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Health Policy Matters

HELPING DECISION MAKERS PUT HEALTH POLICY INTO PRACTICE

This issue

Measuring success in health care – the time has come to do it properly!

Introduction

The time has come for those with responsibility for health policy to demonstrate that what really matters is patient outcomes. The failure to grasp this nettle has been allowed to stand in the way of a really radical rethink about how best to measure success in health care. It is essential to replace measures of activity and workload with measures of outcome if we are to determine the value of medical interventions and whether the 'modernisation' of the NHS is indeed delivering the goods. Instead of trying to establish how successful the NHS is by counting the number of people treated and how long they waited, we need to answer some rather more fundamental questions such as how much good treatment is doing in health terms for patients, where the greatest health gains are likely to be achieved, which activities should be expanded and which make such a small contribution at such a high cost that they should be phased out. This is impossible without the routine measurement of patient outcomes.

It is remarkable that we know so little about the health improvements brought about by the enormous array of activities provided by the NHS, but in recent years some piecemeal attempts have been made to rectify the situation. More data has been made available on death and complication rates associated with particular activities, and NICE has been created to look systematically at whether selected innovations are sufficiently clinically effective and cost-effective to be worth adopting by the NHS. However, the routine monitoring of outcomes has yet to be tackled in a systematic way.

The Initial Challenge

Suppose we were starting from scratch, what would be our vision of the criteria that would be needed to judge how successful our health care system is? We would surely start by measuring the extent to which it enables people to lead longer and healthier lives. Measuring the effects on length of life requires mortality data, which on the whole exists. The stumbling block here is not collecting the data but in attributing it to particular causes related to health care activities. Linking data from HES records to the ONS Register of deaths has been shown to be technically feasible[1] and looks set to become more generally operational in the near future. But death is a relatively rare outcome for most health care activities. The crude mortality rate amongst hospital in-patients is about 3%. The outcome for this group of patients is obvious. But for the overwhelming majority of patients who leave hospital (alive) we know nothing about whether their health status has been changed at all (for better *or* worse). If collecting mortality data does not seem to be a major problem, the same cannot be said for data on quality of life.

If we want to measure the impact of health care on people's quality of life we need to make some important strategic decisions. It is

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impossible to routinely measure *everything* that might impinge on *somebody's* quality of life, so is it good enough to simply concentrate on a small number of attributes that have been shown to be the ones that people care most deeply about? Can we trust patients to describe and rate their own health rather than relying on health professionals to do it? Do we entrust lay people with the job of deciding the value of health, rather than giving this job to experts to make judgements on their behalf? These are general strategic issues of design that influence the way we describe and value quality of life – or more accurately *health-related* quality of life. More specifically, we need such a measure to represent quality of life as a single number. Although profile measures (such as SF-36)[2] have their uses they cannot serve the purposes described here. For these we need to express health status as one number – not a series of separate scores. But supposing we had a general purpose measure, for use by patients but that incorporated the values of the population at large, what sort of practical characteristics would it need?

The task specification would have to include the following:

- it must be possible to use it in periodic surveys of population health to check both on cross-section differences in health-related quality of life between different segments of the population, and on trends in health over time for each such segment and for the population as a whole.
- it must be easy enough to use repeatedly by patients before, during and after treatments, so as to be able to monitor progress, or lack of it.
- it must be possible to aggregate individual-level data to compare the effectiveness of a given treatment for patients with different characteristics, and perhaps also between doctors.
- it should be possible to use such data to compare different treatment regimes for the same condition.
- it could be used to identify which treatments for which conditions make the biggest contribution to the improvement of population health.
- it must be possible to combine it with mortality data so that we could measure changes in both the length and quality of people's lives simultaneously.

How to do it!

This is a tough specification for any measure, but it is the set of tasks for which EQ-5D was designed.[3] EQ-5D is a generic measure of self-reported health status that defines health status in terms of five dimensions – mobility; self-care; usual activity; pain or discomfort; and anxiety or depression. Each dimension is divided into three levels, indicating no problem, some problem or extreme problem. By combining different levels from each dimension, EQ-5D defines 243 health states. For example, having no problems with mobility, self-care or usual activity, but some problems with pain/discomfort and anxiety/depression uniquely defines one such state – referred to as 11122 corresponding to the levels within each of the five dimensions. Two further states – unconscious and dead – complete the full classification of EQ-5D states.

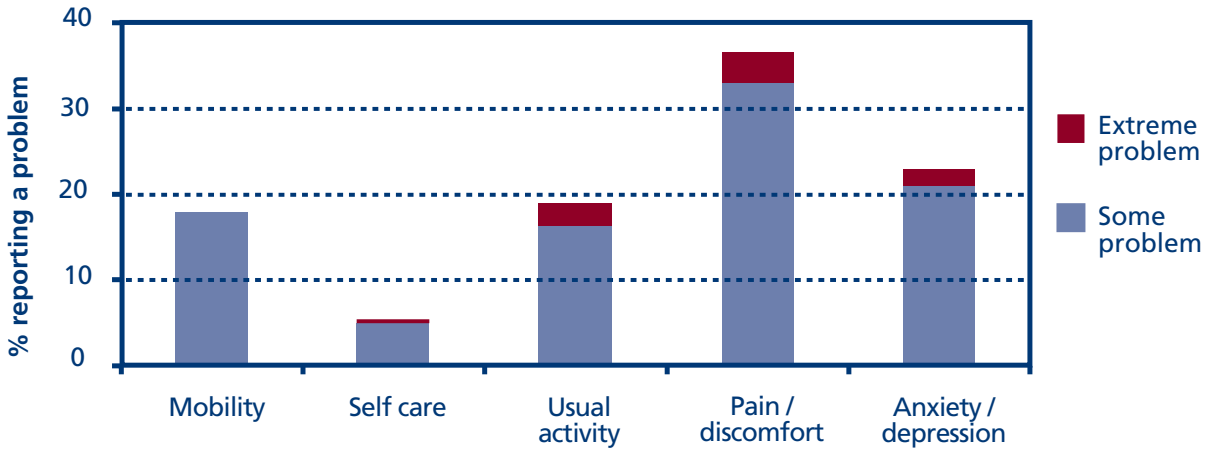
Collecting EQ-5D data is achieved by asking respondents to complete a two-page questionnaire. This is reproduced on pp6-7 and shows EQ-5D in the form used to collect the most recent population-based survey data in the UK. In a health survey, 'respondents' might be members of the general population. In a treatment monitoring study or clinical trial, 'respondents' would be patients. The questionnaire is easily completed and the results can be coded as five digits in a computer record. The thermometer-like visual analogue scale on the second page of the questionnaire is used to obtain the respondent's rating of their own health status on a scale where best and worst imaginable health states are valued 100 and 0 respectively. This information is especially useful in repeated measurements, as it indicates whether people themselves think they are getting better or not, which may or may not correlate with what those treating them think. Three digits are required for the self-rating, making eight digits in all. These are the only *extra* data required to move from activity measurement to routine outcome measurement! The two-page questionnaire takes a minute or so to complete, and has been extensively used in a wide range of applications – from population health surveys (including the 1996 English Health Survey) to clinical trials. The current list of such applications posted on the EuroQoL Group website[4] includes the conditions listed in the box.

It seems that a straightforward mechanism for measuring health outcomes with a proven track record and a substantial research pedigree does after all exist. So it cannot be the data collection burden that is holding us back, so what is it? It could be lack of knowledge about this facility, or lack of vision about its potential, both of which are easily remediable! A much more formidable potential obstacle is that collecting the data is only the beginning …. someone has to work out what it all means.

Acne	Gilles de la Tourette	Osteoarthritis
Acupuncture	Graves eye disease	Pain
Alcohol dependency	Growth hormone	Pancreatic cancer
Angioplasty	Haemophilia	Parenteral nutrition
Angina (treatment options)	Hip fracture/replacement	Peripheral arterial disease
Anorectal reconstruction	HIV infection	Peripheral vascular disease
Asthma	Hodgkin's disease	Physiotherapy
Blood transfusion	Homeopathy	Picture archiving and communication systems
Bone marrow transplant	Hormone replacement therapy	Population health surveys
Breast cancer	Hospital waiting lists	Primary care
Breast cancer screening	Hysterectomy	Prostatic hypertrophy
Bronchitis	Imperforate anus	Prostate cancer
Cardiac surgery	Inguinal hernia	Psoriasis
Cardiology	Incontinence	Psychiatric problems in general practice
Cardiovascular disease	Intensive care	Redundancy
Cataract surgery	Intestinal failure	Rehabilitation
Chemotherapy (impact)	Ischaemic heart disease	End stage renal disease
Chronic fatigue	Joint replacement	Renal oncology
Chronic illness	Leg ulcer clinics	Renal (kidney kidney stone disease)
Cochlear implantation	Liver disease	Respiratory illness
Colles fracture	Liver transplantation	Rheumatoid arthritis
Colorectal carcinoma	Low back pain	Rhinitis
Congestive heart failure	Lung cancer	Road accidents
Conservation work	Lung embolism	Schizophrenia
Cosmetic surgery	Lung transplantation	Sepsis
Cystic fibrosis	Lymphoedema	Sinusitis
Dementia	Magnetic Resonance Imaging	Smoking
Detoxification	Melanoma (stage III)	Stent
Diabetes	Menorrhagia	Stroke
Drug monitoring (nursing home residents)	Migraine	Trauma
Dyspepsia	Multiple Sclerosis	Tuberculosis
Dystonia	Myeloid leukaemia	Turner's syndrome
Elderly (QOL)	Myocardial infarction	Urology
Endometriosis	Neonatal surgery	Vascular surgery
Enteral nutrition	Neural tube defects	Venous leg ulcers
Epilepsy	Neurosurgery	Visual impairment
Erectile dysfunction	Non-Hodgkin's disease	Weight loss
Fabry's disease	Lupus	Women's surgery
Gastro-enteritis	Lymphoma	
General practice	Nutrition	
Geriatrics	Obstructive sleep apnoea	
	Orthopaedic medicine	

Turning data into *information* requires the application of thought. This starts with formulating the questions that such data can help to answer – and a wide range of such questions was mentioned earlier. Those concerning judgements about priorities require something more than the data collected from patients, since some scoring system is needed that reflects the views of the community being served, and for many such purposes this needs to be on a scale in which dead = 0 and healthy = 1 (so that it can be integrated with life-expectancy data). NICE has already confronted this issue and has issued guidance recommending that quality of life data submitted to it should be collected using a preference-based generic measure that reflects the values of the population served[5]. This stipulation is designed to rule out arbitrary scoring systems or those based on professional judgement.

As well as being the simplest of all such measures to use, EQ-5D has an exceptionally well-founded value base, drawn from the views of a representative sample of over 3000 members of the population of England Scotland and Wales – the largest survey of its kind ever conducted in the UK. The results of that survey – commissioned by the Department of Health – are readily accessible[6] and mean that we can say what value, on average, is attached by the general public to any given health state described by the EQ-5D system. A patient's health status as indicated by their responses to five sets of questions in the EQ-5D questionnaire, can therefore be converted into a numeric value.[7] By measuring health status, say before and after treatment, we can compare the corresponding values and compute the value of



Source : Health Survey for England, 1996

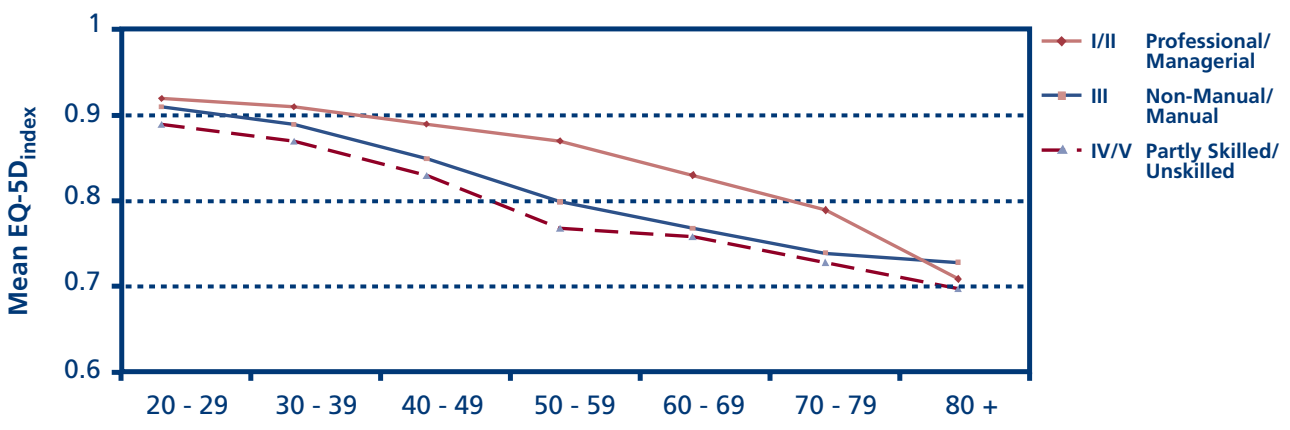
Fig. 1: Self-reported problems in the general population

the change, giving us a quantitative measure of health outcome.

EQ-5D has been fielded as part of national population studies over the past decade, for example in the Health Survey for England, 1996.[8] Figure 1 shows the rate of self-reported problems on each of the EQ-5D dimensions. It is worth noting that a third of the general population report some problem with pain/discomfort. This proportion rises dramatically with age. Health policy is generally silent on this phenomenon.

Using data from national population surveys age/sex norms have been established and EQ-5D (despite its deceptively simple design) has shown its capacity to reflect variations in health status by key population subgroups. For any given age group, those from social classes I and II (professional and managerial) have higher health status than individuals in social classes IV or V (manual, unskilled workers), as shown in Figure 2.

Thus this measure can be used not only to determine the success of investments in health care, but also to identify the nature of health inequalities by going beyond mortality data and the incidence and prevalence of diseases. Data on variations in health-related quality of life are notably absent from the Wanless report[9] and the more recent HM Treasury document.[10] Even today many of the Health of the Nation targets are expressed in terms of the impact of health care programmes on death rates. EQ-5D has already been used in national population surveys as a measure of health status, demonstrating variation across the



Source : Health Survey for England, 1996

Fig. 2: $EQ\text{-}5D_{index}$ by social class/age

population by age, social class, educational attainment, housing tenure and health behaviours. Such normative data can be compared easily with the health of local populations, for example in monitoring specific communities or designated groups of patients.

Beyond observing changes in the health status of individual patients and groups of patients, such data could be consolidated to provide information on the health outcomes of treatment, or to measure the consequences of providing programmes of care. Given the comparative ease with which these data can be collected, it would be possible to record the health status of patients prior to and following treatment, so as to measure outcomes in a standard manner. These outcome data might then be used to monitor the delivery of care, and to inform decisions regarding the specification of services and the auditing of achievement and performance. EQ-5D has demonstrable feasibility as a means of monitoring patient health status and changes in health status in a primary care setting[11] – arguably the toughest environment in which to test such a measure. One observational study of GP attendees collected EQ-5D data on more than 2,000 patients in 10 surgeries over 5 days without discernible logistic problems. The routine use of EQ-5D at the point of GP referral would provide a baseline for measuring subsequent change, for example whilst waiting for hospital treatment. Such data can subsequently be used in numerous ways – both to measure outcomes for individual patients and in aggregate to provide evidence of performance across groups of patients. Reporting such intelligence to Primary Care Trusts would be a natural development once a locality-wide outcome measurement system were in place.

Next steps

The shortcomings of routinely collected data in the NHS have long been recognised.[12] Mortality rates tell us little of relevance to most NHS activity. Waiting times tell us nothing about health outcomes. A simple but effective means of measuring health status exists. In theory, nothing stands in the way of measuring health outcomes in the NHS? So where to next with EQ-5D?

Firstly, we need to stand back from the quagmire of NHS performance indicators. This could be an intoxicating manoeuvre in itself. Thinking creatively at all levels within the NHS about the potential of 'real' outcomes data based on EQ-5D could itself change the way that we do things. But such a process needs political and managerial buy-in, with endorsement from Trust Chief Executives and Health Authorities. Someone in the NHS needs to take outcomes seriously and to champion its cause. At a more practical and immediate level, clinicians and others concerned with direct patient contact could instigate their own outcome measurement regime. If standardised measurement of health status is shown to have independent value in caring for individual patients then this should commend its use by other clinical colleagues. We need a green light for outcome measurement and we need good examples of its practical usefulness. Given the low cost/high information yield of EQ-5D, it would seem incredible were Primary Care Trusts and NHS Trusts not able to initiate such activity themselves. However, a more generalised and co-ordinated approach might lead to a more effective harnessing of local interests. A regional network across Yorkshire, for example, was able to collect EQ-5D data on some 4,000 out-patients to enable podiatry services to be benchmarked across several different Trusts. Such data exchange becomes a possibility where the costs of data collection are relatively trivial. But before anything happens we need to provide all interested parties with the relevant information about EQ-5D itself. EQ-5D is in the public domain and more information can be gleaned via the internet but potential users need to be properly briefed about the measure. Detailed information can be obtained from UK members of the EuroQoL Group that was responsible for designing EQ-5D, but such support is at present unfunded by the NHS. An obvious first step therefore, would be to ensure that EQ-5D Information Packs are provided to all interested NHS users. A limited supply of this material is available on a first-come-first-served basis. But that is no way to begin such a serious enterprise with such dramatic possibilities.

Conclusion

Measuring health outcomes is not an optional extra. Both intuition and experience tells us that this is THE central requirement in generating information about NHS success. Waiting times and mortality rates were always past their use-by date. The arrival of a simple means of measuring outcomes in the NHS underscores that fact. The vision presented earlier, of a health care system that routinely monitored its own performance in outcome terms as reported by its patients, is not an impossible vision. With commitment and systematic experimentation to find the most practical way to embed it into the thinking of all concerned, we could, in the next five years, bring about a radical change in the way success is measured in the NHS. It is a change that is long overdue, and its time has surely come!

The waiting time is over.

Tick one box for each group of statements.

Mobility

- I have **no** problems in walking about ☐
- I have **some** problems in walking about ☐
- I am **confined to bed** ☐

Please tick one box

Self-Care

- I have **no** problems with self-care ☐
- I have **some** problems washing or dressing myself ☐
- I am **unable to wash or dress myself** ☐

Please tick one box

Usual Activities

- I have **no** problems with performing my usual activities ☐
  (e.g. work, study, housework, family or leisure activities)
- I have **some** problems with performing my usual activities ☐
- I am **unable to perform my usual activities** ☐

Please tick one box

Pain/Discomfort

- I have **no** pain or discomfort ☐
- I have **moderate** pain or discomfort ☐
- I have **extreme** pain or discomfort ☐

Please tick one box

Anxiety/Depression

- I am **not** anxious or depressed ☐
- I am **moderately** anxious or depressed ☐
- I am **extremely** anxious or depressed ☐

Please tick one box

- **Please SCORE how good or bad your own health is today.**
- **The best health state you can imagine is marked 100 and the worst health state you can imagine is marked 0.**

Overall, how would you score your own health today between 0 and 100?

SCORE = ☐

Best imaginable health state

Worst imaginable health state

Further information

- on the use of EQ-5D can be obtained from several sources, including the Outcomes Research Group, Centre for Health Economics, University of York or via the EuroQoL Group website http://www.euroqol.org which contains a list of all UK-based members of the Group, across different Universities and Research Institutes.
- Copies of the EQ-5D questionnaire can be obtained from the Centre for Health Economics at York, together with an abbreviated User Guide. Both are currently supplied free on request by contacting:

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References & resources

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3. Brooks R. EuroQol: the current state of play. *Health Policy* 1996;37(1):53-72.
4. EQ-5D was developed by the EuroQoL Group, an international, multidisciplinary network of researchers set up in 1987 to investigate values for health.
5. NICE Guide to the Technology Appraisal Process, June 2001. Revised guidance expected March 2004.
6. EQ-5D UK User Guide. Outcomes Research Group, Centre for Health Economics, University of York.
7. The health state 11122 described earlier, for example, has a score of 0.725. This weighted index is termed $EQ\text{-}5D_{index}$.
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