the science of knowing

Research that matters

Qualitative investigation of dementia specific ACT/SNSW HealthPathways

Final Report

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ACT/SNSW HealthPathways

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About us

The Science of Knowing Pty Ltd is a strategic insight consultancy that specialises in research, policy and evaluation. A full-service, independent company, we maintain a history of success for our clients and projects through a professional, ethical and scientific approach to our work. Our aim is to deliver research that matters, which provides tangible benefits for our clients and contributes to a fair and healthy society.

We have a strong reputation for delivering accurate, evidence-based results that are tailored to our clients' specific needs and objectives. We pride ourselves on providing easy to understand data that is reliable and accurate, helping you to make informed decisions that help to achieve your strategic objectives.

The key to successful research, policy and evaluation is reliably sourcing and understanding the correct information. Making the knowledge process easy, accurate and cost-effective truly is a science – the science of knowing…

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Executive summary

Background and context

Capital Health Network (CHN) is the PHN for the Australian Capital Territory (ACT) and COORDINARE is the PHN for the South Eastern NSW region. CHN works collaboratively with COORDINARE and ACT Health and the Southern NSW Local Health District (SNSW LHD) to implement the cross-border ACT/SNSW HealthPathways program.

The ACT/SNSW HealthPathways program is a cross-border program with four funding partners – CHN, COORDINARE, ACT Health and SNSW LHD. It is one of the few cross-border programs within the HealthPathways community in recognition of the flow of patients between the two regions. The ACT/SNSW HealthPathways program commenced in 2015 and there are now more than 650 pathways that have been localised.

There are currently 30 localised pathways related to dementia care on the ACT/SNSW HP site. CHN and COORDINARE have collaborated with local clinical editors and subject matter experts to develop the pathways and the ACT/SNSW HealthPathways team have undertaken some initial evaluation activities with dementia care clinical working groups in late 2022.

The purpose of this project was to evaluate the ACT/SNSW HP platform by examining the extent to which HP can support health professionals, with a primary focus on GPs and an expanded focus on nursing and allied health professionals in the provision of dementia care in the ACT/SNSW. Capital Health Network and COORDINARE engaged The Science of Knowing to undertake the facilitation of the discussion groups and analysis of findings.

The key objectives of the discussion groups held with GPs and nursing/allied health professionals were to:

- Understand the role/s and opportunities for HP in supporting health care professionals in the provision of dementia care
- Explore the barriers and/or challenges health care professionals and their patients living with dementia experience or have experienced in the ACT/SNSW
- Investigate the informational needs of health care professionals in the provision of dementia care in the ACT/SNSW and what tools or systems they utilise to support them
- Understand the quality and useability of the HP dementia care pathways for health care professionals
- Understand the role/s and opportunities for HP in supporting health care professionals in the provision of support for carers of people living with dementia.

Results

Summary of discussion groups

General practitioners and nursing and allied health professionals were invited by CHN and COORDINARE staff to participate in a discussion group to explore their experiences in dementia care in the ACT/SNSW and HealthPathways' role in supporting them in their work.

Four discussion groups were held between 8th and 29th April 2024, including two face-to-face workshops (one with GPs, one with nursing and allied health professionals) and two held online using Google Meet (one with GPs and one with nursing and allied health professionals). In total, 17 people participated across the four discussion groups – 10 GPs and 7 nursing and allied health professionals.

Qualitative data from the discussion groups was analysed using three main frameworks: content analysis, thematic analysis and framework analysis. Several key themes emerged from the analysis, which are discussed below.

Understanding the patient care journey

Practical challenges in delivering care

Both GPs and nursing/allied health professionals highlighted significant challenges in the diagnosis and management of dementia in primary, tertiary and community care settings. Whilst there was some disagreement about how and when dementia should be

diagnosed, this can be partially explained by the long waiting times for geriatricians across the region.

All GPs agreed that it is critical to 'rule out' other potential causes of any behavioural and/or physical changes and to provide advice to patients and their families/carers about more practical issues (e.g. legal/financial issues, accessing support, lifestyle changes, etc).

It was clear from both GPs and nurses/allied health professionals that dementia and related neurological conditions are complex medical issues requiring regular, ongoing consultations to monitor progression and/or changes in symptoms and to prepare the patient and their family for potential future challenges.

Referrals and access to services

Service accessibility and waiting times were consistently mentioned across all the discussion groups. Participants generally felt that long wait times and convoluted referral processes for specialists hindered efforts to ensure the best quality of care.

There were also several respondents who discussed the lack of availability of tertiary services, including hospital beds, and also community-based services, such as home care support and residential aged care facilities.

Psychosocial support

The degenerative and progressive nature of dementia highlighted the need for ongoing support for patients and carers/families. Both groups of participants recognised the need for building patients' and carers' understanding of the condition itself and its likely progression over time. Health professionals also encouraged both patients and carers to identify people within their support networks who could assist and gaps where they may require additional external support.

Health professionals felt that they should be patient-led in assisting patients and their families with information and resources. Unfortunately, many discussion group participants mentioned a lack of locally available community and specialist psychosocial support, particularly in regional and rural areas.

Informational needs

Patient needs

Health professionals all agreed that patients need a range of information throughout their journey with dementia, from diagnosis to ongoing management to palliative care. The types of informational needs for patients include:

- Educational information about the condition, treatment options, and likely progression trajectories
- Information about local support services and how to access them
- Information about practical issues, such as financial/legal issues, ACAT assessments, etc.
- Resources specifically for carers on how to manage at home and look after themselves
- What to do if circumstances change, such as a sudden decline in the patient's or carer's health
- Empathetic and culturally appropriate information.

GP needs

GPs generally felt that they had sufficient information themselves to effectively manage patients. However, many GPs mentioned that they would benefit from more support assisting patients and their families to access community and government support programs, especially as they typically felt that they lacked the time to adequately support patients in this regard. Further, additional support for GPs in managing the psychosocial aspects of dementia care would likely be beneficial.

Nursing/allied health professional needs

Overall, nursing and allied health professionals felt that they had access to good quality information and educational resources in relation to dementia care.

The most pressing informational need for nursing/allied health professionals that emerged from the discussion groups was information about local services (both clinical and community services). This included contact details for locally available services, as well as referral information, information on current wait times and other potential pathways if the preferred option/s weren't available.

Role of HealthPathways in dementia care

Supporting GPs

Overall, GPs had predominantly positive feedback about the HP dementia care pathways and expressed an eagerness to explore the pages in more detail in their daily practice. Most suggestions for improvements or additional inclusions to HP from GPs related to ensuring

the referral information for local services is up-to-date. Some GPs also mentioned that, while they appreciated the comprehensiveness of the information in the HP dementia pathways, they may also find it beneficial to have a short, one-two page 'cheat sheet', listing key points for each topic.

Supporting nursing/allied health professionals

This group of participants were not regular users of HealthPathways and many were not aware of it at all. However, after exploring the dementia pages briefly in the discussion groups, many participants commented on how comprehensive and useful the information seemed to be. Information about local support services and referral information was highly regarded. And, some of the participants noted that it was useful to see the information and resources GPs are accessing, as it gives them a better understanding of the types of information patients may have received and the assessments they had likely undergone.

Conclusions and recommendations

It is clear from the discussion groups that caring for patients experiencing dementia and their families/carers is complex and involves a range of healthcare professionals and services in order to deliver the best possible care at the right time and place. Achieving this involves effective communication between healthcare and other providers and a common understanding of both the optimal and the available care pathways within the local community.

Participants identified several 'pain points' in the ACT/SNSW regions, centred primarily on long wait times for specialist care and a lack of availability of support services and residential care within local communities. These issues impede the provision of best practice dementia care in the region and cause ongoing stress for healthcare professionals, patients and their families/carers.

HealthPathways has an important role to play in dementia care, particularly in supporting GPs with diagnosis and management and providing information to all healthcare professionals on referral and provider information. While GPs are typically regular users of HealthPathways, there is scope to increase awareness and usage of HealthPathways amongst other health care professionals in the region.

Based on the findings from the discussion groups and insights from existing literature, we are recommending six key actions to further develop and improve the HP dementia care pathways in the ACT/SNSW region, which are outlined below.

1. **Simplify dementia care pathways content** – Boosting accessibility and ensuring the most relevant information is easy to find
2. **Focus on referral and local services information** – This is the most used information, so ensuring its accuracy and relevancy will foster trust and usage
3. **Build awareness of HP amongst nursing and allied health professionals** – Continue engagement with this group and develop strategies to boost their awareness and usage of HealthPathways
4. **Foster LHD buy-in** – Develop a strategy for working collaboratively with LHDs to identify opportunities to embed HP in LHD operations and build staff buy-in and usage of the platform
5. **Address local pain points** – Utilise existing HealthPathways processes to create tangible system improvements that benefit both healthcare professionals and patients
6. **Develop specific strategies for regional and rural areas** - develop strategies to specifically support patients living in regional and rural areas within the broader region to address a lack of accessible and available dementia-care services.

Background and context

Primary Health Networks' objectives

Primary Health Networks (PHNs) have been established across Australia by the Australian Government, with two key objectives:

- Increasing the efficiency and effectiveness of health services for patients, particularly those at risk of poor health outcomes, and
- Improving coordination of care to ensure patients receive the right care in the right place at the right time.

PHNs' geographic boundaries are typically aligned with local health district (LHD) boundaries to assist in collaboration and integration between primary and tertiary health services.

Capital Health Network (CHN) is the PHN for the Australian Capital Territory (ACT) and COORDINARE is the PHN for the South Eastern NSW region. CHN works collaboratively with COORDINARE and ACT Health and the Southern NSW Local Health District (SNSW LHD) to implement the cross-border ACT/SNSW HealthPathways program.

The Department of Health and Aged Care also commenced the Dementia Pathways Project in conjunction with PHNs and Dementia Australia.

HealthPathways

The ACT/SNSW HealthPathways program is a cross-border program with four funding partners – CHN, COORDINARE, ACT Health and SNSW LHD. It is one of the few cross-border programs within the HealthPathways community in recognition of the flow of patients between the two regions. The ACT/SNSW HealthPathways program commenced in 2015 and there are now more than 650 pathways that have been localised.

HealthPathways (HP) is a web-based platform designed for use during a consultation to offer clinicians locally agreed information to make the right decisions, together with patients, at the point of care. Each pathway provides clear and concise guidance for assessing and managing a patient with a particular symptom or condition, and localised information to enable appropriate referrals to local services.

One of the primary objectives of HP is to reduce variations in care due to either variation in referral processes (i.e. criteria) and/or variations in how models of care are delivered by health care practitioners. For these purposes, HP provides a process by which different parts of the health system can collaborate to address these issues and support a shared approach to patient care.

HealthPathways was originally developed in Canterbury, New Zealand in partnership with Streamliners, a software company with online platforms that aim to deliver content to front-line staff. HealthPathways is now being used by organisations across New Zealand, Australia and the UK. The HP program has been implemented in all 31 PHNs across Australia, with 29 using the Streamliners platform, and two publishing their pathways via their organisational website (South Eastern Melbourne PHN and Gippsland PHN). HP generally operates as a partnership between a PHN and LHDs within their catchment.

Dementia care pathways

There are currently 30 localised pathways related to dementia care on the ACT/SNSW HP site. CHN and COORDINARE have collaborated with local clinical editors and subject matter experts to develop the pathways and the ACT/SNSW HealthPathways team have undertaken some initial evaluation activities with dementia care clinical working groups in late 2022.

The purpose of this project was to evaluate the ACT/SNSW HP platform by examining the extent to which HP can support health professionals, with a primary focus on GPs and an expanded focus on nursing and allied health professionals in the provision of dementia care in the ACT/SNSW. The project methodology built on findings from previous evaluation activities of the ACT/SNSW HP Evaluation Framework, as well as feedback from clinicians involved in the dementia care clinical working groups help in late 2022. Methods included facilitated discussion groups with both general practitioners (GPs) and nursing/allied health professionals, as well as analysis of Google Analytics data of user engagement with the dementia care pathways. Capital Health Network and COORDINARE engaged The Science of Knowing to undertake the facilitation of the discussion groups and analysis of findings.

Project objectives

The key objectives of the discussion groups held with GPs and nursing/allied health professionals were to:

- Understand the role/s and opportunities for HP in supporting health care professionals in the provision of dementia care
- Explore the barriers and/or challenges health care professionals and their patients living with dementia experience or have experienced in the ACT/SNSW
- Investigate the informational needs of health care professionals in the provision of dementia care in the ACT/SNSW and what tools or systems they utilise to support them
- Understand the quality and useability of the HP dementia care pathways for health care professionals
- Understand the role/s and opportunities for HP in supporting health care professionals in the provision of support for carers of people living with dementia.

Results

Summary of discussion groups

General practitioners and nursing and allied health professionals were invited by CHN and COORDINARE staff to participate in a discussion group to explore their experiences in dementia care in the ACT/SNSW and HealthPathways' role in supporting them in their work.

Four discussion groups were held between 8th and 29th April 2024, including two face-to-face workshops (one with GPs, one with nursing and allied health professionals) and two held online using Google Meet (one with GPs and one with nursing and allied health professionals). Discussion groups with GPs ran for approximately 2.5 hours, while groups with nursing and allied health professionals ran for approximately 1-1.5 hours.

In total, 17 people participated across the four discussion groups – 10 GPs and 7 nursing and allied health professionals. A participant list is included in Appendix A. Information sheets and a copy of the clinical scenario (GPs only) were sent out to participants prior to each group.

Qualitative data from the discussion groups was analysed using three main frameworks:

- Content analysis – which focuses on quantifying the frequency of feedback about individual themes
- Thematic analysis – identifies the key themes within the data through patterns in meaning, providing a detailed, nuanced account of participants' experiences
- Framework analysis – focuses on broader, systemic issues, which is particularly useful in policy and health research.

Common themes

The content analysis found several commonly recurring themes emerging from the feedback provided by participants in both the GP and nursing/allied health professionals groups. The most commonly mentioned themes included:

- **Challenges in diagnosis** – Both GPs and nurses/allied health professionals noted the difficulties in providing a clear diagnosis for patients and the need for specialist involvement
- **Referrals and access to specialists** – Long wait times and the need for more accessible local services are significant issues for both groups
- **Practical care management** – GPs in particular mentioned day-to-day care management for patients, including medication management and quality of life improvements
- **Psychosocial support** – Both GPs and nurses/allied health professionals highlighted the need for regular, ongoing psychosocial support for patients and carers to support them through the dementia journey
- **HealthPathways usage** – Almost all the GPs were regular users of HP and found the platform useful and credible. The platform is less well used by nursing and allied health professionals, although they almost all agreed that the information provided in HP would be useful in their respective roles
- **Suggestions for improvement with HP** - The main suggestions for improving the useability and benefits associated with HP was ensuring referral information and localised information was up-to-date and comprehensive.

The following pages provide more detail and insights about these themes and how they relate to the objectives of the evaluation, using both thematic and framework analyses.

Understanding the patient care journey

Practical challenges in delivering care

Both GPs and nursing/allied health professionals highlighted significant challenges in the diagnosis and management of dementia in primary, tertiary and community care settings. There were differences in opinions amongst both groups in how and when dementia should be diagnosed, with some health professionals believing that full diagnosis requires the input of a specialist (e.g. geriatrician) and others believing that GPs have adequate skills, resources and experience to diagnose and manage patients themselves.

A key challenge driving this disagreement was the long wait times for geriatricians, particularly in regional and rural areas. Whilst there are visiting geriatricians in some areas, wait lists are often up to six months or longer, even in metropolitan areas. Many GPs stated that they make a referral to a specialist as soon as they suspect cognitive impairment or neurological concerns, and use the wait time to initiate further investigations and gather further contextual information from family and carers.

All GPs agreed that it is critical to undertake several assessments in order to 'rule out' other potential causes of any behavioural and/or physical changes during the presenting consultation, such as hearing checks, vascular conditions, vision and other sensory issues, other neurodegenerative conditions (e.g. Huntington's chorea), and other potential contextual factors (e.g. exposure to chemicals through occupation or hobbies)

It was clear from both GPs and nurses/allied health professionals that dementia and related neurological conditions are complex medical issues requiring regular, ongoing consultations to monitor progression and/or changes in symptoms and to prepare the patient and their family for potential future challenges. For example, there were many comments about providing advice to patients and their families/carers about legal and financial issues (e.g. Enduring Power of Attorney, Advance Health Directives), accessing support (e.g. ACAT assessments, referrals to local community services, residential aged care), driving assessments, medication reviews, lifestyle changes (e.g. physical activity, nutrition, dentition, alcohol consumption, social participation) and other practical issues.

Referrals and access to services

Service accessibility and waiting times were consistently mentioned across all the discussion groups and from both participant groups. As previously highlighted, long wait times for geriatricians is a significant challenge across the region, in all geographic areas. Similarly, respondents noted the sometimes complicated and lengthy referral processes for specialist care. There was generally agreement that timely specialist input and collaboration between GPs and geriatricians resulted in a better quality and continuity of care for patients. As such, most participants felt that long wait times and convoluted referral processes for specialists hindered efforts to ensure the best quality of care.

There were also several respondents who discussed the lack of availability of tertiary services, including hospital beds and other public health services. For example, some participants stated that some patients were ending up in hospital because there weren't any local medical or community services available to assist patients in their homes. Community aged care services are often at capacity or unavailable, particularly in more remote areas of the region. Some respondents commented that patients sometimes don't have access to all the services they require through their aged care service package/program, or that their access to services may reduce once a patient moves from the Commonwealth Home Support Program to a Home Care Package. These complexities in service accessibility can make it difficult for health professionals to deliver the most appropriate care at the right time.

Finally, many respondents commented that there is limited availability of spaces in residential aged care facilities (RACFs), even in metropolitan areas like Canberra city. Patients may wait several months for a room to become available. And, some respondents commented that RACFs can be reluctant to take patients with dementia and complex needs or challenging behaviours and that they can be selective in who they accept into care due to the high level of demand.

Overall, both GPs and nursing/allied health professionals agreed that a lack of timely clinical and community services impacted on the timely delivery of comprehensive care

Psychosocial support

The degenerative and progressive nature of dementia highlighted the need for ongoing support for patients and carers/families. Both groups of participants recognised the need for building patients' and carers' understanding of the condition itself and its likely progression over time. Health professionals also encouraged both patients and carers to identify people within their support networks who could assist and gaps where they may require additional external support.

All participants agreed that health professionals need to be patient-led in assisting patients and their families with information and resources. Patients will vary in their acceptance of the condition and their readiness for education and resources will likely change over time. Many participants stated that health professionals need to respect patients' current state of readiness and provide ongoing support over time, involving family members and support networks as much as possible. Empathic communication and connecting with patients and their families/carers was seen as critical to delivering quality care.

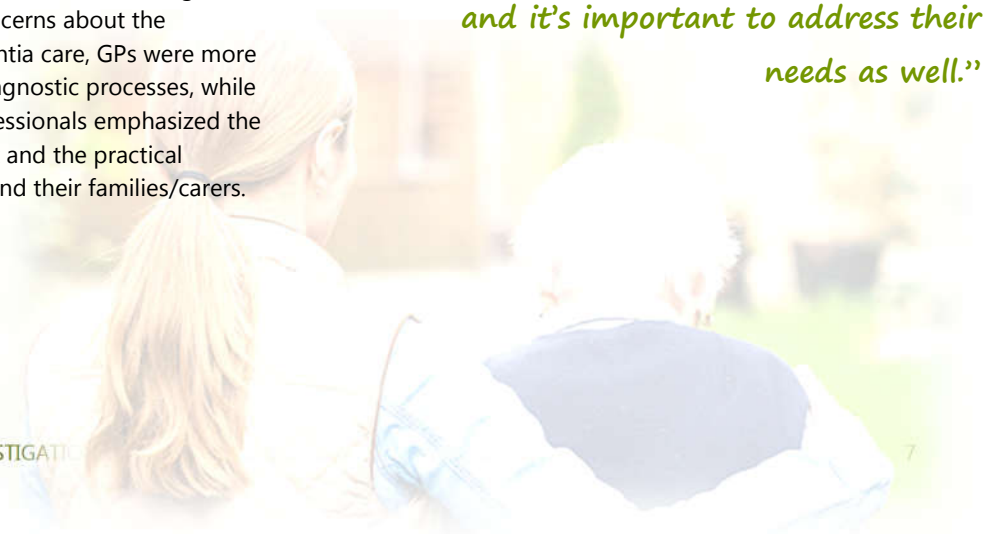
One participant was a social worker operating within a general practice context, as part of a pilot program in the region. This program was widely supported by other participants as being able to provide more comprehensive psychosocial support in collaboration with medical care. This type of program is also able to link patients into other types of psychosocial support services, such as peer support groups.

Unfortunately, many discussion group participants mentioned a lack of locally available community and specialist psychosocial support, particularly in regional and rural areas. And, while both GPs and nursing/allied health professionals share concerns about the psychosocial aspects of dementia care, GPs were more focused on the clinical and diagnostic processes, while nursing and allied health professionals emphasized the importance of holistic support and the practical challenges faced by patients and their families/carers.

"Dementia care isn't just about managing medical symptoms; it's about helping patients maintain their daily activities and quality of life. This requires continuous adjustments and a lot of coordination with other healthcare providers."

"We try to provide as much psychosocial support as we can, but our resources are limited. Referring patients to support groups and psychologists is crucial, but these services are also stretched thin."

"Families often need just as much support as the patients. They are dealing with a lot of emotional stress, and it's important to address their needs as well."



Informational needs

Discussion group participants provided substantial information about informational needs for managing patients with dementia, for patients, families/carers and themselves as health care professionals. They also provided insights into how and where they access locally relevant information.

Patient needs

Health professionals all agreed that patients need a range of information throughout their journey with dementia, from diagnosis to ongoing management to palliative care. As already discussed, when and how to provide patients with information and resources should be cognisant of patients/carers' readiness to receive and absorb new information. A dementia diagnosis is an emotional and challenging time, so health professionals need to be respectful of patients' and their families' wishes. Nonetheless, patients and their carers are often eager to learn more and find support. The types of informational needs for patients include:

- Educational information about the condition, treatment options, and likely progression trajectories, written in easy-to-understand language
- Information about local support services and how to access them
- Information about financial, legal and other practical issues, such as ACAT assessments, EPOAs, ACPs, financial planning, etc.
- Resources specifically for carers on how to manage at home and look after themselves
- What to do if circumstances change, such as a sudden decline in the patient's or carer's health
- Empathetic and culturally appropriate information about disease progression, palliative care and death planning.

Several participants (GPs and nursing/allied health professionals) mentioned Dementia Australia, Carers Australia and the Alzheimer's Association as key sources of information for patients and their families. A few participants mentioned using the patient resource released by Capital Health Network with information and contact details for local support services.

GP needs

GPs generally felt that they had sufficient information themselves to effectively manage patients. They stated that they had access to new research and clinical information that enabled them to provide the most appropriate care and that they could contact specialist colleagues for additional information, if required.

However, many GPs mentioned that they would benefit from more support assisting patients and their families to access community and government support programs, especially as they typically felt that they lacked the time to adequately support patients in this regard. GPs tended to rely on their existing local contacts (e.g. relationships with local specialists and community services) for information. It was clear that GPs generally have the goal of providing patients with high quality healthcare and empathetic support, but their schedules sometimes prevented them being able to do this as well as they would like. As such, additional support for GPs in managing the psychosocial aspects of dementia care would likely be beneficial.

Nursing and allied health professional needs

Overall, nursing and allied health professionals felt that they had access to good quality information and educational resources in relation to dementia care. Many had close relationships with specialists, GPs or other clinical health professionals who they could consult if they needed further information. Collaborative and multidisciplinary care teams were seen as effective tools for learning and knowledge-sharing, particularly when dealing with the complexities of dementia care. Some respondents also had relationships with research institutions, which allowed them to contribute to research projects and access novel and up-to-date information about dementia management.

The most pressing informational need for nursing/allied health professionals that emerged from the discussion groups was information about local services (both clinical and community services). This included contact details for locally available services, as well as referral information, information on current wait times and other potential pathways if the preferred option/s weren't available.

Role of HealthPathways in dementia care

Supporting GPs

Most GPs involved in the discussion groups were regular users of HP and many stated that they open the platform at the start of the day and keep it open all day. They trust the quality of the information available in HP and find the platform useful in their daily practice.

A review of the dementia care pathways on HP during the discussion groups showed that GPs feel the information provided in the pathways is comprehensive and clinically accurate and useful. It was clear that not all GPs had accessed or utilised all of the available pages and were impressed with the level of detail provided. Many GPs stated that they would typically use HP either after a consultation with a patient to double-check that they hadn't forgotten any assessments or tests needed, or in preparation for an upcoming consultation. The driving assessment pathway page was specifically mentioned as being particularly useful for GPs, as this is typically a difficult conversation with patients and they valued the additional information and support provided in the pathway.

Most suggestions for improvements or additional inclusions to HP from GPs related to ensuring the referral information for local services is up-to-date. There were some concerns that some listed services were no longer available or had long wait times, while some other services (e.g. public health services) were not listed. Some GPs also mentioned that, while they appreciated the comprehensiveness of the information in the HP dementia pathways, they may also find it beneficial to have a short, one-two page 'cheat sheet', listing key points for each topic.

Overall, GPs had predominantly positive feedback about the HP dementia care pathways and expressed an eagerness to explore the pages in more detail in their daily practice.

Supporting nursing and allied health professionals

The participants in this group covered several different professions, including nursing in several different contexts (e.g. hospital, specialist, RACF, care coordination), speech pathology and social work. Some of the participants had never heard of or used HP, while others had heard of it, but were not users of the platform. None of this group were regular users of HP. Some participants mentioned the need for more training in HP and how to use it effectively. HealthPathways was seen as a tool with a lot of potential, but not currently being used to its full potential.

However, after reviewing the dementia care pathways in HP during the discussion groups, many participants commented on how comprehensive and useful the information seemed to be. Information about local support services and referral information was highly regarded. And, some of the participants noted that it was useful to see the information and resources GPs are accessing, as it gives them a better understanding of the types of information patients may have received and the assessments they had likely undergone.

Several participants said that they would access HP after the discussion group to have a closer look. The main suggestions for HP were to ensure that the local service and referral information was up-to-date and they said it would be useful if wait times for specialists and other services were listed. Some participants also commented that it might be beneficial for the patient resources to be listed closer to the top of the pages, rather than at the bottom, so they could access it more easily.

Follow-up survey

Discussion group participants were sent a short follow-up survey about two weeks after their group. The survey asked their HP usage after the group and some questions about their opinions about HP's quality and usefulness. Approximately half of the group participants responded to the survey (8 out of 17 participants), including 5 GPs and 3 nursing/allied health professionals.

Almost all of the GPs had accessed HP since the discussion group, primarily because they are regular users of HP already and used it for accessing both information about the dementia care pathways, as well as other pathways, as required in their practice. The nursing and allied health professionals were more likely to have been prompted to access HP by the discussion group itself and they tended to review the dementia pathways more specifically.

Opinions about HP were very high, with all respondents either 'somewhat agreeing' or 'strongly agreeing' with all the opinion questions. This included questions about the usefulness of different sections of the dementia care pathways (e.g. assessment, management, referral), the inclusiveness, comprehensiveness, relevance, credibility, and user-friendliness of the dementia care pathways.

Open-ended comments supported these findings, with positive comments about the usefulness of the information provided. Suggestions included providing a comprehensive summary of the pathways (as previously mentioned in the discussion groups), improving the functionality of the search tool to allow refinement into categories, and continuing public education and discussion about HP.

"I find HealthPathways useful for getting an overview of management protocols, but it could be improved by including more specific case examples and links to local resources"

"Making HealthPathways more user-friendly and accessible, especially for those not as tech-savvy, would be a significant improvement. More training on how to effectively use the platform would also be beneficial."

Conclusions and recommendations

It is clear from the discussion groups with both GPs and nursing/allied health professionals that caring for patients experiencing dementia and their families/carers is complex and involves a range of healthcare professionals and services in order to deliver the best possible care at the right time and place. Both GPs and nursing/allied health professionals in all contexts are eager and committed to providing patients with comprehensive care that enables them and their families/carers to have a high quality of life during a very challenging time in their lives. Achieving this involves effective communication between healthcare and other providers and a common understanding of both the optimal and the available care pathways within the local community.

Participants identified several 'pain points' within dementia care pathways in the ACT/SNSW regions, centred primarily on long wait times for specialist care and a lack of availability of support services and residential care within local communities. These issues impede the provision of best practice dementia care in the region and cause ongoing stress for healthcare professionals, patients and their families/carers.

The discussion groups highlighted that, in general, GPs in the ACT/SNSW region are aware of and typically regular users of HP in their daily practice. They trust the information provided in HP and use it regularly in consultations and as a 'check' either before or after patient visits. Further, they believe HP is credible, relevant and useful in their daily practice. This is supported by HP research in other regions.

However, awareness and use of HP is generally low amongst other health professional groups, with many participants being unaware of HP's existence and/or unsure how it might be useful in their practice. But, once nursing and allied health professionals were introduced to HP, they could often see great value in the information provided.

Based on the findings from the discussion groups and insights from existing literature, we are recommending six key actions to further develop and improve the HP dementia care pathways in the ACT/SNSW region, which are outlined below.

Simplify dementia care pathways content

The content available in the dementia care pathways was generally viewed as credible, comprehensive and high quality. Nonetheless, several group participants stated that it would be beneficial to have some simplified content available, such as a checklist or summarised information, which could be used by GPs in consultations in daily practice or by other healthcare professionals. However, there are some clinical risks associated with simplifying content, which should be thoroughly investigated prior to implementing this.

Many participants also highlighted simple ways that the dementia care pathways could be more user-friendly, such as pinning patient resources at the top of each page so that they are easily accessible. Exploring Google Analytics and web data, where available, to understand the content that is being used most and when will assist in ensuring the pathways are as user-friendly and relevant as possible.

Developing and rearranging the content should be undertaken in collaboration with a range of healthcare professionals to ensure it meets the needs of different audiences.

Focus on referral and local services information

Information about referral pathways and local service availability was consistently mentioned as being the most needed and potentially useful information for all types of healthcare providers. However, there were some comments that users trust the accuracy and/or completeness of this information less than other clinical information available on HP. As such, prioritising this content to ensure it is comprehensive and up-to-date would be beneficial. In addition to utilising updates from the HP feedback facility, it may also be worth establishing a small group of health care professionals

(including GPs, specialists, LHD staff, AH professionals, community nurses/providers) who are familiar and engaged within the local community and knowledgeable about dementia care, who can be consulted regularly (e.g. quarterly) to provide updates on operating services and availability.

Build awareness of HP amongst nursing and allied health professionals

The discussion groups provided ample evidence that nursing and allied health professionals in a variety of contexts (e.g. LHD, community-based providers, RACFs) would find the information and resources available in HP valuable in their practice and within their scope of work in dementia care. The ACT/SNSW HealthPathways program should continue engaging with a range of healthcare professionals to build awareness and usage of HP amongst these healthcare professionals. Education and training opportunities (both face-to-face and online) to educate new users of how to use HP and how it could benefit their practice is recommended. New users should also be encouraged to provide regular feedback on the pathways as part of the platform's continuous improvement process.

Foster LHD buy-in

In most PHN regions across Australia (including in the ACT/SNSW regions), HP is jointly funded by PHNs and LHDs. In some regions, the LHD (or equivalent) is heavily involved in the strategic direction and implementation of HP within the health system, with HP being embedded within LHD programs and services and staff playing an active role in pathway development. Preliminary evidence from these regions suggests that a high level of buy-in at all levels of the LHD may maximise the chance that HP will achieve its potential and have the greatest positive impact on the local health system. HealthPathways' processes, such as work groups and content development, have the potential to improve system flow and reduce pain points by improving referral quality, increasing collaboration and communication between healthcare professionals operating at different levels of the health system and reducing wait times.

Findings from discussion groups in ACT/SNSW suggest that, currently, ACT Health and the SNSW LHD programs operating in the dementia care space are not actively using HP in their practice. One participant commented that the LHD typically has its own ways of doing things, including patient resources, clinical practices, etc and was unsure if other LHD staff use HP in dementia care. This suggests that HP is not embedded in LHD practices, which may limit its ability to contribute to health system reform outcomes.

It is recommended that Capital Health Network and COORDINARE develop a joint strategy for working more collaboratively with their respective LHDs to identify opportunities to embed HP in LHD operations and build staff buy-in and usage of the platform. For this to be successful, LHD staff at all levels will need to understand the potential benefits of HP for them, their staff and their patients.

Address local pain points

As already mentioned, discussion group participants highlighted several 'pain points' in the local region in dementia care. It is recommended that the four program partners of the ACT/SNSW HealthPathways program (Capital Health Network, COORDINARE, ACT Health and the SNSW LHD) undertake further exploration of these issues and utilise HP workshopping processes to identify potential strategies to address them through improved service pathways. As the most critical issue identified was wait times for specialists and a lack of availability of local support services, it will be critical to include specialists and representatives from local community services in these workshops.

Addressing local pain points may not necessarily require the introduction of new programs. An example of a possible strategy to address the need for timely psychosocial support for dementia patients and their families which was mentioned in the discussion groups was the Social Workers in General Practice Pilot Program, which is currently commissioned by the CHN in the ACT. This program was highlighted as being an effective way to deliver responsive psychosocial support for dementia patients, while also improving communication between healthcare professionals.

One of the key strengths of the HP program is its ability to pull together professionals from a range of backgrounds and expertise and harness their knowledge and skills to review and improve service pathways in local regions. This type of collaborative work has the potential to create tangible system improvements that benefit healthcare professionals and patients alike.

Develop specific strategies for regional and rural areas

Several discussion group participants talked about the differences between metropolitan and regional/rural areas in terms of service availability and accessibility for patients experiencing dementia. And, although there are region-wide issues related to specialist wait times, RACF availability, etc, it is clear that people living in regional/rural areas have far fewer care options and are often left under-serviced for long periods of time, resulting in poorer health outcomes and lower quality of life than their metropolitan counterparts.

It is recommended that the ACT/SNSW HealthPathways program and funding partners work collaboratively to develop strategies to specifically support patients living in regional and rural areas within the broader region. A working group involving healthcare professionals and providers operating within these regions and including input from specialists (i.e. geriatricians) from across the region would assist in identifying possible options for reducing barriers to optimal care for families living in these areas.

Appendices

Appendix A: Participant List

Occupation	Region
General practitioner	ACT
General practitioner	SNSW
General practitioner	ACT
General practitioner	SNSW
General practitioner	ACT
General practitioner	ACT
General practitioner	ACT
General practitioner	ACT
General practitioner	ACT
General practitioner	ACT
General practitioner	ACT
Speech pathologist	ACT
Senior and Aged Care Project Coordinator	SNSW
Senior and Aged Care Project Coordinator	SNSW
Aged care nurse	SNSW
Clinical Nurse Specialist	SNSW
Social Worker	ACT
Clinical Nurse Consultant	ACT

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