

# The Economics of Dementia Care

Optimizing the Impacts of National Dementia Strategies  
UK-Korea Workshop  
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# Acknowledgements:

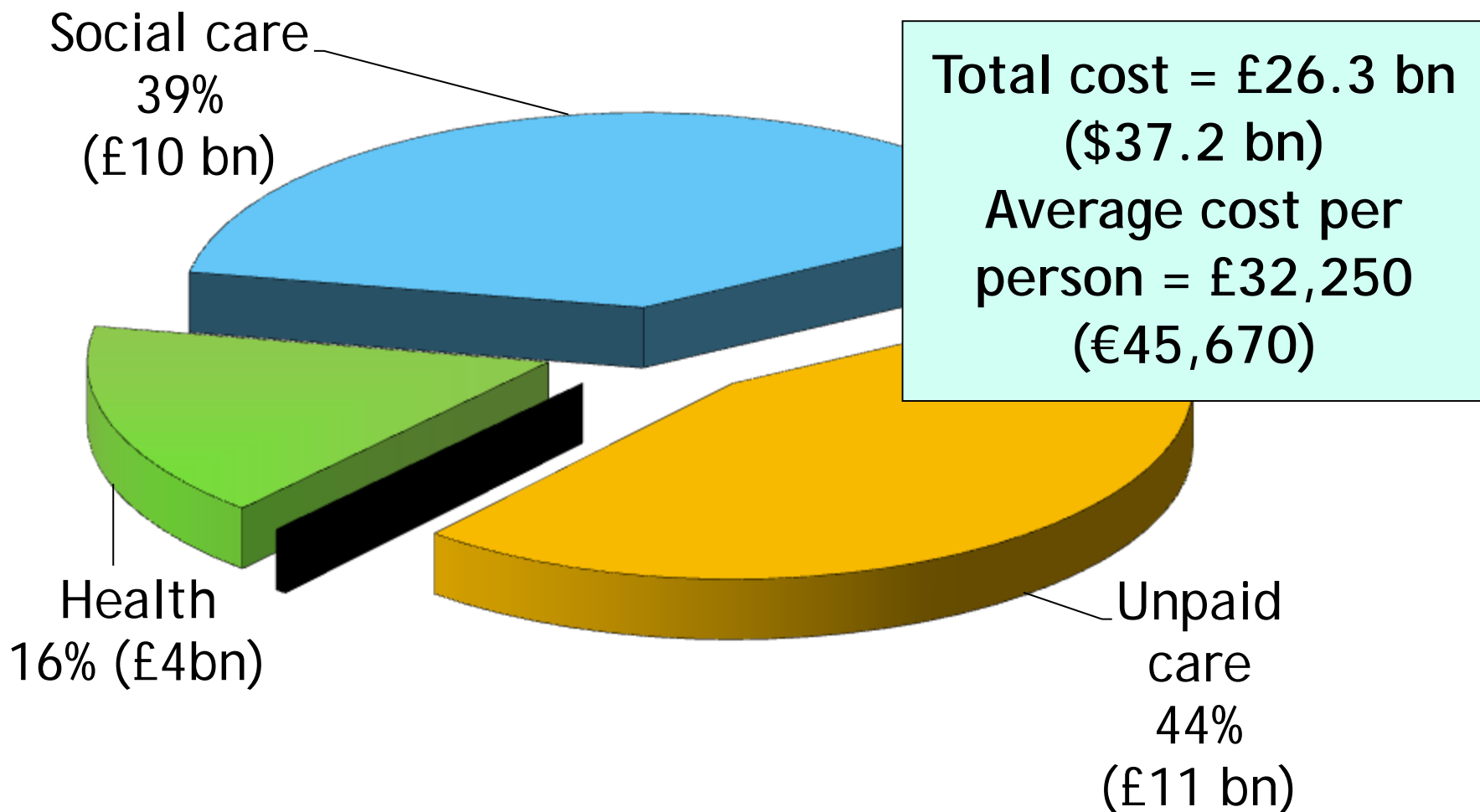
- Some of these slides here have been borrowed from presentations by **Martin Knapp**.
- The opinions, comments and interpretations of all the material presented here do not reflect the views of my current and former co-authors and research funders.

# The future is by definition uncertain...

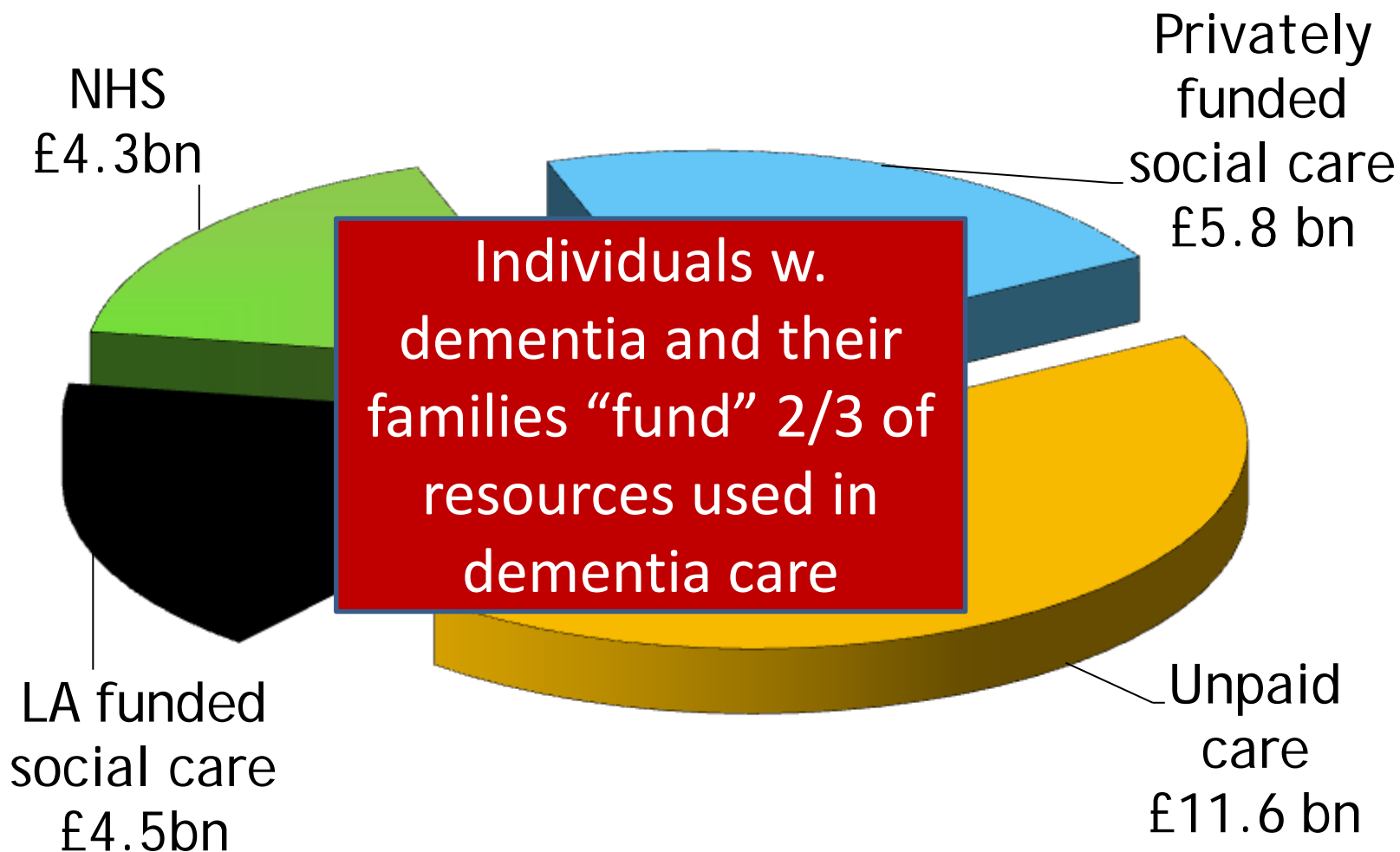


... but one thing we know is that we will need to spend much more on the care of people with **dementia** than we are spending today.

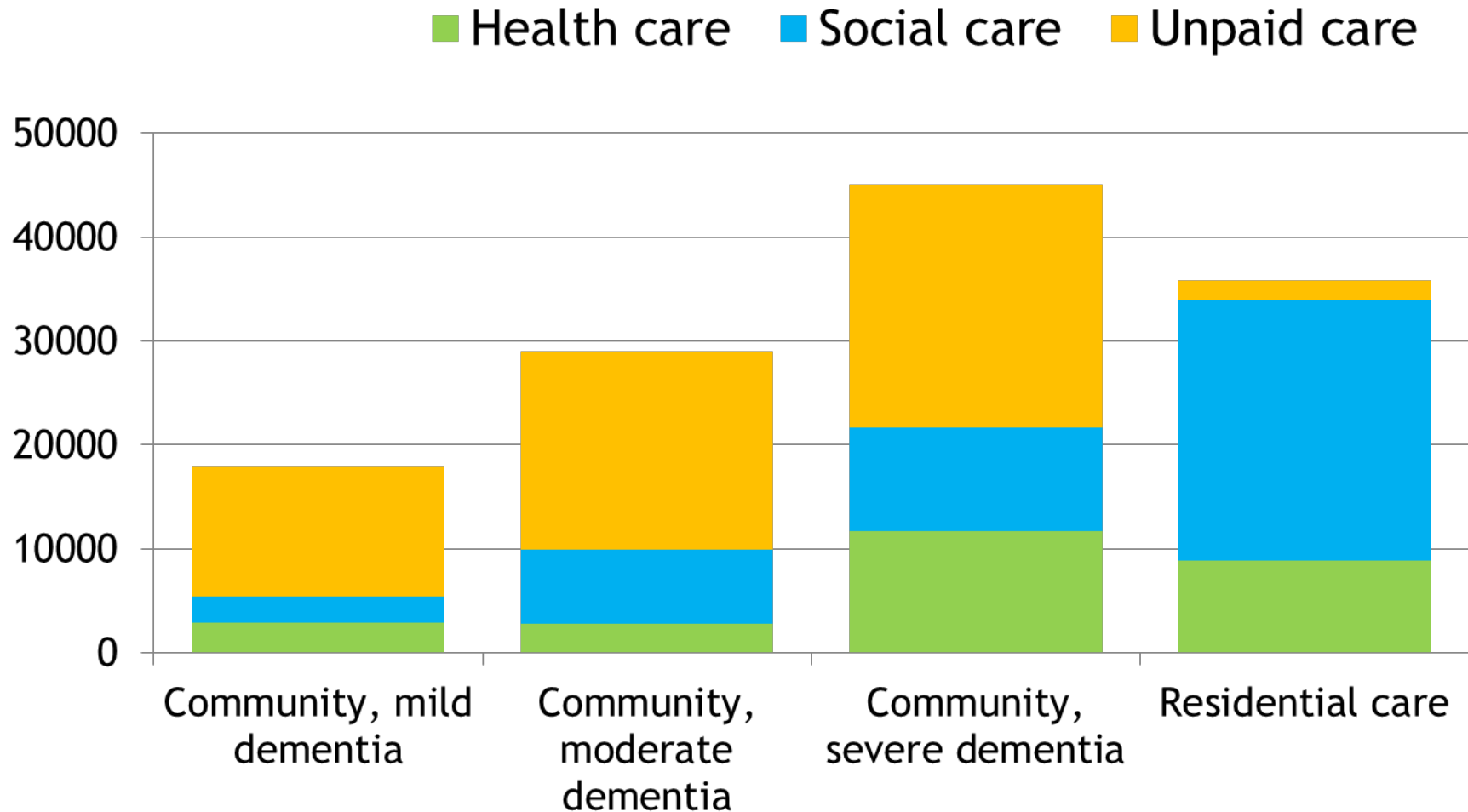
# The costs of Dementia in the UK



# Who bears the costs of dementia?



# The cost of dementia in the UK today - per person per year (£), 2013.



# Future prevalence projections (UK)

There are **816,000** people with dementia in the UK today



UK prevalence  
2012 to 2051

**Although the age-specific prevalence rate might now be slowing, the total number will increase.**

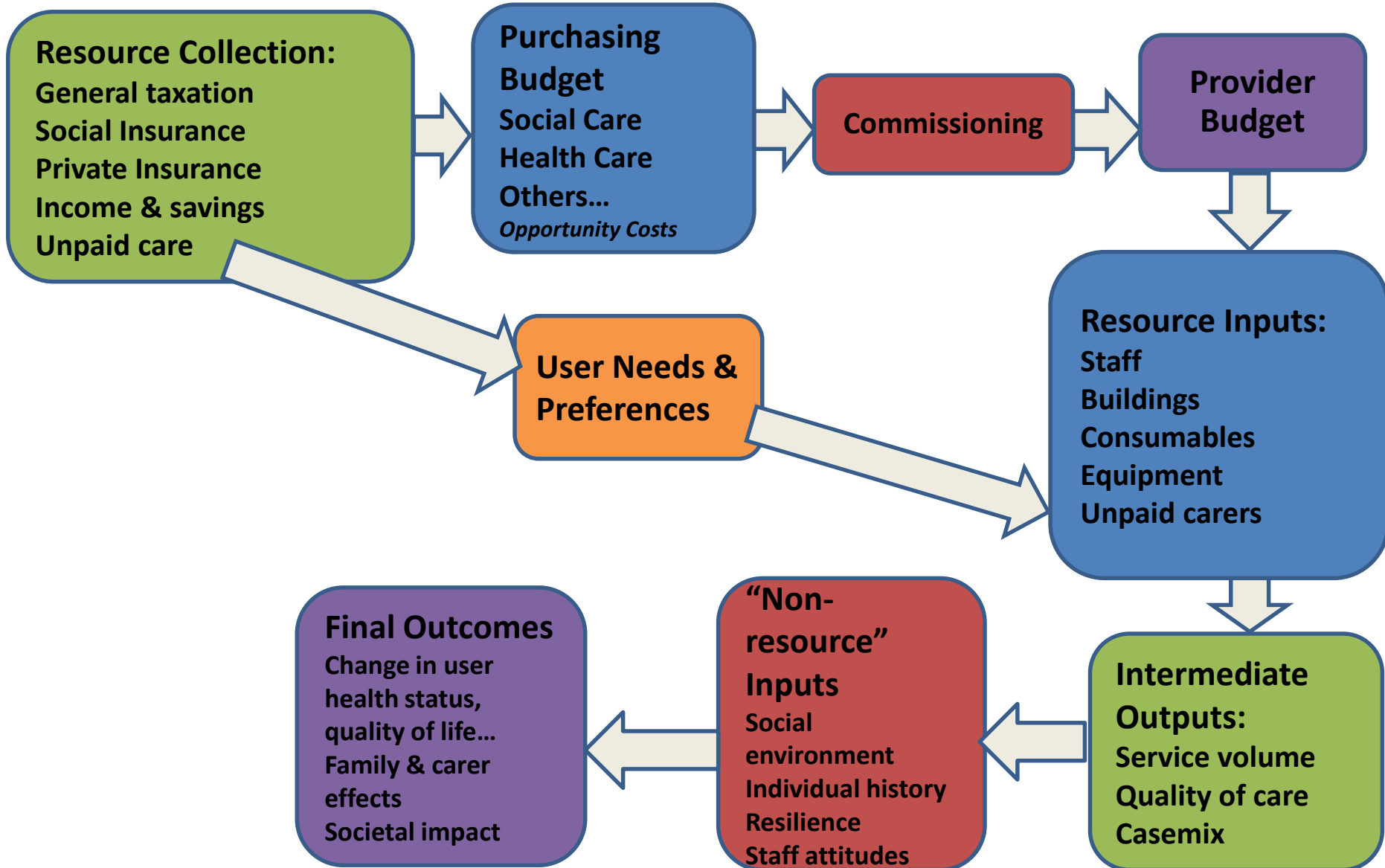
**Hence: big increases in reliance on unpaid carers; & big increases in health & social care service costs**

Economics and dementia care

# **THE PRODUCTION OF WELFARE**

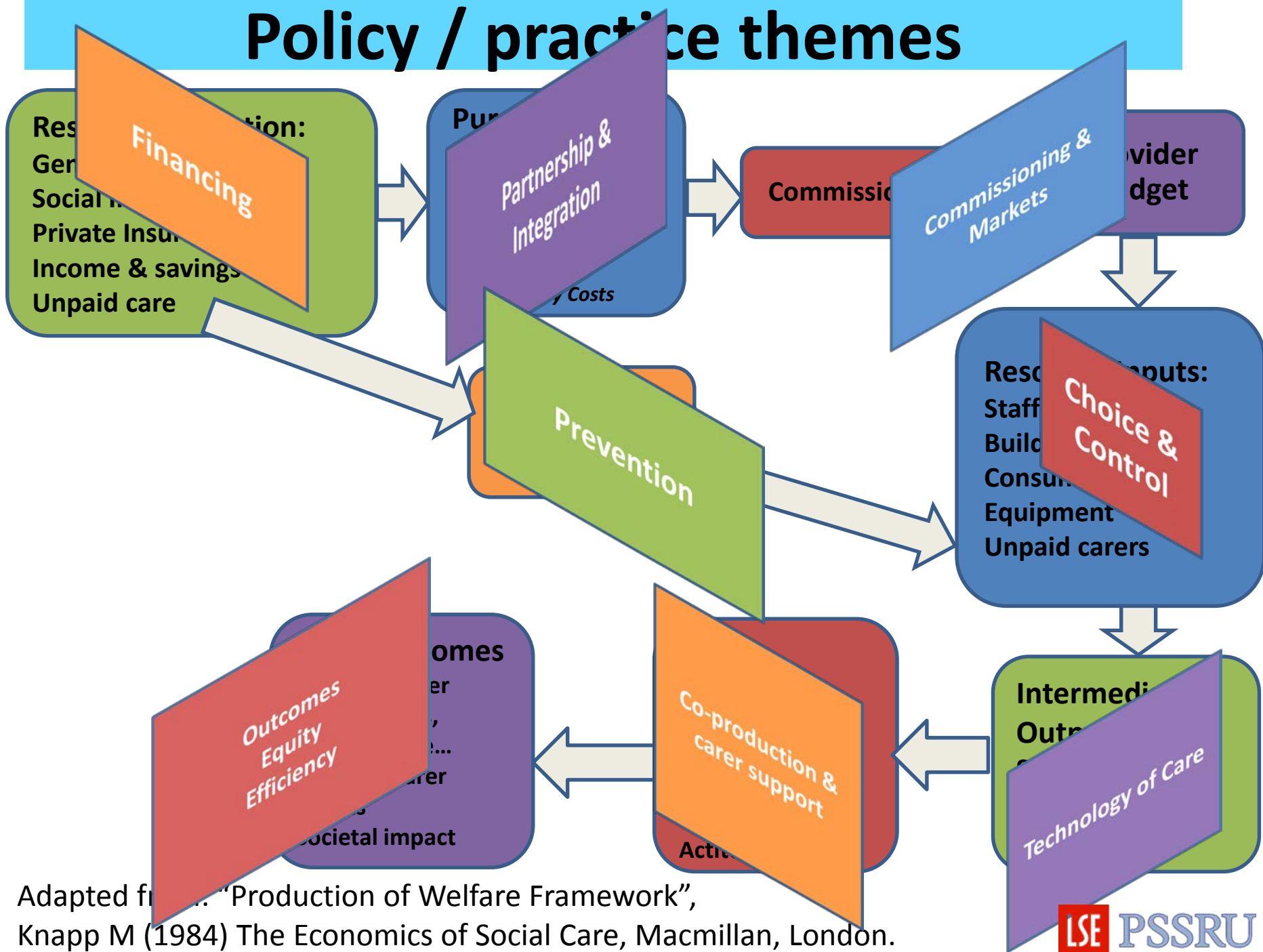


# The Production of Welfare



Adapted from: "Production of Welfare Framework",  
Knapp M (1984) *The Economics of Social Care*, Macmillan, London.

# Policy / practice themes



Adapted from ... "Production of Welfare Framework",  
 Knapp M (1984) The Economics of Social Care, Macmillan, London.

**THE KEY QUESTION TODAY IN  
DEMENTIA CARE:**

# How can we afford to meet the future needs of people with dementia and their carers?

1. Finding ways of decreasing the future numbers of people affected by dementia
2. Ensure we have adequate care financing mechanisms
3. Make sure that we “spend well” on care

# 1. Decreasing the future numbers of people affected by dementia

- Helping/encouraging people to adopt healthier lifestyles to reduce the risks.
- Better management of other chronic health conditions.
- Drugs that moderate symptoms and, eventually, finding a disease-modifying treatment!

## 2. Ensuring we have adequate financing mechanisms

- 2/3 of the £26.3 billion cost of dementia in UK shouldered by carers and people with dementia (Dementia UK 2014, published by the Alzheimer's Society).
- Public expenditure on social care in England has not been keeping up with increased need\*

\*Between 2005/6 and 2012/13, after standardising for changes in need it has been estimated that net social care expenditure decreased by almost £1.5 billion, as a result of reductions in coverage: Fernandez J-L. Snell T. and Wistow G. (2013). Changes in the Patterns of Social Care Provision in England: 2005/6 to 2012/13. PSSRU Discussion Paper 2867.

<http://www.pssru.ac.uk/archive/pdf/dp2867.pdf>

# Determinants of future dementia care costs:

- Demographic changes.
- Changes in prevalence (by severity).
- Availability (and propensity to provide) unpaid care.
- Structure of the care system.
- **Financing system: generosity of public finance**
- Relative price of care and other goods and services.
- Economic growth and other macroeconomic factors.
- Values and public expectations about the quality, range and level of care.
- Other factors? Quality/adaptability of housing, pensions...

# LTC systems and economic sustainability

- Although **demography** is a major driver of LTC expenditure, other changes, such as **shifts from unpaid care to paid care** may have an even bigger impact in a number of European countries.
- Affordability is largely measured as a % of GDP (mostly from “official” economic forecasts), different **rates of economic growth** will be the key to what can or cannot be afforded.



# 3. Spending well on dementia care

**Distinction between “good” and “bad” costs of dementia:**

**“bad costs:** care and treatment due to

- late or missing diagnosis
- unavailability of good quality care
- unplanned crisis admission into hospital, or
- breakdown in community support resulting in earlier admission into a care home than necessary”.

**“good costs:** Appropriate and effective treatment and care responses to needs of individual and carers, following consultation around their preferences”.

<http://www.pssru.ac.uk/blogs/blog/what-does-dementia-cost/> by Martin Knapp

# How to “spend well”

We can use evidence from research to help shift the balance from bad to good costs.

# MODEM

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

2014-2018

@MODEMProject

Improving  
Dementia Care  
ESRC • NIHR



US  
University of Sussex

UNIVERSITY OF  
Southampton

LSE

ILC

Newcastle  
University

LSE PSSRU

# A collaborative study

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# The challenge

How can we provide *high quality care and support* for people with dementia and their carers in ways that are:

- *acceptable* to them
- at a cost considered by society to be *affordable*.

# Research questions

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

# Interventions, costs and outcomes

- ***Interventions of interest***
  - Prevention (e.g. lifestyle, nutrition, exercise etc.)
  - Treatments (e.g. medications, cognitive stimulation and other therapies)
  - Care and support arrangements (e.g. telecare/telehealth, respite, carer training and support programmes, training for care staff)
- ***Costs and outcomes***
  - All resource impacts (health, social care and other), including resources of people with dementia, families and communities.
  - Quality of life, clinical and lifestyle effects
  - Carer outcomes

# Intervention - e.g. CST

- ***Intervention***

- Cognitive stimulation therapy for 8 weeks
- Includes reality orientation, reminiscence therapy) compared to usual care and support.

- ***Costs and outcomes (8-week follow-up)***

- CST had better outcomes (cognition and QOL), but also marginally higher costs
- CST looks more cost-effective than usual care
- Maintenance CST (another 24 weeks) – good QOL and ADL outcomes
- ... also looks cost-effective (not published yet)



# Intervention - e.g. START

- *Intervention*
  - Individual therapy programme (8 sessions with psychology graduate + manual)
  - Techniques to understand and manage behaviours of person they cared for, change unhelpful thoughts, promote acceptance, improve communication, plan for future, relax, engage in meaningful enjoyable activities.
- *Costs and outcomes (8-month & 24-month follow-up)*
  - More effective than standard care and no more costly (from NHS and societal perspectives) – at 8m and 24m
  - Cost-effective when looking at costs and outcomes **for carers** – again over both 8m and 24m
  - Reduces care home admission rate for people with dementia over 24m

# MODEM Project: methods

**Engage** with people with dementia, carers and other stakeholders at all stages.

## **Project:**

- N of people with dementia over the period to 2040
- family or other unpaid support available to them
- costs and outcomes of services and unpaid support.

**Review evidence** of effective and cost-effective interventions for people with dementia and carers (incl. on-going studies)

**Collect data** to cross-walk between measures in studies and population surveys

**Gather experiential evidence** from people with dementia, carers

**Simulate wider roll-out** of evidence-based interventions on outcomes, costs, patterns of expenditure

**Legacy model** so that commissioners, providers, advocacy groups, individuals and families can access our findings and methods, and make their own projections of needs for care and support, outcomes and costs.

# Some research challenges...

- We are still not very good at measuring the indirect costs of care, particularly unpaid care
- What happens to outcomes and costs when you “stack-up” interventions?
- Outcomes: combining the outcomes of people with dementia and those of carers
- Understanding better the impact of changes in severity of dementia and quality of life

# Thank you for your attention

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