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Final Report

Understanding the Journey Better: An exploration of the current "state of play" of the health care journey experienced by people living with cognitive decline and their carers

Important notice

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Amendment History

Version	Date	Change Request Number	Approved by	Change Request Details
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1. Introduction

DXC Australia Pty Ltd (DXC) is pleased to provide this Final Report to Griffith University as the concluding agreed deliverable for work conducted under Activity 25 - Understanding the Journey Better: An exploration of the current “state of play” of the health care journey experienced by people living with cognitive decline and their carers.

This project ran from 1 July 2016 to 20 April 2017 and was conducted by Professor Anneke Fitzgerald (Griffith), Dr Joanne Curry (DXC) and Ms Angelique Olde Meierink (Griffith).

This report outlines DXC’s involvement in Activity 25 which primarily involved working with people with dementia and their carers (the consumers) to provide a snapshot of the ‘current’ state of play in their consumer journey through the health care system.

The outcomes of this project provide vital real-life data on how the journey is experienced at present (current state) and how consumers would like to experience it (future or ideal state). The current state information can be used as a baseline measure to indicate at what points of the journey the CDPC is impacting those living with cognitive decline and their carers, and where research efforts might focus in future years. This mapping of current state and future ideal state will assist with the justification of ongoing CDPC research in this area.

Primary data used to develop the models was obtained directly from people living with dementia and their carers via a series of workshops.
The workshops looked at:

- “what is happening now”;
  this was achieved via the collection of individual lived-experience stories and the development of personal storyboards,
- presentation of the personal storyboards;
  for the purposes of validating the captured data and then
- consumer suggestions for potential opportunities for improvement and
- design of an ideal future state.

The project outputs include the personal storyboard models, a poster, a book chapter and three conference presentations.

The recommendations strongly support the ongoing inclusion of consumers in not only helping to identify what can be improved in the healthcare system but also in providing ideas on how current deficiencies and barriers can be overcome.

2. **Project Outline**

This project contributed to the vision of the CDPC to co-create and synthesize knowledge for the purposes of measuring the change and impact that the CDPC is having on the outcomes for people living with cognitive decline.

The aim of this study was to use the consumer's voices to map the "current state" of the healthcare journey, to identify opportunities for improvement and to propose a design for an "ideal" future state.

This involved:

1. Consulting with people with dementia and their carers about the personal journey they had experienced in a bid to better understand;
    - Services and support they found beneficial
    - Services and support they found to be barriers or difficult to navigate
2. Identifying current pathways and coordination roles for the integration and delivery of care for people with dementia and their carers.
3. Identifying opportunities for improvement in the current processes in order to optimize effective coordination, integration and delivery of care for people with dementia and their carers.
4. Development of a graphical ideal future state storyboard that represented the consumer and carer ideas for improving services/outcomes and overall satisfaction.

3. Project Impact

The overall project aim looked to answer the question *"If we use consumer's voices to map the "current state" of the healthcare journey, can we identify opportunities for improvement and create an "ideal" state".*

The Activity contributed towards two of the CDPC impact categories as follows:

> **Primary Impact:** The centre will evaluate and develop plans to inform the implementation of new guidance and respite models in multiple locations throughout Australia that will assist informal and family carers to identify appropriate care options and pathways (Short Term Impact).
>
> **Secondary Impact**: Government and senior decision makers will have tools and resources for changing attitudes to dementia and cognitive decline, increasing general awareness and promoting greater acceptance (Medium and Long Term Impact).

The Activity specific impacts were:

Short Term	Medium Term	Long Term
Participants have reflected upon their journey and this research is a flagship for the inclusion and acceptance of consumer voices, empowering them to be involved in the development of innovative interventions in the care of dementia related illnesses.	Provides insights for clinical and nursing education, health service design and delivery, policy and role developments around key worker/system navigators. In addition, this research can influence the mission, vision and activities of dedicated dementia organisations and groups, improve service provision and policy concerning service eligibility. Further, it provides the CDPC with specific outcomes that can be used for strategic purposes, indicating, on the basis of evidence, where future research efforts may need to be focused for greatest impact. Evidencing the impact may also assist with future policy changes.	This project approach can be repeated in new/additional projects, to compare and evidence whether the CDPC (or any other influencing party) have had or are continuing to have any impact on what people, living with dementia and their carers experience in real life.

4. Project Approach

Methodology

The DXC approach utilised the Essomenic^{TM} Transformational Change Methodology to understand/design both the current and future state journey. This approach evolved as a result of extensive research in the area of health informatics and has been used to achieve significant results in a wide range of areas including mental health, oncology, community health services, chronic disease management, maternity (both metropolitan and remote indigenous) and ambulatory care.

The methodology relies heavily on the active participation of subject matter experts (SMEs) across the continuum of care including clinicians, management, administration and patients/carers. Such an approach helps to ensure that the resulting service designs support projected workflows and due to the consistent engagement of stakeholders their level of commitment to support and embed changes on a long-term basis are greatly enhanced.

The Essomenic^{TM} approach includes a pioneering patient journey modelling technique that is highly visual using colour-coding and specific shape syntax to produce models that are intuitive to healthcare staff and that promote communication, knowledge transfer and problem ownership across all levels of staff. The term Essomenic means "to show how things will be done in the future" and as such it is an ideal tool to assist in the analysis of proposed patient flows and supporting workflows, best practice compliance, IT touchpoints and human and physical resource requirements.

The Essomenic methodology is shown in Figure 1.

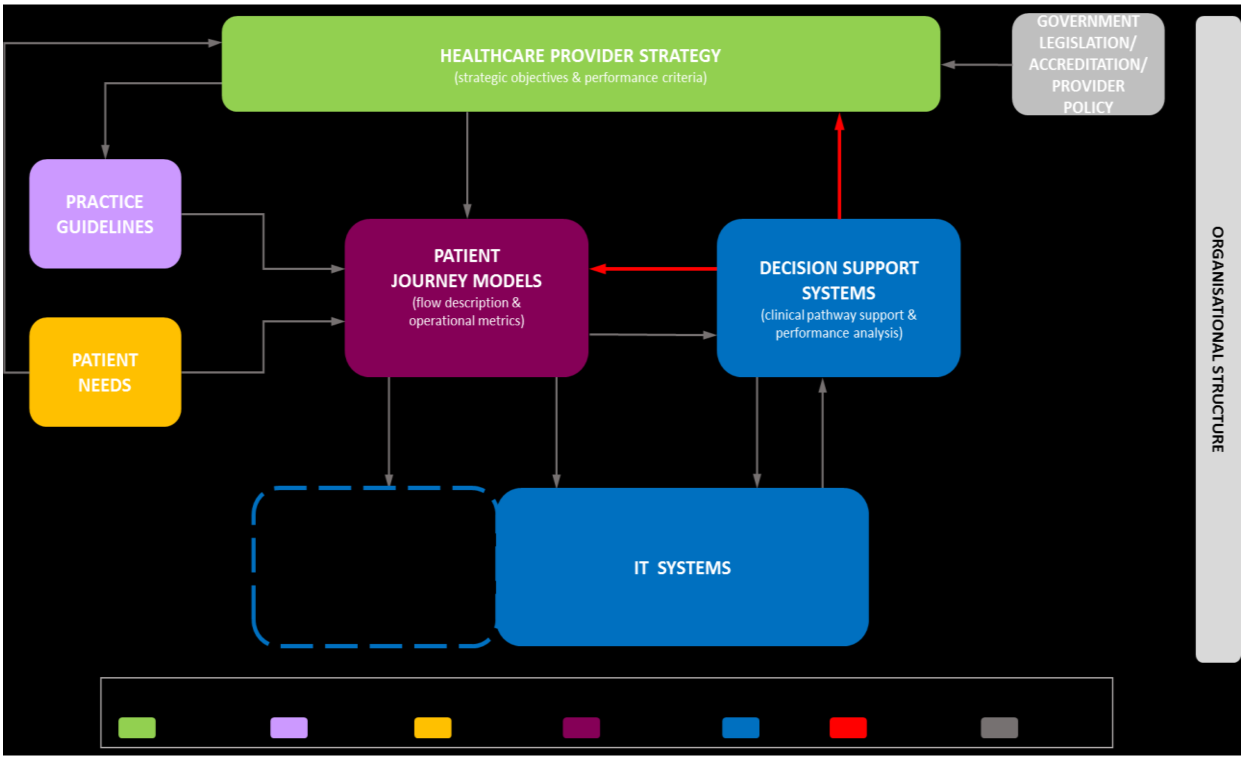

Figure 1. Essomenic Care Logistics Methodology

Human Ethics

Ethical approval for consumer interaction was obtained via Griffith University. Application identifier IBA/12/15/HREC.

Workshops

An interactive approach examining the consumer journey involved the conduct of five (5) face-to-face workshops in Brisbane (2), Sydney (1), Kiama (1) and Adelaide (1). In addition, there were a number of telephone interviews and email correspondences.

The participants came from a wide variety of backgrounds, with differing stages of dementia and from across metropolitan as well as rural areas across 3 States.

Participants included:

- People diagnosed with early onset dementia and their carers;
- People diagnosed with dementia after age 65 and their carers;
- Carers of people diagnosed with dementia who are now living in residential aged care;
- Carers of people previously diagnosed with dementia who are now deceased.

There were 18 individual journey models created and these visually represented and gave voice to participants' real-life experiences. Collectively these depict the 'current state'.

Taking into account the current state of dementia services, participants were then involved in suggesting ideas for improvement and potential solutions to overcome current deficiencies and barriers.

The final activity asked each group to contribute to what an ideal future state journey should encompass and how consumers should flow through the improved system. The resulting future state clearly shows how consumers want services to be designed and how and when they want healthcare professionals to interact with them.

5. Project Outputs

The key outputs of this project are the current and future state models. These are available electronically in the shared directory used by the team throughout the project.

In addition, the team has produced the following outputs:

Book chapter:

Fitzgerald, J.A., Curry, J.M., Olde Meierink, A. (under review). Nothing about me without me: Giving voice to people living with cognitive decline and their carers to create an improved consumer journey. Submitted for review to The Social Reframing of Dementia: The Challenge to Change, Ed Gaynor McDonald, Routledge.

Conference presentations:

Fitzgerald, J.A., Curry, J.M, Olde Meierink, A.H.R. (2016). Understanding the Journey Better: An exploration of the current "state of play" of the healthcare journey experienced by people living with cognitive decline and their carers, presented at CDPC Annual Meeting, Sydney, November 2016.

Fitzgerald, J.A., Curry, J.M, Olde Meierink, A.H.R. (2017). Understanding the Journey Better: An exploration of the current "state of play" of the health care journey experienced by people living with dementia and their carer, presented at Reframing Dementia as Social and Cultural Experience Workshop, Sydney, February 2017.

Fitzgerald, J.A., Curry, J.M, Olde Meierink, A.H.R. (2017). Understanding the Journey Better: An exploration of the current "state of play" of the health care journey experienced by people living with dementia and their carer, presented at Australian Healthcare Week, Sydney, March 2017.

6. Opportunities for Improvement

Using the consumers' experiences and working with them to generate ideas on how to improve the negative aspects of their journeys, five (5) key themes for improvement emerged.

These were:

1. Better recognition of the early symptoms
2. Consistent assessment and diagnostic process
3. Improved communication when delivering a diagnosis
4. Allocation of a 'Systems navigator'
5. Development and review/update of an individual 'dementia wellness plan'[1]

Better recognition of early symptoms

Consumer and Carer Observation(s)

Some participants were very happy with their GP and the support they received when presenting with initial symptoms, for instance:

"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)

However, a great deal of participants felt they were not being heard when they went for a GP consultation. Consumers were sent home with comments such as: "You are probably too stressed" or "You are too young to have dementia".

As a participant stated:

"I asked for tests for my partner to investigate concerns re epilepsy, auditory process etc. The diagnosis was stress." (Participant 1)

One of the consumers felt they were wrongly diagnosed several times. The care partner said:

"I intervened when I discovered that my partner got antipsychotics prescribed because he isn't psychotic and I asked to take him off his meds, and to refer him to someone who can help to diagnose him." (Participant 1)

The main reasons offered by people living with dementia and their carers for delays in recognising early symptoms of dementia are the perceived lack of GP education and knowledge concerning dementia, especially early onset dementia, exacerbated by diagnostic uncertainty during the early stages. In addition, participants perceived GPs were not comfortable conducting cognitive examinations. Participants described their experiences of poor communication regarding a suspected diagnosis and insufficient consultation time. These findings are consistent with the literature (Hansen et al., 2008, Woods et al., 2003, Iliffe et al., 2003).

Potential solution(s)

Participants suggested several solutions to this problem. Most groups mentioned increasing GP awareness and recognition of dementia symptoms including younger onset dementia:

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[1] Excerpts from submitted journal paper: Fitzgerald, J.A., Curry, J.M., Olde Meierink, A. (under review). Nothing about me without me: Giving voice to people living with cognitive decline and their carers to create an improved consumer journey. Submitted for review to The Social Reframing of Dementia: The Challenge to Change, Ed Gaynor McDonald, Routledge.

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

Another suggestion, from the Brisbane focus group discussion, was to refer everybody over a certain age to a clinic for a standard screening for dementia, as is already done for bowel cancer screening. The benefits of proactive, age based screening could include earlier diagnosis, which means earlier recognition of the disease and therefore earlier initiation of appropriate treatment.

Benefit(s)

Diagnosis in the early stages of the disease is said to contribute to both the preventative and on-going care strategy. Early recognition of dementia may offer significant advantages for people with dementia and their carers such as education on the patients' behavioural changes and provide adequate time to address issues of financial, legal and medical care planning. Early diagnosis also reduces uncertainty, can help with planning support and reduces crises (Iliffe et al., 2003, van Hout et al., 2000). Therefore, a proactive approach to the diagnosis and intervention might improve the welfare of people living with dementia and their carers (Bradford et al., 2009).

Consistent assessment and diagnostic process

Consumer and Carer Observation(s)

Although some of the participants stated their assessment and diagnosis process was accurate and quick, many of the participants were unhappy with this process. The individual journey models showed that there was little consistency in the assessment and diagnostic process. Some participants received referrals for a geriatrician, others for a neurologist or psychiatrist.

A barrier to earlier diagnosis is the perceived lack of GPs skills to recognise dementia in early stages. GPs might have difficulty distinguishing normal ageing from dementia and may be unaware of the advantages of early diagnosis (https://www.fightdementia.org.au/files/Timely_Diagnosis_Can_we_do_better.pdf.)

In addition, every person may have different symptoms, and every GP their own work method which might result in a different referral process. Some consumers and carers felt very confused because they were sent to several different types of doctors. Hence, there was no standard referral and assessment process reported in this study.

The variation in the assessment and diagnosis process was extraordinary and this caused intense stress and distress to the person with symptoms and their carers. One carer stated:

"I [carer] couldn't do anything myself anymore. I needed some help myself."
(Participant 3)

Potential solution(s)

A potential solution is to "centralise access to dementia information and services" (Kiama group), hence the suggestion to develop a Dementia Wellness Centre (DWC). The DWC would be a holistic multi-disciplinary centre staffed with specialists (dementia and complimentary disciplines) and could be similar in concept to the Chris O'Brien Lifehouse or the Tennyson Centre (Adelaide) for cancer (Participants in group discussion 2 and 3). The importance of addressing and supporting the progressive neurological changes and concomitant changes experienced by the person living with dementia deserve skilled attention and assistance throughout, in addition to supporting their overall health.

The goals the O'Brien Lifehouse are to facilitate people living with cancer so they do not feel alone and can navigate the confusing components of dealing with their disease, and to turn new findings into better care (Partnership council, 2016). These goals were viewed as appropriate for the suggested "Dementia Wellness Centre". The DWC concept aligns well with the tenants of the O'Brien Lifehouse centre where the aim is to ensure *"the patient is at the centre of everything ... We want to make things easier for people with cancer through integrated treatment, research, education, complementary therapies and support. Everything a patient needs is in one place, including allied health, complementary therapies and psychosocial support."* (Partnership council, 2016).

With such a specialised centre, best practice assessment and diagnostic processes would be delivered using standard pathways, by world leading dementia experts. These practices could then be communicated and expanded to GPs and other service providers to standardise best practice and improve outcomes.

Benefit(s)

A centralised centre where best practice assessments and consultations are performed has several potential benefits. Multiple assessments could be planned on the one day, saving time and travelling for consumers and carers. Healthcare professionals could easily refer consumers to different disciplines and discuss the results of the tests within the multi-disciplinary team, under one roof. In addition, this centre could also be used as a socio-education base where professionals from a variety of disciplines, as well as the community can come together to receive information, support and keep up to date.

Improved communication of the delivery of a diagnosis

Consumer and Carer Observation(s)

The individual experience models showed long delays between noticing the first symptoms and receiving a diagnosis; on average, it took more than four years for participants to receive the diagnosis of dementia. One participant stated that it took 10 years to get the diagnosis of Younger Onset Dementia at the age of 59, suggesting that Younger Onset Dementia is particularly poorly diagnosed.

In addition, many consumers and/or carers said that communication of the diagnosis was poorly conveyed by GPs/specialists. In many cases the diagnosis was delivered very bluntly and with little if any empathy. Due to this and the fact that they received inadequate information about what would happen next, consumers and their carers felt very upset and confused after the consultation. One example provided from the Brisbane group is:

"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)

The couple were in shock when they heard this, and felt there was no support or empathy from the doctor. Some doctors lack skills in communicating a dementia diagnosis and it has been reported that some GPs might be reluctant to diagnose if they believe there are no services or specialists available in their area to assist and support the patient (Phillips et al., 2011).

Potential solution(s)

A pre-diagnosis planning meeting may improve the delivery of the diagnosis. At this meeting the medical staff, including a social worker, would discuss what kind of approach they will take when presenting the diagnosis to the consumer and their carer (with consumer's permission). Due to each person's individual circumstances (their journey so far, experiences and personality) it is best that this approach is individualised. The DWC may have a role in this as well.

"… there should not just be 'one approach fits all.'" (Participants group discussion 4)

GPs and other healthcare professionals require education and guidelines regarding how to communicate with consumers about their diagnosis, and how to respond to and acknowledge the trajectory of the disease (Participants group discussion 1).

Benefit(s)

How people receive a diagnosis is an important part of the rest of their journey. The wording used when discussing the diagnosis and the empathy of the doctor have a direct effect on the sense of wellbeing of the consumer and carers. According to Iliffe et al., (2003) training and education for specialists through workshops (how to communicate the diagnosis to people with dementia and carers) will positively influence the healthcare journey. (Iliffe et al., 2003, Phillips et al., 2011). Therefore, it is important that GPs and healthcare professionals have the support, knowledge and training required to fulfil this role.

Allocation of 'Systems navigator'

Consumer and Carer Observation(s)

Whilst some good ideas have been implemented in this area, such as the key worker program (see https://www.fightdementia.org.au/files/NATIONAL/documents/Alzheimers-Australia-YOD-Keyworker-Brochure.pdf), the consumers and carers described the implementation as poor, with insufficient key worker FTE's across the country to support the number of consumers. According to the participants, these positions are also not always appropriately staffed in terms of skill, i.e. some keyworkers have little knowledge of dementia, or life experiences, or service knowledge (Participants group discussion 1 and 4)

Consumers and carers felt lost in the healthcare process and wanted to have support after the initial diagnosis. They did not know what to look for in terms of services, what would happen next or what needed to be organised. In one of the focus groups this was expressed as:

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

Participants felt there needed to be a service navigator role with specific skills and knowledge. The person in this role would assess the needs of consumers and their carers and recommend the best personal pathway. They would also be the first point of contact for queries and follow-up appointments. At present people have little idea of what services are available or eligibility conditions for such services (Participants group discussion 1 and 4).

Potential solution(s)

Establish a new role such as a 'Service Navigator'. As part of this role a service navigator will perform activities similar to a key worker, care coordinator or case manager. In addition a service navigator will assist with holistic wellness planning, assisting in accessing services and information, whilst problem solving and directing individual consumers in the right direction based on their individual needs. A service navigator can help with the projected care pathway. The service navigator could be someone who experienced caring for a person living with dementia themselves, in a peer-to-peer model. The position would be a paid position, not voluntary position. It could work from a centralised point or as mobile service, or both.

Benefit(s)

Using the service navigator's experiences and knowledge could help direct consumers and carers in the right direction and support them in the individual decision-making processes. This person would assist in providing information about treatment, available research and what needs to be arranged regarding financial and legal issues. He or she would be a first point of contact for questions the consumers and/or carers have. The service navigator would also develop and review a dementia wellness plan in collaboration with the consumer/carers. A mobile service for in-home contact would significantly help reduce the stress of travel for people with dementia.

Development of an ongoing 'dementia wellness plan'

Consumer and Carer Observation(s)

Consumers expressed that many feel lost in the system and often do not know which healthcare services are available for them and what they can expect of the healthcare pathway for someone living with dementia (Participant group discussion 4). Information was judged to be difficult to find and it was unclear when and if they are eligible for certain services. Many participants felt that their future was uncertain, causing anxiety with regards to their ongoing journey.

Potential solution(s)

The development of a personal 'dementia wellness plan' will assist in keeping track of all the needs/support and personal details of the consumer and carers. These will be individualised, taking into account that everybody will have a slightly different journey. However, some milestones are commonly experience and provide guidance in mapping each person's individual dementia wellness plan. According to the attendees this would facilitate a proactive approach rather than a reactive approach. The plans would be developed by the systems navigator (see previous point) with contributions from relevant specialists, allied and community health and the consumer's GP. The system navigator would periodically review and update the individual's dementia wellness plan; changes in consumer condition/circumstances would also trigger a wellness plan review/update.

This dementia wellness plan could be based on the same principles as the Royal Children's Hospital Centre for Community Child Health's 'Parents' Evaluation of Developmental Status (PEDS)' (The Royal Children's Hospital Melbourne, 2016). This is an evidence based screening tool that elicits and addresses parental concerns about children's development, health and wellbeing. PEDS is a simple, 10-item questionnaire that is completed by the parent, educators and healthcare professionals. This process is ongoing, holistic in nature, simple and user friendly requiring practitioners to score/add up concerns using a table. They are then directed to follow the appropriate pathways, which can include referrals, further screening, watching carefully, counselling parents/carers, and/or reassurance. This type of tool could be adapted to fit within the dementia wellness plan, whereby consumers and carers are able contribute information and care and services appropriate to the individual and their carer can be delivered.

Benefit(s)

The consumer-centred dementia wellness plan provides a holistic picture of consumer and carer preferences and agreements for service and care. It would be the pinnacle document containing the plan for the consumer to live well and independently with dementia and listing the support/services to be provided to the carer to ensure they remain physically and mentally fit for the carer role. The dementia wellness plan supports each individual to have choices about how they live their life.

People living with dementia experience a lot of uncertainty. Uncertainty appears to typify the experience of living with dementia. With an uncertain illness trajectory and unpredictable levels of deterioration and stability in symptoms, people with a diagnosis of dementia may live with uncertainty and anxiety and find it hard to make plans or decisions for their future. A regularly updated consumer-centred dementia wellness plan may be able to alleviate some of that uncertainty.

7. Recommendations

The focus group discussions identified many common ‘pain points’ that individuals and carers experienced during their journeys. Analysis of these items, along with input from workshop participants led to the development of an ‘ideal state’ model. This was validated with stakeholders and resulted in a storyboard that depicts the consumers’ preferences for the future relating to end-to-end lived experiences from pre-diagnosis. These models were presented at the CDPC Annual Meeting in November 2016.

The key recommendations include that:

1. Consumers and their carers want to be closely involved in research that impacts them. When reporting on this research at the Annual meeting in 2016, one of the participants publicly expressed *“…for the first time I really felt heard.”(Participant 1)*

2. Consumers and their carers want others to have a much better understanding of the experiences of people living with dementia and their carers, in terms of recognition of early symptoms, delivery of diagnosis, allocation of a systems navigator and review/update of an individual wellness plan.

3. Consumers and their carers want to be involved in identifying opportunities for improvement in current processes in order to optimise effective coordination, integration and delivery of care at the coal-face. For example, they identified: a big delay between recognition of symptoms and actual diagnosis; little coordination of care across providers; lack of knowledge and clarity of clinical pathways; and, carer support and provision of information is reactive rather than proactive.

As a result of this research, consumers and their carers are calling for a clear, individualised wellness plan informed and supported by a centralised point of care that includes an informational program that focusses on social well-being, including individual care pathways, access to services, legal advice, financial planning, end of life planning, regular monitoring of progression, peer support, health and fitness, and other items identified by the participating consumers and their carers.

Such a concept, the “**Future Care Program**”, has been proposed by Professor Fitzgerald and it is strongly recommended that further funding for ongoing development of this concept be supported by the CDPC.

8. Conclusion

To date the detailed progress and findings of this project have been socialised with a number of stakeholder groups including the CDPC directorate, the Consumer enabling sub-unit and members of the Management of Change and Workforce enabling subunit.

This project gave voice to people living with dementia and their carers regarding their lived experiences and provided an avenue to allow them to contribute to improving experiences for themselves and others. The key outcome saw participants identify a specific need for a dedicated multi-disciplinary centre of excellence where consumers and their carers can come together to receive the best up to date information and guidance to navigate through the myriad of services that are or are not available for their future care. This should be a key focus moving forward as it has direct outcomes on consumers well-being and care satisfaction and links very strongly with the vision and mission of the CDPC.

9. Appendix A – Additional Outputs

The full set of outputs are available electronically and are already included in the shared directory used by the Activity 25 team during the project. The following is an additional information flyer publicly available on the Griffith University website.

Griffith University - Business School Research Page

Available at: https://www.griffith.edu.au/business-government/griffith-business-school/departments/department-international-business-asian-studies/research/understanding-the-journey-better-an-exploration-of-the-current-state-of-play-of-the-health-care-journey-experienced-by-people-living-with-dementia-and-their-carers

Understanding the Journey Better

An exploration of the current "state of play" of the health care journey experienced by people living with dementia and their carers

In Australia, the prediction is that by 2050 more than one million people will be living with dementia (Deloitte Access Economics, 2011). To date little research has focussed on the impact of interventions on the real lives of people living with dementia and their carers.

Professor Anneke Fitzgerald and Adjunct A/Professor Joanne Curry are currently undertaking research through the Cognitive Decline Partnership Centre with regard to patient journey modelling. The objectives of this research are to:

1. Give voice to people with dementia and their carers about their individual journeys in order to understand positive and negative experiences.
2. Identify current pathways and roles for the coordination, integration and delivery of care.
3. Identify opportunities for improvement on the current processes in order to optimise effective coordination, integration and delivery of care.

Stories were collected during five two day workshops, with 24 consumers and carers, across Australia. This resulted in 18 storyboards. Patient Journey Modelling software (Essomenic) was used to visualise the stories, documenting personal experiences. Opportunities for Improvement were sought from all participants and aggregated into an "ideal state" journey.

This research resulted in a much better understanding of the experiences of people living with dementia and their carers. Several gaps were identified: there is a big delay between symptoms and actual diagnosis, there is little coordination of care across providers, knowledge and clarity of clinical pathways were largely unknown and carer support was reactive rather than proactive.

Real impact can be achieved when we know what people with dementia and their carers want. This study outlines the opportunities for improvement desired in the current healthcare journey according to those who live with dementia and their carers. Through using consumer voices, an ideal dementia pathway is being presented on a storyboard. Knowing the current state of play is a valuable baseline for creating a future state of play.

Patient Journey Modelling software (Essomenic) has been used to visualise individual stories and document personal experiences.

One of the gaps identified by the research was the substanital delay between symptoms and diagnosis.

IBAS researchers:

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