YOD, is poorly recognised and not well understood by GPs. Participants also noted that, like the general public, they had not been aware that dementia could affect people as young as 59 years of age.

This issue is compounded by inconsistent GP processes in relation to assessment, as described in the previous section. Participants also felt that some GPs would be reluctant to diagnose if they believed there were no services or specialists available in their community to assist and support consumers.<sup>9</sup>

How consumers received their diagnosis was a significant milestone in their journey and evoked many deep-held emotions. Many indicated that the language used when discussing a diagnosis and the empathy conveyed had a direct effect on the sense of well-being of the consumer and their carer/s.

After the diagnostic consultation, consumers and carers reported feeling upset, confused and frustrated. One participant stated:

The doctor said: Well, you have 7 to 10 years to live. Here is some information on Alzheimer's and contact them if you like. We will start him on this medication and see if it slows it down.  
(Participant 4)

Although this couple were left in a state of shock, they received little support from their doctor. Other participants recounted similar experiences.

### 3.3.1 | Suggestions from participants

In a bid to alleviate these experiences, it was suggested that multi-disciplinary, “prediagnosis delivery” planning meetings be instigated by the GP/specialist. Such a meeting would enable providers, including social workers, to meet and discuss what approach should be taken when presenting the diagnosis of dementia to the consumer and their carer (with the consumer's permission). A personalised approach would better suit individuals' needs. One participant stated:

Therefore, there should not just be ‘one approach fits all’. (Participants' group discussion 4)

In addition, participants across the groups felt that GPs and other health-care professionals required specific education and guidelines on how they could deliver the diagnosis in simple terms with empathy and provide clear direction as to what the consumer and their carers could expect as the next steps in their dementia pathway.

According to Iliffe, Manthorpe and Eden,<sup>8</sup> training and education for clinicians through workshops (ie addressing how to communicate the diagnosis to people with dementia and carers) have the potential to influence the health-care journey positively.<sup>9,10</sup> Therefore, in future, it is important to assist GPs and other health-care professionals to have the support, knowledge and training to fulfil their role better.

### 3.4 | Difficulty navigating the service system

There was large variation in the level of knowledge across all of the groups about what dementia and support services were available and eligibility criteria for accessing them. Although some participants knew about a broad range of available services, the majority did not. This indicates that although multiple services do exist, the methods used to disseminate information about them need to be revisited. This potentially may mean changes to current marketing approaches, social media and service designs.

One participant expressed the view that:

It is up to individuals to find information, usually by networking or word of mouth. It is not easy if you don't have a PC (personal computer) or mobile. (Participants' group discussion 4)

Related to this item was the feeling that there are not enough dementia key workers—individuals who could provide information, support, counselling and advice about dementia and dementia services across the country—to manage consumer demand. In addition, participants in group discussions 1 and 4 raised the issue that these positions were not always appropriately staffed and incumbents' skill levels varied. Some key workers have insufficient knowledge of dementia, life experience or service knowledge.

### 3.4.1 | Suggestions from participants

In a bid to relieve the stress and anxiety associated with traversing the dementia system of care, participants suggested a complete redesign of the dementia key worker role. In addition, they wanted the role renamed “systems navigator.” There was extensive discussion around how the role would work and the best time for allocation. In short, the “systems navigator” would be allocated soon after diagnosis and, from then on, would be the first point of contact for consumers and carers, responding to queries, giving service advice, confirming eligibility and scheduling follow-up appointments, as required. The groups felt that this role should be filled by staff with specific and appropriate skills and knowledge. Incumbents needed to have knowledge of and experience in the dementia field and be able to deal with clients in an empathetic manner. With the right foundational attributes, people in this role could then receive training about service availability and access requirements.

The systems navigator job description would support the work of GPs by encompassing activities and roles conceptually similar to those of a key worker. In addition, a systems navigator would be able to assist with holistic wellness planning, service access and service/care information needs, problem-solving and guiding individual consumers and carers in the right direction based on their individual needs and projected care pathway.

The role of a “systems navigator” needs to be developed and implemented as a part of the support services available to consumers and carers. Importantly, a systems navigator should have the appropriate foundational care skills, dementia knowledge and life experience to ensure they can undertake assistance in a variety of areas, provide answers to questions and assist with consumer and carer pathways. A systems navigator could potentially be someone who has

experienced caring for a person living with dementia, as a peer-to-peer model. This service could be implemented from a centralised point or as a mobile service, or combine both delivery modes. The individuals appointed would assist in providing information about treatment, available research and other quality of life issues (eg financial and legal issues). They would be the first point of contact for all consumers and carers, alleviating some of the burden on GPs and specialists.<sup>11,12</sup>

## 3.5 | Development of a “wellness plan”

A significant opportunity for improvement revolved around the need for an ongoing plan for both the person living with dementia and their carer/s. Consumers felt information was difficult to locate, and it was unclear when and if they would be eligible for certain supports and services. In addition, many participants stated that they felt future treatment and disease progression were unclear and, as a result, some experienced anxiety and stress in regard to their ongoing journey.

We just didn't know what to expect next. It would have helped to know. (Participant's group discussion 1,2,3,4)

### 3.5.1 | Suggestions from participants

To assist consumers and carers to better understand disease progression and what their pathway would entail, participants suggested development of a “wellness plan.” The wellness plan is a consumer-centred document containing information on how the consumer can live well and the support or services needed. It would be individualised and specific to the individual's journey including services and supports they and their carer/s required.

A wellness plan would help to overcome the above-mentioned stress and anxiety, by providing the consumer and their carer with a clear outline of what supports and services they would receive and when and to whom they should direct questions or escalate issues.

Information on key milestones experienced by most individuals living with dementia would be able to provide a guideline to map out the initial “wellness plan.” The “wellness plan” would then be specifically tailored to each individual.

According to participants, this would facilitate a personal and proactive approach to their care, providing many benefits over current reactive approaches.

A systems navigator would facilitate development of the wellness plan, with essential contributions from relevant

specialists, allied and community health, and the consumer's GP. The systems navigator would be required to periodically review and update the wellness plan (with input and direction from the multi-disciplinary care team) based on changes in the consumer's condition and/or circumstances, including those of their carers.

It would be less stressful for us if we knew what to expect and had a single point of contact.  
(Participant group discussion 1,2,3,4)

### 3.6 | The Ideal State Consumer Journey Model—a design for the future

The “ideal state” journey model was developed with direct input from workshop participants using the “consumer voice.” The output reused the Essomenic™ approach, producing a visual representation of how the participants want others in the future to experience the dementia continuum of care. The model addresses the five major areas for improvement. It

provides a “storyboard” design for how consumers and their carers would like to experience their journey and what they would like others, involved in the sphere of dementia care, to experience. It incorporates all of the participant-suggested improvements and can be used as a starting point for discussions with policymakers, health-care providers and researchers on the key aspects that consumers and their carers want to be addressed or revisited (see Figure 1).

## 4 | CONCLUSIONS

This research project used the “voice of consumers” to develop visualisations of eighteen personal journeys of people living with dementia and their carers. Participants stated that the consumer-centric, visual approach resonated very strongly with them, far more than the written output that they had been presented with in the past. One participant stated.

For the first time it feels as if we have been listened to, and truly heard. (Participant group 1)

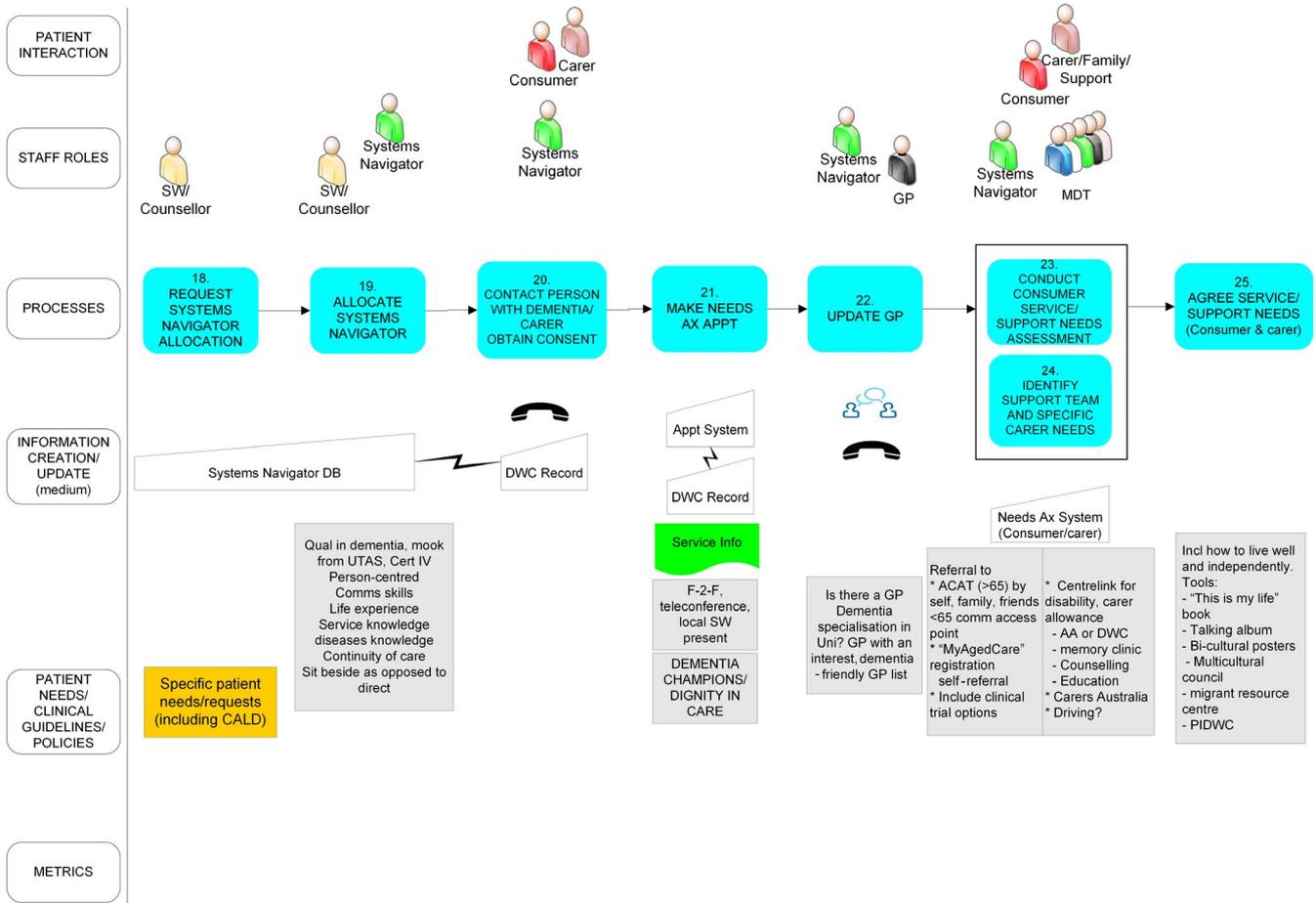


FIGURE 1 Excerpt from the Essomenic™ Ideal State Model—Allocation of a Systems Navigator.

Figure Key: ACAT: Aged Care Assessment Team; AX: Assessment; CALD: Cultural & Linguistic Diversity; DB: Database; DWC: Dementia Wellness Centre; MDT: Multi-disciplinary Team; SW: Social Worker

The findings from this study will assist policymakers, health-care providers and researchers to better plan, respond to and provide for the ongoing needs of people living with dementia and their carers. The five areas of improvement identified by the research have been disseminated to research-related groups and health-care organisations through presentations, newsletters, consumer meetings, social media and word of mouth, as practical options for implementation.

This study focused on what consumers want and need when traversing the health-care system, through listening to their stories. This study received a great response from consumers and carers, with several positive outcomes resulting from the research. Whilst the number of study participants was small relative to the number of people living with dementia, the group included a wide variety of people, including some with YOD. To the best of our knowledge, this is the largest group of people with cognitive decline and their carers to be included in qualitative research on health system reform.

The “storyboards” developed provide irrefutable evidence of what people living with dementia and their carers have experienced throughout their personal health-care journey. The storyboards have provided an excellent understanding of consumer experiences of good initiatives and/or processes and areas that require improvement.

Consumers and carers were open to sharing their experiences freely and hoped that their contribution could assist in additional change and impact. Our research confirmed that consumers want to be involved in research about them and for them and to help others have a more positive experience. Consumers also want to be involved in trialling changes that are made and providing feedback for ongoing research and implementation. Our work illuminates the benefits of conjoint investigation with consumers to deliver research that has real impact.

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## CONFLICT OF INTEREST

The authors declare no conflicts of interest.

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