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Healthy life expectancy and long-term care. Presentation to the Royal Commission on Long-Term Care

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PSSRU discussion paper 1426 March 1998

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The **PERSONAL SOCIAL SERVICES RESEARCH UNIT** undertakes social and health care research, supported mainly by the United Kingdom Department of Health, and focusing particularly on policy research and analysis of equity and efficiency in community care, long-term care and related areas — including services for elderly people, people with mental health problems and children in care. The PSSRU was established at the University of Kent at Canterbury in 1974, and from 1996 it has operated from three sites:

Healthy Life Expectancy and Long Term Care. Presentation to the Royal Commission on Long-Term Care.

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Discussion Paper 1426, March 1998.

Summary

- The Healthy Life Expectancy programme is working, in an international community, to establish the changes in patterns of health through the present demographic transition, and with their consequencies for health policies.
- Many future estimates of the need for long term care tend to be pessimistic. They tend to
 assume that current age-specific rates of disability will continue. A more optimistic
 assumption is that the changes which are producing greater longevity will also improve
 health expectancy.
- Empirical evidence on trends in disability from the UK supports the view that health expectancy is indeed rising, at least at severe levels of disability. On this evidence, it is by no means impossible that the numbers of people needing intensive long-term care will stay the same as at present, even though the population ages. On the other hand, at milder levels of disability there appears to be no such improvement.
- The length of time in disability, and hence the demand for long-term care, is greater among women and those in lower social classes. There are considerable variations between areas of the UK.
- The empirical evidence from the UK remains slight, though it is supported by corresponding
 results in other developed countries. There is an urgent need for a national survey of health
 and disability particularly for elderly people, which will establish the incidence rates of illhealth and recovery, and allow us to project the future need for long-term care with much
 greater certainty.

1. Introduction.

The future demand for long term care will be determined above all else by the future health of the population, particularly in respect to health associated with longstanding disablements.

Future patterns of family structure, informal support, housing, wealth, insurance etc are all important but essentially affect what type of help is sought, and how it will be paid for, not the underlying level of demand.

[SLIDE 1]

One of the main purposes of the Healthy Life Expectancy programme is to monitor and predict long-term trends in health. The intention is to provide empirical evidence that has a crucial role in estimates of future costs of long term care.

Healthy Life Expectancy is a measure of health free from chronic disorders that is as simple in conception as life expectancy, and like it expresses data about populations in a form that has an immediate interpretation at the level of the individual. Calculation methods were developed some years ago, and for a while now we have been applying them to various measures of health¹.

This presentation starts from the proposition that the number of people in future who are going to need long-term care, will be much less than is generally believed today. Indeed, it is possible that the number of people who need intensive long-term care will never increase greatly over present levels.

This presentation is in three parts. The first will be to explain the basis for this proposition. The second is to review what evidence we have about trends, and to consider what they imply. The third is to make a case for the urgent need for improved information so that we in this country could say with much more certainty what our future long-term care needs will be.

2. Will levels of need for long term care necessarily rise?

The reason for the present concern is because of the expected rise in the number of old people, who are the principal users of long term care. For example the number of people aged 85+ in this country has practically doubled in the last 40 years and will do so again in the next 40 years.

Why are there more old people? In theory there are two possibilities. The first is that more people

¹ Bone, M.R., Bebbington, A.C., Jagger, C. et al (1995) *Health Expectancy and its uses.* London: HMSO.

are being born, and the second is that they are living longer. The first of these possibilities can be ruled out immediately. Throughout this century, the number of births has on balance declined, from about 950 thousand a year around 1900 to about 650 thousand now². There have of course been birth booms at certain times, and those of the late 40's and early 60's period will of course be significant in the second quarter of the next century.

However, the increase in numbers of elderly people is entirely due to increased longevity. It can be assumed that this is primarily due to improvements in health enabling people to live longer. The question then is, if health improvements have improved life expectancy, what have they done to healthy life expectancy?

[SLIDE 2]

The second slide shows two possibilities for what might be happening. At the top is a bar representing 75 years of life expectancy, of which 70 years is spent in good health, and 5 in ill-health. The way it is ordered makes it look as if the ill-health will be all at the end. This is not of course strictly the case, and my argument does not rely on it, but it simplifies things if for the moment we assume this is approximately what happens.

Suppose life expectancy increases to 85. At the extreme, this might be managed in one of two ways, represented by the two lower bars. The upper one shows a situation in which the expectation of healthy life remains unchanged, all the additional life is in a state of ill-health. This situation would arise if health advances serve only to keep ill people alive longer, and is a deeply pessimistic assumption. The second one assumes that the health advances that result in greater life expectancy push the amount of healthy life along equally, so people can expect no more unhealthy life than before. This is an optimistic assumption.

Obviously we might also have any situation in between, or even outside these extremes.

It is worth considering what each of these cases implies about trends in numbers. The pessimistic situation says: people over 70 today typically are in ill-health, so let us assume that in future people over 70 will be in ill health. Thus it is supposed that the growth in the number of people over 70 leads to a directly proportional increase in the amount of ill-health.

In the 'optimistic' case, we are assuming that the same number of people continue to be born, and that each person experiences the same amount of ill-health in their life time, as they do present. In this case the number of people who are ill will always stay the same, even though there are more old people in the population.

² B.Werner, "Fertility statistics from birth registrations in England & Wales, 1837-1987." *Population Trends* 48, 4-10.

[SLIDE 3]

What do each of these scenarios imply about estimating future need for long-term care? Most estimates of future demand are based on age-specific need rates. Thus at present, we may have determined from current usage rates that the probability of needing long term care is 1% of people under 60; 5% between 60 and 70, and 30% when over 70.

The pessimistic option is to assume that the age-specific health rates stay unchanged, and the amount of long-term care needed rises roughly proportionally with the number of people over 70. In this case healthy life expectancy will improve comparatively little.

By contrast, the 'optimistic' scenario is to assume that as life expectancy advances, the disablement rates will move forward with it, as in the slide. The implication is that people will be older when the probability of needing long term care starts to rise. Healthy life expectancy will advance much in line with life expectancy, and with a constant birth rate there will be no increase in the number of people who need long-term care³.

Much of the pessimism about our future long-term care needs arises from the implicit assumption that we are in this situation of no improvement in health rates. Often this assumption is used, at least as a starting point, by models predicting future need for long-term care. This way of thinking is characteristic of our time, but it has not always been so. The costings for the Report of the Beveridge Committee, for example, were made on the basis that health would improve Demographers abroad concerned with the same problem seem instinctively to adopt more optimistic starting assumptions.

This tendancy to pessimism may occur because people fail to appreciate that a rise in the elderly population caused by increased longevity is rather different from a rise caused by increased births. If there were more elderly people purely because more people were being born 75 or so years ago, then it would be quite reasonable to assume that levels of need would rise in proportion to numbers.

3. What is the evidence?

Chronic ill-health among elderly people is often characterised by the level of disability it causes. We have been able to establish trends in disability for people over 65 with regard to a range of activities of daily living, using the General Household Survey for 1980, 1985 and 1994⁴.

³ This, and the remark about HLE in the following paragraph, are not invariably true, but seem to hold good in simulations based on current health and mortality rates. See the addendum.

⁴ This is based on Bebbington & Darton (1996) *Healthy Life Expectancy in England & Wales: Recent Evidence.* PSSRU Discussion Paper 1205, tables 2 and 4. Data on limiting longstanding illness is actually for 1981, not 1980.

[SLIDE 4A,B,C,D]

The life expectancy at 65 in these three years will be compared with three health measures.

1. People not able to climb stairs indoors without help, based on data from the 1994/5 General Household Survey. This is a severe disability affecting about 10% per cent of all people over 65. It is closely associated with the need for considerable long-term care. More than 75% of people who enter residential and nursing care are disabled to this extent. Trends in disability free life expectancy are shown, and follow trends in life expectancy fairly closely, as in the optimistic scenario.

2. People not able to go outdoors without assistance. This is a less severe disability affecting about 20% of all people over 65. There has been some improvement but the trend is less.

3. People who say they have a long-standing illness which limits their activities. 40% of all people over 65 are in this condition. There has been comparatively little improvement in the expectation of life free from limiting long-standing illness. The two years of increased life expectancy since 1980 are years of ill-health. This corresponds to the pessimistic scenario.

The interpretation is that at the severest states of disability, there is an improvement in healthy life expectancy in line with improvement in mortality. If so there should be little increase in the numbers of people who at any time are in very severe disability.

However the expectation of disability at moderate levels is increasing. An aging population is producing a proportionately increasing number of people with moderate chronic ill-health. This pattern has been duplicated in studies in several developed countries, including the US, Japan, Australia, Canada, Netherlands, though France has been an exception⁵.

The implication for the demand for long term care, with an aging population, is that demand for services designed for the most disabled will remain much the same, but that demand for services intended for lower levels of disability will rise pro-rata with the number of elderly people.

4. Risk factors

The project has been looking at some of the factors identified with variations in healthy life expectancy. The following is a brief summary of the conclusions.

⁵ See for example Bone, M.R. et al (1995) op. cit. Chapter 5.

Gender: All studies find that women can expect to live a longer time life in ill-health than do men. Women live a greater proportion of their life in ill-health, and as such typically have greater longterm care needs. We have recently applied healthy life expectation techniques to current admissions to residential and nursing home care, that is, regarding admission like another sort of health event. What emerges is that risk of admission is now already very high for women. Based on present admission rates, one in five men and one in three women can expect to enter a residential or nursing home as a permanent resident, at some time in old age.

Social Class

[SLIDE 5] We have examined social class variations based on data for adult men taken from the Disability Survey of 1986⁶. It is well known that life expectancy is higher for people in high social class. It is also true that people in lower social class have more disability, age for age. So people in lower social classes are doubly disadvantaged by having not just shorter lives, but less of their lives in good health. Therefore the social class gap in healthy life expectancy is even greater than the gap in life expectancy. Similar results appear whether we measure social class by own job, by father's job, by level of education, or use correlates like ethnic group. The implication is that the demand for long-term care is, or should be, greater from people in low social classes.

Area of Residence

[SLIDE 6] Area of residence supports the evidence on social class. Those areas with the highest life expectancy tend to have the lowest age standardised disability. This slide, for women this time, is based on the Limiting Longstanding Illness (LLI) question in the 1991 Census. It contrasts places like Manchester and Sunderland, where women can expect to live only 69½ years of which 14 will be with LLI; with places like Surrey and Richmond, where life expectancy is 6 years longer, yet the expectation of life with LLI is under 10 years. Note also the south Wales counties, where life expectancy is fairly average but the expectation of ill-health can be up to 17 years⁷.

5. The Need for Better Evidence.

I will describe the next stages of the present work, and then describe the potential for a national longitudinal survey of health focussing on the chronic illnesses of old age.

Next Stage.

⁶ Results from Bebbington (1993) Regional and social variations in disability-free life expectancy in Great Britain. In Robine, J.M., Mathers, C.D., Bone, M.R. Romieu,I. *Calculation of health expectancies: harmonization, consensus achieved and future perspectives.* John Libby Eurotext.

⁷ From Bone, M.R. et al (1995) op.cit. Chapter 7.

Determining trends in disability is the first stage in predicting the future need for long-term care. What we want to do is to incorporate the findings that come out of this work in a model predicting the financial implications of long-term care needs. We are proposing to the Department of Health to incorporate our results as variants in the model developed by Raphael Wiittenberg. This should be fairly straightforward, and we should have results by the end of August. However, those results are likely to be very imprecise and broad in range. Before undertaking this analysis, our next step will be to check the trends we are reporting using the 1996 General Household Survey

A National Longitudinal Survey of Health & Disability.

The findings from the work so far described seem to be fairly clearcut. Unfortunately there is a weakness in the type evidence we are using. The estimates of healthy life expectancy we are able to construct are based on the prevalence of ill health, from data sources like the General Household Survey. If we want best to be able to predict what will happen in future, it is the current rates of <u>incidence</u> in each age group, and trends in those rates, which will be the best guide we can have to an individual's future expectations. Life expectancies are of course calculated on the current death rates – incidence figures.

Prevalence rates do depend on conditions in the past, when the incidence rates may have been different. Because of this, there is a particular problem in any analysis that has to do with trends through time, such as the one we have presented. There has been a good deal of international effort to examine this, and the weight of opinion is that provided health is changing fairly steadily, with no sudden changes, then prevalence based measures do give a reasonably reliable picture of the general trend. But many commentators do not believe this applies to the present time. Rather, this period has been described as essentially transitional, characterised by the overcoming of degenerative diseases⁸.

Moreover, prevalence rates do not give good measures of prognosis. They cannot be used to make good risk estimates. For example, we cannot estimate the future risk of becoming disabled for someone already in good health, nor how long someone might expect to spend at given levels of disablement. These are vital to individuals who want to make personal plans, for example for future long-term care needs.

What this requires is incidence data, and data which allows us to estimate accurately the rates of transition between different states of health. Recognising the importance of having incidence data in order to predict future health needs, several countries have recently launched such surveys, including France, Canada and Australia. The US has had such

⁸ Omran,A.R. (1971) The epidemiological transition: a theory of the epidemiology of population change. *Milbank Mem. Fund. Quart.* 49, 509-538. Olshansky, W.J. & Ault, A.B. (1986) The fourth stage of the epidemiological transition: the age of delayed degenerative disease. *Milbank Mem Fund Quart* 49, 355-391.

studies for a while, in particular the National Survey of Long Term Care which has been running since the 80's and is now delivering a great deal of relevant findings.

There have been some local studies in the UK. The Melton Mobray and the Nottingham studies of ageing are well known, and provide useful pilots. However, it is clear from these that larger samples are required in order to produce reliable age-specific estimates of transition rates between several health conditions. Moreover the call back period these used, around 4-5 years, has proved longer than desirable for elderly people.

The Department of Health have been commissioning some feasibility studies for such a survey following the recommendations of an internal working group⁹. One is a follow up after 2½ years of people aged 65+ from the 1994/5 General Household Survey. Around 1,400 people have been tracked, and the preliminary results due next month are expected to show the practicality of follow-up surveys with elderly people. We are expecting to undertake analysis at PSSRU in demonstrate the feasibility of constructing national estimates of transition rates between states of health. However the limited nature of the study means that the estimates we produce will do little more than demonstrate the method.

This study is imperative if we are to produce anything like reliable estimates of the future need for long-term care. It is to be hoped that the Commission would consider lending its support to the need for an enquiry of this nature.

⁹ The DH Working Group on Health Expectancy Measures, 1996.

Addendum: The relationship of Healthy Life Expectancy and Life Expectancy.

It is helpful to express each of these in terms of death rates. Based on the usual life-table representation, it can be shown that:

$$e_x = \frac{1}{2} + \sum_{i=x}^{\infty} \prod_{j=x}^{i} (1-q_j)$$

where e_x is the expectation of life at one's x'th birthday, and q_x is the probability of dying while aged x. (The factor of $\frac{1}{2}$ results from a conventional assumption that on average death occurs midway through the year). Similarly, it can be shown that the expectation of healthy life, calculated by Sullivan's method, is:

$$e'_{x} = e_{x} - \frac{1}{2} \{ d_{x} + \sum_{i=x}^{\infty} (d_{i} + d_{i+1}) \prod_{j=x}^{i} (1 - q_{j}) \}$$

where d_x is the proportion of people chronically ill (or disabled) among those aged x.

We can show how changes in death rate affect both life expectancy and healthy life expectancy, in two ways. First by simplification. If (for a distinctly non-human population) it so happens that the illness rates 'd' are the same in all age groups, then the above simplifies to:

$$e'_x = e_x (1-d)$$

Further: if the death rate 'q' is also the same in all age groups then $e_x \rightarrow 1/q$, and the years of illness are given by:

$$e_x - e'_x = \frac{d}{q}$$

In this case it follows:

- If life expectancy increases, and there is no change in the illness rate, there will be an exactly proportional increase in healthy life expectancy;
- If the death rate decreases by some proportion 'p' and the illness rate decreases by the same proportion, the number of years of ill-health remain unchanged.

Second, by simulation. We can consider the effect of changes to death rates and limiting longstanding illness rates in an actual life-table: table 7.1 of Bone et al (1995) *Health Expectancy and its Uses.*

1. On the basis of 1991 death and illness rates, males have:

a life expectancy at birth of 73.4 years;

a healthy life expectancy of 63.7 years;

at constant birth rates, there would be 3.3m disabled males¹⁰.

2. If death rates in every age group fall to 59 per cent of their 1991 rates, but disability rates remain unchanged:

life expectancy would improve by 10 per cent (to 80.8 years); healthy life expectancy would improve by 6 per cent; at constant birth rates, there would be 4.4m disabled males.

 $^{^{10}}$ This is the life-table estimate assuming the numbers of births were always the same as in 1991.

- If both death and disability rates in every age group fall to 59 per cent of their 1991 levels: life expectancy would improve by 10 per cent; healthy life expectancy would improve by 15 per cent;
 - at constant (1991) birth rates, there will be 2.6m disabled males.
- 4. If death rates in every age group fall to 59 per cent of their 1991 levels, increasing life expectancy by 7.37 years, and disability rates (over 30) are slid forward by the same number of years¹¹:

life expectancy would improve by 10 per cent;

healthy life expectancy would improve by 11 per cent;

at constant (1991) birth rates, there will be 3.5m disabled males.

Workings for these four cases copied from the spreadsheet are shown in the table.

The implication is:

- if life expectancy improves while illness rates are unchanged, healthy life expectancy will also improve, but by less.
- if both death and illness rates improve equally, healthy life expectancy will improve more than life expectancy.
- if illness rates move forward in line with the advance in life expectancy, the expectation of ill health and numbers of ill people will be little changed.

¹¹ So that the new disability rate for people aged 30-44 is assumed to be (7.37 x Rate for 15-29 + 7.63 x Rate for 30-44)/15, and so on.

	HLE based on LLI at 1991 Census	Males.	Bone et al.	1995	table 7.1
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Age	q(x)	l(x)	L(x)	e(x)	d(x)	L'(x)	e'(x)
0-4	0.0097	340000	1691772	73.43	0.021	1656245	63.68
5-14	0.0020	336709	3363756	69.12	0.027	3272935	59.39
15-29	0.0118	336042	5010776	59.25	0.035	4835398	49.76
30-44	0.0213	332061	4927901	44.87	0.060	4632226	35.80
45-54	0.0439	324992	3178609	30.68	0.120	2797176	22.32
55-64	0.1292	310729	2906541	21.86	0.261	2147934	14.35
65-74	0.3184	270579	2275025	14.36	0.348	1483316	8.54
75-84	0.6268	184426	1266262	8.74	0.454	691379	4.48
85+	0.1996	68826	344819	5.01	0.608	135169	1.96

Assume all death rates improve by a factor of: 0 588

	0.300						
Age	q (x)	l(x)	L(x)	e(x)	d(x)	L'(x)	e'(x)
0-4	0.0057	340000	1695162	80.80	0.021	1659564	67.76
5-14	0.0012	338065	3378681	76.25	0.027	3287456	63.24
15-29	0.0070	337671	5047427	66.33	0.035	4870767	53.57
30-44	0.0125	335319	4998306	51.75	0.060	4698407	39.42
45-54	0.0258	331122	3268494	37.31	0.120	2876275	25.73
55-64	0.0760	322577	3103227	28.16	0.261	2293284	17.50
65-74	0.1872	298068	2701661	20.07	0.348	1761483	11.24
75-84	0.3686	242264	1976191	13.54	0.454	1079000	6.56
85+	0.1174	152974	1303403	8.52	0.608	510934	3.34

Assume death and disability rates improve by a factor of:

	0.588	J F	2				
Age	q(x)	l(x)	L(x)	e(x)	d(x)	L'(x)	e'(x)
0-4	0.0057	340000	1695162	80.80	0.012	1674230	73.13
5-14	0.0012	338065	3378681	76.25	0.016	3325041	68.60
15-29	0.0070	337671	5047427	66.33	0.021	4943551	58.83
30-44	0.0125	335319	4998306	51.75	0.035	4821966	44.50
45-54	0.0258	331122	3268494	37.31	0.071	3037869	30.50
55-64	0.0760	322577	3103227	28.16	0.153	2626981	21.89
65-74	0.1872	298068	2701661	20.07	0.205	2148837	14.88
75-84	0.3686	242264	1976191	13.54	0.267	1448643	9.44
85+	0.1174	152974	1303403	8.52	0.358	837431	5.47

Assume death rates improve as before and slide disability rates beyond 30 forward by 7.37 years 0.588

	0.388						
Age	q (x)	l(x)	L(x)	e(x)	d(x)	L'(x)	e'(x)
0-4	0.0057	340000	1695162	80.80	0.021	1659564	70.49
5-14	0.0012	338065	3378681	76.25	0.027	3287456	65.98
15-29	0.0070	337671	5047427	66.33	0.035	4870767	56.32
30-44	0.0125	335319	4998306	51.75	0.048	4759803	42.19
45-54	0.0258	331122	3268494	37.31	0.091	2972630	28.35
55-64	0.0760	322577	3103227	28.16	0.157	2615762	19.89
65-74	0.1872	298068	2701661	20.07	0.284	1934711	12.75
75-84	0.3686	242264	1976191	13.54	0.376	1233385	7.70
85+	0.1174	152974	1303403	8.52	0.515	631674	4.13

Note: q(85) is the annual rate.

SLIDE 1

Healthy Life Expectancy: Agenda

1. Monitoring Health Trends

Are improvements in health care postponing the onset of chronic ill-health; or preserving the lives of the unfit?

What is the life-time risk and expected duration of particular states of health?

2. Equity

Are all sections of the population benefitting from improvements in health care?

How should health resources be distributed geographically?

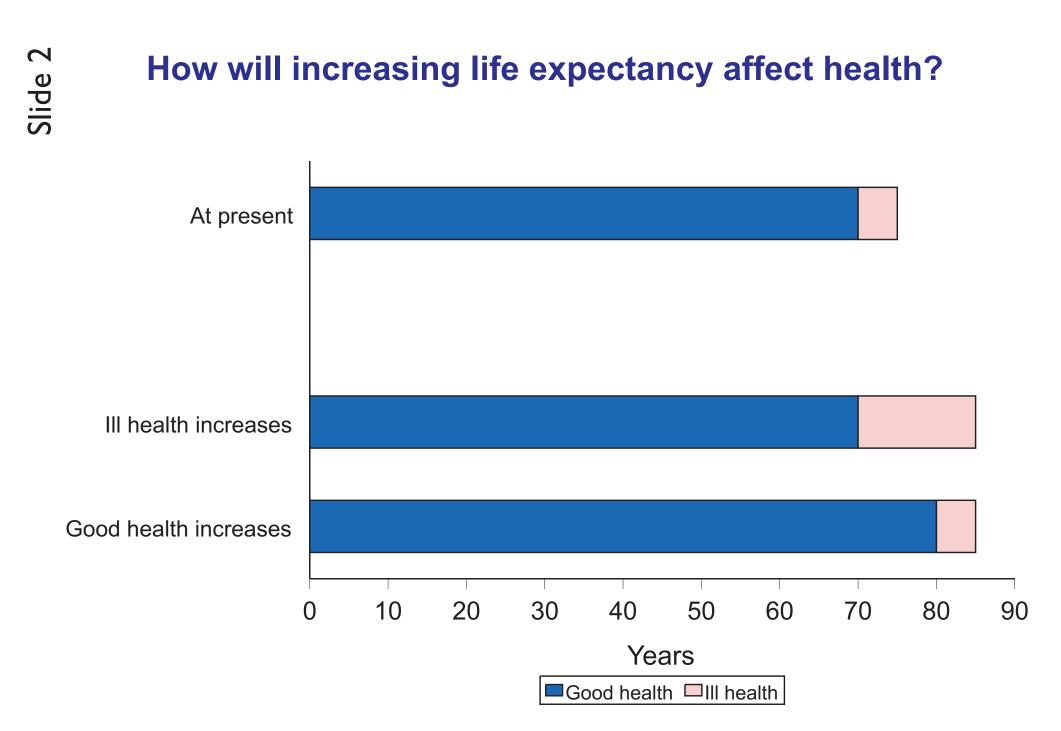
3. Health Care Planning

What is the likely demand for long term care resulting from increasing numbers of old people?

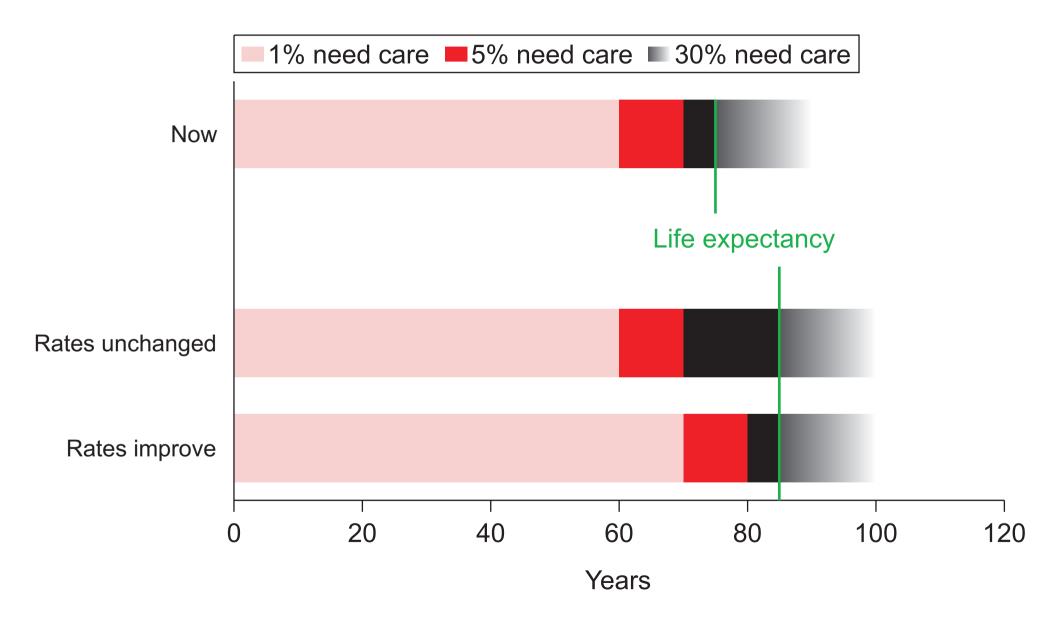
4. Health Outcomes

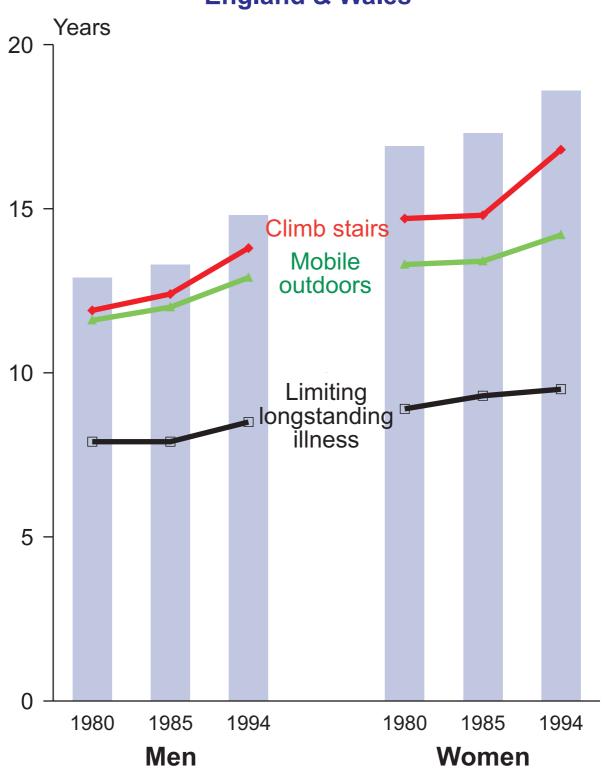
What diseases cause most ill-health?

What national health strategy is likely to bring about the greatest improvement in morbidity?



As life expectancy improves, what is the need for long-term care?





Life expectancy and healthy life expectancy at 65, England & Wales

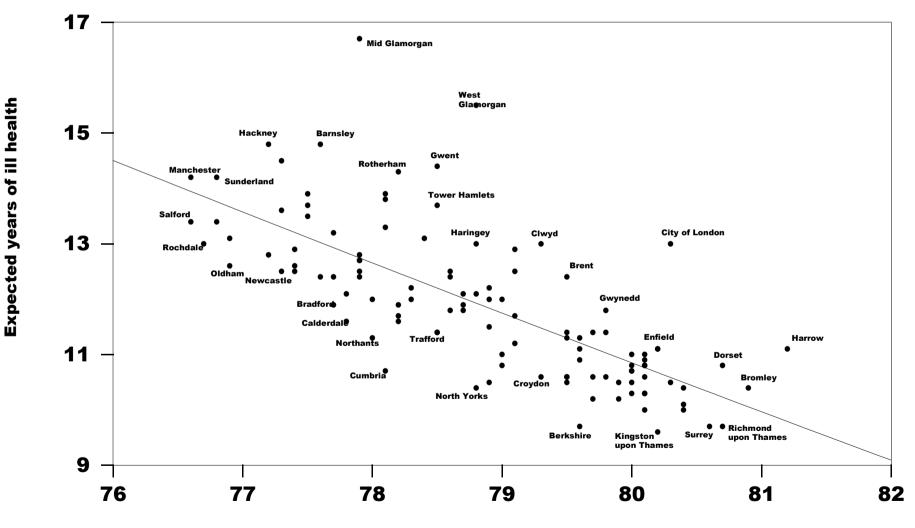
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Healthy Life Expectancy of Males, by Age and Social Class, based on UK Disability Survey (1986-8)

	Life Expectancy	HLE
	(years)	(years)
At Age 20		
Social Class I & I1 Social Class III Social Class IV & V	54.2 51.3 49.2	48.9 43.4 42.0
At Age 70		
Social Class 1&11 Social Class 11 I Social Class IV & V	10.7 9.0 8.7	6.9 5.2 4.2

Based on all categories of disabiliity.

Life Expectancy at Birth by Expected Years of III Health for LAs of England and Wales Women



Life expectancy at birth