Health expectancy and long term care costs

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CONTENTS

Synopsis

The report reviews evidence about the relationship between the changing pattern of life expectancy and chronic ill-health, and forecasts of long-term care costs. Costs concern both the annual gross national cost at future points in time as well as individual predictions of life-time need.

The report contains five sections.

Section 1 discusses the contribution that health expectancy can make to forecasts of LTC costs.

- Most forecasts of future LTC costs project the population age profile, and assume that age-specific utilization (or cost) rates will remain unchanged. This is too simplistic. The health expectancy literature is now beginning to show that prevalence rates for chronic ill-health are changing, and with them assumptions about utilization of LTC.

- Forecasts should be based on projections of future prevalence rates. This can be done by projecting forward the implications of the current incidence and duration of chronic ill-health. The health expectancy literature shows how this is done, and is beginning to produce estimates of current incidence.

- Better still would be to incorporate assumptions about trends in the incidence (and duration) of chronic ill-health.

Section 2 outlines the present state of knowledge about the utilization/cost implications of chronic ill-health.

- If forecasts are based on projections of future prevalence, then it is necessary to incorporate assumptions about the link between states of chronic ill-health, utilization, and hence costs.

- Projections of disability rather than disease should be built into LTC cost forecasting models. However, at present there is a research gap between the measures of chronic ill-health being used in the health expectancy literature and those for which utilization/cost rates are predictable, either from cost analyses or by using resource allocation formulae.

Section 3 reviews the evidence about likely trends in chronic ill-health.

- Present international evidence from the health expectancy literature suggests (i) current age-specific rates of moderate disability are changing very little, so that the expanding elderly population means proportionately more disabled. (ii) numbers of people with very severe disability are not increasing.

- This accords with expectations based on trends in the incidence and treatment of major chronic diseases.

- The net effect is to imply a more optimistic forecast of LTC costs than would be obtained by projections based on assuming constant age-specific prevalence (and hence utilization) rates.

- However, the methodology on which these predictions are based is not wholly reliable. Better predictions, based on projecting current incidence rates, are slowly becoming available.

Section 4 summarises the evidence about likely trends in other factors that affect both the future demand and supply (and hence price) of LTC.

- Future utilization rates and prices will not remain unchanged. Forecasts of future LTC costs ought to take into account changes in other factors affecting the demand and supply of LTC. These include such factors as the availability of informal care, household composition, environment, personal wealth, the demand/supply balance, future national priorities, and the preferences of consumers.

- Most of these factors are pessimistic in their implications for LTC cost forecasts. Prices have shown an inexorable tendancy to rise. Increasing demand will inevitably mean that a smaller proportion can be expected from informal care, and must be met by purchased services.

Section 5 concludes.

- Estimates of LTC costs are not developed in this report. However, actuarial forecasting models should now be able to incorporate much better the evidence of health trends.

- A recent model from the UK is described which considers the implications of changing age-specific incidence rates for disability. Although not based on real data, it illustrates just how sensitive forecasts of LTC costs are to future trends in the incidence of disability.

1. Introduction

1.1 Purpose

This report was undertaken to review recent evidence about the changing pattern of health expectancy, that is the length of time a person lives in good or ill health, and to examine whether it is likely that this will:

- affect projections of future long term care (LTC) costs, either up or down;
- have other policy implications for long-term care costs, for example across modes of care.

Estimates of these costs are not developed in this report, which is a review describing what evidence is available about trends, and what should be taken into consideration when estimates of future costs are developed. Many of the examples are chosen from the UK, though work in France, Netherlands, Australia and elsewhere is cited. The most advanced research in this area comes from the USA and this is referenced particularly where no equivalent exists. However, it is intended that the general conclusions will be applicable to most OECD countries.

The costs of providing long-term care is a matter of increased concern globally, primarily as a result of the fall in mortality, which in particular increases the number of elderly people, and hence the overall prevalence of chronic health conditions.

The usual approach to estimating the future costs of long-term care has been to apply to future population projections, estimates of current age-specific cost rates, or possibly current age-specific utilization rates for treatments and services combined with predictions about future prices. This approach has been used by even sophisticated models such as the HCFA health model, when it has been applied to the question of predicting the implications of an aging population (Burner et al, 1992)[1]. However, costs will not necessarily increase *pro rata* with trends in the numbers of elderly people. The premise of this report is that the relationship between age and long term care need may change.

1.2 Role of Health Expectancy

A core question for predicting future long term care costs is whether the recent lowering of mortality rates, which have lead to an aging of the population, are being accompanied by a corresponding improvement in morbidity rates, particularly among older people.

What makes health expectancy, the number of years a person can expect to live at a given state

[1] The HCFA model was developed for the Medicare/Medicare programmes, but has been extended to include all US health care expenditure. It is not specifically an LTC forecasting model, but is probably the best known health care costing model. See Arnett et al (1986) for a general description.

of health, of particular interest to this question is that it provides a summary measure of the expected life-time duration in ill-health of populations. It is easy to see from the trend in this whether the demand for long-term care is likely to increase or decrease. It offers an answer to the question that has been of lively international debate: whether over the coming decades we can expect an expansion or compression of morbidity:

- Expansion of morbidity occurs when the decline in the incidence of morbidity is less than the incidence of mortality (Olshansky et al, 1991), which produces an increase in the expectation of the proportion of life lived in chronic ill-health, and is associated with a high growth in the prevalence of morbidity. The usual most pessimistic assumption is that age-specific morbidity rates will be unchanged, which is indeed the implicit position of the simplest forecasts of future health expenditure need. However, it is not impossible that age-specific morbidity might get worse in some circumstances.

- Compression of morbidity (Fries, 1980) conversely, means a reduction in the proportion of life lived in chronic ill-health, and is associated with low growth or even a decline in the prevalence of morbidity. Probably the most optimistic assumption is that the expectation of years in ill-health will remain unchanged as life-span increases, (though Fries has argued that the expectation of ill-health may actually fall). This is equivalent, under certain conditions, to an assumption that the prevalence of ill-health remains unchanged.

It is better to base future estimates on health care needs on the current *incidence* of ill-health, rather than current prevalence. Prevalence in chronic health conditions is affected by past history: for example past wars may continue to affect current disablement rates, as may the past state of health care as cases such as polio and thalidomide illustrate. If public health is changing, present prevalence may be a poor guide to the future. This is one reason why it is inadvisable simply to project current average age-specific expenditure rates to predict future long term care costs. Incidence is a better guide to the current state of health care, and hence to predictions of future health. (Of course better still would be an understanding of likely trends in incidence). The health expectancy methodology provides a means of estimating the future prevalence of ill-health in a population based on knowledge or assumptions about the age-specific transition rates between states of health.

Most cost studies focus attention on the cost to nations of ill-health at future points in time. Health expectancy also concerns a dual costing issue: the expected future life-time costs to individuals of their own ill-health. Both types of costing are of concern, though it has been the former which has received more attention. Arguably, the rise in private health insurance will focus much more attention on the latter.

1.3 Methods of measuring health expectancy.

Two rather different methods of measuring health expectancy are available. Both these methods normally measure the expectancy of good health from a particular age forward, but the expectancy of ill-health follows directly.

The first, for which national estimates are now available either at birth or at age 65 from around 35 - 40 countries, is known as Sullivan's method (Sullivan, 1971). This approach is the simpler in that it combines mortality table data with information about the prevalence of ill-health from a cross-sectional study.

The multistate method (Manton & Stallard, 1988) is based on estimates of the age-specific rates of transition between good health, ill-health and death. It requires some form of registration or longitudinal data. This method is much more difficult to put into practice and has only been demonstrated for health expectancies beyond 65.

The appendix provides a full comparison of the two approaches. The multistate method, which provides a true period estimate of health expectancy, is really far more satisfactory as a tool for forecasting future costs. It provides truer evidence of current trends in health, particularly at times when health rates are changing rapidly. It provides the methodology for generating future prevalence rates of states of ill-health, from evidence of current incidence rates.

Section 3 further compares the two methods, in relation to the available evidence.

1.4 Demand and supply.

We cannot consider health expectancy (or rather *ill*-health expectancy) in isolation. If it is not sufficient to base cost forecasts on an assumption that the average age-specific expenditure will remain unchanged, no more is it satisfactory to base them on simple projections of age specific incidence rates of ill health. There are other factors, besides ill-health, which affect an individual's demand for long term care and these can also be expected to change. Moreover, the supply situation for long-term care may also change and this will affect future prices, as well as the optimum balance between substitutable modes of care. A cost forecast should take into account the future balance of demand and supply.

2. The current cost of care.

This section concerns the relevant evidence about cost that is going to be needed by a model that predicts the future costs of care under assumptions of changing need. Essentially there are two bases which might be considered appropriate for costing projections.

- The first is to project forward the cost implications of current standards of care, usually in terms of service utilization rates or costs per patient (but ideally in terms of outcome standards), to a future population and future social conditions. This requires an understanding of the relationship between need and utilization, and hence cost. The heuristic device for this is the cost equation, often developed by fitting an econometric model to observed variations between individuals in needs and costs. The type of evidence available is reviewed in §2.3. Such a function provides a basis for making predictions about costs based on the future assumptions about needs and other cost-raising factors.

- The second is to work through the implications of applying needs-related normative criteria for long-term care services. For example, there may be interest in the future cost implications of a new eligibility criterion. This approach is reviewed in §2.4. Usually these criteria relate to services, and prediction of cost requires separate estimates of the unit costs of these services.

The approaches outlined in §2.3 and §2.4 are useful for what they contribute to understanding what aspects of need are most appropriate to the prediction of future costs. §2.1-2.2 are introductory and define long-term care and issues in the measurement of costs. §2.5 outlines limitations with the existing cost information described in §2.3 and §2.4. §2.6 outlines the other factors that might be expected to appear in a cost function, or equivalently might affect the future unit cost of care.

2.1 Defining long-term care.

There are various ways to define long term care. For the most part it is help given to individuals with chronic physical or mental health conditions which is essentially palliative - concerned to treat or ameliorate the handicapping or disabling consequences of the health condition - rather than to cure or moderate the condition itself. Long term care is associated with chronicity, and in practice the definition is most easily made in terms of the services which are primarily, if not exclusively provided for this purpose. The definition will not include long term interventions which are for the purpose of cure or control such as chemotherapy; nor with health monitoring or prevention; but may include short term palliative care for people with chronic ill-health such as occupational therapy; also possibly terminal care.

Useful distinctions may be drawn between:

2.1.1 *Health and social care*.

Health care interventions have the objective of reducing or ameliorating disability: for example, drugs or physiotherapy to improve mobility; while social care interventions are concerned with compensation or assistance to cope with the effect of the disability on daily life: for example, assistance with the problems caused by mobility difficulties such as shopping.

2.1.2 *Home based care and institution based care*.

The substitution of institutional by home based care is a common theme in the policies of most if not all developed countries: and is having a major impact on costs. Even within institutional care, downward substitution is made from hospital to nursing home care, and from nursing home care to residential care. If the policies are common, the reasons vary. Sometimes it stems from concern with the quality of institutional care or the impact of institutionalisation; sometimes as consequence of greater consumerism, more flexible services and a more market-based approach to providing services; sometimes it is motivated by a desire to re-establish the duties of the family, and to reduce costs to the state (though home based care can be expensive). Challis et al, 1995, argue that a consequence of these changes is increased concern with the targeting of services, and in general an increasing average level of dependence among clients within each service setting.

2.1.3 *The "client groups" for long-term care*.

Because long-term care is concerned with the consequences of ill-health rather than ill-health itself, it is often convenient to distinguish four groups: people with mental handicaps or learning disabilities; those with chronic mental health problems; those with physical handicaps or disabilities arising from chronic illness, and those with problems associated with old age. In the UK, people over 65 take more than 80 per cent of the total expenditure on long-term care, and their rising numbers makes them a particular focus of concern. However, there has been an equally large increase in psychiatric morbidity in the UK in recent years, (Lewis & Wilkinson, 1993), and the long term implications of this must also be of concern.

2.1.4 *Direct and indirect costs*.

Direct costs concern the benefit payments and purchase of the services that provide long-term care. Often these are the main concern of cost forecasts. But they are not all that is lost as a result of using resources to provide long-term care. Unpaid care, given by family, friends and charitable organisations, should not necessarily be regarded as a "free good", even if it cannot be immediately expressed in cash terms. Indirect costs also include, for the state as a whole, the economic loss resulting from both the loss of productive capacity among those who are ill, and the consequences of using other people to care for them. Van Roijen et al (1995) make a recent international comparison of the indirect costs of ill-health.

2.1.5 *Collectively and privately borne costs*.

There are many agencies and individuals who pay for long term care, and these may be classified as follows:

- Costs borne by the state. Direct costs may be divided according to the responsible statutory agencies. Thus in the UK the NHS is responsible for health care, local authorities for social care (through social services, housing and education departments), and the DSS for direct benefits (which are compensatory in nature, including invalidity benefits, attendance allowance).

- Costs borne by voluntary organisations and charities (some of which may be charged back to the state).

- Costs borne by privately purchased insurance.

- Costs borne by individuals, both those in ill health and their "informal carers": family and friends.

There has been much speculation about the future balance between these forms of financing, with an assumption in the UK as elsewhere that the role of the state must decline and that of privately purchased insurance must increase in future, and that efforts must be made to sustain the role of informal care.

2.2 Measuring long-term care costs, and unit costs.

A baseline for future prediction is the current cost of long-term care. It worth while mentioning that in practice, even with a definition that is tied to services and benefits within national accounts, it is by no means straightforward to establish this. Table 1 shows a recent attempt to estimate long term care costs in the UK, by Laing and Buisson (1995). This table includes elderly and younger physically handicapped people, but excludes mental health. It provides a breakdown by class of purchaser; NHS, local authorities, voluntary organisations, private direct costs and informal care costs. Yet although the source provides little commentary, such a table inevitably includes many hidden assumptions, for example:

- Much of public expenditure, particularly for LA's, is in fact recovered through charges to clients.

- Much of the private expenditure, particularly on institutional care, is in effect paid from public funds via social security arrangements.

- There is considerable use of estimates, for example to split out long term hospital care.

- Institutional costs are the total cost including not only care but also the normal living costs of those elderly and handicapped people. It is important not to over-estimate the

additional costs of long-term care. Raised living and accommodation expenses as the result of a health related condition are part of the costs of long term care but ordinary living expenses, and indeed ordinary health care, are not. For example Hurley et al (1995) present a method of estimating the additional costs of a disease by reference to the "normal" health care costs of comparable adults.

- There is great uncertainty about the estimation of informal care costs.

Prediction of future costs needs evidence not about total current costs but rather must be able to attach prices or costs to individual need, usually through the unit costs of treatments or services that may be included in long term care packages. But it is often surprisingly difficult to collect this information even for current services, and even harder to attach monetary values which reflect the long-run marginal social opportunity costs (Netten and Beecham, 1993).

2.3 Models of current standards of care.

The commonest method of forecasting is to project forward the cost implications of current standards of care, usually in terms of service utilization rates or costs per patient, to a future population. This requires an understanding of the relationship between need and utilization, and hence cost. Need is often proxied by age, and it is current age-specific utilization rates that are projected. However this is not appropriate if the relationship between need and age is changing. It is useful at this point to review the state of evidence about the relationship between need and utilization of long term care, and put on hold for the moment the question of how patterns of need will change in future.

Recent literature contains many examples of research to test health scales that are predictive of cost for people with long term care needs. The following are mainly from the UK, though there are equivalents elsewhere.

Mental Handicap. Raynes et al (1994) examine the relationship between disability, cost and quality of care for adults with learning difficulties in community residential establishments, and demonstrate the significance of dependency, measured by the Behavioral Development scale.

Mental Health. Knapp (1995) reports cost function analysis applied to several experimental programmes. In the Maudsley Daily Living Programme, the neurotic syndrome subscore of the Present State Examination and the SAS adjustment (daily living skills) scale were significant in both experimental and control samples. The neurotic syndrome subscale was again significant in the analysis of the Psychiatric Reprovision programme, together with the PSE negative symptoms subscale. In the Care in the Community demonstration programme, a behavioral problems scale was most significant both before and after discharge, while there was little difference between diagnostic groups.

Physical Handicap. Prouse et al (1991) demonstrate that severity of disability is the best

predictor of the cost of home and hospital care for young physically handicapped adults.

Elderly. Snell (1985) shows that variations in costs for elderly people in all settings can be explained by physical disability, mental characteristics, sex, and area of residence. Darton & Knapp (1986) and Judge et al (1986) estimate a cost functions for costs of residents in local authority and private homes respectively, with dependency (DHSS 4-fold scale) proving highly significant. Davies et al (1990) develop a cost function for domiciliary care in which significant factors are "critical interval" needs, household IADLs, incontinence, health events. O'Shea & Blackwell (1993) confirm that the cost of community care increases with dependency. Utting (1993) describes a new dependency scoring system based around mobility, feeding, continence and mental awareness, for costing care packages with very frail elderly people.

It is evident from this that a variety of health indicators have been tested. For elderly and younger physically handicapped people, it is activities of daily living, mental state, incontinence that seem to be predominate. For mental health, it is behaviour and neurotic symptoms. It is noteworthy that diagnosis rarely appears as significant in these models. There is a separate literature providing cost functions associated with particular chronic diseases.

2.4 Modelling the costs of resource allocation criteria.

Forecasts are often required to work through the implications of applying needs-related criteria for allocating long-term care services. Usually these are short-run forecasts, but there is no reason why the longer term implications should not be considered. This would seem appropriate at a time when many agencies and countries are attempting to improve radically the criteria for allocating state and insurance funded long-term care, and past utilization rates might be irrelevant.

Resource allocation criteria which affect costs could be of several types.

- Eligibility criteria for the purchase of care;

- Criteria for reimbursement to provider organisations (where these are based on client circumstances and not primarily an inducement to raise quality);

- Tools for resource allocation to agencies, for example geographic distribution formulae (in this case it is usual to establish a link between need and some more easily measurable surrogate).

In each of these cases, the allocation criterion has a direct effect on costs. Otherwise, even when these assessment tools are not immediately prescriptive, their use by case managers is intended to sharpen targeting and hence tighten the relationship between needs and costs. This is particularly true of assessment instruments designed for use by case managers. For example, this is the intention behind the Minimum Dataset Systems currently being developed

in the US (HCFA, 1993), and in Australia (Black & Madden, 1995).

Several compendia of assessment instruments are available: for example the Royal College of Physicians & British Geriatrics Society (1992); Rubenstein et al, (1995).

There are few examples of published eligibility criteria, where a decision to purchase long-term care is made directly on the basis of assessment instruments. Glaser (1991, p368) questions whether strict rules for purchasing long-term care could be sufficiently reliable in individual cases. This is not to say that eligibility rules are not used, but typically they are internal, contain scope for discretion, and are subject to rapid adjustment with changes in the availability of resources. Challis et al (1995) recently reviewed assessment criteria used long-term care for elderly people by local authorities. Table 2 shows the domains that were identified in an analysis of 50 assessment instruments being used for purchasing decisions about home and institutional care by local authorities.

Challis et al (1995) cite the Australian Resident Classification Index (DHHCS, 1992) as a model example of a standard assessment instrument for reimbursement. This is being used for nursing homes. The index contains 14 items and on this basis 5 levels of care need are defined: residents are funded for care hours per week on this basis. A similar index is being developed for residential homes.

The use of assessment systems within resource allocation falls under the heading of "needs based planning". Such systems define target groups of individuals according to the extent or nature of their need and then provide incentives to managers to achieve a match between levels of service allocations and this grouping. An early example in the UK was the Balance of Care model, developed originally for elderly people (Bowen & Forte, 1987). Perhaps the best known internationally is the Resource Utilisation Groups (RUGS III, Fries et al, 1994) which comprises seven clinical groups of elderly people in nursing home care, ranked by cost. These are rehabilitation, extensive services, special care, clinical complex, impaired cognition, behavioral problems, and reduced physical function. These groups themselves are defined in terms of ADL's, depression etc (except for rehabilitation).

It is of course quite practicable to apply the threshold rules of these normative criteria as definitions in constructing health expectancy. Given suitable data one can predict not just the number of people who at a point in time will be within the defined thresholds, but the rate of incidence of new cases, the length of stay within given thresholds, and the lifetime probability of having needs at that level.

2.5 Limitations of these approaches.

The literature reviewed above is subject to a number of limitations for modelling future health care costs than might be hoped.

For the cost function studies, in part this is because of the inconsistencies in the measures of health that have been investigated, and lack of consistent results from one study to another.

More serious however is that throughout these studies the relationship between health state and the cost of long term care is generally weaker than what most independent commentators believe to be truly the case, or certainly than what is appropriate. In the UK where most of these services are purchased by statutory agencies. This result has been associated with concern about the quality of assessment and review, the targeting of services, and consequently poor horizontal and vertical equity (Davies et al, 1990; Parker, 1990). Challis et al (1995) identify similar concerns in Sweden, Holland (following the Decker review of 1987), France, Germany and Israel.

A problem with many of the resource allocation criteria is that often they deal with only a subset of people with long-term care needs. For example, ARCI and RUGS reviewed above, are designed essentially for assessing people already in long-term care, when the most important resource decision has already been made. Systems designed to classify all potentially eligible people, such as Balance of Care and the Australian MDS, do not yet meet with general acceptance. This approach is best suited to projecting the cost implications of a specific programme, rather than long-term care generally.

These resource allocation criteria are essentially centrist in concept. They work best for services purchased on behalf of consumers by a single agency: state or insurer, where rationing rules can be applied. This raises the issue of take-up, where the consumer may in some cases want or get less of the service than he is judged to need. *Take-up* rates are very significant to some long-term care services, particularly if the consumer faces some charges, or there are access problems. Unless this is taken into account, applying resource allocation criteria as a basis of predicting future cost, will overestimate that cost. At one stage in the UK, normative models were estimating the gross need for domiciliary care at up to three times the existing level of provision, but an experiment to increase services accordingly resulted in under-use (Latto, 1982).

3. Trends in Long-standing Health.

The evidence of section 2 confirms that health is by far the most important indicator of long-term care need: though significantly it is not disease so much as the resulting state of disablement that seems to be related most closely to costs. Section 2 outlined many ways in which health can be measured. What is needed is some means of projecting forward these measures through time, in order to estimate future costs.

In practice there is a gap between the measures of need examined in cost studies and those for which epidemiological evidence about trends has been considered. This is not a large bridge to cross (and in §3.3 an example is cited which has), but will not be attempted here. This section reports the evidence on trends in states of health that are not too distant from those described in section 2, at least for elderly and younger physically disabled people.

Broadly speaking this evidence relates to two different types of health state. The first, following the ICD framework, concerns trends in specific diseases, and in particular in the expectation of life lived with particular diseases or types of disease. It is here perhaps that the future is most predictable (§3.1), but the link to long-term costs less certain. The second, following the ICIDH classification, concerns the consequences of diseases, in particular their effect on disability and handicap (§3.2-§3.3).

3.1 Trends in diseases causing chronic ill-health.

In recent years there have been considerable changes in both the incidence and the survival associated with many of the more common disabling conditions. Changes in lifestyle, developments in medicine and the organisation of services, improvements in drug therapy and surgical intervention, and changes in clinical attitudes towards older and disabled patients have all played a part. This subsection reviews this pattern of change in the recent past and expectations for the immediate future, in the incidence and duration of chronic disabling ill-health conditions.

3.1.1 *Which diseases are most important?*

One of the best sources of evidence about trends in diseases and their impact on disability, at least for elderly people, is coming from the US National Long Term Care Survey. This indicates a downward trend in age-standardised morbidity prevalence in many chronic diseases during the 1980's. Unfortunately results are so far unpublished and cannot be cited (see also §3.3).

A review of the health of elderly people in the United Kingdom (MRC, 1994) identified the consequences of cardiovascular and cerebrovascular disease, sensory problems (particularly vision and hearing), osteoarthritis, osteoporosis, incontinence, dementia and depression as the major causes of disability in later life. Bone et al (1995) followed methodology proposed by Mather (1992) in order to estimate the relative importance of different diseases to overall disability. Mather's analysis was based on the definition of disability used with the Australian

1988 Disability Survey. Bone et al (1995) reanalysed the 1986 UK Disability Survey, which defines 13 types of health-related disability, from abilities of daily living through to behaviour and communication problems.

In order to estimate the importance of separate diseases to overall disability, the "cause deleted" method was used (Tsai, 1978). This method compares healthy life expectancy ignoring morbidity and mortality caused by specific illnesses, with the normal measurement of healthy life expectancy, using Sullivan's method. It has the weakness that no allowance is made for the interaction of multiple illness, and requires that morbidity and mortality is attributed to just one main cause. Nevertheless it provides a basis for comparing the contribution of different diseases.

Table 3 shows the UK results, for diseases classified in terms of ICD9 chapters. The final column shows an interesting contrast between diseases. Those which have a negative score are essentially "disabling" diseases, whose reduction would contribute most to decreasing the duration of ill-health. These include diseases of the musculo-skeletal system (arthritis, osteoporosis etc), nervous system disorders (blindness, deafness), and mental conditions. On the other hand reduction in "life-threatening" diseases will actually increase the expectation of disability. These are principally neoplasms (cancer) and circulatory diseases (heart disease, stroke). Mather's (1992) results follow a similar pattern, though showing a much greater potential for reduction in injuries, due to different handling between the two surveys.

The "substitute morbidity" effect as people survive life-threatening conditions to increase their exposure risk to other conditions, has been investigated more fully in the Netherlands (Van de Water et al, 1995). Barendregt et al (1994) have used a different approach, modelling cross-sectional data to demonstrate that increased survival following stroke and heart disease substantially increases the expectation of life with disability.

It is therefore useful to focus on evidence on trends and likely future developments in these conditions that most affect the expected duration of ill-health. What ideally we require is to understand the incidence of these diseases, their expected duration either to death or recovery, and the likely severity of the disablement: and hence the extent of need for long term care that results. The empirical evidence is however patchy and these cannot be dealt with systematically. The present brief overview focuses on trends in cancer, stroke, heart diseases, arthritis and dementia.

3.1.2 *Cancer*

Recent trends in the incidence of cancer are reviewed by OPCS (1994). Table 4 shows mortality trends in the UK. Overall, there is little change in incidence at the present time, but the site of incidence and consequently the duration is changing quite fast. Thus there is a the decrease in "avoidable" cases, principally lung cancer among men and cancer of the cervix among women, also cancers of the digestive system. However there have been significant increases in other common cancers, particularly cancer of the prostate (men) and lung cancer (women).

3.1.3 *Heart disease*

There has been a significant decline in both morbidity and mortality (cf table 5) from the modification of risk factors in those at high risk of coronary heart disease (particularly hypertension, smoking, high serum cholesterol levels, and being overweight) which is likely to continue into future decades. Evidence from the Whitehall study of male civil servants (Shipley et al, 1991) suggests that cholesterol reduction in late middle age may reduce risk of CHD in old age. The benefits of risk factor modifications have also been demonstrated for blood pressure reduction (Farnsworth, 1993) and smoking cessation (Hermanson et al, 1988). Such data indicate that programmes of risk factor treatment may have a significant impact on future CHD mortality and morbidity rates.

Thus incidence is lower, but also new therapies mean that duration can be longer, and it is reasonable to expect changes in survival following acute MI, particularly with growing acceptance that treatment can be effective for older patients.

3.1.4 *Stroke*

Acute stroke represents one of the most common causes of mortality and morbidity among older people in the UK, contributing substantially to subjective reports of chronic ill health (Goddard and Savage, 1994). Nevertheless, epidemiological trends show a continuing decline in stroke incidence since the early 1960s (Casper et al, 1992). Although the reasons underlying falling stroke mortality throughout this period are not clearly understood, lifestyle changes and improvements in "socioeconomic resources" may well account for the trends. Using state event models to examine Dutch national data sets, Niessen et al (1993), for example, predict that patterns of stroke incidence will continue to decline in the Netherlands up to 2005.

Improvements in survival through the clinical management of acute stroke can also be expected, though at present the style of care appears to be associated with more clear-cut advantages than specific drug therapies, and the implication is that disability can be controlled but rarely eliminated (see for example, the overview of 15 controlled trials by Sandercock et al, 1993).

3.1.5 *Arthritis and Rheumatism*

The Central Health Unit Report (1992) on the health of the elderly identified these as by far the single most important disabling disease. The last decades have seen enormous advances in treatment for these conditions, with the introduction of anti-inflammatory drugs and routine replacement surgery. However, unlike the other conditions reported here, there seems to have been comparatively little investigation of the net effects of these improvements, and analysis of trends, at least in the UK. Undoubtedly improvements will continue to take place, though at the present time the focus seems to be more on service delivery issues and improvements in supportive care (e.g. Daltroy & Liang, 1993). The "substitute morbidity" effect is important. The prevalence of arthritis and rheumatism at a disabling level may well increase as a result of lowering death rates from other diseases. There are also some concerns that the effect of long term treatments with anti-inflammatories may eventually increase the incidence of other

disabling conditions.

3.1.6 *Dementia*

Although neglected for some time, clinical and research attention to dementia has developed rapidly over the past 10 years, with epidemiological data clearly identifying the condition as a major public health issue. From cross-sectional data Roelands et al (1994) have recently estimated that by the age of 85+, however, it was found that 20% of remaining life for men, and 30% for women, would be spent in the demented state.

At the present time, the foreseeable advances in care are only likely to influence survival rates associated with this condition, slowing the progress of disablement. These are first, the developments of new therapeutics which slow, but do not reverse the deterioration. Second, refinements in broader clinical management and supportive care which optimise post onset disability management. However Van Dijk et al (1991) found little evidence internationally of increasing survival from dementia, though possibly there are improvements for Alzheimer's disease specifically. The value of developing and marketing therapeutics which extend but do not modify this condition, has been questioned (Spagnoli, 1991).

3.1.7 *Conclusion*

The evidence from this review is mixed. Certainly we can conclude that the incidence of the principle conditions responsible for chronic ill-health, and their prognosis in terms of duration, severity, and likelihood of recovery, are not going to remain constant over the next 20 years or so. For cancer, if improvements take place they may open the way to "substitute morbidity" by health conditions which have a longer term disabling effect. The foreseeable reductions in CHD and stroke mortality among older people will leave more people disabled in the medium run (hopefully not at the severest end of disablement) and again increase chances of contracting other disabling diseases. For musculo-skeletal conditions and dementia, foreseeable improvements in mortality are only likely to increase prevalence. On balance, therefore, it seems likely that in the medium term the prevalence of disabling chronic conditions will increase.

What will happen in the longer term is not predictable, and there is no reason why ultimately we should not be optimistic. There seems to be a changing attitude towards the active treatment of older patients (Grimley Evans, 1991), and a growing body of evidence that treatment strategies formerly reserved for younger patients can be successfully deployed. It may well prove possible to find cures or significant reversals to chronic illnesses which have hitherto been regarded as the inevitable consequence of old age.

3.2 Trends in disablement, from Sullivan's method.

Several countries have now produced healthy life expectancy figures for more than one point in time, based on measures of handicap or disablement, which section 2 argued are more closely related than disease to the costs of long-term care. These estimates all use Sullivan's

method", combining period estimates of life expectancy with prevalence rates for disablement.

The international collaboration "Réseau Espérance de Vie en Santé" (REVES) is monitoring and reviewing these. The most recent contribute to the World Health Report is by Robine et al, 1995. Although there is some consistency in the measures of health used on each occasion, definitions of disablement or handicap vary between country. The same methodology has been employed for other health states, in particular measuring dementia-free life expectancy. Robine et al (1995) have assembled these national trends into broad types of measure, for selected OECD countries. The results for females are shown in tables 6 and 7. Table 6 shows that, with the doubtful exception of Canada, overall the trends indicate an expansion of morbidity. Whereas life expectancy has increased by about 6 years over a 25 year period, disability-free life expectancy at birth has remained around 63 years, varying partly according to the exact form of measurement. In the UK for example these trends have been produced from analysis of the General Household Survey, a national annual survey of around 20,000 respondents which asks about limiting long-standing illness:

- Do you have any long-standing illness, disability or infirmity?
- Does this illness or disability limit your activities in any way?

Thus the years of life expectancy gained appear to be years of disability.

Table 6 uses trends based on very inclusive measures of disability. Some of the countries included have monitored life expectancy free of different levels of disability. Trends in very severe disability are shown in table 7. These are more optimistic and suggest that improvements are taking place in line with advances in mortality.

Table 7 shows no UK figures, but a time series for people over 65 in the UK based on ability to perform certain Activities of Daily Living without help has recently been calculated (Bone et al, 1995). Inability to perform ADLs represents a severe level of disability, and the figures show similar trends to those of table 7.

This evidence indicates that the aging of the population is currently being accompanied by a pandemic of light to moderate disability, but that there is stability or even compression of disability of the more severe levels.

3.3 Trends in disablement, from the multistate method.

Despite this consistency in the healthy life expectancy trends, the above evidence is not wholly reliable. As discussed in §1.3, health expectancy calculated by Sullivan's method may fail to capture changes in the health status of a population as they occur, and indeed during a period of rapid improvement it is quite likely that Sullivan type measures will initially show an expansion of morbidity, even when morbidity is keeping pace with mortality. Furthermore equating residence in institutions with a particular level of disability will confound trends if the changes in role for institutional care that are taking place in many countries will affect the proportion or kind of people in institutions. (In defence of this approach, the length of time

over which these trends have now been measured does start to preclude these effects, which simulations have suggested are most noticeable during the early phases of change in morbidity).

Information about transition rates in states of health will be the key to improved projections of future costs. The 'healthy life expectancy' methodology can be used, for example, to predict the future prevalence of disability from current *incidence* rates.

The need for better information about the current age/sex rates of transition into and out of health states is widely recognised in many countries. The problem is that accurate measurement of incidence rates requires either:

- Registration information for states of ill-health. This is commonly available for notifiable diseases, but not for general states of disability or handicap, though some consideration is being given to this in the UK through GP surveillance systems, particularly for the very old.

- Longitudinal data about health states for individuals at successive points in time. A longitudinal survey must be large specially if these are to be used with younger people for whom changes in chronic health state are comparatively rare, and even larger with effective replacement methods if they are to be sensitive to small changes through time.

The result is that despite their potential, longitudinal surveys monitoring changes in health state are usually limited in scale and locality, and have invariable been focused on elderly people for whom the rate of change in health state is faster.

There is however one major exception that should be described. This is the US National Long Term Care Survey (NLTCS) based on a sample of 34,000 people aged 65+ drawn from Medicare records. Manton et al (1993a, 1993b) have now produced transition rates between levels of disability defined in terms of ADL's and also using their GOM profiles, based on the two year interval 1982-4 and the five year interval 1984-9. The GOM profiles define seven states: active, cognitively impaired, moderate IADL, physically impaired, frail, highly frail and institutionalised. These are ideal types produced by latent class analysis of health-related conditions. This approach has the conceptual advantage that it is easy to discuss appropriate interventions for a profile, but a practical problem with this approach is that real people represent composites of the profiles. The result is that estimates of transition probabilities, costs, etc, require complex mathematical modelling.

An example of the two-year transitions for ADL categories is shown in table 8. This does not show age specific rates, but these are also published. The reliability of these rates depend on a number of factors. Even with a sample of this size, the sampling errors of some of the smaller rates are probably larger than desirable. Non-response is a major problem for longitudinal health estimates, because the correlation between it and health status is well established. No more than 5% of the required follow-up set in 1984 were lost, and some imputation of these non-respondents was possible from their Medicare records.

It is worth noting that the estimated transition probabilities indicate a good deal of recovery from chronic states of ill-health. For example 49% of survivors among men aged 65 in the 'frail' GOM profile category are 'active' two years later.

The average annual per capita Medicare costs of each of the GOM profiles has been computed, thus providing the essential machinery for projecting future costs. There are large cost differences between the profiles.

The NLTCS transition probabilities have been used to simulate cohort life expectancies at each state of health. However future population prevalence, and hence a forecast of costs do not appear to have yet been published though this would be quite straightforward.

So far there is no evidence from the NLTCS as to trends in these transition rates. The published estimates for the GOM profiles (op cit, table 7) are said to be adjusted for anticipated decline in disability particularly at younger ages and at lower disability levels, but the empirical basis for this is unclear. It has been claimed of the NLTCS (unpublished evidence) that it is finding a falling age-standardised morbidity prevalence in many disease categories and hence compression of morbidity, also a decline in co-morbidity, but greater persistence within given health states and hence an expectation that the increasing demand for long-term care services will persist.

Other countries are examining the possibility of developing similar data sets. Foremost among these is the Australian Longitudinal Study of Ageing with people aged 70+, which will also eventually provide another set of national estimates of transition probabilities and multistate estimates of healthy/unhealthy life expectancy.

4. Trends in other factors influencing long-term care costs

This section considers factors other than population size and age structure, and the prevalence of ill-health, that may affect future costs of long term care. An individual's demand for long term care is affected by his social and material environment and their expectations, and these are also changing. Demand is complicated when the purchaser is distinct from the consumer, as with state provided services, and to a lesser extent, other insurers. Costs may be affected by other factors that enter resource allocation assessments (see for example table 2) particularly if these purchasers operate within budgetary constraints. Finally, the supply situation for long-term care may also change and this will undoubtedly affect prices. A cost forecast should take into account the future balance of demand and supply.

4.1 Personal Factors affecting demand.

The following factors should not necessarily affect the number of people demanding long-term care, but will affect what kind of care is provided, and hence its cost and just as significant, who pays for it.

4.1.1 *Informal Care*

Table 1 shows that informal care in the community, and in particular, from family and household, dwarfs all other sources of long-term care. Proportionally small changes in its availability could have much greater consequences on the demand for purchased care. It has been argued that social trends are likely to reduce the availability of care. Such trends include:

- A greater proportion of working women, particular at middle and older ages who are among the main providers of informal care.
- Reduction in birth rate since the 1930's and with reducing size of families fewer close relations to provide help.
- Increased divorce rate, breaking the cohesiveness of families and perhaps resulting in fewer daughters-in-law prepared to help.
- Greater mobility, so that many elderly people have moved away from the communities where they lived and where they might best expect to get help.
- Greater mobility, so that children have moved further away from their parents, and communities are no longer as stable as they once were.

In view of the substantial rhetoric about the effect of these changes, empirical evidence is in comparatively short supply.

4.1.2 *Household composition*.

Quite apart from their role in providing informal care, other household members affect the nature of the long-term care that is required by disabled people. For example:

- The reluctance to split married couples means that care providers are much more likely to attempt to support a disabled married person in the community than in a long-stay institution.

- Where other household members help a disabled person they may have support needs of their own. This is likely to increase the demand for services such as respite care and day care.

Thus trends marital status and household composition are likely to affect the nature of long-term care being sought, if not its scale. In the UK, there has been a steady fall in the average household size of adults with limiting long-standing illness, with more living alone, though numbers in married couple households have remained stable.

4.1.3 *Environment*.

Housing and locality can either facilitate or disable people with incapacities. On the one hand, there are increasing requirements to improve access facilities, both in homes and localities, and more receptive attitudes among the public generally to accommodating the needs of disabled people. Others point to the problems with the decline of localised services, particular shops and public transport, and in services willing to provide home deliveries etc. Urban environments are felt to be increasingly hostile and rural environments increasingly isolating, for disabled people.

There seems to be little evaluative evidence concerning whether changes in the environment are on balance, increasing or reducing the demand for long-term care, and little consensus on future trends.

4.1.4 *Financial circumstances.*

The resources available to a person with long-term care needs; in particular home ownership, pension and private insurance, will determine access and the context in which care will be provided and hence have a major impact on how costs are met (Wilkin et al, 1992).

- Housing. In 1990 around 55 per cent of adults with limiting long-standing illness in the UK either own or are buying their own home (from analysis of the 1990 GHS). The proportion seems likely to rise with each succeeding generation. For pensioners, this opens the opportunity for equity release schemes which provide scope for purchasing long-term care. Home reversion plans involve the sale and either lease back (at a nominal rent) of the property, or use of the resources to cover institutional care. These schemes are growing, particularly as they are obligatory for certain forms of state institutional care, even though there has been some popular opposition.

- Insurance. There is a growth of interest in new social care benefit schemes. The Netherlands introduced compulsory long-term care insurance some time ago, and Germany, where the problem of an aging population is most acute, have recently followed. There is a general expansion in private insurance schemes, though their high cost (and presumably younger people's unreceptiveness) makes them of limited popularity. Insurers are of course concerned about the lack of actuarial data on which to base risk. For a recent review of European policies, see George et al (1995).

4.1.5 *Expectations.*

Arguably, future generations will have higher expectations and so demand better, and hence more costly, long-term care than the average standards at present.

4.2 Purchasers and Demand.

Societal values do change through time and with them assumptions about the best options for care, as well as the willingness of society to pay, or to provide informal care. The rise in demand has caused questions about the capacity of insurance systems, and the willingness of nations to deflect increasing large percentages of their GDP to long-term care (Burner et al, 1992). Arguably, this is beyond the scope of financial forecasting.

4.3 Supply and price.

Finally we turn to reasons why costs may vary, for reasons which are to do with the supply rather than the demand for long-term care. Most forecasts for future long-term care costs simply assume that the price of services will remain constant, so that the future cost will be proportional to level of demand.

4.3.1 *The supply of labour.*

An indication of the potential problem with the supply of long term care in future comes from the dependency ratio: the ratio of children and those of pensionable age to the number of working age. Current projections in the UK suggest the dependency ratio will move from 64% to 80% by 2030, this increase being entirely due to the rise in numbers of the elderly (OPCS, 1993).

This is further complicated because of the importance of informal help in long-term care, and because the labour "pool" for formal and informal care overlap. If the price of labour increases, this will tempt away people who might otherwise have provided informal care. and so rising demand could cause many people to seek purchased help in the public or private sectors who formerly might have obtained informal care. If is assumed that purchased help is more expensive than informal help, then this will have a disproportionate effect on cost.
It follows that rising demand may affect costs not just in proportion, but as a result of the indirect effect on the demand-supply balance which affects the marginal costs of care.

Whether or not this is the case is a matter of knowing the elasticity of supply to price.

4.3.2 *Technology*

Technology advances and occasionally this can have a large effect on long-term care costs, as the example of mental health during the 1980's illustrated, where new drug therapies promoted the de-institutionalisation of many long term care cases. However, the postwar history of medical technology is far more typically to offer new or improved treatments at higher cost.

4.3.3 *Overall effect on prices*

Prices may vary with demand-related pressures, supply shortages, technology, and indeed the pricing policies of suppliers. Put together, these can have a significant effect. In the UK, Bebbington & Kelly (1995) estimate unit cost inflation for care provided by local authorities expanded by 47% in real terms over the 1980's. Price inflation is built into the HCFA model of healthcare costs. Burner et al, 1993, consider it is likely to be the single major force behind health expenditure growth in the US over the next 40 years.

A complication for these supply arguments is that if, for example, the price of long-term care rises, particularly in the direct costs borne by clients, then undoubtedly demand will fall even if this implies a changing standard for long-term care. So expenditure may be rather less sensitive than price to social changes.

5. Conclusion, and an illustration.

The work on health expectancy has produced some empirical consensus for developed countries as to trends at present. These are stability in life expectancy with severe disability, but an expansion of morbidity at less severe levels. Thus a minimally better assumption than constant age-specific costs through time, might be to assume that the gross demand for the most intensive long-term care will remain at a roughly constant level regardless of changes in the age-structure; while the demand for less intensive care will remain at present day age-specific levels. Such an assumption would undoubtedly lead to more optimistic estimates of long term care costs.

Future costs will depend on a considerable number of factors. It has been argued that future prices ought to be taken into account, and consideration should be given not only to the total cost of long-term care, but also how the burden of that cost might fall, the role of informal care, and also the life-time cost for individuals as well as the annual cost for society. For many of these factors the forecast is pessimistic in terms of costs. On the other hand, the growth of personal wealth may help to make more resources available, or spread the burden.

Even if estimates are continue to be made on a simple basis, it is at least useful to bear in mind these other factors, at the risk of neglecting the obvious. For example, in a related example for health care generally, Murray et al (1994) report that when applied to third-world countries, if the Health Resource Allocation Model is broadened to allow for expansion of the health infrastructure, then it will predict significantly lower costs for the same health gains.

However, there is no reason now why the more advanced actuarial models of health care finance, should not take on board estimates of health transition rates of the sort that are coming from the NLTCS.

We end with a brief review of a significant UK study that has attempted such an actuarial modelling approach for forecasting long-term care costs, and has indeed included age-specific health transition rates for projection future prevalence. It is due to Nuttall et al (1993). This model is concerned only with people over 65. It incorporates assumptions about trends in a number of the other factors discussed in this review. The model is however not based on real data, other than to provide some very broad starting parameters.

Estimates of future disability are based on a multi-state cohort model of health, disability and death. With the simplifying assumption of irreversible disability, a three-state model can be represented by the formula

$$l_x^d = (1 - q_{x-1}^d)\ l_{x-1}^d + i_{x-1}\ l_{x-1}^h\ (1 - ‰\ q_{x-1}^h)\ (1 - ‰\ q_{x-1}^d)$$

where l_x^d denotes the number of people who will be disabled when aged x, q_x^h and q_x^d denote healthy and disabled mortality rates, and i_x the incidence rates for disablement. Rough and ready estimates for the incidence and disabled mortality rates are produced partly using prevalence based methods akin to those used for healthy life expectancy (overall mortality rates are of course known accurately). Projections then apply assumptions about

improvements in these rates: partly on known mortality trends and partly using guesses. The result is a central projection which predicts a rise from 6.4m disabled people in 1991 to 8.5m in 2031: a rise from 15.4% to 18.5% of the total population. The disabled are divided into low, moderate, regular and continuous need and projections produced for each group. Significantly, the rate of rise is projected to be highest at the continuous level of disability.

An interesting refinement is to test sensitivity to different assumptions. Plausible variants produce a range which predict from 14.0% to 20.3% of the population will be disabled by 2031: even the most optimistic predicts more at the severest levels of disability.

To estimate the cost of long term care, a guess is made about the cost of care required at each level of need. (For low, moderate, regular, and continuous care this amounts to £35, £105, £210, £315 per week at 1991 prices). This gives a gross figure of £42bn per annum in 1991, close to estimates produced by a similar method to table 1. Assuming constant unit costs, under the central projection this would rise to £62bn by 2031, equivalent to a rise of £1,345 to £2,014 per annum per adult of working age. Variants are also produced assuming changes in unit cost. The result is a range of estimates of total cost between £29bn and £102bn, by the year 2031.

Finally, the authors consider the consequences of changes in the availability of informal care for how these costs would be met. At present (see table 1) about 77% of costs are met by informal care. If informal care is unable to increase its supply at all, this would mean that by 2031 it is meeting only 53% of total costs, leaving a shortfall of £15bn. If this were to be met entirely by state funding, it would imply state funding would virtually need to triple. The potential for increasing private funding is discussed but not quantified. The case for long term care insurance is argued.

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7. References

Arnett, R.H., McKusick, D.R., Sonnefeld, S.T., Cowell, C.S. (1986) Projections of health care spending to 1990. Health Care Financing Review 7, 1-36.

Barendregt, J.J., Bonneux, L., van der Maas P.J. (1994). Health expectancy, an indicator for change? Journal of Epidemiology and Community Health 48, 482-7.

Bebbington, A.C.(1992) Expectation of life measured from the OPCS Disability Surveys. In Robine, J.M., Blanchet, M., Dowd J.E., Health Expectancy (OPCS series SMPS no 54) London: HMSO.

Bebbington, A.C., Kelly, A. (1995) Expenditure planning in the personal social services: unit costs in the 1980's. J. Social Policy 24, 385-411.

Black, K., Madden, R. (1995) National Minimum Data Set: report on the 1994 full-scale pilot test. Canberra: Australian Institute of Health & Welfare.

Bone, M.R., Bebbington, A.C., Jagger, C., Morgan, K., Nicholaas, G. (1995) Health expectancy and its uses. London: HMSO.

Boon, N.A. (1991). New deal for old hearts: age alone should not be a barrier to treatment. British Medical Journal 303, 70.

Bowen, T., Forte, P. (1987) The Balance of Care system. London: DHSS Operational Research Service.

Burner, S.T., Waldo, D.R., McKuslick, D.R. (1992) National health care expenditure through 2030. Health Care Financing Review 14, 1-30.

Casper, M., Wing, S., Strogatz, D., Davis, C.E., & Tyroler, H.A. (1992). Antihypertensive treatment and US trends in stroke mortality. American Journal of Public Health 82, 1600-1606.

Central Health Monitoring Unit (1992) The health of elderly people: an epidemiological overview. London: HMSO.

Challis, D., Carpenter, I., Traske, K. (1995) Towards a national standard assessment instrument for residential and nursing home care. PSSRU, University of Kent, discussion paper 1179.

Crimmins, E., Saito, Y., Hayward, M. (1992b). Sullivan and multistate methods of estimating active life expectancy: two methods, two answers. In: Calculation of health expectancies: harmonization, consensus achieved and future perspectives. Eds Robine J-M, Mather CD, Bone MR, Romieu I. Colloque INSERM/John Libbey Eurotext Ltd.,226,155 -160.

Darton, R.A., Knapp, M.J. (1986) Factors associated with variations in the cost of local authority Old People's Homes. Chapter 8 of Judge, K. and Sinclair, I., Residential care for elderly people. London: HMSO.

Davies, B.P., Bebbington, A.C., Charnley, H. (1990) Resources, Needs and Outcomes. Guildford: Ashgate.

Davies, L.M., Drummond, M.F. (1994) Economics and schizophrenia: the real cost. Brit. J. Psychiatry 165 supp 25, 18-21.

Department of Health, Housing and Community Services (1992) Classification of Nursing Home Residents: Handbook for Directors of Nursing. Canberra: DHHCS.

Dunnell, K. (1995) Are we healthier? Population Trends 82, 12-18.

Farnsworth, T.A., Heseltine, D. (1993). Treatment of elderly hypertensives: some questions remain unanswered. Age and Ageing 22,1-4.

Fries, B.E. et al (1994) Refining a case mix measure for nursing homes: Resource Utilisation Groups (RUG-III), Medical Care, 32, 668-685.

Fries, J.F. (1989) The compression of morbidity; near or far? Milbank Memorial Fund Q. 67, 208-232.

George, V., Taylor-Gooby, P., Bonoli, M.G. (1995) Squaring the Welfare Circle in Europe: European Welfare Futures. University of Kent, UK.

Glaser, W.A. (1991) Health Insurance in Practice. San Francisco: Jossey-Bass.

Grimley-Evans, J. (1991). Aging and rationing: physiology not age should determine care. British Medical Journal 303, 869-870.

Health Care Financing Administration (1993) The Minimum Data Set Reference Manual. Natick: Eliot Press.

Hermanson, B., Omenn, G.S., Kronmal, R.A., Gersh, B.J. (1988). Beneficial six-year outcome of smoking cessation in older men and women with coronary artery disease. New England Journal of Medicine 319,1365-1369.

Hurley, S.F., Bond, L.M., Carlin, J.B., Evans, D.B., Kaldor, J.M. (1995) A method of estimating baseline health care costs. J. Epidemiology and Community Health 49, 525-531.

Judge, K., Knapp, M.R.J., Smith, J. (1996) The comparative costs of public and private residential homes for the elderly. Chapter 10 of Judge, K. and Sinclair, I., Residential care for elderly people. London: HMSO.

Knapp, M.R.J. (1995) The economic evaluation of mental health care. Aldershot: Arena.

Laing & Buisson (1995) Laing's Review of Private Healthcare, 1995. London: Laing & Buisson publications.

Latto, S. (1982) Managing the care system. In Glendenning, F. (ed) Care in the Community: Recent Research and Current Projects. Beth Johnson Foundation, University of Keele.

Levenstam A.K., Bergbom, E.I. (1993) The Zebra system: a new patient classification system. J. Nursing Management 1, 229-237.

Lewis, G., Wilkinson, G. (1993) Another British disease? A recent increase in the prevalence of psychiatric morbidity. J. Epidemiology & Community Health 47, 358-361.

Manton, K.G., & Stallard, E. (1988). Chronic disease modelling: mathematics in medicine No 2. London, Charles Griffin & Company Ltd.

Manton, K.G., Corder, L.S., Stallard, E. (1993) Estimates of change in chonic disability and institutional incidence and prevalence rates in the elderly population from the 1982, 1984 and 1989 National Long Term Care survey. J. Gerontology (Social Sciences) 48, 153-166.

Manton, K.G., Stallard, E., Liu, K. (1993) Forecasts of active life expectancy: policy and fiscal implications. J. Gerontology (Special Issue) 48, 11-26.

Mathers, C.D. (1992). Health expectancies in Australia 1981 and 1988. Australian Institute of Health: AGPS, Canberra.

Medical Research Council. (1994). The health of the UK's elderly population. MRC Topic Review, London, Medical Research Council.

Murray, C.J.L, Kreuser, J., Whang, W. (1994) Cost effectiveness analysis and policy choices: investing in health systems. Bull. World Health Organisation 72, 663-674.

Netten, A., Beecham, J. (1993) Costing community care: theory and practice. Aldershot: Ashgate.

Niessen, L.W., Barendregt, J.J., Bonneux, L., Koudstaal, P.J. (1993). Stroke trends in an ageing population. Stroke, 24, 931-939.

Nuttall, S.R., Blackwood, R.J.L., Bussell, B.M.H., Cliff, J.P., Cornall, M.J., Cowley, A., Gatenby, P.L., & Webber, J.M. (1993). Financing long-term care in Great Britain. J.Inst. Actuaries.

Office of Population Censuses and Surveys (1994)

Olshansky, S.J., Rudberg, M.A., Carnes, B.A., Cassel, C.K., Brody, J.A. (1991) Trading off longer life for worsening health: the expansion of morbidity hypothesis. J. Ageing & Health 3, 194-216.

O'Shea, E., Blackwell, J. (1993) The relationship between the cost of community care and the dependence of old people. Social Science & Medicine 37, 583-590.

Prouse, P., Ross-Smith, K., Brill, M. et al (1991) Community support for young physically handicapped people. Health Trends 23, 105-109.

Raynes, N.V., Wright, K., Shiell, A. (1994) The cost and quality of community residential care: an evaluation of the services for adults with learning difficulties. London: Fulton Press.

Richardson, J. (1994) Cost utility analysis: what should be measured. Social Science and Medicine 39, 7-21.

Robine, J.M., Romieu, I., Cambois, E., van de Water, H.P.A., Boshuizen, H.C., Jagger, C. (1995) Contribution of the network on health expectancy and the disability process, t othe World Health Report (WHR95). Montpelier: REVES.

Royal College of Physicians and British Geriatrics Society (1992) Standardised Assessment Scales for Elderly People. London: RCP/BGS

Rubenstein, L., Weiland, D., Bernabei, R. (1995) Geriatric Assessment Technology: the State of the Art. Milan: Editris Curtis.

Sandercock, P.A.G., van den Belt, A.G.M., Linley, R.I., & Slattery, J. (1993). Antithrombotic therapy in acute ischaemic stroke: an overview of the completed randomised trials. Journal of Neurology, Neurosurgery and Psychiatry 56,17-25.

Schoen, R. (1988). Practical uses of multistate population models. Ann Rev Sociol 14:,41-61.

Shipley, M.J., Pocock, S.J., Marmot, M.G. (1991). Does plasma cholesterol concentration predict mortality from coronary heart disease in elderly people? 18 year follow up in the Whitehall study. British Medical Journal 303,89-92.

Snell, M.C. (1985) Community care for the elderly: costs and dependency. Social Science and Medicine 20, 1313-18

Spagnoli, A. (1991). Clinical relevance in drug trials for Alzheimer's disease and related disorders. International Journal of Geriatric Psychiatry 5,265-267.

Sullivan, D.F. (1971). A single index of mortality and morbidity. HMSA Health Report 86,347-54.

Tsai, S.P., Lee, E.S. & Hardy, R.J. (1978). The effect of reduction in leading causes of death: potential gains in life expectancy. American Journal of Public Health 68, 996-971.

Tsevat, J., Weinstein, M.C., Williams, L.W., Tosteson, A.N.A., & Goldman, L. (1991). Expected gains in life expectancy from various coronary heart disease risk factor modifications. Circulation 83, 1194-1201.

Utting, D. (1993) Keeping score. Community Care 981, 19.

Van de Water, H.P.A, Van Vliet, H.A., Boshuizen, H.C. (1995) The impact of substitute morbidity and mortality on public health policy. Leiden: TNO-PG.

Van Dijk, P.T.M., Dippel, D.W.J., & Habbema, J.D.F. (1991). Survival of patients with dementia. Journal of the American Geriatric Society 39, 603-610.

Van Roijen, L., Koopmanschap, M.A., Rutten, F.F.H. et al (1995) Indirect costs of disease: an international comparison. Health Policy 33, 15-29.

Wilkin, J.C. et al (1992) Financing of long-term care costs: government proposals. Record (Journal of Society of Actuaries) 18.

Wilkins R., Chen J. & Ng E. (1994). Recent trends and longer term prospectives for health expectancy in Canada. The 7th International Meeting of the Network on Healthy Life Expectancy (REVES) Canberra 1994. (to be published)

World Health Organization. (1984). The uses of epidemiology in the study of the elderly: Report of a WHO Scientific Group on the Epidemiology of Aging. Geneva: World Health Organization, 1984 (Technical Report Series No 706)

Table 1: Expenditure on long-term care of elderly, chronically ill and physically disabled people, UK, 1993/4.

	£m	£m
Private nursing homes	2,762	
Private residential homes	1,820	
Total, private institutions		4,582
Voluntary nursing homes	253	
Voluntary residential homes	591	
Total, voluntary institutions		844
NHS long-stay geriatric hospital beds	866	
NHS elderly mentally ill hospital beds	502	
NHS younger physically disabled beds	52	
LA homes for elderly and YPH	1,196	
Total, public institutions		2,616
NHS district nursing	1,170	
NHS day care	150	
NHS chiropody	130	
Total, NHS community health		1,450
LA home care	900	
LA and voluntary day care	275	
LA other domiciliary care	270	
LA meals on wheels	90	
LA aids and adaptations	70	
Total, LA non-residential care		1,605
Private aids and adaptations	160	
Private home care	470	
Total, private non-residential care		630
Total of above		11,727
Informal care		41,000

Source: Laing & Buisson, 1995. Local authority costs expenditures are gross of client charges. Informal care values each hour provided at £7.00.

Table 2: Assessment domains for long term care of elderly people used by 50 local authorities

Functional/continence	%	Cognitive/psychosocial	%
Hearing/communication	96	Customary routine	90
Vision	90	Cognitive functioning	88
ADL Feeding	84	Behavior	82
ADL Transfer	88	Depression/anxiety/mood	58
ADL Bathing	92	Social integration	42
ADL Toileting	88		
ADL Dressing	94	Social/Environment	
ADL Grooming	40		
ADL Mobility	94	Participation in assessment	90
IADL Manage medication	80	Carer needs	90
IADL Prepare food	88	Financial circumstances	84
IADL Prepare hot drink	44	Home environment	96
IADL Shopping	80		
IADL Housework	82	Clinico-medical	
IADL Laundry	74		
IADL Manage money	76	Skin/feet condition	86
Rehabilitation needs	8	Disease/health conditions	58
Continence management	76	Nutritional status	58
		Dental	30
		Treatments	20
		Medication	18

Source: Challis et al (1995). Percentages are of assessment instruments which broadly cover this topic: structured questioning is much less.

Table 3. Life years and healthy life years saved from birth by the elimination of specific causes.

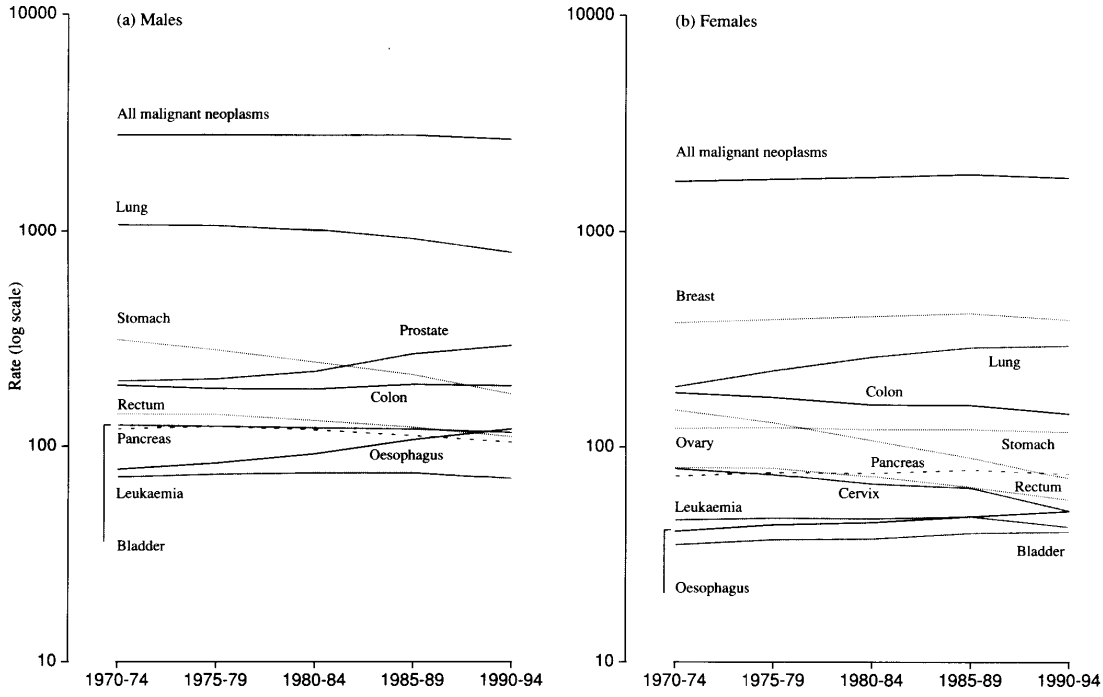
	Cause	Life Expt	HLE Expt	Effect on disability
Men				
1	Infectious diseases	72.48	64.76	-0.04
2	Neoplasms	75.73	66.64	+1.33
3	Endocrinal, metabolic	72.58	64.94	-0.12
4	Blood organs	72.44	64.69	-0.01
5	Mental disorders	72.53	65.34	-0.57
6	Nervous system	72.66	66.63	-1.73
7	Circulatory system	79.79	70.35	+1.68
8	Respiratory	73.56	66.24	-0.44
9	Digestive	72.70	65.03	+0.09
10	Genito-urinary	72.51	64.86	-0.11
11	Pregnancy	72.40	64.64	0.00
12	Skin	72.41	64.69	-0.04
13	Musculoskeletal system	72.44	66.11	-1.43
14/15	Congenital (& natal)	72.69	64.93	0.00
16	Signs and symptoms	72.60	65.01	-0.17
17	Injuries, poisonings	73.38	65.97	-0.35
	Undeleted	72.40	64.64	0.00
Women				
1	Infectious diseases	78.20	68.06	-0.05
2	Neoplasms	81.72	70.08	+1.45
3	Endocrinal, metabolic	78.36	68.35	-0.18
4	Blood organs	78.18	68.00	-0.01
5	Mental disorders	78.37	68.94	-0.76
6	Nervous system	78.40	70.13	-1.92
7	Circulatory system	86.38	73.55	+2.64
8	Respiratory	79.21	69.03	-0.01
9	Digestive	78.52	68.41	+0.08
10	Genito-urinary	78.25	68.15	-0.09
11	Pregnancy	78.13	67.94	0.00
12	Skin	78.14	67.99	-0.04
13	Musculoskeletal system	78.26	71.45	-3.38
14/15	Congenital (& natal)	78.40	68.22	-0.01
16	Signs and symptoms	78.30	68.41	-0.30
17	Injuries, poisonings	78.64	68.71	-0.26
	Undeleted	78.13	67.94	0.00

Source: Bone et al (1995). Effect on disability is measured as:

(Cause deleted LE - Cause deleted HLE) - (Undeleted LE - Undeleted HLE)

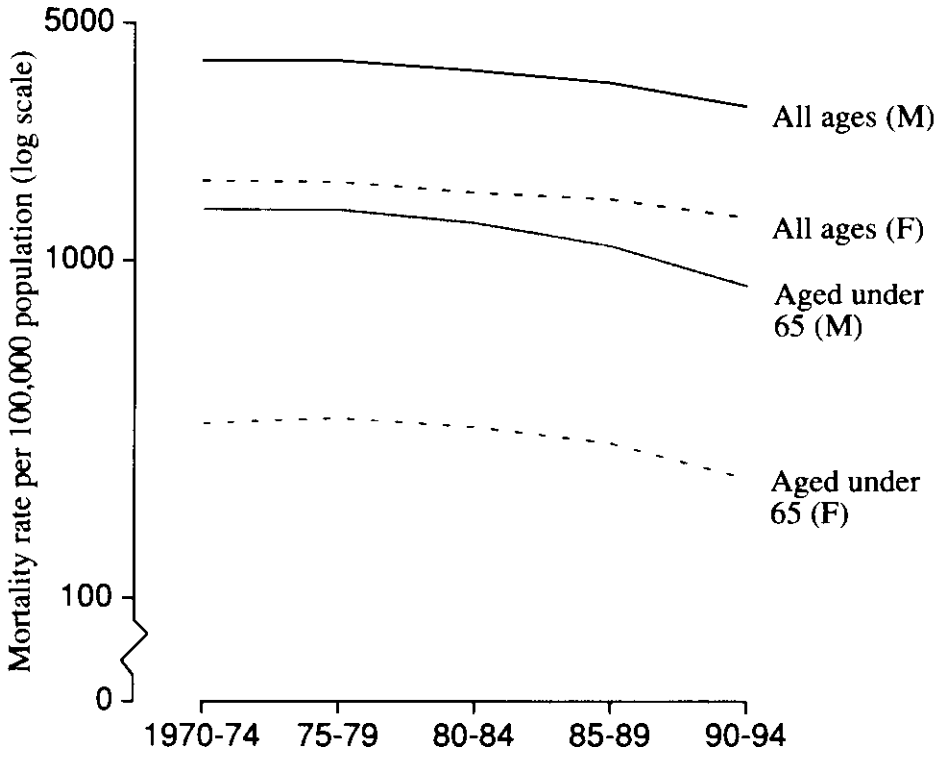
Figures show the expected *increase* in years of disability resulting from the elimination of each disease.

Table 4: Main types of cancer: age-standardised death rates per million population by sex, 1970-74 to 1990-94, England and Wales



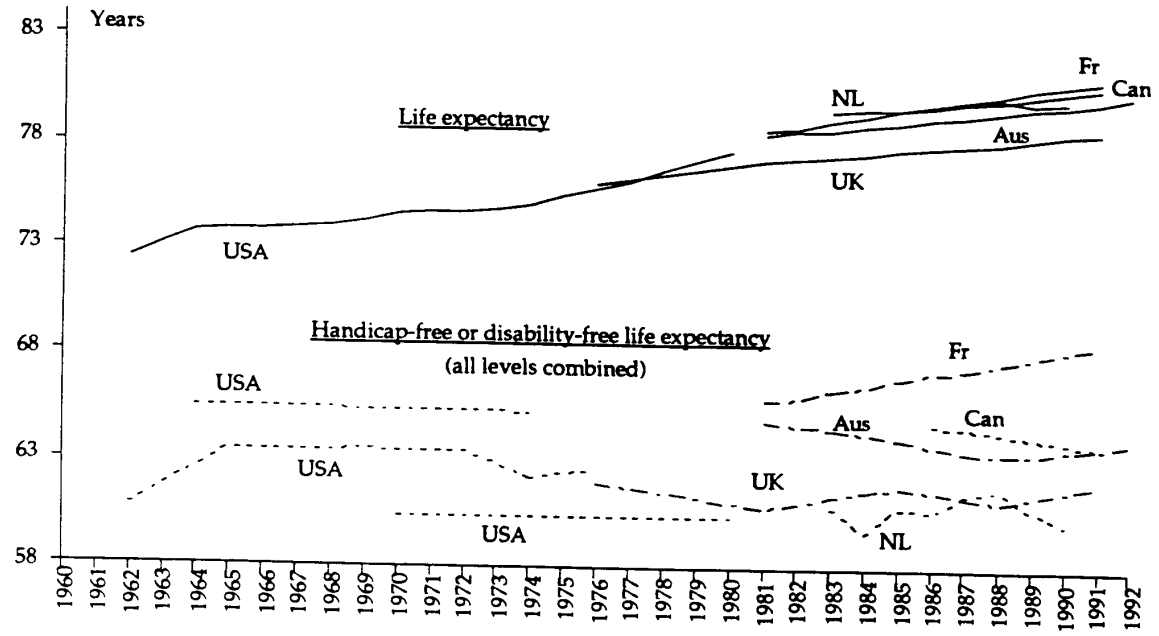
Source: Dunnell (1995)

Table 5: Standardised mortality rates for coronary heart disease by sex and age, 1970-94, England and Wales



Source: Dunnell (1995)

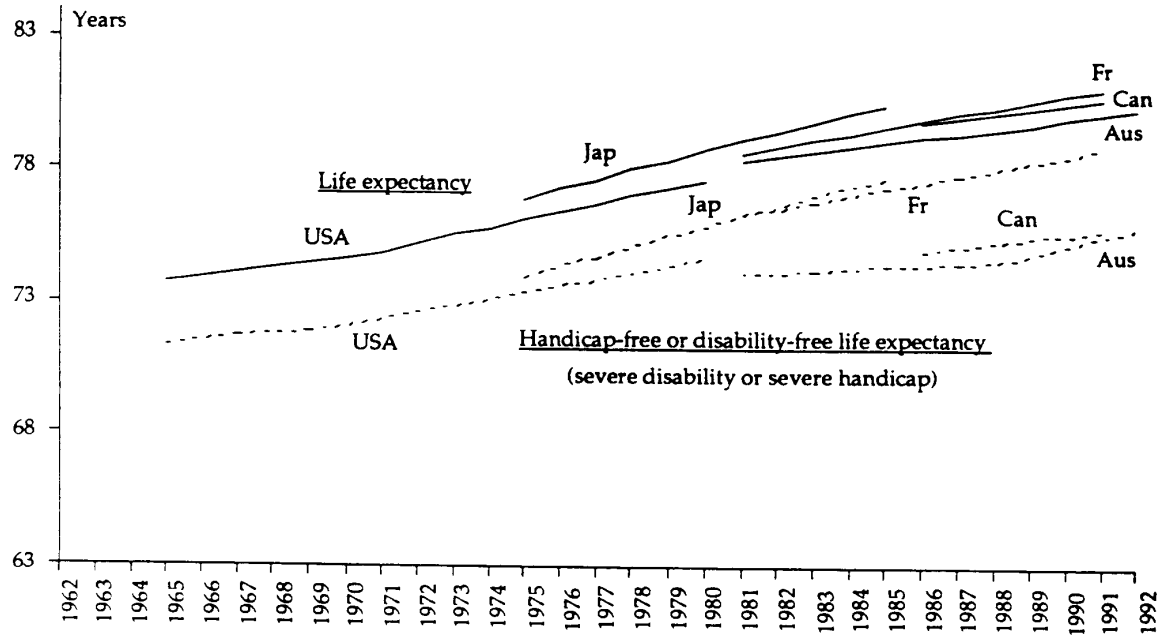
Table 6: Disability/handicap-free life expectancy, females at birth.



Source: Robine et al (1995).

These graphs are based on definitions that typically include all people with any permanent restriction of activity: the ones at the bottom may include short term restrictions as well.

Table 7: Severe disability/handicap-free life expectancy, females at birth.



Source: Robine et al (1995).

These graphs are based on definitions that typically include people who are bedridden or unable to live outside an institution.

Table 8. Changes in Functional Status in the U.S. Elderly Population (% Distribution): Estimates from the 1982, 1984, and 1989 National Long-Term Care Survey.

Disability Level	Non-disabled	1 ADL only	1-2 ADLs	3-4 ADLs	5-6 ADLs	Institu-tional	Dead
Nondisabled							
1982-1984	85.3	3.4	3.2	1.1	0.9	1.2	4.9
1984-1989	86.5	2.4	2.5	.9	.8	1.3	5.7
1ADLs only							
1982-1984	16.7	31.4	20.0	5.5	5.5	7.1	13.9
1984-1989	7.5	42.1	18.7	3.9	4.3	5.3	18.2
1-2 ADLs							
1982-1984	10.6	12.5	30.5	11.0	6.8	8.1	20.5
1984-1989	3.4	5.5	46.9	12.8	4.1	8.0	19.5
3-4 ADLs							
1982-1984	3.4	4.0	17.7	19.0	18.3	9.0	28.5
1984-1989	.2	1.2	10.9	44.7	11.1	8.9	22.9
5-6 ADLs							
1982-1984	1.1	4.1	8.5	9.4	32.3	9.1	35.5
1984-1989	.4	1.3	3.9	6.0	41.5	7.6	39.2
Institutional							
1982-1984	1.2	1.3	1.7	1.7	1.5	56.2	36.5
1984-1989	.2	.5	.9	.4	.8	59.1	38.1

Source: Manton, Corder & Stallard (1993).

Appendix: Methods of calculating Health Expectancy

(Adapted from Bone, Bebbington, Jagger et al, 1995).

Two main ways are used to calculate Health Expectancy: one is the Sullivan method (Sullivan, 1971), and the other is the multistate life table method (Manton and Stallard, 1988, Schoen, 1988). Sullivan's method is the most commonly used because it is applied to cross-sectional data on the prevalence of disability which are widely available from regular surveys and censuses. If the rates at which people become ill remain relatively stable over the long term, it produces good health expectancy measures for monitoring the health of a population over time. All the results presented in tables 6 and 7 are based on the Sullivan method.

The use of prevalence data assumes that people of a given age will later experience the same prevalence of morbidity as those older than themselves. This is unsatisfactory because current prevalence depends on the past history of cohorts; for example, the decline in smoking means that younger cohorts will not experience the same prevalence of smoking related diseases and any consequent disabilities as those now in their 60's and 70's. A truer picture of the way the health status of the population is evolving is given by the rates at which people are currently becoming ill or recovering, and more generally by the rates of transitions between health states. It is these rates which drive the future evolution of prevalence rates, and which are affected by interventions long before the impact on prevalence is manifested. Transition rates are therefore essential for making projections and will produce much better and more informative estimates than prevalence rates of the effect of health care and other interventions.

Health expectancy is calculated from transition rates by the multistate life table method. The multistate method can be used to calculate the Health Expectancy of a population at a particular time (like the Sullivan method), or to calculate the Health Expectancy of successive cohorts of the population as they pass through life - or its later years. The second application improves understanding of health trends and longer term projections of the health state of the population.

Both methods of calculating Health Expectancy are based on that for life expectancy, which is one of the values produced in a standard life table. Just as the latter summarises information about mortality, so these methods summarise information about both mortality and morbidity.

In what follows we describe each method in more detail, and compare their advantages and disadvantages.

The life table and life expectancy

To appreciate the difference between the Sullivan and multistate life table methods, it is useful to recall features of the standard current life table.

The current life table, among other things, shows for someone of a given age (eg, at birth) the further years of life they can on average expect - *if they were to experience the currently prevailing age specific mortality rates*. The basic information required to construct a life table is a series of age specific mortality rates, derived from:

- the numbers in the population at successive ages at a given time point (eg, the midpoint of a specific year - often a census year);

- the numbers of deaths occurring at each age during a defined surrounding period (eg, the whole calendar year).

The mortality rate (${}_nq_x$) is the basic function of the life table, from which all other functions are derived.

Box A1: Calculating the expectation of life without disability by the Sullivan method

1. For each age/sex group obtain the life table schedules l_x and the expectation of life e_x for the year of interest.

   Calculate:

   $$ {}_nL_x = e_x.l_x - e_{x+n}.l_{x+n} $$

   ${}_nL_x$ is the conventional life table measure of the average number of person years lived in the age interval x to x+n.

2. Obtain the disability rate ${}_nd_x$ in each age group observed in a survey or census. If they are excluded, add the numbers in institutions catering for the disabled. Calculate the average number of persons aged x to x+n living without disability in each age/sex group as

   $$ {}_nLWD_x = {}_nL_x(1-{}_nd_x) $$

3. Calculate life expectancy without disability as

   $$ elwd_x = (\Sigma LWD_x)/l_x $$

   where the summation is from age x upwards.

Health Expectancy : Sullivan's Method

Unlike conventional life tables, Sullivan's method uses prevalence rates; that is, in the case of morbidity. As noted earlier, the proportion with morbidity at each age at any one time depends on the past history of the population - for example, experience of an earlier war or epidemic. Consequently, Health Expectancy calculated in this way may be biased. It represents the current health status of the population, but takes no account of current rates of becoming ill and of remission, unless they have remained unchanged for a long period. If rates have remained unchanged, and measurement is accurate in both cases, Sullivan's method produces the same Health Expectancy values as the more elaborate multistate method; otherwise the Sullivan indicator lags behind the multistate version. Simulations suggest, however, that Health Expectancies derived by Sullivan's method will be very similar to those calculated by the multistate method even when morbidity and remission rates (transition rates) have changed, providing the changes have been smooth and relatively regular over the longer term (Robine and Mathers, 1993). It is for this reason that it was said

earlier that in *certain* circumstances (i.e. where there are no abrupt changes in transition rates) Sulllivan's method produces good health expectancy measures for monitoring the health of a population over time and for comparing the health of different populations.

The information needed to apply the Sullivan method is:

- data from current life tables

- the age specific prevalence of disability in the population, which is often available from a regular survey or census (although estimates may need to be made for the population in institutions).

Essentially, the method involves partitioning life expectancy into years with and without morbidity. The method of calculation is shown in Box A1.

Health Expectancy : Multistate Method

Multistate tables yield measures of Health Expectancy based on movements between health states; that is, transitions. The Health Expectancies may be for the whole population of a particular age (population based), or for those in a given health state at that age (status based). The method therefore makes it possible to compare Health Expectancies for those in different health states and to show the rates of moving between states during a specified time interval. The rates at which people acquire various kinds and levels of disability, and the time they spend in these health states before improving or dying determines their need for different health and social services. It is because they yield both more accurate and richer information that multistate life tables provide a better basis than the Sullivan method for predicting service needs and for estimating the effects of particular interventions. In addition, the transition probabilities allow the prediction of the life-time risk to individuals of particular states of ill-health, and projections of the future health state of the population, and so of related health and social care needs.

As noted earlier, multistate life tables may be used to derive Health Expectancies for a population at a particular period, or for real cohorts.

The information needed to calculate Health Expectancy by the multistate method is:

- the health/disability/handicap status of individuals in a population at successive time points from which the intervening transition rates can be calculated;

- information about deaths among those individuals during the period of observation.

The data can be obtained from a longitudinal sample survey or recording system of the relevant population in which data for those initially included are recorded over time. The method of calculation is shown in Box A2.

Box A2: Calculating health expectancy by the multistate life table method.

Illustrated here for three health states, healthy (0), unhealthy (1) and dead (2).

1. Form the 2x2 matrix $\mathbf{M}_x$ of transition rates at age x as follows

$$\mathbf{M}_x(1,1)={}_{01}\mu_x+{}_{02}\mu_x,\ \mathbf{M}_x(1,2)=-{}_{10}\mu_x,\ \mathbf{M}_x(2,1)=-{}_{01}\mu_x,\ \mathbf{M}_x(2,2)={}_{10}\mu_x+{}_{12}\mu_x$$

where ${}_{ij}\mu_x$ denotes the estimated proportion of people in living in state i at age x who are in state j at 'n' years later. The diagonal entries of $\mathbf{M}_x$ give the total force of transition out of the state.

2. Calculate

$$\mathbf{P}_x = [\mathbf{I}+\tfrac{1}{2}n.\mathbf{M}_x]^{-1}[\mathbf{I}-\tfrac{1}{2}n.\mathbf{M}_x]$$

where $\mathbf{P}_x$ are the transition probability matrices. The (ij)th element of $\mathbf{P}_x$, ${}_{ij}P_x$, is the probability that a person in state i (i=0,1) at age x will survive and be in state j (j=0,1) at age x+n.

3. The familiar life table relationships are now carried forward in matrix notation as follows

$$\mathbf{l}_{x+n}=\mathbf{l}_x.\mathbf{P}_x$$

where $\mathbf{l}_0$ is a 2x2 diagonal matrix with entries a and b with a=10,000 x (proportion observed in state 0 in lowest age group at first observation), and b=10,000 - a.

4. Calculate

$$\mathbf{L}_x=\tfrac{1}{2}n.[\mathbf{l}_x+\mathbf{l}_{x+n}],\ x < N,\ \text{the upper age bound of the life table,}$$

and

$$\mathbf{L}_N=\mathbf{M}_N^{-1}.\mathbf{l}_N$$

5. If ${}_0l_x = {}_{00}l_x + {}_{01}l_x$ denotes the number of survivors in state 0 at age x and ${}_0L_x$ the number of person years lived by these survivors, with ${}_1l_x$ and ${}_1L_x$ denoting the equivalent quantities for state 1. Then the total years lived beyond age x in state i (i=0,1) is given by

${}_iT_x=\sum {}_i\mathbf{L}_k$ where the summation is from x to N.

6. The healthy life expectancy at age x is then given by

${}_0e_x={}_0T_x/{}_0l_x$

Unhealthy life expectancy follows the same way. The method is easily generalised to 'k' health states.