

# Using economic evidence to model an improved dementia care pathway

IV Workshop on the evaluation of public policies for sustainable Long-Term Care in Spain  
ILPN

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# What is Dementia?

A broad category of **brain diseases** that result in a set of symptoms that may include memory loss and difficulties with thinking, problem-solving or language, that are severe enough to affect daily life. They may also experience changes in their mood or behaviour.

# Why Dementia?

1. The burden of disability associated with dementia is rising faster than any other cause.
2. Significant and increasing % of health spending. Largest cause of need of Long-Term Care.
3. Huge costs to society, and in particular to families of people with dementia.
4. We are a long way from finding a cure.
5. There is huge room for improvement in terms of prevention, care and of prevention of “bad costs”

# Moving on from cost-effectiveness

- How do we use evidence from economic evaluations to inform policy?
  - Beyond “recommending” a wider implementation of cost-effective interventions
- How do these interventions fit into the current service structure:
  - Where is the population for which the results are relevant?
  - Where do the interventions fit in the current system?

# MODEM

**A comprehensive approach to modelling  
outcome and costs impacts of  
interventions for dementia**

2014-2018  
@MODEMProject

June 2017

# Research questions

1. How many people with dementia will there be over the period to 2040; and what will be the costs and outcomes of their treatment, care and support *under present arrangements*?
2. How do those costs and outcomes *vary* with the characteristics and circumstances of people with dementia and their carers?
3. How could future costs and outcomes change (in level and distribution) if *evidence-based interventions were more widely implemented*?

# Interventions, costs and outcomes

## Interventions of interest

- **Risk-reduction** (e.g. lifestyle, nutrition, exercise etc.) and prevention (e.g. falls) ... *but not mid-life prevention (cf. PHE)*
- **Treatments** (e.g. medications, cognitive stimulation therapy)
- **Care and support arrangements** (e.g. home care, telecare, respite, case management, end-of-life care)
- **Carer-focused arrangements** (e.g. carer training and support)

## Costs and outcomes

- All resource impacts (health, social care & other), including resources of people with dementia, families and communities.
- Quality of life, clinical & lifestyle effects, for people with dementia and carers.

# MODEM – key components

**Engagement** with people with dementia, carers, other stakeholders.

**Systematic mapping of literature** of effective & cost-effective interventions for people with dementia & carers (*MODEM Dementia Evidence Toolkit*).

**Collection new data**, analyses of data from trials and large surveys.

**Experiential evidence** from people with dementia & carers

**Suite of simulation models to estimate:**

- Number & characteristics of people with dementia, 2015 to 2040
- Number & characteristics of family or other unpaid support to them
- Costs of services & unpaid support
- Quality of life, health & related ‘outcomes’
- **Impact of a wider roll-out** of evidence-based interventions on outcomes, costs, patterns of expenditure

**Legacy model** for local projections of needs, outcomes and costs.



# Systematic mapping of literature

**Systematic mapping** of empirical evaluations of interventions to:

- Prevent or delay dementia onset
- Reduce symptom severity
- Improve quality of life of people with dementia and/or carers

**Review of previously published systematic reviews**

**Our own reviews** of areas in which we have identified gaps

The review informs **choice of interventions** for modelling

Mapping of value in its own right:

- **Identification of evidence gaps**
- **Implications of different methods** for use of evidence for modelling
- Publicly available via ***MODEM Dementia Evidence Toolkit***

# Dementia Evidence Toolkit

1. A **searchable database** of journal articles on dementia treatment, care, support and risk reduction interventions (developed as part of MODEM).
2. Non-technical **summaries of evidence** on the **effectiveness** (and **cost-effectiveness**) of key care and treatment **interventions**.

<http://toolkit.modem-dementia.org.uk/>

# MODEM cohort data collection

- Cohort of **300 dyads**: people living with dementia & carers.
- 100 each with mild, moderate & severe dementia; clinical population from Sussex.
- Interviewed at **baseline & 52-week** follow-up.
- Various measures of need, care use, outcomes - allow **cross-walking** between different measures & studies.
- Detailed questions on **use of care services** by people with dementia and **provision of unpaid care**.
- Questions on **use of technology** in second wave
- First wave **analysis** almost finished; second wave **collection** ends September 2017

# MODEM suite of models

1. **Macro-simulation** projection model of long-term care need and costs (LSE)
2. **Dynamic micro-simulation** projection model, PACSim, estimating the disabling consequences of dementia (Newcastle)
3. **Dementia care pathways model** maps current care pathways; used to model how interventions impact on use of services, costs and quality of life (LSE)

# Macro-simulation model: bringing it all together

## Dynamic micro-simulation

projection model on  
disabling consequences of  
dementia

Numbers of people with dementia by age,  
gender, disability (interval need), cognitive  
function (MMSE)

Baseline: current care  
packages, link to **care  
pathways model** to  
estimate impact of  
adopting interventions

Type of care: none, unpaid only,  
formal home-based, unpaid and  
formal care, residential care

Relationship between type  
of care/interventions, costs  
and outcomes from the  
**care pathways model**

Societal costs by  
source (NHS,  
social care, users,  
carers)

Person with  
dementia  
outcomes

Unpaid carer  
outcomes

# Population Ageing & Care Simulation (PACSim)

PACSim aims to model:

- Health and associated care needs of the English population from 2014 for the coming decades
- Impacts of interventions for risk factor reduction, disease prevention and treatments that slow down progression to disease and disability with a particular emphasis on interventions for dementia

Data sources:

- Understanding Society, ELSA, CFAS

# Dementia care pathways model

- **Describes stages of care** experienced by people with dementia & their family carers - in terms of numbers of people, costs & outcomes
- Provides **baseline from which to model impacts** of interventions – e.g. implementation of different models of care and expansion of availability of interventions across eligible groups
- Built from **wide consultation** on pathway elements – with people with dementia, carers, clinical staff, researchers, national clinical director etc.

# Care pathways model - continued

## 1. Pre-diagnosis to referral

- Early symptom identification & first service encounters, including GP assessments and hospital-based screening

## 2. Diagnostic process

- From point of referral to diagnostic services (memory clinic, other specialists), including diagnostic disclosure

## 3. Post-diagnostic support

- Includes care, treatment and support during first year after diagnosis

## 4. Continuing care

- Medication reviews
- Addressing behavioural and other symptoms and co-morbidities
- Formal social care support

## 5. End of life care

- Assumed to be last year of life with dementia

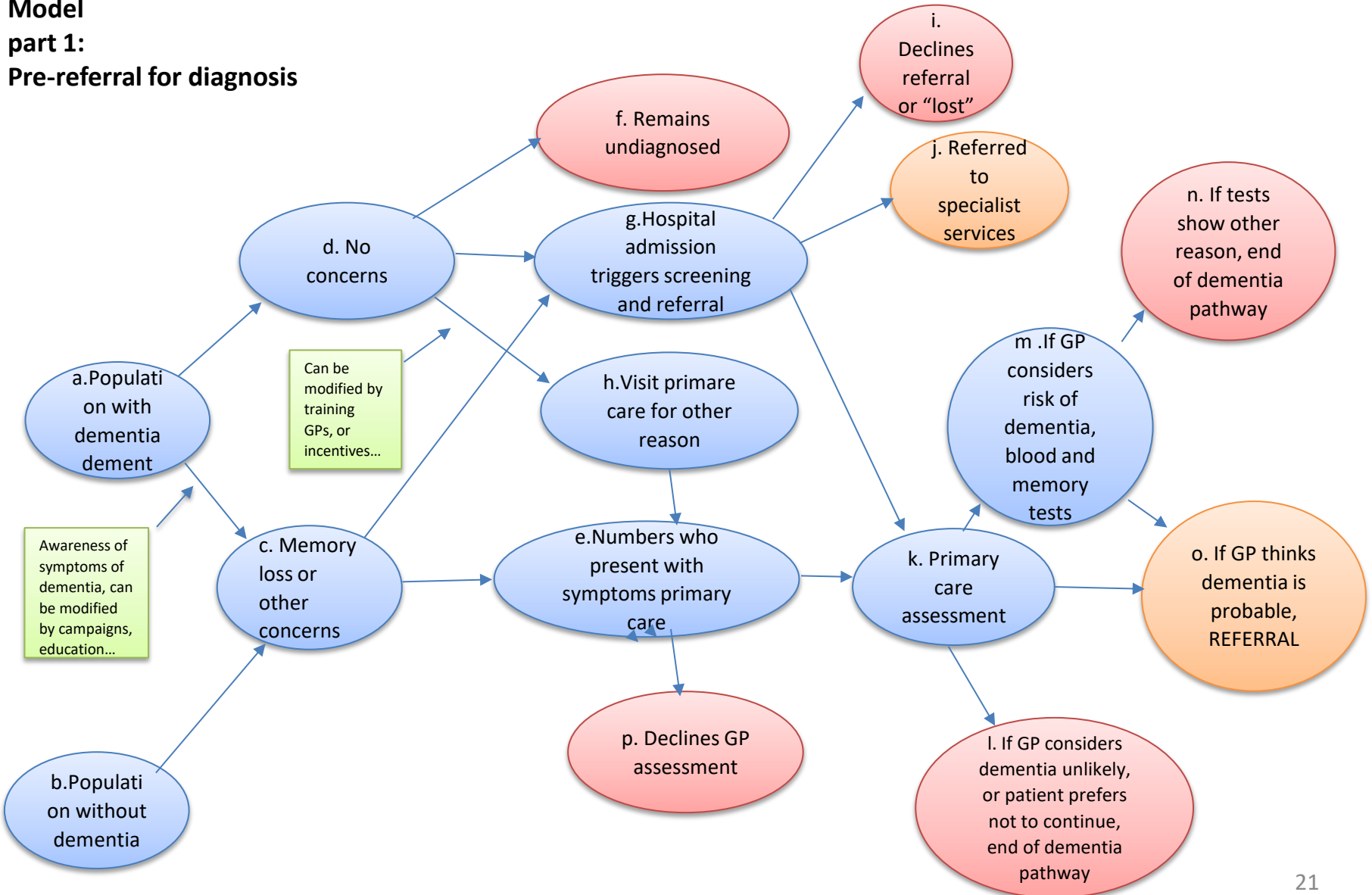


## Care pathways - extract

## MODEM Dementia Care Pathway Model

## part 1:

## Pre-referral for diagnosis



# Candidate interventions for ‘new pathway’ modelling

**Direct & strong evidence** of cost-effectiveness for:

- Anti-dementia medications (AChEIs, memantine), both separately and in combination
- Cognitive Stimulation Therapy (CST)
- Carer support: specifically Strategies for Relatives (START)

**Indirect economic evidence** for:

- Advance Care Planning
- Dementia Care Planning
- *Care management*

*Still considering how to include evidence for social care*

# From RCT/economic evaluation to the dementia care pathway: many questions

- Which is the population for whom the intervention was cost-effective?
- Through which mechanisms were the changes in outcomes observed in the RCT happen and where there other effects that weren't measured?

# An example: Cognitive Stimulation Therapy

## Evidence:

- **Effectiveness:** 2 studies found improved *cognition* (or slower deterioration), measured with MMSE and ADAS-Cog and improved *Quality of Life*: QoL-AD / DEMQOL (slightly inconsistent results for different measures/studies). Also interaction between CST and anti-dementia medication (multiplicative effect)
- **Cost-effectiveness:** health and social care costs of intervention were slightly higher than control group. Additional cost was £20 per person over 8 weeks, which included the costs of intervention. Cost of achieving 1 point improvement in MMSE was £90. Cost of achieving 1 point improvement in QoL-AD was £27.

## Modelling questions:

- Should we model separately the impact on people in care home and in the community? (differential effects on some outcomes, very different costs)
- What is the relationship between the 2 primary outcomes, improved cognition and quality of life?
  - *Is the increase in quality of life is related to the improvement in cognition, or is it independent. Because CST is an enjoyable activity (e.g. evidence from the qualitative study), it is plausible that the quality of life impact is independent of the improvement in cognition. Also, we know that the relationship between improvement in cognition and quality of life is not necessarily linear.*

# Where are we now?

Finding great interest in the “Dementia Care Pathway” as a platform for modelling, also at local level. Will make this an “open resource”.

Still working on the model, will show the results at the next workshop!

For any questions and suggestions in the meantime, please email me at [a.comas@lse.ac.uk](mailto:a.comas@lse.ac.uk)

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