



Institute
and Faculty
of Actuaries

Public Data for the Private Sector

Dame Karen Dunnell
Chair of Longevity Science Panel

<http://www.longevitypanel.co.uk/viewpoint/public-data-for-private-sectors/>

01 August 2016

Background

- Insurance companies and actuaries have always had access to anonymised information from:
 - Administration and Survey data
- Comparable data from the NHS and other public services could throw light on health status, care and other needs.
 - Anonymised individual records allow users to build models and carry out analyses that provide more accurate estimates for different population groups in our society
- But access has become more difficult

What's gone wrong with data access

Generally

- Confusing and complex legislation
- Unclear definition of 'Public Good'
- Loss of public trust

Care.data

- Public trust challenge
- Infer from HES experience
- Initiative cancelled

Ageing population presents new challenges

House of Lord's 'Ready for Ageing?' highlighted problematic areas:	Examples of financial solutions
Health & social care	Nursing homes, long-term care insurance
Releasing housing assets	Lifetime mortgage
Housing	Retirement villages and other residential arrangements
Pensions and savings	Annuities, secondary annuity market and other financial products

Social care needs data: Definition & Concept

- **Measures of frailty.** Examples include the Edmonton Frail Scale which incorporates measures for cognition, nutrition and hospital admissions within a year.
- **Measures of Daily Living (DL).** Data on how such measures of disability vary across socio-economic group would help price LTC products appropriately for each individual.
- **Measures of disease and co-morbidity.** Although data on mortality from specific disease are readily available, the prevalence of chronic diseases such as dementia, Parkinson's disease or cardiovascular disease is harder to find, especially differentiated by socio-economic group.
- **Rates of progression** between morbid states of disability, severe disease, recovery or death would also be helpful to predict the level of care likely to be needed over time.

Social care needs data: Analysis

- **Unit of analysis** – e.g. individual or grouped
- **Staff**
- **Potential users of social care**
- **Local authority vs national**
- **Rates of progression** between morbid states of disability, severe disease, recovery or death would also be helpful to predict the level of care likely to be needed over time.

Release of housing equity needs data

- mortality and survival rates of homeowners of various socio-economic circumstances and health status;
- data tracking how morbidity and disability change with ageing, and how these affect the need for, and timing of, care home use; and
- incidence of care home entry of various sub-populations, such as different age and gender groups, people in different socio-economic circumstances, and those with different health status, morbidity and risk factors.

Housing the ageing population needs data

- To understand facilities required for the elderly
- To know the cost for health & social care
- To know contribution of specialist housing to local economy and potential health & care savings

Pensions industry needs data

Better access to anonymised individual-level health data could add to the public good by:

- improving the estimation of individual life expectancy in a pension scheme or retirement product, taking account of health information;
- understanding the relationship between risk factors such as smoking status and obesity to provide a better and more realistic estimate of life expectancy and social care needs; and
- testing of models used by the finance sector, as is already successfully done for those regularly used by clinicians.

Pensions industry needs data for Secondary Annuity Market & Medically Underwritten Annuity

Circulatory		Larger Prevalence	Central Nervous System	Other
<i>Angina</i>	Heart failure	<i>Diabetes</i>	Dementia	Arthropathy: Rheumatoid arthritis Osteo-arthritis
<i>MI</i>	Cardiomyopathy	<i>Cancers – main sites with stages</i>	Parkinson's	Barrett's oesophagus
Atrial Fibrillation	Aortic aneurysm	<i>COPD</i>	Mental health	Alcohol
<i>Stroke – ischemic; haemorrhagic</i>	Heart valve disorders	<i>Asthma</i>	Motor Neurone	Liver or kidney failure
TIA	Arrhythmia – non-AF Peripheral vascular		<i>MS</i>	Liver cirrhosis and Hep C

We recommend:

- 1. The formation of a coherent and publicly acceptable legal structure and entity to govern the collection, management and dissemination of public statistics, data and information to support the public good.**
- 2. The ‘public good’ be defined in a way that includes any activity that benefits society or the economy, particularly where that activity is aligned with public policy.**
- 3. Strategies are employed to improve the appropriate access of both the public and private sectors to all publicly-funded data, information and statistics, while protecting the privacy of individuals and the public interest.**
- 4. Private sector and public bodies are included in discussions to specify what public data and information are needed for the benefit of society and the economy.**