TheCumberlandInitiative
TRANSFORMING HEALTHCARE QUALITY AND COSTS

Whole Systems Partnership

Dementia Prevalence: Modelling the evidence

Using System Dynamics to explore the impact of evidence for dementia prevalence & service impact

Context

- Between 2009 and 2014 WSP applied a population level 'whole system' dementia simulation tool to support a dozen health and social care communities to plan for strategic change across these services;
- Critical to this work was an understanding of underlying health needs, based on estimates of dementia prevalence, primarily based on research carried out on needs in the late 80's and early 90's;
- This was an important model assumption because a foundational stone on which National Strategy was based was early recognition and diagnosis – for which clear targets were set nationally.

Brief model demonstration – a retrospective….

The basis for our expectations of dementia prevalence – CFAS I

- But what if the denominator of our expected population prevalence sum were to be wrong?
  - The Cognitive Function and Ageing Study I has increasingly formed the basis of estimates of dementia prevalence since its publication in 1998;
  - The work was carried out in 6 areas across England and Wales between 1989 and 1994 providing a robust evidence base that has underpinned a wide range of modelling and forecasting in this area;
  - Using this evidence and age specific estimates of prevalence, repeating this exercise in 2011 would have led to us expecting to find a prevalence of 884,000.

The evidence from CFAS II

- CFAS II undertook to repeat the CFAS I study between 2008 and 2011 using the same approach;
- It found that instead of 884,000 the estimate for 2011 should be 670,000, which equates to 6.7% of the >65 population instead of 8.3%;
- The interpretation presented by the researchers is:

"That this study provides further evidence that a cohort effect exists in dementia prevalence. Later-born populations have a lower risk of prevalent dementia than those born earlier in the past century."

What does this mean

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- A simple sum to demonstrate:
  - If we expect 884,000 people to have dementia in 2011 & project this forward by +2% pa to 2015 (2% being an approximate age specific growth in prevalence) we would expect 957,000 people with dementia in England and Wales by that date;
  - And if we seek to achieve a 66% diagnosis rate at that date this would be 632,000 people with a diagnosis;
  - If, however, the true level of dementia in 2011 is 670,000, projected forward to 2015 this would equate to 725,000 even if we apply the same 2% increase each year;
  - Expecting to have 632,000 diagnoses when there are only 725,000 with dementia would equate to 87% not 66%.

Is this good or bad?

- There are less people with dementia than we expected – surely that's good news?
- Yes, but if we retain the previous estimate for dementia prevalence we risk both effectiveness and efficiency:
  - Effectiveness because there are is a point beyond which the balance of risk and benefit from a diagnosis for an individual switches;
  - Efficiency because we risk building capacity for a population that is actually significantly less in number.

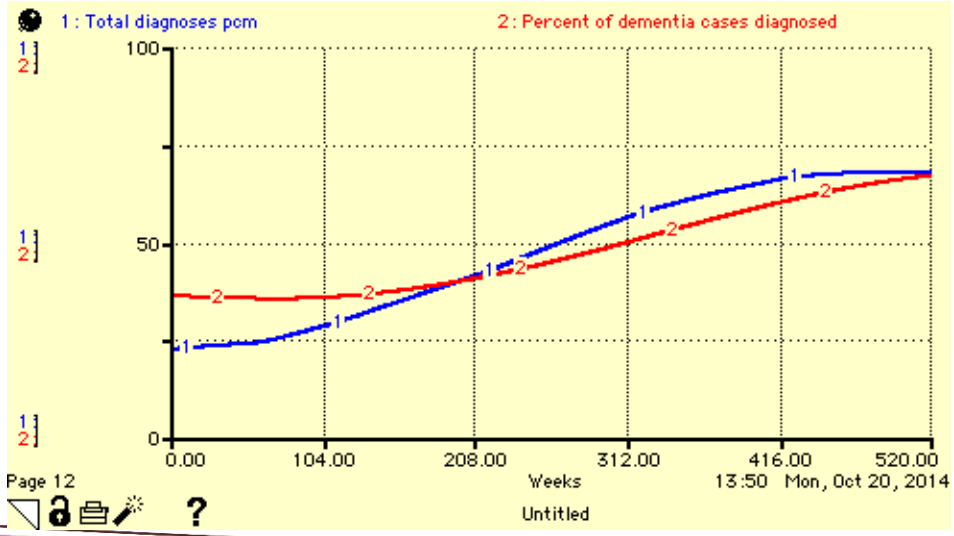
Risks of over-diagnosis

- There is debate within the medical fraternity about the risks of over-diagnosis, and published evidence that it can be harmful (though not specifically in dementia?):
  - It can encourage interventions where the balance of risk and benefits are questionable or potentially harmful;
  - It can lead to raised levels of anxiety with its own attendant health risks;
  - It can lead to an over-medicalisation of a condition that is actually the consequence of a wide range of health determinants;
  - It can lead to an over commercialisation of early intervention and screening.
- As in all things there is a balance – but getting the facts right is the best starting point for judging the right balance.

What role simulation and modelling?

- Modelling of population health needs using System Dynamics has already been used to explore strategic responses to policies such as early diagnosis in dementia;
- Learning from the use of this approach has, for example, demonstrated the relationship between diagnosis rates and overall prevalence, for example…….

Progress in achieving higher levels of diagnosis within the population lags behind the increase in the actual diagnoses being made each month.



The role of modelling and simulation

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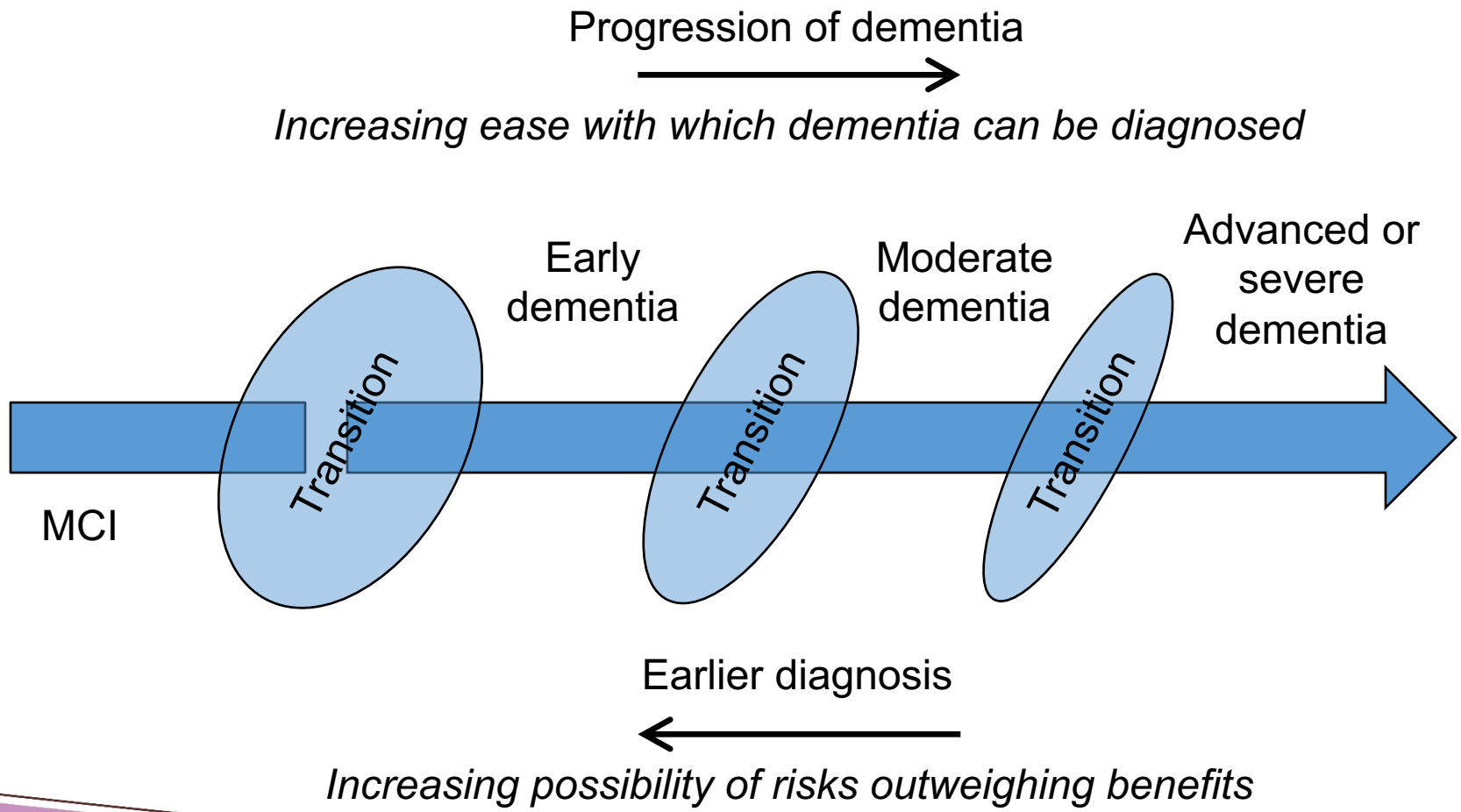
- Modelling and simulation of this sort can:
  - Provide a simple and jointly owned system design in which the different assumptions can be played out;
  - Demonstrate the extent of benefit or risk to adopting different underlying assumptions;
  - Provide a potential basis for resolving difference as it uses otherwise disparate and static data items in a way that produces a system response.

What are the risks in the system?



Three states for the system

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- Historically most late dementia was diagnosed but only some where there were moderate needs – this situation was deemed to represent a system where the benefits of earlier diagnosis would outweigh any risks;
- The current drive to higher levels of diagnosis requires, and is premised on, earlier diagnosis – potentially bringing the system into a balance of benefits and risks;
- However, if – as the evidence now suggests – there are fewer people with dementia this might cause the system to enter a state where the risks of over diagnosis outweigh the benefits.

What questions does the data pose?

- Is there a risk of over-diagnosis?
- What is the interface between Mild Cognitive Impairment (pre-dementia) and clinically diagnosed dementia?
- What drivers are there to increase diagnosis rates?
- Does the drive to increase diagnosis rates go beyond the level at which benefit can be evidenced?
- If there's no benefit beyond a certain level are resourced being well used?
- How does CFAS II impact on these questions?

Other possible explanations for the increased need presenting to services

- Complexity – there is ample evidence of the increase in complexity and multiple needs amongst the older population; when dementia is present earlier stages may present more challenges today than they would have 20 years ago due to co-morbidity;
- Shift to the community – because more people are being supported in the community the % of people in care homes, or in hospital, who have dementia can be expected to increase even if the absolute number does not;
- Changes in family and neighbourhood make-up has eroded the ability of the these institutions to support people with dementia;
- The very fact that there is a higher level of diagnosis will mean that services are more aware of these dementia patients or clients than they might have been before.

Conclusions

- The key policy and implementation challenge of addressing the population health needs of people with dementia can be informed by the use of modelling and simulation because:
  - It can act as a testing ground for the impact of new evidence;
  - It can demonstrate the balance of high level risk and benefit for particular population health needs;
  - It can help facilitate discussion and provide insights into the wider system behaviour;
  - It can provide sufficient intelligence to inform jointly owned actions based on the best available evidence;
  - It can suggest new areas where evidence needs to be gathered to help explain the behaviour of the system.

Discussion

- To what extent does this example of population health modelling provide a template for other similar modelling needs?
- What lessons can we learn from the change in the evidence base as it impacts on our modelling and simulation?
- People with a diagnosed dementia increasingly have other co-morbidities – how can we best accommodate this in any modelling and simulation at a population health level?
- Other topics…….