

Eurohealth

RESEARCH • DEBATE • POLICY • NEWS

Volume 17 Number 2-3, 2011

Ageing and long-term care

Balancing fair protection
and financial sustainability

Mapping long-term care
services across Europe

Impact of chronic disease
on need for long-term care

England: NHS reform and NICE's new role • Germany: effect of hospital ownership on performance
EU Directive: patients' rights in cross-border health care

COMMENTS

Meeting the challenge of ageing and long-term care

The European population aged over 80 is expected to more than double by 2050, leading to significantly increased demand for long-term care (LTC). This demographic shift is accompanied by changing social patterns, e.g., smaller families, different residential patterns and increased female labour force participation, all contributing to an increased need for paid care. Thus, accurate projections on population ageing and morbidity are needed to determine future planning challenges for LTC.

Many of the contributions in this double issue reflect presentation made at an expert seminar jointly organised by the London School of Economics, the International LTC Policy Network, and the Health Status, Health Care and LTC Research Network. Comas-Herrera and colleagues look at the different assumptions used in forecasting future LTC expenditure. Specifically, they discuss the changes in cost projections when different scenarios are used for rates of disability and dementia. Jagger et al. also look at modelling future demand for LTC. In their article they have opted to use the term – the 85 and over age group – rather than the previously used term ‘oldest old’, because this reflects the reality of changing demographics where 85 is now considered not that old!

For specific countries, Hanson and Magnusson present a specific type of Information and Communication Technology (ICT) that is used in Sweden by older people with chronic conditions and their carers at home. Results of an evaluation of the technology are presented and challenges discussed. Continuing on the ICT theme, Hendy et al. look at recent developments regarding four remote care programmes undergoing implementation in the United Kingdom. They note some success, but also the continued challenge due to the current policy and reimbursement landscape. With regards to the hospital setting and long-term residential care in Finland, Murphy and Martikainen distinguish between age and proximity to death as predictors of service use.

Colombo and Mercier reflect on some findings of a recent OECD study. Cost projection scenarios for LTC are shown alongside policy recommendations on how to provide fair LTC protection, while ensuring that over the long run this protection is fiscally sustainable. Drawing on the same study, Tjadens et al. look at the sustainability of the care workforce, while Salvador-Carulla reports on an approach to map and better compare LTC care services across Europe.

In the Health Policy Developments section, Zanon discusses implications for the National Health Service in England stemming from the European Directive on patients' rights in cross-border health care. Also from England, with major health reforms under discussion, this issue provides a reflection from the National Institute for Health and Clinical Excellence (NICE) on their work to date and what the future may hold. For Germany, Tiemann and colleagues look at the effects of hospital ownership on efficiency, quality of care and other dimensions of performance following the introduction of diagnosis related groups (DRGs) and other reforms.

Stay tuned. From the next issue, *Eurohealth* will revamp its look and enhance navigation through dedicated sections, including a new thematic section that will integrate the Observatory's health policy bulletin *EuroObserver*.

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Published by LSE Health and the European Observatory on Health Systems and Policies.

Eurohealth is a quarterly publication that provides a forum for researchers, experts and policymakers to express their views on health policy issues and so contribute to a constructive debate on health policy in Europe.

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The European Observatory on Health Systems and Policies is a partnership between the World Health Organization Regional Office for Europe, the Governments of Belgium, Finland, Ireland, the Netherlands, Norway, Slovenia, Spain, Sweden and the Veneto Region of Italy, the European Commission, the European Investment Bank, the World Bank, UNCAM (French National Union of Health Insurance Funds), the London School of Economics and Political Science, and the London School of Hygiene & Tropical Medicine.

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Design and Production: Westminster European
Printing: Optichrome Ltd

ISSN 1356-1030

LSE Health

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Introduction:

The demand for long-term care for older people

Lisa Trigg

Forecasting the demand for long-term care (LTC) is a challenge complicated by a range of factors, including future trends in longevity and health, government policies in both health and social care, access to health care systems, and a range of social and demographic factors, not least of which is the availability of informal carers.

Many of the articles in this issue tackle on the one hand, the challenges of forecasting LTC demand and on the other hand how to reduce this demand. Most of these articles are based on presentations made at an expert seminar on “Ageing and Long-term Care Needs” held at the London School of Economics and Political Science on 20 May 2011, organised by the International Long-term Care Policy Network, in conjunction with the Health Status, Health Care and Long-term Care Research Network.* The Research Network is part of the European Observatory on Social and Demographic conditions, sponsored by the European Commission’s Directorate General for Employment, Social Affairs and Equal Opportunities.**

Forecasting long-term care needs

Projections surrounding population ageing are vital to assist governments and institutions in understanding the likely scale of the challenge facing LTC systems and to develop policies accordingly. The Organisation for Economic Co-operation and Development (OECD) forecasts that the percentage of those aged 80 and over is likely to more than double from 4% in 2010 to nearly 10% in 2050 in OECD countries.¹ Behind these figures lies a critical question for the planning of LTC needs, regarding the extent to which increases in life expectancy are matched by improvements in healthy life expectancy, the so called ‘compression of morbidity’.

A 2007 OECD study showed that evidence from different countries is contradictory, with levels of disability in decline in some countries and on the increase in others.² National differences were also shown in a presentation by Jean-Marie Robine exploring the patterns emerging around the health and longevity of the oldest old, particularly in the centenarian population in the Five Country Oldest Old Project.³

With reductions in mortality for many chronic diseases, there is a need for a better understanding of the extent to which chronic disease impacts on healthy life expectancy and the onset of dependency. In her article, Carol Jagger describes ongoing activities to gather data from a large UK cohort of individuals to model the relationship between multiple morbidities, levels of disability and mortality for older people, as well as the impact of these factors on the need for LTC. Changes in any of these factors can then be used to model the impact on future life expectancy and healthy life expectancy under different scenarios based on the prevalence of chronic disease in older people.

This epidemiological approach to forecasting the need for LTC also forms one of the approaches described by Adelina Comas-Herrera in examining the future outlook for increased numbers of older people suffering with dementia. The other approaches discussed take an arguably more straightforward approach to forecasting, for example, by extrapolating past trends or by assuming that age-specific disability rates will continue at the same level.

Adoption of the different models results in different levels of optimism (or pessimism) in outlook. Interestingly, a Delphi consensus exercise established that the panel took a ‘moderately optimistic’ view that future disability levels caused by dementia would be reduced due to scientific advances and changes in risk factors.⁴

Another study by Mike Murphy and Pekka Martikainen uses extensive data collected by Finnish municipalities on the use of health and LTC to investigate predictors of their use. Specifically, they describe their finding that, while proximity to death has been found to be positively correlated to the use of acute health care, age (or time from birth) is more important for forecasting the use of LTC. The impact of other factors should not be underestimated; a key determinant for the use of long-term residential care being marital status.

Managing the demand for long-term care

Some of the key findings from the latest OECD report on the future demand for LTC are highlighted by Francesca Colombo and Jérôme Mercier. They estimate that the demand for formal LTC workers is likely to at least double by 2050, with average spending expected to rise from a current average of 1.3% of Gross Domestic Product to a worse case scenario of 2.9% for OECD-EU countries.*** Given this expected increase, it is not surprising that governments continue to seek ways of reducing or moderating demand for formal LTC, or at least for the most expensive option of residential care. As

* Additional information and presentations are available for download at: <http://www2.lse.ac.uk/LSEHealthAndSocialCare/LSEHealth/eventsAndSeminars/expertseminaronaging.aspx>

** Contract No. VC/2008/932

*** Including Austria, Belgium, Czech Republic, Denmark, Finland, France, Germany, Greece, Hungary, Ireland, Italy, Luxembourg, Netherlands, Norway, Poland, Portugal, Slovak Republic, Spain, Sweden and the United Kingdom.

well as recognising the desire of individuals to stay within their own homes and to retain some degree of independence, in theory these approaches should also deliver more cost-effective options for the provision of LTC.

However, a major challenge is how to take relatively small pilot schemes and local projects and adapt and expand them for regional or national implementation. Elizabeth Hanson and Lennart Magnusson report on a regional initiative in Sweden based on the use of information and communication technology to support ageing in place, through the provision of education and training, multimedia support and videophone contact with professional carers and other families. The programme has been well-received by both the families involved and the local municipality in terms both of the effectiveness of the support as well as the cost savings shown at an individual level by avoiding wider use of health and social care services. However, the authors highlight a number of challenges to the uptake of these programmes on a wider scale, for example, the requirement to change fundamental work practices, the effort required to build ongoing support, and not least the need for rigorous and extensive evidence on costs and benefits to justify their adoption at a national level.

These are themes echoed in Hendy et al's article, which describes the implementation of a set of randomised controlled trials of remote care services in the UK. The findings of their research identified a number of barriers to scaling up remote care, i.e., the need for strong and consistent leadership; the transferability of lessons learned in pilots to wider projects; the need for fundamental changes in working practices; and the need for the broad policy interventions and service redesign to ensure integration between different organisations. The approach of using randomised controlled trials has been adopted to counter the historical difficulties of using data from smaller projects to justify more extensive investment, such as challenges encountered during the UK-based Partnerships for Older People Project in measuring quality of life outcomes and the impact of projects on the use of health and residential care.⁵

Notwithstanding advances in medical care and improvements in health status, the requirement for LTC will inevitably grow as populations age. Establishing the true extent of this challenge will allow govern-

ments to design and implement strategies for supporting this care, particularly from the perspective of adequate and appropriate strategies for financing. Identifying more cost-effective options for delivering care is acknowledged as a priority in order to reduce costs and to improve the quality of life of older people. Further challenges remain in overcoming existing hurdles to implement successful services and technologies on a large scale.

REFERENCES

1. Colombo F, Llena-Nozal A, Mercier J, Tjadens F. *Help Wanted? Providing and Paying for Long-term Care*. Paris: OECD Publishing, 2011.
2. Lafortune G, Balestat G. *Trends in Severe Disability Among Elderly People: Assessing the Evidence in 12 OECD Countries and the Future Implications*. OECD Health Working Paper No 26. Paris: OECD Publishing, 2007.
3. Robine JM, Cheung SLK, Saito Y, Jeune B, Parker MG, Herrmann FR. Centenarians Today: New Insights on Selection from the 5-COOP Study. *Current Gerontology and Geriatrics Research* 2010;1-9.
4. Comas-Herrera A, Northey S, Wittenberg R, Knapp M, Bhattacharyya S, Burns A. Future costs of dementia-related long-term care: exploring future scenarios. *International Psychogeriatrics* 2011;23:20-30.
5. Windle K, Wagland R, Forder J, D'Amico F, Janssen D, Wistow G. *National Evaluation of the Partnerships for Older People Projects: Final Report*. Canterbury: Personal Social Services Research Unit, University of Kent, 2009.

Now available in Russian

Caring for people with chronic conditions. A health system perspective



Edited by
**Ellen Nolte and
Martin McKee**

Copenhagen: World
Health Organization 2010,
on behalf of the European
Observatory on Health
Systems and Policies

256 pages

ISBN: 978 0 335 23370 0

The complex nature of many chronic diseases, which affect people in many different ways, requires a multifaceted response to meet the needs of patients. The traditional relationship between an individual patient and a single doctor is inappropriate, yet there is little agreement about what should replace it.

Many countries are experimenting with new approaches to delivering care in ways that meet the complex needs of people with chronic disorders, redesigning delivery systems to coordinate activities across the continuum of care. Yet while integration and coordination have an intuitive appeal, policy makers have had little guidance to help them decide how to move forward.

Now available in Russian, this book systematically examines some of the key issues involved in the care of those with chronic diseases. It synthesises the evidence on what we know works (or does not) in different circumstances. From an international perspective, it addresses the prerequisites for effective policies and management of chronic disease.

Taking a whole systems approach, the book:

- Describes the burden of chronic disease in Europe
- Explores the economic case for investing in chronic disease management
- Examines key challenges posed by the growing complexity in health care including prevention, the role of self-management, the health care workforce, and decision support
- Examines systems for financing chronic care
- Analyses the prerequisites for effective policies for chronic care

Caring for people with chronic conditions is key reading for health policy-makers and health care professionals, as well as post-graduate students studying health policy, health services research, health economics, public policy and management.

Available at: <http://www.euro.who.int/en/home/projects/observatory/publications/studies>

Help wanted!

Balancing fair protection and financial sustainability in long-term care

Francesca Colombo and Jérôme Mercier

Summary: The number of people over the age of 80 is expected to double as a share of the total population of OECD countries over the next forty years, leading to significantly increased demand for long-term care (LTC) services. Meanwhile, declining family size, changes in residential patterns of people with disabilities and rising female participation in the formal labour market will contribute to a decline in the availability of family carers, leading to an increase in the need for paid care. After outlining LTC cost projection scenarios, this article provides policy recommendations on how to provide fair LTC protection, whilst ensuring that this protection is fiscally sustainable in the long run.

Keywords: Long-term care financing, long-term care costs, financial sustainability

The share of the population aged 80 years and over is expected to more than double in coming decades across the OECD, growing from 4% in 2010 to close to 10% by 2050 (Figure 1). Although the speed at which populations are ageing varies considerably across countries, and despite uncertainties about future trends in disability among the older population,¹ these demographic transformations are expected to significantly increase demand for long-term care (LTC) services. Meanwhile, declining family size, changes in residential patterns of people with disabilities and the rising female participation in the formal labour market will contribute to a decline in the availability of family carers, leading to an increase in the need for paid care.

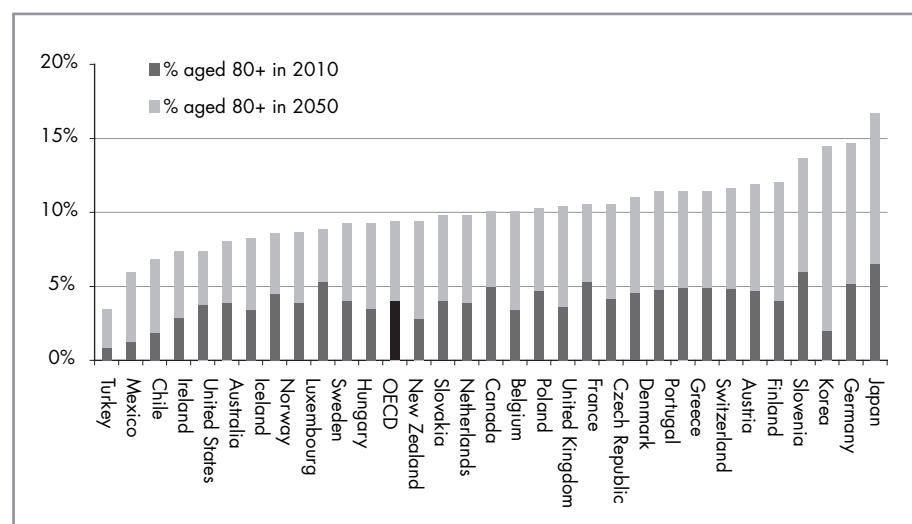
These transformations will put upward pressure on total expenditure of formal long-term care systems, and this will occur concurrently with the growth of other major age-related expenditures, such as public pensions and health services, with the potential risk of shifting costs to future

generations. This means that the way expenditures and revenues are set, particularly in the area of LTC, needs to be more forward looking. After outlining LTC cost projection scenarios, this article provides policy recommendations on how to provide fair LTC protection, whilst ensuring that this protection is fiscally sustainable in the long run. In doing so it draws on findings of a major report prepared by the OECD.²

Sizing the challenge ahead: projected LTC costs

On average OECD countries allocate 1.5% of their Gross Domestic Product (GDP) to LTC. Some countries spend more than 2% of their GDP (for example, the Netherlands, Sweden, Denmark and Norway) while some others allocate less than 0.5% (for example, Portugal, Hungary). Regardless of the share of GDP spent on LTC, systems target resources

Figure 1: The share of the population aged over 80 years in the OECD, 2010 and 2050



Source: ⁴

Francesca Colombo is Senior Health Policy Analyst, Health Policy Division and Jérôme Mercier is an Economist, Directorate for Employment and Social Affairs, Organisation for Economic Co-operation and Development, Paris, France.

among beneficiaries very differently; the same can also be said with respect to how LTC financing takes place.

While still relatively small, there is concern across OECD countries that the demographic and societal changes we have described will lead to higher future ageing-related costs. According to the 2009 European Commission projection scenarios, public LTC spending of OECD-EU member states as a share of GDP is expected to at least double by 2050. LTC expenditures are expected to fall in the range of 2.2% to 2.9% of GDP by 2050, relative to about 1.2% in 2007.³ Complementary OECD projections for selected non-European OECD countries are consistent with these findings and Table 1 presents projections for six different scenarios (See Box).

Taken together, these projections suggest that LTC spending might at least double or even treble in the Czech Republic, Japan, Hungary, the Netherlands, New Zealand and Slovakia. Most cost growth is likely to occur if new LTC beneficiaries receive formal care in institutional settings.

Policies for fair yet financially sustainable LTC coverage

There is a strong rationale both for pooling the financial risk associated with LTC costs and for providing basic universal coverage for personal-care services, that is help with so-called activities of daily living such as bathing, dressing, getting in and out of bed, regardless of individual financial means. LTC expenditure rapidly becomes unaffordable for even relatively well off people. For those requiring a large range of services, LTC expenditure can represent as much as 60% of disposable income for all but those in the upper quintile of the income distribution.

Many countries are indeed moving to universal LTC coverage. But, within a universal system, policies are needed to reconcile projected demand for (and cost of) LTC, with financial sustainability. A toolkit of policies to strike this delicate balance between fairness and fiscal sustainability is now outlined.

First, support should be targeted where the need is the highest. Such targeted universalism requires balancing three features of LTC coverage schemes:

The need-level triggering entitlement to coverage. Stringent assessment criteria can be in place even within universal LTC schemes, as is the case in the Republic of

Box: Six scenarios used in projections of future costs of long-term care

Baseline or pure ageing scenario: future demand for LTC is projected assuming that the number of years with disability will increase in line with future gains in life expectancy. LTC spending will double from around 1.2% to 2.4% for OECD-EU member countries and to 2.9% of GDP for non-European OECD countries by 2050.

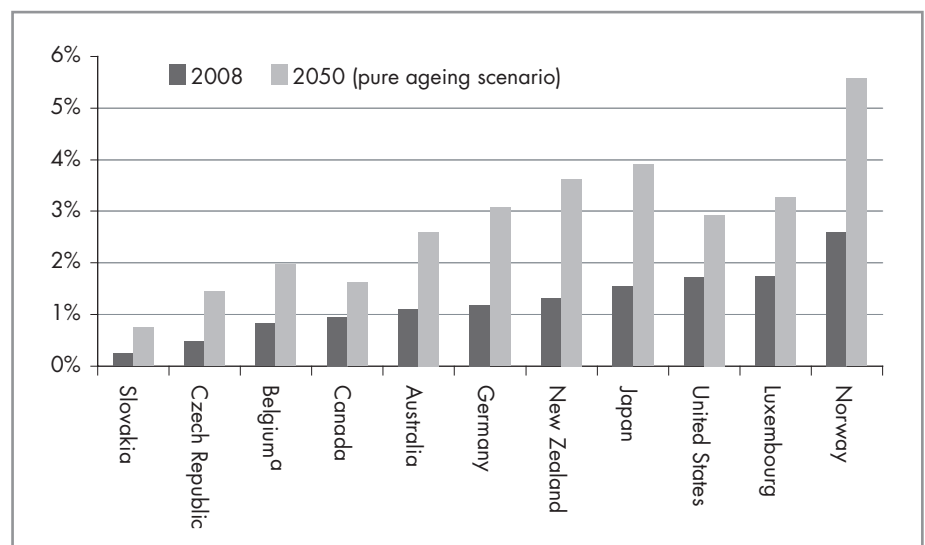
Healthy ageing scenario: gains in life expectancy will lead to a delay in the onset of disability, with half of the increase in lifespan considered to be years with lower levels of dependency. Total public LTC costs could decrease by about 5% to 10% by 2050, relative to the baseline scenario.

Productivity gains scenario: the cost of providing LTC grows at a slower rate than real GDP per worker, for instance thanks to the implementation of new reforms or the introduction of new technologies allowing for more care being provided for the same cost. This would bring a decrease of about 10% in projected public LTC expenditure, relative to the pure demographic scenario.

Fourth scenario: LTC costs will grow at a faster pace than average wage rates in the economy. Such cost pressure could arise as a result of the expected growing demand for LTC workers in the context of a shrinking workforce (Figure 2). LTC spending would grow by about 10%, relative to the baseline scenario.

Fifth and sixth scenarios: Under both these scenarios a shift from family to formal care would result in all 'new' beneficiaries respectively receiving care at home or in an institution. Public LTC costs would grow by 5% to 20% across EU Member States, compared with 10% to 35% for non-EU OECD countries.

Figure 2: Percentage of full time equivalent nurses and personal carers relative to total projected working population



Sources: 3–6.

Notes: a. Refers to institutions only

For the purposes of the analysis, the number of LTC workers includes nurses and personal carers working in an institution or at home, expressed on a FTE basis. The analysis is limited to employed LTC workers and generally does not include other LTC workers under different working arrangements, such as self-employed individuals. The range of occupations considered as nurses and personal carers, as well as the definition of full-time equivalent may vary across countries. Data for Australia, New Zealand and the United States refer to 2007. Data for Canada and Luxembourg refer to 2006.

Korea and Germany, for example, relative to Japan. Over the years, there have been efforts to target benefits to those with the highest care needs in Sweden and the Netherlands, while Japan moved low need users to a prevention system in 2006.

The level of cost-sharing on LTC benefits. No LTC system is entirely free. In France, a LTC cash benefit pays up to €1,235 per

month for a high-need/low-income user, but only €27 per month for the highest-income users, while in Sweden there is a cap for cost-sharing on home-help services of €180 per month. Paying higher benefits to low-income dependents as in France, Austria and Australia ensures access to care for those who need it without excessive public expenditures.

Table 1: LTC expenditure as percentage of GDP in 2050 (base year prices)

	Base year	Prevalence of dependency scenarios		Changes to the LTC cost structure scenarios		Decline in the availability of family care scenarios	
		Pure ageing scenario	Healthy ageing scenario	-1% of GDP per worker	+1% of GDP per worker	All home care	All residential care
EU^a	2007						
Austria	1.3	2.5	2.4	2.3	2.7	2.6	2.6
Belgium	1.5	2.9	2.8	2.6	3.2	3.1	3.5
Czech Republic ^b	0.2	0.6	0.5	0.6	0.6	0.6	0.7
Denmark	1.7	3.4	3.2	3.1	3.7	3.7	3.4
Finland	1.8	4.2	4.2	3.8	4.7	4.5	5.3
France	1.4	2.2	2.1	1.9	2.5	2.3	2.6
Germany ^c	0.9	2.3	2.2	2.1	2.5	2.4	2.7
Greece	1.4	3.3	3.2	2.9	3.7	3.5	3.9
Hungary	0.3	0.5	0.5	0.4	0.6	0.7	0.9
Ireland	0.8	1.8	1.8	1.6	2.0	1.9	2.2
Italy	1.7	2.9	2.8	2.6	3.2	3.3	3.9
Luxembourg	1.4	3.1	3.0	2.8	3.4	3.3	3.8
Netherlands	3.4	8.2	7.7	7.5	9.0	8.4	9.2
Norway	2.2	4.5	4.3	4.1	4.9	4.6	5.3
Poland	0.4	0.9	0.9	0.8	1.0	1.1	0.9
Portugal	0.1	0.2	0.2	0.2	0.2	0.2	0.2
Slovakia	0.2	0.5	0.5	0.5	0.5	0.6	0.5
Spain	0.5	1.4	1.3	1.3	1.5	1.4	3.0
Sweden	3.5	5.5	5.3	5.0	6.1	5.8	6.3
United Kingdom	0.8	1.3	1.2	1.2	1.4	1.3	1.3
OECD-EU average	1.3	2.4	2.3	2.2	2.7	2.5	2.9
Selected non-EU OECD countries	2006						
Australia	0.8	1.8	1.6	1.7	2.0	2.0	2.4
Canada	1.2	2.7	2.4	2.4	2.9	2.7	3.4
Japan	1.4	4.0	3.5	3.6	4.4	4.0	4.4
New Zealand	1.4	3.9	3.6	3.5	4.3	4.6	6.2
United States	1.0	1.9	1.7	1.7	2.1	2.2	2.6
Selected non-EU OECD average	1.2	2.9	2.6	2.6	3.2	3.1	3.8

Sources: OECD calculations based on ^{3,6,7}

- Notes: a. Public LTC expenditure as presented in the European Commission 2009 Ageing Report. For 2007, figures may differ from those found in OECD Health Data, as information from Eurostat was used to complement available data. Public LTC expenditure may reflect a broader range of expenditures, including cash or in-kind support for services for instrumental activities of daily living.
- b. Data for the Czech Republic only reflect public health insurance fund expenditure and do not include expenditure on attendance allowances.
- c. The projection unit costs are indexed to GDP per worker and do not reflect current German legislation under which all LTC benefits are indexed to prices.

The types of services included in coverage. Targeting the basket of services needs to address users' legitimate requests for choice, with appropriateness and flexibility over time. A special challenge will be posed by the growing number of users with cognitive dependencies. To address arbitrages in setting the basket of services and to enhance user choice, a number of countries such as Austria, France, Germany, Italy, the Netherlands and the United Kingdom are providing cash entitlements to care.

Second, there is a potential role for governments to facilitate the mobilisation of cash to help users pay for the costs of board and lodging in LTC institutions. It is to be expected that LTC users will need to allocate a share of their income or accumulated savings to pay for meals and housing, no matter where they live. Yet these costs, typically not covered by public LTC schemes or subject to significant cost sharing, can be twice or thrice as much as the cost of personal care services. They can rapidly force users to deplete all their accumulated income and assets. There are a number of possible mechanisms to help users with low and moderate incomes but accumulated assets to turn some of these assets (for example, a house) into cash to pay for such expenses. An example of public measure is the Irish Nursing Home Loans under which a resident can defer to the time of his or her death their nursing home contribution set on the basis of the value of their non-financial assets, such as their home. Under the scheme the value of their principal residence is included in the financial assessment for a three-year period.

Third, once a basic LTC protection system has been designed, it is vital to ensure that financing is fiscally sustainable over the long-run. All OECD countries have yearly budgeting mechanisms to align LTC revenues and expenditures, but the expected long-term increase in age-related spending requires forward-looking financing policies such as:

Tax-broadening, i.e., financing beyond revenues earned by the working-age population. Japan, the Netherlands, Belgium and Luxembourg complement payroll contributions with alternative revenues sources.

Better pooling across generations, which implies avoiding unduly charging (dwindling) young population cohorts to pay for LTC costs of a growing cohort of old people. In Japan, LTC premia are levied on those aged 40 years and over. In Germany,

retirees are also required to contribute premia to social LTC insurance, based on their pensions.

Pre-funding elements, which implies setting aside some funds to pay for future obligations. While a fully-funded system may not be justifiable given the uncertainty surrounding future LTC needs, private compulsory LTC insurance in Germany includes some pre-funding elements. The Singapore EldersShield Programme is, in principle, fully-funded. In tax-funded LTC schemes, this would mean building a favourable fiscal position through a lower debt-to-GDP ratio.

Innovative approaches exploiting consumer inertia and public-private partnership. Voluntary funding schemes based on automatic enrolment with potential opt-outs are being implemented in the United States (the so-called Class Act) and have been established in Singapore. These initiatives borrow features from both public and private insurance, although the voluntary nature of enrolment remains a challenge to their management.

Conclusions

As OECD countries age, addressing the trade-off between providing 'fair' basic universal coverage and achieving fiscal sustainability will become more urgent. Convergence towards targeted universalism on the benefit eligibility side and broad collective financing on the revenue side have the potential to strike a reasonable balance between these two competing priorities.

REFERENCES

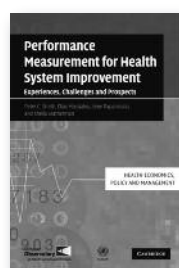
1. Lafortune G, Baléstat G. Trends in severe disability among elderly people: assessing the evidence in 12 OECD countries and the future implications. *OECD Health Working Papers* 2007; 26.
2. Colombo F, Llena Nozal A, Mercier J, Tjadens F. *Help Wanted? Providing and Paying for Long-term Care*. Paris: OECD, 2011. Available at www.oecd.org/health/longtermcare
3. Directorate General for Economic and Financial Affairs and Economic Policy Committee. *The 2009 Ageing Report: Economic and Budgetary Projections for the EU-27 (2008–2060)*. Luxembourg: Commission of the European Communities, 2009.
4. OECD Labour Force and Demographic Database. Paris: OECD, 2010.
5. OECD Health Data. Paris: OECD, 2010.
6. Duval R, de la Maisonnette C. Long-run GDP growth scenarios for the world economy. *OECD Economics Department Working Papers*, 2009; 663.
7. OECD. Projecting OECD health and long-term care expenditures: what are the main drivers? *OECD Economics Department Working Papers*, 2006; 477.

ACKNOWLEDGEMENT

This article is based on Colombo, F. et al (2011), Help Wanted! Providing and Paying for Long-Term Care published by the OECD. The opinions expressed and arguments employed herein do not necessarily reflect the official views of the OECD.

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Cambridge University Press, 2009

726 pages

ISBN: 978 0 521 13348 7

Edited by Peter C. Smith, Elias Mossialos, Irene Papanicolas and Sheila Leatherman

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The impact of changing patterns of disease on disability and the need for long-term care

Carol Jagger, Ruth Matthews, James Lindesay and Carol Brayne

Summary: Projections of need for long-term care generally assume constant age-specific disability prevalence or reductions based on the improved health of incoming older cohorts. Explicit linkages to trends in disabling diseases are rarely made. We address this through a macro-simulation model, SIMPOP, with three health scenarios: (i) constant age-specific disease prevalence; (ii) reduced disease prevalence and disease-specific disability; and (iii) continued trends of increasing disease prevalence and disabling effect. We find that assumptions of constant or reduced age-specific disability prevalence in all age groups over the next 20 years still result in large increases in the numbers requiring long-term care.

Keywords: Ageing, disability, simulation model, age-related disease, long-term care.

Disability, as measured by the ability to undertake basic activities of daily living (ADLs) for self-care, is a major driver of the need for long-term care (LTC). Projections of future need for LTC generally assume that either the prevalence of disability will remain constant within age groups or that it will reduce as incoming cohorts of older people are healthier. The latter view is not universally held; an OECD review of the trends in ability to self-care at age 65 and over found that only half of the eight countries included showed clear decreases in disability rates.¹ Moreover evidence for this in the United Kingdom is equivocal, with one study suggesting an increase of 31% in the prevalence of moderate disability in the young old (65–69 years) between 1991 and 1997², whilst another reported a decrease in high dependency between 1998 and 2008 of 6% in men and 39% in women.³

Focussing solely on disability as a driver of LTC neglects the fact that all conceptual models of the disablement process begin

with active pathology or disease.⁴ Cardiovascular and cerebrovascular disease, sensory problems (vision and hearing), arthritis, incontinence, dementia and depression are major causes of late-life disability⁵ and there have been considerable temporal changes in a number of these. However, very old age, where demand for LTC is greatest, is not characterised by single diseases but by multi-morbidity.⁶ In addition to the co-occurrence of disease, treatments for one disease may have beneficial effects for others whilst lifestyle factors such as smoking and obesity, the latter with increasing prevalence over time, are risk factors for a number of diseases. Not only do these relationships cast doubt on the assumption that age-specific prevalence rates of disability will remain constant, but they also imply that projecting disability through models of single diseases and their risk factors is unrealistic. This article reports the findings from a macro-simulation model, SIMPOP, on how trends and treatments in multiple

chronic conditions: arthritis, coronary heart disease (CHD) and strokes, as well as dementia and cognitive impairment, might impact on disability and the future demand for LTC. It is worth noting that assumptions about future disability levels have a very important impact on future expenditure on LTC*.

Modelling the impact of multiple diseases on disability

The macro-simulation model, SIMPOP, projects the number of older people (aged 65+ years) with disability from two-year transition probabilities to and from disability and to death derived from the MRC Cognitive Function and Ageing Study (MRC CFAS),⁷ and then applied to the 1992 mid-year England and Wales revised population estimates. Disability was based on inability to perform activities of daily living and chosen to be parsimonious with a model of LTC needs and costs.⁸

Disability prevalence at baseline (1991–92) ranged from 3.7% at 65 to 66 years to 58.7% at 91 years and over. The sixteen diseases and conditions included in the

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* In Comas Herrera *et al* in this issue, the disability scenarios presented here are used to show how sensitive future LTC expenditure will be to changes in disability.

model were generally self-reported, although diagnostic scales were used for angina, peripheral vascular disease and cognitive impairment. Estimates of the prevalence of CHD (defined as heart attack and/or angina), stroke, arthritis, diabetes and Parkinson's disease in 2006 from SIMPOP were compared to the Health Survey for England (HSE) 2005,⁹ and were found to be close, the exception being diabetes whose prevalence was then increased in SIMPOP to national values. More detail on SIMPOP and the measures are available.¹⁰ The condition with the highest prevalence was arthritis which was reported by 52.3% of the 65+ population at baseline.

Health and disease scenarios

Three parameters for each disease could be altered in SIMPOP to mimic future changes in mortality and morbidity: the disease prevalence and the probabilities of death and disability within two years conditional on the disease. To inform the magnitude of change, literature on arthritis, stroke, CHD and dementia, in both those currently aged 65 years and over and in those who would be 65+ by 2030, was systematically reviewed for evidence on: trends and risk factors; disease-specific disability; preventive strategies and treatments and their efficacy, cost-effectiveness and diffusion.¹¹ Given the paucity of data on the impact of interventions in any of the disease areas, particularly on disability, we assumed a change of 5% in either the transition probabilities to onset of disability or to death to represent a small impact, and 10% a moderate impact. Based on the reviews, three global scenarios were developed and applied to SIMPOP to produce numbers of older people with and without disability and age-specific disability and disease prevalence from 2010 to 2030 (Box 1).

Projections under different health scenarios

The Central Health Scenario suggests that between 2010 and 2030 there will be an increase of 49% in the total older population (65+), from 9.2 million to 13.7 million, although there will be a much greater rise in the numbers with disability (89%, 901,000) (Table 1). This results from the rising numbers of older people with key disabling diseases which occur despite the scenario's assumption of constant disease prevalence, since numbers in the 85 and over age group increase by 139% over the time period in contrast to the 65–74 age

Box 1: Global health scenarios modelled in SIMPOP

Central Health Scenario

Prevention strategies and effective treatments offset the negative influences of obesity and other cohort trends; for example, the emergence of ethnic minorities (with increased CHD, stroke and diabetes) into older cohorts. Age-specific prevalence of diseases, incidence of, and recovery rates to dependency, all remain at 2006 levels and mortality rates decline at levels commensurate with the Office for National Statistics principle projections.

Improving Population Health Scenario

Individuals take their health seriously with a decline in risk factors, particularly smoking and obesity, reducing the prevalence of stroke, CHD, arthritis and mild cognitive impairment (CI) (by 2% every two years from 2012). The health service is responsive with high rates of technology uptake for disease prevention and excellent diffusion rates of treatments to all who can benefit, particularly in terms of control of vascular risk factors (10% decrease in disability onset for arthritis, stroke, CHD and mild CI from 2012 and a further 5% reduction in mortality from stroke, CHD and mild dementia from 2016). New cohorts of older people are healthier than previous ones (5% reduction in prevalence of disability for each cohort).

Continuation of Current Trends Scenario

Current obesity trends of 1–2% increase annually continue, resulting in higher prevalence of arthritis, stroke, CHD and vascular dementia (2% increase every two years from 2012) but also their associated disability (10% increase in onset of disability for these diseases). Ethnic minorities enter the older population in significant numbers and add to the prevalence of stroke and CHD. Treatments continue to focus on reducing mortality (further 5% reduction in mortality from stroke, CHD and mild CI from 2016).

group which increases by 41%. Moreover, growth in the numbers aged 85 and over has two further consequences. Firstly, there are different proportionate increases in diseases, from 40% for diabetes to 80% for dementia, the prevalence of the latter rising more strongly with age. Secondly, the prevalence of disability increases (Table 1), showing that constant disease prevalence with population ageing does not imply constant disability prevalence.

Improvements in the prevalence of disability for the incoming cohorts (65–66 year olds) in the Improving Population Health Scenario have a modest effect on the numbers with disability and prevalence by 2010, mostly in the youngest age group (Table 1). Further reductions in mortality due to disease prevention will cause the size of the older population as a whole to increase further, by 52% with 172,000 fewer disabled older people than under the Central Health Scenario. Nevertheless, these reductions are relatively small when compared to the extra numbers requiring LTC under the Central Health Scenario, some 901,000 between 2010 and 2030. In addition, with this level of health improvement the prevalence of disability still increases, by 2.4% in those aged 85 plus (Table 1).

If current health trends continue there will be slightly fewer older people in total than projected under the Central Health Scenario

and marginal increases in the numbers with disability and diseases, particularly stroke and dementia. But the prevalence of disability at a level that will require LTC will rise by over 10% in the oldest old.

Conclusion

How realistic are the scenarios that we have explored and why were they selected? The Central Health Scenario assumes a 'status quo' in that levels of disease and onset and recovery from disability will remain at the same levels as they were between one and two decades earlier. This scenario may also reflect that any positive health changes, such as reductions in risk factors or more effective treatments for disease, are offset by the changing composition of new cohorts which will comprise greater proportions of ethnic minorities, particularly those from South Asia, who are known to have high rates of CHD, diabetes and stroke, though little is known of whether the disabling effects of these diseases are the same as for the white population. Thus, the Central Health Scenario can be thought of as representing the effect of population ageing alone. This scenario clearly shows that population ageing will result in an increasing trend in disability prevalence and a substantial increase of almost one million in the numbers of older people needing LTC, many of these being the very old with multiple diseases

Table 1: Simulated total and disabled populations (thousands) aged 65+ for Central Health Scenario, Improved Population Health Scenario and continuation of current trends

	2010	2020	2030
Central Health Scenario^a			
Total population (1,000s)	9,181	11,224	13,663
Disabled population (1,000s)	1,011	1,366	1,912
Prevalence of disability			
65+ (%)	11.0	12.2	14.0
65–74 (%)	5.2	5.5	5.4
75–84 (%)	11.9	12.7	13.5
85+ (%)	31.1	34.7	37.9
Improved Population Health Scenario^b			
Total population (1,000s)	9,189	11,324	14,033
Disabled population (1,000s)	985	1,128	1,740
Prevalence of disability			
65+ (%)	10.7	10.7	12.4
65–74 (%)	4.7	4.5	4.1
75–84 (%)	11.9	11.8	12.0
85+ (%)	31.1	32.3	33.6
Continuation of Current Trends Scenario^c			
Total population (1,000s)	9,181	11,186	13,438
Disabled population (1,000s)	1,011	1,431	2,058
Prevalence of disability			
65+ (%)	10.7	12.8	15.3
65–74 (%)	4.7	5.7	5.8
75–84 (%)	11.9	13.4	15.2
85+ (%)	31.1	36.7	42.7

Notes:

^a Assumption of no change in age-specific prevalence of disease, incidence and recovery rates to disability, and mortality rates continuing to decline at levels commensurate with Office for National Statistics principal projections.

^b Assumption of reduction in the prevalence of arthritis, stroke, CHD and mild dementia by 2% every two years from 2012 and for moderate/severe dementia every two years from 2016, a 10% decrease in disabling consequences of arthritis, stroke, CHD and mild dementia from 2012, a further 5% reduction in mortality from stroke, CHD and mild dementia from 2016, and prevalence of disability in 65–66 year olds reducing by 5% every two years.

^c Assumption of increase in the prevalence of arthritis, stroke, CHD and mild dementia by 2% every two years from 2012 and for moderate/severe dementia every two years from 2016, a 10% increase in disabling consequences of arthritis, stroke and CHD from 2012 and a further 5% reduction in mortality from stroke, CHD and mild dementia from 2016.

and conditions, and with 80% more older people with dementia.

Evidence for reductions in the levels of disability in the older population worldwide are varied.^{1,12} Even in countries such as the United States where declines have occurred in the region of 1–2% per year over the last 20 years, these are alongside increases in the prevalence of chronic disease, suggesting that more effective treatments and greater use of assistive technology are

allowing older people to remain independent. Our choice of reductions of 2% every two years is therefore conservative in US terms but optimistic for countries such as Sweden where disability prevalence has increased. More importantly, assumptions that the prevalence of disability will remain constant are optimistic since even with improving population health, disability prevalence in the very old has continued to increase. Our worst-case sce-

nario assumes a continuation of current health trends, although the ageing of the Asian population in the United Kingdom, with its higher levels of CHD, stroke and obesity, suggests that this scenario may be optimistic. If current levels of health prevail and obesity trends continue, the older population with disability at a level that will require care will almost double between 2010 and 2030. Thus, efforts should now be focused not only on disease prevention but on slowing down the progression to disability.

REFERENCES

1. Lafortune G, Balestat G. *Trends in Severe Disability Among Elderly People: Assessing the Evidence in 12 OECD Countries and Their Future Implications*. Paris: OECD, 2007.
2. Jagger C, Matthews RJ, Matthews FE *et al*. Cohort differences in disease and disability in the young-old: findings from the MRC Cognitive Function and Ageing Study (MRC-CFAS). *BMC Public Health* 2007;7:156.
3. Donald IP, Foy C, Jagger C. Trends in disability prevalence over 10 years in older people living in Gloucestershire. *Age and Ageing* 2010;39(3):337–42.
4. Verbrugge LM, Jette AM. The Disablement Process. *Social Science and Medicine* 1994;38(1):1–14.
5. Stuck AE, Walthert JM, Nikolaus T, Büla CJ *et al*. Risk factors for functional status decline in community-living elderly people: A systematic literature review. *Social Science and Medicine* 1999;48:445–69.
6. Collerton J, Davies K, Jagger C *et al*. Health and disease in 85 year olds: baseline findings from the Newcastle 85+ cohort study. *British Medical Journal* 2009;399:b4904.
7. The Medical Research Council Cognitive Function and Ageing Study. Cognitive function and dementia in six areas of England and Wales: the distribution of MMSE and prevalence of GMS organicity level in the MRC CFA Study. *Psychological Medicine* 1998;28:319–35.
8. Wittenberg R, Darton R, Comas-Herrera A, Pickard L, Davies B. Demand for long-term care for older people in England to 2031. *Health Statistics Quarterly* 2001;12:5–17.
9. Craig R, Mindell J (eds). *Health Survey for England 2005. Volume 2: Chronic Diseases*. Leeds: The Information Centre, 2007.
10. Jagger C, Matthews R, Lindsay J,

Robinson T, Croft P, Brayne C. The effect of dementia trends and treatments on longevity and disability. *Age and Ageing* 2009;38:319–25.

11. Jagger C, Matthews RJ, Spiers NA *et al.* *Compression or expansion of disability?* London: King's Fund, 2006. Available at <http://www.kingsfund.org.uk/document.rm?id=8290>

12. Parker M, Thorslund M. Health trends in the elderly population: getting better and getting worse. *The Gerontologist* 2007;47:150–58.

ACKNOWLEDGEMENTS

We are grateful for the cooperation of the then Family Health Service Authorities (a function now embraced by Primary Care

Trusts) and local general practitioners and their staff for all their assistance in MRC CFAS (Medical Research Council/Cognitive Function and Ageing Studies). Thanks are especially due to the residents of East Cambridgeshire, Liverpool, Ynys Mon, Dwyfor, Newcastle upon Tyne, Nottingham and Oxford for their continuing participation in the study.

Disability, dementia and the future costs of long-term care

Adelina Comas-Herrera, Juliette Malley, Raphael Wittenberg, Bo Hu and Carol Jagger

Summary: Increasingly sophisticated efforts to project future long-term care (LTC) expenditure highlight that this is very sensitive to assumptions made about future rates of disability and dementia. This article reviews different ways of formulating such assumptions and gives examples of their impact on future LTC expenditure projections in England. Using disability scenarios from an epidemiological model (based on assumptions about chronic diseases and their outcomes and expected treatments), suggests that assuming constant prevalence of disability may be optimistic. The projections indicate that investing in cost effective public health and management of chronic conditions measures that moderate disability or slow down the progression of dementia may produce good returns in terms of reducing the future costs of LTC.

Key words: disability trends, dementia, long-term care expenditure, compression of disability, chronic conditions

As the numbers of older people rise, so do concerns about future levels of expenditure on long-term care (LTC) and how this care should be funded. In the last decades there have been increasingly sophisticated efforts to project future LTC expenditure, both at national and international levels. As LTC services are very labour intensive and there is limited scope for productivity improvements,¹ the idea that future LTC costs could be contained as a result of care needs not growing as fast as the future number of

older people has attracted a great deal of attention. However, in many countries there no evidence that this may be the case.²

Projections of LTC demand and associated expenditure have shown that relatively small changes in the prevalence rates of functional disability can have a substantial impact on future expenditure.^{3,4} This means that it is important to choose carefully the assumptions made about future

disability and dementia rates of older people, as increases in the future numbers of older people may not necessarily be accompanied by increases of the same magnitude in the number of people requiring LTC.

Projecting LTC expenditure

This article reviews different approaches to choosing assumptions about the future care needs of older people, including: extrapolation from past trends; hypothetical decreases in prevalence rates in order to take into account changes in life expectancy; asking experts for their views about the future; and projections based on expected changes in the prevalence of chronic conditions and mortality rates.

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Assuming rates remain constant over time

The most basic method for projecting future LTC expenditure is to multiply age-specific LTC expenditure by the future number of people in each age group. This method assumes, implicitly, that disability rates do not change over time^{5,6} and that ageing is the only driver of expenditure. More complex projection methods allow explicit analysis of the impact of changes in the prevalence of functional disability and dementia (and socio-demographic variables) on LTC expenditure.

In the face of the inevitable uncertainty about future disability trends, many projections of future LTC expenditure have assumed, as a base case, that disability and dementia rates by age remain constant over time,^{3,7,8} while the future number of older people needing care changes as a result of changes in life expectancy and other socio-demographic factors. The impact of changes to the unchanged prevalence assumption is then explored by changing the prevalence rates by a small percentage per year (such as 1% or 0.5%).

This assumption has often been criticised as being pessimistic because it does not consider possible postponements in disability as life expectancy increases. Because age-specific prevalence is unchanged while age-specific mortality rates are reduced, this assumption assumes that in the future older people will, on average, spend a longer period of their life in disability.

Extrapolating from past trends

Another approach, taken by Jacobzone *et al.*⁶ involves identifying past trends in disability rates and then extrapolating those past trends into the future. There are two main problems with this approach.

The first is that evidence from past trends is limited because consistent longitudinal data on the health and disability status of older people is only available for a few countries (see Jagger *et al.* in this issue).

The second problem is that the past may not necessarily be the best predictor of the future. Social, economic, scientific and environmental changes can dramatically alter the patterns of mortality and disease. Epidemiologists use the term 'epidemiological transition'⁹ to describe these shifts in disease patterns. In recent years, for example, there have been important reductions in the age-specific mortality rates for major cardiovascular diseases, which have in turn led to further delays in mortality which, combined with higher rates of

obesity and lower smoking rates, could potentially lead to new increases in disability rates.¹⁰

Projections based on hypotheses linked to changes in life expectancy

In the context of the debate about the relationship between the postponement of mortality and possible postponements of disability, another approach used in LTC projections has been the modelling of hypothetical assumptions that link expected rise in life expectancy with assumptions about changes in age-specific disability rates. An example of this is a scenario often called the 'Brookings scenario' as it was originally used in projections by Wiener *et al.*¹¹ at the Brookings Institution. A typical example of this scenario can be described as follows: if life expectancy at age 65 is projected to rise by three years between 2007 and 2030, then the disability rate of a person aged 65 in 2007 would be applied to a person aged 68 in 2030.

This assumption effectively decreases disability rates and, to a certain extent, can compensate for increases in the number of older people when projecting LTC expenditure.^{3,4,8} A similar version of this method has been used by the European Commission's Economic Policy Committee (EPC) in the context of their projections of future LTC expenditure.¹² In fact, the 'reference' (or base case) LTC projection in the EPC's latest projections assumes that disability rates will be postponed by half the increase in life expectancy.

In the case of England, results from the Personal Social Services Research Unit (PSSRU) Aggregate Long-Term Care for Older People Model³ show that, if we assumed that for every year of life expectancy gained, disability rates could be pushed back by one year, future LTC expenditure for older people would amount to 1.9% of Gross Domestic Product (GDP), compared to 2.7% under the constant disability assumption.

This scenario has the advantage of being intuitive, not requiring information about disability trends, and being easy to calculate. However, due to its hypothetical nature, the results of this scenario should be treated with caution as they are not grounded on evidence.

Asking experts their views about the future

Another approach, particularly as projections of LTC expenditure tend to be carried out by economists, is to consult with experts in the field, in order to obtain their views about future trends in disability and dementia rates. This normally involves using consensus building methods (such as a Delphi or focus group) in order to find a set of assumptions about the future that a group of experts agree with.

The Delphi approach was used to obtain scenarios about the future prevalence of dementia and the future care needs of individuals living with dementia.¹³ A panel of experts on dementia, including old age psychiatrists, neurologists, public health doctors, basic scientists, health economists and service professionals, considered various future scenarios and were, overall, moderately optimistic about the impact of future scientific advances and changes in risk factors on the future prevalence rates of dementia. However, the panel also warned that improvements in the quality of care were required, which may offset some of the potential savings from decreased prevalence.

This type of research does present some important challenges. First of all, it is very difficult to establish the representativeness of a panel of experts. Second, translating the view of the expert panel into scenarios that can be modelled may not be straightforward, unless the panel is given very clear parameters.

Using projections from epidemiological models of chronic conditions and their disabling and mortality outcomes

As the paper by Jagger *et al.* (in this issue) highlights, the process by which older people develop care needs is complex and understanding how those care needs emerge is key to being able to model them. As part of the MAP2030 project, the SIMPOP* model by Jagger *et al.* has been linked with the PSSRU Aggregate Long-Term Care for Older People Model,³ enabling the PSSRU model to produce projections of future expenditure on LTC for older people for the health and disease scenarios in SIMPOP.

Combining the Central Health Scenario disability rates obtained by the SIMPOP

* SIMPOP is a macro-simulation model that projects the numbers of older people (aged 65+ years) with disability from two-year transition probabilities to and from disability and to death, and is then applied to the 1992 mid-year England and Wales revised population estimates. See Jagger *et al.* in this issue.

model (which assumes unchanged prevalence of chronic conditions and risk factors) with the PSSRU aggregate model results in higher future LTC expenditure than in the previously used base case assumption of unchanged age-specific disability rate (by 2032, total LTC expenditure would have grown to 3.2% of GDP rather than 2.7%).

The reason for this is that if the prevalence rates of chronic conditions and risk factors remain unchanged and their disability and mortality outcomes also remain unchanged, while life expectancy continues to increase, more older people will be spending longer periods of their life in disability; hence, the overall age-specific prevalence of disability will increase. This suggests that maintaining unchanged disability rates in the LTC model (in the context of increased life expectancy) would be an optimistic assumption, compared to an assumption of unchanged prevalence of chronic conditions.

Under the Improving Population Health Scenario, LTC expenditure in 2032 would amount to 3.0% of GDP. This compares with 2.7% projected under the constant disability rates assumption. The Continuation of Current Trends Scenario would result in even higher levels of expenditure – 3.3% by 2032.

Conclusions

Making projections about the future of any kind inevitably involves a great deal of uncertainty and, despite best efforts, all past projections will always turn out to have been at least slightly wrong. Choosing the right assumptions about the future levels of care needs is a clearly important aspect of making projections of future LTC expenditure.

This article has reviewed different assumptions made about future disability trends and methods, in the context of increased life expectancy. Recent projections from our epidemiological model in England suggest that assuming constant disability or dementia prevalence rates is an optimistic rather than pessimistic assumption.

Policy-makers using LTC expenditure projections to make decisions need to be aware of quite how much uncertainty there is about future disability rates and that substantial investment in public health and the management of chronic conditions will be required to avoid LTC expenditure growing even faster than expected.

REFERENCES

- Oliveira Martins J, de la Maisonneuve C. *The Drivers of Public Expenditure on Health and Long-Term Care: An Integrated Approach*. OECD Economic Studies, No. 43, 2006/2. Paris: OECD, 2006.
- Lafortune G, Balestat G and the Disability Study Expert Group Members. Trends in severe disability among elderly people: assessing the evidence in 12 OECD countries and the future implications. *OECD Health Working Papers* 2007; 26.
- Wittenberg R, Pickard L, Comas-Herrera A, Davies B, Darton R. Demand for long-term care for elderly people in England to 2031. *Health Statistics Quarterly* 2001;12:5–16.
- Rothgang H, Comas-Herrera A, Wittenberg R. Dependency rates and health expectancy. In: Comas-Herrera A, Wittenberg R (eds). *European Study of Long-Term Care Expenditure. Report to the European Commission, Employment and Social Affairs DG*. PSSRU Discussion Paper 1840. London: PSSRU, 2003.
- Economic Policy Committee. *Budgetary Challenges Posed by Ageing Populations*. Brussels: Commission of the European Communities, 2001. At: http://europa.eu/epc/pdf/summary_en.pdf
- Jacobzone S, Cambois E, Robine JM. Is the health of older persons in the OECD countries improving fast enough to compensate for population ageing? *OECD Economic Studies* 2000; 30:1. .
- Wittenberg R, Pickard L, Comas-Herrera A, Davies B, Darton R. *Demand for Long-Term Care: Projections of Long-term Care Finance for Elderly People*. University of Kent: PSSRU, 1998. Available at: <http://www.pssru.ac.uk/pdf/lcprep98.pdf>
- Comas-Herrera A, Wittenberg R, Pickard L, Knapp M. Cognitive impairment in older people: future demand for long-term care services and the associated costs. *International Journal of Geriatric Psychiatry* 2007;22:1037–45.
- Olshansky SJ, Ault AB. The fourth stage of the epidemiologic transition: the age of delayed degenerative diseases. *The Milbank Quarterly* 1986;64(3):355–91.
- Reuser M, Bonneux LG, Willekens FJ. Smoking Kills, Obesity disables: a multi-state approach of the US Health and Retirement Survey. *Obesity* 2009;17:783–89.
- Wiener JM, Illston LH, Hanley RJ. *Sharing the Burden: Strategies for Public and Private Long-term Care Insurance*. Washington: The Brookings Institution, 1994.
- Economic Policy Committee. *2009 Ageing Report Economic and budgetary projections for the EU-27 Member States (2008–2060)*. Brussels: Commission of the European Communities, 2009. Available at: http://ec.europa.eu/economy_finance/publications/publication14992_en.pdf
- Comas-Herrera A, Northey S, Wittenberg R, Knapp M, Bhattacharyya S, Burns A. Future costs of dementia-related long-term care: modelling scenarios about the future. *International Psychogeriatrics* 2011;23(1):20–30.

ACKNOWLEDGEMENTS

This paper arises from work undertaken as part of the Modelling Ageing Populations to 2030 (MAP2030) project funded under a grant from the New Dynamics of Ageing Programme in the UK, a cross-research council programme (RES-339-25-0002). All responsibility for analysis and interpretation and views expressed rests with the authors.



INTERNATIONAL LONG-TERM CARE POLICY NETWORK

ILPN is a network of professionals, institutions and associations involved in long-term care (LTC).

The network was launched in September 2010 to promote global exchange of policy evidence and knowledge related to LTC and is presently based at the London School of Economics and Political Science, United Kingdom.

ILPN is the first network of its kind providing an interface between researchers, policy makers and other stakeholders, facilitating contributions to, and sharing of the evidence base, which would be of significant assistance in shaping and improving policies and practices in LTC. From an academic point of view, the Network will foster international research collaborations, and will assist the development of international comparative policy analysis.

For further information about the Network and how to join go to:

<http://www2.lse.ac.uk/LSEHealthAndSocialCare/PSSRU/ILPN/ILPNNetwork.aspx>

Long-term care: valuing care providers

Frits Tjadens and Francesca Colombo

Summary: Long-term care can be defined as consisting of nursing care and assistance with so-called instrumental activities of daily living (ADL), such as washing, eating, getting in and out of bed, provided to people with reduced functional and health status over an extended period of time. This article discusses some trends in demography and use of long-term care (LTC) as a context for policy options related to family care and LTC workforces in Organisation for Economic Cooperation and Development (OECD) countries. It draws on a new OECD report on long-term care,¹ reviews some of the outcomes in terms of long-term requirements for human resources for LTC and discusses options to reduce demand for care and to support family carers.

Keywords: Long-term care workers, informal carers, human resources, carer support

More need for long-term care, but fewer potential providers expected

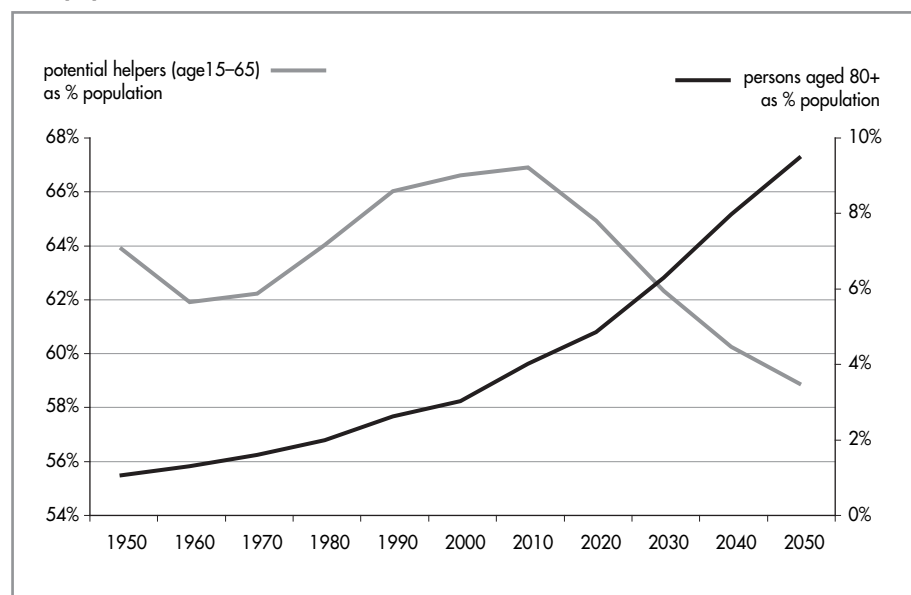
More than half of all LTC users are aged over 80 years in OECD countries, varying from 27% of people in this age cohort in Hungary to 64% in Japan.¹ In Europe, one in four people aged over 85 years has had personal experience with a prolonged need for care.² Yet, use of LTC varies widely across countries: of those aged over 80 years between 2% of women and 3% of men in Poland, and 46% of women and 32% of men in Norway, use formal LTC services.

People aged 80 years or older are the fastest growing population segment in Europe, and life expectancy at age 65, and even at age 80, keeps increasing.³ In thirty of the OECD* countries, almost 10% of the population will be over 80 years of age by 2050, a near tripling compared to the current share across the OECD. Over the same period the share of the population aged between 15 and 64 years is set to decrease from 67% in 2010 to an unprecedented 58% by 2050 (Figure 1). The number of people in an 'extended caring-age' population (15–79 years) for each person aged over 80 years will drop to less than a third of 2000 levels: in 2000 there were 26 people per person over 80 falling

to less than eight people per person by 2050. Meanwhile, the average age of people in this 'extended caring-age population' will increase due to the higher share of people aged between 65 and 79 years.**

Family relationships and household models are changing too, due to decreasing fertility rates, individualisation and increasing geographical distance between family members. Increased divorce and falling

Figure 1: Working age population and population aged over 80 years as share of the total population, OECD, 1950–2050



Source: OECD Labour Force and Demographic Database, 2010.

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* These data consider 30 of the 34 OECD member countries. It does not include recent accession countries: Israel, Chile, Slovenia, and Estonia, who all have relatively young populations. Nevertheless, the overall trend remains unchanged.

** In Japan, Germany, and a number of Middle and Eastern European countries (Bulgaria, Latvia, Lithuania, Romania, Estonia, Hungary, Poland, Slovakia, Slovenia) this will coincide with a steep reduction in the overall size of the population.

marriage rates contributed to an increase from 16% in 1960 to 29% by 2001 in the share of single-person households in the EU25 2001.⁴ Almost one in three people aged 55 years and over lives alone in Europe.⁵ As the most intensive (and burdensome) family care is provided within a household,^{1,6} those living alone may particularly find themselves in need of formal LTC services. The growth of the absolute number of older people living alone may therefore add to the increase in the need for care resulting from population ageing, even though the shares of those living alone at age 60 or 80 in the European Union are expected to remain more or less stable.⁴

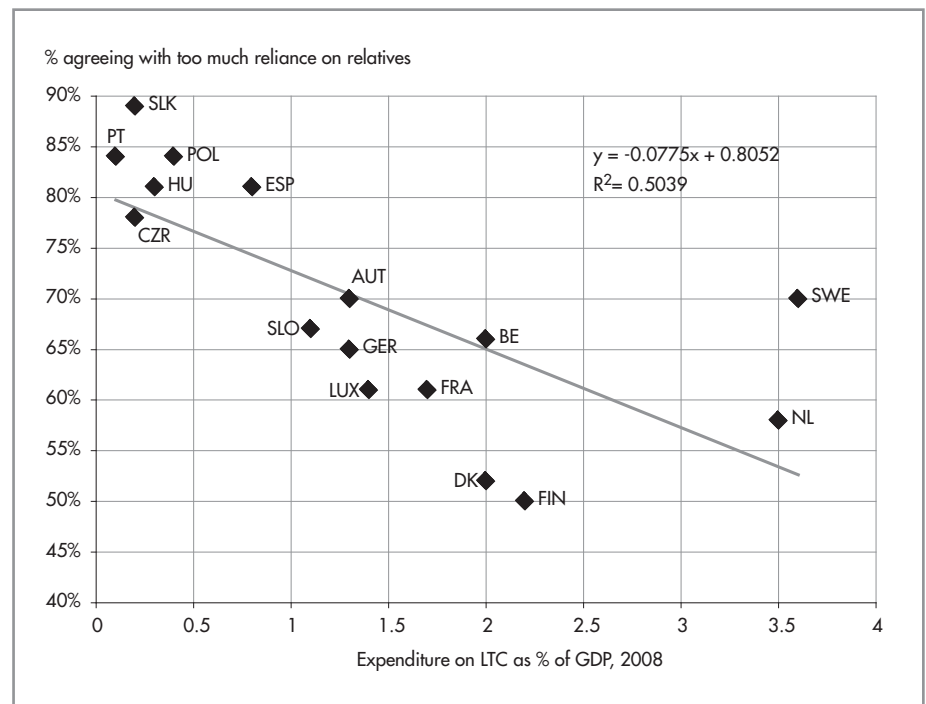
Demographic trends suggest increasing tensions between the need for care and the supply thereof. While family networks are thinning, these trends may result in larger shares of the population being required to care for a family member or friend. Furthermore, the increase in the number of the oldest old living alone and the reducing caring potential in societies will increase demand for LTC workers. How will countries cope?

Care workers: recruit them, keep them and increase productivity

The LTC workforce consists mostly of women working part-time; which in the LTC sector occurs more often, and with fewer hours per week, than in other sectors of the economy. While these workers often have a high appreciation of their work, (staffing) shortages, bad management, harsh circumstances, poor working conditions and a lack of recognition or valuation of their job contributes to poor job satisfaction and a feeling of dissatisfaction with the outcomes of their work, leading nurses in Europe, for instance, to burn out.⁷ Wages are usually lower than a country's average wages, work experience does not translate into higher wages, secondary benefits are often not granted, shifts are broken and do not easily enable reconciliation between family and caring tasks, contracts require utmost flexibility but do not offer job security and the work can be physically and psychologically demanding and burdensome. Worker-safety measures may be lacking and violence from those cared for is not uncommon. All these factors stimulate high and costly turnover and can contribute to low productivity and care quality.¹

Yet it remains the case that more than half of the EU27 population believe that older people rely too much on their relatives for

Figure 2: LTC expenditures as a share of GDP and share of population that believe there is too much reliance on relatives for caring tasks, EU, 2007–08



Sources: ⁸ and OECD Health Database, 2010.

Note: Data relating to expenditure Slovakia and Luxembourg refer to 2006 and 2005 respectively; expenditure data underestimate private out of pocket payments or user co-payments. Data for Belgium, Czech Republic, Denmark, Iceland, Norway, and Switzerland represent nursing LTC only. Iceland: institutional care only

support and care, ranging from 42% in Denmark to almost 100% in Bulgaria.² Enhancing the supply of formal care workers can be seen as one way to support family carers: indeed, the higher a country's LTC expenditure, the fewer the number of people who think that there is too much reliance on relatives (Figure 2).

A growing number of countries are developing formal LTC coverage and delivery systems. Yet, many OECD countries struggle with the recruitment and retention of LTC workers. Attracting and retaining workers, and improving productivity may well be required to face up to future demand. How can countries implement such policies? The next section discusses the main challenges in managing demand for LTC workers and creating successful policies.

Even with shrinking recruitment pools, there is potential for growth in the LTC workforce

While the LTC sector is set to more than double by 2050, two major recruitment pools for LTC workers are shrinking: (1) middle-aged women; (2) inactive women and those with low qualifications (due to both rising labour market participation and

educational levels). In addition, the global nursing shortage^{8,9} may lead to increasing nursing shortages in the LTC sector, as competition between countries, regions and sectors to attract nursing professionals intensifies. Often, LTC systems and employers are in a bad position to compete in times of nursing shortages due to low wages, lack of targeted training and job prospects and poor working conditions.

In most countries, the LTC sector employs a relatively small share of the working-age population, estimated at 1.5% across the OECD. There is reason to assume that an expansion of this workforce is not only much needed, but also possible. This often takes place in parallel to the development of formal LTC coverage schemes. For example, in countries such as Luxembourg, New Zealand and Japan, the LTC workforce as a share of the working-age population is projected to reach the *current* size of the LTC workforce in Norway, Sweden or the Netherlands by 2050.^{1*} A relatively 'old' country with a substantial LTC workforce, the Netherlands, prepares to manage with a fully domestic LTC workforce until 2025, through a wealth of measures.^{10,11} Rapidly ageing countries like Germany and Japan have successfully

managed an expansion in their LTC insurance systems, and encouraged the development of a large LTC workforce since the 1990s. Similarly, Spain, in the phase of preparation and implementation of its LTC law, experienced steep growth in its LTC workforce.

Proactive policies can facilitate the matching of supply with demand

The OECD expects many countries to implement policies to stimulate an adequate supply of LTC workers in the future, often as a response to current or expected workforce shortages. Three main policies to develop an adequate supply of LTC workers exist:

1. Improving recruitment.

Countries aim to ensure adequate worker inflows by using the available workforce pools better, by opening up new recruitment pools – such as those who have left, not yet entered or are distant from the labour market, including men and migrants. Another possibility is attracting foreign-born workers into the sector, even though few countries – such as Canada and Australia – specifically include LTC as a sector for labour immigration schemes or quotas. In some countries people in need of care who face high out-of-pocket payments and/or those receiving cash-for-care benefits, have managed to mobilise ‘ad-hoc’ – albeit sometimes unqualified or uncontracted – LTC workers, even when the ‘regular’ sector faces shortages. Finally, the decreasing average length of stay in hospitals could become an advantage for the LTC sector, where interactions with those in need are longer lasting.^{12,13}

2. Improving retention

The key question, however, may be how to retain workers and how to stimulate them to work more hours per week and for longer periods. Although wages in the LTC sector clearly matter, rising pay does not seem to be the primary or only solution. More important is the extent to which LTC work and the workforce are valued. Workforce policies could include specific measures targeting the challenges of an ageing LTC workforce.¹⁴ ‘Worker-friendly’ policies – amongst which improving benefits, working conditions, empowering workers and giving them a say about work content, (continued) edu-

cation and career development, and increasing job status – will have a significant impact on the ability to maintain LTC workers in their current occupations.¹ Worker-friendly policies could translate into better working conditions and contracts, for example substantial shares of women across the OECD would prefer to work more hours. This would help a shift from LTC occupations being merely dead-end jobs to professions with opportunities for the workers to improve their qualifications, for instance by offering options for personal and professional growth. One such option is the setting up of courses and training modules that have a recognised value in the system beyond the current employer, for instance by implementing a system of national certification for training modules. Such a system, set up to stimulate both performance on the job as well as professional growth is, however, rare in OECD countries.

3. Increasing productivity

Increasing productivity and improving value for money can go hand in hand with improvements in working conditions. More say and more responsibilities for workers, can lead, for instance, to lower levels of sickness leave.¹¹ Technology can contribute to both productivity and quality of care, even though evidence of cost-effectiveness of technology in LTC is still scarce. Across the OECD, variations in the number of LTC workers per LTC recipient and in skill mix (i.e., the share of nurses relative to the share of lower-skilled LTC workers) suggests that there is scope for enhancing productivity by changing staffing ratios and workers’ mix of skills or qualifications. For instance, delegation of nurses’ tasks to lower-qualified care workers has been shown to lead to higher productivity without loss of quality.¹⁵ Similarly, new mixes of tasks and functions can improve productivity, while leading to both better quality of care (and quality of life) for the care recipient and better quality of work for the worker.

Reducing demand: targeting services and stimulating self-management

So far we have only looked at the supply of LTC services and, consequentially, the need for LTC workers. LTC is a highly labour intensive sector and approximately 60% of all LTC funding is directly related

to the LTC workforce. Reducing the demand for care could mitigate the anticipated rise in LTC expenditure and the need for LTC workers. One strategy is to target services more narrowly towards those most in need of care. This seems to be occurring in the aftermath of the economic crisis. Another strategy is to reduce the demand for care through preventive approaches and enhancing self-management. Both are currently occurring but country circumstances vary widely, just like their consequences for LTC systems and ageing societies.

Economic crises and cutbacks change the dynamics of LTC labour markets

In the wake of economic crisis, LTC often acts as a ‘safe haven’, reducing the sense of urgency to further develop and implement job improvement and retention strategies for LTC workers. For instance, numbers of (hard-to-fill) vacancies have recently dropped in England and the Netherlands. People stay in the sector longer and more people apply for jobs in LTC in the United States. As baby-boom generation LTC workers stay on the labour market for longer, the expected need for a high number of replacements is mitigated.

The consequences for enrolment in nursing education, however, are mixed. Where governments pay most costs, entry to training courses for LTC workers has increased, as in the Netherlands. In the United States on the other hand, where individuals pay a substantial share of the fee for their own tuition, the loss of a job or assets by parents may lead to fewer possibilities to pay for their children’s education and thus may limit enrolment on LTC training courses. Furthermore, post-crisis cuts in funding for educational facilities may endanger the future supply of qualified workers.

Social protection, including LTC is among the most widely targeted area for public expenditure cuts (see <http://tinyurl.com/3vpymu3>). Nonetheless, during the first half of 2010 the current crisis had not yet triggered cost-cutting measures in the LTC sector in half of all EU countries.¹⁶ Policies were rather aimed at de-institutionalisation, as well as improving access both to home care and end-of-life care.

As the crisis progresses, new measures may well target LTC services, almost directly impacting on the need for care workers.¹⁷ While such strategies risk ignoring long-term growth in need and endanger the sustainability of some LTC services, they

* Changes in coverage or access of LTC services will impact on the required workforce. If, for instance, the Czech Republic aims for a more comprehensive and easier accessible LTC system, this will require more services and thus, a bigger than projected LTC workforce.

can encourage a reduction in waste and a desirable focus on improving value for money and productivity in the sector. However, such strategies may well increase the burden on family carers.

Preventive and supportive strategies

Other strategies to reduce the gap between the demand for and supply of care aim specifically to reduce the demand for care. Colombo *et al* discuss two options.¹ One strategy involves preventing the need for care from arising. Healthy ageing, or better dependency-free ageing, is seen as an important option, even though evidence about reduction or compression of disabilities among elderly populations is inconclusive.¹⁸ A second strategy aims to reduce or postpone the growth in the need for care, for instance by supporting self-management and by implementing preventive approaches. Japan recently changed its entitlement to social LTC insurance for mildly disabled older people to a 'prevention system', with the aim of enabling those eligible for support to remain independent longer and better. Such approaches could also be combined with more adequate support strategies for family carers, and promise to delay and reduce the need for formal care services.

A result of both strategies may be that LTC systems focus more on the growing number of people having more complex – and more costly – needs.¹⁹ However, the focus of both strategies differ. While strategies to reduce demand primarily focus on enabling disabled people to manage their situation better, other strategies may focus on de-institutionalisation. Cutbacks may primarily target entitlement rules or the basket of services, and may not take preventive approaches into account.

Supporting family carers is a three-win strategy but how to do it?

Whatever the strategy, a larger proportion of the population may well become family carers, or may care for a dependent person more often, repeatedly or simultaneously. Those carers will age themselves.²⁰ However, while it could be expected that friends and more distant relatives will provide more care in the future,²¹ according to data from the Survey of Health, Ageing and Retirement in Europe, friends only substitute for care by adult children in situations with a modest need for care,²² leaving the main burden to close relatives.

Family carers already provide the bulk of long-term care. In Europe, employed women aged over eighteen spend eleven hours per week caring for a disabled or frail person, compared with almost eight hours by employed men.²³ The opportunity costs of caring can be long lasting. According to OECD analyses based on household surveys in several EU and non-EU countries, 'heavy caring' (more than 20 hours per week), is associated with a reduction in paid work, a higher risk of poverty and a 20% higher prevalence of mental health problems than among non-carers.¹ Deteriorating health status, financial problems due to extra costs and loss of income (for the caree or the family carer), and a lack of information and training are also reported (see <http://eurocarers.org/userfiles/file/Factsheet2009.pdf>). Moreover, juggling care and other responsibilities can lead to time management problems and isolation, while caring by an overburdened family carer can affect the quality of care, the (care) relationship and the health status of both the person cared for and the family carer. Finally, where caring affects labour-market participation, it can reduce or delay earnings and opportunities (including pension rights).

Supporting family carers is a three-win arrangement, for carers (who provide care out of love or duty*), for the 'carees' (who prefer to be cared for by family and friends) and for governments (who would otherwise face higher costs for formal care services and need all available support for their dependent populations).¹ But currently only two in seven people in Europe are satisfied with the public support available to those caring for dependent older relatives.⁵ Family carers experience problems accessing support, such as a lack of information, costs related to access or use of support, waiting lists for supportive services, bureaucracy, a lack of transport, or even a caree's negative attitude.²⁴ Some family carers do not see themselves as a group for whom services are available,²⁵ or may feel stigmatised by the term,²⁶ and thus may be hard to target.²⁷ In addition, while support for carers is in demand, for some major support mechanisms – including financial payments and employment-related measures – there is little evidence of (cost)-effectiveness.^{6,28–31}

Better support for family carers is therefore

required, but not easy to arrange. Needs, options and hurdles need to be balanced. For governments wishing to support family carers, there are opportunity costs as well. For instance, policies for family carers may need to balance the benefits of supporting carers with incentives for carers to participate in the labour market. It is also important to address any possible tension arising from the 'monetising' of social relationships. Support measures may lead to greater bureaucracy, which can be burdensome for family carers and whose value is hard to prove. Formalisation of the position of the family carer, for example in terms of rights and duties, provides more clarity for both governments and family carers, but it also holds risks for family carers, including liability issues.³²

Supporting family carers needs to become a key aspect of any LTC system, and may well require a mix of measures such as cash benefits, flexible leave options for working family carers and other support forms, such as information, training, respite services and peer support. However, a crucial outstanding question is how to do this effectively, when there is still a dearth of evidence on cost-effectiveness.

Conclusions

Between now and 2050 the need for care is likely to more than double across the OECD, while the pools of those available to care will shrink. As LTC workforces are relatively small, there are several potential options for growth, especially if countries implement targeted policies aimed at recruitment, retention and productivity improvements. Policies to reduce demand should also be undertaken. While, in the wake of economic crises, policies aimed at cutting back social protection services may well reduce the need for LTC workers, such policies do not necessarily reduce the need for care, nor do they affect options for self-management, such as strategies to stimulate disability-free ageing, or strategies to reduce a growing need for care. Whatever the strategy, family members, already providing the bulk of LTC, are likely to bear the brunt. As heavy caring can have long-lasting opportunity costs and may endanger the quality of care, and life as well as the social relationship between the family carer and caree, supporting family caring seems especially

* Those caring out of duty experience high burden differently than those caring out of love. Those caring out of love are better able to cope with higher intensity or longer duration of care than those caring out of duty.³³

important for the future. It is also a three-win arrangement: for governments, for the person cared for and for the family carer. However, supporting family carers is also associated with opportunity costs. Finding the right balance will become one of the major challenges in the years to come. Comprehensive approaches are required to better prepare for ageing societies, including healthy – or dependency free – ageing strategies, policies to integrate health and care, initiatives to prevent the need for care from arising or increasing, as well as better valuing of care workers and supporting family carers.

REFERENCES

1. Colombo F, Llena Nozal A, Mercier J, Tjadens F. *Help Wanted? Providing and Financing Long-term Care*. Paris: OECD, 2011. Available at www.oecd.org/health/longtermcare
2. Eurobarometer. *Health and Long-term care in Europe. Special Eurobarometer 283*. Brussels: Commission of the European Communities, 2007.
3. Huber M, Rodrigues R, Hoffman F, Gasior K, Marin B. *Facts and Figures on Long-term Care: Europe and North America*. Vienna: European Centre for Social Welfare Policy and Research, 2009.
4. Commission of the European Communities. *Demography Report 2008. Meeting Social Needs in an Ageing Society*. Commission Staff working document. Brussels: European Commission, Directorate-General for Employment, Social Affairs and Equal Opportunities, 2009.
5. Eurobarometer. *Family Life and the Needs of an Ageing Population. Analytical Report. Eurobarometer 2247*. Brussels: Commission of the European Communities, 2008.
6. Glendinning C, Arksey H, Tjadens F, Moree M, Moran N, Nies H. *Care Provision Within Families and its Socio-economic Impact on Care Providers Across the European Union*. York: Social Policy Research Unit, University of York, 2009.
7. van der Schoot E, Ogińska H, Estryń-Behar M. Burnout in the nursing profession in Europe. In: Hasselhorn H-M, Tackenberg P, Muller BH (eds). *Working Conditions and Intent to Leave the Profession Among Nursing Staff in Europe*. Stockholm: National Institute for Working Life, 2003.
8. World Health Organization. *World Health Report 2006: Working Together for Health*. Geneva: WHO, 2006.
9. Colombo F, Dumont J-C, Hurst J, Zurn P. *The Looming Crisis in the Health Workforce. How Can OECD Countries Respond?* Paris: OECD, 2008.
10. Klein Breteler J, Theeuwes J, Bos J, Boereboom M. *Zorg voor mensen, mensen voor de zorg; arbeidsmarktbeleid voor de zorgsector richting 2025* [Care for people, people for care, labour market policy for the care sector to 2025]. Den Haag: Zorginnovatieplatform, 2009.
11. Plexus. *Werken in de zorg*. [Working in Care] Breukelen: Plexus, 2011.
12. Thomas C, Hosein R, Yan J. *Assessing the Export of Nursing Services as a Diversification Option for Caricom Economies*. Barbados: Caribbean Commission on Health and Development, 2005.
13. Yeates N. *Migration and Social Policy in International Context: the Analytical and Policy Uses of a Global Care Chains Perspective*. Arusha Conference: New Frontiers of Social Policy, 12–15 December 2005.
14. van Houten G. Working longer requires better working. *Foundation Focus Issue* 2011;9:8.
15. Verkaik R, Francke AL, van Meijel B, Spreeuwenberg PM, Ribbe MW, Bensing JM. The introduction of a nursing guideline on depression at psychogeriatric nursing home wards: effects on certified nurse assistants. *International Journal of Nursing Studies* 2011;48(6):710–19.
16. *2010 Update of the Joint Assessment by the Social Protection Committee and the European Commission of the Social Impact of the Economic Crisis and of Policy Responses*. SOC 793; ECOFIN 786. Brussels: Council of the European Union, 2010.
17. Forder J, Fernandez J. *The Impact of a Tightening Fiscal Situation on Social Care for Older People*. London: London School of Economics and Political Science, 2010. PSSRU Discussion Paper 2723.
18. Lafortune G, Baléstat G. *Trends in Severe Disability Among Elderly People: Assessing the Evidence in 12 OECD Countries and the Future Implications*. OECD Health Working Papers 2007;26.
19. Tjadens F. *Internationale signalen. Een eerste toetsing van de ActiZ lange-termijn visie en 'de 12000' in internationale context* [International signals: an initial review of the ActiZ long-term perspective and 'the 12,000' in an international context] Alphen aan den Rijn: HASCA, in press.
20. Sadiraj K, Timmermans J, Ras M, de Boer A. *De toekomst van de mantelzorg* [The future of care] Den Haag: Sociaal en Cultureel Planbureau, 2009.
21. Peters A, Wilbrink I. *Krimp achter de voordeur. De toekomst van mantelzorg voor ouderen* [Shrink behind the front door. The future of family care for older people] Utrecht: Movisie, 2011.
22. Kalwij A, Pasini G, Wu M. *Home Care for the Elderly: Family, Friends, and the State. Discussion Paper 07/2009*. NETSPAR: Network for studies on pensions, aging and retirement, 2009.
23. Anderson RM. *Second European Quality of Life Survey. Overview*. Dublin: European Foundation for the Improvement of Working and Living Conditions, 2009.
24. Triantafyllou J, Mestheneos E. *Services for Supporting Family Carers of Elderly People in Europe: Characteristics, Coverage and Usage*. Hamburg: Universität Hamburg, 2006.
25. Tjadens F, Duijnste M. *Visie op mantelzorg* [Vision of Care] Utrecht: Nederlands Instituut voor Zorg en Welzijn, 1998.
26. Gerstenberger B, Anderson R. Support for a juggling act – what employers can do to support workers who care. *Foundation Focus* 2011;9:9.
27. Tjadens F, Visser G, Sangers S. *Family Care in Europe: the Contribution of Carers to Long-term Care, Especially to Older People*. Utrecht: Eurocarers, 2007.
28. Eager K, Owen A, Williams K. *Effective Caring: a Synthesis of the International Evidence on Carer Needs and Interventions. Volume 1: the Report*. University of Wollongong: Centre for Health Service Development, 2007.
29. Lee H, Cameron MH. Respite care for people with dementia and their carers. *Cochrane Database of Systematic Reviews* 2004; 2 Art. No.: CD004396. DOI: 10.1002/14651858.CD004396.pub2
30. Parker G, Arksey H, Harden M. *Meta-Review of International Evidence on Interventions to Support Carers*. York: University of York, Social Policy Research Unit, 2010.
31. Mason A, Weatherley H, Spilsbury K et al. A systematic review of the effectiveness and cost-effectiveness of different models of community-based respite care for frail older people and their carers. *Health Technology Assessment* 2007;11(15).
32. Flohimont V, van Limberghen G, Tasiaux A, Baeke A-M, Versailles P. *Reconnaissance légale et accès aux droits sociaux pour les aidants proches* [Legal Recognition and Access to Social Rights for Family Carers] Louvain-La-Neuve: Aidants Proches ASBL, 2010..
33. Tjadens F, Woldringh C. *Achtergronden van informele zorg. Een onderzoek bij ouderen naar mogelijkheden en problemen* [Backgrounds of informal care. A study on opportunities for and problems of older people]. Nijmegen: ITS, 1991.

Use of care services in relation to proximity to death among older people: Evidence from Finland

Mike Murphy and Pekka Martikainen

Summary: An analysis of register data for Finland shows that the use of health and social care services by older people varies by both age and proximity to death. Acute health care use depends more on proximity to death, suggesting that the need for such services will be less than might have been expected given the likely increase in numbers of older people. However, this is more than offset by a greater use of residential long-term care especially by the “old old”. The balance of care is likely to shift from acute to long-term care services.

Key words: long-term care, ageing, proximity to death, Finland

Determinants of health care costs

The use of health and social care services depend on individuals' sex, age and health/disability status, as well as external factors such as availability of facilities and health care technology. Service use rises sharply with age and therefore the future number of older people is often assumed to be an important determinant of overall use. A simple widely-used assumption is that future demand for health care remains constant within each sex and age-group so that changes in provision depend only on changing population numbers.

However, the average costs of acute health care services, principally based on use of hospital services, are greater at any given age for those who die relatively shortly afterwards ('decedents') than those who do not ('survivors'). Fuchs¹ concluded that: "health care spending among the elderly is not so much a function of time since birth as it is a function of time to death. The principal reason why expenditures rise with age...is that the proportion of persons

near death increases with age". Studies in a number of countries confirm the robustness of these conclusions, typically finding that acute care in the last year of life accounts for about one third of total lifetime costs.²

The implications of whether the use of services is affected more by proximity to death than by age are substantial. If age is the key driver, then increased longevity will lead to more care use at older ages. However, if proximity to death is more important, then pushing back the age of death will reduce the number of deaths occurring in a given year. Moreover, most studies find that acute health care costs in the last year of life fall with later age at death.³

Much less is known about the relationship of social care costs, including long-term care costs, with age and proximity to death,³ although an early Canadian study found that: "those dying at older ages have more rather than less expensive deaths, largely due to heavy nursing home use by the very elderly".⁴

Data and methods

Most studies have been based on cost-oriented data from service providers which may relate to selected sub-populations and often contain little socioeconomic infor-

mation on service users (and none on non-users). Finland has good data on joint use of long-term care (LTC) and community and hospital facilities, so we use a 40% random sample of the Finnish population aged 65 and older at the end of 1997 with information on socio-demographic factors that were followed to death in 1998–2003 or to the end of 2003. The number of days in hospital and long-term institutional care was assessed in each calendar year between 1998 and 2003 (for survivors), and the number of days in twelve month intervals before death (for decedents). The initial population size was 301,263.⁵

Differentials by age and sex

Days in both hospital and LTC increase with age for men and women, although women spend more days in care than men do, especially for LTC (Table 1). For the 'young old', use is low among survivors, but much higher among decedents especially for hospital care. Decedents typically have around 60 more days in hospital than survivors at any age. Decedents also use LTC more than survivors, but the difference is smaller than for hospital days. The number of days in LTC overtakes days in hospital around age 80. As populations age, this will change the balance of use between the two sectors.

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Table 1: Average number of days spent in hospital and long-term care by sex and age group for those who do not die and those who die in subsequent 12 months, Finland 1998–2003

Sex and age group	Hospital		Long-term care		
	Survivor	Decedent	Survivor	Decedent	
Males	65–69	4.2	48.0	2.2	10.1
	70–74	6.0	56.4	4.2	18.9
	75–79	9.8	65.7	9.1	29.2
	80–84	14.8	72.2	18.3	45.1
	85–89	21.2	78.6	35.5	66.0
	90–94	27.4	80.7	62.6	91.8
	95+	31.2	85.5	84.4	119.2
	Females	65–69	3.5	63.7	2.3
70–74		5.9	71.4	5.2	27.8
75–79		10.8	81.3	12.6	44.0
80–84		18.2	89.3	28.5	67.7
85–89		29.4	96.1	54.7	93.2
90–94		42.5	104.3	88.4	118.2
95+		59.2	107.8	128.0	146.1

Source: Authors' analysis of 40% Finnish register-based population sample

Differentials by marital status

Use of services varies among socio-demographic groups such as by marital status (Figure 1). All groups show increasing use of services with age (apart from decedents' use of hospital care for the oldest age groups). Among the groups shown, the main difference is between those who are married, and the three non-married groups, which are very similar, especially below age 90. Married people are lower users of services, substantially so in the case of LTC. This reflects the availability of a co-resident partner (and possibly better health) among the married. While the proportion of older people who are married is likely to increase for some decades in Finland, as for many Western countries, this will reverse sharply for cohorts born from the 1950s.

Differentials by socioeconomic status: occupational class and educational level

Socioeconomic differences in health and mortality exist up to the highest ages even in the most egalitarian countries with comprehensive, high-quality welfare services, such as in the Nordic countries. While substantial socioeconomic differentials in health and mortality exist, differentials in the use of care services are relatively small compared with those, for example, by marital status. People with the highest levels of education are the lowest users at

Figure 1: Days in care in previous 12 months by age, survival and marital status

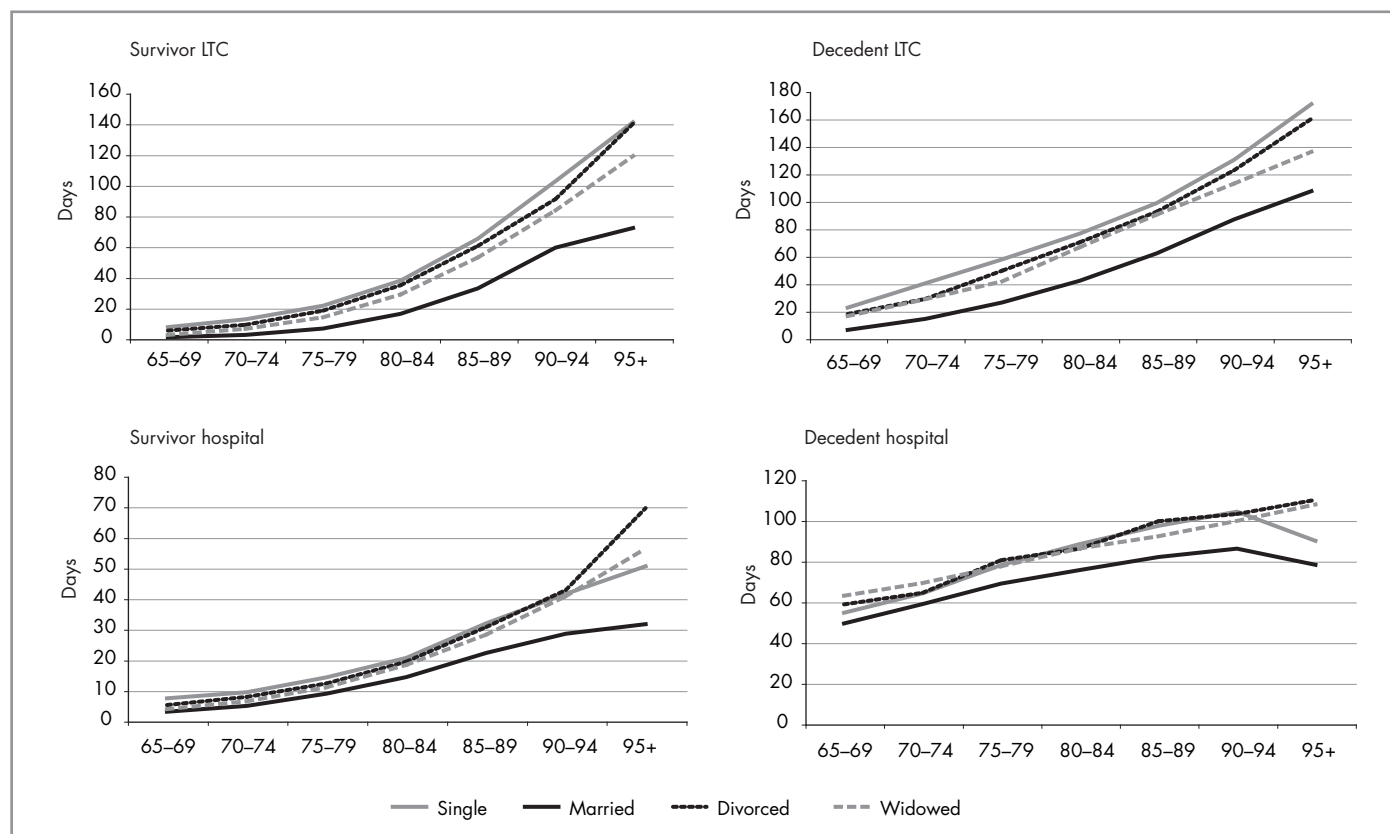
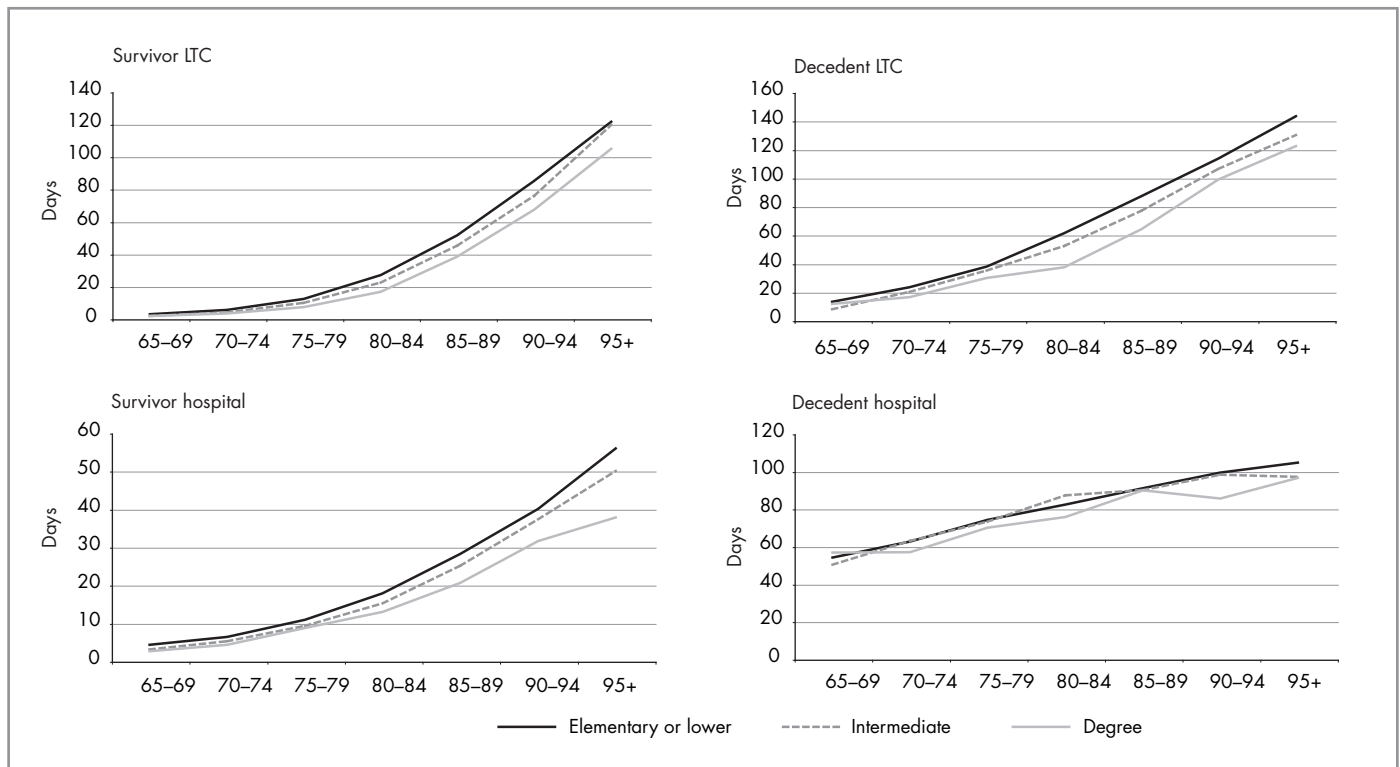


Figure 2: Days in care in previous 12 months by age, survival and educational level



any given age, followed by the intermediate group and then by the lowest education group (Figure 2). However, the longer life expectancy of better educated groups means that their overall expected lifetime use of services will not be less. While the educational level of the population is increasing, the lower use at any given age by better educated groups is likely to be more than offset by the higher proportions of these groups surviving to the highest ages, when the use of services is much more substantial.

Proximity to death or time to death?

Early studies compared decedents and survivors in the last year of life, where decedents' additional use of hospital care is mainly concentrated. However, the 'penalty' associated with proximity to death does not exist only in the twelve months preceding death; it can be observed up to 30 years before death.⁶ LTC use patterns are rather different, at younger ages, there is little additional use among those who are close to death compared with those who survive longer, but the gap widens with age, so that among those aged 90–94, a person who dies within the next twelve months spends twice as many days in LTC on average as someone who survives for six years.

Concentration on the last year of life therefore understates the additional use of

services associated with proximity to death especially for LTC. This is because a substantial fraction of excess hospital care occurs in the last twelve months of life (especially in the few months immediately before death). While the end-of-life expenditures of older patients may be lower per year, they are typically disabled longer and their illnesses often continue for years so that people in the US who die at age 73 and 93, for example, cost Medicare nearly the same amount⁷ and, of course, older people are much greater users of long-term residential care.

Summary and conclusions

These results are consistent with earlier cost-orientated studies that found that proximity to death is more important for acute care use, but age is more important for LTC. Populations in Europe will continue to age considerably in future decades, especially for the oldest-old from about 25 years time. The demand for health care might not increase wholly in line with the number of older people⁸ and health status improvement may tend to reinforce the cost lowering tendencies on acute care of proximity to death. However, the view that needs may not increase in line with the number of older people because of the 'proximity to death' effect is optimistic, since the implied additional LTC needs (bed-days in our case) overwhelm such factors. LTC needs are likely to grow more

quickly than acute care needs for older people, other things being equal.

A model that incorporates proximity to death implicitly assumes improvement in health status since lower mortality increases the time to death at each age and postpones intensive use of services. While some studies show the proportion of life spent in poor health is increasing (an expansion of morbidity), others suggest the opposite (a compression of morbidity). The lack of clear trends makes it difficult to predict health status in the future. It might be thought that later age at death would push back the onset of disability; however, even with optimistic assumptions about improvements in health status it is still likely that there will be no change in the proportions of people entering or time spent in nursing homes,⁹ nor average lifetime health care costs.⁷

Recent Organisation for Economic Cooperation and Development (OECD)¹⁰ and European Union¹¹ studies have incorporated proximity to death in forecasts of health care. The inclusion of proximity to death is likely to become increasingly important for forecasting health care needs and costs, especially for the balance between acute and social care for older people, although other factors such as future changes in marital status distributions may also be important to future projections of social care needs.

REFERENCES

1. Fuchs VR. Though much is taken: reflections on aging, health, and medical care. *Milbank Memorial Fund Quarterly. Health and Society Special Issue: Financing Medicare: Explorations in Controlling Costs and Raising Revenues* 1984;62(2):143–66.
2. McGrail K, Green B, Barer ML, Evans RG, Hertzman C, Normand C. Age, costs of acute and long-term care and proximity to death: evidence for 1987/88 and 1994/95 in British Columbia. *Age and Ageing* 2000;29:249–53.
3. Payne G, Laporte A, Deber R, Coyte P. Counting backward to health care's future: using time-to-death modeling to identify changes in end-of-life morbidity and the impact of aging on health care expenditures. *The Milbank Quarterly* 2007; 85(2):213–57.
4. Roos NP, Montgomery P, Roos LL. Health care utilization in the years prior to death. *The Milbank Quarterly* 1987;65(2):231–54.
5. Murphy M, Martikainen P. Demand for long-term residential care and acute health care by older people in the context of the ageing population of Finland. In: Doblhammer G, Scholz R (eds). *Aging, Care Need, and Quality of Life*. Wiesbaden: VS Verlag für Sozialwissenschaften, 2010, pp.143–62.
6. Engberg H, Oksuzyan A, Jeune B, Vaupel JW, Christensen K. Centenarians – a useful model for healthy aging? A 29-year follow-up of hospitalizations among 40,000 Danes born in 1905. *Aging Cell* 2009;8:270–76.
7. Lubitz J, Cai L, Kramarow E, Lentzner H. Health, life expectancy, and health care spending among the elderly. *New England Journal of Medicine* 2003;349(11):1048–55.
8. Lafortune G, Balestat G, Disability Study Expert Group Members. *Trends in Severe Disability Among Elderly People: Assessing the Evidence in 12 OECD Countries and the Future Implications*. OECD Health Working Papers No. 26. Paris: OECD, 2007. Available at: www.oecd.org/dataoecd/13/8/38343783.pdf
9. Laditka SB. Modeling lifetime nursing home use under assumptions of better health. *Journal of Gerontology: Social Sciences* 1998;3(4):S177–87.
10. Organisation for Economic Co-operation and Development. *Projecting OECD Health and Long-Term Care Expenditures: What are the Main Drivers? Economics Department Working Papers No. 477*. Paris: OECD, 2006. Available at: www.oecd.org/dataoecd/57/7/36085940.pdf
11. Economic Policy Committee and European Commission. *The 2009 Ageing Report: Economic and budgetary projections for the EU-27 Member States (2008–2060)*. Brussels: EU, 2009. Available at: http://europa.eu/epc/pdf/2009_ageing_report.pdf

Implementing remote care in the UK: an update of progress

Jane Hendy, James Barlow and Theopisti Chrysanthaki

Summary: In 2009 we reported in Eurohealth on the challenges of implementing 'remote care', the use of information and communication technology (ICT) to support health and social care remotely. We discussed the potential of these technologies both in the United Kingdom and elsewhere to transform the lives of the elderly and those with long-term chronic conditions. In this article, we report on recent UK developments, presenting findings from our research and examining implementation progress.

Keywords: Remote care, long-term conditions, ICT, telecare, United Kingdom

Due to a rapidly ageing population and the increased spread of chronic diseases, current care systems are increasingly seen as untenable. Linked to these concerns is the recognised value of preserving people's independence, including enabling older people to remain in their homes. One potential solution is to use technological

innovation to support people remotely in their own home or the wider community. Commonly called telecare or telehealthcare, remote care systems have been around for over a decade, with 8,000 published studies reporting on their impact.¹ Despite the technology appearing to work and positive user feedback, health and care

services have been slow to show that remote care implementation can result in a significant shift in care services from hospital to home. In the United Kingdom, we estimate that between 300,000 and 350,000 people use some form of remote care (not including traditional pendant alarms).

Remote care services can be split into two main types. Telecare is used for the monitoring of changes in an individual's condition or lifestyle, including emergencies, in order to manage the risks of independent living. Examples include

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movement sensors, falls sensors, and bed/chair occupancy sensors. These technologies are generally provided to patients with social care needs. Telehealth is the remote exchange of data between a patient and health care professional to assist in the diagnosis and management of a health care condition. Examples include blood pressure monitoring and blood glucose monitoring. These technologies are generally provided to patients with long-term health conditions such as diabetes. However, growth for all these technologies has been slow and the potential market size in the United Kingdom could be at least 1.4 million.²

In terms of changing this position, the United Kingdom has taken a strong lead. While there are examples of remote care schemes in other countries, major UK initiatives such as the Preventative Technologies Grant and the Whole System Demonstrators Programme (WSD)³ represent the most important concerted effort by a national government to stimulate this innovation. Over the next few years these initiatives should provide many opportunities for learning about the potential benefits and pitfalls of remote care.

Research

We have been conducting research into the progress of these initiatives since their inception. We followed five cases attempting to implement remote care during the timeframe of the Preventative Technologies Grant (April 2006 – April 2008). This funding was positioned as a catalyst for change, giving local service providers in England the push they needed to trial remote services.

However, the funding was not ring-fenced, leading to huge discrepancies in levels of remote care spending and activity, with some organisations progressing well but others making little progress. The focus then shifted away from providing cash to generating evidence of effectiveness. The government sponsored reportedly the largest randomised controlled trials of remote care services (the WSD). The trial involves implementing remote care services in 6,000 homes. The UK Government views the trial as providing ‘gold standard’ evidence that remote care benefits individual users, delivers health improvements, and is a cost effective means of future care delivery.

As part of the WSD evaluation team, we are following the progress of the three trial sites (June 2009 – March 2012).⁴ Between

Table 1: Case study sites

Funded initiative	Preventative Technology Grant	Department of Health WSD	King's Fund WSDAN	Non WSD-related sites
No. of case study sites	5	3	6	3
Period of research study	April 2006–April 2009*	June 2009–March 2012	June 2010–June 2011	June 2010–June 2011

* The authors' study of the Preventative Technologies Grant extended one year after the grant ended.

June 2010 and June 2011 we also examined the implementation of remote care in six additional sites. These additional sites are not part of the trial and so not subject to trial protocol criteria and RCT controlled management processes (thus we have a comparison between those sites which provide remote care in an environment constrained by the trial protocol criteria, supported by external funding and project management team and those that are delivering remote care in a so-called ‘natural’ environment).

Three of these six additional sites also had implementation support in being part of the King's Fund Whole System Demonstrator Action Network (WSDAN).⁵ The WSDAN was commissioned by the Department of Health as an additional tool for sites that bid to be in the original trial but were unsuccessful. The WSDAN supplied research and development activities to support lessons learnt in the main trial. The last three sites we examined had no additional support (see Table 1). During this period (2006–2011), we conducted over 200 interviews, and made over 300 hours of observations, with data collection continuing.

Findings

Findings from this large body of work are still emerging but it is appropriate to consider progress made, and implications for the United Kingdom and other governments wishing to stimulate the uptake of remote care. Because remote care is cross-sectoral (involving health and social care professionals, user communities and public-private partnerships) and ranges across multiple policy frameworks and spending constituencies, scaling-up existing pilot schemes has proved challenging. Embedding remote care in mainstream care services requires spanning multiple complex networks and organisational contexts, across which these new technologies and their associated systems

of practice are located and operationalised. For success, contextual and cultural differences between different care organisations need to be addressed, with the right incentives for innovation adoption put in place across the care system.

Building engagement and a shared language

Overall, we found that practical operational tasks such as training staff on how to do referrals and use the technology is not enough to build the necessary shared language and vision to push large scale implementation forward. Engaging staff and ‘selling’ remote care beyond the realm of enthusiasts to an organisation-wide audience requires huge amounts of energy and continuous commitment, leadership and top level support.

Prior to the new funding, all our cases had developed small remote care projects without additional support. These projects highlighted the local nuances and practicalities of referral, assessment, monitoring and response processes. However, a project-based approach can also create problems with wider engagement. Despite our cases having a history of joint health and social care working, as implementation progressed we found existing rivalries becoming heightened. Much of this rivalry stemmed from early champions developing remote care projects in their area. Even in cases with a long history of ‘joined up’ working, the creation of small pockets of activity and excellence were divisive, serving to create issues of ownership that pushed people apart rather than together.⁶

Rapidly changing organisational priorities and a constantly moving workforce means implementation is often an uncertain, non-linear process. During the course of our research many key staff left, taking their knowledge and commitment to remote care with them. Developing joint working is particularly labour intensive because if left unattended, people quickly revert to

old ways of doing things. Senior leadership was critical in legitimising the increased risks and labour involved in scaling up this innovation and counterbalancing the arguments of sceptics.

Scalability issues

Until very recently, remote care has stayed firmly within the realms of projects and small trials. Our research suggests that these have limited usefulness when developing larger mainstream services. Across all our cases issues 'resolved' in small projects did not translate when attempting to implement remote care more widely. Lessons from pilot projects were difficult to disseminate and often dissolved because partnerships that adequately covered the boundaries of the pilot broke down when requiring larger resources.

Developing remote care services on a larger scale requires new levels of integration between different care organisations, re-focused beyond individual patient benefits, professional development, or particular service providers and technologies, to one of wider system benefits, such as reduced unplanned hospital and care home admissions. For some cases this need to re-design existing services was a welcome opportunity to do things better; for others redesign was not addressed, as staff appeared to struggle to change and move beyond the boundaries of their previous role.

Across all sites we found high levels of support for remote care as a new model of service delivery. Many interviewees had an informed view of its benefits and disadvantages based on the experiences of staff delivering the new service. For these staff remote care was seen as providing a positive contribution to the provision of care for patients with long-term conditions. Despite this positive attitude, we observed divides between the rhetoric and actual practice of integrated working. At an organisational level, senior staff expressed being fully engaged and committed to implementing remote care processes and working in a more integrated manner. However, frontline staff often knew very little about it, and perceived such changes as a threat to their professional practice and autonomy.

For large scale uptake, sustained implementation of remote care needs to be situated as an organisation-wide initiative and marketed as part of 'normal business'; a tool that everyone in the care system can and needs to engage with. Constant and

sustained attention needs to be paid to the job of winning hearts and minds and maintaining commitment and momentum. This is easier if a cogent and 'joined-up' approach to remote care is developed from inception.

Many hurdles to delivering this new model of care delivery were embedded at a systemic level. For example, budgetary silos meant that the costs of implementation were often situated in one sector (social care) whilst perceived cost-benefits were achieved across another (acute care). This meant that there were inbuilt disincentives to invest resources in remote care. More broadly, achieving the strategic redesign of systems and services was felt to require organisations involved in care services to be open to change and to embrace a culture that was prepared to experiment, allow for mistakes and collectively learn from them. Across our cases this culture was more likely to occur when top level management actively supported new and risky ideas, allocated a range of permanent staff and actively encouraged them to engage in cross-sectoral change initiatives.

Conclusion

Together, the Preventative Technologies Grant, WSD and other initiatives around the United Kingdom represent the largest single investment in home monitoring systems in any country. These offer significant research opportunities, providing important lessons on the implementation, integration and sustainability of these new services. Gold standard evidence from the WSD will certainly help care providers make more informed investment decisions. However, the mixed picture that our case studies presents, with many still struggling to move beyond small trials five years on, suggests more help is needed if we are going to address the organisational challenges of scaling up remote care.

Our work suggests that organisations need to be clear about these challenges. The reality of organisational and professional divisions needs to be recognised and negotiated. This should partly involve 'selling' remote care to local stakeholders by collecting evidence that increases their receptiveness, and identifies and mitigates potential risks from the outset. Open communication about the limitations of remote care services and active management of expectations and organisational differences also results in less animosity and more shared understanding of what remote care can realistically achieve.

Focusing attention on how to stimulate uptake by using existing levers within the systems for payment and reimbursement, and service commissioning also would be useful. A central government policy shift from the current situation where remote care services are optional to one where they are an integral part of a care package, unless there is good reason for exclusion, would also do a great deal to smooth the way forward.

REFERENCES

1. Barlow J, Singh D, Bayer S, Curry R. A systematic review of the benefits of home telecare for frail elderly people and those with long-term conditions. *Journal of Telemedicine and Telecare* 2007;13:172-79.
2. Barlow J, Hendy J, Chrysanthaki T. Sustaining innovation in remote care – four lessons. *International Congress on Telehealth and Telecare*. Presentation at the King's Fund, London, 2 March 2011.
3. Whole System Demonstrator. At: http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_100947.pdf
4. Bower P, Cartwright M, Hirani S, et al. A comprehensive evaluation of the impact of telemonitoring in patients with long-term conditions and social care needs: protocol for the Whole Systems Demonstrator cluster randomised trial. *BMC Health Services Research* 2011;11:184. At: <http://www.biomedcentral.com/1472-6963/11/184>
5. Goodwin N. The state of telehealth and telecare in the UK: prospects for integrated care. *Journal of Integrated Care* 2010;18(6):3-10.
6. Hendy J, Barlow J. The role of the organizational champion in achieving health system change. *Social Science & Medicine* (in press).

ACKNOWLEDGMENTS

This article is based on research projects funded by the EPSRC-funded Health and Care Infrastructure Research and Innovation Centre (HaCIRIC) and the Department of Health, UK.

The role of ICT support services to promote ageing in place

The ACTION service

Elizabeth Hanson and Lennart Magnusson

Summary: ACTION (Assisting Carers using Telematics Interventions to meet Older people's Needs) is an innovative example of an Information and Communication Technology (ICT) based support service that is currently running in Sweden to help empower older people with chronic conditions and their family carers in their daily lives. The service is outlined and the main evaluation findings are presented. Sirpa explains how ACTION has been of direct benefit in her caring situation. The main lessons learned over a fourteen year period of implementing ACTION in Sweden are highlighted, concluding with the main challenges facing researchers, policy makers and decision makers in the immediate future.

Key words: family caregivers, frail older adults, empowerment, videoconferencing, multimedia, Sweden

ACTION, 'Assisting Carers using Telematics Interventions to meet Older people's Needs', stemmed from an EU-funded project (1997–2000) and is an Information and Communication Technology (ICT) based support service designed together with older people with long-standing chronic conditions living at home and their family carers to help empower them in their daily lives. It is currently running as a mainstream service in the Borås municipality in western Sweden, with implementation projects in an additional twenty municipalities across Sweden.

ACTION is a self-care and family care support service which promotes 'ageing in place' as older people with chronic illnesses and their family carers are able to access relevant and accessible information, education and support when needed from the comfort of their own home. Furthermore, the ICT based service helps to promote social inclusion within the current digital

information society for those older citizens who are at risk of being excluded from the benefits afforded by modern technology.¹

The ACTION service in brief

The ACTION service consists of the following integrated components:

1. Multimedia educational caring programmes
2. The ACTION application
3. The ACTION call centre
4. Education and support

Multimedia educational programmes

The multimedia educational programmes are based on carers' and older people's needs identified from the empirical literature and extensive user consultation in the EU and Swedish ACTION projects. These programmes are: caring skills in daily life; planning ahead; respite care; economic support; a service guide; coping strategies;

living with dementia; and life after a stroke. Additionally, there are programmes for physical and cognitive training and online games for leisure^{2,3}.

ACTION application

The ACTION application consists of a personal computer with broadband connection which is installed in each family's home. Families also have access to the Internet itself and email facilities. The multimedia programmes are accessed over the Internet. Internet videophone facilities are provided via a small web camera placed on top of the computer screen and an integrated user-friendly videophone programme installed in the computer. This enables families to have visual and oral contact with other participant families, as well as with care practitioners at a dedicated call centre.

ACTION call centre

The ACTION call centre is run by practitioners with experience in caring for older people and their families. They maintain regular contact with families to ensure that they are managing their situation as well as providing advice and support on an as need basis. They are also responsible for computer education and facilitate and maintain informal networks between users.

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Education and supervision

Fourth, families are invited to take part in an initial education programme to learn how to use the ACTION service, as the majority of users are predominantly computer novices. This programme consists of a series of small group 'hands on' computer education sessions during which participants get to know each other and subsequently initiate videophone contact. Additionally, the comprehensive education, follow-up and certification programme, including regular supervision, is targeted at care practitioners working in the ACTION call centres in the municipality.⁴

Evaluation results

Evaluation results from successive projects with a total of approximately 400 users reveal that the majority, similar to Sirpa, are highly satisfied with the service and consider it to have helped improve everyday quality of life. The over-riding result is that both family carers and the older person they care for feel less isolated as they developed informal support networks with other participant families in similar situations. Also, service users feel that new technology is good to use providing that it is easy to understand and use and is of direct benefit in their caring situations. Nearly all users were previously computer novices and included older people with chronic long-standing conditions and older family carers who are to a large extent housebound due to illness and/or caring responsibilities^{2,5,6}. In this way, ACTION helped to enhance their social inclusion.

Questionnaire and interview data revealed that after using the ACTION system in their own homes for a minimum period of three months, participant family carers, such as Sirpa, felt more competent and secure in their caregiving role; they had gained more control over their individual caring situation and had increased their self confidence in their ability to care. Focus group interview data with ACTION call centre practitioners highlighted that they experienced improved job satisfaction as a result of working in partnership with families to help empower them in their situation. They saw significant scope for future development in the area of telecare as a means of providing a more effective way of providing 'non-hands on' elements of care such as advice, information giving and support for older people with long term care needs and their family carers.^{5,6}

**User testimonial:
Sirpa and Magnus's story**

Over an eight year period, Magnus (aged 90) had a series of four strokes which severely affected his eyesight and caused a dual-sided paresis which led to him being wheelchair bound. Previously, he and his wife Sirpa (aged 70) had enjoyed an active social life and they shared a mutual interest in sailing. Sirpa has cared

for Magnus since the onset of his first stroke. Initially, she continued to work full-time. However, she found it increasingly difficult to combine paid work and care so that she retired early in order to devote more time to Magnus.

Sirpa described her caring role as follows, "I care for Magnus at home in the same way as he would be cared for if he was in a hospital ward. I've now got a stair lift that I use, I change his incontinence pads and do what has to be done. But even if I'm strong and I'm often in a good mood, I can also be lonely and sad sometimes too".

Sirpa described how ACTION had practically helped her in her caring situation, "Sometimes, Magnus gets food stuck in his throat. Before I didn't know how to do the Heimlich manoeuvre but by looking at ACTION I learnt how to do it. It's a dramatic experience but at the same time it's a part and parcel of our day to day life you could say".

Summing up her overall experiences of ACTION she explained, "I think that above all I've got a greater understanding. At one time Magnus was sullen and angry. So then I read about how depression can affect stroke survivors. I got an explanation for his anger and depression and I learnt how to approach him. For us it's become quite a lonely life. Many of our friends that we had before via work or sailing they've disappeared one after the other. It's not easy for them to know how you should relate to someone who can no longer talk or who sits paralysed in a wheelchair. So, contact with others in a similar situation is incredibly important. As well I can always ring to someone at ACTION (call centre). They've become an important part of my day to day life – someone to share both feelings of joy and sadness is important, just as Magnus and I used to do earlier".

Photo: Johanna Wulff

At the municipality level, a small cost descriptive study involving five ACTION families revealed reduced care costs with an average saving of €10,300 per family per year as a result of reduced use of home help services and delayed entry to nursing home. A Needs Assessor who knew the families well was asked to calculate what they should have needed in terms of care services if they had not received ACTION. The researcher (LM) then carried out a cost calculation which was sent to the families prior to a home visit in which the researcher and Needs Assessor reviewed the data together with the respective participant families. All the families except one agreed with their cost calculation. The carer who did not agree explained that she could never accept under any circumstances to 'send' her husband to a nursing home. In this case, the costs were modified accordingly.⁷

Main lessons learned

There are relatively few examples of ICT based support interventions for older people and their carers within Europe that have successfully undergone the transfor-

mation from a project to a mainstream service. This leads to the question of what are the critical success factors behind ACTION? The main reasons behind ACTION's success can be summarised as follows.

First, the service was designed together with older people with chronic illnesses and their carers to meet their needs, preferences and situation, as opposed to being based solely on what professionals consider older people want and need (see⁸ for methods of user involvement within the design of ACTION).

A second success factor is the overall acceptability of the mode of delivery of the service which means that ACTION continues to have an innovative appeal and is a socially desirable phenomenon amongst end users many of whom are computer novices.

Third, the service is research-based and has undergone iterative cycles of development and evaluation based on extensive feedback from all key stakeholder groups. Interestingly, the cost evaluation data together with the quality of life data proved to be

critical in the formal decision making process taken by Borås's older people social services committee in 2004 to integrate the ACTION service within their existing support services for older people. Furthermore, in the case of Borås municipality, the ACTION service has received ongoing support from all key stakeholder groups from end users, care practitioners, decision makers, politicians and representatives of voluntary and pension organisations through to business partners and university representatives. Without solid partnerships and co-operation with all these diverse players the continued adoption of the service would not have been possible.

Nevertheless, there remain significant hurdles as the ACTION service has not penetrated all 290 municipalities in Sweden. The key challenges largely reflect those previously identified within the empirical literature in the field and which can be summarised as follows: implementing ACTION within everyday practice is not simply about installing and learning to use the technology, rather it involves changing the way in which care practitioners and managers view and carry out their work. Namely, to work proactively in partnership with older people to help empower families to manage their caring situations, rather than being crisis oriented. A second and related barrier is the negative attitudes held by many health and social care professionals regarding the use of modern technology within care for older people. To this end we have developed a comprehensive education, supervision and certification programme directed at staff involved in implementing ACTION in municipalities, so as to provide credible role models (see www.actioncaring.se).

A third challenge is the continuous work required to maintain ongoing support from all stakeholder groups. Frequent staff turnover rates at management and grass-roots level in the municipalities calls for regular awareness raising and education sessions with front-line staff, management and other health and social care professionals working with older people, as well as user and carer representatives.

A fourth challenge, which is commonly highlighted within the empirical literature, is the lack of rigorous empirical evidence. Similarly to the ACTION service, there is some evidence with regards to its impact at the level of the individual/family. However, it is much more difficult to

reveal the long-term cost effectiveness of the service at a meso or organisational level and further at a macro or societal level. Frequently quoted challenges in the literature are the lack of a suitable comparator, the need for sufficient data collected on a systematic basis over time, and the need for sensitive outcome measures.

A fifth challenge is the lack of a sufficient critical mass of end users that have used ACTION over a prolonged period of time. Municipalities are often wary of investing in more than twenty users and for a longer period than a year. This leads to a 'Catch 22' situation as the lack of rigorous evidence is often cited as the main reason for decision makers in Sweden to decline making a major investment in ACTION.

A sixth challenge concerns the need for a sound and responsive business plan and model. In order to make ACTION more widely available following the EU project, a university spin-off research and development company was established and a business agreement struck with Telia Sonera, Sweden's largest telecommunication company. Nevertheless, a business plan needs to continually respond to the demands of a fluid market so that other potential options are considered, such as a consumer oriented model in which the service is offered directly to private users and/or entering into collaboration with a civil society organisation to jointly offer the service.

A seventh challenge concerns the need for suitable policy to be in place at all levels: local, regional, national and EU level as this helps to 'push-start' the use of new technology based solutions within health and social care for older people. Finally, funding from governmental and research and development agencies in Sweden has been crucial for the continued research and development of the ACTION service. In the future, there needs to be strategic larger-scale and long term implementation work, otherwise there will continue to be the risk of financing small-scale pilot projects which may duplicate results without creating a sufficient critical mass to have the significant impacts outlined in this article.

ACKNOWLEDGEMENTS

The authors extend their gratitude to Sirpa and Magnus who kindly gave us permission to report on their experiences of using the ACTION service for the purposes of this special issue. We would also like to thank Sirpa for directly participating in a videoconferencing session during the LSE Seminar in which she openly shared her experiences as a family carer and explained how she and her husband used the ACTION service. In so doing, she acted as a source of inspiration to many of the delegates present.

REFERENCES

1. Kubitschke L, Cullen K, Müller S, et al. *ICT and Ageing: European Study on Users, Markets and Technologies, Final Report*. Bonn: Empirica & Work Research Centre on behalf of European Commission Directorate General for Information Society & Media, Unit ICT for Inclusion, 2010. Available at: http://www.ict-ageing.eu/ict-ageing-website/wp-content/uploads/2010/D18_final_report.pdf
2. Magnusson L, Hanson E, Nolan M. The impact of information and communication technology on family carers of older people and professionals in Sweden. *Ageing and Society* 2005;25(5):693–714.
3. Hanson E, Magnusson L, Arvidsson H, et al. Working together with persons with early stage dementia and their family members to design a user-friendly technology based support service. *Dementia* 2007;6(3):411–34.
4. Magnusson L, Hanson E. Partnership working: the key to the AT- technology transfer process of the ACTION service. *Technology & Disability*, (special issue in press). Available from the first author at lennart.magnusson@hb.se
5. Magnusson L, Hanson E, Brito L, et al. Supporting family carers through the use of information technology – the EU project ACTION. *International Journal of Nursing Studies* 2002;39(4):369–81.
6. Bergström I, Blusi M, Höijer C. *Utvärdering av ACTION. Anhörigstöd i glesbygd [Evaluation of ACTION. Family care support in rural areas]* (in Swedish). Stockholm: Swedish Institute for Assistive Technology, 2010. English summary available from: www.hi.se
7. Magnusson L, Hanson E. Supporting frail older people and their family carers living at home using Information and Communication Technology: A Swedish case study cost analysis. *Journal of Advanced Nursing* 2005;51(6):645–57.
8. Magnusson L. *Designing a Responsive Support Service for Family Carers of Frail Older People using Information and Communication Technology*. Gothenburg: Acta Universitatis Gothoburgensis, 2005.

Classification, assessment and comparison of European LTC services

Development of an integrated system

Luis Salvador-Carulla, Cristina Romero, Germain Weber, Hristo Dimitrov, Lilijana Sprah, Britt Venner and David McDaid for the eDESDE-LTC Group

Summary: It is important that a common coding system and classification standardised system for assessing long-term care (LTC) services is used to help facilitate meaningful comparisons across and within countries. This article describes the development and piloting of such a classification system – the eDESDE-LTC tool, now available in six European languages.

Key words: Long-term care, Europe, service classification, information systems

Health services are very difficult to compare across different territories, particularly when they are aimed at the long-term care (LTC) needs of people living with complex conditions. Previous service comparison studies in Europe have often failed to provide useful information for health planning in areas as diverse as mental health,¹ ageing² or services for functional dependency.³ There are many potential reasons for this including the influence of historical and contextual factors in the development and organisation of services, as well as the increasing complexity in integrated care arrangements. One major reason is that services with the same name in different jurisdictions can perform very different activities and functions. This terminological variability appears across all levels of complexity in care settings, from day centres to rehabilitation and hospital units. We even lack a common definition for ‘hospital’ and ‘service’.

Access to services across Europe is hampered by an inadequate framework and knowledge of available resources. The

development of a common coding and assessment system can also help in the better allocation of resources for the population. As an increasing number of databases in Europe are linked in order to help address this information gap, it is important to facilitate a greater degree of ‘semantic interoperability’, that is the development of a common language that can be used across different information systems and databases. A common coding system, using a standardised method of assessment, may help overcome these challenges and enable better comparisons of data to inform policy and practice. The development of such a system was the objective of the EC funded eDESDE-LTC (Description and Evaluation of Services and Directories in Europe For Long-Term Care) project.

Led by the PSICOST Research Association and the Catalunya-Caixa Foundation in Spain, eDESDE-LTC brought together a core group of partners in six European countries with further input from experts in the development of service mapping systems, health agencies at national,

regional and municipal levels, and academic specialists in semantics, ontology and health care decision support systems.

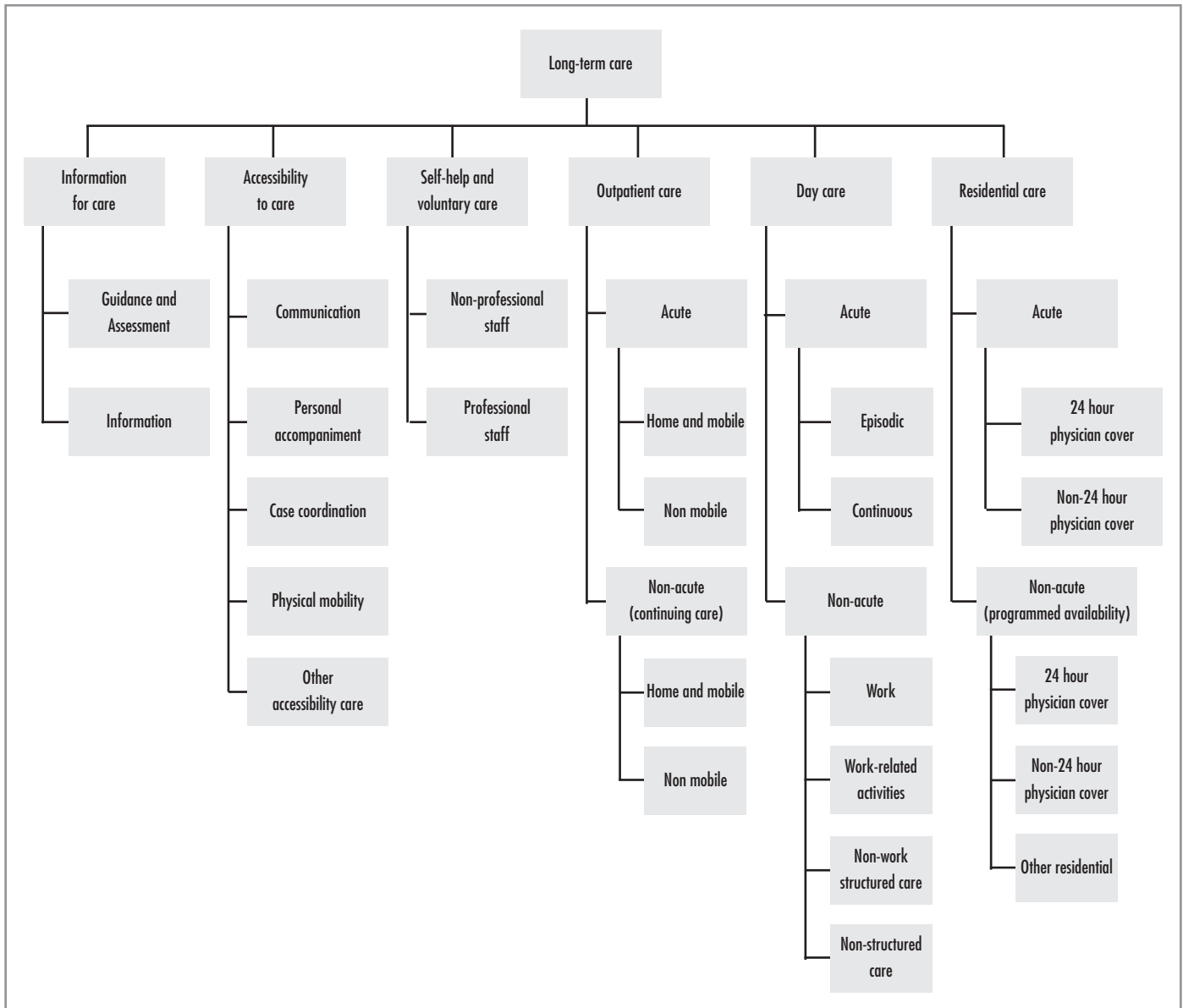
Approach

A starting point for this mapping system was work previously undertaken to help classify and standardise the mapping of mental health services and the context in which those services were delivered in Europe.^{4,5} The eDESDE-LTC instrument was also informed by a review of existing coding and classification instruments, not only in respect of mental health, most notably the European Service Mapping Schedule (ESMS),^{6,7} but also building on the original DESDE instrument used to map services for people with disabilities.¹ The eDESDE-LTC instrument was developed iteratively, informed by feedback from sessions with expert nominal groups in six countries. Usability of the instrument was assessed in relation to a series of quality domains: feasibility and relevance; consistency; inter-rater reliability; and validity.

The final eDESDE-LTC Toolkit incorporated the instrument, coding system, training, and evaluation packages (see <http://www.edesdeproject.eu>). This toolkit, we believe, is unique in being able to assess the availability and use of services for LTC, both in small health areas and at regional and national levels. The hierarchy of the instrument has been arranged as a

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Figure 1: eDESDE-LTC tree structure of main and secondary branches



tree structure (Figure 1). It has six main areas of services (Help with Accessibility, Information, Self-Help, Outpatient Support, Day Care and Residential Care) and 89 specific service codes. The classification system includes a decimal identifier, formal description and identification label (Figure 2), to allow for future semantic interoperability in European health and social information systems and databases.

Mapping services in Sofia and Madrid

The potential use of the instrument can be illustrated through experience in its piloting in urban areas of Sofia and Madrid. Piloting indicates that the instrument that can be applied in very different environments, as is the case in these two cities where very different patterns of LTC services are to be found. National, regional

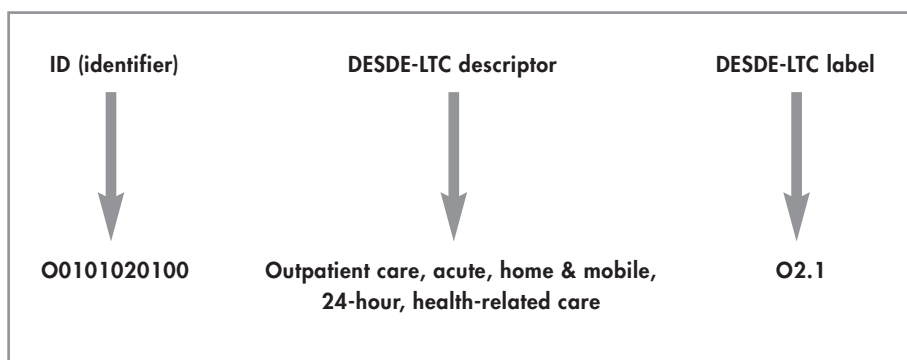
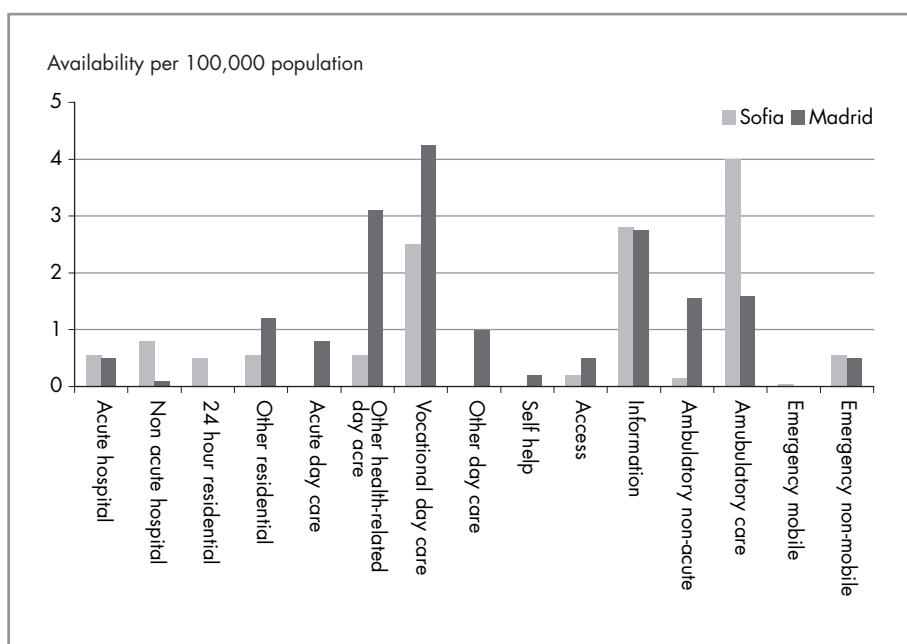
and local health and social care planners in both settings were consulted. Figure 3 illustrates the availability of different types of care service for people with all LTC care needs in the two cities, including frail older people, people with physical and mental health problems, and those with intellectual disabilities.

The instrument can be used to highlight differences in the availability and distribution of key services. Geographical mapping software, for instance, can be used to plot hot spots where services are concentrated in both cities. In Sofia there appears to be a heavy reliance on the provision of care within formal long-stay institutions; while in Madrid the mix of services and the availability of places for these services suggests that the LTC system relies to a much greater extent on the provision of support

to enable individuals to remain living independently in the community.

Careful interpretation of findings is however required; it is important to understand the context in which services are delivered. For instance, the absence of a specific type of service in an eDESDE-LTC analysis could signal the fact that no provision of that type exists in a locality, but it could also mean that these functions are provided as part of a non specialist service.

In addition to work in piloting the instrument, feedback from potential users of the instrument in different countries has been positive. eDESDE-LTC is regarded as a very useful and promising instrument, although more could be done to improve clarity and ease of use so as to make

Figure 2: Principal characteristics of the DESDE-LTC classification system**Figure 3: Availability of main service types for long-term care target groups in Madrid and Sofia**

training less complex. Currently training requires a face-to-face intensive course conducted by experienced trainers. The written eDESDE-LTC training package is a useful complementary tool but it is not a substitute for this face-to-face training. In addition, guidance might in future be provided on data collection and interpretation; the latter might be aided by a context checklist to help in the interpretation of results. Another future objective is to move to a fully computerised version of the questionnaire and coding system using structured algorithms. A more simplistic front end, negating any need to see any of the detailed coding structure, would help expedite training and facilitate use of the instrument.

Further impact

In Spain, in addition to piloting work undertaken in the city of Madrid, the eDESDE instrument and coding system have subsequently been used to map

services in three of the country's seventeen regions: Cantabria, Catalonia and Madrid. Awareness of the instrument has also been strengthened by citation in version 2.0 of the International System of Health Accounts⁸ and the mapping tool is also now being used to inform a new European Seventh Framework funded project (REFINEMENT) analysing the financing, efficiency and quality of mental health systems in Europe.

Conclusions

The eDESDE-LTC instrument and coding system has been designed to be ontologically consistent and semantically interoperable, with the intention of improve linkages between different relevant information systems. It can aid in meaningful service comparison, which in turn is an important consideration for the future planning of LTC services within specific geographical catchment areas. In future it might also be used as a tool to aid

in equity impact assessments, where the focus on is eligibility, availability, accessibility and use of services within and across different geographical catchment areas.

REFERENCES

1. Salvador-Carulla L, Poole M, González-Caballero JL, Romero C, Salinas JA, Lagares-Franco CM. Development and usefulness of an instrument for the standard description and comparison of services for disabilities (DESDE). *Acta Psychiatrica Scandinavica* 2006;114(Suppl. 432):19–28.
2. Johri M, Beland F, Bergman H. International experiments in integrated care for the elderly: a synthesis of the evidence. *International Journal of Geriatric Psychiatry* 2003; 18(3):222–35.
3. EUROSTAT. *Feasibility Study: Comparable Statistics in the Area of Care of Dependent Adults in the EU*. Luxembourg: Office for Official Publications of the European Communities, 2003.
4. Beecham J, Munizza C. Assessing mental health in Europe: introduction. *Acta Psychiatrica Scandinavica* 2000;102 (suppl 405):5–7.
5. De Jong A. Development of the International Classification of Mental Health Care (ICMHC). *Acta Psychiatrica Scandinavica* 2000;405:8–13.
6. Johnson S, Kuhlmann R, and the EP-CAT Group. The European Service Mapping Schedule (ESMS): development of an instrument for the description and classification of mental health services. *Acta Psychiatrica Scandinavica* 2000;405:14–23.
7. Salvador-Carulla L, Romero C, Martínez A et al. Assessment instruments: standardisation of the European Service Mapping Schedule (ESMS) in Spain. *Acta Psychiatrica Scandinavica* 2000;405:24–32.
8. International Health Accounts Team. *A System of Health Accounts Version 2.0. Pre-Edited Version*. Paris: Organisation for Economic Co-operation and Development, 2011. Available at: <http://www.oecd.org/dataoecd/27/51/47406956.pdf>

ACKNOWLEDGEMENTS

The eDESDE-LTC project was supported by the Executive Agency of Health and Consumer (EAHC) Project Ref. 2007/116. We also acknowledge the Spanish Research Agency, Instituto Carlos III, for funding related work on the European Service Mapping Schedule II (ESMS-II). A full list of members of the e-DESDE-LTC group and project collaborators is available at <http://www.edesdeproject.eu>

NICE supporting England and Wales through times of change

Tarang Sharma, Nick Doyle, Sarah Garner, Bhash Naidoo and Peter Littlejohns

Summary: NICE has evolved over the last twelve years to accommodate the growing needs of the NHS and the wider health community. In today's resource-constrained environment, the Institute has been supporting the NHS by highlighting disinvestment opportunities alongside producing recommendations for best practice. It has established new programmes of work to support the national health agenda and is expected to move to include social care in the coming years.

Keywords: NICE, NHS reforms, disinvestment, quality standards, social care

Background

The National Institute for Health and Clinical Excellence (NICE) was established in 1999 to improve the quality of care for patients and provide robust guidance for the National Health Service (NHS) within England and Wales.¹ The Institute has received international acclaim for providing evidence-based recommendations by using transparent and participatory processes that involve all relevant stakeholders. The remit of NICE expanded in 2005 to include guidance for public health, and in 2010 it established dedicated programmes to identify and promote innovative diagnostics and devices that provide significant quality and efficiency improvements in patient care, and NHS Evidence, a web-based portal giving access to accredited high quality evidence. The current coalition government has proposed expanding its remit to include social care² and using NICE's evaluations of cost-effectiveness to inform 'value-based pricing' of pharmaceuticals.

Supporting disinvestment

In 2006, NICE was formally asked to help the NHS 'reduce spending on treatments that do not improve patient care' by sup-

porting disinvestment.³ NICE has improved the visibility of the disinvestment recommendations from its guidance by creating a database summarising all the published NICE guidance that recommends complete discontinuation or stopping routine use of clinical practices/interventions.⁴ The NICE 'referral advice' recommendations database contains all referral recommendations from NICE clinical guidelines, cancer service guidance and public health guidance.⁵ Additionally, NHS Evidence has developed a collection of case studies from the field and opportunities from Cochrane reviews that highlight improvements in quality of care and provide potential productivity savings for the NHS's Quality, Innovation, Productivity and Prevention (QIPP) programme.⁶

NICE Quality Standards

NICE's Quality Standards Programme started in 2009 and aims to provide sets of 'specific, concise statements that act as markers of high-quality, cost-effective patient care, covering the treatment and prevention of different diseases and conditions'.⁷ The Institute has already published nine quality standards, a further eleven are under development, and the goal is to

achieve a library of 150 over the next five years.

Health and Social Care Bill

The Health and Social Care Bill², which is currently passing through the UK parliament, contains a number of items that widen NICE's remit. The Bill makes quality standards an essential component of the government's plans for achieving better outcomes for the NHS. NICE will thus have a significant role in supporting the proposed NHS Commissioning Board,⁸ the body which will be responsible for ensuring continuous improvement in the quality of health care. NICE will also produce public health quality standards to support the new national public health service, Public Health England, and social care quality standards. Quality standards will therefore become an important mechanism for encouraging integration of health, public health, and social care services.

Amendments to the Bill based on the recommendations of the NHS Future Forum's report⁹ clarify that the NHS will be required to fund drugs already recommended by NICE when a value-based pricing regime for new drugs is introduced in 2014. Under value-based pricing, the Institute will continue to provide definitive guidance on the use of new drugs. The Bill also changes the Institute itself from a Special Health Authority to a Non-

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Departmental Public Body, giving it a stronger foundation for the future.

Discussion

NICE has been established as an organisation devoted to providing robust guidance for resource allocation of health care and will continue to provide clinical and public health guidance. NICE has been evolving to meet the needs of its service users within a changing policy climate. It is also well placed to provide guidance to social care, and is working to consider the methods most appropriate for this. NICE is expected to have a greater role in the new NHS in the years to come with it receiving cross-party support in parliament and continues to be committed to supporting health and care in England and Wales.

REFERENCES

1. Rawlins M. In pursuit of quality: the National Institute for Clinical Excellence. *Lancet* 1999;353:1079–82.
2. House of Commons. Bill 221 Health and Social Care 2010–2011. At: <http://services.parliament.uk/bills/2010-11/healthandsocialcare.html>
3. Pearson S, Littlejohns P. Reallocating resources: how should the National Institute for Health and Clinical Excellence guide disinvestment efforts in the National Health Service? *Journal of Health Services Research & Policy* 2007;12:160–65.
4. National Institute for Health and Clinical Excellence. *The NICE 'Do not Do' recommendations database*. NICE, 2011. At: <http://www.nice.org.uk/usingguidance/donotdorecommendations/index.jsp>.
5. National Institute for Health and Clinical Excellence. *NICE 'referral advice' recommendations database*. NICE, 2011. At: <http://www.nice.org.uk/usingguidance/referraladvice/index.jsp>
6. NHS Evidence. *Quality, Innovation, Productivity and Prevention (QIPP)*, 2011. At: <http://www.evidence.nhs.uk/qipp>
7. National Institute for Health and Clinical Excellence. *NICE Quality Standards*, 2011. At: <http://www.nice.org.uk/about/nice/qualitystandards/qualitystandards.jsp>
8. Department of Health. *Developing the NHS Commissioning Board*, 2011. At: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_128118
9. NHS Future Forum. *Summary Report to the Proposed Changes to the NHS*. Department of Health, 2011.

Which type of hospital ownership has the best performance?

Evidence and implications from Germany

Oliver Tiemann, Jonas Schreyögg and Reinhard Busse

Summary: The German hospital market has been subject to a variety of health care reforms over the past two decades. In particular, the introduction of diagnosis-related groups (DRGs) has aimed to increase the performance of hospitals. This article reports on recent studies comparing the performance of public, private non-profit and private for-profit hospitals in Germany. The results of our analysis show that public hospitals have higher efficiency, while private hospitals provide superior quality of care compared to their public counterparts. Finally, we draw conclusions and policy implications taking other hospital and market characteristics into account.

Key words: Germany, hospitals, for profit, performance, quality

Introduction

Because of increasing cost pressure, the hospital sector in Germany has been subject to a variety of health care reforms aimed at stabilising expenditures at sustainable levels over the past two decades. In 1993, the full-cost reimbursement system was replaced by global budgets, both of which had been made up of per-diem charges. In 2003/04, a new system of reimbursement based on diagnosis-related groups (DRGs) was introduced. Since then all 1,800 German hospitals that provide inpatient acute care receive DRG payments from statutory health insurance funds and private health insurance companies. In addition, the introduction of DRGs was preceded by the implementation of an external quality assurance programme (as opposed to the internal system of individual hospitals). This included a number of mandatory measures, including a nationwide benchmarking exercise based on 206 quality indicators. These two ele-

ments represent the most significant reforms in the German hospital sector since the system of dual financing was introduced in 1972, which made the state responsible for capital costs, while running costs were paid by sickness funds or private patients. The chief motivation behind this fundamental overhaul of the old reimbursement system was to set financial incentives that would increase the performance of German hospitals.^{1,2,3}

Germany traditionally has had a multi-ownership structure in the hospitals market which is also legally stipulated. German hospitals can have public (usually owned by counties or municipalities), private for-profit, or private non-profit (usually owned by religious communities) ownership status. Due to substantial over-capacities and the rapid changes currently taking place in the regulatory and competitive environment, the German hospital sector is now facing an extensive process of

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consolidation and reorganisation. In this context, hospitals are considering mergers, acquisitions and cooperative agreements as ways to improve competitiveness. Between 1995 and 2008, a substantial number of local and regional governments in Germany sold their hospitals to private for-profit and private non-profit owners. The total number of private for-profit hospitals increased by 44%, which represented a rise in market share from 6% to 18% measured in terms of hospital beds.⁴ During the same period, the share of private non-profit hospitals remained relatively constant. Although there are several possible reasons for this development, the main driver has been the need to increase hospital performance.

How to measure hospital performance

There are different concepts used to measure the performance of organisations. Measures often used in other industries, such as return on investment or other profitability measures, are not regarded as appropriate to compare the performance of public and non-profit providers. Therefore, measures such as cost per case, revenue and efficiency are used in the hospital context. In particular, efficiency is a measure that has been frequently used in the hospital context over the last decade. Efficiency or, more explicitly, technical efficiency is a measure of how well an organisation produces output from a given level of input.

Finally, quality of care is often used as a performance measure for organisations in the medical context. In fact, most studies on hospital performance, particularly from the United States, use quality of care. Indicators used as proxies for quality of care range from rather rough but robust measures such as in-hospital mortality to very detailed measures such as the rate of post-surgical infections that may be focused on specific conditions. The latter approach has the disadvantage that not every hospital treats the same conditions and that these indicators may be subject to manipulation. Thus, in-hospital mortality rates or, if available, post-hospital mortality or readmission rates are commonly used as measures for quality of care to compare large numbers of hospitals, for example, all the hospitals in one country.

Evidence from other countries

In contrast to the assumed behaviour outlined in theory, and often assumed by policy makers, there is no evidence that private ownership is associated with higher

efficiency compared to other ownership types. In four of eleven international studies comparing all three different types of ownership in terms of efficiency, public hospitals were found to be less efficient than their counterparts, while six studies showed that publicly owned hospitals were more efficient than private for-profit and non-profit hospitals. One study found no significant efficiency differences associated with ownership. Shen *et al.* 2007⁵ and Hollingsworth 2008⁶ provide good reviews of these studies. However, none of these studies has considered parameters for quality of care in addition to efficiency, although the relationship between ownership, efficiency and quality of care is of considerable practical and policy importance.

One reason for this might be the paucity of validated measures of quality of care. The absence of quality measures requires the implicit assumption that there are no systematic variations in quality of care among public, private non-profit and private for-profit hospitals, or that variations in quality do not systematically affect efficiency. The large empirical literature on ownership unfortunately does not provide evidence on the impact of ownership on quality of care. However, studies examining the relationship between efficiency and quality of care have provided evidence of an inevitable trade-off between these two measures.⁷

Findings from Germany

In the past, there was a lack of detailed data on the German hospital sector, which meant that the quality and the quantity of the information used to assess efficiency was very limited (for example, aggregate state-level data). Thus, evidence on the efficiency of German hospitals was very limited. Just recently, data on all hospitals in Germany became available for research purposes, enabling new perspectives on the 'black box' of hospital efficiency and quality of care.

The first two studies that were conducted since the hospital database became available^{8,9} used the same data but with different methods to determine hospital efficiency. Both found clear evidence that public hospitals have higher efficiency than hospitals with other forms of ownership, i.e., private non-profit and private for-profit hospitals. Stated differently, public hospitals are able to use the available resources most efficiently to produce a given output. These findings are in line

with previous studies from the United States, but may be surprising from a policy perspective. However, in order to draw policy implications we have to look deeper into this issue by considering the characteristics of the German hospital market, as well as other organisational determinants of hospital efficiency.

First, it has to be considered that efficiency is only one way of measuring performance. For-profit hospitals may have found a different way to maximise their profits (i.e., financial surplus) than hospitals with other forms of ownership. Indeed, they may seek to maximise their profits by maximising revenues instead of minimising inputs at a given output. Wörz¹⁰ supports this view, having found that private for-profit hospitals (and especially hospital chains) were able to generate significantly higher revenues per case on average than hospitals with other forms of ownership. Even after the introduction of DRGs in Germany, there are still a substantial number of additional reimbursement components being paid on top of DRGs that can be negotiated at the hospital level (for example, certain expensive drugs). Indeed, these additional components account for approximately 20% of total reimbursements for non-psychiatric inpatient care.¹ Shen *et al.*⁵ found comparable results for the United States hospital sector, concluding that the mission of private for-profit hospitals puts greater emphasis on earning profits (i.e., higher revenues per case due to higher prices) compared to public hospitals, which focus primarily on efficiency, i.e. cost containment.

Tiemann and Schreyögg⁹ further suggest that public hospitals outperform their private for-profit and non-profit counterparts up to a size of approximately 1,000 beds. From 1,000 beds onwards, the private for-profit hospitals operated with greater efficiency. However, most private for-profit providers in Germany operate within a size range of 50 to 800 beds, while only a few hospitals in private-for profit ownership had more than 1,000 beds. The same study also found that private for-profit hospitals show a comparably low level of efficiency in very competitive markets, i.e., in geographical regions with many competitors. If private for-profit hospitals operate in regions with less competition, then the size of these entities approaches that of other ownership types. Here, it is important to recognise that private for-profit and non-profit hospitals operate primarily in urban and other more

competitive areas, whereas public hospitals operate both in urban and non-competitive regions. Thus, private-for-profit hospitals have two major disadvantages which may be due to wrong strategic decisions taken in the past: (1) their hospitals are too small and (2) they operate in areas that are too competitive.

Finally, the study suggests that private for-profit hospitals provide higher quality of care, measured as risk-adjusted in-hospital mortality rates, compared to other types of ownership.⁹ This is in contrast with the common assumption that information asymmetries exist in the hospital market and thus particularly for-profit hospitals have the incentive (i.e., profit-seeking) to increase efficiency at the expense of quality of care. However, in the German hospital sector, information asymmetry has decreased over the last decade due to a variety of health care reforms aimed at quality assurance (for example, the mandatory publication of quality reports and nationwide benchmarking exercise mentioned earlier). Thus, the strategic importance of quality of care in markets with substantial overcapacities (i.e., cut-throat competition) may have been underestimated so far. There is also evidence that private for-profit hospitals (and especially private for-profit hospital chains) operating in more competitive regions have improved their quality management and hospital outcomes in order to attract patients.³

Policy implications

Recent studies show that public ownership in Germany is associated with significantly higher efficiency than other forms of ownership; while private for-profit ownership, in particular, is associated with lower efficiency. Although this finding is striking, it would not be appropriate to conclude that private for-profit ownership may not be an efficient form of operating hospitals.

As the development of the German DRG-system progresses, options to focus on revenue are likely to decrease and thus private for-profit hospitals will automatically increase their focus on efficiency. However, it may be an important implication for policy makers that private for-profit hospitals in Germany and in the United States, if anything, tend to focus on revenue. Therefore, DRG-systems have to set incentives to increase hospitals' focus on efficiency which finally helps to improve the allocation of health care resources. However, the observed negative

association between efficiency and quality of care (i.e., in-hospital mortality) suggests that improvements in efficiency may lead to lower outcomes (or vice versa). Consequently, it is of crucial importance to monitor outcomes when introducing payments based on DRGs.

Moreover, linking DRG-based reimbursement rates to process quality or outcomes is a promising approach to overcome the trade-off between efficiency and quality of care. While this is still relatively rare, it is possible to refine DRG systems to integrate direct incentives for improving quality.¹¹ For example, DRG-based payments can be adjusted at the hospital level by increasing/decreasing payments for all patients treated by a hospital, if that hospital provides above/below-average quality as measured through hospital-level quality indicators (cf. for example Commissioning for Quality and Innovation (CQUIN) in England).¹² Similarly, it is possible to increase payments to a hospital for all patients falling into one DRG if the hospital scores above average on DRG-specific quality indicators, or to adjust payments for individual patients if quality can be monitored at the individual patient level. Germany provides an example for this by including the second admission into the first DRG if the patient is readmitted within 30 days, i.e. the second stay is not reimbursed separately.²

Finally, it is striking that private for-profit hospitals in Germany have recognised the strategic importance of quality of care. This may be one effect of recently established quality assurance programmes, which have substantially increased transparency regarding the quality of care. This may suggest that the introduction of quality reports, which oblige hospitals to deliver data regarding the quality of care for defined conditions, has been an important and valuable decision. Twenty-seven of the 206 quality indicators are already available for public use.³ These developments may well suggest that further quality indicators, as well as data on long-term results after hospitalisations, should be made available to the public.

REFERENCES

1. Schreyögg J, Tiemann O, Busse R. Cost accounting to determine prices: how well do prices reflect costs in the German DRG-system? *Health Care Management Science* 2006;9(3):269–79.

2. Geissler A, Scheller-Kreinsen D, Busse R. Germany: understanding G-DRGs. In: Busse R *et al* (eds). *Diagnosis Related Groups in Europe. Moving Towards Transparency, Efficiency and Quality in Hospitals*. Maidenhead: Open University Press, 2011.

3. Busse R, Nimptsch U, Mansky T. Measuring, monitoring, and managing quality in Germany's hospitals. *Health Affairs* 2009;28(2):294–304.

4. Federal Statistical Office of Germany. *Fachserie 12 Reihe 6.1.1 – Grunddaten der Krankenhäuser und Vorsorge- oder Rehabilitationseinrichtungen 2009* [Basic data of hospitals and preventive and rehabilitative institutions 2009]. Wiesbaden, 2011.

5. Shen Y-C, Eggleston K, Lau J, Schmid C. Hospital ownership and financial performance: what explains the different findings in the empirical literature? *Inquiry* 2007;44(1):41–68.

6. Hollingsworth B. The measurement of efficiency and productivity of health care delivery. *Health Economics* 2008;17(10):1107–28.

7. Shen Y-C, Eggleston K, Lau J, Schmid C, Chan J. Hospital ownership and quality of care: what explains the different results? *Health Economics* 2008;17(12):1345–62.

8. Herr A. Cost and technical efficiency of German hospitals: does ownership matter? *Health Economics* 2008;17(9):1057–71.

9. Tiemann O, Schreyögg J. Effects of ownership on hospital efficiency in Germany. *Business Research* 2009;2:115–45.

10. Wörz M. *Erlöse – Kosten – Qualität: Macht die Krankenhausträgerschaft einen Unterschied? Eine vergleichende Untersuchung von Trägerunterschieden im akutstationären Sektor in Deutschland und den Vereinigten Staaten von Amerika* [Revenues – Costs – Quality: Does Hospital Ownership Make a Difference? A Comparative Analysis in the Acute Hospital Sectors of Germany and the USA]. Wiesbaden: VS Verlag, 2008.

11. Or Z, Häkkinen U. DRGs and quality: for better or worse? In: Busse R *et al* (eds). *Diagnosis Related Groups in Europe. Moving Towards Transparency, Efficiency and Quality in Hospitals*. Maidenhead: Open University Press, 2011.

12. Department of Health. *Using the Commissioning for Quality and Innovation (CQUIN) Payment Framework – A Summary Guide*. London: Department of Health, 2010.

Health care across borders:

Implications of the EU Directive on cross-border health care for the English NHS

Elisabetta Zanon

Summary: The EU Directive on patients' rights in cross-border health care, agreed in March 2011, extends the reach and choice of patients beyond their traditional, national borders. Adapting to the rights and demands of the 'European patient' will be a challenge for health care organisations, forcing them to think differently about how they plan, finance and provide health care. The Directive, however, offers opportunities too for those providers with the expertise and the resources to adapt to a more European market. This article looks at the implications of the Directive for the English National Health Service (NHS).

Key words: cross-border health care, patient mobility, NHS, patients' rights, entitlements, England

The way health care in Europe is planned and the range of providers that patients have access to could look very different in the years to come with the implementation of the EU Directive on cross-border health care.¹ The Directive, which clarifies the rights of patients to receive health care in other EU member states, was adopted in March 2011 after a lengthy EU decision-making process. The legislation will have to be implemented nationally by October 2013 and will have the effect of extending patient choice beyond national borders with significant implications for both English National Health Service (NHS) commissioners (the NHS equivalent of an 'insurer' in the context of cross-border health care) and providers.

The NHS European Office engaged throughout the EU decision-making process to ensure the rules struck the right balance between the increasing mobility of our citizens and patients on the one hand and the member states' responsibility for

the organisation, management and funding of their health care systems on the other. We undertook a wide consultation process with the aim of assessing the potential implications for the NHS,² followed this with a briefing putting forward NHS views on the proposals³ and, more recently, summarised in a new publication the implications for the NHS of the agreed Directive.⁴

The extent of our involvement was dictated by the symbolic nature of the Directive and the genuinely uncertain consequences the Directive could have. While the implications of the Directive discussed in this article are an early reading of the situation and the true impact on our health care system is still largely unknown, adapting to these new challenges and taking advantage of the coming opportunities is in our own hands.

What the Directive says

It is important to note that the Directive speaks with the voice of the patients – it is their rights it clarifies. Its underpinning rationale is that it should be as easy as possible for patients to have access to health care abroad, subject to the same conditions that apply to accessing health care at home. The legislation confirms that it is always the home health system that decides what

health care is available to its citizens, regardless of whether they are treated at home or abroad. In the case of the NHS therefore, patients will be required to have their eligibility to health care assessed by a general practitioner. This provision is particularly important to the NHS which, unlike social insurance systems, does not have a 'basket' of health care to which all patients are entitled, but instead makes decisions on eligibility locally, taking into account the circumstances of individual patients.

From the perspective of our health care system, the Directive has been generally welcomed, owing to the fact that it provides clarity for those in charge of planning care. Importantly, it allows EU member states the option of introducing prior authorisation for patients seeking care abroad, applicable to health care which is subject to planning requirements and which involves at least one night in hospital, or which requires the use of highly specialised and cost-intensive medical equipment. Authorisation can only be refused in limited circumstances and decisions have to be taken in an objective and non-discriminatory manner, for example when a patient could be exposed to a high safety risk that cannot be regarded as acceptable.

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Further information on the role and work of the NHS European Office can be found at www.nhsconfed.org/europe

Authorisation cannot be refused when a patient is experiencing 'undue delay' in receiving treatment and while there is no formal definition of what constitutes 'undue delay', judgements must be based on a clinical assessment of what is a medically acceptable period for the individual clinical circumstances of the patient.

The Directive clarifies that commissioners are not required to pay more than the cost of a patient's treatment if provided by the NHS and there is no requirement to pay travel, accommodation or other expenses that would not be covered if treatment were provided by the NHS.

One of the biggest issues concerning cross-border health care is how domestic costs are determined. The Directive states that each country should have a transparent mechanism for calculating the reimbursement a patient is entitled to, but the detail of this is left for the country to determine.

For NHS health care which is not covered by a tariff – currently around 60% of care – defining levels of reimbursement could be tricky given prices are subject to negotiation and geographical variations. Furthermore, NHS tariffs may cover a package of care, rather than just one procedure, which means costs may need to be 'unbundled' if a patient receives a different package of care abroad. With regards to matters of quality, safety and liability of care, responsibility rests with the country where the health care is provided. This means that standards set by the UK regulatory bodies will not apply to treatment provided abroad and NHS hospitals treating patients from other EU countries will do so to NHS standards.

What will be the main implications for NHS organisations?

It is unlikely that there will be a large increase in the numbers of UK patients travelling abroad. Currently, the numbers are small – it has been estimated that only around 1,000 UK NHS patients a year go abroad for care. But commissioners should be mindful that one of the reasons given by patients for travelling abroad is the opportunity to receive treatment more quickly. So in the event that NHS waiting times increase in the coming years, we could see larger numbers of patients looking to access health care abroad funded by the NHS.

Neither is the Directive expected to have a major impact on NHS budgets, with patients in principle reimbursed for costs

no higher than NHS treatment. But commissioners will need to bear in mind that authorisation cannot be refused in cases of 'undue delay'.

On a positive note, the legislation will end the current uncertainty about the rights of NHS patients considering travelling abroad and how commissioners handle requests from them. With the NHS expected to move to a system of greater local variation under ongoing NHS reforms, a key issue will be for commissioners to have a clear 'list' of the types of health care they do and do not provide. This will be crucial for minimising uncertainty for commissioners and patients, and for reducing the possibility of legal challenge from patients who want to access treatments that are not routinely available on the NHS.

Looking at the impact on providers, it is possible that the NHS could see an increase in requests from overseas patients for access to treatment in some clinical areas, especially for those NHS trusts that provide highly specialised care and have an international reputation. In such cases it is essential that sufficient capacity is planned for, so that additional patients can be treated to the benefit rather than the detriment of NHS patients.

It is important to emphasise, however, that European patients must not automatically be classed as private patients as this would be discriminatory and contrary to EU law. Providers will instead have to offer these patients the option to be classed as either 'paying' NHS patients or private patients, with only the latter being subject to private fees.

One issue for providers seeking more overseas patients is the fact that NHS tariffs are often higher than the prices of other EU countries. Patients will only be reimbursed up to the cost of health care in their own country and would have to cover the difference personally wherever NHS care is more expensive.

There are real opportunities for those trusts with specialist expertise, especially in the diagnosis and treatment of rare diseases, which are expected to emerge from the establishment of 'European reference networks'. The Directive states that these networks will concentrate knowledge in medical areas where expertise is rare and this could have a positive impact on participating NHS trusts in terms of international reputation, collaboration and improved patient care.

What will happen next?

The Directive is due to be fully implemented by October 2013. The implementation will take place in parallel to a vast programme of NHS reforms in England, raising many questions about how the rules will be implemented on the ground and which organisations will be responsible for its different provisions.

It will be during the transposition into national law that key issues regarding the practical implementation of the Directive will be decided, such as:

- decisions around how the process of prior authorisation will work in practice;
- how to ensure that patients can access detailed information on their entitlements to health care;
- how many contact points for cross-border health care will be established across the country and which organisations will be responsible for this function;
- which data on cross-border health care will have to be collected; and
- how the cost of cross-border health care will be calculated, in particular for those procedures which are not subject to tariffs.

Further to this, work will continue to be conducted at EU level to develop a number of provisions in the Directive, such as the concept of 'European reference networks', and to put forward guidelines to support member states with the implementation of the Directive.

Despite the EU Directive now being agreed, it is clear that a number of important decisions on the application of the rules have still to be taken and that our work to engage and influence them will continue over the next couple of years.

REFERENCES

1. Directive 2011/24/EU of the European Parliament and of the Council on the application of patients' rights in cross-border healthcare. *Official Journal of the European Union*, Brussels, 2011. Available at: <http://eurlex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:L:2011:088:0045:0065:EN:PDF>
2. NHS European Office. *A European Health Service? The European Commission's Proposals on Cross-Border Healthcare*. Brussels: NHS Confederation, 2008.

Available at: <http://www.nhsconfed.org/NationalAndInternational/NHSEuropeanOffice/OurWork/Pages/CrossBorderHealthcare.aspx>

3. NHS European Office. *Healthcare in Europe. NHS Views on the European Commission's Proposals on Cross-border*

Healthcare. Brussels: NHS Confederation, 2009. Available at: <http://www.nhsconfed.org/NationalAndInternational/NHSEuropeanOffice/OurWork/Pages/CrossBorderHealthcare.aspx>

4. NHS European Office. *Patient Choice Beyond Borders. Implications of the EU*

Directive on Cross-border Healthcare for NHS Commissioners and Providers. Brussels: NHS Confederation, 2011. Available at: <http://www.nhsconfed.org/NationalAndInternational/NHSEuropeanOffice/OurWork/Pages/CrossBorderHealthcare.aspx>

Towards fairer care funding in England

David McDaid

The question of how to fund long-term care (LTC) services in England has long vexed policy makers. The system has always been a complex mix of substantial out of pocket payments for personal care, supplemented by means tested support. It remains difficult for the public to understand and has been accused of being unfair: thrifty individuals who make provision for old age or save to pass on assets to their children lose out. The lack of any meaningful private LTC insurance means there is no mechanism to mitigate the risk of catastrophic costs should someone need care and support.

Recognition of inequities, whilst mindful of need for a sustainable system of public support, has been the spur for several reports and reviews commissioned by government, as well as by independent bodies since 1998. For differing reasons none led to major change.

July 2011 saw publication of the latest report from the independent Commission on Funding of Care and Support.¹ This was established by the Coalition government in July 2010 to review funding for care and support in England. In particular it was asked for recommendations on partnership funding between individuals and the state for care. It also considered how people could protect their assets, including homes, against care costs.

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Chaired by economist Andrew Dilnot, alongside former Labour Health Minister Lord Warner and Care Quality Commission Chair, Dame Williams, recommendations include national criteria for care to eliminate discrepancies in care entitlements between local authorities. Individual contributions towards costs of social and LTC needs should be capped between £25,000 and £50,000. Other than £10,000 per annum for accommodation and food, all other costs would be met by the state. Theoretically this cap could stimulate development of LTC insurance products. The Commission also recommended that the mean-tested threshold for care support be increased from £23,250 to £100,000. Full implementation, assuming a £35,000 contribution cap, would cost £1.7 billion (0.25% of public expenditure) rising to £3.6 billion by 2025. Overall, the package would mean no-one should spend more than 30% of their wealth on care needs.

Reaction

Government reaction to the report has been muted. Health Minister Andrew Lansley welcomed the report in Parliament, but made reference to significant cost implications "which the government will need to consider against other funding priorities and calls on constrained resources... we have to consider carefully the additional costs to the taxpayer of the Commission's proposals against other funding priorities". This reaction might also reflect political nervousness that the recommendations could be viewed as a way for homeowners, i.e. those in higher socioeconomic groups, to benefit finan-

cially at a time when deep cuts are being made across the welfare state.

Reaction has been more upbeat from non-governmental organisations, with many calling for continued momentum to publish a White Paper setting out governmental plans by Easter 2012. The Association of British Insurers see the proposals as a way of reducing uncertainties which have made the development of LTC insurance difficult.

Perhaps most critically, there have also been renewed calls for the political parties to put aside differences to work together. This previously has been difficult to achieve. Prior to the general election in 2010, LTC became a politically charged issue, with efforts to build cross-party consensus failing amid accusations by the then opposition Conservatives that government plans to reclaim some of the costs of LTC from the estates of individuals after death would amount to nothing short of a 'Death Tax'. Encouragingly, there have been calls since the publication of the Commission's report by politicians in all parties for a mature apolitical debate on the issue. It remains to be seen whether this will help facilitate the development of a LTC funding model acceptable to the public, that all the political parties are willing to be held accountable for.

REFERENCES

1. *Fairer Care Funding. Report of the Commission on Funding of Care and Support*. London: Department of Health, 2011. Available at <https://www.wp.dh.gov.uk/carecommission/files/2011/07/Fairer-Care-Funding-Report.pdf>

NEW PUBLICATIONS

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Help wanted? Providing and paying for long-term care

Francesca Colombo, Ana Llana-Nozal, Jérôme Mercier and Frits Tjadens



Paris: OECD Publishing, 2011

ISBN: 978-9-2640-9758-2

328 pages

Paperback €75. E-book: €52

This book examines the challenges countries are facing with regard to providing and paying for long-term care. As life expectancy pushes into the late 70s for men and well into the 80s for women, ever more people want help in order to be able to live their lives to the full for as long as possible.

How will demographic and labour market trends affect the supply of family and friends available to care for them? Can we all rely on family carers as the sole source

of support for frail older people? Should family carers and friends be better supported, and if so how? Can we attract and retain care workers – is it just a matter of paying them better? Will public finances be threatened by the cost of providing care in the future? What should be the balance between private responsibility and public support in care-giving? Can we reduce costs by improving efficiency of long-term care services?

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Executive summary

Long-term care: growing sector, multifaceted systems

Sizing up the challenge ahead: future demographic trends and long-term care costs;

The impact of caring on family carers

Policies to support family carers

Long-term care workers: needed but often undervalued

How to prepare for the future long-term care workforce?

Public long-term care financing arrangements in OECD countries

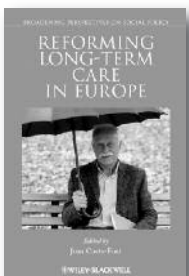
Private long-term care insurance: a niche or a 'big tent'?

Where to? Providing fair protection against long-term care costs and financial sustainability

Can we get better value for money in long-term care?

Reforming long-term care in Europe

Edited by Joan Costa-Font



Chichester: Wiley-Blackwell, 2011

ISBN: 978-1-4443-3873-7

184 pages

Paperback €24

This book provides a topical analysis of features and developments in long-term care in Europe. It compares European countries that are often less studied, including those in Eastern Europe, France, Spain

and Portugal, with the experiences of reform in Germany, the UK, Netherlands and Sweden, looking at a range of issues including approaches to financing and maintaining quality.

Contents:

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Devolution, diversity and welfare reform: long-term care in the 'Latin Rim'

One uniform welfare state or a multitude of welfare municipalities? The evolution of local variation in Swedish elder care

Reforming long-term care in Portugal: dealing with the multidimensional character of quality

News

NEWS FROM THE INSTITUTIONS

Health priorities of the Polish Presidency tabled in Brussels

On 14 July in Brussels, Ewa Kopacz, Polish Minister of Health, presented the health priorities of the Polish Presidency at a session of the Environment, Public Health and Food Safety (ENVI) Committee of the European Parliament. The session was also attended by Adam Fronczak, Vice-Minister of Health. "Poland assuming the Presidency in the European Union Council coincides with the initiation of the new TRIO programme, attended by Poland jointly with Denmark and Cyprus," Minister Kopacz said. "All works we have planned shall focus on the promotion of activities targeting an improvement in the health of European Union citizens and protecting European societies against common risk factors," she added.

Priorities highlighted by the Minister in her speech included: action to tackle differences in health status across Europe through influence on the determinants of health, with special attention paid to correct nutrition and physical activity; prevention and control of respiratory diseases in children; prevention and treatment of communication disorders in children, including the use of e-health and other innovative measures; and the prevention of brain and neurodegenerative diseases, including Alzheimer's disease.

More information at
<http://pl2011.eu/en/content/health-priorities-polish-presidency-tabled-brussels>

First informal meeting of ministers of health under the Polish Presidency

On 5 and 6 July 2011 in Sopot, Poland, an informal meeting of Ministers of Health of the European Union was held. Also in attendance were representatives of the European Commission (DG SANCO), the World Health Organization's Regional Office

for Europe and Marc Sprenger, the Head of the European Centre for Disease Prevention and Control (ECDC).

"The issues addressed at the forum of the EU Council by presiding states result from health policy followed both by the European Union and Member States, and concern topics that constitute vital, social health problems," stressed minister Ewa Kopacz during the sessions. She also pointed to the fact that these issues should be incorporated in the EU's work and priorities, as well as be acceptable for international partners. "Poland, in its work on health-related matters, is planning to address subject matter connected with the reduction of health differences among European societies, especially with regard to children," the Minister of Health remarked.

The talks focused on the health priorities of the Polish Presidency, in particular – closing the gap in health between Europe's societies, through such measures as providing equal opportunities to children with communication disorders. Issues concerning nutrition and physical activity as health determinants for EU citizens and organ transplantation and donation were also raised. Opportunities and benefits brought by technologies developed in the field of e-health were also discussed. Other topics included the hazardous impact of so-called designer drugs on the state of health of European societies.

A major point on the agenda was the situation related to the epidemic of food poisonings caused by E. coli bacteria. "In our capacity as the Polish Presidency, we concentrate on early detection of threats to the health security of EU citizens and an effective information flow. The recent E. coli outbreak has shown how important it is," said Minister Kopacz in Sopot. "In our talks, we have decided to continue the initiative to set up an European Blood Bank and to exchange information on dialysers."

As was highlighted by Minister Ewa Kopacz, both while preparing to assume the Presidency of EU and during the Presidency, Poland attaches considerable weight to health issues, including public health. The Minister emphasised the significance of early prophylaxis and promotion of health for strong modern societies. "From an economic point of view, it has been conclusively proven that any expenditure allocated for programmes of early medical intervention for hearing, sight and speech, is much lower than the outlay spent on special care in the pre-school and school period or on the provision of special jobs for these children when they reach adulthood," she noted. "It is very important for us, as the Polish Presidency, to improve the exchange of information between EU countries, to share experiences in a more active way, and to foster solidarity in health" added the Minister.

More information on the informal meeting is available at
<http://pl2011.eu/en/content/informal-meeting-ministers-health>

Digital Agenda: addressing the challenges of an ageing population

On 26 May 2010, the EU's Council of Competitiveness Ministers identified the Joint Programming Initiative (JPI) *More Years, Better Lives, the Challenges and Opportunities of Demographic Change*, as an area where joint research programming would provide a major added value to the current, fragmented efforts by Member States.

The JPI initiative is bringing together prominent scientists in economics, social sciences, health and technology, together with representatives from industry, policy making and user organisations in order to foster the development of better knowledge on the impact of ageing. This is the first time that Member States will work together to fund strategic research on the ageing population.

Press releases and other suggested information for future inclusion can be emailed to the editor
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This agenda is being implemented through joint actions and projects involving a substantial commitment of funding and participation from involved countries. The European Commission is providing financial support for the coordination of the initiative. This is expected to start delivering concrete results after 2012, such as science based recommendations for adapting pension systems based not only on age, as is currently the case, but on capacity to work.

The initiative will also provide a major contribution to the European Innovation Partnership for Active and Healthy Ageing and the Digital Agenda for Europe. It complements ageing related research activities in the Seventh Framework Programme (FP7), the Ambient Assisted Living Joint Programme and the Competitiveness and Innovation Programme.

Therefore, as part of this initiative, on 15 July 2011, the European Commission called on EU Member States to develop and pursue a common vision on how to coordinate research at EU level in the field of ageing.

A Recommendation just adopted by the Commission urges Member States to participate in the Joint Programming Initiative on ageing populations in research areas such as how to retain people in the labour market, how to help older people remain active for as long as possible, in good health and with a better quality of life and how to make our future care systems sustainable.

This issue is of critical importance given that more than 30% of Europeans will be 65 or over in 2025, while the number of those over 80 will almost double in the same period. So far thirteen countries have committed to participate in the Joint Programming Initiative, led by the German Ministry for Research and Education. The twelve additional countries participating at present are Austria, Denmark, Finland, France, Italy, The Netherlands, Poland, Spain, Sweden, Switzerland, Turkey and the UK, while a further three countries are observers (Belgium, Ireland, Norway). The Commission is a non-voting member of the governing structure.

The Recommendation calls on Member States to include the following actions, as part of their research agenda on ageing:

- identifying and exchanging information on relevant national programmes and research activities, as well as exchanging

best practices, methodologies and guidelines;

- identifying areas or research activities that would benefit from joint coordination or pooling of resources;
- considering the changing needs of older people when defining the objectives for ageing research programmes;
- sharing, where appropriate, existing research infrastructures or developing new facilities such as coordinated data-banks or the development of models for studying ageing processes;
- encouraging better collaboration between public and private sectors and between different research activities and business sectors related to demographic change and population ageing;
- creating networks between centres dedicated to demographic change and population ageing research.

Speaking of the initiative Neelie Kroes, European Commission Vice-President for the Digital Agenda said that it “will develop new science-based knowledge on the effects of demographic change.” She added that she was looking forward to “further Member States joining so that we can look for new opportunities generated by an ageing society, and not be overwhelmed by its challenges.”

More information at <http://www.jp-demographic.eu/>

High level of premature illness and death amongst men is preventable, concludes report

The *Men's Health Report* published on 25 August by the European Commission highlights the state of men's health in Europe as a serious public health concern. Commissioned by the European Commission's Public Health Programme, the report was led by Professor Alan White from Leeds Metropolitan University and carried out by a consortium of authors. Its purpose is to inform policy makers, health professionals, academics and the wider population of the health challenges men face.

Patterns emerging from data taken from all EU-27 countries, as well as Norway, Iceland, Switzerland, Lichtenstein, Croatia, Turkey and the former Yugoslav Republic of Macedonia, show marked differences in health outcomes amongst men both between and within countries. Poor lifestyles and preventable risk factors

account for a high share of premature death and illness in men, illustrating that their health disadvantage is not necessarily written in the genes but can be remedied in part by targeted policies and actions.

Key findings from the report include observing that more than 50% of premature deaths among men are avoidable. Even though there have been big reductions in cardiovascular morbidity and death amongst men, cardiovascular disease is still one of the greatest risks to health and the principal cause of death in the older population.

One challenge is to increase the rate of engagement of men in routine or preventative health checks. Depressive disorders in men, as well as other mental health problems, are under detected and under treated in all European countries. This is partly due to men being less likely to seek help than women. The report also notes that prostate cancer has become the most diagnosed cancer in Europe, while testicular cancer, despite effective treatment, still remains the first cause of cancer deaths among young men aged 20–35 years.

The report is available at http://ec.europa.eu/health/population_groups/docs/men_health_report_en.pdf

Commission publishes report of public consultation on revisions to the Tobacco Products Directive

Tobacco is the single largest cause of avoidable illness in the European Union (EU) and the estimated cause of death of over 650,000 people in the EU every year. At global level, the World Health Organization (WHO) estimates that tobacco use will kill nearly six million people this year alone. This figure could reach eight million by 2030 if steps are not taken to reverse this worrying trend.

On 27 July the European Commission's Directorate-General for Health and Consumers published results of a public consultation on the upcoming revision of the Tobacco Products Directive. The current Directive (2001/37/EC) dates from 2001. Since then, significant scientific progress and international developments have taken place. In particular, the EU and twenty-six of its Member States are Parties to the WHO Framework Convention on Tobacco Control (FCTC) which entered into force in February 2005. The review of the Tobacco Products Directive is a response to these developments as some of the current provisions of the Directive

have now become outdated, resulting in a significant divergence between Member States' laws on the manufacture, presentation and sale of tobacco products.

The consultation on the revision of the Tobacco Products Directive was launched last autumn. Respondents were asked to give their input on a number of policy options including: mandatory pictorial health warnings – or graphic images – on packs of tobacco; plain or generic packaging; regulating harmful and attractive substances in tobacco products; and restricting or banning the sale of tobacco products over the internet and from vending machines.

The consultation has generated an unprecedented 85,000 responses. The vast majority of contributions have come from individual citizens, illustrating the great interest in EU tobacco control policy. Other respondents represented industry, non-governmental organisations, governments and public authorities.

Contributions varied significantly. For example, those in favour of mandatory pictorial health warnings and plain packaging stressed that these measures would significantly weaken the advertising effects of the packaging and provide equal protection for European citizens. Opponents, on the other hand, raised legal concerns arguing that these measures would have little or no impact on the uptake of smoking.

Those in favour of regulating ingredients said that restricting certain additives alongside sweet, fruity, floral, and candy flavours could prevent young people from taking up smoking and would facilitate intra-EU trade by bringing into line existing national regulations on ingredients. Opponents argued that regulating ingredients and additives would do little to prevent young people from taking up smoking and could discriminate against certain varieties and brands of tobacco.

The results of the consultation will be taken into account in the ongoing impact assessment which addresses the economic, social and health impacts, as well as the feasibility of various policy options. The outcome of the impact assessment will be presented together with a legislative proposal next year.

A report summarising the public consultation is available at http://ec.europa.eu/health/tobacco/consultations/tobacco_cons_01_en.htm

New brochure on EU funding possibilities to promote active ageing

The Committee of the Regions, AGE Platform Europe and the European Commission have issued a brochure presenting EU funding possibilities for regional and local initiatives to promote active ageing and solidarity between generations. The brochure aims to make a particular contribution to the European Year for Active Ageing and Solidarity between Generations 2012.

The majority of initiatives to promote active ageing – throughout 2012 and onwards – will be taken without financial support from the EU, but in some cases EU funding will play a role. The brochure shows what resources are available and invites regional and local stakeholders to make the best possible use of them, preferably working in partnerships involving several countries. The brochure presents numerous examples of projects which have received EU funding. It also includes short presentations of the most relevant EU funding programmes to support new active ageing projects.

The brochure can be downloaded at <http://ec.europa.eu/social/BlobServlet?docId=7005&langId=en>

Illicit drug use in Europe still a major threat to public health

Illicit drug use in Europe still represents a major threat to public health and is responsible for between 7,000 and 8,000 fatal overdoses every year in the EU. So stated Wolfgang Götz, Director of the Lisbon-based European Monitoring Centre for Drugs and Drug Addiction (EMCDDA), ahead of the International Day Against Drug Abuse and Illicit Trafficking on 26 June. Götz also noted that Europe's drugs problem are changing, with more problems now associated with the use of stimulant drugs such as cocaine, while new substances are increasingly appearing on the European market.

Götz went on to highlight achievements made since the 1990s in scaling up of care for drug users, noting that at least one million people in the EU receive some form of treatment for drug problems per year. The wider availability of clean needles and syringes for drug injectors has also been linked to both a reduction in new drug-related HIV infections and an overall decline in levels of injecting drug use.

He also noted the increased focus on public health in European drug policies,

citing an example from Portugal. The Portuguese case study, he argues, illustrates how it takes many years of action against an ongoing severe drugs problem to develop a new drug policy model.

Innovative responses are required and must be subject to evaluation. Götz added that “we should acknowledge the importance of developing innovative responses and evaluating them thoroughly. Without such an approach, many of the interventions which are today at the heart of our drug policies would simply not exist.” A new EMCDDA series of drug policy profiles outlining the development and characteristics of national drug policies in Europe and elsewhere in the world has now been launched.

The Portuguese drug policy profile is available at <http://www.emcdda.europa.eu/publications/drug-policy-profiles/portugal>.

COUNTRY NEWS

France: proposed reform of pharmaceutical regulatory system

French Health Minister, Xavier Bertrand, has outlined a bill to overhaul the country's drug regulatory system in the wake of the scandal over the continued use of the anti-diabetes drug benfluorex in France, long after it was banned in other countries. The medicine is estimated by different studies to have caused 500 to 2,000 deaths in France, mainly from heart valve damage. The oral drug, marketed as Médiator, was taken by more than five million people in the country and often prescribed for weight-loss until it was withdrawn in November 2009 when new research revealed the extent of the heart-valve problem.

The new legislation, which will be debated in parliament in September 2011, proposes to introduce fines and penalties for those in the health sector who fail to declare any conflicts of interest. It will focus on preventing conflicts of interest at all levels of the health service from the ministry down, increasing transparency in decision-making on drug approvals, ensuring that all drugs offer real benefits, improving training for health professionals, and providing better information for professionals and the public. Measures will include a French ‘Sunshine Act,’ where drug companies will be fined if they do not declare

all agreements with outside groups, stricter controls on prescribing drugs for unauthorised uses, changes in drug marketing methods, and a ban on the financing of medical students by drug companies.

The Health Products Safety Agency, *Agence Française de Sécurité Sanitaire des Produits de Santé* (AFSSAPS), the regulatory body which was severely criticised for its role in the Médiator affair, will also be renamed as the *Agence Nationale de Sécurité du Médicament*, the National Agency for the Safety of Medicines (ANSM). It will be given new powers so that new drugs have to pass a more rigorous approval process. New drugs will be compared with existing medications and not just placebos.

If adopted into law, the whole package of reforms will be reviewed in two years. However, even before the law has been passed, work has begun on reassessing the 19,000 drugs now authorised in France, of which 12,000 are on the market. Bertrand has hinted that many of these drugs may be dropped. The Minister has also stated that the French system must be capable of reacting as fast as the US Food and Drug Administration (FDA), citing an example in which the FDA added a contraindication for another diabetes drug, just 48 hours after it was suspended from the French market.

Finland: Downward trend in smoking and alcohol use, increase in the use of snus among adolescents

The downward trend in daily smoking among adolescents has continued to fall over the period from 1977 to 2011, with adolescents starting to experiment with smoking at an older age than ever before in Finland. Alcohol use and binge drinking have also decreased among adolescents below the age of 18 years. On the other hand, snus (moist snuff) use and exposure to narcotic drugs have become more common.

This information appears in the nationwide Adolescent Health and Lifestyle Survey 2011 carried out at the University of Tampere, School of Health Sciences. The questionnaire was completed by 4,566 adolescents aged from 12 to 18 years. The survey, which is funded by the Ministry of Social Affairs and Health, has been conducted biennially since 1977.

More information at
<http://www.stm.fi/en/pressreleases/pressrelease/view/1563478#en>

Hungary introduces 'fat tax'

Food considered to be unhealthy, including crisps, soft drinks and chocolate bars, are now subject to a new tax in Hungary. The new law, which came into force on 1 September is aimed at improving the health of the nation. Initially called 'the hamburger tax', the measure was dubbed the 'crisps tax' or 'fat tax' after the Hungarian government decided that it would not affect fast food restaurants. The new law also does not cover some traditional Hungarian cuisine, such as goose fat.

Hungarians will have to pay a 10 forint (€0.37) tax on foods with high fat, sugar and salt content, as well as increased levies on some carbonated soft drinks and alcohol. The expected annual proceeds of €70 million will go toward state health care costs, including those associated with addressing the country's 18.8% obesity rate, which is more than 3% higher than the European Union average of 15.5%.

Hungarian Prime Minister Viktor Orban has said that those who live unhealthily have to contribute more. In other words, the new law is based on the idea that those whose diets land them in the hospital should help foot the bill, particularly in a country with a health care deficit of €370 million.

The controversial 'fat tax' is the most comprehensive on unhealthy foods in the world to date; but other European countries are also moving in this direction. Denmark is one of several European countries to tax fizzy soft drinks, and it has imposed a levy on sweets for nearly 90 years. The country was also the first in the world to pass a law banning trans fats, with Austria and Switzerland following closely after. Later in 2011 Denmark also plans to levy a 'sin tax' on foods with high saturated fat content. Romania also considered a 'fat tax' scheme to raise €700 million a year that would be earmarked for health services, but the idea was ditched in March due to the sharp rise in general food prices.

There are differing opinions over the potential impact of the legislation. Concerns have been raised about the impact on low-income groups, given that Hungarians already spend 17% of their income on food and already pay an extra 25% tax on most food and drink products they consume, one of the highest rates within the EU. While generally supportive of the new tax, Archie Turnbull of the Brussels-based European Public Health Alliance, a

network of public health non-governmental organisations, suggested in a letter to the Hungarian government that it "consider using other pricing mechanisms or subsidies to make the healthy options of fresh fruits and vegetables more widely available and affordable."

German Parliament gives approval for limited embryo screening

On 7 July in a free vote the German Parliament approved by 326 to 260 a bill that allows prospective parents worried about genetic diseases to screen test-tube embryos before bringing them to term. The Bundestag moved to allow some "pre-implantation genetic diagnosis (PID)", in which a cell or two are extracted from a developing embryo to test for genetic disorder. But it also imposed strict conditions: doctors can perform the screening only when the parents have a strong likelihood of passing on a genetic defect, or when the chances of miscarriage or stillbirth are (genetically) high. In all other respects the country's strict Embryo Protection Law will remain in place.

German Chancellor Angela Merkel was among those opposed to the measure. Many opponents fear the tests could lead to so-called 'designer babies.' Germany has also been particularly cautious in allowing genetic procedures because of atrocities under the Third Reich. Since PID tests are only feasible among parents who have already opted for in-vitro fertilisation, they tend to be relatively rare. Experience in the United Kingdom has shown that genetic screening can increase the chances an embryo will 'take' and lower the likelihood of miscarriage or stillbirth.

Momentum toward the vote had been growing in Germany. In July 2010, the Federal Court of Justice ruled that three screenings performed by a Berlin doctor did not violate the country's 1990 Embryo Protection Law. The law recommends a three-year jail term for anyone using an embryo in a way that fails to promote its survival. The court ruled that since the goal of PID was a healthy pregnancy and a healthy child, the screenings were lawful.

Spain: Law passed on mandatory generic prescribing

The Spanish government has passed new laws to increase generic prescribing and cut up to €2.4 billion per annum in the country's pharmaceutical expenditure. Doctors will have to write prescriptions using a drug's generic name and pharma-

cists will be obliged to fill that prescription using the cheapest available generic drug. The move will not affect newer branded drugs, whose patents prevent cheaper generic versions coming to market, but it will impinge upon companies with older patented medicines that have lost this protection and face generic competition.

The rule change will be most concerning to small-to-medium sized firms (SMEs) that rely on single blockbusters for the majority of their revenue. It will also have a negative impact on the bigger companies that market branded statins and blood thinners, two groups of medicines that tend to succumb to generic substitution in times of austerity.

The law also states that patients should only be told the chemical name of the drug being prescribed, regardless of whether it is a patented medicine or a generic, meaning patients will now not know what drug their doctor intended to prescribe.

Prime Minister, José Luis Rodríguez Zapatero, told parliament the measures would help Spain continue to lower the cost of drugs to the state, a move that began last year and which has led to the first-ever fall in the national pharmaceutical bill. This year's bill was already cut by 10%, in part because of measures that had increased the use of generic drugs.

Speaking to the *Guardian* newspaper Basque nationalist deputy Josu Erkoreka, whose party backed the move, said that the new legislation will lead to "an important saving for the public accounts and will, without doubt, benefit most people who use public health services. The interests of the big drugs companies must give way to public interest, and what matters is reducing the deficit and lowering the drugs bill for millions of people who use public health services." However Catalan nationalist deputy, Josep Antoni Duran i Lleida told the *Guardian* that he feared that jobs would be lost in the pharmaceutical sector.

Scotland: Alcohol sales at all time high

Alcohol sales are now 23% higher in Scotland than in England and Wales, the biggest difference ever recorded during the 17 years measured since 1994. The new figure is contained in a report published on 30 August by NHS Health Scotland. The publication shows that on average 2.2 more litres of pure alcohol per adult were sold in Scotland than in England in 2010; 11.8 versus 9.6 litres. This equates to 22.8 units of alcohol per adult per week in Scotland,

above the recommended upper weekly limit of 21 units for men.

In addition almost 2.5 times more vodka was sold per adult in Scotland through off-sales than in England and Wales. Cabinet Secretary for Health and Wellbeing Nicola Sturgeon commenting on the report said that "for too long Scotland's unhealthy relationship with alcohol has gone unaddressed. These shock statistics show that the difference between alcohol consumption in Scotland and England and Wales is now at its highest rate for seventeen years. This is a situation that must be tackled head on."

The impact of excessive consumption is estimated to cost the country £3.56 billion each year. The government have through their Alcohol Framework outlined a package of over 40 measures to reduce alcohol related harm. From October 2011 quantity discounts will be banned and off-sale promotions restricted. The government also intend to introduce a Minimum Pricing Bill to the Scottish Parliament in the autumn to further reduce consumption of alcohol. Minister Sturgeon said "minimum pricing can and will help us to redress the balance when it comes to our unhealthy relationship with alcohol."

The report Monitoring and Evaluating Scotland's Alcohol Strategy is available at <http://www.healthscotland.com/uploads/documents/16664-completeReportMESASAugust2011.pdf>

Northern Ireland: details published of health and social care review

On 25 August Health Minister Edwin Poots appointed five external advisers to a panel which will provide expert advice and independent assurance on the Review of Health and Social Care Services in Northern Ireland.

The review, announced in June, is being led by John Compton, Chief Executive of the Health and Social Care Board. The Minister has appointed the five external members to provide advice, drawing on a range of relevant expertise and skills. He has also published detailed terms of reference for the review.

The Minister said that "it is clear that the full range of health and social care services is unsustainable in its current form if we are to deliver the best outcomes for everyone, and if we are to maintain the highest levels of quality and safety of the services provided. It is important therefore that this review examines the future pro-

vision of services including our acute hospital configuration; the development of primary health care services and social care; and the interfaces between the sectors.

The review needs to proceed without delay given the seriousness of the situation facing our health services. However, it must also be evidence-based with robust analyses and conclusions on future service delivery. I have decided therefore to appoint this panel of expert advisers to provide independent assurance to the review team and myself. The review will benefit immensely from the experience and knowledge of external members, including backgrounds in health policy and health care, business and academia."

The panel members will be Professor Chris Ham (Chief Executive of the King's Fund), Professor Deirdre Heenan (Provost and Dean of Academic Development at the Magee Campus, University of Ulster), Dr Ian Rutter (General Practitioner), Paul Simpson (retired senior civil servant) and Mark Ennis (Executive Chair of Scottish and Southern Electricity Ireland).

The Minister said the five advisors would bring a wealth of knowledge and skills to this important exercise. The Minister has asked the review team to report to him by the end of November. He said "I have set a challenging timescale for the completion of this Review because it is important that clarity is provided urgently on the future direction of health and social care services here. Our system cannot continue to operate as it has done: there are simply not the resources to do so; and action will be required to ensure we provide safe and effective services to the people here for the future."

The detailed terms of reference for the review are available at <http://www.dhsspsni.gov.uk/hsc-provision.htm>

England: 'Nudging' alone unlikely to be successful in changing the population's behaviour

On 19 July the House of Lords Science and Technology Sub-Committee published a report on *Behaviour Change*. It examined how successful nudging has been in changing people's behaviour in relation to obesity. It looked at food labelling and restrictions on advertising, and asked how it was possible to change the choices people make about travel in order to reduce car use. The report – the culmination of a year-long investigation into the

way the Government tries to influence people's behaviour using behaviour change interventions – finds that 'nudges' used in isolation will often not be effective in changing the behaviour of the population. Instead, a whole range of measures, including some regulatory measures, will be needed to change behaviour in a way that will make a real difference to society's biggest problems.

Other findings and recommendations from the Committee include:

- the Government must invest in gathering more evidence about what measures work to influence population behaviour change;
- they should appoint an independent Chief Social Scientist to provide them with robust and independent scientific advice;
- the Government should take steps to implement a traffic light system of nutritional labelling on all food packaging;
- current voluntary agreements with businesses in relation to public health have major failings. They are not a proportionate response to the scale of the problem of obesity and do not reflect the evidence about what will work to reduce obesity. If effective agreements cannot be reached, or if they show minimal benefit, the Government should pursue regulation.

The new report contradicts an earlier document produced for the Communities and Local Government Department that suggested people could be 'nudged' into giving to charity or volunteering. The theory of nudging comes from the book *Nudge*, by Richard Thaler and Cass Sunstein. Thaler is working with the Behavioural Insights Team, which is based at the Cabinet Office and is examining issues such as promoting charitable giving.

Baroness Julia Neuberger, chair of the Lords sub-committee that carried out the review, said "there are all manner of things that the Government want us to do – lose weight, give up smoking, use the car less, give blood – but how can they get us to do them? It won't be easy and this inquiry has shown that it certainly won't be achieved through using 'nudges', or any other sort of intervention, in isolation.

"Behaviour change interventions are nothing new. Governments have tried to change our behaviour before – through

legislation, marketing campaigns and even 'nudges', for example, rumble strips on the road to get us to drive more slowly. And businesses also try to influence our behaviour all the time – supermarkets influence us through the location of, and promotions for, certain foods and all businesses use advertising and marketing to change our behaviour"

She added that the Committee welcomed the government's "desire to take the science behind behaviour change seriously in an attempt to find an effective solution" but noted that "changing the behaviour of a population is likely to take time, perhaps a generation or more, and politicians usually look for quick win solutions. The Government needs to be braver about mixing and matching policy measures, using both incentives and disincentives to bring about change. They must also get much better at evaluating the measures they put in place."

The report and executive summary are available at <http://www.publications.parliament.uk/pa/ld201012/ldselect/ldscitech/179/17902.htm>

Romania: Change of Health Minister

Romania's Health Minister Cseke Atilla resigned on 4 August in protest that his ministry had not received sufficient funds in the country's budget settlement. On 13 July, the Minister told the media that the Health Ministry needed an extra 4 billion Lei (about €948 million). He said the Romanian National Health Insurance House (CNAS), the state body tasked with collecting funds from taxpayers' health contributions, faced serious financial problems and needed three quarters of this budget. However the budget revision allotted only 341 million Lei to CNAS, through the ministry, to pay arrears and 1.7 billion Lei in commitment appropriations for medicine with or without a personal contribution.

According to the Romanian Act Media news agency, in a news conference Minister Atilla said that he had warned as early as December that an upward budget adjustment was needed. Atilla, who was the nineteenth Minister of Health since 1990, noted that over the last twenty years Romania has had the lowest Gross Domestic Product (GDP) percentage assigned to health, regardless of government or minister in charge. He also referred to the steps taken towards reforming the system, including the decentralisation of 370 hospitals in the previous

year, stricter regulation of sick leave and the release of a number of vacant staff positions. Stressing that his resignation was not political, he said that reform measures will and must continue.

The new Minister is Ritli Ladislau. Ladislau, was proposed by the Hungarian party in Romania, the UDMR, which is a junior member of Prime Minister Emil Boc's centre-right government. The new minister will also coordinate the activities of CNAS which historically had been run independently of the ministry, though this caused discontent among previous health ministers who complained that they were unable to undertake reforms without having the control of finances.

Ladislau will now also have to continue reforms and apply measures agreed with the European Commission and the International Monetary Fund (IMF). Romania has been struggling to reform its public health sector, which has fallen into a state of growing disrepair as a result of chronic underinvestment. Hospitals around the country are understaffed and short of specialists and modern medical equipment. Low health sector salaries have prompted an exodus of doctors and nurses who have gone abroad to seek better paid jobs.

Romania: new rules on reimbursement of some drugs

As of 1 September 2011 the Romanian Ministry of Health has introduced a new methodology for calculating reimbursements for drugs included on the so-called C2 list. The C2 list includes over 1,400 drugs used in national programmes for outpatient and inpatient care. It includes medicines distributed under national health programmes for the treatment of cancer, tuberculosis, AIDS, diabetes and some other chronic diseases. As compared to other drugs on the Romanian pharmaceutical market, the drugs included in the C2 list are the most expensive.

According to the revised provisions, the reimbursement of any C2 list drug cannot exceed 120% of the retail price of a cheaper substitute (generic with the same active substance) in the same therapeutic group. The new methodology does not apply if there is no generic equivalent to the innovative drug, in which case 100% reimbursement will remain in place. Due to the changes in the reimbursement methodology, the Romanian National Health Insurance House (CNAS) predicts savings of about RON 150 million (€36 million) per year in its health programmes.

News in Brief

2012 World Congress on Public Health

The 13th World Congress on Public Health will take place in Addis Ababa, Ethiopia from 23-27 April 2012. The main theme is 'Moving Towards Global Health Equity: Opportunities and Threat'. The deadline for the submission of abstracts is October 21.

More information available at
<http://wfpaha.confex.com/wfpaha/2012/cfp.cgi>

Self-assessment of public health services in the Republic of Uzbekistan

Since independence, significant changes have begun to take place in the health system of Uzbekistan. By 1991, Uzbekistan had a rather developed health system but it was characterised by a centralised structure and imperfect managerial mechanisms. In 1998, a Presidential decree adopted the National Health System Reform Programme on a phased approach to the formation of the national health system model. It is based on the principles of strict observance of social protection conditions for the population, universal availability of guaranteed medical care, and phased transition of some health institutions on mixed and private funding sources.

This new assessment of the public health service in Uzbekistan was undertaken by the working group of the Ministry of Health with the involvement of specialists of different areas, and organised under the coordination of the World Health Organization (WHO) Regional Office for Europe team for Public Health Services, with the WHO Country Office in Uzbekistan.

The report is available at
<http://tinyurl.com/3n4rjkk>

Wales: Improving picture for children's mental health services

Mental health services for children and adolescents in Wales have expanded and changed for the better, with faster access to treatment and an increase in specialist staff, a new independent report shows.

The report on the provision of Specialist Child and Adolescent Mental Health Services provides data collected between 2007 and 2011. Key findings include: an increase of 25% in the workforce between 2007 and 2011; growth in the number of

cases worked with and consultations carried out; a reduction in the number of people waiting to be seen; a reduction in the length of wait for people to be seen; a reduction in lengthy treatment times.

More information at
<http://www.wales.nhs.uk/sitesplus/888/news/19609>

Launch of pilot European Innovation Partnership on Active and Healthy Ageing

The pilot European Innovation Partnership on Active and Healthy Ageing aims to increase the average healthy lifespan in the EU by two years by 2020. It pursues objectives to improve the health and quality of life of Europeans with a focus on older people; support the long-term sustainability and efficiency of health and social care systems; and enhance the competitiveness of EU industry through business and expansion in new markets. The pilot Partnership will provide a forum for stakeholders through a series of workshops and a high-level steering group will assist with preparatory work. Its main role is to draw up a strategic implementation plan with operational recommendations.

More information at
http://ec.europa.eu/health/ageing/innovation/index_en.htm

Denmark: Report on health status of men and review of effective interventions to promote their health

This new report published by National Board of Health is intended to identify which health promotion and disease prevention initiatives and indicators can be used to monitor initiatives to improve the health of men in Denmark. Data on socioeconomic trends, life expectancy, mortality, self-reported morbidity and use of health care services are provided.

Updating a previously published systematic review, the study authors conclude that there are several effective measures to improve men's health, but that larger studies are needed to confirm this. Moreover the evidence base does not support the view that targeting interventions at men is more effective than targeting interventions at everyone.

A summary version of the report is available in English at
<http://tinyurl.com/3zl9g5b>

Polio kicked out of Europe

The European Regional Certification Commission for Poliomyelitis Eradication (RCC) announced on 24 August that Europe will retain its polio-free status after the importation of wild poliovirus type 1 in 2010. At their 25th meeting in Copenhagen, the RCC noted that wild poliovirus transmission has been interrupted. No new cases have been reported since September 2010 because countries have taken effective action. The response of Member States was commended, especially their efforts to protect their populations and stop the transmission of the poliovirus. This was done through synchronised additional immunisation activities, often involving nationwide vaccination campaigns.

More information at
<http://www.euro.who.int/en/what-we-do/health-topics/communicable-diseases/poliomyelitis>

Netherlands: Experience of personal health budgets

A new case study report from the UK based Health Foundation looks at the use of personal health budgets (persoonsgebonden budget or PGB) in the Netherlands.

The adoption of PGB arose partly from limitations in the traditional health care system, but also from a desire to offer service users more choice and control over their care. There was also a belief that handing control of budgets to the end user would help to reduce costs. Implementing PGB has not been without its difficulties, but the system is highly popular with both the public and politicians. Through a range of perspectives, from the Health Ministry to a carer, this case study entitled *The Personal Touch* explores the challenges and successes of the PGB.

The case study can be accessed at
<http://www.health.org.uk/publications/personal-health-budgets/>

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Eurohealth is a quarterly publication that provides a forum for researchers, experts and policy makers to express their views on health policy issues and so contribute to a constructive debate on health policy in Europe

European
Observatory 
on Health Systems and Policies

LSE Health

ISSN 1356-1030