

The background of the slide is a large, circular image. It shows an elderly woman with white hair and a young woman with brown hair. They are both looking down at something in their hands, which appears to be colorful, interlocking blocks or toys. The image is partially obscured by a dark blue circular graphic element that frames the text.

Enhancing The Dementia Care Pathway:

**Northamptonshire 'Sprint'
Outputs**



Contents

Foreword	2
Attendees	3
Executive summary	4
Introduction	6
Methodology	8
Session One: Treatment and Care Pathways Within the 65 and Under Persona	9
Session Two: Treatment and Care Pathways Within 65 and Over Persona	10
How to Advance Existing Care Pathways: Change	12
Six Stages of the Northamptonshire UEC Model: Enhanced model	14
Conclusion	16
About Us	17

Foreword

One year on from the publication of the Dementia Commission's 2023 Report, the country still faces large variations in dementia diagnosis, exacerbated by unprecedented resource constraints across the NHS. Despite this, the last twelve months have seen progress in dementia care and we now understand more than ever the challenge that faces the country. We remain optimistic about the future of dementia care.

A sprint roundtable, organised in Northamptonshire by independent policy institute, Curia, in summer 2024 looked to solutions to improve the task that faces NHS commissioners, patients, carers and clinicians. By exploring the existing care pathways, and collaborating on ways to enhance it, this sprint roundtable was able to fully depict the scale of the mission. We learned from system leaders alike on how to think about next steps for the future of building effective dementia care pathways.

This report details a change management plan for enhancing dementia care pathways for integrated care systems (ICS) across the country. The main focus of this proposed care management plan is on recognising the early onset signs of dementia, encouraging the role of early intervention and improving the ability of patients to live well with dementia.

The plan looks to build on the current model that exists in Northamptonshire. Attendees at the roundtable sought to answer the question of how the existing national care pathways – delivered at a local level – could be enhanced. Borrowing lessons from Northamptonshire, this plan sets out how this pathway could be applied in ICSs across the country. Enhancing the model will help ensure diagnosis rates of early dementia improve, a crucial step as the population continues to age and become more at risk of the disease.

The focus of the event was to explore the dementia care pathways for two different groups of patients: those under the age of 65; and those over the age of 65. Different proposals to amend the dementia care management plan were proposed depending on the group being discussed, and findings showed that the early onset age group needed more targeted support and interventions to help them in their journey on the dementia care pathway.

As Curia's sprint progressed, it was agreed that the current dementia care pathway model does work in practice, but enhancements could still be made, in some instances across the country. Crucially, attendees identified that the current care pathway is missing a fundamental step – early intervention. Traditionally, the care pathway for dementia starts when a patient or family member suspects dementia symptoms, yet the change management plan advocates for an earlier step that could help identify the warning signs of dementia so that patients can be supported appropriately at an earlier stage.

Sprint attendees championed a smoother care pathway, one that is streamlined, simpler to navigate and enables earlier diagnosis. By getting patients faster access to a memory assessment service, they can receive their diagnosis quicker and also eliminate the burden of what can be a time-consuming process to secure a GP appointment, which still leads to the same assessment. Bypassing primary care in such instances can remove an unnecessary element of the pathway.

The plan ends with suggestions for ways in which dementia pathways across the country can be enhanced to support patients, families, and carers once a diagnosis has been made. Additional care should be directed to these groups so that they feel empowered and assisted to live well with dementia. This is particularly prevalent for those who are younger when they receive their diagnosis, and the role of employers in these instances should be adjusted to bring about a much-needed transformation in the way the workplace supports and recognises dementia.

We encourage NHS leaders, commissioners, and clinicians to use this change management plan as a guiding tool to improve the performance of dementia services and dementia diagnosis within your ICS. Thank you to those who participated in the sprint roundtable, particularly Northamptonshire carers for working in collaboration with the group to come up with new solutions.



**Lord James O'Shaughnessy
and Professor Gillian Leng CBE
Advisers of the Health Care and
Life Sciences Research Group**



Attendees

Name	Job Title	Company
Lord James	Research Group Advisor	Curia UK Health, Care and Life Sciences Research Group
Professor Gillian Leng CBE	President	Royal Society of Medicine
Ben Howlett	CEO	Curia UK
Mark Major	CEO	Northamptonshire Carers
Dawn Panter	Assistant Director	Northamptonshire Carers
Gwyn Roberts	Population Health Programme Manager	Northamptonshire ICB
Adam Townsend	COO	Vuit
Dr Hilda Hayo	Chief Admiral Nurse and CEO	Dementia UK
Alison Clowes	Local System Influencing Manager	Alzheimer's Society
Rob Hasker	Local Services Manager	Alzheimer's Society
Dr Alison Ward	Associate Professor	University of Northampton
Melanie Gray	Head of Strategic Commissioning and Contracts	North Northamptonshire Council
Professor Jacqueline Parkes	Professor	University of Northampton
Louise Birkett-Swan	Psychology Lead for Dementia and Older People	Northamptonshire Healthcare Foundation Trust
Olatomide Fadipe	Local Systems Influencing Officer	Alzheimer's Society
Howard Feng	Co-founder	Med Frontier UK
Shui Liu	Co-founder	Med Frontier UK
Amey Carrington	Senior Day Care and Transport Co-ordinator	Age UK Northamptonshire
Mandy Staples	Director of Nursing	NHS Northamptonshire
Paul Birch	AD Population Health and Health Intelligence	NHS Northamptonshire
Gimmi Shrestha	Junior Clinical Fellow Bank	Northampton General Hospital
Jennifer Kerti	Manager Young People with Dementia Team	Northamptonshire Healthcare NHS Foundation Trust
Gabby Rapp	Research Assistant	Curia UK



Attendees at the Northamptonshire Dementia Sprint.

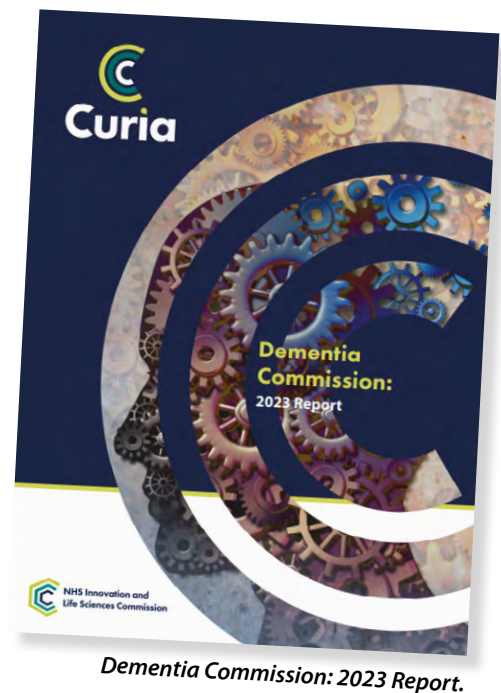
Executive summary

Curia delivered a sprint roundtable designed to put patients and clinicians at the heart of enhancing dementia care pathways. The discussion focused on the current model in Northamptonshire. The plan is designed to enable those involved in the commissioning and delivery of dementia support to use this thinking to improve care delivery and enhance this in a way that benefits and improves the outcomes of patients, at a national level. Last year, the Dementia Commission, co-chaired by Lord James O'Shaughnessy and Professor Mike Bewick, set out its vision for dementia care in its *Dementia Commission: 2023 Report*. The report reflected on what dementia care should look like for the next ten years and agreed that the following five components were crucial to allow those with dementia to live long, healthy lives. These five components are

- **Accurate Diagnostics:** simple, non-invasive, cost-effective diagnostic options effective prior to the onset of symptoms
- **Therapeutic Choices:** a range of treatment options that can prevent or reverse the effects of dementia
- **Personalised Care:** tailored not only to an individual's circumstances but also their phenotype and genotype
- **Holistic Approach:** offering not only appropriate medical interventions, but also addressing the social, emotional, and psychological needs of the individual, their families, and their carers
- **Supportive Environment:** dementia-friendly communities that reduce stigma and promote inclusivity

As a way of delivering upon these five components, the 2023 *report* detailed, in part, the need to seek a new vision for dementia care pathways. Specifically, it highlighted that current treatment and care pathways in dementia are not fit for the purpose of treating dementia patients with respect and dignity. Specifically, the report noted that dementia care pathways needed to be transformed to involve patients and their carers in decision-making, and that by leveraging the social care workforce, integrating health and social services, and exploring technology-driven care solutions, could enhance the overall quality of care and make the journey more patient-centric.

One key output from last year's report was the Commission's commitment to work with stakeholders – through a roundtable sprint meeting facilitated by the commissioners – to model new care pathways to ensure patients are at the heart of the care pathway. One year on from the publication of the Commission's initial *Dementia Report*, this paper provides detail on the outputs from the sprint roundtable, which brought together senior figures in the dementia and health and care sector – including patient groups, clinicians, commissioners, strategy leaders, policymakers, and innovation experts – to think through an innovative approach to redesigning and enhancing the pathway. Attendees at the sprint roundtable were tasked to produce, by the end of the session, a fully mapped care pathway for a dementia patient that models the recommendations of the Dementia Commission into a change management plan.



Key strategies were:

1. Earlier intervention:

- Identifying the risk factors of dementia at an earlier stage, using place-based approaches.
- Introduction of public health awareness campaigns about early symptoms of dementia.
- Education of clinicians and health workers on identifying the early onset symptoms of dementia.

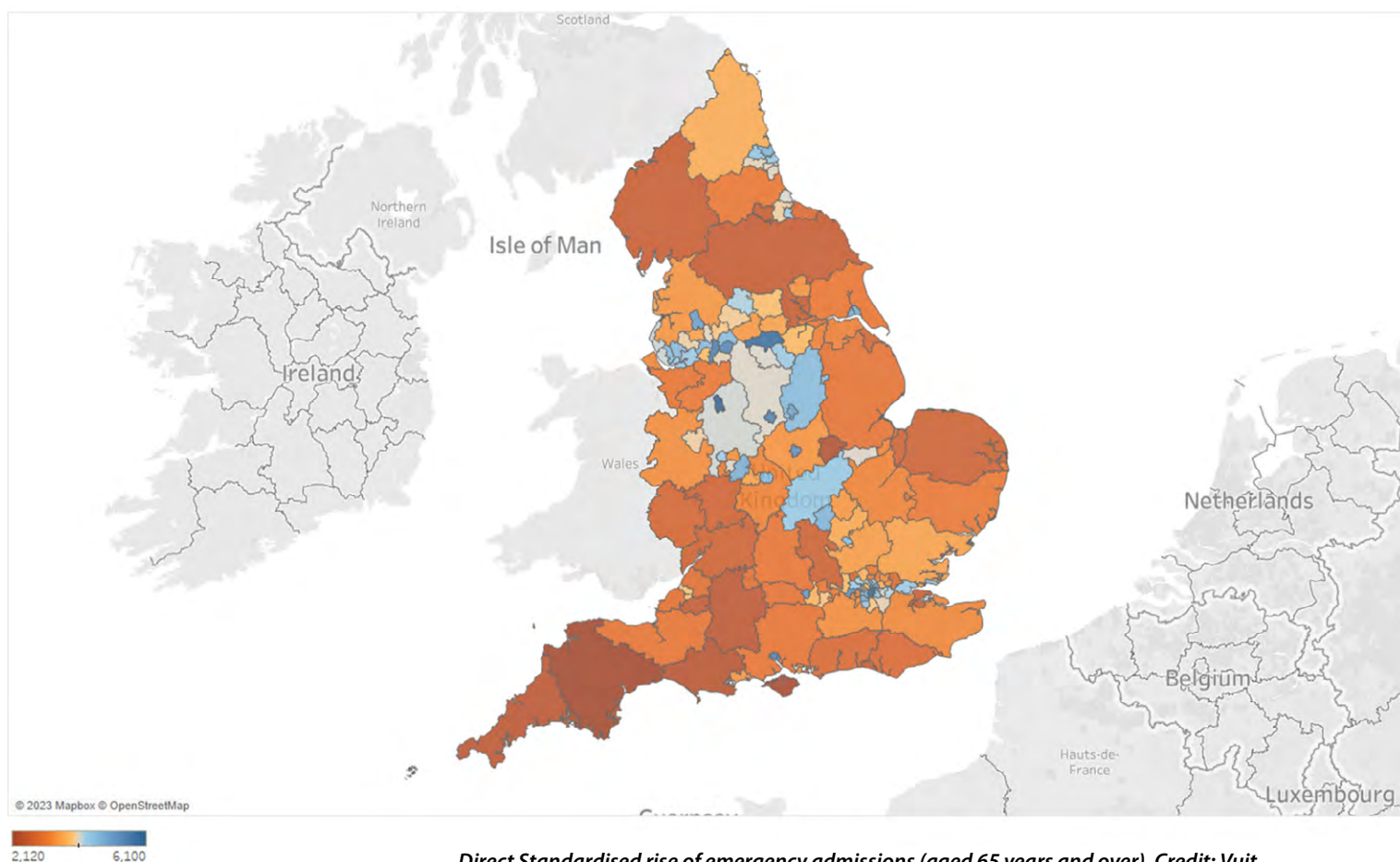
2. Improved referral routes

- Direct referrals to a memory assessment service, rather than the need to be referred by a GP, would improve access times to getting a dementia assessment.
- The current pathway is time-consuming, and it can take a long time to secure a GP appointment.
- Patients will be able to access supportive care in a quicker time frame.

3. Living well with dementia

- More support is needed for those with early onset dementia, including occupational health support.
- Employment rights with regard to a dementia diagnosis need to be better signposted.
- Families should be provided with more information on how to support loved ones following a dementia diagnosis.

Local Authority Map of Dementia: Direct standardised rate of emergency admissions (aged 65 years and over)



Introduction

There are currently an estimated 982,000 people living with dementia in the UK, and this figure is predicted to rise to over 1.4 million by 2040.¹ With dementia more prevalent in those age 65+, and with the number of people in Northamptonshire over the age of 65 continuing to increase faster than the rest of the population in the UK, there is a real need to understand what can be done for the elderly population in this region who are much more likely to see higher incidence rates of dementia. This is coupled with the fact that Northamptonshire is experiencing unwarranted under-diagnosis in dementia – which can lead to increased diagnoses at the emergency care level, as opposed to diagnosis through primary care, and is putting pressure on the health system in the Northamptonshire ICB area.

1 <https://www.alzheimers.org.uk/about-us/policy-and-influencing/local-dementia-statistics>

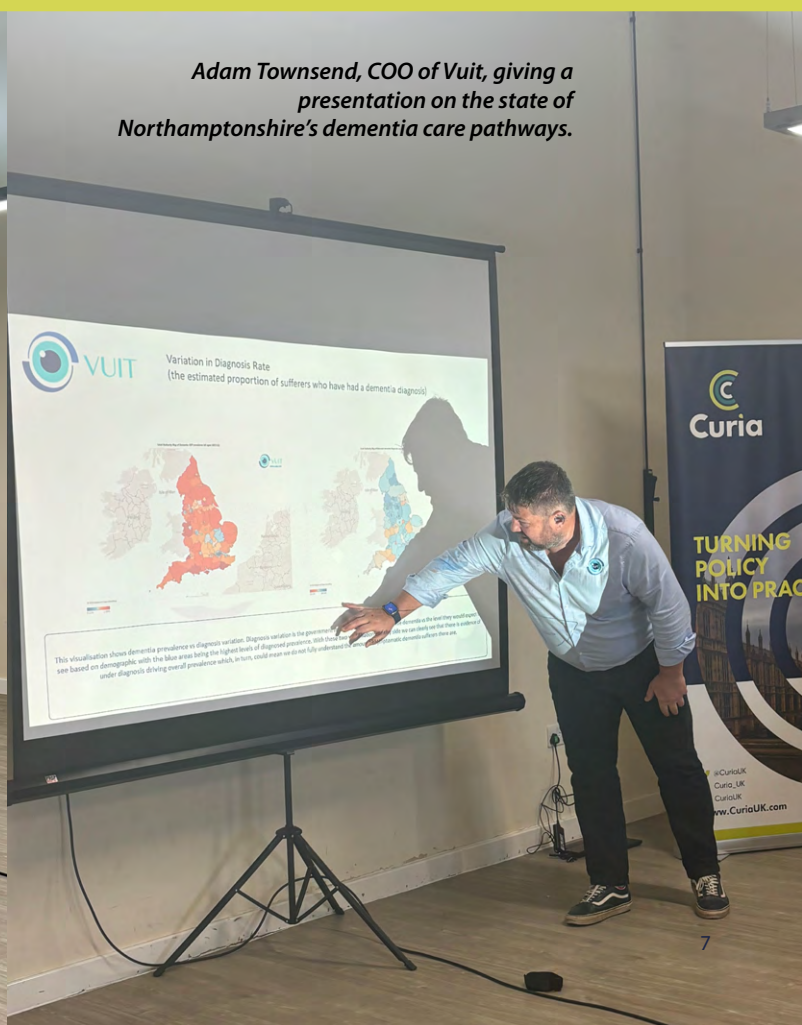
For the first part of the session, the group heard from the CEO of Northamptonshire Carers, Mark Major, and Co-Founder and COO of Vuit, Adam Townsend, on the state of dementia care within Northamptonshire and what has worked locally in delivering care for patients with dementia.

It is clear from the attendees that there is an opportunity in Northamptonshire through the new community diagnostic centres to improve dementia diagnosis, with the ICB being very determined in its ambitions to scale up. It's not just a local challenge, but a national one; with huge variability in dementia diagnosis rates at the local level, this requires national support to improve primary care practices to diagnose early onset dementia better.

Higher undiagnosed dementia prevalence combined with a higher age cohort has a consequential effect on emergency care in the region. The experience from Northamptonshire shows that many patients are attending emergency care undiagnosed with dementia, which is not the right place to support them. Attendees highlighted the need to utilise data with higher accuracy to better understand how to achieve improved outcomes for a larger amount of people by deploying resources in a targeted way. Additionally, there is a need to support communities to be aware of the risk of dementia.



Gwyn Roberts presenting the current ICB care model in Northamptonshire.



Adam Townsend, COO of Vuit, giving a presentation on the state of Northamptonshire's dementia care pathways.



Attendees of the Northamptonshire Sprint taking part in brainstorming sessions on how to enhance the existing care pathways.

Methodology

Attendees took part in two evidence-gathering sessions. The morning session focused on the 65 and under dementia group, which was held by the Northamptonshire Carers. Attendees were then introduced to the concept of the sprint, which sought to highlight the importance of a behavioural shift in transforming public services and care pathway planning. Participants were split into two groups to discuss how best to deliver the Commission recommendations in the context of a new/reformed dementia care pathway, with two different personas. These two groups were

1. 65 and Under with Dementia
2. 65 and Over with Dementia

These groups were selected due to the fact that they are likely to experience different traits for the same condition. Those 65 and under, within the 'young persona', may be diagnosed with depression and/or anxiety, be experiencing menopause, be aged between 30–50, be in a working environment, and/or have a young family. Oppositely, those aged 65 and over, with an 'older persona', may be experiencing memory problems ahead of diagnosis that are conflated with being elderly, may be experiencing delirium, and could be dependent on their partner for daily tasks.

Groups considered and developed innovative solutions to the current care pathway in Northamptonshire and how to establish ways to enhance the current operation, as well as agree and align on the most impactful solutions to do this. These breakout groups were specifically designed to brainstorm innovative ideas for advancing the care pathway.

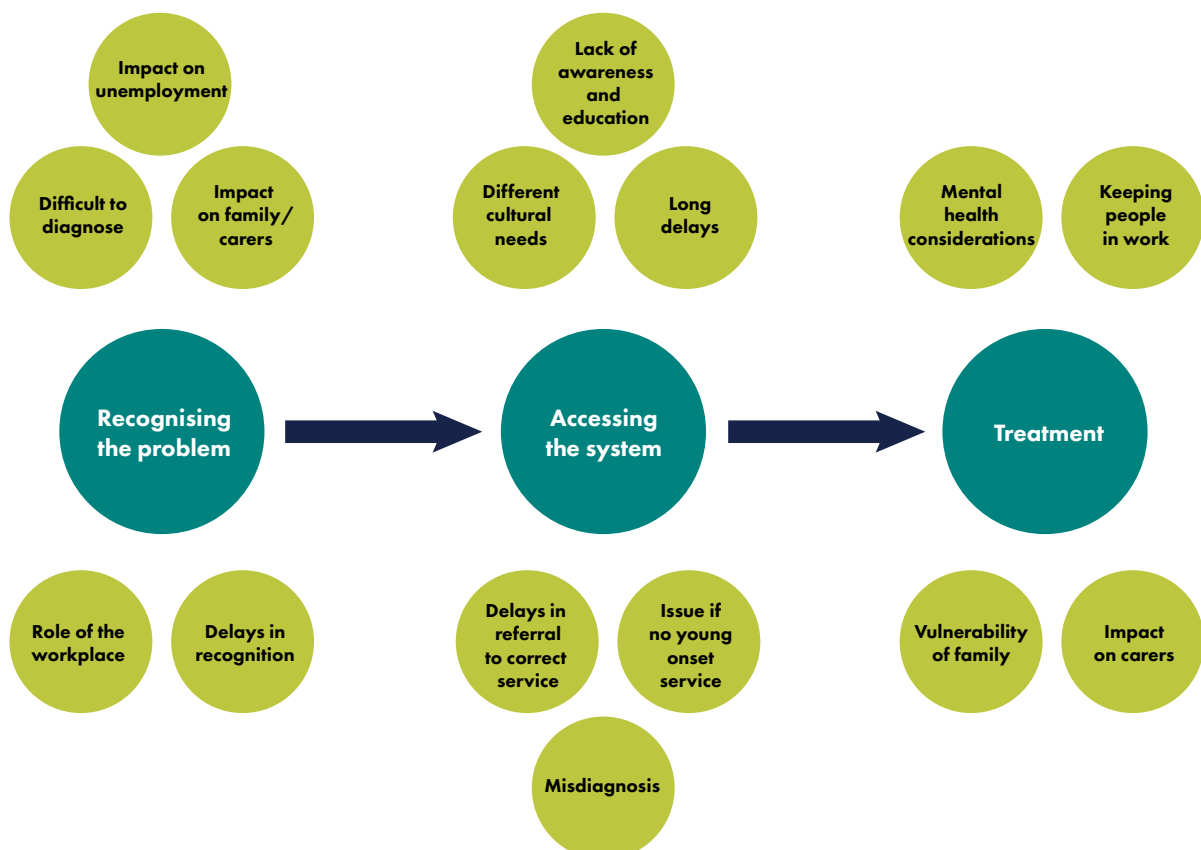
Following these sessions, the groups came together for the second evidence-gathering session, focusing on the 65 and Older Person Dementia Group. This group thought about how to enhance the current care pathway model. This was followed by the designing and creating of an action plan for immediate implementation, bringing the two groups together to produce a single implementation plan for each of the two personas.

Session One: Treatment and Care Pathways Within the 65 and Under Persona

Within those aged 65 and under, there are often long delays in recognising and diagnosing early onset dementia. There is frequently a lengthy delay in the GP referring a patient to the young onset service, and attendees agreed that it is much more difficult to diagnose those under the age of 65, compared with those who are older.

There are several key barriers within the treatment and care pathway for those under the age of 65. Discussion focused on the lack of education and awareness. Specifically, there is a lack of education amongst GPs to recognise the signs of early onset dementia as most GP training focuses on dementia diagnosis in later, older years. Patients often experience inappropriate treatments for their condition because they are being misdiagnosed for something else. Additionally, there is a lack of awareness of early onset dementia, not just in clinical settings but also in settings that would likely be more familiar to those of a younger age group, including families, carers, and the workplace. Indeed, those who are younger and experiencing early onset symptoms are more likely to be working and are therefore likely to experience their symptoms whilst at work. Attendees acknowledged that there is a lack of awareness in the workplace for those who are experiencing early onset symptoms. Moreover, for this cohort, the individual may experience difficulties holding down a job whilst facing dementia symptoms, and this can put financial pressure on families. Finally, an additional challenge related to this cohort is that those who have early onset dementia are much less likely than an older group to have others their own age who understand the condition, which results in a lack of help and understanding from their natural support group. Mental health concerns are more likely to be felt more acutely within this cohort.

Patient pathway under 65





Attendees taking part in evidence gathering at the 65 and over afternoon session whilst they partake in 'throw the hoop.'

Session Two: Treatment and Care Pathways Within 65 and Over Persona

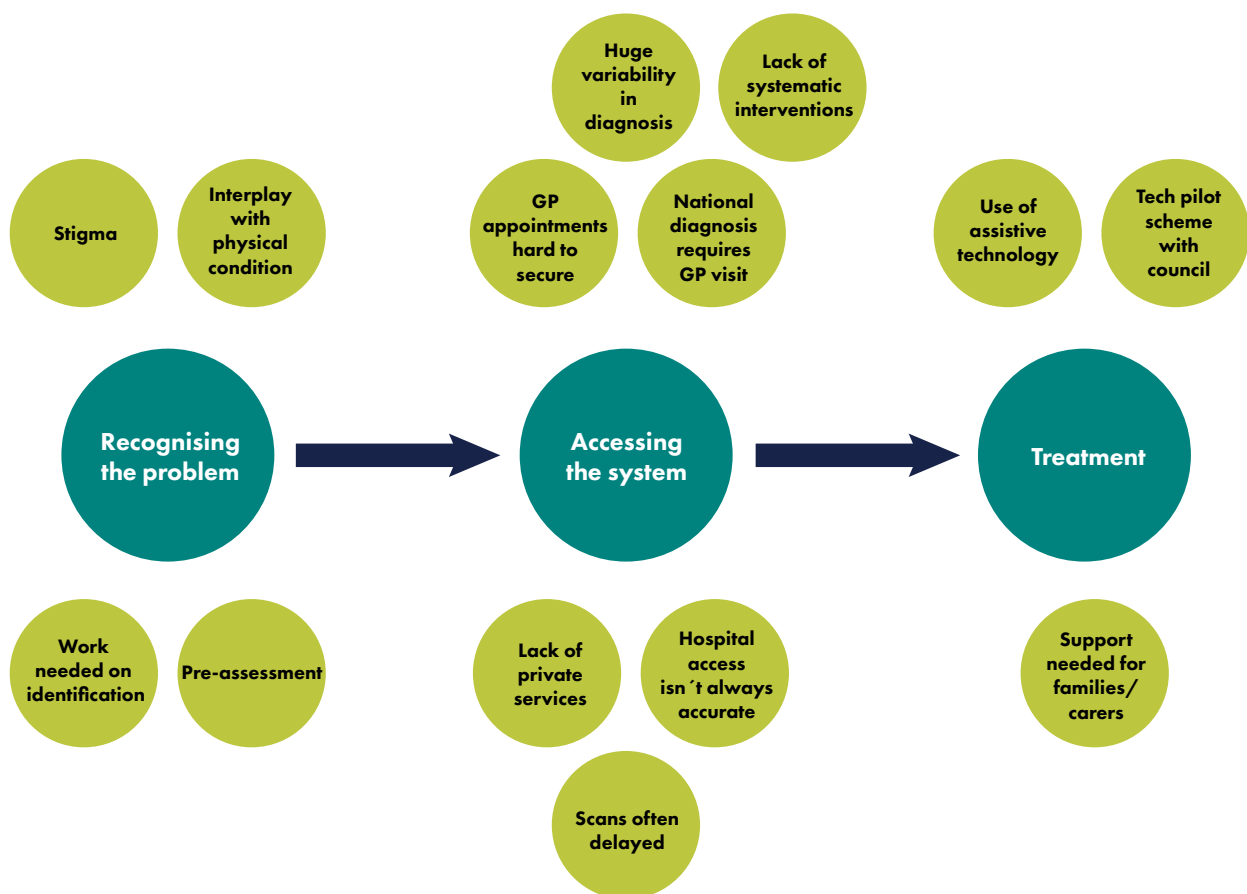
Regarding the 65 and over persona, the group found that there is indeed variability in the diagnosis phase of dementia, whether this be identified by the individual themselves or through their carer and/or a health professional. When considering the treatment and care pathways within the 65 and over persona, there are many barriers that stand in the way of a timely diagnosis. Firstly, there is difficulty in securing a GP appointment in the first instance, given pressures on the health system nationwide, and this is further exacerbated by the feeling that there is variation across GP practices within Northamptonshire, whereby some are hitting their dementia diagnosis targets and some are falling far short. Attendees pointed out there is nothing systematic being done at the ICB level in Northamptonshire to address this variation in diagnosis rates.

Secondly, capacity is a large concern for Northamptonshire when it comes to diagnosis. It was felt that even if diagnosis and referral rates were being met, there would be huge difficulties in getting all patients seen in memory clinics in a timely manner. Attendees revealed that there is anger amongst those who are on the waiting list to be seen for their dementia diagnosis, which is undoubtedly being experienced due to the lack of capacity and thus, putting pressure on waiting times. Thirdly, there are challenges with patients generally not being understood when presenting themselves to the health service, and this leads to an incorrect outcome for the patient, whereby their diagnosis could be missed.

Additionally, the group highlighted several difficulties that would need to be addressed as part of any reform of a care pathway. A patient being identified through the emergency pathway doesn't necessarily speed up diagnosis. They are likely to be in an unfamiliar environment, and a patient being assessed for dementia when they're unwell could lead to an incorrect baseline of the person's condition. One attendee questioned how a proper dementia assessment can take place in an acute setting given they would be presenting to the system when they are potentially unwell with another condition.

Moreover, attendees discussed how there appears to be faster responses for other serious conditions, such as cancer, and how this differentiates to diagnosis and treatment of dementia. Attendees agreed that whilst the lack of an effective long-term treatment for dementia may influence this, early interventions with dementia could have an impact on wider health gains, such as a reduction in attendance at emergency services, as well as financial savings in the health system. Finally, attendees found that data wasn't being utilised enough with regard to technology in dementia support, and they felt that this was particularly lacking in how to understand and make early interventions for patients.

Patient pathway over 65





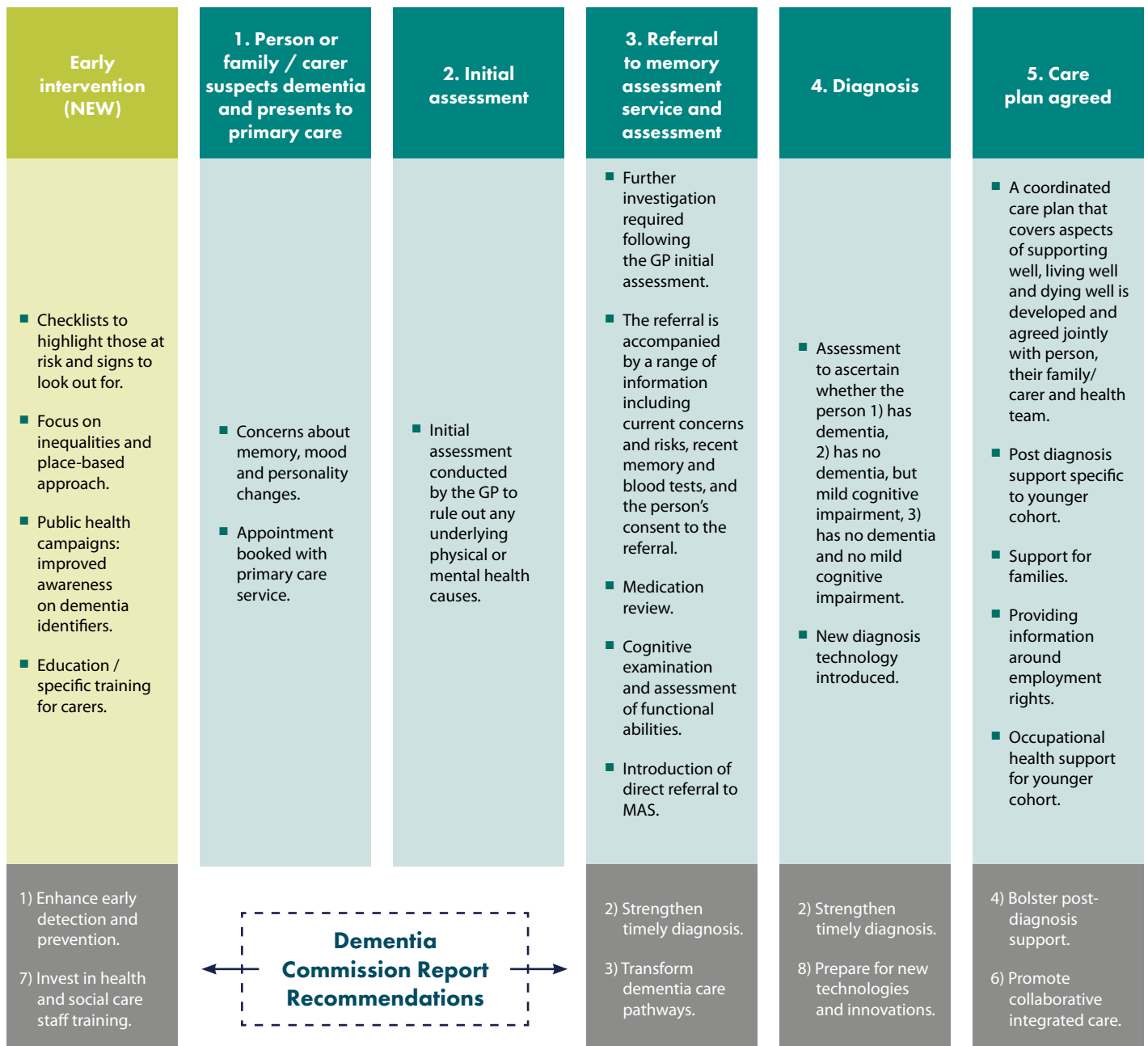
How to Advance Existing Care Pathways: Change

The typical five stages of the national dementia care pathway are:

1. Person or family member/carer suspects dementia and presents to primary care
2. Initial assessment
3. Referral to memory assessment service and assessment
4. Diagnosis
5. Care plan agreed

Following the discussion at the sprint, the table below includes proposed advancements to the current care pathway in Northamptonshire. As is visible, the majority of suggestions focused on how to intervene in dementia diagnosis earlier in order to have the opportunity to best predict outcomes for patients, and how to improve the 'Living Well' aspect of the pathway, improving the care plan once it had been agreed so that people can live better with dementia. The table below sets out where the proposed advancements in the care pathway link to the aforementioned ten recommendations of the Dementia Commission, demonstrating how the groups considered this when discussion how to enhance the care pathway.

Dementia care pathway: proposed advancements



Six Stages of the Northamptonshire UEC Model: Enhanced model

- Checklists to highlight those at risk and signs to look out for.
- Focus on inequalities and place-based approach.
- Public health campaigns: improved awareness on dementia identifiers.
- Education/specific training for carers.



Empowered Self Care & Active Prevention

- Introduction of direct referral to Memory Assessment Services (MAS).



Rapid access to Primary and Community Care

- New diagnosis technology introduced.



Co-ordinated Urgent care & Crisis Response

Patients at risk of escalation

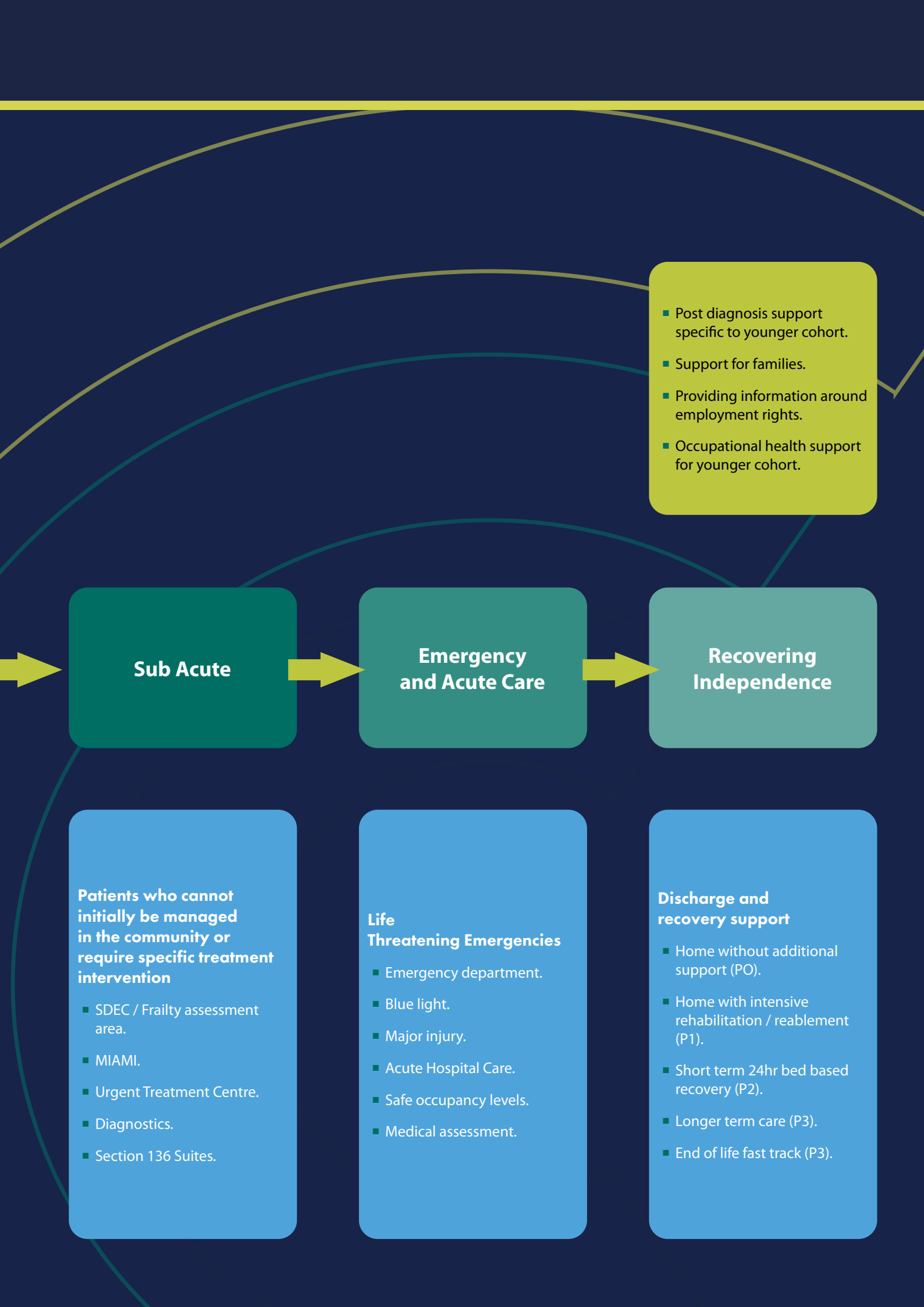
- Holistic Care Plan with crisis planning.
- Keyworker support.
- Remote monitoring.
- Long term condition groups.
- Lifeline response.
- Advanced care plan for those at end of life.
- Domiciliary care.
- Enhanced healthcare in care Homes.

Patients with an immediate but not life threatening need

- Same day primary care.
- In hours & out of hours.
- Community pharmacy.
- Minor injury access inc some local diagnostics.
- Planned service at home.
- MIND Cafes.
- 111 Advice.

Patients requiring intensive support to remain out of hospital

- EMAS.
- Single point of access for clinical triage.
- 2hr UCR 9 domains inc falls response.
- Step up bed.
- Urgent Respite Care.
- Local diagnostics.
- Respiratory Hubs.
- UCAT.
- Crisis houses.
- Triage vehicles.



Conclusion

Although there was a significant amount of discussion on how to improve the current dementia pathway, what became clear through the roundtable is that the current pathway is working effectively. The thinking and design that has gone into the current existence of the pathway can deliver, however, there are enhancements that can be made to this at every integrated care system

Attendees took part in extensive discussions to understand how the pathway could be modified to reap better rewards. The key themes that came from the roundtable were the need for a much larger focus on earlier intervention when it comes to dementia care, and how to support those living with dementia better once they have received a diagnosis.

Firstly, much discussion focused on a part of the pathway that is currently missing from national guidance – earlier intervention. We know that the country is living longer, with people now living into their 80s and 90s, but this means living longer in ill health. There is a need to intervene earlier to identify dementia risk factors before it is too late. This is especially important given the long waits for diagnosis that are prevalent across the NHS. Attendees felt it important for a new method to give attention to the role of place-based approaches, particularly when considering those who are most at risk; integrated care systems should take a population health management approach to dementia care and incorporate this into their awareness raising of the health condition. There is a real need for education of the early signs of dementia – by introducing public health awareness campaigns and better educating clinicians about the early symptoms, pressure on the local health system could be avoided and this can lead to improved experiences for the patient.

The introduction of a direct referral to a memory assessment service is something that will speed up diagnosis times and reduce pressures on primary care. The current pathway is seeing something of a 'bottleneck' when trying to access GPs to diagnose dementia. This is challenging for clinicians and can sometimes lead to a misdiagnosis. Local integrated care systems should consider referring patients directly to the MAS, rather than first going through the GP. By encouraging such ICS pathway development, coupled with local bodies investing technology funding into diagnostic services, patients will be able to be diagnosed and access local supportive care at a quicker rate.

Finally, the sprint highlighted the need for improved care and support once the care plan has been agreed. This could include additional support to families and carers of those with dementia, but additionally, more specific assistance for those with early onset dementia. The roundtable demonstrated that those with early onset dementia are more likely to still be in employment, therefore, more effort and attention need to be directed to how early onset dementia can impact a patient's work life and financial situation. Additional information on employment rights would be incredibly useful for this younger cohort. Integrated care systems should work with anchor institutions within their geography on how they can support workers who are at risk of dementia and how local employers can be better educated to implement policies that can help those who are diagnosed.

The findings from the sprint, whilst based on the experience of the dementia care pathway within Northamptonshire, are applicable nationwide. The issues discussed are not isolated to this ICB, in fact, poor diagnosis of dementia care is varied across the country and the recommendations of the amended pathway can be applied anywhere. It is hoped that this plan can be useful to other leaders when considering earlier intervention, as well as focusing on improving the standards of living well with dementia.

About Us

Curia

Independent, cross-party, and not-for-profit – as a policy institute, Curia turns policy into practice as the UK's first “do tank”. Curia is currently hosting three research groups

- Health, Care and Life Sciences Research Group
- Industrial Strategy Research Group
- Foreign Policy and Defence Research Group

As well as hosting ad hoc investigations into contemporary, relevant policy topics, Curia provides evidence-based consultancy services, due diligence, and socio-economic and environmental analysis. Research groups share best practice through partner publishing and broadcasting agency Chamber UK.

This work was partially funded by Flatiron Health UK. However, Curia retains full editorial independence over the content and conclusions of this report. While Flatiron Health UK contributed to the funding and provided a case study, all recommendations and editorial decisions have been made independently by Curia, ensuring that the report reflects Curia's analysis and perspectives.

www.curiauk.com



