NHS
South East
Clinical Delivery and Networks

Modelling the Dementia Pathway from GP Referral to First Treatment

Wessex Mental Health and Dementia Clinical Network

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Contents

Forward

The Wessex Mental Health, Dementia and Neurological Conditions Network is committed to supporting a collaborative approach to innovating, designing and delivering mental health, dementia and neurological services across Wessex.

Networks are uniquely positioned to bring together those who commission, provide and support services, providing a neutral and equitable platform where challenges and opportunities can be explored, and solutions planned. Wider understanding of system pressures and policy drivers can be shared whilst continuing to work with stakeholders to ensure that patient outcomes and experience remain a priority.

An accurate and timely diagnosis of dementia can ensure appropriate post diagnostic care and improved quality of life for people with dementia and their families. In 2019 the Network viewed this from the perspectives of time to diagnosis and imaging use in dementia diagnosis.

Working collaboratively with Dorset CCG and Wessex CLAHRC we used data modelling approaches and real, local, patient-level data to understand pathway flow to diagnosis. Using this baseline, change scenarios were modelled to demonstrate short- and long-term impact on the pathway.

Thank you

Dr Chris Kipps
Clinical Director

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Executive summary

This project demonstrated the use of patient level flow data to model current activity and create a simulation model for use in scenario planning in clinical service transformation at regional level.

The project showed that:

- Extraction of useful, patient level data was achievable
- A simulation model could be created based on the available data
- The simulation model was able to demonstrate the impact of different scenarios across a range of time-scales

Further uses for a modelling approach to solve pathway challenges were also identified.

Project Team

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Project Aims

The NHS England delivery plan for dementia includes maintaining a diagnosis rate of at least two thirds predicted prevalence and increasing the numbers of people receiving a dementia diagnosis within six weeks of a GP referral.

The dementia diagnosis rate (DDR) is reported based on the recording of diagnosis in primary care data systems. There is no standard data extraction or reporting for waiting time and flow through the memory assessment pathway.

A review of patient level data could provide insight as to the events and processes (appointments, testing, scanning) that occur from the point of referral receipt to the point at which a diagnosis is recorded and treatment initiated. From this the model of activity can be used to ask ‘what if’ questions to visualise the impact of pathway changes in real time and act as an aid to decision making.

What did we do?

Wessex Clinical Network worked with Dorset CCG and the CLAHRC Methodological hub to identify available data and map the pathway.

Identification of available data

- Map the current dementia assessment pathway
- Build a simulation model using Simul8 software
- Test a range of scenarios using the model.

Mapping the pathway

Dorset CCG and Dorset Healthcare Trust described the patient pathway as summarised below. Two services provide support and care for patients with memory concerns, namely:

- Memory advice and advisory service (MSAS)
- Memory assessment service (MAS)

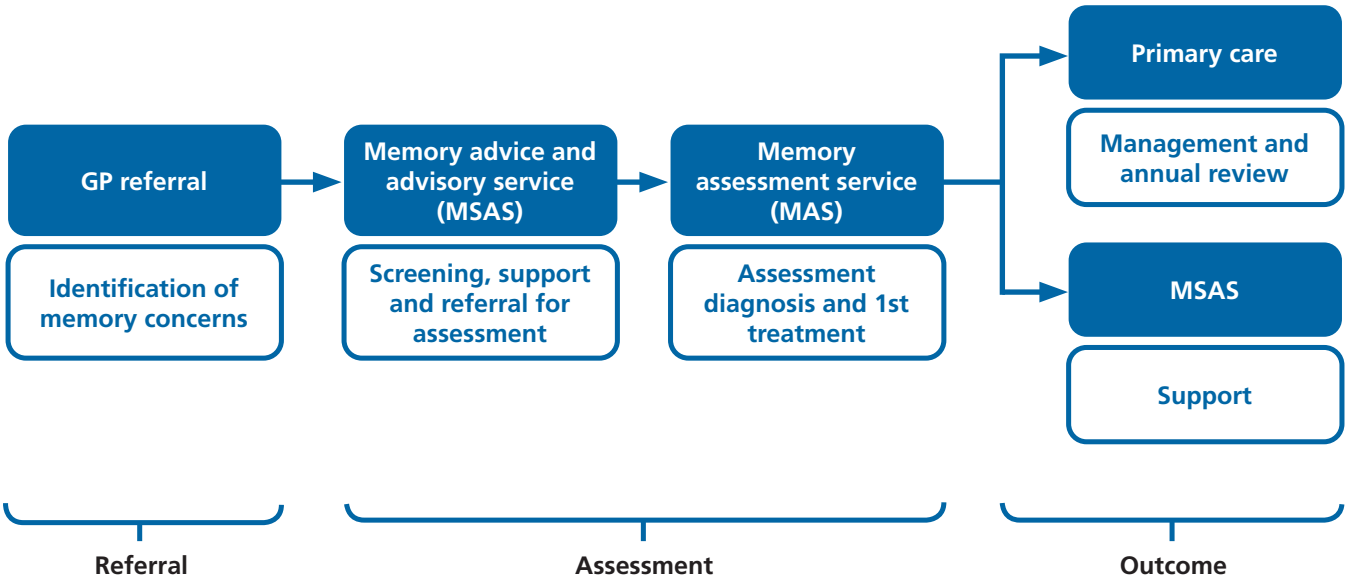


Figure 1: Existing memory assessment and support pathway

Data Sources

Individual patient-level activity within the Memory Assessment Service was identified. This was pseudonymised to comply with information governance rules, and shared with the project team by Dorset Healthcare Trust.

Data from April 2015 to March 2018 was selected to reflect recent activity. The dataset included some partial pathways (people who started a pathway before this and people who had an initial, but incomplete pathway, starting within the timeframe).

Four datasets were reviewed: MSAS referrals data together with MAS referrals, diagnosis and contacts data (see below).

MSAS data table

Referrals data (MSAS)
- Date of referral
- Demographics including GP practice

MAS data tables

Referrals data (MAS)
- Date of referral
- Demographics including GP practice
- Link ID

Diagnosis data (MAS)
- Date
- Diagnosis (including dementia, MCI and no diagnosis
- Demographics
- Link ID

Contacts data (MAS)
- Date of event, location and event type
- Practitioner/staff group
- Attendance
- Outcome
- Demographics including GP practice
- Link ID

Figure 2: Datasets identified

Data Limitation

Linked IDs connected the MAS datasets; however, the match was not perfect as the link was per patient and some patients had more than one referral and/or diagnosis within the time period. Consequently, dates were used alongside IDs to achieve the most appropriate feasible matching.

It was not possible to link the MAS data with the MSAS data as these services are provided by NHS and non-NHS organisations using different identifiers.

Data was not provided on:

- The availability and use of appointments in either service
- Diagnostic imaging within the MAS service, specifically
  - the proportion of patients requiring scanning
  - the time taken for scanning and reporting

Building the Simulation Model

A simulation is an approximate imitation of the operation of a process or system. Simulation models are more accurate than data averages as they are based on rules and constraints identified by analysis of real data and pathways and take variation in the system into account.

Once the simulation accurately represents the real process it can be used to experiment with new rules and constraints to understand the short and long-term impact of these changes on the system.

Simul8 was used to create a model of the dementia pathway based on analysis of the patient level data including:

- Volume and frequency of MSAS referrals over time
- Volume and frequency of MAS referrals over time
- Frequency distribution and types of MAS contacts
- Frequency distribution and types of MAS diagnoses

Scenario modelling

The simulation allowed us to model:

- Current demand and capacity for the Dorset Memory Assessment Service (MAS)
- The impact of implementing a 6-week referral to 1st treatment pathway
- Different pathway scenarios; in this case, the impact of removing the Dorset Memory and Assessment Service (MSAS) step of the pathway.

The modelled scenarios were based on potential pathway transformations under consideration by commissioners at the point in time.

Description of the model

- In this pathway all patients enter at the point that they are referred into the system, and go directly to the MSAS system. A proportion of patients are given information, advice and signposting to other services at this stage. These patients then exit this model.
- Remaining patients continue along the pathway with a referral into the MAS service and a first appointment is booked. At the first appointment, some patients will undergo assessment and receive a diagnosis. At this point these patients will leave the system with a diagnosis and are discharged back to their GP.
- The majority of patients are referred for external tests, usually brain imaging, after which they return to be booked into further MAS appointments. The number of appointments and types of tests varies between patients and the waiting times in this part of the system vary according to the availability of appointment slots.
- Some patients will leave the system without having an appointment; this is represented in the model as natural attrition.
- Each individual patient is modelled separately, so variation in type of diagnosis and number of appointments both before, and after, diagnosis are accounted for within the model.

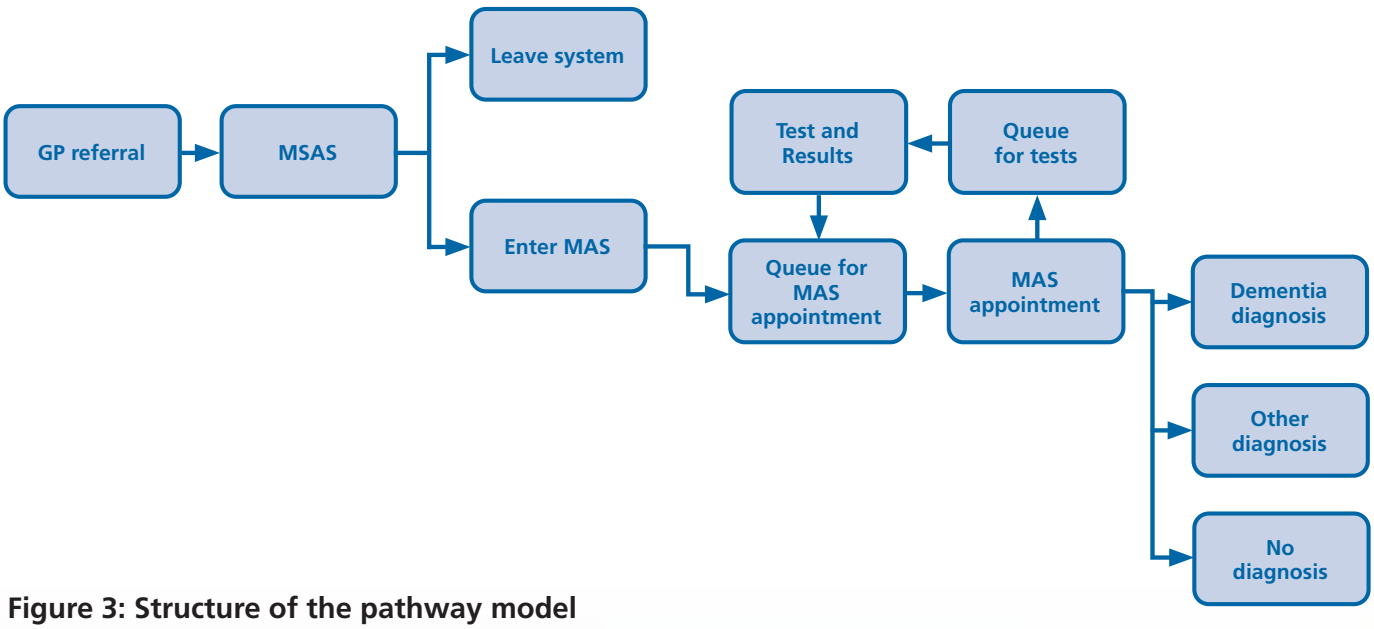


Figure 3: Structure of the pathway model

Results

Activity analysis was performed and described in terms of flow and diagnosis.

Flow through the pathway

- There is no significant pattern apparent in referrals or patient contacts by day of week, season or apparent trend over time
- In the MAS service, 82% of appointments are attended; 7% are not attended (this rises to 12% of telephone contacts).
- In MAS 5% are cancelled by the hospital (these may be simple adjustments to appointment time, and the number of hospital cancellations has decreased over time), 10% are cancelled by patients.
- An average of 2% of appointments appear to be annual reviews based on the observation that these patients have between 10 and 14 months between appointments. These patients have a recorded diagnosis.

Diagnosis

- The time from referral to diagnosis has reduced from by an average of 25 days from 147 days (2015) to 122 days (2017).

Year	Average time from referral to diagnosis
2015	147 days (21 weeks)
2016	124 days (17.7 weeks)
2017	122 days (17.4 weeks)

Table 1: Average time from referral to diagnosis

- The majority (62%) of patients appear to have a diagnosis recorded by their second appointment; the remaining 38% have 3 or more appointments to reach a confirmed diagnosis.
- Dementia diagnosis sub type (including MCI and 'no diagnosis') does not affect pathway duration
- A small group of patients appear to be waiting a significantly longer time for a diagnosis (see table 2). A range of factors including case complexity, patient choice and data quality may play a role. This subgroup has been identified for a targeted audit to identify any themes.

Waiting TIme	Number of patients
>200 days	14%
>365 days	2%

Table 2: Proportion of patients with long waiting times for diagnosis

Modelling the future

Timely diagnosis and good quality post diagnostic care remain key performance targets for dementia services. The model was used to understand the potential impact on capacity and flow of removing the Memory Support and Advisory Service (MSAS) and implementing direct referral from GP to the memory assessment service (MAS).

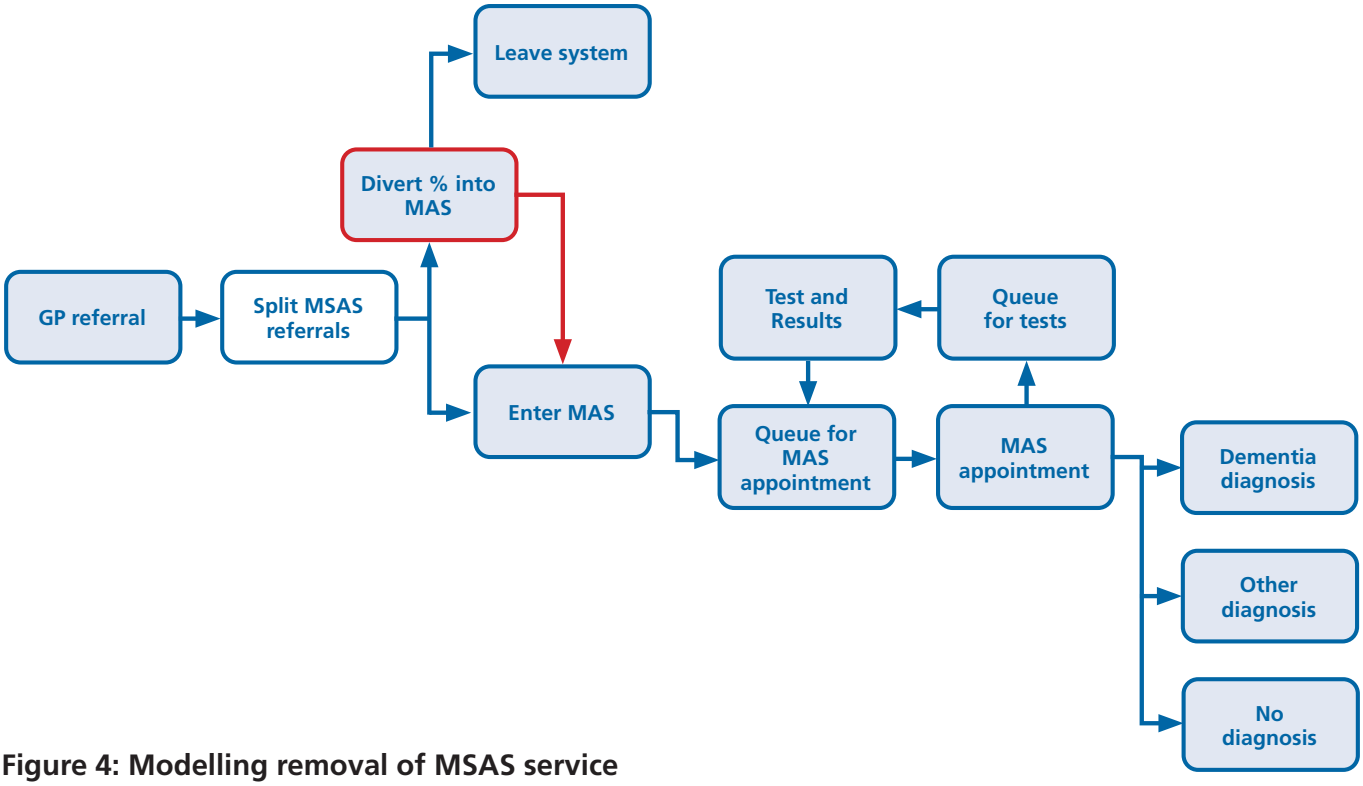


Figure 4: Modelling removal of MSAS service

Assumptions

- New decision-making processes (referral criteria) will decide the proportion of patients remaining in primary care for support and information and those who are referred for memory assessment and diagnosis
- A proportion of patients previously seen and supported by MSAS are likely to be referred to MAS instead of being managed in primary care
- Patients arriving in MAS, who previously would have been supported and discharged from within MSAS, will only require one MAS appointment and be discharged.

Modelling changes in appointments to maintain current flow

The table below shows the number of new appointments that the model predicts would be needed in the MAS service as result of removing MSAS. This was modelled in terms of the proportion of patients currently seen by MSAS who would potentially be redirected to MAS. The number of new appointments is calculated based on the number that are needed in the model to keep up with patient arrivals and prevent a build-up of queues (waiting times).

% of MSAS patients potentially going direct to MAS if MSAS removed	Average daily number of appointments needed in MAS to accommodate increase
0%	34 – current level of appointments
25%	37 (+3 appointments per day)
50%	40 (+6 appointments per day)
75%	43 (+9 appointments per day)
100%	46 (+12 appointments per day)

Table 3: Modelling of potential changes in appointment numbers required to maintain current flow levels

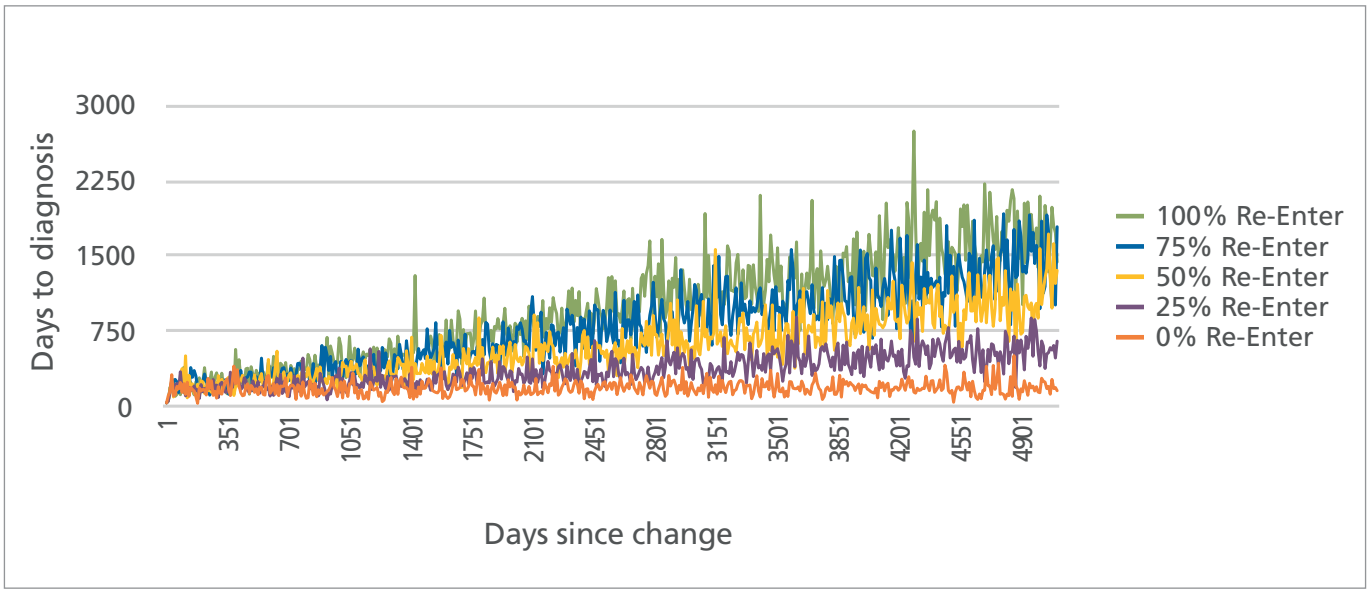
Modelling changes in waiting times from referral to diagnosis

If the number of appointments available in MAS remains at the current level and a proportion of patients currently leaving via MSAS are redirected into MAS (following the removal of MSAS) the overall number of patients waiting in the system will increase. This will be reflected in an increase in the overall time from referral to diagnosis.

For example: If 50% of the patients who would have left via MSAS are seen in MAS, with no additional capacity (appointments, staff), then in 20 years patients will wait between 982 days (4 years) and 1624 days (8 years) for diagnosis.

The model can be used to understand the changes to time from referral to diagnosis over time. There is significant variation in the time to diagnosis between patients due to difference in numbers of tests required. In order to mitigate this, and demonstrate the cumulative impact of changes over time, the model has been run for a 20 year period.

Figure 5: Changes in waiting time from referral to diagnosis over time (10 day moving average)



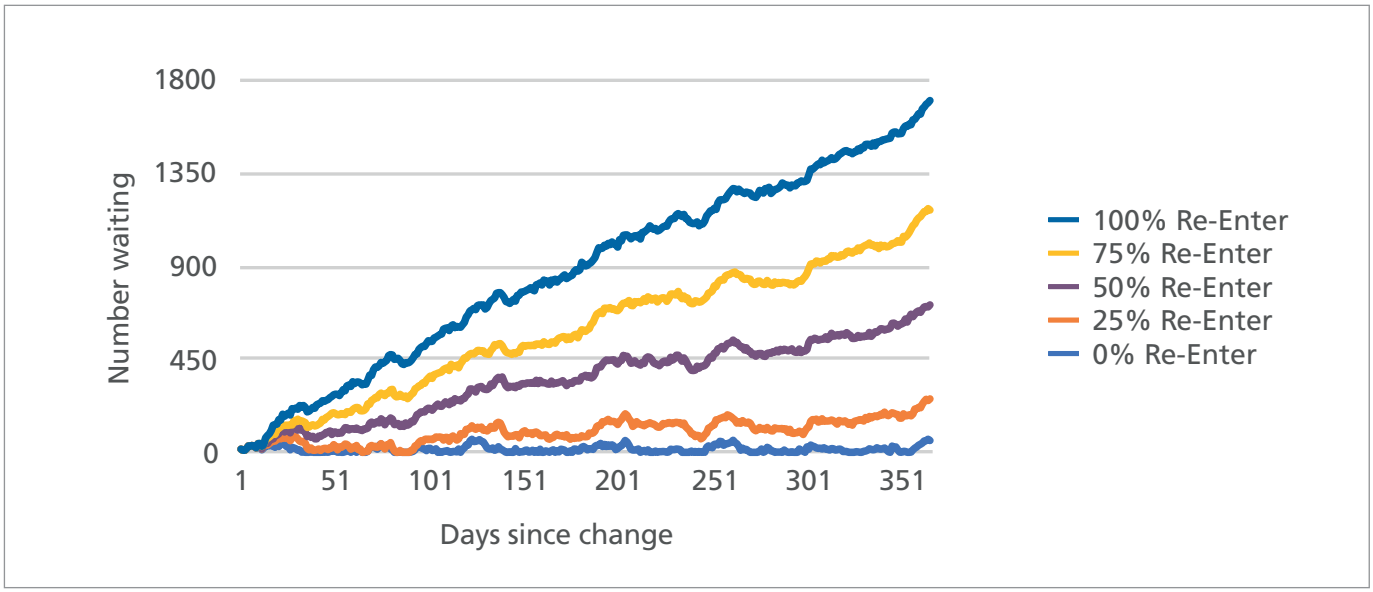
Coloured lines show the effect of increasing numbers (percentage) of patients entering the MAS service as a result of service configuration changes.

Modelling changes in the numbers of patients queuing in the system

The impact of increasing numbers of patients (previously MSAS patients) with no increase in capacity (appointments, staffing) can been more clearly by modelling the numbers of patients waiting (queuing) in the system.

For example: If 50% of the patients who would have left via MSAS are seen in MAS, with no additional capacity (appointments, staff) then in 1 year the number of additional patients queuing in the system will increase from 0 to 692.

Figure 6: Changes in number of patients waiting for their next appointment (queuing in the system)



The graph shows how the numbers waiting for appointments will change over 1 year depending on the proportion of people who enter the MAS system after service reconfiguration.

It should be noted that scenarios modelled above are conservative. It has been assumed the patients who would have left via MSAS but are now being seen by MAS, only have one appointment in MAS and leave without a change in diagnosis. In reality, it is likely that some patients would go on to have diagnostic tests and further appointments.

Conclusion

Delivering and maintaining an estimated population dementia diagnosis rate of 66.7% remains an NHS England target. Current datasets rely on numbers of diagnoses in the population at set points in time. There is no current dataset to demonstrate flow and capacity in memory assessment and diagnosis pathways.

This project was undertaken by Wessex stakeholders to understand the current capacity and demand in the dementia pathway from GP referral to confirmed diagnosis in the Dorset area.

Extracting anonymised but individually coherent patient level pathway data is challenging. Data is stored on a range of systems along a care pathway. This is additionally complicated where external and voluntary sector organisations are commissioned to provide a part of a pathway using their own data standards (non-NHS number identifiers). Data accuracy and level of completion is variable as different teams across different areas develop a range of understanding of completion requirements and definitions. Information governance regulations are challenging to navigate and can take many conversations across different organisations over a period of time. Some data (imaging, tests and reporting times) could not be linked and provided to the project.

Using the available patient pathway data, it was possible to develop a model populated by current activity. Based on this, the model could simulate future activity based on differing scenarios including the removal of steps from within the existing pathway. This predicted the subsequent impact on appointments required to maintain flow, queuing and capacity within the pathway and time spent within the pathway from referral to diagnosis.

The model demonstrated that while the impact of change may seem obvious, accurate prediction for strategic planning is challenging in complex systems with considerable patient level variation. Problems may be building in a system with little visible initial impact. Models can be used to derive early warning thresholds (red flags) for action in sufficient time to avert a crisis.

This methodology can be useful to researchers in understanding data mapping and modelling and commissioners and providers in redesigning and transforming services. The learning from this work focussed on the dementia pathway but could be adapted to inform other pathways.

Lessons Learned

- Extraction of flow data at a patient level across organisational boundaries is challenging. This project was used as a case study inform an AHSN workshop on STP data flows in July 2018. The workshop resulted in recommendations for future STP data flow models and governance arrangements.
- Modelling can offer scenario evaluation as part of strategic planning but may be less effective where data is not available in real-time
- Scenario modelling with real data highlights specifics areas for more detailed evaluation such as in-depth clinical audit of outlying data.
- Clinical practice, which often involves a high degree of variability, may obscure patterns that are better exposed by modelling which averages out variation over time.

Next Steps

The model can be used to test further scenarios relevant to commissioner and provider decision making. These have been divided into process changes affecting demand, capacity and flow and clinical decision-making affecting diagnosis and outcomes. The data requirements of future work have been identified.

Flow opportunities

- GP led diagnosis
- Earlier identification of people with MCI likely to progress to dementia
- Proportion and order of imaging stages
- Effect of diagnosis made in an acute setting

Diagnosis opportunities

- Workforce changes and impact on diagnosis pathway
- Later re-referal of 'No diagnosis patients'
- Earlier diagnosis through early appropriate use of imaging
- Age and co-morbidity effects
- Impact of diagnosis at an earlier stage of progression
- Variation in diagnosis due to geographic location, organisational culture and clinical risk tolerance

Data requirements

Linked data

- Within organisations
- Across organisations
- National datasets

Enough data

- Volume
- Timefame
- Quality

Comprehensive data

- Diagnosis
- Scans and test dates
- Longitudinal process
- Severity and co-morbidities
- Independent vs supported living and geographical location
- Referrals
- Outcomes
- Appointment capacity
- Clinical structures and workforce skill mix

Wessex Clinical Network: Dementia publications and products

Supplementary information

Clinical Networks support the delivery of sustainable improvement working across all parts of the local healthcare system, following and improving patient pathways. This work is undertaken through partnership and collaborative working with multiple clinicians, providers and commissioners across both boundaries and organisations. For further information see our website *https://wessexsenate.nhs.uk/*

The Wessex Clinical Network has created a range of publications to support quality improvement in dementia care

The View – A monthly newsletter with topics highlighting useful developments in dementia and mental health in the Wessex area *https://wessexsenate.nhs.uk/clinical-networks/mhdn/*

Dementia research in Wessex – The Dementia Strategy group heard from some of the studies improving care for those with dementia in Wessex and considered how to support to the relationship between research and implementation. Published January 2020
https://wessexsenate.nhs.uk/download/wessex-dementia-research/

Younger Onset Dementia in Wessex – Dementia presentation in younger adults has specific challenges for health and social care. The Dementia Strategy group considered how the development of a YOD Network would enable quality service development for a small population over a wide geographical area. Published January 2020 *https://wessexsenate.nhs.uk/download/younger-onset-dementia-services/*

A review of diagnostic imaging for dementia in Wessex – Imaging is an important part of the dementia diagnosis pathway. This review aims to understand the factors that influence this and offers recommendations for further development. Published January 2020
https://wessexsenate.nhs.uk/download/a-review-of-diagnostic-imaging-for-dementia/

Modelling the dementia pathway – Working collaboratively with Dorset CCG and Wessex CLAHRC we used data modelling approaches and real, local, patient-level data to understand pathway flow to diagnosis. Using this baseline, change scenarios were modelled to demonstrate short- and long-term impact on the pathway. Published July 2019
https://wessexsenate.nhs.uk/download/modelling-the-dementia-pathway/

Antipsychotic prescribing in dementia – Summary of guidelines, local practice and national data. Includes recommendations for local safer management. Published January 2020
https://wessexsenate.nhs.uk/download/antipsychotic-prescribing-for-dementia/

Transforming Dementia Services: Peer review and learning – Peer review and learning - dementia care remains a key priority for the Wessex region. Two major local reviews of the Dementia pathway were undertaken in with the potential to improve care for a significant number of the local population. The Dementia Strategy Group heard presentations on both projects and considered the challenges and learning which could be shared across wider transformational projects. Published: June 2019
https://wessexsenate.nhs.uk/download/transforming-dementia-services-peer-review-and-learning/

Dementia care in Wessex is Excellent: Discovery – Infographic defining excellence in dementia care and how the elements of a whole system approach can support this. Published January 2019 *https://wessexsenate.nhs.uk/download/a-whole-system-approach-discovery-infographic/*

Dementia Diagnosis Toolkit – This toolkit was designed to support the dementia assessment process and appropriate timely diagnosis primarily for GPs diagnosing in care homes. It can also be used to rule out other conditions, provide an explanation to a person for their symptoms and allow them access to treatment and good post diagnostic support and care. Published August 2018 *https://wessexsenate.nhs.uk/download/dementia-diagnosis-toolkit/*

Wessex Health Lines – An online platform created in 2015 to share quality improvement projects in dementia which has been further developed to include Mental Health, Healthy Ageing and services for people with a neurological condition. Also included dedicated pages for neurological and cancer research. *https://wessexhealthlines.nhs.uk/*

A strategic Vision for Mental Health, Dementia and Neurology across Wessex 2016-2020/21 – This strategic vision was the blueprint for developing mental health, dementia and neurological services across Wessex. It was written primarily with those who commission and provide these services in mind, however was also of wider interest to anyone living and working in Wessex. Published: June 2016 *https://wessexsenate.nhs.uk/download/a-strategic-vision-for-mental-health-dementia-and-neurology-across-wessex-2016-2020-21/*

National links

The Community Mental Health Framework for Adults and Older Adults, (September 2019), National Collaborating Centre for Mental Health – Describes a new model for place-based community mental health model moving away from siloed hard to reach services towards joined up care and whole population approaches. *https://www.england.nhs.uk/wp-content/uploads/2019/09/community-mental-health-framework-for-adults-and-older-adults.pdf*

NHS Mental Health Implementation Plan (July 2019) – Framework for delivery of the Long-Term Plan for Mental Health services. *https://www.longtermplan.nhs.uk/publication/nhs-mental-health-implementation-plan-2019-20-2023-24/*

NHS Long Term Plan (January 2019) – Vision for the delivery of National Health Services over the next 10 years. *https://www.longtermplan.nhs.uk/publication/nhs-long-term-plan/*

Dementia Care Pathway Implementation guide and resource pack (July 18) – Supports improvements in the delivery and quality of care and support for people living with dementia and their families and carers. *https://www.england.nhs.uk/mental-health/dementia/implementation-guide-and-resource-pack-for-dementia-care/*

Notes

NIHR | Collaboration for Leadership in Applied Health Research and Care Wessex

NHS Dorset Clinical Commissioning Group

NHS Wessex Clinical Networks