W13: Modelling disease progression and economic outcomes of dementia interventions: exploring options for a complex health problem

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Brendan Mulhern

Panellists

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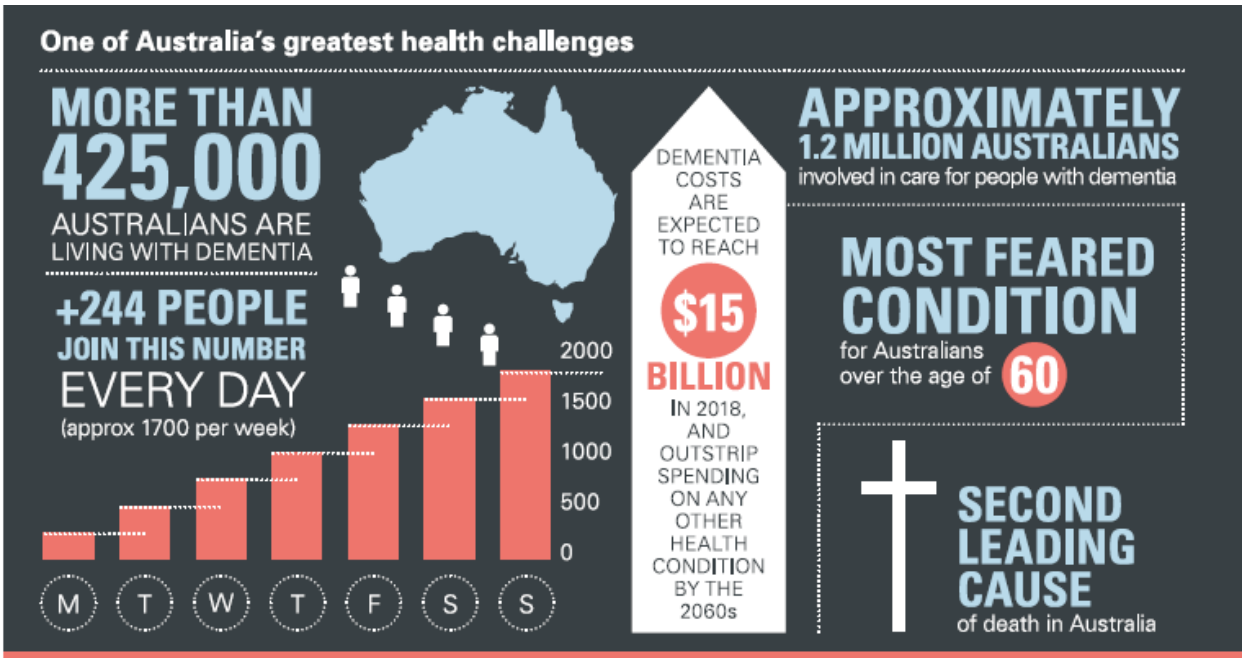
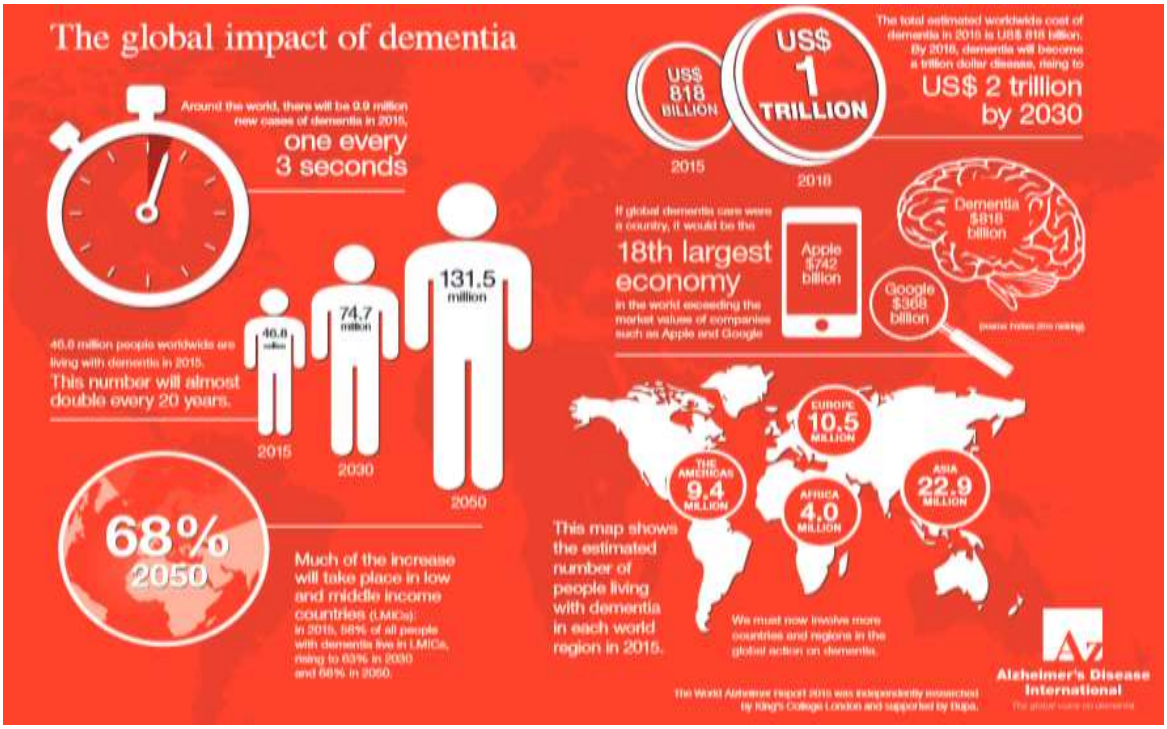
COGNITIVE DECLINE PARTNERSHIP CENTRE



Source: https://www.nnidr.gov.au/sites/default/files/files/Boosting%20Dementia%20Research%20Initiative%20Early%20Outcomes%20Report.PDF



Impacts (World)

- Close to 50 million people, doubling every 20 years estimated to be 131.5 million in 2050
- Much of the increase will be in low and middle income countries
- More than 50% of residents in Australian government-subsidised aged care facilities (RACF) have dementia
    - 44% of RACF residents with dementia also had a diagnosis of a mental illness
- In high-income countries only 20-50% of people with dementia are recognised and documented in primary care.
    - This rate is much lower in low- and middle-income countries where statistical reporting systems are less comprehensive

Which are effective treatments for dementia?

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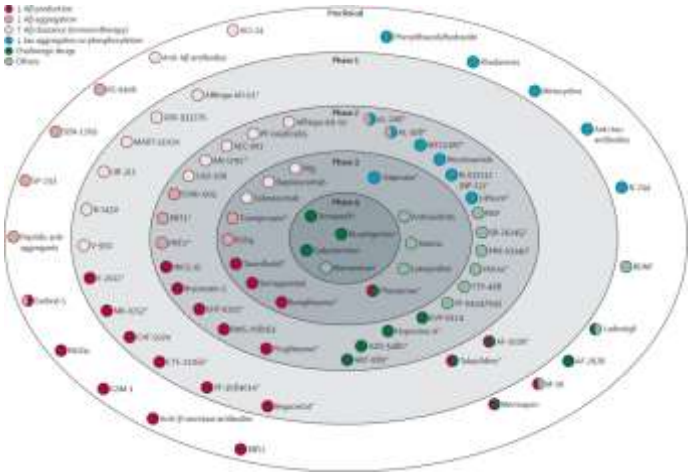
The decades long search for effective ways to treat or prevent Alzheimer's disease is littered with failures …

But precision medicine—an approach that is changing the treatment of cancer and spawning targeted therapies for a wide range of diseases—may open new avenues for the treatment of Alzheimer's disease.



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Treatment - drug

- There is no cure and limited treatments available for dementia
  - Current treatments for AD are not considered disease modifying because they only provide symptomatic improvements and are not associated with improvements on patient survival
  - Over 200 drugs have undergone clinical trials, however only 3 cholinesterase inhibitors (donepezil, galantamine and rivastigmine) and 1 receptor antagonist (memantine) have shown sufficient safety and efficacy
- Blow to future hopes for a better treatment this year:
  - Pfizer announced it was halting research efforts in this area after many years of failed trials
  - Others may follow

Experts: Try non-drug treatment first to manage dementia

BY ABC News Radio | August 2, 2018

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Future treatments

- Targets now being sought in mild cognitive decline and pre-dementia states
- As there is a larger population:
  - Cost likely to be high
  - Number needed to be treat likely to be high
  - There will be an imperative to show high value

Current work happening

- Even though there is no current therapy to evaluate, some groups of researchers and funders are preparing models for dementia:

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International Pharmaco-Economic Conference on Alzheimer's Disease

- IPECAD is the only conference that exclusively addresses issues related to the economic evaluation of drug treatments for Alzheimer's disease.
  - Group of people are developing an open access model for health economic evaluation of AD
- The model will describe progression from pre-dementia states such as at-risk or Mild Cognitive Impairment to dementia and death. The goal of the model is to enable the estimation of the impact of various innovations in Alzheimer's disease.
  - http://www.ronhandels.nl/category/projects/

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MODELLING DISEASE PROGRESSION AND ECONOMIC OUTCOMES OF DEMENTIA INTERVENTIONS: EXPLORING OPTIONS FOR A COMPLEX HEALTH PROBLEM

Jasmine R. F. Pwu, PhD
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An early exercise in Taiwan

INTERNATIONAL JOURNAL OF GERIATRIC PSYCHIATRY
Int. J. Geriatr. Psychiatry (in press)
Published online in Wiley InterScience
(www.interscience.wiley.com) **DOI**: 10.1002/gps.1842

Cost-effectiveness analysis of donepezil for mild to moderate Alzheimer's disease in Taiwan

Jong-Ling Fuh* and Shuu-Jiun Wang

Neurological Institute, Taipei Veterans General Hospital and National Yang-Ming University School of Medicine, Taipei, Taiwan

The choice of disease states

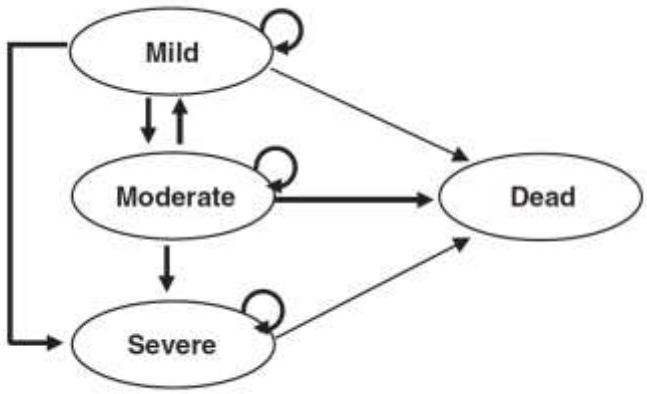
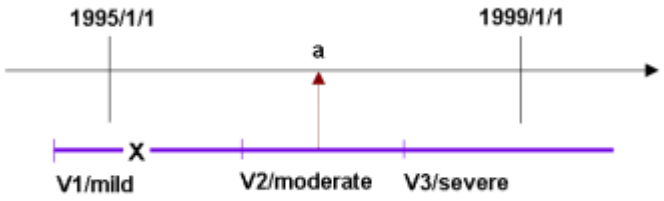


Figure 1. Model structure for the study.

RWE used



V1~V2: data abandoned
V2~a: at risk of moderate
a: presumed time moderate-severe occurs
a~1999/1/1: severe state

Transition probability estimation

INTERNATIONAL JOURNAL OF GERIATRIC PSYCHIATRY
Int J Geriatr Psychiatry 2004; **19**: 266–270.
Published online in Wiley InterScience (www.interscience.wiley.com). **DOI**: 10.1002/gps.1076

Measuring Alzheimer's disease progression with transition probabilities in the Taiwanese population

Jong-Ling Fuh[1]*, Raoh-Fang Pwu[2], Shuu-Jiun Wang[1] and Yu-Hsin Chen[2]

[1]*Neurological Institute, Taipei Veterans General Hospital and National Yang-Ming University School of Medicine, Taipei, Taiwan*
[2]*iStat Healthcare Consulting Co., Ltd, Taiwan*

Table 1. Demographic and neuropsychiatric measures

Measure	Patients taking CEIs ($n = 194$)	Patients not taking CEIs ($n = 171$)	p-value
Follow-up (months)	30.2 ± 17.9	27.4 ± 15.2	0.14
Male:Female	96:98	73:98	0.19
Education (years)	8.2 ± 5.2	7.8 ± 5.9	0.45
Age	73.1 ± 7.4	73.6 ± 8.6	0.58
MMSE score	16.9 ± 6.9	12.0 ± 7.9	<0.001*
CDR score of 1/2/3 or above	130/38/3	86/63/45	<0.001†
Delusion or hallucination (%)	18.0	39.2	0.003†

MMSE = Mini-Mental State Examination; CDR = clinical dementia rating scale.
*The finding was statistically significant via student t-test, $p < 0.05$.
†The finding was statistically significant via Chi-square test, $p < 0.05$.

Table 2. Estimated annual transition probabilities

Beginning state	Ending state			
	Mild	Moderate	Severe	Dead
Total patients ($n = 365$)				
Mild	0.690	0.234	0.054	0.022
Moderate	0.070	0.518	0.331	0.081
Severe	0.000	0.000	0.816	0.184
Dead	0.000	0.000	0.000	1.000
Patients not taking CEIs ($n = 194$)				
Mild	0.648	0.246	0.075	0.028
Moderate	0.086	0.399	0.395	0.120
Severe	0.000	0.000	0.791	0.209
Dead	0.000	0.000	0.000	1.000
Patients taking CEIs ($n = 171$)				
Mild	0.752	0.219	0.022	0.007
Moderate	0.046	0.696	0.243	0.015
Severe	0.000	0.000	1.000	0.000
Dead	0.000	0.000	0.000	1.000

Effectiveness estimation

Table 3. Hazard ratios associated with sex, age, psychotic symptoms, and CEI use

Transition	Male sex	Age ≥ 75 years	Psychotic symptoms	CEI use
Mild to moderate	0.96 (0.62–1.48)	1.00 (0.97–1.03)	0.99 (0.60–1.62)	0.35* (0.22–0.55)
Mild to severe	0.71 (0.35–1.43)	0.98 (0.94–1.02)	0.98 (0.45–2.11)	0.13* (0.05–0.34)
Moderate to severe	0.78 (0.46–1.32)	0.99 (0.96–1.01)	1.03 (0.81–1.31)	0.28* (0.15–0.52)
Mild to dead	4.03* (1.10–14.74)	1.08 (0.99–1.17)	1.71 (0.52–5.58)	NA
Moderate to dead	2.53 (0.83–7.66)	0.99 (0.93–1.05)	1.05 (0.74–1.49)	NA
Severe to dead	2.95 (0.85–10.21)	1.03 (0.96–1.10)	2.97 (0.85–10.38)	NA

Numbers in parentheses are 95% confidence intervals.
CEI = cholinesterase inhibitors; NA = not applicable.
*$p < 0.05$.

Results

Table 2. Cost-effectiveness analysis results of base case analysis over a 5-year study span

Comparison	Total cost	Incremental costs	QALY	Incremental QALYs	Incremental cost-effectiveness ratio
non-pharmacological	65,373		1.687		
Donepezil	57,220	−8,153	2.211	0.525	Dominant

QALY = quality-adjusted life years.

Table 3. Cost-effectiveness analysis results from the healthcare perspective over a 5-year study span

Comparison	Total cost	Incremental costs	QALY	Incremental QALYs	Incremental cost-effectiveness ratio
non-pharmacological	4,750		1.687		
Donepezil	8,427	3,677	2.211	0.525	7,009

QALY: quality-adjusted life years.

Challenges faced

- Model structure
- Model types
- Data
  - Transition probability
  - Costs
  - Endpoint choices – QALYs?
- Perspectives

Review of the modeling CEA studies

Modeling: targeted population

- Mild-to-moderate (or moderately severe) AD
- Moderate-to-severe AD
- Mild-to-moderate and Moderate-to-severe AD
- General AD living in the community
- Mild cognitive impairment (MCI) due to AD

Concept models

By disease severity according to:	Modeling techniques
• Cognitive function ▫ CDR ▫ MMSE	Markov models, microsimulations
• Cognitive function and activities of daily living (DAL) ▫ MMSE and basic ADL (B-ADL) / instrumental ADL (I-ADL)	Markov models
• Patients' location of care ▫ Not institutionalized and institutionalized	Markov models, Survival partition model
• The need of FTC	Markov models
• Continuous interrelated changes over time in cognition, behavior, and function	Discrete event simulation

(Hernandez et al, 2016)

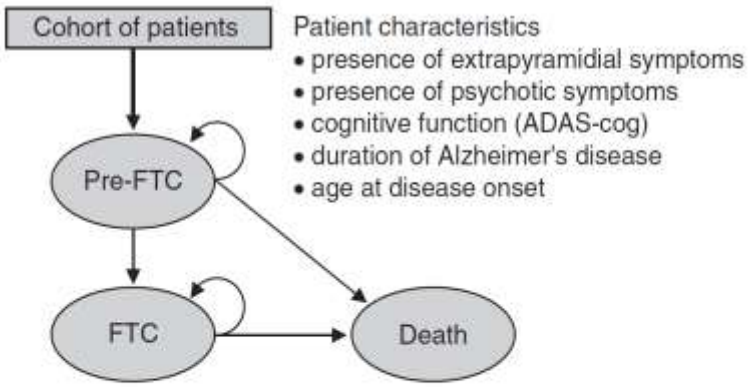


Fig. 1. Outline view of the cost-effectiveness model. **ADAS-cog** = Alzheimer's disease assessment scale-cognitive subscale; **FTC** = full-time care.

Pharmacoeconomics 2005; 23 (12)

Data source

Mix of the following…

- RCT (and placebo arm)
  - And open-label extension study
- Longitudinal study

Endpoints of CEA

- Non-severe life years gained
- QALY gained

Utility – big issue!

Table I. Overview of Markov models of the use of donepezil in mild-to-moderate Alzheimer's disease (AD)

	O'Brien et al [60]	Lanctôt et al [100a]	Neumann et al [61]	Stewart et al [62]
Trial details				
Country	Canada	Canada	US	UK
Time horizon[b]	5y (24-wk cycles)	Progression of AD through 4 stages until death	1y (6-wk cycles)	5y[c] (6-mo cycles)
Costs included	Nursing home care, community services, medications, unpaid caregiver time	Medication, laboratory tests, physician visits (in- and outpatient), institutionalisation costs	Direct medical and nonmedical costs[a], unpaid caregiver time	Not specified but included direct costs and informal care
Perspective	Societal	Government payer	Societal	Societal
Year of costing	1997	NR	1997	1997
Discounting rate (per annum)	5%	3%	3%	6%
Donepezil dosage (mg/day)[b]	5	NR	5/10[b]	5
Stage of disease at drug initiation[b]	Mild-to-moderate	Mild	Mild	Mild
Results				
Total treatment cost (per patient for the study period)				
Donepezil	$Can80 305	$Can97 668	$US50 239	£45 119
No donepezil	$Can81 187	$Can105 204	$US49 750	£44 278
Donepezil vs no donepezil	↓ $Can882	↓ $Can7506	↑ $US489	↑ £841
Outcome (per patient)				
Parameter	Expected years with non-severe AD[a]	QALYs	QALYs	Expected years with non-severe AD
Donepezil	2.41	2.27	0.678	1.69
No donepezil	2.21	1.96	0.663	1.57
Donepezil vs no donepezil	↑ 0.20	↑ 0.31	↑ 0.015	↑ 0.12
Sensitivity analyses				
Sensitive to:	Appropriate prescribing of donepezil, mortality rate, disease severity at treatment initiation	Disease severity at treatment initiation, duration of terminal disease stage, institutionalisation rates	Extent and duration of drug effect, severity of disease at treatment initiation, drug cost	Mortality rate, discounting rate

a Abstract and personal communication (K. Lanctôt, Department of Psychiatry, Health Outcomes and Pharmacoeconomics Research Centre, Sunnybrook and Women's College Health Science Centre, Toronto, Ontario, Canada, 19 May 1999).

b For results presented in this table. Analyses may also have included results for other time horizons, dosages or disease stages (see text).

What years did the data used for modelling disease progression come from?

Hybrid approach to model dementia progression and evaluate dementia interventions

Kim-Huong Nguyen, Tracy Comans and Dylan Knowles

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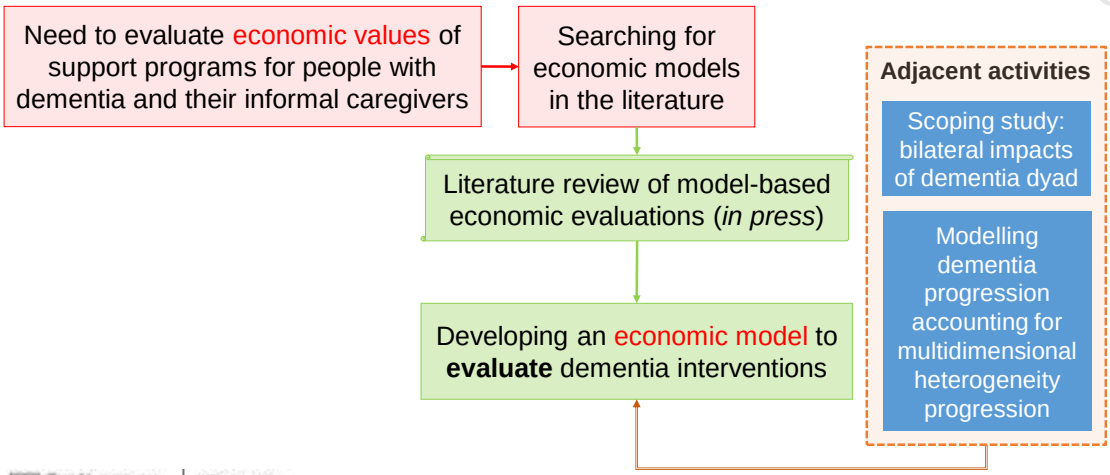
Research rationale



Objectives of the model

- Originally, we wanted a model that can evaluate both pharma and non-pharma interventions:
  - For pharma interventions, the intervention cost is often contained within the cost of medication → so scaling up is not a real issue
  - For non-pharma intervention (NPI): largely labour cost + issues like availability of services in a particular geographic location (equity) + more variability in intervention delivery due to human factors (efficacy) → scale-up is more challenging

Objectives of the model

- Then we wanted something more because:
  - We think the role of carers is more than just a passive “collection of costs and QALYs” (they impact the progression and likelihood of the person with dementia moving into a residential aged care facility)
  - There is a real substitution effect between NPI and care time/resources spent by informal carers (regardless of intervention efficacy/effectiveness)
  - The trade-off between funding entities are also evident (not just in dementia): high quality / comprehensive aged care and primary care provision often benefits hospitals and EDs by reducing demand; but high and more comprehensive care means higher spending …

Modelling choices

Source: Borshchev (2016) The big book of simulation

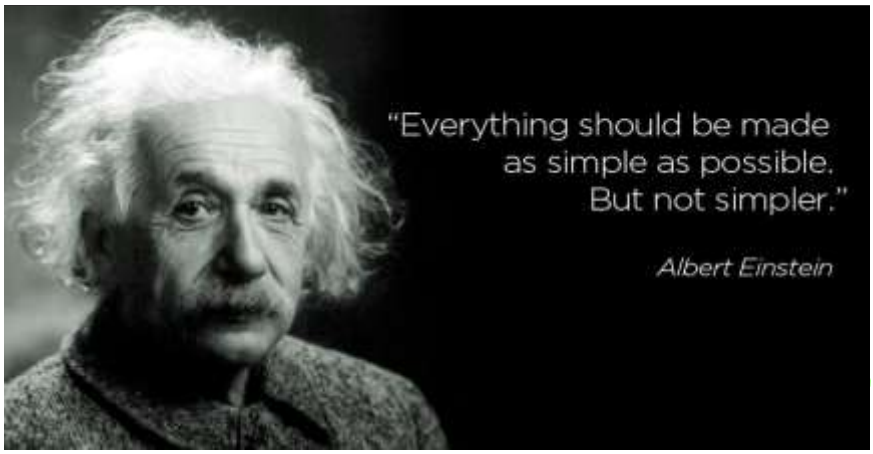
Our obvious option – Markov model

- **Person with dementia** → dementia progression modelled by a standard Markov method (with health states)
  - Accumulate costs and outcomes (LYs, QALYs) for each health states (average costs and outcomes per state plus events)
- **Carers** → changes of health status (dependent on disease progression of the person with dementia)
  - If using a Markov method, they can accumulate costs and outcomes by health states
  - Or a simpler option, they can be treated as a cost or quality accumulator for the person with dementia (currently done in the literature)
- All services can be modelled as average costs (severity-adjusted) per HS or average event cost (e.g. hospital admission, temporary respite care)

Challenges

- Model two Markov processes and allow them to interacts with each other
  - This means expanding the disease progression model into a large number of health states or branches with the carer's health state nested within the person with dementia's health states
- Allow for resource constraints (i.e. patients competing for resources and queuing) within a Markov model
  - When we looked for modelling options, TreeAge does not offer this function yet – now you can do some quasi-DES
  - If one DES process is difficult to do, don't know how we can manage 2–3 of these (hospital, aged care services in the community, nursing home)
- Understand requirements for scale-up or complementary and substitutionary effects between services

Modelling choices



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So we revised our objective

Need to evaluate economic values of support programs for people with dementia and their informal caregivers

→ Searching for economic models in the literature

↓ Literature review of model-based economic evaluations (*in press*)

↓ Developing a hybrid model to capture **dementia progression** + **service utilisation** to **evaluate** dementia interventions

Adjacent activities

- Scoping study: bilateral impacts of dementia dyad
- Modelling dementia progression accounting for multidimensional heterogeneity progression

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Hybrid (multi-method) modelling

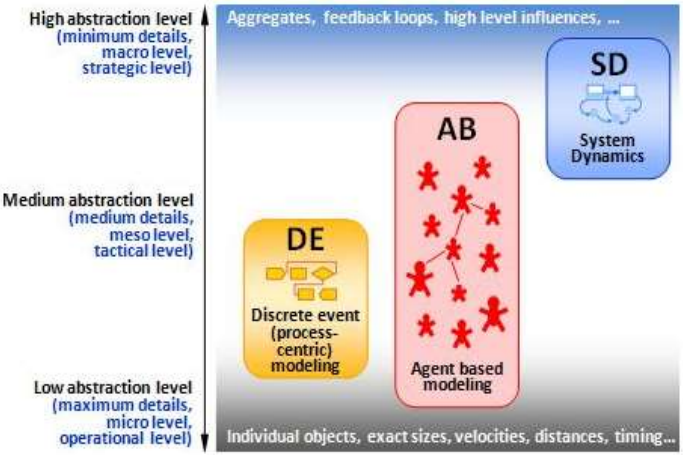
These methods are the different viewpoints that a modeller can take when mapping the real world system into the world of models.

Agent based model	Discrete event simulation	System dynamics

Model applications …

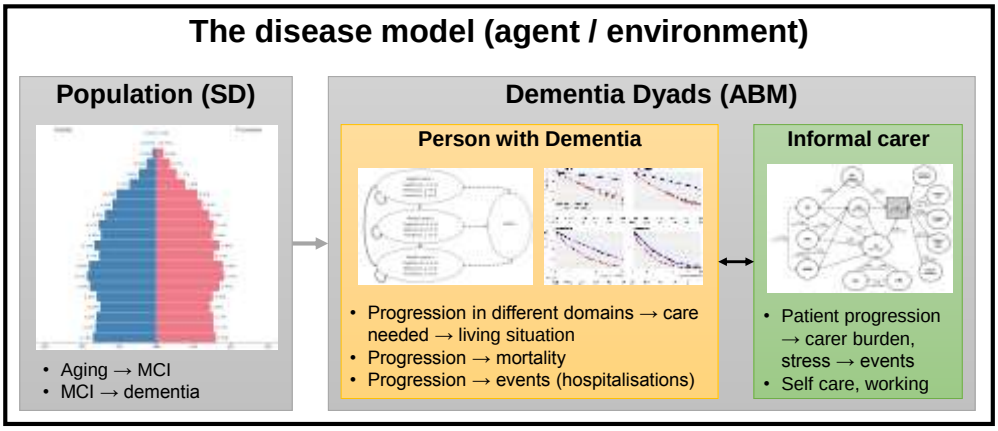
SD inside agent
(e.g. patient making aged care purchase)

Agents become entities
(e.g. patients going to hospital)



Source: Borshchev (2016) The big book of simulation

Core dementia component



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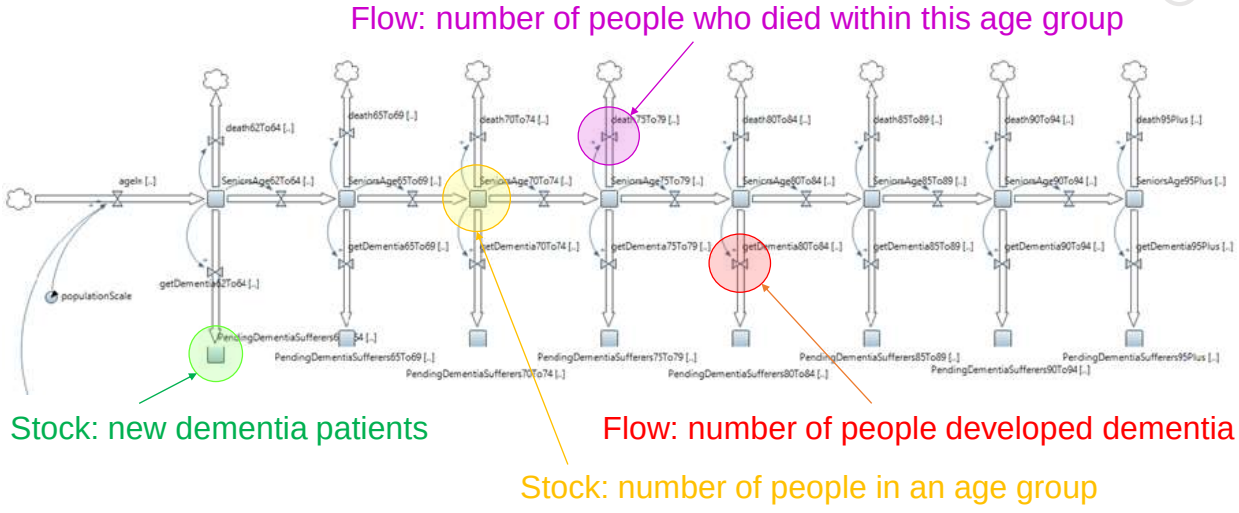
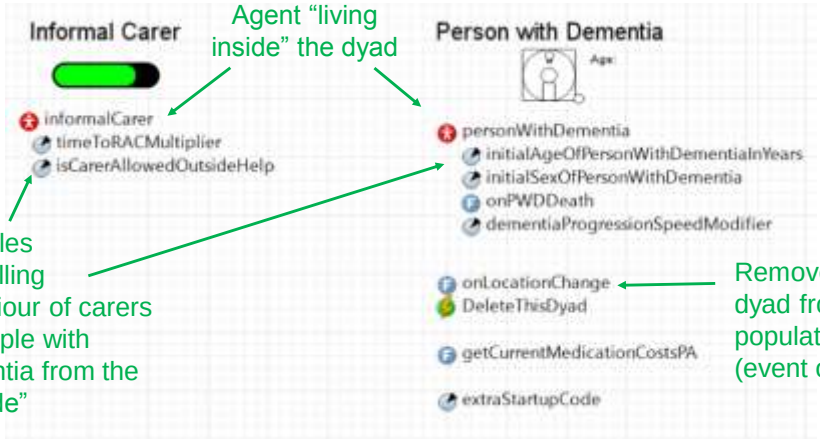
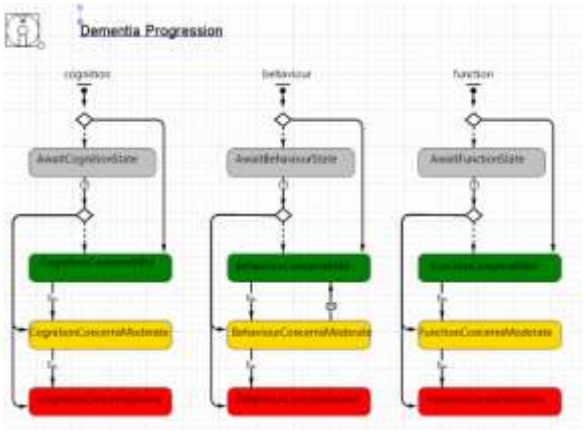
Population pyramid (system dynamics)



Dementia dyads



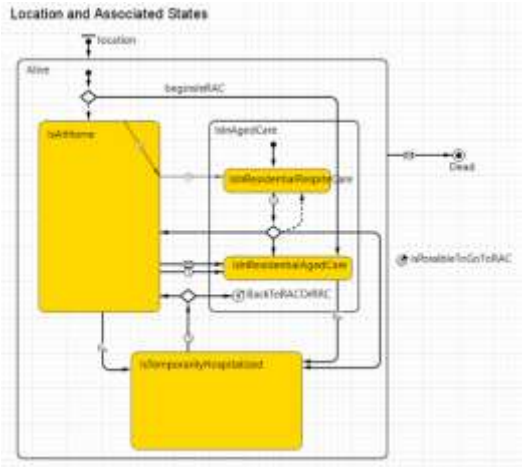
Person with dementia (ABM)



- 27 health states using 3 state charts
- Transition probabilities informed by a table function
- Dementia patients can enter the disease process at any severity level
- (They are generated from the population pyramid)

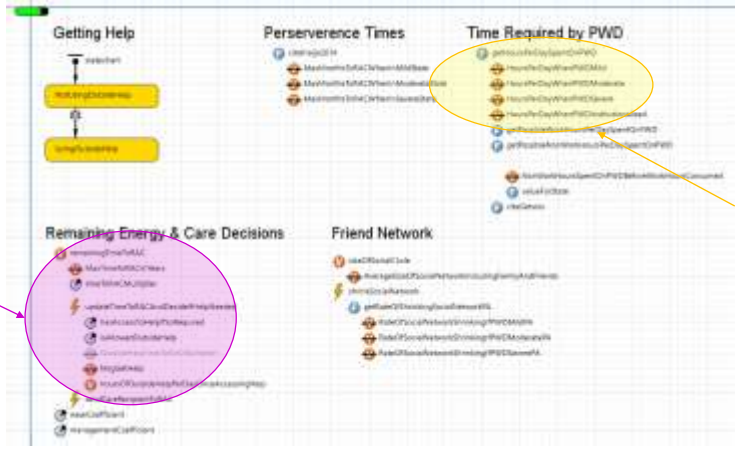
Person with dementia (ABM)

- They are able to live either at home (community) or RACF (nursing home) or temporarily in hospital.
- The location depends on:
  - Their health states (red-green-yellow)
  - The carer's ability to support them at home → interaction with the carer "agent"



Informal carers (ABM)

Functions, variables control how the carer recharge and remains providing care



Functions, variables that allow dementia progression impact on informal carers

Future plan – next model iteration

- ABM can accommodate continuous changes in health conditions (by changes in clinical indicators such as MMSE, ADL, NPI, etc.)
  - We will change the discrete (27) health states (statecharts) using table functions that incorporate a system of questions estimating dementia progression over time
  - This will allow us to incorporate trial data directly to the models if trials collect clinical indicators used in the model (there is always the possibility to having extra functions and to turn them off when not needed)
- Incorporate bilateral impacts of dementia patients and carers
  - Using the links identified in the literature and using results of the literature as cross-validation data
- Develop the remaining components

Hybrid model challenges

- Complex models are data hungry and computational expensive
  - Ours is no different: at the moment, we have a lot of place holders and most inputs are sourced from the literature – this can be improved gradually when more data becomes available
- Building a hybrid model is time consuming
  - It has been a steep learning process for us. The software is very visual with lots of functions (great) but allowing for complex rules and interactions requires extra Java coding (challenging)
- If the question is "whether or not a intervention is cost-effective, this method is possibly unnecessary …
  - But if we want to generate knowledge on what works and what doesn't – and to understand economic impact (welfare analysis) then maybe it is not so?

Measuring outcomes in dementia: A critical perspective

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Introduction

- Measuring health and quality of life outcomes in dementia is challenging:
  - Difficulty in self and proxy report
  - Difficulty in measuring subjective concepts
  - Wide range of impacts of condition on the person's life
  - Interaction of co morbidities
- Valuation of outcomes also requires careful consideration
- Both generic and condition specific measures used in dementia, and both have advantages and disadvantages
- This may lead to issues with the accuracy of QALYs used in dementia

Generic measures used in dementia

Instrument	Domains	Number of health states	Number of studies
EQ-5D	Mobility, self-care, usual activities, pain/discomfort, and anxiety/depression	243/ 3,125	45
HUI 2/3	Vision, hearing, speech, ambulation, dexterity, emotion, cognition, and pain	24,000/ 975,000	15
QWB	Mobility, physical activity, and social activity	1,170	4
15D	Mobility, vision, hearing, breathing, sleeping, eating, speech, elimination, usual activities, mental function, discomfort and symptoms, depression, distress, vitality, and sexual activity	31 billion	3
AQoL	Illness, independent living, social relationships, physical senses, and psychological well-being	16.8 billion	2

Li L; Nguyen K-H; Comans TA; Scuffham P. Utility-Based Instruments for People with Dementia: A Systematic Review and Meta-Regression Analysis. Value in Health, 21(4): 471 - 481

Psychometric properties of generic measures

		EQ-5D	HUI2/3	QWB	AQoL	15D
Feasibility	Average patient-rated completion time (min)	4.5	16.3	18.7	NA	NA
	Average proxy-rated completion time (min)	2.3	7.7	11.3	NA	NA
	Average missing items	1%	19%	24%	NA	NA
Precision	Shows ceiling effect	Yes	No	No	No	NA
	Shows floor effect	No	Yes	No	No	NA
Reliability	Test-retest reliability	Moderate	Moderate	Strong	Weak	Weak
	Inter-rater agreement	Weak	Weak	Weak	Weak	Weak
Validity	Number of relevant attributes included	10	11	25	NA	NA
	Convergence validity	Strong	Inconclusive	Moderate	Moderate	Weak
	Known-group validity according to MMSE	Moderate	Inconclusive	NA	Moderate	NA
Responsiveness	Responsiveness	Medium	Low	Low	Low	NA

EQ-5D-5L - Improving generic measurement?

- English value set derived using TTO and DCE
- Ranges from -0.285 to 1 (Devlin et al 2018)
- Easton et al (2018) - 5L demonstrated strong known group validity in relation to clinically recognised cognition/physical functioning thresholds

MOBILITY
I have no problems in walking about
I have slight problems in walking about
I have moderate problems in walking about
I have severe problems in walking about
I am unable to walk about

SELF-CARE
I have no problems washing or dressing myself
I have slight problems washing or dressing myself
I have moderate problems washing or dressing myself
I have severe problems washing or dressing myself
I am unable to wash or dress myself

USUAL ACTIVITIES (e.g. work, study, housework, family or leisure activities)
I have no problems doing my usual activities
I have slight problems doing my usual activities
I have moderate problems doing my usual activities
I have severe problems doing my usual activities
I am unable to do my usual activities

PAIN / DISCOMFORT
I have no pain or discomfort
I have slight pain or discomfort
I have moderate pain or discomfort
I have severe pain or discomfort
I have extreme pain or discomfort

ANXIETY / DEPRESSION
I am not anxious or depressed
I am slightly anxious or depressed
I am moderately anxious or depressed
I am severely anxious or depressed
I am extremely anxious or depressed

Devlin N, Shah K, Feng Y, Mulhern B, van Hout B. Valuing Health-Related Quality of Life: An EQ-5D-5L Value Set for England. Health Economics. 2018 doi: 10.1002/hec.3564.
Easton T, Milte R, Crotty M, Ratcliffe J. An empirical comparison of the measurement properties of the EQ-5D-5L, DEMQOL-U and DEMQOL-Proxy-U for older people in residential care. Qual Life Res. 2018;27(5): 1283-94.

What about condition specific measures?

- Condition specific measures have been developed in many areas where generic instruments have been shown not to perform well
- A range of instruments available/being developed in dementia:
  - DEMQOL-U and DEMQOL-Proxy-U (Mulhern et al 2012)
  - Dementia Quality of life Index (DQI; Arons et al 2016)
  - Alzheimers Disease – Five Dimension (AD-5D; Nguyen et al 2017)
- Each has different criteria, development methodology and valuation method
- Evidence of psychometric performance is limited at present

Mulhern B, Rowen D et al (2012). Development of DEMQOL-U and DEMQOL-Proxy-U: Generation of preference based indices from DEMQOL and DEMQOL-Proxy for use in economic evaluation. Health Technology Assessment, 17(5).
Arons A et al (2016). A Simple and Practical Index to Measure Dementia-Related Quality of Life. Value in Health.
Nguyen K, Mulhern B et al (2017). Developing a dementia-specific health state classification system for a new preference based instrument AD-5D. Health and Quality of Life Outcomes, 15: 21.

How do they compare?

DEMQOL-U	DQI	AD-5D
• Developed from 29 item DEMQOL using psychometric and Rasch analysis • 5 dimensions, 4 levels (1024 states)	• Used conceptual framework, qualitative work and expert input • 6 dimensions, 3 levels (729 states)	• Developed from 15 item QOL-AD using psychometric and Rasch analysis • 5 dimensions, 4 levels (1024 states)
• Valued using TTO with UK general population • Range from 0.986 to 0.243	• Valued using paired comparisons with professionals and general population • Range from 1 to -0.103	• Valuation using DCE with duration and Best Worst Scaling ongoing in Australia • Initial model range 1 to -0.7
		

Valuation of dementia health states

- Range of approaches used for valuation in the general population and people with dementia
- Each has specific methodological features that impact value set characteristics

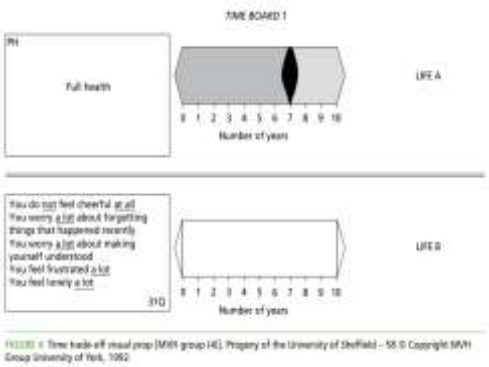

Table 1 Presentation of a DCE task		
	Health description A	Health description B
	You have poor physical health	You have excellent physical health
	You have good mood	You have fair mood
	You have fair memory	You have fair memory
	You have good living situation	You have fair living situation
	You have good ability to do things for fun	You have good ability to do things for fun
	You live in this state for 4 years and then you die	You live in this state for 7 years and then you die
Which scenario do you think is better?		

Table 2 Presentation of a BWS task		
Best	Health description	Worst
0	You have good memory	0
0	You have poor mood	0
0	You have excellent physical health	0
0	You have fair living situation	0
0	You have fair ability to do things for fun	0

Valuation by people with dementia

- Evidence that valuation tasks are cognitively complex and difficult to complete. Can lead to incomplete data and compromised data quality
- Evidence of differing preferences (people with dementia value states lower than the general population using TTO). Leads to different value sets?
- Further comparisons with other methods ongoing

Discussion (1)

- Measurement of QoL in dementia an ongoing challenge given population and range of impacts of condition
- Ongoing qual work to understand how the measures perform.
- Condition specific measures should be more sensitive given content is directly related to condition. Further psychometric evidence at descriptive and value set level is required
- Using condition specifics can compromise comparability, so an option is to use both types of measures
- What about wider outcomes? ASCOT? ICECAP? eQALY?

Discussion (2)

- Valuation is also a challenge. Further w work to understand the limits of the methods in patient populations is required
- Collecting a sample large enough for full patient value set is
- May lead to revised methods/protocols that are amenable to completion
  - e.g. valuing small numbers of states or partial health states?

Your thoughts?

- Should there be new inter-country projects to update estimates of disease progression?
- Is it appropriate to use generic utility measures for dementia?
- Should we incorporate carer QALYs in economic models? Why or why not?
- How will we be able to fund new therapies for pre-dementia?