



# Mental Health Research Review

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Published by: PSSRU, University of Kent at Canterbury, Canterbury, Kent CT2 7NF

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## Director's introduction

Martin Knapp

Mental health continues to be high on policy and practice agendas. If the National Service Framework (NSF) was the policy announcement initiative which dominated the last two years, then the next two could well be dominated by the attention that NICE, the National Institute for Clinical Excellence, is paying to mental health. The decision from the NICE review of the cholinesterase inhibitor drugs for Alzheimer's Disease earlier this year has been followed by the review of the atypical antipsychotics for schizophrenia. Each raises economic questions, and in each case the research community has been able to offer some — but by no means enough — of the answers. The programmes of research in the Centre for the Economics of Mental Health, Institute of Psychiatry, and the PSSRU at both the London School of Economics and University of Kent, are contributing to this developing evidence base.

The NSF and the NICE reviews are the national headline grabbers, but on a day-to-day basis local practice and policy decisions are taken that affect the lives of millions of people with mental health problems and their families. Economic considerations also have a part to play in these decisions. Sometimes that part is

explicit, carefully fashioned and evidence-based, but sometimes not.

As each year passes the volume of available economic evidence grows and, broadly speaking, the quality also improves. This eighth annual Mental Health Research Review describes many of the research and related activities undertaken by CEMH and PSSRU. It also lists the publications that give the details. As ever we hope that MHRR can help disseminate valuable research information on mental health economics and policy.

This autumn there is an excellent opportunity to discuss many of the economic issues in the mental health field. There will be a conference in London on 11-12 October on Mental Health Service Research, and abstracts are now being invited for presentations at the event: details are on the back cover.

Finally, can I extend my thanks to Paul McCrone and Dave McDaid for editing this issue of MHRR so expertly. Congratulations are also in order for Paul, and also for our former CEMH colleague, Daniel Chisholm, on gaining their PhD degrees.

## Editors' introduction

Paul McCrone and David McDaid

The purpose of the *Mental Health Research Review* is to present mental health care research carried out by the Centre for the Economics of Mental Health (CEMH) and the PSSRU. Our hope is that the Review is of practical use to those involved in the organisation and provision of services. As in previous years, there is a strong health economics flavour to this work. Space only permits us to discuss a selection of the work carried out by the two groups and details of other projects can be found by contacting the CEMH or PSSRU.

Innovative mental health services are being developed across the world and Anita Patel and Meredith Harris describe different components of a service for children and adolescents in Melbourne, Australia. They discuss the use of health economic methods to determine the cost-effectiveness of these schemes, in particular the Early Psychosis Prevention and Intervention Centre which has already been shown to have clinical success.

Daniel Chisholm and Martin Knapp discuss the LIDO study which, among other things, seeks to estimate the economic burden of depression in six countries. To make valid comparisons between countries two key methodological obstacles need to be overcome. First, it is necessary to take into consideration differences in the supply of services in each country. Supply differences inevitably lead to differences in utilisation and costs regardless of differences in the *need* for such services. Second, to make comparisons it is necessary to use a common currency which requires an appropriate exchange rate to account for differences in prices in different countries. If these issues are successfully dealt with, the LIDO study will have benefits for other international studies in this and other areas.

In England the use of secure psychiatric beds has increased substantially over recent years. This trend is discussed by Paul McCrone. It is pointed out that this is very much an issue facing inner city areas. Existing methods of resource allocation (the currently used York formula and two alternatives) are shown to account for less than half the observed variation in bed use, and this suggests that a separate funding formula for secure provision is required.

There has been debate in the UK and elsewhere as to the form that community care for people with mental health problems should take. The UK 700 study compared intensive case management with standard case management. Sarah Byford describes how in this randomised trial neither the outcomes (in particular the number of days spent in hospital) nor the costs of the two types of case management were statistically different.

Jennifer Beecham, Jack Astin and Kate Mummery report on a project to generate Mental Healthcare Benefit Groups (to categorise patients) and Mental Healthcare Resource Groups (to categorise levels of resource use), as an aid to resource management. This development is dependent on adequately sized datasets and the authors have used those collected by the PSSRU and CEMH over a number of years. The results are encouraging, with resource costs shown to be higher for groups of patients with high self care needs and greater past use of inpatient care.

David McDaid and Franco Sassi report on a study to measure aspects of the burden borne by informal carers of people with Alzheimer's Disease in England, Italy and Sweden. They provide evidence that carers' perception of burden is in part determined by cultural factors, with Italian carers reporting much higher levels of difficulty compared with their counterparts in the other two countries. However, despite this difference, the majority of carers still wish to retain primary caring responsibilities. Further research is required to examine context- and culture- specific factors, in order that appropriate formal services are provided which meet the needs of carers.

Adelina Comas-Herrera and colleagues report on a new research project being undertaken to investigate the impact of cognitive impairment on long-term care demand and expenditure in England. A model will be built to project the future number of older people with cognitive impairment, their demands for services and the costs of care over a 30 year period. A previous model was highly sensitive to changes in functional dependency, but did not look separately at cognitive ability. The new model is important, as cognitive impairment may be associated with a higher rate of institutionalisation than physical dependency.

Finally, Martin Knapp, David McDaid and Andrew Healey discuss some issues of mental health care finance and delivery in low and middle income countries, as part of work undertaken on behalf of the World Health Organisation. Mental health care services have tended to be neglected in comparison to public health care interventions in low income countries, in part because of the stigma associated with mental health. Issues of revenue generation and collection mechanisms, the generation of a cost-effective evidence base for resource allocation, and equity are presented.

The editors would like to thank all those who have contributed to this edition of the Review, especially Nick Brawn, who put it all together. We hope you find it useful and we would appreciate your comments and suggestions concerning the Review and the projects discussed.

## **Early psychosis services in Australia**

Anita Patel and Meredith Harris

The relevance and importance of health economics has received much attention in recent mental health service developments worldwide. However, there is a substantial body of pioneering work that remains to be evaluated from an economic perspective. As part of CEMH's growing programme of international research, a health economics collaboration project was set up with Mental Health Services for Kids and Youth (MH-SKY) in Melbourne, Australia.

MH-SKY Youth Program provides a comprehensive integrated mental health service for young people living in the western and north western metropolitan regions of Melbourne, Australia. Its catchment area is serviced by two public psychiatric hospitals and four adult mental health services, with an estimated resident population, as at June 1999, of approximately 852,000 (Australian Bureau of Statistics, 2000). The service provides a number of programmes, some of which are described below.

One of the largest and most prominent programmes is the Early Psychosis Prevention and Intervention Centre (EPPIC). This provides specialist, comprehensive early interventions through a range of sub-programmes, for example, case management teams, inpatient unit and family work. The work of EPPIC is described further in the 'economic evaluation' section below.

The Older Adolescent Service (OAS) provides a series of services to non-psychotic 15-18 year olds with emotional and/or behavioural problems. These include crisis intervention, individual, group and family therapy, consultation and liaison, case management, referral and community education. Specialist intervention programmes include eating disorders, health damaging behaviours and depression/anxiety disorders.

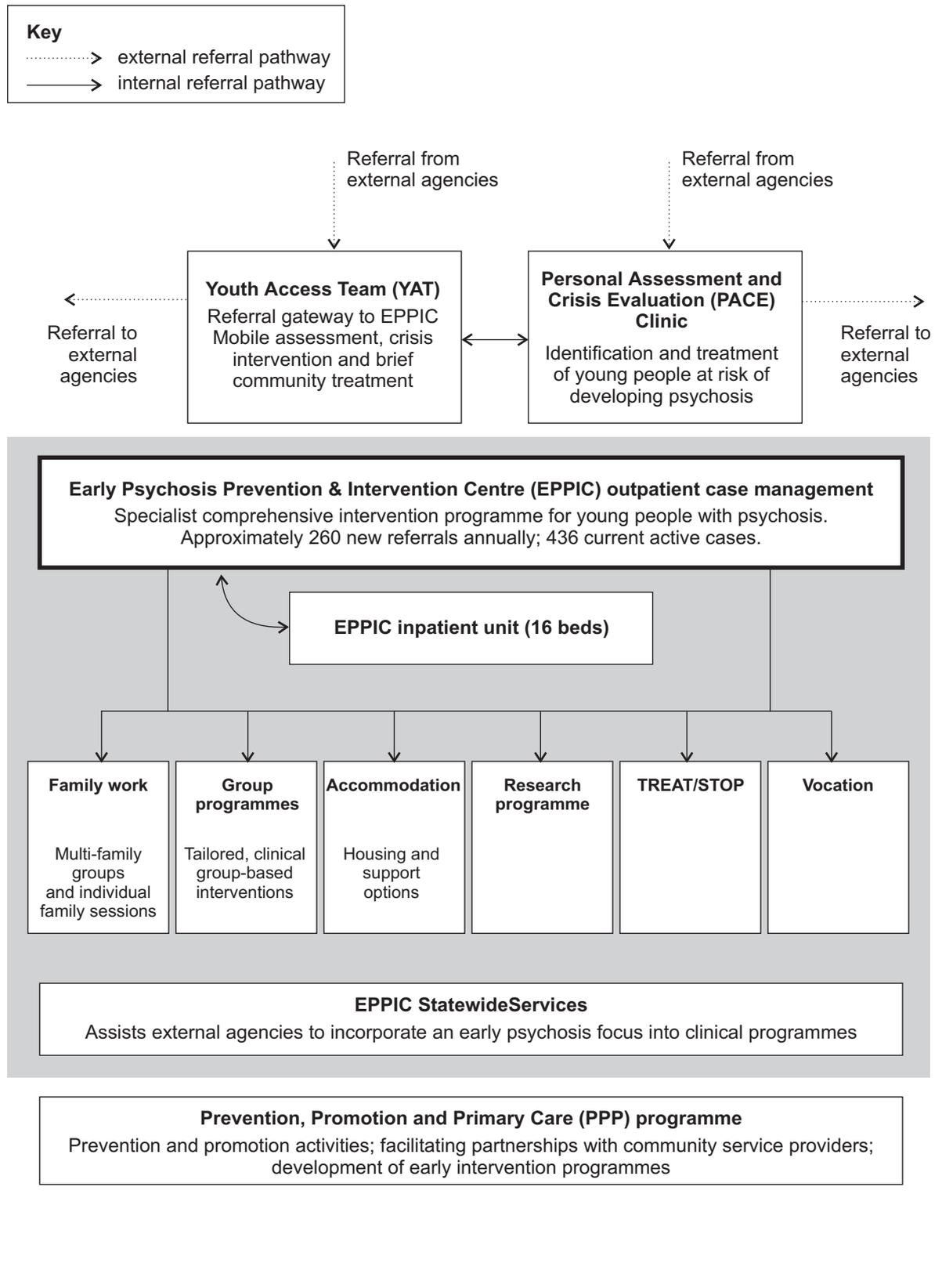
The Youth Access Team (YAT), the first point of contact with EPPIC and OAS, is a multidisciplinary mobile assessment, crisis intervention and community treatment team. YAT performs a number of functions within the MH-SKY Youth Program, including after hours triage, community based treatment and community education.

Additionally there is a research centre at MH-SKY that has evaluated many of these services over the years, mainly in real life (rather than research) settings. Given the increasing need to demonstrate the cost-effectiveness of services, a health economics collaboration project was set up with the overall aim of developing the profile of health economics at MH-SKY. The project incorporates three main strands: analysis of existing health economic data, input into the design of new projects and health economics education and training.

### **Economic evaluation**

Although a number of projects including health economic components have been conducted at MH-SKY in recent years, attention has mainly focused on EPPIC. This is a community-based service developed in the early 1990s to implement strategies of early detection and intensive intervention in young people experiencing an emerging psychotic disorder. The rationale for this model of care was based on an accumulation of evidence suggesting that reduced delay in treatment and specialist intervention early in the course of psychotic disorders may be associated with a better prognosis (McGorry et al., 1996). Figure 1 summarises the key elements of EPPIC services (further details can be found at their website <http://www.eppic.org.au>).

**Figure 1 EPPIC services and referral pathways**



Although EPPIC has now evolved into a successful model of care that is being replicated worldwide, its cost-effectiveness compared to alternative existing service models is yet to be determined. It has however been shown that EPPIC is more cost-effective than its immediate precursor service. Average annual costs (from a government perspective) were found to be lower by AUD7110 per patient, coupled with an improvement in outcomes, compared to a historical cohort of patients from the pre-EPPIC service (Mihalopoulos, McGorry and Cater, 1999). However, these results were not conclusive, due to issues related to study design, unavailability of full cost information and the unsteady state of the service given that it had only just been set up.

Therefore, a further study was conducted between 1996-98, comparing EPPIC (n=98) with two concurrent models of care in other areas within the state of Victoria. One of these was an enhanced adult area mental health service (n=43), while the other was a standard adult area mental health service (n=27).

Detailed resource use and other economic data collected as part of that study are now being examined in the health economics collaboration project, in order to re-investigate the cost-effectiveness of EPPIC. Costs will be estimated for each patient for their initial psychosis episode and for a twelve month follow-up period after stabilisation. Although the main study perspective is that of the state government and costings will focus on the use of health services, it may also be possible to examine other costs such as patient expenditure on travel, lost employment, and family burden. Costs of the three models of care will be compared alongside three principal outcomes measures — quality of life, the Brief Psychiatric Rating Scale, and the Scale for the Assessment of Negative Symptoms. Results will be reported in future publications.

### New projects

There are a number of new projects coming on stream at MH-SKY, as well as others at the design stage. Although it was not possible to incorporate comprehensive economic evaluations into some of these due to resource constraints and/or because it was too late in the design stage to feasibly include an economic component, discussions have been able to identify key economic issues that could be addressed.

One such project is the Compass Project, a community awareness campaign launched in April 2001. It aims to increase the mental health literacy of young people and their families through the use of multi-media strategies and has been implemented across the western metropolitan Melbourne and Barwon regions of Victoria. The principal aim of the project is to reduce the duration of untreated illness for first onset psychosis and increase the treated incidence of depression in young people aged 12-25. There are a number of key issues related to the economics of health promotion that need to be considered. For example:

- What is the opportunity cost of funding the Compass strategy, which aims to reduce morbidity and burden at population level, versus increasing funding for individual treatment following the delay period?
- What will be the additional cost of increased service utilisation due to increased treated incidence of depression amongst the target population?

Unfortunately, a framework for answering these important questions could not be added as the project was already in the final planning stage. However, it was possible to incorporate some basic resource use measures into population survey instruments. These will, we hope, provide some indication of the impact on a range of health, social and other services following the campaign. It may also be possible to examine the cost-effectiveness of the use of different media in mental health promotion.

### Key points

- Innovative schemes for detecting and treating mental health problems are important components of catchment area mental health services.
- The needs of patients with psychotic and non-psychotic disorders require different styles of service provision.
- Health economic methods can determine the cost-effectiveness of such schemes and should be used more widely.

## Education and training

In addition to research activity, health economics training has been incorporated into existing programmes of seminars and workshops in order to provide both clinical and research staff with an understanding of the importance and application of economics in mental health care. These sessions provided an introduction to economic issues and basic skills that can assist in the design, conduct and analysis of future service evaluations at MH-SKY.

Anita Patel is a Research Worker at CEMH. Meredith Harris is Evaluation and Quality Assurance Officer at MH-SKY.

## Acknowledgements

We thank Eli Lilly, Australia for funding this project. Thanks are also extended to MH-SKY staff involved in setting up the health economics collaboration project and for providing help and support during Anita Patel's visit.

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### News from staff

**Daniel Chisholm**, now based at WHO Geneva, has recently been awarded a doctorate in philosophy for his thesis, *Cross-cultural mental health care evaluation: developing and demonstrating methods for economic analysis*. The objectives of the thesis were: to develop appropriate methodologies for mental health care service utilisation and cost measurement; to generate comparative service utilisation, cost and outcome data; and to explore the relationship between cost, psychiatric symptoms, quality of life, needs and disability. The thesis was based on three international, collaborative studies: an EU-funded study of the needs and costs of schizophrenia care in five European health care systems (EPSILON); an international study of the quality of life and economic correlates of major depression in primary care (LIDO); and a mental health economics demonstration project in India and Pakistan (MENDIP). The use of these methodologies in the three source projects has demonstrated the feasibility of undertaking multinational comparative studies, revealed the extent of cross-cultural variation in the use and cost of mental health services, and highlighted the complex set of inter-relationships that exist between costs, needs and outcomes.

**Andrew Healey** travelled to Mozambique in December, in order to gather data for a descriptive analysis of mental health service financing and provision in the country, as part of work on mental health care financing commissioned by the World Health Organisation. Evidence was gathered from a variety of secondary published sources, interviews with civil servants at the Mozambican Ministry of Health in Maputo, and a small amount of anecdotal evidence derived from personal communication. Evidence from Mozambique, whilst unique, may be indicative of some of the challenges faced by those wishing to deliver mental health care services in low income countries, particularly those in sub-Saharan Africa.

# **The economic burden of depression: evidence from an international study in primary care (the LIDO study)**

Daniel Chisholm, Martin Knapp and the LIDO Group

## **Introduction: the global burden of depression**

Depression is one of the most common psychiatric disorders and constitutes a significant public health burden as a result of its high prevalence, long duration, likelihood of recurrence, under-diagnosis and inadequate treatment (Bland, 1997). An accumulating body of evidence has emerged, particularly over the last five years, which clearly demonstrates the immense burden that depression imposes upon individuals, families and whole communities throughout the world (Ustün and Sartorius, 1995). A notable finding from the *Global Burden of Disease* study (Murray and Lopez, 1996) was that by combining the mortality and disability effects of disease into a single metric (the Disability Adjusted Life Year or DALY), the immense burden of global disease attributable to neuropsychiatric disorders, and depression in particular, became readily apparent. Major depression is estimated to be the fourth largest contributor to the global burden of disease (3.7% of all causes), and by 2020 is projected to become the single largest contributor in developing regions, owing to high prevalence rates (particularly among women), non-detection (90% in some regions) and severity (a disability weight of 0.6 out of 1 in untreated form).

The burden or consequences of depression have also been usefully gauged from an economic perspective in a series of national 'cost of illness' studies which attempt to attach monetary values to a range of societal costs. Where a comprehensive cost estimate has been attempted, total estimated costs amount to £3.4 billion in the UK, and between \$30-40 billion in the US in 1990 price levels (Kind and Sorensen, 1993; Rice and Miller, 1995). Despite the considerable social and economic burden that depression places on countries throughout the world, however, there is a paucity of research on the cost consequences of depression and its treatment in an international context (Chisholm, 2000).

## **Objectives of the LIDO study**

The overarching aim of the Longitudinal Investigation of Depression Outcomes (LIDO study) was to explore the relationship between major depressive disorder in primary care patients and their quality of life and resource use. This would be accomplished in a multi-centre, cross-national observational study. The participating centres were located in Barcelona (Spain), Be'er Sheva (Israel), Melbourne (Australia), Porto Alegre (Brazil), Seattle (USA) and St Petersburg (Russia). Patients attending primary care facilities of the participating sites were invited to complete a screening assessment. For patients meeting initial eligibility criteria (a CES-D score > 16), a baseline assessment was conducted, which included administration of a depression diagnostic instrument (CIDI). Patients who were diagnosed as clinically depressed by the CIDI, but who were not currently, or in the previous three months, receiving treatment for depression, were enrolled into the study and followed up over a one year period, during which they were assessed periodically on their depressive symptoms (and any co-morbidity), quality of life and resource utilisation (Patrick et al., 2001). Specific objectives of the economic dimension of the LIDO study include:

1. Comparison of the extent to which (treated and non-treated) people with depression make use of services.
2. Measurement of the economic impact of depression on individuals and health services.

3. Exploration of the associations between service costs, depressive symptoms and quality of life, including how treatment received at baseline predicts costs in later follow-up periods, how medical and/or psychiatric co-morbidity influences costs, and whether improvement in depression is associated with significant reductions in direct or indirect health care costs.

### **Methods for multinational mental health economic studies**

A prevailing issue for multi-national studies is the extent to which it is possible or sensible to pool site-specific clinical and economic data in order to make comparisons between countries (Drummond et al., 1992). A key concern of the LIDO study was therefore the feasibility of combining service use and costs data from the six participating sites. For the economic component of the study, we pursued a tripartite approach to the collection of data (Chisholm et al., 2001):

**1. Socio-demographic and service profile (site-level)** The uptake and subsequent effectiveness of services is determined to a variable extent by the availability, accessibility, and quality of primary and secondary health services. It was therefore important to have an understanding of the features that characterise each site's local service system. Specifically, data were collected on the basic demographic profile of the local catchment area population, the estimation of availability of secondary care services (based on the Service Mapping Schedule; Johnson et al., 2000), and the caseload and working practices of each primary health care centre. In addition to these quantitative indicators, a qualitative written description of the local health care system was elicited.

**2. Resource utilisation questionnaire (individual-level)** A range of primary care, psychiatric, social and general medical services were identified which together were considered a comprehensive profile of potential service receipt for the patient population at the six sites. The three main categories of service contact were: primary care and outpatient services (including contacts with primary and mental health care professionals), daycare services (provided to several patients at a time and usually offering a combination of treatment and/or support for problems related to mental illness), and inpatient hospital services (incorporating both psychiatric and general medical admissions). All prescribed drugs (not just those related to depression) were also recorded.

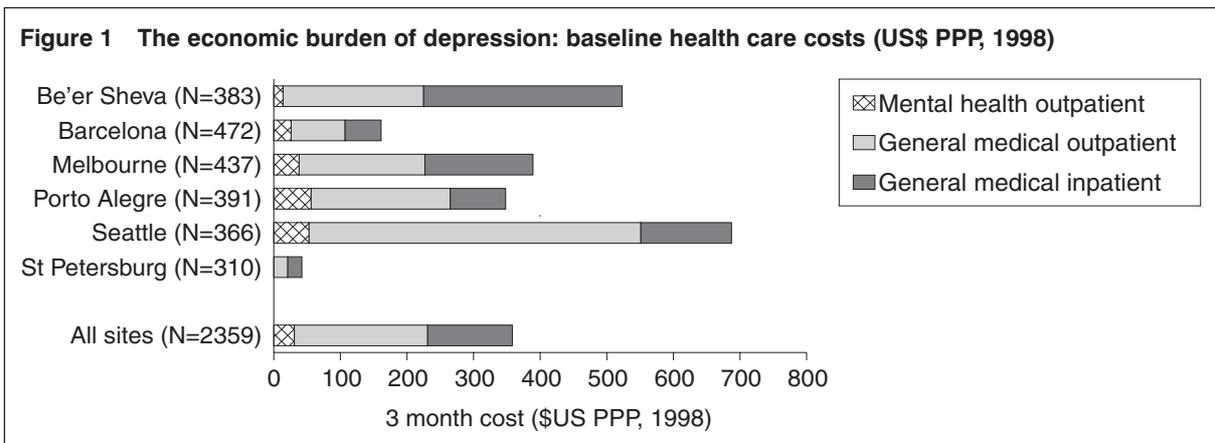
**3. Unit costs of health care (site-level)** Unit costs of all items on the resource utilisation questionnaire were calculated in each site using a standardised protocol and set of templates. Four main categories of cost were quantified: salaries/wages of staff employed in the direct care and management of patients; facility operating costs where the service is provided; overhead costs; and capital costs of the facility (land, buildings, etc.). National service costs were subsequently converted into a single, common currency (\$US) using purchasing power parities, the rates of currency conversion which eliminate differences in price level between countries.

### **Early findings**

**Health system differences** The usefulness of capturing site-level data on socio-demography and service provision is made apparent from consideration of table 1, which shows a considerable diversity between participating sites with respect to the financing, provision and availability of health services. For example, there is a threefold difference in the per cent of GDP dedicated to health care generally and a seven-fold difference in the number of psychiatric hospital beds per 100,000 population, as well as a more basic split between public versus private financing or provision.

Health care system indicator	Barcelona (Spain)	Be'er Sheva (Israel)	Melbourne (Australia)	Porto Alegre (Brazil)	Seattle (USA)	St Petersburg (Russia)
Total expenditure (% GDP)	8.0	8.2	7.8	6.5	13.7	5.4
Public sector (% total spend)	71	75	72	49	44	77
Main finance source (sector)	Public	Public	Public	Private	Private	Public
Main provider (sector)	Private	Private	Public	Private	Private	Public
Overall typology (sector)	Semi-public	Semi-public	Public	Semi-public	Private	Public
Medical beds per 100k pop.	604	545	400	558	499	782
Psychiatric beds per 100k	70	193	27	75	42	195

**Service cost differences** Figure 1 shows health care costs — computed by multiplying average resource utilisation rates by their unit costs — for the total baseline sample at each site. A key finding is that even after adjustment for core demographic variables, site, and the relative price of health care services in the six sites, through the application of purchasing power parities, very marked differences remain, reflecting differential levels of service volume or uptake. Most starkly, there was a 20-fold difference in the total average service cost between study subjects in Seattle (\$700 over three months prior to baseline) and St Petersburg (\$35 over the same period). For all sites combined (n=2,359), the mean adjusted health care cost for the three months preceding baseline assessment was \$362 (95% confidence interval, 321-404), made up of general medical outpatient and primary care (\$200; 55%) and inpatient care (\$127; 35%). Although depression treatment was a baseline exclusion criterion, these estimates also include a small amount of mental health service use (\$35; 10%), incurred between enrolment and baseline assessment.



The extent to which these estimates represent an excess economic burden on society can be (crudely) gauged by converting these three-month values into annual figures and comparing resulting annual costs to total health care expenditure estimates for each country (WHO, 2000). The costs of currently untreated depression in Barcelona and St Petersburg are just over half the average per capita expenditure, in Melbourne and Seattle costs are broadly equivalent, whereas in Be'er Sheva (150%) and Porto Alegre (325%) costs far exceed average per capita health care expenditure. These estimates do not of course take into account other significant contributors to societal costs of depression, including informal care-giving and lost work opportunities, which substantially increase the level of excess economic burden. For example, an average of 3.7 work days (inter-site range: 1.5-8.0) were lost for the total baseline sample in the 3 month period prior to baseline assessment, at an estimated mean cost per subject of \$225 (95% confidence interval, 192-260).

## Concluding remarks

A principal methodological challenge when conducting economic analysis of psychiatric disorders in a multi-national context is to obtain comparable data. In the LIDO study, a tripartite approach was pursued in an attempt to overcome (or at least reveal) known or expected inter-site differences in health systems or service costs. The reported baseline findings suggest that the use of a standardised data collection strategy, together with systematic adjustment for price differences, is sufficient for all but the most extreme inter-country comparisons (represented in this case by Seattle and St Petersburg). Ongoing analysis of the LIDO study dataset will be informed by such considerations, with varying combinations of sites and site-level variables being introduced into pooled analyses of the inter-relationship over time between depression symptoms, quality of life and costs, with the expectation that pooled data for certain combinations of countries — that is, those with similar socioeconomic and health system characteristics — will be more informative than others. In the process, we seek to generate new insights into the extent to which site-level characteristics, such as relative levels of service provision, access, and expenditure, affect individual costs and outcomes. Such insights will point to opportunities in different regions of the world for reducing the current burden of depression, the economic consequences of which have been clearly identified both here and in other mental health services research studies.

### Key points

- There is a paucity of research on the cost consequences of depression internationally.
- Using a standardised approach to data collection, the LIDO study has revealed the variable and often high economic burden associated with depression in six countries worldwide.
- A considered, multifaceted approach to data collection and analysis is required for pooled, comparative analysis of the economic and quality of life correlates of depression.

## Acknowledgements

Development and conduct of the LIDO study was a collaborative effort between the research team, a panel of study advisors, and the site investigators in each of the six field centres. Eli Lilly and Company, Indianapolis, Indiana, USA, provided the overall project sponsorship, and Health Research Associates, Inc. (HRA), served as the international coordinating agency for the study.

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### The EPSILON study

The objectives of the EU-funded EPSILON (European Psychiatric Services: Inputs Linked to Outcome Domains and Needs) study were to develop mental health outcome measures for use in five European centres (Amsterdam, Copenhagen, London, Santander and Verona) and to collect and analyse clinical and economic data with these measures from patients with schizophrenia. The measures covered needs, costs, service satisfaction, quality of life and carer burden. The study is largely complete although the findings continue to be disseminated. The table below summarises findings from two of the measures — the Camberwell Assessment of Need and the Client Socio-demographic and Service Receipt Inventory (figures are means).

	Amsterdam (n=61)	Copenhagen (n=52)	London (n=84)	Santander (n=100)	Verona (n=107)
Costs (£)					
raw	3778	9934	6071	1558	5819
adjusted	4112	7460	6771	1444	5730
Needs					
raw	6.3	5.2	6.0	4.8	4.9
adjusted	6.2	4.4	6.2	4.9	5.3

The raw figures show the actual mean service cost and the actual mean number of needs (out of a maximum of 22) in each centre. Services were most expensive in Copenhagen and least expensive in Santander. Amsterdam and London had the most number of needs; Santander had the least. Potential differences in the background characteristics of the samples drawn from each centre led to comparisons being made after such differences were adjusted for. After adjustment the mean costs in Copenhagen fell by more than £2000 but remained the highest while that centre had the lowest number of needs after adjustment.

Further details of these two aspects of the study are reported in two publications:

- Knapp, M., Chisholm, D., Leese, M., Amaddeo, F., Tansella, M., Schene, A., Thornicroft, G., Vazquez-Barquero, J.-L., Knudsen, H.-C., Becker, T. and the EPSILON Study Group (2001) Comparing patterns and costs of schizophrenia care in five European countries: The EPSILON study, *Acta Psychiatrica Scandinavica*, in press.
- McCrone, P., Leese, M., Thornicroft, G., Schene, A., Knudsen, H.-C., Vazquez-Barquero, J.-L., Tansella, M., Becker, T. and Chisholm, D., for the Epsilon Study Group (2001) A comparison of needs of patients with schizophrenia in five European countries: the EPSILON Study, *Acta Psychiatrica Scandinavica*, 103, 370-379.

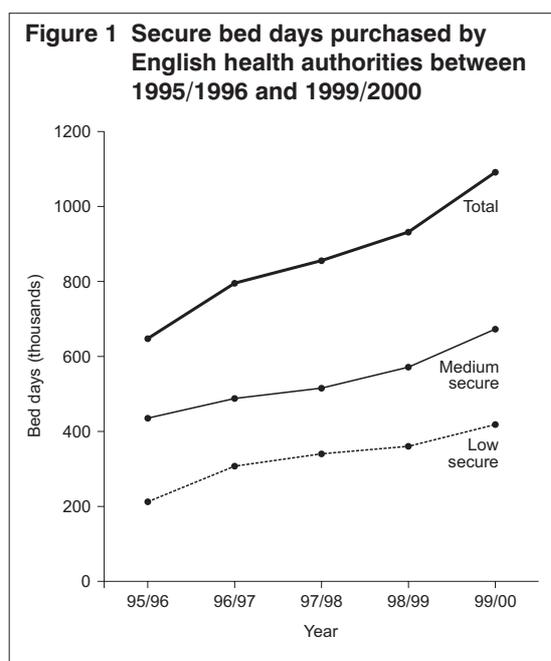
# Predicting the use of low and medium secure beds

Paul McCrone

## Introduction

Mental health care in the UK consists of a number of distinct but inter-connected components. Most people with mental health problems are seen in primary care settings, but those with more serious conditions are likely to be referred to specialist services (Goldberg and Huxley, 1992). For a small minority who pose a serious risk to themselves or others secure care may be required and this can be in settings provided by NHS Trusts, the independent sector or one of the high secure hospitals. In recent years there has been much concern over the provision and cost of secure mental health services. For instance, high profile cases have led the government to propose the detainment of people with severe personality disorders who are considered to be a risk to the community (Home Office/Department of Health, 1999) thereby emphasising the blurred responsibilities of mental health professionals (care versus containment). At the same time there is an awareness that resources are limited and that secure care in some areas accounts for an increasing proportion of total mental health care spending. This paper seeks to address three questions. First, what changes have occurred in the use of medium and low secure beds over the past five years? Second, what differences are there between health authority areas in the use of secure beds? Third, how well do resource allocation tools predict secure bed use? The emphasis is on low and medium secure beds. High secure beds are financed differently and are less under the control of local purchasers and providers. In addition it is possible that the high secure hospitals will have a reduced role in the future and may even be closed. Because definitions of the level of security may differ from area to area most of the paper will analyse low and medium secure beds together. The focus here is on English health authorities.

## What changes have occurred in the use of medium and low secure beds over the past five years?

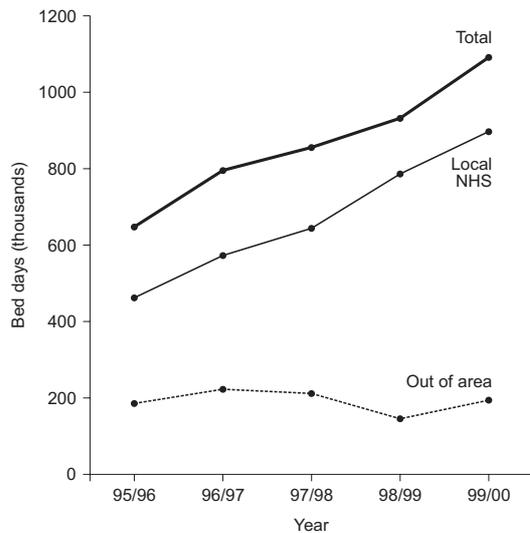


Each year the number of medium and low secure bed days purchased by health authorities in England and Wales is recorded as part of the NHS Common Information Core. Figure 1 shows that the number of bed days purchased has risen substantially from 641,272 in 1995/6 to 1,091,510 in 1999/2000 — an increase of 70%. It can also be seen that the rise has been distributed fairly evenly between medium and low secure bed days. To accommodate this increase in bed use there has been a rise in local provision (but this does include contracts with the independent sector) whilst out of area treatment has remained fairly static (figure 2).

## What differences are there between health authority areas in the use of secure beds?

In order to compare bed use between different health authorities it is necessary to standardise for population size. Table 1 shows the five health authorities with the lowest and highest levels of medium and low secure bed use per 1000 population in 1999/2000. The

**Figure 2 Secure bed days purchased by English health authorities between 1995/1996 and 1999/2000 from local NHS trusts and out of area**



**Table 1 Use of medium and low secure beds by health authorities in England in 1999/2000**

	Use per 1000 population
<i>Five lowest</i>	
Northumberland	1.34
Worcestershire	2.33
Solihull	5.14
North Derbyshire	5.85
Wirral	6.36
<i>Five highest</i>	
East London and the City	56.91
Manchester	61.15
Kensington, Chelsea and Westminster	63.80
Camden and Islington	101.59
Lambeth, Southwark and Lewisham	134.28

average use across England was 21.73 bed days per 1000 population. Perhaps not surprisingly it is inner-city health authorities that make most use of secure beds whilst rural areas have a low level of use. There was a 100 fold difference between the use of beds in Lambeth, Southwark and Lewisham and the use of beds in Northumberland. In 1999/2000 Lambeth, Southwark and Lewisham also made more use of out of area beds compared to other health authorities (58.65 bed days per 1000 population) followed by East London and the City (27.43). Thirty-six health authorities made no use of out of area beds and the average was 3.63 bed days.

The largest increase in medium and low secure bed use between 1995/6 and 1999/2000 was again in Lambeth, Southwark and Lewisham (table 2), and with the exception of Bedfordshire all the health authorities showing large increases were in urban or inner city areas. Only fifteen health authorities saw a reduction in bed use over this period whereas 80 saw an increase. The average increase was 8.21 bed days per 1000 population. (Restructuring of boundaries means that three 1995/6 health authorities (East Norfolk, North West Anglia, Cambridge and Huntingdon) and two 1999/2000 health authorities (Cambridgeshire and Norfolk) have been omitted from analyses comparing these two years.)

**How well do resource allocation tools predict secure bed use?**

Differences in service use between geographical areas are to be expected given that needs for care are likely to be linked to socio-economic factors. For many years it has been recognised that health care resources should be allocated according to indicators of 'need' and a number of ways have been developed to identify such

**Table 2 Health authorities in England with the largest increases and decreases in medium and low secure bed use between 1999 and 2000**

	Change per 1000 population
<i>Five with highest decrease</i>	
Solihull	-23.36
Isle of Wight	-19.23
East and North Hertfordshire	-18.37
Barnet	-9.33
Avon	-5.84
<i>Five with highest increase</i>	
Manchester	+29.76
Bexley and Greenwich	+34.65
Bedfordshire	+37.23
Brent and Harrow	+40.24
Lambeth, Southwark and Lewisham	+85.91

factors. A summary of three of these (UPA 8, MINI and the York index) is given in box 1 below and an excellent review is given by Cohen and Eastman (2000). Currently NHS resources are allocated according to the York formula which contains a specific index of psychiatric need. This index was produced by identifying factors that explain variations in the number of inpatient episodes whereas the MINI examined variations in the number of people admitted during a year. They are both therefore based on utilisation and as such they are not necessarily indicators of need because utilisation may not be at its optimal level. The UPA8 is different in that it was determined by factors that general practitioners felt affected their work and was not calculated using utilisation data. In theory therefore it is more appropriate as an indicator of true need. However, it was designed for use in general health care and does not address the specific issue of psychiatric need.

To determine how well the three allocation methods could explain variations in bed use regression models were constructed taking bed days per 1000 people as the dependent variable and the three indexes in turn as the independent variable. This was performed for each of the five years although it should be noted that only bed use changes over time as the indexes are based on census data. The York Index was able to explain between 31% and 42% of variation in bed use, the UPA8 between 35% and 47% and the MINI between 35% and 42%. The striking similarity between the three is not surprising given that they were based on similar variables drawn from the same census year and this suggests that the

### **Box 1 Resource Allocation Indexes**

#### **York Index of Psychiatric Need**

The University of York was commissioned by the NHS Executive to produce a formula by which resources could be allocated to Health Authorities according to need. As part of this a specific index of psychiatric need was developed (Smith et al., 1996). The aim of this was to identify variables that explained variations in the number of inpatient episodes between 'synthetic wards'. A range of demographic factors were examined and these were mainly from the 1991 census. The supply of services was controlled for because it was felt that this would influence utilisation. Using multilevel modelling techniques an index of need was generated based on the following variables: proportion of households headed by a lone parent, proportion of dependants with no carer, proportion of people born in New Commonwealth, proportion of people of pensionable age living alone, standardised mortality ratio for those aged below 75 and the proportion of adults who are permanently sick.

#### **Mental Illness Needs Index (MINI)**

The MINI was designed specifically to aid resource allocation and planning for mental health services. It was developed by Glover et al. (1998) by identifying population characteristics that explained variations in the prevalence of hospital admission in the electoral wards comprising the (then) North East Thames Regional Health Authority (comprising 2.4 million people aged between 15 and 64). Potential predictors (chosen on theoretical grounds) were drawn from the 1991 census and a model was produced using multivariate analysis. The final model from which the index was calculated included the number of people who were single/widowed/divorced, permanently sick, unemployed, without a car, living in a household that was not self-contained and living in a hostel/lodging house etc.

#### **Underprivileged Area Score (UPA8)**

This was developed by surveying general practitioners to find out what population based factors contributed to an increased workload or pressure of work (Jarman, 1983 and 1984). The aim was to identify factors that could be measured using census data and eight were finally chosen: number of children aged under five, unemployment, whether born in UK or elsewhere, number of single parent households, number of elderly people living alone, overcrowding, social class and number of people moving in past year. Based on scores for these factors (between zero representing no problem and nine representing serious problems) an index of need was generated.

York Index is no less appropriate in explaining bed use variations than the other two indexes. However, it still leaves most of the variation in bed use unexplained. Table 3 reveals the health authorities which used substantially fewer or more beds than predicted in 1999/2000. It can be seen that the York Index was not able adequately to predict bed use in these areas that were predominantly urban or industrial in nature. The five health authorities for which the York Index was most accurate were Oxfordshire, Shropshire, Manchester, South Derbyshire and North Cumbria. With the exception of Manchester these are relatively rural areas. None of the resource allocation indexes were able adequately to explain variations in the increase in bed use of the past five years, although again they were all similar in their predictive power (York Index 17%, UPA8 16% and MINI 13%).

## Discussion

There has been a major increase in medium and low secure bed use over the past five years in England and there exist wide variations between health authorities with the most use being made by inner-city areas. The established York Index performs as well as existing alternatives but still seriously under-predicts bed use in some areas whilst over-predicting in others. This in itself is not surprising as there will inevitably be local issues which affect bed use patterns and which would not be accounted for by any index. Also the existing indexes are (unavoidably) based on data which are now relatively old, although their predictive ability has been quite stable over the past five years. However, there is a fundamental issue connected with the three indexes which needs highlighting. Both the York Index and the MINI were designed to aid the allocation of resources for mental health care in general. However, there may be factors that are specifically related to the use of forensic services which are not included in these indexes. For instance, it is likely that the crime rate in an area will be of influence. This may reflect a real change in need or it may influence the policy and practice of mental health care provision. Similarly, the presence of specific services connected with the criminal justice system such as bail hostels and prisons may also influence service use. Further work is required to identify such factors that may explain variations in secure bed use and this is crucial if future funding formulae are to allocate resources appropriately.

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**Table 3 Health authorities showing greatest difference from York Index prediction**

Authority	Difference between actual and predicted bed use
<i>Five most over-predicted</i>	
Wolverhampton	-21.43
Tees	-20.43
West Pennine	-19.97
Sandwell	-19.74
Birmingham	-19.15
<i>Five most under-predicted</i>	
Barking and Havering	+20.51
Bedfordshire	+22.00
Morecambe Bay	+24.16
Camden and Islington	+46.44
Lambeth, Southwark & Lewisham	+82.01

## Key points

- The use of secure psychiatric beds in England has risen by about 70% over the past five years.
- Inner-city areas account for a disproportionate amount of secure bed use.
- The existing York index, and alternatives such as the MINI and the UPA8, explain between 31% and 47% of variation in bed use.
- A specific formula is required to allocate resources for secure psychiatric services which takes into account criminal justice system and supply-side factors.

## **Child and adolescent mental health**

**An important area of work at the CEMH and PSSRU is the evaluation of child and adolescent mental health services. A summary of some current projects is given below.**

- A randomised trial of cognitive-behaviour therapy and fluoxetine versus fluoxetine alone in persistent adolescent major depression; in collaboration with the Departments of Child and Adolescent Psychiatry at the Universities of Manchester and Cambridge. The study will include assessment of cost-effectiveness and cost-utility. Contact: Sarah Byford
- A randomised controlled multi-centre treatment trial of adolescent anorexia nervosa, including assessment of cost-effectiveness and patient acceptability; in collaboration with the Departments of Child and Adolescent Psychiatry at the Universities of Liverpool and Manchester. The study compares specialist inpatient treatment, specialist outpatient treatment and general management in Child and Adolescent Mental Health Services. Contact: Sarah Byford
- A study of children and adolescents admitted to psychiatric inpatient care. This will explore the clinical pathways leading to admission and subsequent to discharge, changes in health needs during and subsequent to admissions, and predictors of health gain. The study will also examine direct and indirect costs to health, social care and educational services during and after treatment. It will also allow a detailed description of the progression through treatment for this group and an investigation of the cost-effectiveness of treatment and the predictors of health gain. Contact: Jennifer Beecham
- A follow-up study to evaluate suicidal children growing up; in collaboration with the Department of Child and Adolescent Psychiatry at the University of Manchester. The study will include assessment of long-term psychosocial outcomes and costs. Contact: Sarah Byford
- A study in collaboration with the Department of Child and Adolescent Psychiatry at the University of Manchester to assess the needs of children with severe and complex mental health problems and how well these needs are being met. These young people often require multi-agency involvement over a long period of time and this study will additionally assess current practice in multi-agency management and the cost of packages of care provided by each agency. Contact: Sarah Byford
- An evaluation of the costs and effectiveness of different models of service delivery for children with behavioural difficulties has recently been completed; in collaboration with the Department of Child and Adolescent Psychiatry at the University of Manchester. Contact: Sarah Byford
- A randomised trial of individual versus group psychotherapy for girls who have been sexually abused; in conjunction with the Tavistock Clinic and the Child and Adolescent Service of the South London and Maudsley NHS Trust. Contact: Paul McCrone and Martin Knapp
- An analysis of the service costs in adulthood of people who as children received psychiatric care for depression or depression with conduct disorder; in collaboration with the Department of Child Psychiatry at the Institute of Psychiatry. Contact: Paul McCrone and Martin Knapp
- A five-year follow-up study based on a sub-sample of the Twins Early Development (TED) database which comprises about 1000 pairs of twins from the 1994-96 birth cohort. Postal questionnaires are being used, including a variant of the CSRI, with a follow-up telephone call to assess the children's mental health. Undertaken in conjunction with Dr Derek Bolton and Patrick Smith (IoP). The inclusion of a limited economic component is seen as a foundation for a larger longitudinal study. Contact: Jennifer Beecham
- A study which aims to develop a method for collecting costs-related data in Children and Adolescent Psychiatry (CAP) inpatient units, to estimate total and unit costs for each CAP inpatient unit, and to analyse the variations in costs between CAP inpatient units. This is in conjunction with Royal College of Psychiatrists Research Unit. Data collection is now complete and a report will be submitted to the Department of Health Policy Research Programme in summer 2001. Contact: Jennifer Beecham
- A one-year study exploring the cost and outcome implications of a single-site, multidisciplinary Behaviour Resource Service. In this service, home-based support is provided to children of aged 4-18 years who have learning disabilities and challenging behaviour. A more standard service in Hampshire is providing the comparison group. Contact: Martin Knapp and Jennifer Beecham
- A project which focuses on the processes and outcomes for children with mental health needs entering the child protection system; in conjunction with the Policy Research Bureau. It will track how multidisciplinary teams deal with at-risk young people and will map, cost and compare the approach of a sample of local authorities to identifying and providing mental health services for at-risk children. The project is due for completion in December 2002. Contact: Jennifer Beecham

## **Financing, economics and mental health**

Martin Knapp, David McDaid and Andrew Healey

The recent World Health Day, *Mental Health: Dare to Care*, was dedicated firstly to raising awareness of the continuing need for better access to effective mental health care across the globe and secondly to reducing the stigma often associated with mental disorders. This event was part of the World Health Organisation's ongoing *Mental Health Reform Initiative*, undertaken on the premise that 'mental health has until recently been a low priority on international and national agendas'. The initiative aims to provide information to assist policy makers with decisions on the development and implementation of mental health care, vis-à-vis other policy priorities, and its centrepiece will be the publication of this year's *World Health Report*, which is devoted to mental health.

As part of the process of providing information to feed into preparation of the World Health Report, a team at the PSSRU was commissioned to examine economic aspects of mental health care, in particular the differing methods of financing employed across the world. An interim report was prepared, on the basis of an extensive literature review, expert consultation and field visits. The report identified numerous issues of interest both to policy makers and researchers, some of which are briefly flagged up here. A series of papers based on material from this report will be available later in the year.

### **Data collection**

More than 400 million individuals worldwide suffer from mental or neurological disorders. Improving our knowledge of all potential costs and services associated with these disorders is important. For instance there is a de-institutionalisation trend in both the developed and developing worlds. One of the consequences is that financial and psychological costs may be shifted to family carers even though quality of life could be much better for the former inpatients. Changes of this kind in the balance of funding need to be examined carefully if policies such as hospital closure are to achieve the aims that many people express for them.

A major challenge in preparing our report has been the lack of data for low and middle income countries. Decision-makers in those health systems will be similarly constrained. This suggests that more investment in empirical research will be required in order to provide decision-makers with the right information, although the pros and cons of diverting resources away from health care treatments to data gathering and research would also need to be weighed up.

Knowledge of the mixed economy of mental health care, including the important roles of groups as diverse as donors and traditional healers in low income countries, needs to be improved. One possibility is for countries to consider 'mapping' their mental health care systems, looking especially at who provides services and how they are funded. Gaps, strengths and weaknesses in services provided, how they are resourced and what links there are between purchasing and provision could all be identified.

### **Financing mental health care**

Our report discusses equity in relation to health status (or outcomes), access to those interventions that might improve health status, and the financial burden of securing that access. Limited data have meant that the focus is predominantly on inequity in the finance of mental health. Out-of-pocket payments are the mainstay of mental health finance in many of the world's poorest countries, but they create so many disincentives to seek treatment and are so regressive that urgent attention needs to be given to finding collective, redistributive alternatives.

Pre-payment systems can eliminate much of this inequity. However, regardless of the merits of various pre-payment systems such as taxation or insurance, there are substantial obstacles to their use in low/middle income countries, for instance because of the state of the economy and the informality of much employment. In the short-term, countries may need to consider alternatives such as community-based health insurance, despite the weaknesses of existing schemes. One option for the medium term might be to consider building a system of prepayment through a combination of compulsory insurance and taxation, which means linking employment-based, municipal or community insurance schemes. In time, these could be strengthened and developed into horizontally-integrated systems with universal coverage.

User charges provide a more immediate source of revenue for under-resourced health systems, but of course exemptions are needed to ensure that services are accessed by people in greatest need and that access is not entirely dependent on income. However, very little is known about the price or income elasticities of demand for mental health interventions. In addition, the identification of those eligible for exemptions and the administration of the system should not be so cumbersome as to eat away at the fee revenue collected.

It is vital to protect funds for mental health care in situations where resources are very limited. The poorest countries in the world not only devote the smallest proportions of GNP to health but also appear to allocate the smallest proportions of health expenditure to *mental* health. The current high concentration of identified mental health care expenditure on institutional care (in excess of 80%) in many low/middle income countries might be argued at least to provide a ring-fenced mental health resource. Unfortunately, the quality of that provision is sometimes scandalously poor. The quandary is whether to support the shift of care to the community, without guarantees of financial ring-fencing.

### **Efficient and equitable use of resources**

There is an obvious need for more economic as well as clinical insights. Strong consideration should be given to conducting more economic evaluations (ideally alongside or as part of clinical or wider evaluations). To date, very little such evaluation appears to have been conducted in developing countries. However before embarking on any such activities it would be prudent to review the priorities for evaluation and, of course, to assess the cost-effectiveness of undertaking cost-effectiveness evaluations.

In looking at methods for choosing interventions or treatments or practices, the choice of evaluative technique will need to be considered carefully. Seemingly less powerful but actually very helpful techniques, such as cost-effectiveness and cost-consequences analyses may be more feasible and more useful, in the short term at least, than cost-benefit or cost-utility analyses. There would be virtue, too, in investing in 'knowledge brokers', who could help decision-makers become more aware of and interpret the results of economic and clinical evaluations.

### **Conclusion**

There are no universal models for mental health financing, no universal blueprints for the mixed economies of provision or finance, and no universally relevant results from economic evaluations. All are and need to be context-specific. But lessons *are* transferable across countries and health systems. There is enough commonality of experience and of purpose across the world to recognise that insights gained in one setting can often be transported — cautiously perhaps — to other settings. Certainly there are conceptual models that could be used quite widely to structure the collection of local evidence and stimulate local discussion. Our ongoing work will be exploring these commonalities.

### **World Health Day on the internet**

World Health Day.  
*Mental Health:  
Stop exclusion,  
dare to care.*  
7 April 2001:  
[www.who.int/  
world-health-day/  
index.en.html](http://www.who.int/world-health-day/index.en.html).

## Publications by CEMH and PSSRU authors

These four pages give brief details of selected recent and forthcoming publications.

Further details of CEMH Working Papers and PSSRU Discussion Papers, including those cited in this *Review*, are available from the PSSRU librarian (telephone 01227 827773; email [pssru\\_library@ukc.ac.uk](mailto:pssru_library@ukc.ac.uk)) or Janice Dickson at the CEMH (0171 919 3198; [cemh@iop.kcl.ac.uk](mailto:cemh@iop.kcl.ac.uk)). Recent papers, research summaries, and previous issues of the *Mental Health Research Review*, can be accessed and downloaded free of charge from the PSSRU website: [www.ukc.ac.uk/PSSRU/](http://www.ukc.ac.uk/PSSRU/).

Issue 12 of the *PSSRU Bulletin*, which covers the Unit's work as a whole, is available free of charge. The PSSRU also publishes a book series under the Ashgate imprint, monographs, and newsletters.

We aim to disseminate findings as widely as possible, but both PSSRU and CEMH have to charge for printed copies of papers. If a paper is published as a journal article or book chapter we advise interested readers to obtain that publication from a bookshop, library (through the inter-library loan system if necessary) or website.

### **A comparison of needs of patients with schizophrenia in five European countries: the EPSILON study**

Paul McCrone, Morven Leese, Graham Thornicroft, Aart Schene, Helle Charlotte Knudsen, José Luis Vázquez-Barquero, Michele Tansella, Thomas Becker, Daniel Chisholm and the EPSILON Study Group (2001) *Acta Psychiatrica Scandinavica*, 103, 370-379.

### **A European perspective on social anxiety disorder**

Yves Lecrubier, Hans-Ulrich Wittchen, Carlo Faravelli, Julio Bobes, Anita Patel and Martin Knapp (2000), *European Psychiatry*, 15, 5-16.

### **A randomised controlled trial to evaluate the effectiveness and cost-effectiveness of counselling patients with chronic depression**

Sharon Simpson, Roslyn Corney, Pat Fitzgerald and Jennifer Beecham (2000), *Health Technology Assessment*, 4, 36.

### **Aims, outcome measures, study sites and patient sample: EPSILON Study 1**

Thomas Becker, Martin Knapp, Helle Charlotte Knudsen, Aart Schene, Michele Tansella, Graham Thornicroft, Jose Luis Vazquez-Barquero and the EPSILON Study Group (2000), *British Journal of Psychiatry*, 177 (supplement 39), s1-s7.

### **Alternative strategies for stroke care: a prospective randomised controlled trial**

Lalit Kalra, Andrew Evans, Inigo Perez, Martin Knapp, Nora Donaldson and Cameron Swift (2000), *The Lancet*, 356, 894-900.

### **Alzheimer's disease in the UK: comparative evidence on cost-of-illness and volume of health services research funding**

Ana Lowin, Martin Knapp and Paul McCrone (2001), *International Journal of Geriatric Psychiatry*, in press.

### **Assessing mental health in Europe**

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### **Benefit groups and resource groups for adults with intellectual disabilities in residential accommodation**

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## Conferences

CEMH and PSSRU staff regularly contribute to health care conferences. A selection of conferences where a mental health topic was presented in the past year are listed below:

- World Congress on Innovations in Psychiatry, London, April 2000.
- European Network for Mental Health Service Evaluation, Fourth International Conference, Leipzig, April 2000.
- American Psychiatric Association Annual Conference, Chicago, May 2000.
- Fifth Workshop on Costs and Assessment in Psychiatry, University of Chicago, May 2000.
- First Brazilian Conference on Economics and Mental Health, Sao Paulo, Brazil, May 2000.
- Nordic Research Course on Psychiatry and Mental Health Promotion, Tampere, Finland, June 2000.
- Annual meeting of the International Society of Technology Assessment in Health Care, The Hague, June 2000.
- Joseph Rowntree Foundation workshop on Cost-effectiveness and Independent Living, June 2000.
- Economic Evaluation Workshop, Centre for Health Economics, University of York, July 2000.
- CINP, Brussels, July 2000.
- Australian Health Outcomes Conference, Canberra, August 2000.
- ECNP, Munich, September 2000.
- Third Annual European Conference of the International Society for Pharmacoeconomics and Outcomes Research, Antwerp, November 2000.
- Evidence-based Service Development at the Interface of Health and Social Care, Cardiff, February 2001.
- Home Office Research and Statistics Conference, London, March 2001.

# **The UK700 case management trial: review of the economic evidence**

Sarah Byford, on behalf of the UK700 Group

## **Introduction**

Intensive case management (ICM) has been advocated for the care of severely psychotic patients, with evidence suggesting that a reduced caseload is beneficial in terms of the effectiveness and quality of case management care (Intagliata and Baker, 1983; Harris and Bergman, 1988, Thornicroft, 1991). Because of reduced caseload size, ICM is a more expensive form of management than standard case management (SCM). What is unknown, however, is whether this additional expenditure can be justified in terms of reductions in the use of other resources or improvements in patient outcomes. Existing evidence is scarce and conflicting. Studies have tended to involve small sample sizes and concentrate mainly on differences in the use or cost of psychiatric inpatient care (McCrone, Beecham and Knapp, 1994; Marshall, Lockwood and Gath, 1995; Quinlivan et al., 1995; Holloway and Carson, 1998; Johnston et al., 1998).

This paper reviews the results of an investigation of cost-effectiveness, carried out as part of the UK700 case management trial, a multi-centre randomised controlled trial comparing ICM with SCM for the treatment of severely psychotic patients. The main findings are reported along with initial results of an exploration of the factors that influence the cost of caring for this group of patients.

## **Methods**

Patients were recruited from four inner city areas and were eligible for inclusion if they were aged between eighteen and 65, had suffered from a psychotic illness of at least two years and had been admitted to a psychiatric hospital at least twice, once within the last two years. Patients were randomly allocated to two years of either ICM (caseload size ten to fifteen) or SCM (caseload size 30 to 35) and assessed at baseline, twelve and 24 months. The primary outcome measure was days in hospital for psychiatric problems over 24 months. Secondary measures included clinical status, quality of life, unmet needs, social disability and patient satisfaction.

The perspective of the trial was that of all service providing sectors in society, thus enabling the differential impact of case management on each sector to be quantified. Information on the use of all hospital and community services was collected prospectively for each patient over the study period. All unit costs were calculated for the financial year 1997/98 and future costs were discounted at an annual rate of 6%.

All analyses were carried out on an intention to treat basis. Although costs were not normally distributed, analyses compared the mean costs in the two groups using standard t-test methods, with the validity of results confirmed using bootstrapping (Efron and Tibshirani, 1993; Barber and Thompson, 1998). Multiple regression was used to adjust for baseline characteristics of patients and sub-group analyses were performed using tests of interaction. Sensitivity analyses were carried out to assess the robustness of results to assumptions made in the costing procedure.

For further information on the rationale and the methods of the UK700 case management trial, see UK700 Group: Creed et al., 1999; UK700 Group: Burns et al., 1999. Further details of the economic evaluation can be found in UK700 Group: Byford et al., 2000.

## Results

A total of 708 patients were randomised to either ICM or SCM and adequate data for costing purposes was available for 667 (335 ICM and 332 SCM). No significant differences were found between ICM and SCM in terms of the primary outcome measure, days in hospital for psychiatric problems over 24 months (means 73.5 and 73.1 days, difference 0.4 days, 95% confidence interval -17.4 to 18.1), nor any of the secondary outcome measures (UK700 Group: Burns et al., 1999).

Table 1 details the total cost of all services used by the intensive and standard groups over the two-year follow-up period. No significant differences were found in the total costs of care per patient between ICM and SCM (means £24,553 and £22,704 respectively;  $p=0.29$ ). Adjustments for baseline variables did not materially alter these results ( $p=0.48$ ).

Two year costs (£)	Intensive (n=335)		Standard (n=332)		Difference in means (intensive-standard) (95% CI)
	Mean (SD)	% of total cost	Mean (SD)	% of total cost	
<i>Total cost by providing sector</i>					
Health authority services	16149 (20042)	66	14532 (18714)	64	1617 (-1332 to 4566)
Staffed accommodation	6168 (11324)	25	6000 (11219)	27	168 (-1546 to 1882)
Social services	1299 (2448)	5	1319 (2190)	6	-20 (-374 to 333)
Non-statutory services	478 (1151)	2	542 (1487)	2	-64 (-265 to 139)
Prison & police custody	459 (3481)	2	311 (2728)	1	148 (-328 to 624)
Total two-year cost	24553 (23408)	100	22704 (22000)	100	1849 (-1605 to 5304)

Source: UK700 group: Byford et al. (2000).

No statistically significant sectoral differences between ICM and SCM were found. Case management constituted 13% of the total cost of care of the intensive group (mean £3,089) and 6% of the standard group (£1,259). The largest proportion of total cost was borne by the health sector (66% intensive; 64% standard). Staffed accommodation, provided mainly by social services departments, also made a relatively large contribution to the total costs of care (25% intensive; 27% standard).

Given that neither form of case management demonstrated dominance in terms of either costs or effects, a formal cost-effectiveness analysis was not required. Figure 1, however, shows the 95% joint confidence region for the average differences between ICM and SCM in costs and in psychiatric hospitalisation. The interior of the ellipse gives the range of values for the true average cost and inpatient differences that are compatible (at a 95% confidence level) with the data from the trial. The orientation of the ellipse is a consequence of the strong relationship between total costs and hospitalisation. The zero origin is near the centre of the region, showing the lack of evidence of differences in either costs or hospitalisation. There is thus no evidence that ICM is more cost-effective than SCM, or indeed vice versa.

No significant differences in the effect of ICM on costs were found between the four centres. Sub-group analyses according to ethnic group (African Caribbean and other) and severity of social functioning, measured by the Disability Assessment Schedule (DAS) (Jablensky, Schwartz and Tomov, 1980) also showed no evidence of differential effects.

In a separate UK700 study, ICM was found to be significantly more beneficial for patients with borderline intellectual functioning as compared to those of normal IQ (Hassiotis et al., 2001). For this patient group, tests of interaction

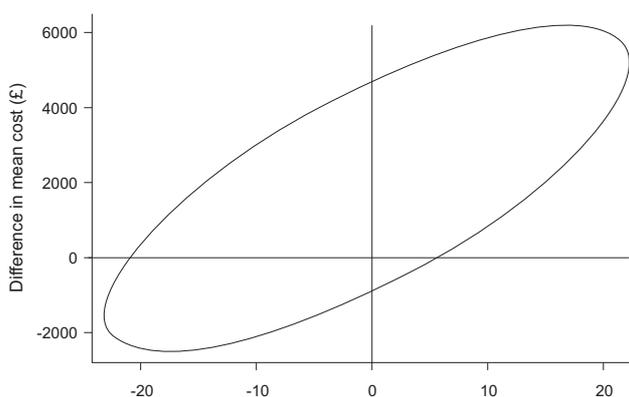
between case management status and IQ status found ICM to be associated with reductions in days spent in hospital, hospital admissions, needs and total costs and increased patient satisfaction. ICM compared to SCM reduced the total costs of care among borderline IQ patients (£23,808 and £28,983, respectively) and although this difference did not quite reach statistical significance ( $p=0.059$ ), the result became significant after adjustment ( $p=0.047$ ). Given improvements in outcome and, at worst, equivalence in costs, ICM appears to be a more cost-effective strategy for this subgroup of patients than SCM.

In a further UK700 study, multiple regression analysis was used to explore the influence of baseline characteristics on the cost of caring for patients with severe psychotic illness, to provide information to aid budgetary planning and to assess the appropriateness of current expenditure patterns (Byford et al., 2001). Significantly more money was spent on younger patients, those with longer duration of illness, those who had spent less time in independent living and those who had spent longer in hospital for psychiatric reasons (see table 2). Marital status, level of social disability and number of unmet needs were also found to be associated with total cost, but less strongly.

## Conclusion

No statistically significant differences were found between ICM and SCM in terms of either total two-year costs per patient or the main clinical outcome measures over the two-year period of the trial. Sensitivity analyses did not alter this result. Figure 1 clearly shows the lack of evidence to suggest that intensive case management is more, or indeed less, cost-effective than standard case management for patients with severe psychotic illness. This multi-centre, randomised trial indicates that intensive case management by mental health

**Figure 1 95% confidence region for the difference in mean two-year cost per patient (£) against difference in psychiatric hospitalisation over two years (intensive-standard)**



Source: UK700 Group: Byford et al. (2000)

**Table 2 Multivariate predictors of total two-year cost (£)**

Variable (n=651)	Coefficient (95% confidence interval) <sup>a</sup>	P-value
Age (years)	-383 (-590 to -175)	<0.001
<i>Marital status (compared with single)</i>		
Living as married	-5657 (-10754 to -560)	
Divorced/ separated/ widowed	-397 (-4565 to 3770)	0.08
<i>Months independent living (compared with none)</i>		
1-12 months	-1673 (-8352 to 5006)	
12-24 months	-11552 (-16585 to -6520)	<0.001
Duration of illness (months)	28 (9 to 47)	0.004
Days in hospital for psychiatric reasons over previous two years	61 (45 to 76)	<0.001
Social disability (DAS)	1563 (-357 to 3482)	0.11
Number of unmet needs	560 (-132 to 1252)	0.11

### Note

a. For continuous variables (e.g. age) the coefficient indicates the increase or decrease in cost per unit increase in the covariate (e.g. per year of age). For categorical variables the coefficient is the difference in cost between the specified group and the comparison group indicated in brackets next to the variable name.

Source: Byford et al. (2001).

## Key points

- No beneficial effects of intensive case management on costs, clinical outcome, or cost-effectiveness were observed for a broad group of patients with severe psychotic illness.
- The effect of intensive case management on costs and outcomes was found to be no different in African Caribbeans compared to other ethnic groups, or in the severely disabled compared to moderately disabled patients.
- Improvements in outcome and lower total costs of care suggest that intensive case management may be a more cost-effective method of treatment than standard case management for patients with a dual diagnosis of borderline intellectual functioning and severe psychotic illness.
- Characteristics that predict high costs in a population of patients with severe psychotic illness include being young, single, having a longer duration of illness and having been more dependent on supported accommodation and psychiatric inpatient care in the past.

workers with a reduced caseload has no clear beneficial effect on costs, clinical outcome, or cost-effectiveness in severely psychotic populations. Evidence does suggest, however, that ICM may be a more cost-effective form of care than standard case management for patients with a dual diagnosis of severe psychotic illness and borderline intellectual functioning.

Exploration of the factors that influence the cost of caring for patients with severe psychotic illness suggests that total costs are influenced more by age, illness duration and previous levels of dependence than by diagnosis or measures of illness severity. Service planners should be aware of the considerable cost implications of patients with a high degree of dependency on statutory services and the implications these may have for future resource allocation and the targeting of mental health services.

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## **LSE Health and Social Care: Launch Conference 10 January 2002**

This one-day event will celebrate the establishment of LSE Health and Social Care — formed by the grouping together of PSSRU and LSE Health.

The conference will be primarily concerned with the future of health and social care in the UK and internationally. Themes will include: health and social care funding; equity and efficiency; regulation and competition.

Attendance will be free, but registrations are needed in advance to assist with the planning of catering and other arrangements.

Full details will be posted on the LSE Health and Social Care website: [www.lse.ac.uk/Depts/lsehsc/](http://www.lse.ac.uk/Depts/lsehsc/).

## **An economic evaluation of forensic psychiatric services in England**

A project starting in June 2001, funded by the Department of Health, to be conducted by the PSSRU at LSE in collaboration with the Academic Section of Forensic Psychiatry at St Bartholomew's and the Royal London School of Medicine and Dentistry

Follow-up data have been collected on clinical relapse, criminal offending and use of hospital and community forensic mental health services for a sample of over 1000 mentally disordered offenders discharged from seven Regional Medium Secure Units (RSU) across England. The earliest date of discharge from each of the RSUs was 1989, and patients have been followed up over periods ranging from five to nine years. Data collected are from official records (e.g. medical case notes, Criminal Records Office data) or from interviews with key supervisory staff. Additional data have also been compiled for patients on the treatment they received while in an RSU, the nature of admission (including those made under the 1983 Mental Health Act) and the circumstances surrounding discharge into the community.

The economic evaluation will seek to cost the time spent by patients within Medium Secure Units and their subsequent use of community-based forensic psychiatric services and treatments. Multivariate econometric procedures will be employed to test for and to quantify linkages between identified outcomes and costs, including criminal offending and the incidence of clinical relapse. A number of policy-related questions will be addressed in the economic analysis. These include:

- The extent to which length of stay and the characteristics of treatment within medium secure units are linked to patient outcomes
- The cost and outcome implications of legal coercion placed on patients to accept supervision after discharge into the community
- The implications in terms of cost and outcome of different models of after-care delivered in community settings
- The extent to which costs and outcomes differ between forensic psychiatric services provided by the NHS and private sector providers

For more details of the project contact Andrew Healey at the PSSRU, LSE Health and Social Care, London School of Economics, London WC2A 2AE. Telephone 020 7955 6134, email [A.T.Healey@lse.ac.uk](mailto:A.T.Healey@lse.ac.uk).

# Linking datasets, people and resources

Jennifer Beecham, Jack Astin and Kate Mummery

## Introduction

Over the past fifteen years, researchers at the PSSRU and the Centre for the Economics of Mental Health have undertaken numerous costs-related studies in community-based mental health care. The aim of the analyses described below was to find out whether the sum of data from these studies was larger than its component parts; could we address broader mental health policy issues by amalgamating and re-analysing these data? Specifically, could we test the application of Healthcare Resource and Benefit Groups — together forming the Healthcare Framework — in mental health?

The Healthcare Framework was devised by the NHS Information Authority to assist in the internal management of NHS resources. Healthcare Benefit Groups (HBGs) are groups of people who have similar health care needs and who are likely to have similar outcomes given the same package of care. Healthcare Resource Groups (HRGs) are sets of activities (procedures or interventions) that consume similar amounts of health care resources. HRGs have already been developed in relation to all inpatient episodes of care for all diagnoses (NHS Executive, 2000). Less work has been undertaken on developing the Framework for people with complex and/or long-term care needs or for community-based services, but some progress has been made in learning disability services (Comas-Herrera et al., 2000, 2001). A Mental Healthcare Framework needs to incorporate the demands made on services during rehabilitation and maintenance phases as well as acute episodes (Sanderson, Anthony and Mountney, 1995; Huxley et al., 1996).

The development of community-based mental healthcare resource and benefit groups (MHBGs and MHRGs) requires the statistical analysis of a large number of cases, and their scope and reliability needs to be tried out for as many types of health care interventions and mental health service contexts as possible. The PSSRU/CEMH datasets allow developmental work in this area as they comprise detailed data on the characteristics, needs, service utilisation and costs for clients supported in a range of care environments.

## Building the linked dataset

The first task in developing Mental Healthcare Benefit and Resource Groups was to locate the relevant research datasets and within those, to identify the components of a cross-walking dataset. Our focus was on people who have severe mental health problems, predominantly those with schizophrenia and related disorders. The studies ranged from large evaluations of community-based care for people who had left long-stay psychiatric hospitals to smaller studies of employment or outreach services. All studies were carried out in the late 1980s and 1990s.

Building the linked dataset was a complex task as the eight studies identified during the design stage used a variety of different assessment schedules. The final linked dataset contains 90 variables for 3342 people, including the following:

- Reference data such as an identifier for each person and each research project.
- Demographic data such as age, marital status, and percentage of life spent in psychiatric hospital.
- Activities of daily living (ADL) measures, including dichotomous variables for ability to shop for personal items, prepare simple snacks, or manage a weekly allowance.

- Behaviour-related measures, re-coded as indicator variables and including items such as self-harm, depression, aggression, and mood disturbance. A measure of cognitive impairment was also included.
- Information relating to psychiatric symptoms. This was retained in the dataset, but excluded from these analyses due to the complexities of comparing the various measures employed in the original studies.
- All service use (yes/no) and component and total cost variables; average costs per week in 1996-97 prices (Netten, Dennett and Knight, 1998). Sub-totals were also calculated for accommodation and living expenses and for six mutually exclusive service sets. Service location (hospital or community), whether services were specialist or generic, and the provider agency identified the service sets.

### The identification of groups of clients with similar needs (MHBGs)

The first step towards deriving mental health benefit groups (MHBGs) was to ensure that the distribution of differences along some very basic criteria was not too wide and that small groups of 'outliers' would not distort the picture for the whole sample. If too many groups were identified the results would be difficult to use in practical resource allocation scenarios; too few groups, however, and the complexity of working with people with such diverse support needs would not be reflected.

This preliminary analysis showed that 92% of the sample were unemployed, 89% were not formally detained under the Mental Health Act and 83% were white. Given the high frequency of these characteristics, the sample was reduced to only people in these categories. A further identifying variable was uncovered — the type of accommodation in which people were living. About half of the sample were living in residential or supported living environments. The analyses below concentrate on this population, as it is likely to include the more expensive groups of people to support. Further analysis would be required for people supported in their own homes.

Factor analysis was used to reduce the complexity of the data, resulting in the identification of eleven key variables. (Details of these analyses are given in Beecham, Astin and Mummery, 2001.) Table 1 shows the characteristics of the

Group	Age	Life	Male	Married	Social	Self	Money	Mood	Aggression	Harm	Cognitive
Less than 10% of life spent in hospital	<30	3	.66	.05	.12	.19	.43	.34	.16	.11	.13
	30-45	3	.69	.20	.18	.22	.46	.29	.14	.08	.11
	45-60	2	.63	.44	.15	.28	.43	.32	.18	.09	.15
	60-75	2	.57	.51	.22	.40	.44	.28	.15	.04	.26
	>75	4	.28	.64	.39	.66	.72	.27	.23	.03	.37
More than 10% of life spent in hospital	30-45	24	.49	.07	.23	.35	.60	.40	.31	.06	.19
	45-60	17	.58	.19	.22	.40	.63	.32	.28	.04	.20
	65-75	13	.48	.23	.29	.47	.60	.30	.23	.02	.25
Average	45-60	7	.55	.33	.22	.35	.50	.30	.20	.06	.20

*Notes*  
 Life: percentage of life spent in psychiatric hospital. Male: 1 = male. Married: 1 = currently married. Social: 0 = minor or no problems with social mixing and maintaining conversations with staff or residents. Self: 0 = minor or no problems with activities such as shopping, preparing snacks, keeping room tidy, maintaining personal appearance, getting up and using time. Money: 0 = minor or no problems in handling money or budgeting a weekly allowance. Mood: 0 = minor or no problems relating to mood swings/depression. Aggression: 0 = minimal or no problems relating to aggression towards people and property. Harm: 0 = minimal or no problems relating to self-harm or suicidal thoughts or actions. Cognitive: 0 = has no cognitive impairment.

eight groups created by the analysis. Some known trends can be recognised. For example, as people get older their ADL skills deteriorate, noticeably for self-care skills (**self**) among people over 60 and for self-care and budgeting skills (**money**) among people over 75 years old. The variable describing social skills (**social**) is more stable but the skills do decrease markedly for people over 75 with a score well above the average for the full sample.

For the behaviour-related variables the pattern is more complex. More people have problems with cognitive functioning (**cognitive**) as they get older but there is a trend for symptoms of mood swings/depression to improve. There is also an increase in aggressive behaviour (**aggression**) in older people who have spent less than 10% of their life in hospital. Generally, people who have spent more than 10% of their life in hospital are less able in each of the ADL areas than people who have spent less of their life in hospital and they are more likely to have behaviour problems.

### **The identification of groups of people consuming similar resources (MHRGs)**

The individual service receipt and cost variables and the sub-total costs for accommodation and living expenses and the six service sets were extensively tested for associations that would help distinguish mental healthcare resource groups (MHRGs). The sub-totals for the service sets were found to lead to the sharpest divisions. Four groups of people were identified.

- People with high social care costs (greater than £60) — essentially greater users of social work services.
- People with low social care costs but with high costs associated with use of day activity services.
- People with low social care costs and low day activity costs but with high (greater than £85) hospital-based service costs.
- People with low costs in all service sets.

The costs associated with the set of specialist community-based mental health services was not a clear grouping variable but these costs were high for people with high social care costs or high hospital costs.

### **Combining MHBGs and MHRGs**

The first set of analyses looked for associations between the groups derived from the service set costs (MHRGs) and MHBGs defined in table 2 and also for groups defined using only the ADL and behaviour variables. The only significant result was that people with low costs in all service sets had scores for the demographic, ADL and behaviour variables that were close to the average for the whole group.

Subsequent analyses looked for associations between total costs and the MHBG components. These met with some success; the results were robust but fewer domains and measures could be incorporated. The only variables that were found to correlate consistently with the total costs of care were those identifying self-care abilities (**self**) and the percentage of a person's life spent in hospital (**life**). These two variables enabled six groups to be defined (table 2). The analyses excluded 37 people who self-harmed and who were also cognitively impaired and a further 147 people for whom some of the cost data were missing.

Table 2 shows that total costs increase moving from Group 1 to Group 13. Noticeably, people who have spent more of their life in hospital have higher total costs, a finding that holds constant at all levels of self-care skills. Indeed, people who have spent more of their life in hospital and who have good self-care skills

Group	Hospital £ per week	Community £ per week	All services £ per week <sup>a</sup>	Accomm. £ per week <sup>b</sup>	Total £ per week <sup>c</sup>	Number in group
<b>Group 1</b> No problems with self-care, less than 10 per cent of their life spent in a psychiatric hospital.	16	41	57	200	257	420
<b>Group 2</b> Moderate self-care skills, less than 10 per cent of their life spent in a psychiatric hospital.	23	40	63	221	284	163
<b>Group 3</b> Very poor self-care skills, less than 10 per cent of their life spent in a psychiatric hospital.	22	30	52	241	293	145
<b>Group 11</b> No problems with self-care, more than 10 per cent of their life spent in a psychiatric hospital.	11	45	56	294	350	115
<b>Group 12</b> Moderate self-care skills, more than 10 per cent of their life spent in a psychiatric hospital.	9	39	48	340	388	90
<b>Group 13</b> Very poor self-care skills, more than 10 per cent of their life spent in a psychiatric hospital.	17	30	47	366	413	102
<b>Group B5</b> People who self-harm.	37	37	74	227	302	128
<b>Group B2</b> People who are cognitively impaired.	15	37	52	267	319	265

**Notes**

a. All services: includes the costs of all hospital and community-based services that are funded from outside the accommodation budget (the two previous columns).

b. Sub-total of all costs related to accommodation and living expenses.

c. Total cost: includes the costs presented in the previous four columns (all services plus accommodation costs).

are more costly to support overall than are people who have poor self-care skills but who have not spent so much of their life in hospital.

As all of the sample members lived in staff-supported congregate living environments it is not surprising to find that total costs are dominated by the accommodation-related costs. Although in this dataset we cannot distinguish different types of accommodation or different levels of support provided within them, accommodation-related costs show similar associations to the MHBGs as do total costs. Total and accommodation costs for the groups of people who self-harm or who are cognitively impaired fall between Group 3 and Group 11. There is little variation between the groups in terms of hospital or community service costs although people who have spent less of their life in hospital tend to have slightly higher mean costs for recent admissions to hospital and for use of day activity services.

## Conclusion

There are a number of limitations to this work, not least because the data were not originally collected with developing a Mental Healthcare Framework in mind. Our original sample was reduced by more than two-thirds due to the difficulties of calibrating the various measures employed in the original studies. It may be that data from a larger sample using more consistent measures would produce different results. Data on psychiatric symptoms were not employed here yet for people experiencing acute episodes of mental ill-health, symptom severity is likely to be an important component of a Mental Healthcare Framework. On a more positive note, it is often only trained psychiatric professionals who can assess mental health symptoms. By excluding these measures, a wider range of people can use the groups. Finally, we need to be aware that services have developed considerably since the earlier studies were undertaken. The full impact of the National Service Framework for mental illness has yet to be felt in most localities but is likely to further change the supply of services. In turn this will affect the way people use services and the costs of support.

Limitations aside, the findings from this work provide some of the first evidence for a Mental Healthcare Framework for community services. Our findings

suggest that despite individual variations, Mental Healthcare Benefit Groups can be identified using demographic characteristics and broad assessments of skills in activities of daily living and behaviour. Groups of people using similar sets of resources (MHRGs) could also be identified; however the associations between the two were too weak to develop a full Mental Healthcare Framework. Only self-care skills and psychiatric history showed any strong associations with total support costs.

The work described above certainly shows that the development of a Mental Healthcare Framework for community-based mental health care is a complex matter. However, these findings also reinforce concerns about using diagnosis as the sole measure for mental health benefit and resource groups. Underlying characteristics, skills and behaviours have a large part to play in linking people and resources.

### Acknowledgements

The analyses summarised above could not have been completed without the initial work undertaken by Justine Schneider to identify datasets and set out the criteria for selecting and standardising the data. Kate Mummery undertook the complex task of creating and describing the final linked dataset for these analyses.

### Key points

- The effective management of mental health care resources requires valid indicators of patient needs and resources.
- Mental Healthcare Benefit groups can be constructed using demographic characteristics and measures of daily living skills and behaviour.
- Mental Healthcare Resource Groups, characterised by different levels of service cost, can be identified but the association between these and the Benefit groups is presently weak.
- Diagnosis is an insufficient indicator of resources and need.

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# **The burden of informal care for Alzheimer's Disease: carer perceptions from an empirical study in England, Italy and Sweden**

David McDaid and Franco Sassi, on behalf of the TASIE group\*

Dementia of the Alzheimer type and related disorders greatly impact not only on the lives of sufferers but also on their unpaid informal carers, who usually are spouses or children. Carers are more likely to suffer from stress, take prescribed medication and visit their physicians compared with non-carers (Burns and Rabins, 2000). Social isolation that can occur in caregiving may mean that carers may only come to the attention of formal support services when a crisis occurs and informal care arrangements break down (Wenger, 1994). Increasing our understanding of the burden on informal care, and how this is affected by the use of support services, may contribute to the future development of services.

As part of a European project (Sassi and McDaid, 1999), an empirical study was undertaken to measure aspects of the burden borne by informal carers of people with probable Alzheimer's disease living in the community in England, Italy and Sweden. Qualitative data on the caring experience and its economic impact were also collected as part of the project. Logistic regression analysis was used to examine the relationship between burden of informal care, as perceived by carers, and a number of potential determinants. In the long term data collected from this study could be used to help develop a utility-based instrument for measuring the burden of informal care. Some qualitative findings from the study are briefly highlighted in this short report.

## **Methods**

Non-random samples of primary carers were selected in the three countries. Determinants of burden would be studied in light of cultural differences and the availability of formal/informal care in the three countries. All carers were interviewed by means of a structured telephone interview questionnaire.

Although identification of carers through general practitioners was deemed to be the least biased method for recruiting subjects for the study, in practice it was not possible to adopt the same recruitment methods in the three countries because of cultural differences, ethical problems and differences in referral procedures. In particular, primary care does not have a gate-keeping role in Sweden and it was felt that general practitioners would not be able to identify a large number of patients and carers. Therefore, multiple recruitment sources were used in Sweden: district physicians (general practitioners); an investigation clinic based at a university hospital; and a population-based register comprising Alzheimer's Disease patients living in Stockholm; the Swedish Alzheimer's Association and district visitors from the Swedish church. In Italy, there was a limited response by general practitioners, who generally felt unable to identify relevant patients and carers due to a lack of suitable information systems at a practice level. Subjects were therefore recruited through Federazione Alzheimer Italia. The original strategy of recruitment was used in England, augmented by additional recruitment predominantly from a memory clinic in Leicester.

## **Data collection**

Data were gathered on demographics of the carer and person being cared for. Respondents were asked to rate the disease stage using the World Health Organisation's definition of symptoms associated with mild, moderate and severe Alzheimer's Disease. Six questions on aspects of the caregiving experience were

included: self-care ability of the person with AD, communication ability of the person with AD; need to supervise; ability to cope; employment status; and impact on social life. The final section of the questionnaire identified health and social services used by carers and patients, as well as the amount of time spent on caregiving tasks.

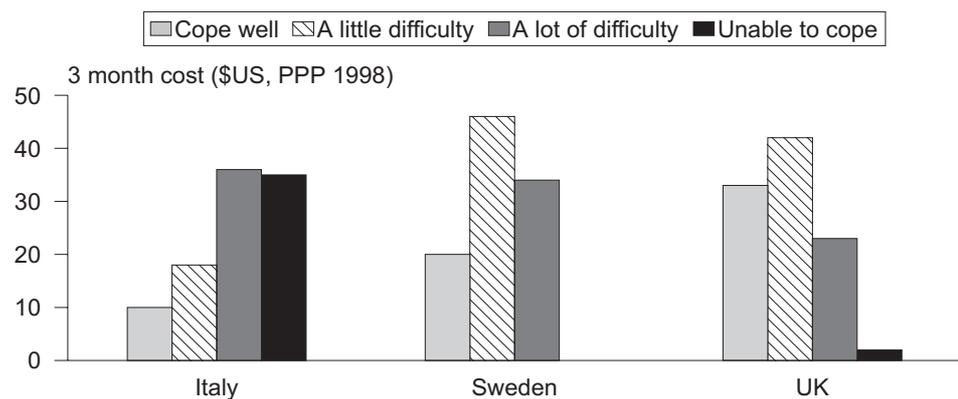
## Results

One hundred carers in England, 212 in Italy and 97 in Sweden participated in the study. In each of the three countries female carers outnumbered male carers by approximately two to one. Italian carers were markedly younger than those in Sweden and England (median ages were 48, 69 and 67, respectively). This was due to a higher proportion of daughter carers participating in the study in Italy. The median age of people with dementia being cared for ranged between 73 and 79. Almost 60% of people being cared for were married. Between 76% and 94% of patients in the three countries were felt to be in either the mild or moderate stage of Alzheimer's disease.

### Perceptions of the caregiving experience

Carers in Italy felt that their charges were the most limited in the ability to perform activities of self-care. In contrast in both Sweden and the UK patients were perceived to have more ability to provide self-care (figure 1). The ability of patients and carers to communicate and need for supervision similarly differed in

**Figure 1 Perceptions of caring**



the Italian group. Carers in the Swedish and UK groups also reported that they found the caring process less difficult to cope with, with only a very small proportion of UK carers (2%) and no Swedish carers reporting that they were totally unable to cope with caregiving activity. In contrast 35% of Italian carers stated that they could not cope at all with their caregiving situation. Italian carers reported a higher impact on the ability to maintain employment compared with the other two groups. This is again partly reflected in the age and relationship differences between the groups. Social relationships and leisure were also more affected in the Italian carer group. Despite the higher level of subjective burden reported by Italian carers in virtually all parameters, carers in all three countries overwhelmingly wished to maintain a hands-on role with caregiving tasks, with less than 5% of carers wishing to cease caregiving entirely.

### Service use

Service use was markedly different in the UK and Sweden compared with Italy. One striking statistic was the virtual non-use of daycare in Italy (less than 1% of

carers) compared with over 40% in the other two countries (see table 1). More carers in Italy reported having visits to medical specialists such as neurologists than in England or Sweden (finding not adjusted for personal characteristics).

**Table 1 Percentage of carers who reported using formal services**

	Medical services outside home	Medical services at home	Domiciliary assistance	Respite care	Carer services	Day care
Italy	83	14	47	5	8	1
Sweden	36	21	33	51	40	40
UK	43	46	42	57	67	46

## Discussion

Although sample selection was not entirely free from bias, as in many studies of informal carers, qualitative data does appear to suggest that aspects of perceived burden are in part related to cultural factors. The motivation to provide care is complex, and can be dependent on many factors including a sense of obligation, love, satisfaction from the caring process, financial dependency and access to formal alternatives. In this study, even when reporting high levels of perceived burden, and differing use of formal support services, most carers still expressed a wish to retain primary responsibility for the tasks of caring.

Further research is required to examine context-specific and culture-specific factors; to augment existing knowledge of the psychological determinants of burden, of the motivations to care and satisfaction related to the caring process, and of the determinants of service use; and to explore ways in which the use of services affects levels of burden and the appropriateness of services offered to carers and persons with AD. Services need to be tailored to take account of the psychological needs of carers: even when services are available, carers are likely to use these only to a very limited extent (Dello Buono et al., 1999).

## Acknowledgements

This study was primarily supported by a grant from the European Commission, with an additional educational grant from Pfizer Ltd. The views expressed in this paper represent those of the authors and not those of sponsors.

\* Additional members of the Transnational Analysis of the Socio-Economic Impact of Alzheimer's Disease in the European Union (TASIE) group: Caterina Cavallo, Derek King, Martin Knapp, Gunilla Nordberg, Jolanta Sabbat, Gabriella Salvini-Porro, Eva Von Strauss, Bengt Winblad, Anders Wimo.

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## Key points

- Alzheimer's Disease not only has a major impact on the patient but also on those family members and friends who provide care for them.
- Carers in Italy were on average younger than those in the UK or Sweden and also had greater difficulties in coping.
- Substantial differences were found in service use, with carers in Italy using daycare less than those in the other two countries but accessing specialist medical services more.

## **Cognitive impairment: its implications for future demand for services and costs**

Adelina Comas-Herrera, Raphael Wittenberg, Linda Pickard, Martin Knapp and Bleddyn Davies

Cognitive impairment has a considerable impact on the quality of life of sufferers, their families and other caregivers. It also has major health service and social care implications, in turn generating high costs. Re-analysis by Lowin, Knapp and McCrone (2001) of the comprehensive work by Bosanquet, May and Johnson (1998) and Kavanagh et al. (1995) suggests that the gross annual cost of Alzheimer's disease in the UK today lies somewhere between £7 billion and £15 billion (depending on the costing of informal care).

Future demand for services for people with cognitive impairment is expected to rise with the projected increase in the numbers of older people. The development of pharmacotherapies and other treatments might slow down the rate of cognitive decline or reduce behavioural disturbance, reducing not only the numbers who will be affected but also the intensity of care they will need. Demand for services could also be affected in the future by changes in the availability of informal care and by changes in the balance between community and institutional care.

The PSSRU has recently started a research project to investigate the impact of cognitive impairment on long-term care demand and expenditure. The aim is to understand better the implications of cognitive impairment for future demand for and costs of long-term care. The project is financed by the Alzheimer's Research Trust.

The project will involve projecting, for the next 30 years, the future numbers of older people with cognitive impairment, their demand for services and the costs of their care. It will build on the PSSRU long-term care financing model (Wittenberg et al., 2001), which was constructed as a part of a project on long-term care finance funded by the Department of Health. This model has shown that projections of demand for long-term care are very sensitive to assumptions about the future prevalence of functional dependency (Wittenberg et al., 2001), which is measured using the ability to perform activities of daily living (ADL). The current model does not take account separately of cognitive impairment. There is evidence, however, that people with cognitive impairment are more likely to be in institutional settings than people who are only physically frail (RIS MRC-CFAS, 1999) and that cognitive impairment significantly increases the levels of stress experienced by informal carers (Davies and Fernández with Nomer, 2000). It has also been found that looking after someone with cognitive impairment is associated with high levels of depression.

The first part of the project will involve projections of numbers of older people with cognitive impairment in England to 2030, using information from the MRC Cognitive Functioning and Ageing Study (MRC-CFAS, 1998) on the prevalence of cognitive impairment by age and gender in their five study areas. This will be applied to population projections in the PSSRU financing model. Projections will be made on the basis of the Government Actuary's Department's principal, high and low assumptions about future mortality rates. Projections will also be made on varying assumptions about trends in age-specific prevalence rates of cognitive impairment.

The second part of the study will involve projections of services required for people with cognitive impairment and of expenditures for England to 2030. This will involve analysis of data from the CFAS Resource Information Study (RIS) to examine the association between levels of cognitive impairment and services

received in the four areas included in the RIS (McNamee et al., 1999). Expenditure projections will use information on services from the RIS and information on unit costs of care from the PSSRU unit costs study. There will be scope to examine the implications for projected expenditure of changes in the prevalence of cognitive impairment, in patterns of care and in real unit costs of care.

The third part of the study will examine the relationship between cognitive impairment and difficulty in performing activities of daily living and instrumental activities of daily living. This will involve analysis of CFAS data on cognitive impairment and ability to perform activities of daily living among older people. Information from the PSSRU survey of residential care will also be used for those in residential care. The analysis will contribute to the possible inclusion of cognitive impairment in the main PSSRU long-term care financing model. Its inclusion in the model will enable projections to be made of the effects of possible changes in the prevalence of cognitive impairment or physical disabilities or both.

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The work by Lowin, Knapp and McCrone mentioned in this article is due to appear in the *International Journal of Geriatric Psychiatry* (see the full reference above). The aims of the study, commissioned by the Alzheimer's Research Trust, were to review the economic cost of Alzheimer's Disease, to determine the level of research expenditure directed at this illness and to make comparisons with cancer, stroke and heart disease.

The direct costs of Alzheimer's Disease were estimated to be between £7.06 billion and £14.93 billion — substantially greater than stroke (£3.2 billion), heart disease (£4.05 billion) and cancer (£1.6 billion excluding informal care costs). Research expenditure on Alzheimer's Disease was 57% of that on stroke, 10% of that on heart disease and 3% of that on cancer. The authors recommend, in the light of these two findings, further discussion of the distribution of public funding into this disease.

## **Other recent and current work at the CEMH and PSSRU**

### **Costs of heavy inpatient service users**

It is well known that in psychiatry a small number of patients use a disproportionately high amount of resources. This study (led by Dr Philip Harrison-Read from the Park Royal Centre for Mental Health) aimed to identify the characteristics of the heaviest 10% inpatient service users in a London borough and to measure their service use and costs. The group so-called 'heavy users' (n=193) was compared with a group of 400 'ordinary users'. While the diagnostic and demographic characteristics of heavy and ordinary service users were similar, the heavy service users had healthcare costs that were three times as high in a particular year. Heavy inpatient users were shown to have significantly more community contacts than ordinary users and also to have significantly more cases of failing to appear for appointments.

CEMH contacts: Anita Patel and Martin Knapp

#### *References*

Ben Lucas, Philip Harrison-Read, Peter Tyrer, Jonathan Ray, Katherine Shipley, Matthew Hickman, Anita Patel, Martin Knapp and Ana Lowin (2001) Costs and characteristics of heavy inpatient service users in outer London, *International Journal of Social Psychiatry*, 47, 63-74.

Phil Harrison-Read, Ben Lucas, Peter Tyrer, Jonathan Ray, Katherine Shipley, Shaeda Simmonds, Martin Knapp, Ana Lowin, Anita Patel and Matthew Hickman (2001), Heavy users of acute psychiatric beds: randomised controlled trial of additional assertive outreach treatment in an outer London borough, *Psychological Medicine*, in press.

### **Costs and outcomes management in supported housing**

Providers of housing engage with a variety of care needs among vulnerable populations. This study examined the relationships between those needs, living environments and the costs of care and support. Tenants in the most costly arrangements were assessed as having a greater number of needs than those in other accommodation categories. However, several tenants in more independent arrangements were reported as having many and/or particularly severe needs. These tenants received higher levels of informal care than those in more highly supported housing. People who expressed a lack of basic skills received less support within their accommodation arrangements than others. Tenants' needs were of importance in explaining cost variations, and there was also a relationship between cost and the physical condition of the building and its furniture and fittings. This study provided information as a benchmark for further study of more effective management of housing and support.

CEMH contacts: Angela Hallam and Martin Knapp

#### *Reference*

Krister Järbrink, Angela Hallam and Martin Knapp (2001), Costs and outcomes management in supported housing, *Journal of Mental Health*, 10, 99-108.

### **Alcohol misuse**

A randomised controlled trial has recently begun, to evaluate the effectiveness and cost-effectiveness of a brief intervention by alcohol support workers aimed at reducing alcohol misuse in patients attending an accident and emergency department. This trial is being carried out in collaboration with Imperial College, London.

CEMH contact: Sarah Byford

### **Severe personality disorder**

A study of dangerous people with severe personality disorder has recently been funded by the Home Office and will involve an evaluation of assessment tools, management strategies and costs of care. This study is being undertaken in collaboration with the Imperial College of Science, Technology and Medicine in London, Arnold Lodge in Leicester and the University Department of Psychiatry in Oxford.

CEMH contact: Sarah Byford

## PSSRU

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The PSSRU was established in 1974 at the University of Kent at Canterbury. Two further branches opened in 1996 — at the London School of Economics and at the University of Manchester — with the aim of further strengthening the Unit's work on equity and efficiency in social care, and organisation, financing and funding issues. PSSRU research is funded by the Department of Health, other government departments, research councils, charitable trusts and international social welfare organisations.

## CEMH

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The Centre for the Economics of Mental Health was established at the Institute of Psychiatry in November 1993 with initial funding from the Bethlem and Maudsley Research Trust. Today its research and other activities are supported by the Institute of Psychiatry, the Medical Research Council, the Department of Health, the European Commission and a number of other funders. The Centre promotes, conducts and disseminates health economics research in the field of mental health, broadly defined. Particular fields of interest currently include children and adolescents with mental health problems, people with schizophrenia, people with dementia and adults and children with intellectual disabilities.

For enquiries about the CEMH, contact Janice Dickson on 020 7848 0198.

For enquiries about the PSSRU, contact Judy Lee (University of Kent) on 01227 827672 or Maureen Weir (LSE) on 020 7955 6238.

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