Science and Society

Public dialogue in scientific research

Commissioner Busquin on the role of DG Research

Frank Vandenbroucke discusses the successes of the Belgian Presidency

Challenges and opportunities in mental health policy
Towards a science-society?

Science is by its very nature political. Scientific discoveries and inventions shape society and economy fundamentally, and scientists are cast as both savours and wreckers in the popular imagination. Since the Luddites destroyed the power looms that began the industrial revolution, society at large has had an ambiguous relationship with scientific progress. But while the potential, and occasionally the reality, of science’s ability to cause harm is ever present, the ability of science and technology to do good and their role in underpinning economic growth and prosperity are clear.

The relationship between science and society has been repeatedly challenged in recent years through issues such as BSE, GM crops, the MMR vaccine and the debate over the medical use of genetics. What the more crisis ridden of such events have in common is a failure of communication between scientists and politicians, and between both of them and the general public. Despite these events, a recent Eurobarometer survey (Eurobarometer 55.2) shows the European public to be very respectful of scientists and extremely supportive of scientific research, though with a feeling that they are insufficiently informed and a concern to defend their choices as consumers over issues such as GM foods. The attitude of most of the public can be described as ‘positive, with reservations’. It shows that there is a need for a more intelligent engagement between ‘science’ and the public. As Nick Pidgeon says here, a key issue in any dialogue between science and the public rests on an understanding of the nature of risk and of the types and levels of uncertainty that scientific knowledge entails. It is perhaps because politicians perceive a need to present absolute certainties and stark choices to their electorates that they have on occasion made such poor communicators of scientific issues.

The relationship between science and society is not confined to public engagement and dialogue. As Commissioner Busquin points out, a vital issue for Europe is the decreasing interest that young people have in pursuing a scientific career. The European Union has declared its aim of attracting to remaining in – science-based careers, it cannot be achieved if more people are attracted into – and from LSE Health and Social Care.

Europe’s future economic performance will be built in large part on the effectiveness of its scientific research and development and ensuring public trust, engagement and consent is essential to its success. The knowledge-economy will demand a science-society.

Mike Sedgley
Editor
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Minister for Social Affairs and Pensions, Belgium

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ERRATUM: The editorial team would like to acknowledge the following error in the Special Issue of eurohealth (volume 7, number 3): ‘Implementing Hospital Reform in Central and Eastern Europe and Central Asia’. Rachel Jenkins is Director of the World Health Organisation Collaborating Centre, Institute of Psychiatry in London, UK, not Director of the Institute of Psychiatry as it appeared. Our apologies for this mistake.
INTERVIEW WITH FRANK VANDENBROUCKE

Frank Vandenbroucke
Minister for Social Affairs and Pensions, Belgium

Interview by Mike Sedgley, Editor, Eurohealth

The development of European policy in the areas of health and welfare is taking place at a time when there are many new pressures on the welfare systems of Member States. Pressures caused by social change, demographic developments and technological innovations simply could not have been envisaged when the structures of the welfare state were devised. Is the European Social Model able to withstand these pressures, and where does this model stand at the beginning of the 21st Century?

There are certainly fundamental changes taking place that alter the context within which welfare systems operate. Many of the traditional assumptions that informed the structures of welfare systems no longer apply. It is, for example, more difficult to relate what people contribute and what they receive from welfare systems, as people live far longer and as traditional family relationships decline. All these factors create a challenge for policy makers. Demographic ageing, in a society where you can rely less on the traditional family structure than you could 40 or 50 years ago, creates important challenges for care of the elderly and for healthcare systems. This is a problem of organisation common to all European Member States.

The European social model will need to be adapted to these new social factors but it must not be undermined by them. Indeed, many of these changes reinforce the need for social solidarity in many areas of welfare but we should not be rigid in the way we approach them. Reform will be necessary if the challenges are to be met and the pressures withstood.

Does the recent performance of the American economy relative to the European challenge the view that the European approach to welfare and social solidarity can underpin economic growth and efficiency?

I am not that old, in fact I am still rather young, but I have already lived through a period where Germany was seen as the ideal economic model, then Japan was the model, and now we have been through a period where the American economy was booming and continued to boom and it was said that this was the best model. I am not so enthusiastic about this modelling game. As a matter of fact, I think that over the last 30 years various economies, various national economies, have been successful and then less successful for a variety of reasons.

The question is not black and white: Is there a unique model of market economy that is the most efficient? The question should be put another way, particularly given the crucial factor that the social context is changing. If we want to uphold the kind of social model that underpins most Western European societies, we need to assess the assets and liabilities in that model for economic growth and efficiency – and ask how we can exploit the assets and perhaps diminish the liabilities. We have a number of assets, such as social cohesion and social dialogue, which create trust. Research over the past 10 years has shown that trust is a productive input into the economy and can assist in economic growth.

Furthermore, the economy of the future is going to be a knowledge based economy and clearly a society where the large majority of citizens has access to new ways of communication, new media, is a better starting point than a society where only half of the population has such access. This access in Europe is made possible for the large majority of people simply through their purchasing power.

Let me be even more specific: a society where your pensioners have enough purchasing power to venture into e-commerce, the internet, and so on is a better society for the knowledge economy to develop in than a society in which a lot of pensioners are so poor that they don’t have access to those things. This idea has been termed ‘cognitive Keynesianism’ – where an educated society can create demand for knowledge based goods and services. Consumer demand for the products of a knowledge economy is therefore greater where more people have access to information technologies.

Do you think the welfare state should therefore be seen in itself as economically productive?

I am not saying that any type of welfare state will stimulate economic growth and efficiency. You need an intelligent welfare state that is far more proactive than is the case with most welfare provision at present. It must work in a more preventative way and pay more attention to investment in human capital. Welfare systems ought to have the egalitarian outlook to human capital, which the
traditional welfare state has, but there is a lot of progress needed in the particular way in which the welfare state functions. In basic terms, the idea of a welfare state with broadly egalitarian aims is not at all at odds with economic growth and efficiency.

Is there a sufficient political consensus among European countries about what pensions, health services and all the other various aspects of the welfare state ought to be across the continent? Are we going to see different Member States approaching the problems of welfare cost containment in different ways, and do you think a European approach to welfare is possible if there are diverse interpretations of what kind of provision there ought to be?

I think we do need a new approach. Clearly our institutions are very different, both for historical reasons and because of differences in social culture. For these reasons, it would not be a sensible objective of European social policy to aim for uniformity, let alone homogeneity. We will continue to see very different types of practical policy measures taken in different Member States.

On the other hand, I am convinced that there is a tendency towards convergence and that is because notwithstanding our very different histories and different institutions, we are now confronted with very similar problems. We face the same questions: What is the role of the general practitioner? What is the role of evidence-based medicine? How can pharmaceuticals best contribute to the efficacy of our system? And in fact if you look at the evidence of the 1990s, there has been significant convergence across Member States in employment and welfare policies.

We will not persuade each other to adopt the system of another country. But within those systems there is enough convergence and enough similarity in challenges for there to be common European objectives that encapsulate common European values, even though there will not be commonality in everyday policy and implementation.

Is the EU effectively pulling in two directions, with the single market introducing competition between national regulation and taxation regimes – possibly undermining the long term ability of governments to sustain welfare provision?

I think there is a need for nuance in this area. Many people are afraid that free movement of capital, people and services will induce a ‘race to the bottom’ in terms of taxation and financing of the welfare state. But in fact the most demanding pressures our welfare states face are not from external competition but from internal social and demographic developments within each welfare system. It is wrong to immediately look for an external scapegoat: the pressure has been internal and sociological.

The second point is that welfare retrenchment has not occurred as a response to the single market. Indeed, quite the contrary. A number of European Member States have reacted to the creation of a single market in Europe not by rolling back welfare but by introducing new social pacts. This is the case in Ireland and the Netherlands, among others countries, where there has been a rethinking of the architecture of the welfare state but certainly not a retrenchment.

There have been new social pacts, in revised but revitalised forms. So there are these two important nuances or provisos. However, it has been shown that increased factor mobility may lead to under provision of insurance and so have an effect on European welfare states. The issue of factor mobility will become more important and it will impact more on the welfare state than it does today, not least because of the incorporation of the central and eastern European countries. As we are now only at the beginning of enlargement, I believe we need to introduce common objectives on social policy now. This is something that cannot wait.

What were the main aims of the Belgian presidency, and, given this important context and timeframe, what do you think were its principal successes?

The ambition of the Belgian Presidency was to make operational as a methodology the “open coordination” that was launched in the year 2000. We wanted to build on Lisbon, where a great deal of progress was made. The Lisbon summit established a common European approach and philosophy that social protection and economic growth are not enemies but are mutually reinforcing and this is now confirmed as the basic idea which we in Europe share.

On a more practical level, Lisbon defined a new methodology of cooperation which we coined ‘the open coordination method’. This is a process of planning, examining, comparing and adjusting policies on the basis of mutual feedback and common objectives among Member States. The idea at Lisbon, where social policy was given specific emphasis, was to begin open co-ordination of policy in the fields of social
inclusion and pensions, and the key task of the Belgian Presidency was to make this operational.

We wanted to define a set of common indicators with regard to social inclusion in order to be able to monitor in a quantitative way each Member State’s performance. We were able to find agreement on a set of 18 quantitative indicators concerning social inclusion that will from now on guide our work at the EU level and will be used by all the Member States in their National Action Plans on Social Inclusion, which have to be submitted every two years.

“I’m convinced that enlargement will be extremely detrimental if there is no clear vision of what drives the European social model.”

We also made significant progress in reaching a common approach to pensions. We decided to establish open coordination for pensions policy, for which we identified 11 common objectives. On this basis, the Member States will be called upon to submit national strategic reports in which they describe how they aim to achieve those objectives. From this, we will draw common conclusions which we will integrate into the broad economic policy guidelines.

In doing this we correct an imbalance that has existed between a purely economic approach to pension policy and a more social approach.

These are the key results of the Belgian presidency because we are now able to say that we delivered on the Lisbon promise.

How broad were your aims in this area? Did you aim to achieve the same for healthcare as you did for social inclusion and pensions?

The challenge of ageing is even more difficult in the field healthcare than in the field of pensions. Pensions are relatively easy to project; healthcare and care for the elderly are much more complicated issues. The committees that prepared the work on pensions will now also work on the impact of ageing on healthcare and care for the elderly before the Barcelona summit.

Apart from the reports of the economic and social protection committees, there is another initiative which I think is very welcome: the Commission issued a Communication on healthcare which in my view appeals to the open method of coordination. What the Commission is aiming at is applying some sort of open coordination through the issue of healthcare, which means that you set forth common objectives and you try to learn from each other. That’s very welcome. I do believe that open coordination can be very helpful because it makes you look a bit further than your own territorial waters and so I would like the Spanish Presidency to take up this initiative by the Commission.

There is a logical progression here. We now have open coordination on social inclusion up and running and have just launched open coordination on pensions. We defined the objectives and the policy. The next step is to engage in some kind of open coordination on healthcare. I hope some Presidency will take this up very soon. The challenge will be to convince Member States that this is not an exercise in achieving uniformity and nor is it a naming and shaming exercise.

Cross border healthcare in the EU has been under the spotlight following the recent Court of Justice rulings on this subject. Did the Belgian Presidency help to clarify any of the issues in this area?

Yes. Indeed, there was a further significant achievement of the Presidency: on the portability of social rights for people who are mobile within Europe. This is governed by Regulation 1408/71 which guarantees pension rights and healthcare, and sickness invalidity benefits for people who move between countries in Europe. We aimed to get agreement politically on the parameters for the modernisation and simplification of this regulation so that the next presidencies can engage in the practical work of its amendment. We were able to find agreement on this and, very importantly, achieved a real breakthrough with regard to the extension of social security coordination to non-EU nationals. Who, up until this day, are not covered by this regulation.

Mobility of patients and services is partly regulated by 1408/71 but we are confronted with judgements by the Court of Justice that create a rather different framework and that is the reason why we wanted to draw attention to this challenge. This is why we
organised a conference on the impact of European integration on healthcare systems and on our capacity to organise socially our healthcare systems, as the bridge between our presidency and future presidencies.

**What were the obstacles that you felt you had to overcome during the Presidency to achieve the results you did?**

There were two barriers to overcome. One is that, of course, our pension systems and certainly our healthcare systems are very different because they have different histories and they reflect different social cultures. We had to make it very clear that when engaging in this new form of cooperation we would fully respect subsidiarity in these areas and not encroach upon the competencies of national government. We had to emphasise that we were not aiming for uniformity. This is a sensitive issue for some Member States such as the United Kingdom, Sweden and Finland.

Nevertheless, whether we like it or not, healthcare is becoming, in part, a European issue. This is because competition policy is an EU responsibility and many Member States are introducing elements of competition into their healthcare systems. So through that we have an important European dimension in healthcare policy.

The second difficulty is different but also related to Member State sensitivities about their national competencies. If we define common social objectives for pension systems, if we define common objectives for social inclusion, if we develop a measuring system, then what we are effectively doing is looking over each others’ shoulders, which can be extremely annoying for a national government.

It is vital to remember that this kind of open coordination exercise is not intended to ‘name and shame’ or to point to the ‘bad pupils’ and say how bad they are. The issue is to monitor progress and to learn. If you are not able to monitor progress, open coordination will simply produce hollow phrases and a nice declaration. So we need quantitative analysis.

Social inclusion is a multi-dimensional thing. It’s about income but also about access to services such as healthcare, education and housing. And of course whether or not you are socially excluded in one country might be determined by a somewhat different aspect of social life than in a lot of countries. Hence, you need a multi-dimensional set of indicators in which each Member State can recognise its own priorities.

**Do you ever see a greater role for the Commission in the area of healthcare and welfare?**

Well, the open coordination is an intergovernmental process where the Commission has a very important role to play. The Commission is able to draw conclusions in a somewhat impartial way and then present it to the Council, but it’s not an easy process and there is a lot of discussion with the Member States. I think you need the Commission to play a role in these processes, as an active initiator of ideas and a as structure for thinking within.

**How, then, can the issues of welfare best be progressed at the European level over the coming months and years?**

In the immediate short term, we need to ensure that the Spanish Presidency continues with the work begun at Lisbon and carried forward under the Belgian Presidency. The key meeting will be the forthcoming summit in Barcelona. The reports of the economic and social protection committee will inform this meeting.

What we need now is an explicit Treaty statement that expresses the basic values of the Community as they relate to healthcare and other welfare policies.

I tend to think that a specific treaty provision is needed because we need to enshrine in the treaty some basic values of healthcare policy in order to give guidance politically to the Court of Justice, to the Internal Market Council, and other decision bodies that impact more and more on healthcare. A specific Treaty provision would also make clear the autonomy of the Member States to pursue healthcare policies they think fit for their citizens. The problem at the moment is one of political guidance. To return to the issue of the Court, I think it is certainly unfair to blame the Court of Justice for what they do because they are simply doing what they are charged with doing: interpreting the Treaty.

We should also make operational a number of principles that were agreed at the Lisbon summit and which defined the whole ambition of the Belgian presidency, before the window of opportunity created at Lisbon is lost. I’m convinced that enlargement will be extremely detrimental if there is no clear vision of what drives the European social model and on its objectives – and these should go far beyond solemn declarations.

“We need to introduce common objectives on social policy now. This is something that cannot wait.”
Two and a half years ago, when I took my position as Commissioner for Research, I insisted that research should be recognised as a vital policy area for the European Union. At the Lisbon summit in March 2000, Heads of State and Government endorsed the creation of a European Research Area and adopted a new strategic objective for the European Union for the next decade, which is to make Europe the most competitive and dynamic knowledge-based economy in the world.

Since then, we have initiated a series of measures to generate the dynamic of a new European research policy, namely in the field of the mobility of researchers, the coherent development of modern research infrastructures and the coordination of national activities and programmes. On these and other points – and I am thinking in particular of intellectual property, the problem of the Community patent, and venture capital – much still remains to be done and over the past two years I have launched actions and initiatives which will gain in impetus during the coming months.

EU support for research is organised in four-year programmes. The Sixth Framework Programme for research 2002–2006 has been conceived with a completely different objective in mind than the previous programmes. It has been designed above all to be a structuring instrument for making the European Research Area happen.

One important aspect of the European Research Area is to develop cooperation between the research sector and society. In fact, the European Union will be promoting efforts aimed at strengthening and improving dialogue between academia and society. We need to increase interest in and knowledge about research as a whole, while getting researchers and decision makers to be more keenly aware of the concerns expressed by ordinary citizens. It is particularly important that issues relating to ethics and safety are dealt with completely openly and are the subject of broad discussion throughout the whole of society. Citizens’ confidence in research is a necessary condition for the progress of science.

I see the European Commission’s role in research as no longer limited to the mere management of programmes but to stimulate a closer interaction between science and society.

Among other activities, we have established a European life sciences group (ELSG), to examine the wide-ranging challenges and opportunities that the development of the life sciences raises for society. The group assists the Commission in launching and conducting the public debate on the priorities of European research.

In December 2001, the ELSG and the Commission organised a conference on stem cell research to provide a discussion platform to encourage debate on the multiple issues surrounding recent advances in this field. The position emerging from these public discussions as well as from the debate in the EU institutions is that reproductive cloning should be prohibited but that the EU should continue to support research using all sources of human stem cells, including stem cells from existing embryos, as long as such research is permitted in the countries where it is to take place.

In another area of the life sciences, we have set up a forum on cancer research bringing together managers and scientists with the aim of overcoming fragmentation of
European efforts and poor coordination between various networks of excellence. Above all, I want scientists to go back to the debating table. Europe needs to make sure that it has a sound basis for discussing issues that have an impact on society. A conscious political decision in this field is not possible without informed advice and public debate.

To meet the challenge we launched an action plan in December 2001 to develop a stronger and more harmonious relationship between the world of science and society at large. The Commission’s plan sets out 38 measures to popularise science in education and culture, to involve citizens in science policy and enhance governance in science, to encourage women into scientific careers and to better address ethical questions. These actions will require a concerted effort by actors in the Member States, the regions, and by citizens, with the European Commission acting as a catalysing force.

In this context, the Eurobarometer survey on ‘Europeans, science and technology’ published by the Commission in December 2001 offers a unique insight into how European citizens view science and technology.

Demand for reinforced control
As is often the case with such surveys, there are both positive and negative messages. On the one hand, science continues to enjoy a large measure of confidence among Europeans. Citizens expect a lot from scientific progress and want political decisions to rely more on experts’ advice. For example, a majority (80.5 per cent) of Europeans believe that scientific and technological progress will help to cure diseases such as AIDS and cancer. On the other hand, there are also concerns and scepticism expressed by ordinary people regarding some issues: 80 per cent of Europeans feel the authorities ought to formally oblige scientists to observe ethical rules.

For example, there is today a real concern that the public associates anything scientific with crises of one kind or another, such as BSE, climate change and so on. Science is often perceived as a kind of Pandora’s box out of which rather dubious inventions sometimes spring. This feeling has increased over the past 15 years. But science has more often been the instrument both of recognising such crises and of solving them – something that people often forget. It is science that is pushing society to look at the necessary changes which must be made in the light of such threats, the causes of which are primarily economic, industrial and demographic.

But there are positive points. In the case of BSE for example, it is the operation of markets, not science, that is mostly to blame. Scientists have been called in and they will be the ones expected to repair the damage. Research investments are directed towards developing reliable tests and improving the understanding of the disease. As a matter of fact, crises of this kind can also strengthen science and its image, as well as the image of public research underpinning this kind of work.

The Eurobarometer clearly shows that scientists enjoy a very strong image in society, but it is an ambiguous one. The power of knowledge that they possess leads to suspicion of the work they do. People would like them to communicate more – and better – about their work.

A majority of Europeans call for reinforced control of research activities particularly in terms of consumer protection, employment and social issues. But on the other hand, we must avoid ethical considerations, vital as they are, becoming an obstacle to future research. Freedom of research and freedom of thinking are essential; it is the application of research that must be subject to democratic control.

A gap between science and society?
Another significant problem today is the fact that science is failing to attract young people. It is not their interest in science per se that is lacking, so much as a question of how science is taught. Science studies are seen as too dry. Our teaching methods are too concerned with the need to fill minds rather than to stimulate them. Pupils must be placed in laboratory situations where they carry out experiments and use their intuition. Science is not all theory.

Moreover, school is not everything. Parents must also be made aware of the need to stimulate interest and, outside school, educational infrastructures such as science centres and museums, which include an element of fun, must be developed. Curiosity and reward is what drives the acquisition of knowledge.

This is a very serious problem and we are sounding the alarm. The future of research is already under threat from an unfavourable demographic trend, which is only compounded by a lack of interest. This problem has been resolved in part in
“Freedom of research and freedom of thinking are essential; it is the application of research that must be subject to democratic control.”

the United States by attracting researchers from abroad – from Europe and Asia in particular. The European Union must do something quite urgently.

Also worrying is the gap opening up between science and society in general. Nearly 50 per cent of Europeans see themselves as neither informed about nor interested in science. Only 29 per cent of Europeans say they are interested in science and technology and believe they are well informed. A significant proportion (14.7 per cent) say they are ‘interested’ but ‘not informed’ – revealing a potential knowledge gap.

However, as always, surveys of this kind throw up their fair share of contradictions and paradoxes. Europeans seem to have a good understanding of the importance and opportunities of science and, more surprisingly perhaps, of research policy. There is, for example, an impressive approval rating for scientific cooperation and the coordination of research in Europe. I am pleased to see that Europeans are very supportive of the concepts underlying the European Research Area. And they are thinking very much as Europeans. They would like to see Europe become more involved in a number of fields, such as consumer protection, employment, social affairs – and science. They would like the European Union to have more levers to intervene in these areas.

Scientific culture

A principal question for me as Research Commissioner is how people can acquire a scientific culture. As our societies are deeply influenced by science and technology, we have the obligation to ensure that citizens have a background that allows them to understand, in general terms, new technological developments and to participate in democratic decisions on them.

The survey again shows that while people very much want to increase their scientific culture, they often do not know how to go about it. It also shows little change of scientific culture compared with 1992, which, depending on your point of view, can be greeted with relief or disappointment.

Acquisition of scientific culture is limited because opportunities for doing so in most people’s daily and professional lives are limited. Paradoxically, one of the main reasons for this is that the technology incorporated in the most common products is hidden and requires no explanation. People use a mass produced product with their eyes closed; otherwise it would be a specialised product destined for a small market.

Acquisition of scientific culture should be one of our priorities. We must also combat the many false ideas and perceptions about science. The image of science given through various media is often misleading or, in any event, incomplete.

We must invest in knowledge at all levels and especially in scientific information. This is clear from the fact that a large number of people say there is not enough science on television – a result that I find particularly surprising. It is crucial that our society, and the scientific community in particular, value and reward science communication more highly.

Scientists also have an important responsibility. If science continues to fascinate young people, why is it that they are so reluctant to study it? If medical and scientific professions are still considered to be the noblest by the majority of Europeans, why are fewer and fewer young people entering them? There are clearly many facets to the conundrum, which reflect weaknesses in teaching, the narrow scope of careers, and aspects of the way science is perceived by the general public and young people in particular.

However, it must also be acknowledged that the sciences (in the plural) bear a share of the responsibility for their declining popularity. Science is becoming more complex due to ever increasing sub-divisions and becomes less comprehensible to the general public for whom many research themes seem too sophisticated, if not futile. Parallel to this fragmentation of categories is an overlapping of tasks: the university researcher must also keep an eye on funding, while the private sector researcher ignores commercial considerations and technical applications at his peril. There is the ambiguity of sciences as a source of progress but also one of fear, and of scientists driven both by the desire to share their knowledge and to wield power.

To a degree, the sciences are isolated, removed from culture, excluded from debates, marginalised in the media. At a time when their influence has never been so great, there is an urgent need to work together to reintegrate science into society and kick start the dialogue between scientists and citizens. It is striking to see that many if not all the problems raised by the relationships between science and society are in fact – at least to some extent – communication problems.
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Six years ago the European Commission, through its Interfaces Programme within the then DGXIII (now replaced by DG Research), asked a number of research organisations to “review the activities of European institutions (that were) developing public understanding of science, and study the possibility of expanding existing initiatives”.

Specialist research consultants Metra Martech represented the UK in the review, the findings of which were made public some five years ago. This article now looks back at those findings and reports on subsequent progress.

The picture in 1995

Metra Martech’s Triangle (See Figure 1) summarises the principal reasons for communicating science to the public. Our findings of what was required were broad ranging, including:

– Publicising scientifically approved databases and encouraging environmental and consensus seminars that enable informed democratic participation in complex scientific and ethical decision making.

– Training journalists in science communication, and scientists in how to cooperate with journalists.

Our suggestions laid the groundwork for several subsequent EU initiatives (including those now being achieved via the world wide web), but two aspects of our findings are still alive today:

1) For politicians to channel funds into (beneficial) scientific advances, they need informed public support. But, to provide this, society must first understand the pros and cons.

2) Keeping the public up to date on scientific advances requires commitment, not just from the researchers but also from the government.

These move us beyond the basic discussion about improving the communication of things scientific to the public and on to the need for a well informed citizenry as a matter of social policy. Health and environment were key subjects in 1995 and they remain the top issues today.

Subsequent developments within the UK

Recent years have seen crucial mistakes in the political presentation of scientific developments to the UK public. They derive from the very different positions of the politician seeking certainty to reassure his or her constituency, and the scientist constantly pushing forward the boundaries of uncertainty. And they are exemplified by the politicians’ pronouncements on BSE, foot and mouth, genetically modified crops, the single vaccine MMR and stem cell research. Categorical statements from ministers have suggested certainty where none existed. They have confused a 75 per cent likelihood with scientific certainty. You might invest in a new commercial venture which offered a 75 per cent chance of success, but only the desperate would gamble with their health at those odds.
The present British government is, at last, developing the idea of public consultation on matters relating to scientific development, but there is a lot of lost ground to make up (as illustrated in the Wellcome research detailed below). We citizens cannot remain in the dark for much longer. This means more dialogue, more deliberate airing of the scientific dilemma, more publicity for the conflicting views of dedicated scientists, and more discussion of the real and justifiable commercial pressures. Unless this happens, the British public will trust no one. And the politicians will find it ever more difficult to justify approval of new processes, and to provide assisted funding for the new work, that will keep the UK in the first division.

**Recent work at European level**

 Meanwhile, authorities within the EU are enthusiastically continuing research into *Science, Technology and the Public*. That is the name given to an internet-enabled forum launched by the European Commission’s Research Directorate-General. It is presented as part of the EC’s so-called Human Potential programme.

Other ideas backed by the EC include the conceptually memorable Third Circle, and the EU’s response in the form of AlphaGalileo. The idea of the third circle is that scientists, journalists and the public constitute three separate ‘circles’. AlphaGalileo is an information gathering and disseminating programme that aims to communicate particular scientific events to the public. It is based on the belief by many scientists that journalists fail to do justice to their work. Many journalists, on the other hand, believe that scientists are poor communicators. At the end of the day, it is the public – the ‘third circle’ – who suffer from this communication breakdown. The challenge for AlphaGalileo is to convince science journalists to take up the information resources it provides.

It is arguable, however, that this three circle approach lacks a dimension – namely, the paramount influence of the political dimension. This includes lobby groups as well as elected politicians.

A more general, and more ambitious, EC initiative is encapsulated in a working document published in November 2000 entitled *Science, Society and the Citizen in Europe*. Confusingly, this document makes no mention of the EC’s Human Potential programme, though it does claim to “form part of the projected development of a European research area in which aspects relating to ‘science, society and the citizen’ constitute a major component.”

**Need for a debate**

As with the first of three objectives of the EC’s document, the aim of this article is to underpin a debate by providing a frame of reference for discussion.

There are several key points in the document:

- The relationship between science and society today is something of a paradox.
- Advances in knowledge and technology are greeted with growing scepticism.
- Major economic, financial and commercial interests are increasingly linked with the advance in knowledge.
- Greater capacity among the better informed and better educated members of the public to apply their critical faculties to developments they regard as being imposed rather than desired.
- The erosion of confidence in political authority.
- Use by the Commission of the results of the broad debate this document stimulates to take policy initiatives designed to lead to concrete action.

There are many other recent studies supporting the need for more informed debate. The extracts that follow illustrate the point from a European perspective.

**Research in the UK**

Further food for thought relevant to public attitudes to science is provided by research done in the UK. Under the umbrella of *Science and the Public*, the Wellcome Trust and the UK’s Office of Science and Technology (OST) sponsored two UK based, interrelated, reviews. The first investigated existing science communication activities whilst the second researched public attitudes to science, engineering and technology. The underlying premise of the two organisations is that some scientific developments are so fundamental that there needs to be a public debate before politicians and scientists make decisions about them. The sponsors further believe that the quality of the debate is likely to be better if there is a dialogue between specialists and non-specialists rather than a one way flow of factual information.

So, as with the EC, the UK initiative was designed to start a consultation process.

“Recent years have seen crucial mistakes in the political presentation of scientific developments.”
But, whilst the EC papers seem to want to encourage thinking in terms of future EU-wide ‘governance’ of the situation, the Wellcome review boldly states its key findings to be:

- Science communication activities tend to be skewed towards activities that provide facts about science rather than activities that highlight the ethical and policy issues raised by science.

- The majority of those surveyed were ‘amazed’ by the achievements of science, although some expressed concerns about its regulation and control.

Other findings included:

- Some sections of the public are under-targeted by the communicators (for example, female adults).

- Some communication providers felt that the science community should perhaps be looking more into ‘the scientific understanding of the public’, rather than the ‘public understanding of science’, and analyse what the public wants and needs from science.

- Eight out of ten people agreed that Britain needs to develop science and technology to enhance its international competitiveness, and that scientists and engineers make a valuable contribution to society.

- Nearly three quarters of the general public agreed that research that advances knowledge is needed even if it brings no immediate benefits.

However, even though the public attitudes survey was conducted before the recent foot and mouth epidemic and the Government-commissioned report on the BSE fiasco:

- Over half the respondents thought that scientists seem to be trying new things without stopping to think about the risks.

- Less than 50 per cent of the public were persuaded that the benefits of science are greater than any harmful effects.

Many of the current questions posed do not go back the full 29 years, but the most noticeable feature of those that do is that only one of them demonstrates an uninterrupted one way change of public attitude. Unsurprisingly, this relates to the ever diminishing respect for the civil uses of nuclear energy which, having started relatively high in 1972, had practically halved within the next 20 years, where it has remained. This reflects the build up of public enthusiasm by the government, based on apparently scientific reasoning, gradually eroded by realisation that only part of the truth had been exposed at the time.

For practically every other aspect, the French surveys uncover just the same ups and downs in public attitudes as do studies in the UK. Ups and downs in opinion probably vary according to specifically national factors. For example, French respect for science and technology in relation to the conquest of space began quite low in 1972 and rose consistently until 1989 (as the French space programme blossomed), but has drifted downwards subsequently.

The biggest shift in French public apprehensions over the last decade appears to relate to chemical additives in food production. Today, almost 90 per cent of French citizens are hostile to the use of such additives, compared to around 70–80 per cent over the previous two decades. This apparent rejection of large scale commercialised food production methods is to be expected, given that political support of the small farmer in France is a creed.

Other evidence of public concern

Further evidence of the international concern now given to public attitudes to science, comes from the fact that parts of the French based survey were later extended to Germany, the UK and the USA, with some surprising results. In relation to the quality of the air in towns, for example, only three per cent of French respondents were prepared to admit to any improvement, compared to a quarter of the Germans and well over a third of the British and Americans. And in respect to the quality of food, less than 30 per cent of the French can see any improvement compared to over 40 per cent of the Germans and 70–80 per cent of the original fast food devotees!

On socio-political issues, there are different inter-country variations. In answer to the suggestion, “Some people say that science
shouldn’t have the right to do certain things because they would transform nature too much”, 83 per cent of the French were in general agreement compared to 75 per cent in the UK, 70 per cent in the US and just 63 per cent in Germany.

By contrast, the statement “Even if some types of research are likely to bring some moral principles into question (for example artificial reproduction techniques or brain surgery), it is necessary to continue with the research all the same” produced percentages that vary rather less. France recorded 67 per cent agreement, Germany 73 per cent, the US 78 per cent and the UK 80 per cent.

The challenge today
In the past two or three years, the world wide web has massively increased the chance for all relevant views to be available to individuals who care to inform themselves. But many will not; which brings us back to the three circles mentioned earlier: the scientist, the journalist and the public. The message for today is that no amount of improvement in the communication of science to the public will succeed if politicians insist on giving easy answers in the name of science, which are quickly exposed as unfounded or even untrue.

REFERENCES

Public dialogue in science and technology

Parliament and the policy process

“doctors, scientists and engineers are held in high regard, while businessmen and politicians are least well regarded”

Within Europe, as with many advanced economies, there is growing interest in engaging the public more directly in policy and decision making. While this has been a feature of public policy in some EU countries for many years (particularly Denmark and the Netherlands), it is a relatively new practice in the UK. Working within the British Parliament, the Parliamentary Office of Science and Technology (POST)* has reviewed recent developments in public dialogue, focussing on science and technology and drawing on experience from other policy areas.1

Recent years have seen increasing concerns across Europe about a widening ‘democratic deficit’ resulting in a decline in participation in political processes. This is characterised by declining trust in authority and expertise, particularly in the field of science and technology. Controversies over BSE (mad cow disease), GM foods and medical scandals are recent examples of such trends. A recent Eurobarometer Survey highlighted a number of important features in this regard. For instance, the figure shows Europeans’ esteem for professions. It

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shows that doctors, scientists and engineers are held in high regard, while businessmen and politicians are least well regarded.

The survey showed that, while the overall general view of science among Europeans is positive, science is no longer seen as a panacea for many widespread problems such as poverty, environmental degradation, resource depletion, etc. Furthermore, many feel that science should be subject to ethical controls – 80 per cent of Europeans subscribe to the view that “the authorities should formally oblige scientists to observe ethical rules”. However, problems are not all laid at the feet of the scientists: for instance, large majorities firmly blamed industry, government and farmers for BSE.

Governments are clearly concerned by such trends and have made some responses to them. Within the EU, the Commission has recently undertaken a number of initiatives aimed at addressing these issues. In particular:

The European Group on Ethics in Science and New Technologies. The Group was established in 1997 as an independent, pluralist and multidisciplinary body that advises the European Commission on ethical aspects of science and new technologies in connection with the preparation and implementation of Community legislation or policies. It has provided opinions on subjects as diverse as human tissue banking, human embryo research, personal health data in the information society, doping in sport and human stem cell research. At a specific request of the President of the Commission, the Group also wrote a Report on the Charter on Fundamental Rights related to technological innovation.

A White Paper on European Governance (COM(2001) 428 final). This proposes opening up the policy making process to get more people and organisations involved in shaping and delivering EU policy. It promotes greater openness, accountability and responsibility for all those involved.

An Action Plan for Science and Society (COM(2001) 714 final). This was compiled as part of the Commission’s plans to establish a European Research Area. The action plan covers: promotion of scientific and education culture; bringing science policies closer to citizens; and putting responsible science at the heart of policy making.

In the United Kingdom, recent activities have included:

- The Phillips Report on the BSE crisis in the UK. This identified clear lessons to be learned in the way that government goes about seeking and using scientific advice. In particular, the report called for greater openness, transparency and public involvement in the process.

- A set of guidelines on the use of scientific advice in policy making (Guidelines 2000). These were first issued in 1997 (in the wake of the BSE crisis), and strengthened in 2000. Three key messages are put forward:
  - think ahead and identify early the issues on which scientific advice is needed;
  - obtain a wide range of advice from the best sources, particularly where there is scientific uncertainty;
  - publish the scientific advice and all relevant papers.

- A Code of Practice for Scientific Advisory Committees. This provides more detailed guidance specifically focussed on the operation of scientific advisory committees and their relationship with government. They also aim to put Guidelines 2000 into day to day practice. Issues included in the Code include (among others): the committee’s role and remit; early identification of issues; balance of expertise; conflicts of interest; role of the secretariat; reporting of risk and uncertainty; dealing with dissenting views; publication of material; communication with the public; open meetings; public consultation; peer review; communication with the media and information exchange.
The need for public dialogue

A common thread can be seen to be emerging whereby public bodies are increasingly seeking views from outside people and organisations. Among the methods traditionally used are questionnaires, opinion polls, and invitations for written submissions. However, these have failed to stimulate widespread enthusiasm and do not encourage deliberation between those taking part. Such methods also tend to underrepresent social groups such as young people, old people, people with disabilities and those from ethnic minority and religious groups. There has thus been a move towards more innovative public dialogue, using consultation methods that attempt to broaden the basis on which policies and decisions are made (see Box).

Such methods allow institutions to have greater interaction with citizens; engaging them in dialogue to increase the range of fora within which people can express their views, values and experience, and so participate in policy and decision making. There is increasing recognition that public dialogue can assist decision making when information (including scientific information) is incomplete. It can provide valuable insights that may help to define questions, and to assess and evaluate solutions. Indeed, in the context of science and technology, an inquiry by the science and technology committee in the House of Lords (the upper house of the British parliament) concluded that open, transparent dialogue is necessary. Also, that institutions dealing with scientific and technological issues need to make dialogue the norm, rather than the exception.

The practice of dialogue

Dialogue would be just meaningless chatter without ensuring that dialogue processes are effective. The practice of dialogue, however, remains patchy and variable. For instance, in the UK, local government and health authorities are well down the path while the Research Councils and academic institutions are only just starting to engage in such activities. Others are not engaging in public dialogue at all, either because they see no value in it, or they see it as someone else’s responsibility.

Three key elements can be discerned that help an organisation maximise its chances for successful dialogue:

– Objectives: setting out why dialogue is being sought
– Legitimacy: ensuring the process is acceptable
– Evaluation: identifying the quality of the process

Objectives for dialogue

It has become very clear that defining the objectives for dialogue is critical for ensuring effectiveness. Where objectives are clearly defined and agreed, the process will command more respect, and is more likely to have a constructive outcome. However, some institutions have been accused of engaging in dialogue purely because they felt that they ought to and hence with no (or poorly defined) objectives. Similarly, some are concerned that dialogue may have been used cynically to legitimise previously made decisions.

Legitimacy and authority

The ‘legitimacy’ of any process to engage the public depends on three key factors:

– Fairness: Participants often express concern that their views might be ignored. Thus, formal and clear links between dialogue and decision making are required.

– Method and timing: Dialogue ought to be fit for purpose. In addition, it should not necessarily force consensus when

INNOVATIVE CONSULTATION METHODS

Two features characterise many of the more innovative forms of public consultation and dialogue:

• They are deliberative – participants interact, engage in considered debate and modify their views based on information, shared views and respect for different perspectives.

• They are inclusive – i.e. they seek out the views of all that stand to be affected by a decision. In particular, opinions are canvassed from previously excluded, or hard to reach groups.

While each process seeks to meet its own objectives, all come within the scope of two overarching objectives: supporting democracy, and making better decisions. Among the more commonly cited goals for dialogue are to:

• provide elected representatives with the considered views of informed lay people;

• find areas of common ground and dissent;

• increase trust in decision makers;

• increase support for decisions; and

• promote the personal development of participants.

Among the growing number of methods available, the more common include:

• Deliberative opinion polls

• Citizens’ juries and panels

• Standing consultative panels

• Consensus conferences

• Internet dialogues

• Focus groups

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unnecessary; and that it should take place when it can have the greatest effect.

- Participation: The 'appropriate' people should take part in the dialogue, depending on the objectives (e.g. lay citizens, groups that are difficult to reach, or statistically robust population samples).

Evaluation and effectiveness

Criteria are being developed to evaluate the quality of a dialogue process and its outcome. However, evaluation needs to be tailored to specific circumstances, according to the objectives sought and the methods used. Nevertheless, there are some attempts to draw together more widely applicable sets of measures, but as yet no universal criteria have emerged. This raises concern among some that there is no firm basis for learning lessons to identify either good or bad practice. If this remains the case then bad practice will go unnoticed, good practice will not be disseminated, and dialogue will be justified on limited case by case, anecdotal evidence (and some wishful thinking).

Further development

If the trend of increasing public dialogue in science and technology is to continue and be effective, three items might be required before dialogue can be developed further:

- Building the required skills. There needs to be sufficient numbers of trained dialogue process designers and facilitators, and 'intelligent clients' who can recognise their own needs and work effectively with practitioners in building dialogue processes that are fit for purpose.

- Providing sufficient resources. There is a perception that dialogue is a lengthy and costly process, but the evidence does not support this claim. Indeed, many have pointed out that the full economic and political costs of not engaging in dialogue should be considered.

- Providing a learning resource. This would enable institutions to learn from experience, including from those outside of their traditional fields of view. An interesting development in the UK has been the Public Involvement Awards run by the Institute for Public Policy Research.²

Conclusion

Overall, then, we can see that there are high level moves at EU and Member State level towards increasing the role of public involvement generally in political life and specifically in policy and decision making involving science and technology. However, turning the welcome rhetoric into reality will not be straightforward. Current practice of public dialogue is widespread, but the objectives and methods are varied, and new processes are developing continually. Moreover, quality is variable, and difficulty to measure. However, there is good evidence to suggest that successful public dialogue requires:

- high level commitment from the organisation sponsoring the dialogue;

- an institutional culture within the sponsoring body that recognises the value dialogue to its business;

- sufficient funds and skilled personnel both within the sponsoring body and in the profession of dialogue design and facilitation;

- a clear idea of why dialogue is being sought;

- clear ways to show how dialogue has informed decision making;

- an agreed system for measuring impact and quality.

An underpinning question is how experience can be widely shared, good and bad practice identified and dialogue furthered on the basis of sound evidence.

These are clearly exciting times for public dialogue. If approached in the right spirit, and with sufficient commitment and resources, there is great potential to improve the processes of decision and policy making on science and technology both in individual Member States and in the EU as a whole.

This article represents the views of the author only and not necessarily those of the Board of POST or the British Parliament.

References

1. A report of this review is available on POST’s website: www.parliament.uk/post/pr153.pdf
2. See website: www.ippr.org.uk

² POST is a member of the European Parliamentary Technology Assessment (EPTA) network of which it holds the Presidency for 2002. The Partners in EPTA are bodies performing science and technology assessment studies in order to advise parliaments on the possible social, economic and environmental impact of new sciences and technologies. Its coverage includes: the European Parliament, the Council of Europe, Austria, Belgium, the Czech Republic, Denmark, Finland, France, Germany, Greece, Italy, the Netherlands, Norway, Switzerland and the United Kingdom. See website: www.eptanetwork.org
Science, uncertainty and society

Developments in science and technology have made life demonstrably safer in relation to a whole range of health issues, and the benefits of such advances are enjoyed across almost all sectors of society. However, and somewhat paradoxically, the research evidence on attitudes to science and technology also suggests that trust in science and scientists appears to be at a particularly low ebb. This has been accompanied by a number of prominent risk controversies: genetic modification of food, mobile telephones, MMR vaccination to name just three. Indeed, wherever we turn ‘risk’ appears to be at the very top of the public policy agenda. Why is this the case?

Public attitudes towards science and its application are complex, and certainly not the product of ill informed or ignorant opinion. Rather they touch upon deep issues of uncertainty in science and trust in governance, which scientists and policy makers would do well to heed. Accordingly the time is right for a new relationship between science and society, involving more deliberative and participatory approaches to risk management.

Risk assessment and scientific and technological uncertainty

While hazards and their consequences are often very real the concept of risk is fundamentally a social construct, developed initially by engineers and decision theorists to provide predictions about future worlds. Matters are not simplified here by the range of different technical definitions of risk one finds being used in practice, the two most common being (1) the probability or chance of a loss and (2) the probability multiplied by the potential magnitude of that loss. By the latter definition something that seems very low in likelihood can still be seen as risky, and hence worthy of attention. However, simple definitions such as this also preclude a more nuanced view of scientific uncertainty. And it is important to recognise from the outset that science, by its very nature, deals with a range of qualitatively different uncertainties, having very practical impacts upon the nature, and reliability, of risk assessment that can be attempted.

A basic distinction can be made between decisions under risk, uncertainty, and ignorance. We face decisions under risk when a well defined system has known probabilistic properties – for example, dice. We can be confident in the chances of throwing a six from empirical evidence of repeated throws of this or a similar dice. Population epidemiology typically deals with risk because one is able to evaluate known health outcomes across a group of individuals given certain assumptions about similarity of behaviour, genetic makeup, or exposure to disease.

Decisions under uncertainty occur where a system is well defined, the possible outcomes are known (as in an election between two specific individuals), but we do not have long-run evidence of the behaviour of this specific system (by definition any election is unique, only being held once). In this case a more subjective judgement has to be made, based upon available evidence, regarding the uncertainty that candidate X will win on the day.

Finally, decisions under ignorance occur when we do not have a well developed model of the system or issue under consideration, and hence only an imperfect view of the potential consequences and uncertainties. The unintended consequences (social, environmental and health) of the human genome project would be examples where current knowledge does not allow full characterisation of all future risks.

Unfortunately many of the long term risk controversies that we face in society are both fraught with such deep uncertainties, and involve high stakes for those involved. Where this is the case we move out of the realm of formal risk assessment, which can only fully work where sufficient data is available, and need to adopt other methodologies and tools: including use of the precautionary principle to guide societal risk management, as well as greater stakeholder involvement in risk management efforts to reflect public values on technological futures.

Human and organisational factors

All of the above problems of dealing with risk and uncertainty are compounded when it is recognised that the application of science and technology is critically dependent

Nick Pidgeon

“Openness may be a necessary but is certainly not a sufficient condition for achieving trust.”

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Scientists need to understand the public as much as the public must understand science. Connecting the two is both a research challenge for all EU member governments."

upon human and organisational activity. In this respect hazardous activity almost always involves so-called ‘socio-technical’ systems (a product of the interaction of social and physical systems). Most of the time risks are managed relatively safely by the humans and organisations in charge of them, but research also shows that a familiar pattern of events underlies the major failures that do from time to time occur. In particular these can be characterised as organisational failures of foresight, labelled by the late Barry Turner a ‘Man-Made Disaster’. Here a series of systemic factors and communication failures within the responsible organisations contribute to oversight of an ‘incubating’ hazard. In effect a group of individuals, or even a whole set of institutions, is subtly and unintentionally deflected from asking, or acting upon, the right critical questions about the collective view and received assumptions about the world and its hazards. That is, organisational thinking becomes locked-in to a flawed and prevailing model of the world. Under such circumstances available ‘warnings’ and critiques, in particular from outsiders, are also likely to be downgraded or dismissed.

In the UK the contemporary context to many risk controversies, and with it to public attitudes to science, is set by recent events such as the Brent Spar affair, genetic modification of food, foot-and-mouth disease, and above all the impacts of the BSE/\text{sCJD} crisis. The UK inquiry report into BSE\textsuperscript{6} paints a picture of a government grappling with high decision stakes and deep scientific uncertainty. In particular, the report notes that, prior to 1996:

- Precautionary actions were blunted by the belief that BSE was not a major human health threat, which was fuelled by a particular interpretation of the assumptions about risk contained in the 1989 Southwood report on BSE and human health.

- Assessments of (apparently minimal) risk were not communicated sufficiently to those charged with ensuring the adequacy of public health controls.

- Fear of ‘overreaction’ fuelled a reluctance to reveal the risk to the public.

At root BSE was an organisational (rather than simply a health or medical) failure, and it is this lesson which is the most important one to be learned. Dealing with human and organisational issues sets a significant problem for risk assessment practice too.

Risk perception: control, equity and trust

As a field of science policy research the study of public attitudes to risk evolved out of initial work by psychologists in the 1970s and 1980s on risk perceptions, which aimed to map the cognitive and social processes underlying both lay and expert conceptualisations of risk. The initial focus was on explaining public acceptability of nuclear power – although over time a much wider range of technological and health risks have been studied. Perceived risk and its acceptability have been found to vary as a function of a number of factors, including:

(a) Qualitative aspects of hazards, such as levels of perceived control and voluntariness – the perception of a lack of consent;

(b) Cultural and institutional affiliations;

(c) Societal values and beliefs concerning, for example, the equity of activities for which the benefits and risk burdens are unevenly distributed across society.

Accordingly, two hazards with ostensibly similar risks in epidemiological terms might still differ widely on some of these other characteristics, and hence provoke differing public responses in terms of acceptability.\textsuperscript{7} Labelling of GM food has become a particular concern precisely because people feel they want control over the risk. GM food raises equity concerns as well, because the benefits are perceived to go to large companies, while the risks fall on the individual consumers.

More recent sociological and social psychological work has highlighted the role of trust (or distrust) in regulatory and risk managing institutions as a further driver of attitudes towards risk. From empirical work we know that ‘trust’ is a complex and multi-faceted concept, depending upon an individual or organisation exhibiting (or being perceived to exhibit) a number of attributes:

- Independence (from stakeholder or political influence)
- Expertise (in the problem domain)
- Perceived public interest (above all else)
- Consistency of position
- Actions congruent with words
- Adequate means (e.g. resources) to meet objectives

Some sociologists would go so far as to argue that reliance upon expertise and institutionalised risk management has become
one of the defining features of a modern globalised ‘risk society’, with people increasingly distanced in terms of direct understanding or control from many of the sources of risk that they fear will impact upon their lives. It is hardly surprising, therefore, to find a healthy degree of lay scepticism, and in some cases profound alienation, when expertise is found wanting, is uncertain or contested, or is unable to articulate sound theoretical scientific principles and risk assessments that allow appreciation of the actualities of risk management in a complex and messy world. On top of this people have a fairly good appreciation of the human fallibilities that underlie major failures and disasters, from the direct experience of their everyday lives.

**Science and society**

So what might be done? The recent House of Lords Science and Technology Committee report on Science and Society reinforces the view that the UK is experiencing an apparent crisis of confidence in governance and science (fuelled in particular by the experiences of BSE and the GM crops controversy). The traditional response to such a position has been to engage in one way science education. However the Lords report also notes that there has been a failure of the traditional one-way ‘deficit model’ of science risk communication. We can no longer assume that merely educating and informing people about science and technology will itself lead to resolution of risk controversies. Evidence from work on risk perception and its communication noted above would also support this view. There is a need to change institutional terms of reference and procedures, and in particular to broaden the base of public consultation and dialogue on risk issues: in effect, a move to a two-way relationship between scientists and society. As a society we need to move beyond traditional public understanding of science efforts if we are to resolve some of the most contested risk issues: in particular scientists need to understand the public as much as the public must understand science. Connecting the two is both a research and a public policy challenge for all EU member governments.

The official inquiry into BSE in the UK contained three sets of conclusions relating to the Science and Society agenda. There is a need for openness in government as a precondition to re-establishing credibility and trust in risk management and policy; for an overhaul of the use of scientific advice by government (to allow more external critique and testing of assumptions); and for explicitly addressing risk and uncertainty in the risk management and risk communication process.

There are very good reasons to encourage openness in the handling of risk issues, not least because it allows for the external critique of (or at least a ‘fresh eye’ on) risk assessments, together with any explicit or implicit framing assumptions that have been made, that is so critical to societal learning. Had sufficient external critique been brought to bear upon the assumptions made in the 1989 Southwood report, a greater urgency in dealing with BSE and human health might then have ensued. However, it is also important to recognise that while improving trust is a goal desired by agencies and many other parties, openness may be a necessary but is certainly not a sufficient condition for achieving trust. Trust depends upon a variety of complex institutional factors, and not just transparency per se. Addressing all of these issues should be seen as part of a wider process that emphasises participatory approaches to risk management (including citizens’ juries, deliberative polling etc.) as a means of using the best scientific evidence alongside public values in the debate about risk futures. Although we do not as yet know all of the unintended consequences of such initiatives, they should surely be at the forefront of the relationship between scientists, governments and civil society across the EU today.

**References**

Action by self-help groups and the intervention of the European Parliament have led to a change of policy by the Commission on silicone breast implants. This change, namely in the form of a resolution of the European Parliament (EP) (approved on 13 June 2001) and a Commission Communication (published on 15 November 2001), proposes tighter controls on the safety of breast implants, reinforced mechanisms to check that these rules are observed, and an upgrade in European standards for breast implants. These proposals are part of a joint drive by the Commission and Member States to improve implant quality, information provision and post-surgical follow up.

**Process of change**

Petitions by self-help groups to the EP prompted it to commission a comprehensive assessment on silicone breast implants, to look not only at scientific findings but also to assess the concerns of interest groups, with the aim of providing to the Parliament several policy options. The call for this study on the health risks posed by silicone breast implants was announced by the Scientific and Technological Options Assessment (STOA) of the EP and was awarded by tender to a group in Madrid led by José M Martin-Moreno (see Box 1). The findings from the group’s final report are largely reflected in the recent Commission Communication. In light of the proposals contained in this report, and after discussions with the Commission and national authorities, the EP opted for stricter rules on silicone implants. There was a broad consensus in favour of a Community-wide policy that would retain the present legal framework but introduce specific measures to increase and improve information for patients, tracking and surveillance, quality control of implants, and key research.

**The study**

The study consisted of an assessment of silicone breast implants based on a comprehensive, unbiased analysis of the scientific literature on the subject and of interested actors. Most important, we incorporated an analysis of the views of different interest groups. With this aim, and attempting to reflect all views, both positive and negative, we interviewed patients and received information from self-help groups, women’s groups, specialist surgeons, silicone breast implant manufacturers, scientific societies, and Member States. All of this information was incorporated into the study.

We made summaries of the responses from different interest groups and included them as tables. To reflect the more difficult, ‘greyer’ input, such as information from self-help groups and individuals, we dedicated a stand-alone section in the report summarising these views and reflected these positions in the analysis. We sent all original, primary information received directly to the EP, because of its extremely sensitive nature and to avoid any potential bias in our analysis.

The result of our assessment pointed to three alternative policy options, and gave details of the pros and cons of each option. We stated that, in view of the evidence, the
option that proposed additional measures for maximising the benefits of breast implants and limiting the risks in the EU context, appeared to be the most balanced approach (see Box 2).

Discussion and conclusions
There are extremely strong interests at stake on either side of this issue and we often received conflicting information from different interest groups. Thus, our aim was to capture the complexity of the issue but try to get to its essence in a way that would enable the EP to make the most appropriate decision.

The soundest, most robust scientific data on silicone breast implants show insufficient or unconvincing evidence of an association between serious health disorders and implants. As public health professionals, our first inclination was to focus on the numerous epidemiological studies on the subject (for example, recent comprehensive analyses such as the United States Institute of Medicine Report on the Safety of Silicone Breast implants), which point to inconclusive evidence of an association between silicone breast implants and the two main causes of concern: cancer and connective tissue diseases. However, as our analysis began to concentrate on the greyer, more subjective responses of individuals, limitations to the existing studies and clear areas for improvement became apparent. Moreover, relatively frequent local complications related to the surgical procedure and durability of breast implants (rupture, deflation, contracture), which are problematic but not life-threatening, appeared to have been neglected in previous systematic reviews.

No matter how rigorous, there are always limitations and potential sources of error in scientific research. In the case of silicone breast implants, additional complications exist for various reasons: the different stages and varieties of implants that have existed; little tracking or surveillance; and inherent methodological limitations (studies focusing on a few well defined connective tissue diseases or cancer and not a comprehensive evaluation; small sample sizes; and different kinds of implants, present for varying periods of time). Delving into the ‘greyer’ areas of assessment drew yet more attention to these shortcomings, highlighting the need for further research.

Yet just as important, the lesson learned from this assessment was that regardless of whether there are real health risks from silicone breast implants, there are certainly very clear areas requiring immediate improvement.

This analysis underlined the importance of the human angle and the need to take account of this along with scientific evaluation. In a healthcare technology such as silicone breast implants, patient satisfaction, and the way in which the technology suits the patient, need consideration. Even if the majority of users are satisfied with a technology or procedure, a great deal of critical information can be learned from those who are not. Here, a considerable body of users had similar views and concerns, and an analysis of these positions uncovered important deficiencies in the surgical procedure itself and in information given to the patient about the implant and its aftermath. The analysis revealed that certain groups of women in Europe have traditionally felt that they have had no ‘voice’ whatsoever. They have felt shunned from the researchers who have been studying the issue, ignored by surgeons and their governments, and they have felt that their position has not been adequately taken into account. This study, like others should do in the future, incorporated these positions and the resulting analysis pointed to real areas for improvement, areas which would not necessarily have been identified from just assessing scientific research alone.

The resolution of the EP and the recent Commission Communication have important policy implications, calling for tighter regulation of silicone breast implants and better, more appropriate information. The initiative taken by self-help groups, STOA’s commissioning of this independent report, and the receptivity of the EP have led to the better understanding, application and quality of this important technology.

Box 2 PROPOSALS
The seven measures proposed by our group were:
1. To facilitate consensus on a breast implant consent form, including information related to alternatives, benefits and risks.
2. To guarantee marketing control over breast implants in order to avoid any kind of incorrect and misleading information.
3. To improve certification, technical standards, and regulation.
4. To promote the elaboration of clinical guidelines, standards of care and the development of quality assurance systems.
5. To facilitate consensus, promotion and support of effective surveillance systems to report adverse effects and long-term effects.
6. To consider silicone breast implants a research priority and make funds available in the EU research programmes, specifically focusing on some of the shortcomings to date.
7. To foster tolerance and self-esteem and other conceptual alternatives to breast implants, in collaboration with active groups in this field.

REFERENCES (not marked in text)
Mental health: familiar challenges, unprecedented opportunities?

Last autumn’s publication of the *World Health Report* was an important staging post in the worldwide campaign to improve the recognition, assessment and treatment of mental health problems. It will, of course, remain forever merely a report unless it prompts, catalyses or accelerates action on the ground. Fortunately the report is just one high profile part of a broad, evidence based and concerted campaign – by the WHO and others – to raise awareness, broadcast good practice, support initiative and guide practical developments (see John Henderson’s article pp.22–24).

Mental health services in Europe are deficient in many respects, but they are vastly better than in most other parts of the world. That is probably scant comfort to those strategic decision makers in European health systems struggling to secure a bigger slice of the budget for mental health services. Nor is it much comfort to those front-line professionals denied budgetary approval for a new medication or unable to find a skilled therapist to deliver cognitive behavioural therapy or simply without enough time to give consumers the attention they deserve.

**Resource challenges**

Taking a resource perspective – which is a narrower view than that adopted in the *World Health Report* – there are several principal challenges facing Europe’s mental health systems.

One resource problem common to most countries is resource insufficiency: not enough financial or other resources are made available for mental health. This most fundamental of challenges is discussed by Anna Dixon (pp.25–28), who points to the surprisingly wide variation even between EU countries in the share of total health expenditure going on mental health services. As her article makes plain, there are numerous financing dilemmas confronting mental health systems in Europe.

A second challenge is resource distribution: available services are poorly distributed, being available in the wrong place and at the wrong time. For example, there is a tendency for the best and widest range of services to be concentrated in large cities. Whilst mental health problems appear to be more prevalent among urban than rural populations, there are substantial unmet needs in rural areas. A related issue could be that some services are available only to higher income groups, even though many of the common mental health problems are associated with low income. David McDaid’s paper on equity addresses these and related matters (pp.29–31).

More generally there is a need for European governments to tackle the age old problem, not only of social exclusion of people with severe and enduring mental illness, but also of substantial social disadvantage for people with common mental disorders. Philippe Bronchain describes some of the European initiatives designed to tackle these problems (pp. 32–33).

A third challenge is resource inappropriateness: available services do not match what is needed or preferred. A clear example of this is the continued dominant position of large psychiatric asylums in some countries. These large and often remote 19th Century facilities have largely fallen into both disrepair and disrepute. Many are still open, providing asylum for people in a distressed state, but many continue to accommodate people who do not need to be there, often in conditions of very poor quality of care.

In cost terms, these hospitals account for high proportions of available mental health budgets whilst supporting small proportions of the total population in need. One of the quandaries, of course, is that they do at least provide a recognisable and ring-fenced mental health resource and closing a large psychiatric in-patient facility can lead to the leakage of resources out of mental health. But protecting a decaying, dehumanising resource that abuses human rights just because it has the label ‘mental health’ is surely misguided.

The challenge is to design community based services that can help people with chronic mental health problems to thrive. This is not easy, even with the political will and the right funding. As Jocelyn Catty et al argue (pp.34–36), the international evidence suggests that it is not as straight-
In Europe and worldwide, 2001 has proved to be a significant year for mental health policies, their development and implementation. For the first time in the 50 years plus of its history, the World Health Organisation declared World Health Day, 7 April 2001, as a day devoted to Mental Health under the slogan “Stop Exclusion: Dare to Care”. The main aim of the Day was to raise awareness, increase knowledge and to begin a process of changing attitudes about mental health issues. In particular, communities around the World rallied around a call to end stigmatising and discriminatory practices towards people with mental health problems and their families.

At WHO Headquarters in Geneva, the Director General, Dr Gro Harlem Brundlandt, joined the European Union Commissioner for Health, Mr David Byrne. In her address, Dr Brundlandt invited all peoples and governments around the World to observe the World Health Day in recognition of the burden that mental disorders impose on the people and families affected by them. The message was not only of concern that the economic burden of mental disorders was wide ranging, long lasting and large but also that important advances had been achieved by researchers and clinicians in reducing suffering and the accompanying disabling effects of mental disorders.

Mr Byrne drew attention to the impact of mental disorders on working capacity and personal relationships, as well as the economic burden that this places on society. He emphasised the Commission’s intention in the forthcoming public health programme to distinguish between mental health and mental diseases. The activities of the European Commission in the field of mental health will be essentially within the general context of prevention and health promotion.

At the 54th World Health Assembly of the member states of the WHO, in Geneva, in May 2001, four ministerial round tables...
discussions took place concurrently. Ministers from around 150 countries shared recent developments and approaches in mental healthcare in their respective countries. The ministers agreed unanimously that both governments and societies have a long overdue debt towards their populations in regard to mental health.

On 4 October 2001, the World Health Report 2001 was launched by the World Health Organisation, with the title ‘New Understanding, New Hope’. In this report the United Nations Health Agency seeks to break the vicious cycle of stigma, discrimination and neglect of people with mental disorders.

In releasing the annual report, devoted for the first time to mental health, the Director General of WHO declared that a lack of urgency, misinformation and competing demands are blinding policy makers from taking stock of the situation where mental disorders today are among the leading causes of death and disability in the world. The report invites governments to make strategic decisions and choices to bring about positive changes in the acceptance and treatment of mental disorders. The report claims that much of preventive practice, cure and treatment are affordable to all.

On 25–27 October, 2001, during the Belgian Presidency of the European Union, the Belgian Minister for Consumer interests, Health and Environment (Magda Aelvoel), together with the WHO Regional Office for Europe and the European Commission hosted a conference, ‘Coping with stress and depression related problems in Europe’, attended by Gro Harlem Brundlandt and David Byrne on the opening day.

Dr Brundlandt informed the conference that WHO, during the last three years, has sought ways to give greater priority to mental health in the various areas of global public health policy. She stated that there were at least three important factors contributing to the increasing importance of mental ill health in the global burden of disease.

1. Rapid change – from new technology to new methods of work, to new fashions in entertainment and culture.
2. Poverty – today more than three billion people, half the world’s population, live on less than two US Dollars per day.
3. Ageing – over the coming decades a great demographic shift will take place in both developed and developing countries.

There are currently around 600 million people in the world aged 60 years or more. This figure is expected to rise to 1.02 billion within the next 20 years.

Although mental health is part of the WHO definition of health since its adoption more than 50 years ago, for many years there were few attempts to address it directly. Like its patients shut away in separate mental institutions, mental health was not part of public health priorities.

Commissioner Byrne informed the conference that the enlarged competence of the European Union in the public health area, pursuant to Article 152 of the Amsterdam Treaty, does provide opportunities to develop work on mental health issues at Community level. The Treaty clearly sets out key community objectives and places a strong emphasis on tackling health problems at EU level. It does this by addressing risks to health and the determinants of health, at the same time respecting the responsibilities of the Member States for the organisation and financing of health services.

The Commission will concentrate on mental health rather than mental diseases. Furthermore the Treaty emphasises that a high level of health protection has to be pursued in all relevant Community policies and actions. These concern, for example, education, environment, labour and social welfare policies and communication.

Mental health and the fighting of mental health problems, together with stigma and discrimination of people suffering from mental health disorders, will remain high priority areas on the public health agenda of the Commission. The new public health programme will be a valuable asset for all stakeholders in the field to continue the forward looking and promising work they have started in the past under the Community action programmes on health promotion and health monitoring. The Commission will continue to support actively initiatives in mental health that show, in the framework of this new programme, that these can be sustained over the long term.

In September 2001 the European Commission Directorate for Health and Consumer Protection held a symposium jointly with WHO Regional Office for Europe in Brussels organised by the Belgian Ministry of Health and the Finnish National Research and Development Centre for Welfare and Health, (STAKES). For WHO EURO, the symposium, titled
Preventing premature death

1. and disseminate guidelines for mental health, collect evidence of best practices, develop forces for each have been established to work with three objectives in Europe. Task forces for each have been established to work with three objectives in Europe. Task. During the year the WHO EURO programme on mental health and its visibility in the political agenda of Europe has made much progress in 2001 we may well have a feeling of achievement of the desired new understanding sought for by the World Health Report 2001. However as to the new hope of the Report, this will continue only if we continue to engage the attention of our politicians, decision makers, fellow health professionals and also the support and contribution of our patients, their families and carers.

2. Fighting stigma and discrimination. Stigmatisation of people with mental health problems prevents them accessing services, which can mean they do not recover and reintegrate into society. Discrimination is a major contribution to the burden created by untreated mental health problems and must be combated.

3. National assessment and planning. The countries of Europe are diverse and national mental health services should be planned and funded to meet their particular needs. National mental health plans are available currently in only two-thirds of the countries of Europe. National mental health audits are of value to facilitate each country’s planning for investment in mental health services and promotion, and to evaluate the impact on mental health of changes in social policy.

Where next for policy?

While there is not a single mental health policy for Europe there may be common policy issues for the EU Member States and the member states of the WHO European region. Mental health policy also needs to be reinforced by coherent national alcohol and drug policies, as well as social welfare services such as housing.

The WHO World Health Report 2001 carries a powerful Chapter on policy and service provision and much of that is relevant to the countries of the European region notwithstanding the many advances achieved by a number of countries in Europe. Some key elements that are common and appropriate to all countries include the need for up-to-date mental health legislation, which is consistent with international human rights obligations. An ultimate goal will be to shift from large outmoded psychiatric hospitals to comprehensive community based treatment and care. There are many advantages to be gained by the integration of mental healthcare into general healthcare, including primary healthcare. The adequate development and training of human resources for the mental health sector demands constant review.

While the work on the promotion of mental health and its visibility in the political agenda of Europe has made much progress in 2001 we may well have a feeling of achievement of the desired new understanding sought for by the World Health Report 2001. However as to the new hope of the Report, this will continue only if we continue to engage the attention of our politicians, decision makers, fellow health professionals and also the support and contribution of our patients, their families and carers.

REFERENCES (not indicated in text)

Successive initiatives have attempted to increase the profile of mental health both in the European Union and, more recently, by the World Health Organisation at international level. In order to achieve these commitments and recommendations, Member States will have to commit resources, both financial and human. The way in which resources for mental health care services are generated and allocated may have implications for both the development of policy and for service users.

National policymakers must take into account the impact on the wider economy and political acceptability, when formulating and implementing funding policies. Evidence of the impact of funding on mental health services has been a lower priority. Yet if international organisations and national governments want to improve the mental health of the population, they will need to consider these implications carefully. Through an understanding of the characteristics of mental health services and that part of the population with mental health problems, it is possible to evaluate methods of funding mental health care.

Characteristics of service users

In general, the same principles apply to the financing of mental health services as they do to the financing of general health services. But there are a number of characteristics which are more likely to be associated with mental health problems that demand special consideration:

- Many mental health problems tend to be chronic in nature, requiring access to services on an ongoing basis. However, the intensity of service use will vary over time due to the pattern of incidence of acute episodes, thus requiring flexibility in the delivery of care.

- In most countries and cultures, mental health problems carry a stigma. Individuals may be slow to recognise or seek treatment for mental health problems and conversely it may be more difficult for the healthcare system to identify and treat individuals.

- The impact of mental health problems tends to generate multiple needs for support – social support, housing or income support. This range of services is in turn delivered by multiple agencies operating both inside and outside the healthcare system.

- People with mental health problems have a higher probability of being unemployed, tend to have on average lower incomes and are more likely to come into contact with the criminal justice system. Social deprivation and unemployment also contribute to the onset of mental health problems thus reinforcing this pattern.

- For those with cognitive disorders, there may be problems associated with informed choice and compliance in treatment can be difficult to maintain.

Some of these salient features of mental health problems can generate financing difficulties:

- they are identifiable as high risk/high cost with the need for complex interventions;

- there can be user and societal fear and mistrust;

- fragmentation due to multiple agencies and ‘silo budgeting’;

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– catastrophic financial costs associated with serious disorders;
– widespread user ignorance.

Sources of revenue
In its global survey of mental health financing, for which 171 countries provided information, WHO found that tax based financing was the primary source of funding for mental health services in 60 per cent of countries. Out-of-pocket financing was the primary source in 16 per cent of countries, social insurance in 19 per cent, private insurance in two per cent and grants from outside sources in three per cent. These results are strongly influenced by which countries responded and do not reflect the mix of funding sources within countries.

The method of funding mental health services differs between Member States but largely reflects the dominant method of funding healthcare in general, i.e. pre-payment through taxes or social insurance contributions. More significant is the diversification that has taken place within most Member States as a result of the shift away from institutionalised psychiatric to community care. For example, in (West) Germany until 1975 most people with chronic mental illness were hospitalised. Long-stay inpatient facilities were mainly funded through regional budgets. A change in policy at that time led to an increase in the number of community care homes, which are funded out of subregional (municipal) budgets. As a result, large discrepancies in the provision of community mental health services emerged depending on the budgets and policies of municipalities. Another trend has been an increase in ambulatory care for the mentally ill. In Germany, short stay and ambulatory care are mainly funded by insurance funds. Sickness funds reimburse ambulatory doctors for diagnosis and/or therapy of a psychiatric disorder. Sickness funds and pension funds finance visits to day clinics attached to hospital psychiatric units. Hospital services for crisis interventions are paid either by insurance funds or social assistance (funded from taxation). Finally, some services are funded by private health insurance or directly by the patient such as drug and alcohol rehabilitation in private clinics. With the introduction of long term care insurance dependent patients, and their carers, may receive benefits in kind or in cash. This includes those with chronic cognitive problems.

In predominantly tax financed systems, such as the UK, where budgets for healthcare and social care are separate, problems of fragmentation also exist. Healthcare benefits available under the NHS are funded from general taxation and are universal and free at the point of use, whereas social care benefits are funded from local authority budgets, are means tested and often subject to cost sharing. Thus the shift from inpatient care to community care has also shifted the responsibility for funding many services for people with mental health disorders from the NHS budget to local social service budgets, again leading to regional variation in service levels. Hence the introduction of recent reforms to establish joint budgeting and service commissioning to ensure better coordination between health and social services.

“For mental health services users, the deployment of resources is as important as the amount.”

Private medical insurance (PMI) does not play a significant role in most Member States. Only in Germany and the Netherlands does PMI provide the main cover for a significant proportion of the population. In the Netherlands, mental healthcare is covered by a separate universal public insurance scheme for exceptional medical expenses (AWBZ). Proposals to reform medical insurance have proposed transferring mental healthcare to the curative medical insurance benefits package (ZFW/WTZ). This might result in people with mental health problems being excluded from PMI (WTZ). In Germany, those with an income which exceeds £25,000 can choose to opt out of the statutory system. The PMI sector calculates premiums according to individual risk so anyone with a recognised mental health problem will choose to remain in statutory insurance. Consequently, there is a concentration of high risks in the statutory insurance sector.

User charges are another potential way of raising resources but these push the responsibility of paying for healthcare onto those with the greatest need, who are often the ones who can least afford to pay. Evidence of the impact of charges on access in the European context has not received as much attention as the US RAND Corporation
Most studies, however, show that charges deter access particularly amongst the low income, the unemployed, the elderly and the chronically ill (see 5, for example). Any increase in user charges is likely to adversely affect access for those with mental health problems, due to a combination of their chronic state, the stigma attached to their illness and impact on their employment opportunities and earning capacity.

Resource allocation
Generally, there has been low prioritisation attached to treating mental health problems, particularly milder or more moderate ones. Given wider concerns about containing healthcare expenditure growth in most Member States and the limits on increases in public expenditure, it is perhaps too optimistic to expect decision makers to prioritise the use of public resources for mental health. Overall allocations to mental health are difficult to quantify. According to survey data collected by WHO, Belgium, Luxembourg, the Netherlands, the Republic of Ireland, Sweden and the United Kingdom spend more than five per cent of their total health budgets on mental health.6 However, France and Norway spend less than five per cent. The accuracy of this data depends on the definition of mental healthcare adopted in each country and local budgets may not be fully accounted for (see Figure 1). Considering the burden of neuropsychiatric conditions in Europe, these resources are not substantial. Neuropsychiatric disorders account for 20 per cent of the total number of disability adjusted life years (DALYs) and 43 per cent of years lived with a disability (YLDs) in Europe.1

For mental health services users, the deployment of resources is as important as the amount. Even where resources are provided, aspects of the social context and features of the wider service system can compromise coordination or threaten to jeopardise quality.

Mental health services have often been separated off from other healthcare services, either in their organisation and/or in their financing (see Figure 2). There is no reason to accept such a bifurcation as inevitable but it is relevant to understand what factors prompted it and some of the consequences of ‘silo budgeting’. Whether ring fencing of mental health financing from general healthcare financing is appropriate or necessary will depend on the context. For example, in low income countries where mental health services are not yet established, the ring fencing of resources might be necessary to kick start service provision.

Increasingly, the purchasing of health services is being devolved away from the national level to lower levels of administration/government (as in the United Kingdom, Portugal and Sweden). The desire to contain costs and to make purchasers more responsive to the needs of the population has led to greater use of budgets. To ensure that equity and efficiency goals are met, budgets are set according to risk adjusted capitation methods. In social insurance based systems, insurance funds compete for subscribers (as in Germany
and the Netherlands), in order to maintain solidarity, budgets are adjusted to reflect the risk of members. Risk-adjusted capitation can deter attempts to cream-skim the most desirable individuals into insurance plans. This is particularly important for individuals with mental health problems who may be more easily identified as potentially costly members of the insurance pool.

The lack of incentives for purchasers to provide high quality services for mental health service users, has led to the inclusion of mental health as a separate risk factor in some resource allocation formulae. In England the Resource Allocation Working Party (RAWP) established in the early 1970s developed a formula which combined information on mortality and deprivation in determining weighted capitation funds to be allocated to healthcare purchasers. It was only in 1994 that specific needs indices for psychiatric and community psychiatric care were introduced.

In Germany, reforms to the risk compensation scheme (RCS) are being discussed in order to make the scheme more sensitive to the morbidity of insurees. Concern arose for two reasons, the lack of mobility of chronically ill patients between funds and the disincentive funds had to provide high quality care. Of the 1.2 million people who changed funds in 2000 only 800 were chronically ill. Social health insurance funds (sickness funds) in Germany are required to accept all applicants, however, they may participate in more covert forms of risk selection such as exclusive internet marketing, which may deter certain patient groups, or by not providing coordinated programmes of chronic disease care. Since January 2002, funds that offer better care for the chronically ill are not penalised but instead funds will receive a higher allocation through the RCS for every member enrolled in a disease management programme. This should benefit those with chronic mental health problems.

Stockholm county council uses a measure of previous healthcare utilisation in the allocation formula and the Netherlands uses a measure of disability status. Policymakers must ensure in the design of allocation formulae that purchasers are not given incentives to under provide services to mental health service users.

“Policymakers must ensure in the design of allocation formulae that purchasers are not given incentives to under provide services to mental health service users.”

Conclusions and recommendations

Protection of mental health service users is best achieved through universal coverage with risk pooling between rich and poor, and healthy and sick. Any increase in the use of user charges or individual risk rated private insurance will discriminate against some people with mental health problems. An increase in the use of risk adjusted capitation budgets has accompanied the devolution of purchasing and the introduction of competition between insurers in several Member States. The resource allocation formulae utilised for healthcare must account for the high cost of serious psychiatric disorders and ensure that there are proper incentives to guarantee high quality services to chronically ill patients.

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Mental health is an intrinsic component of overall personal wellbeing, yet it is often neglected in comparison with the physical aspects of health. The impact of mental disorders in Europe is substantial, accounting for 20 per cent of all disability adjusted life years, and 43 per cent of all years lived with a disability. Globally, mental disorders account for three (unipolar depressive disorders, self inflicted injuries and alcohol use disorders) of the top 20 causes of disease burden in the general population, increasing to six (additionally schizophrenia, bipolar depressive disorder and panic disorder) in the 15–44 age range. The recent publication of the World Health Report 2001 focused exclusively on mental health, is a welcome development. Its principal aims include raising awareness and understanding of mental health issues among decision makers, developing and revising national mental health policies, enshrining rights of access to health and other support services, as well as protecting the human rights of all people with mental disorders. Perhaps the most important objective set out in the report however, is that of tackling the stigma associated with mental disorders, which can act as a barrier towards effective treatment and understanding. Individuals and their families may be reluctant to come into contact with medical and social support services because of this stigma and shame.

The costs and consequences of poor mental health can be high both in terms of social and economic capital. They can exacerbate a situation of deprivation that can be especially challenging; poverty and social exclusion can both precipitate or follow mental health problems, which in turn can lead to employment difficulties and further reduce an individual’s ability to access treatment. Mental illness might also increase the risk of family break up and suicide.

Addressing mental health inequalities
Promoting better mental health, developing and ensuring access to appropriate health and social welfare services for those with mental health disorders, and tackling the related social problems present great challenges right across Europe. The nature of many mental health disorders means that individuals can be more vulnerable than many other members of society. Periodically they may have difficulty in making rational choices, and an increasing number will suffer from permanent cognitive impairment, as European populations age. Inequalities in mental health, and inequalities in access to mental healthcare are substantial but have received less attention than that given to physical health. Many studies have found evidence of a strong correlation between social class and the incidence of mental disorder but the relationship is complex. Whilst there is evidence suggesting that those who have suffered from the most social disadvantage have higher rates of schizophrenia, the incidence of affective disorders for example, has been reported to be more evenly distributed between social classes.

There also appears to be a clear link between poverty and poor mental health. Poverty may increase stress levels and lead to mental illness, although it may be that the onset of mental illness that leads to poverty if support mechanisms are not provided to help individuals maintain their employment and family life. During times of economic downturn, the fear of
potential unemployment may also be associated with increased rates of mental disorder. Other risks include the lack of social support networks, gender, being a single parent, caring for a relative, or suffering from other serious illnesses.

Ethnic minorities can have higher rates of mental health disorders than the local population. This may be due to a combination of cultural and environmental factors, including the effects of racism. Studies in the UK have reported that although Afro-Caribbean first generation immigrants had the same risk of schizophrenia as the general population, second generation relatives had higher rates than in the general population.\(^2\) The rapid transition from command economies as observed in eastern Europe has also generated new problems. Income differentials, historically narrower than in the west, have widened during the last 10 years, and overall mortality rates have increased. Depression, alcohol dependency and poverty have all been identified as major contributory factors, especially among the most disadvantaged members of society.

Further longitudinal research is required to increase our understanding of the causes and consequences of poor mental health. Whilst there has been a great increase in the use of evidence based medicine for mental healthcare interventions, epidemiological research on social factors influencing mental health have been scant, and researchers have largely had to rely on secondary data collected for other purposes.\(^3\) In many cases there is still a need to collect basic data on population groups and their experiences, as has been advocated for migrant populations in Ireland.\(^4\)

While some mental disorders are due to genetic predisposition, identifying important social, cultural and environmental factors linked with mental health, would allow policy makers to target resources towards the most vulnerable groups, and in particular intervene to promote good mental health. The ongoing work in relation to social inclusion and mental health of the European Foundation for the Improvement of Living and Working Conditions discussed by Robert Andersen in this issue, may help to identify effective interventions, in different contexts. Such interventions are likely to involve co-ordination between a number of different agencies, including those within the health, social service, education, housing and criminal justice systems reflecting the myriad of potential causes and consequences of mental health problems.

**Inequalities in access to appropriate services**

One of the WHO’s key recommendations is to provide care in the community whenever possible, as this will produce better outcomes than institutional care. A broad consensus to move towards de-institutionalisation has been taking place across western Europe for more than 20 years, and this change is now underway in many countries in central and eastern Europe. Despite the similar intentions across Europe, the rate of change has varied markedly, and support services leave much to be desired in many countries. For instance, Goldberg from a survey of European psychiatrists reported community mental health services existed in fewer than half of localities in Spain, Portugal, Greece and Ireland, and only as pilot schemes in eastern Europe.\(^5\)

Care in the community can only work effectively, if support mechanisms are provided in the community, otherwise these vulnerable individuals may find it difficult to re-engage into society, and are at a greater risk of becoming homeless, being incarcerated, or requiring other social services. In Italy for instance, moves towards de-institutionalisation began in the mid 1970s, and whilst successful in closing down specialist mental hospitals, the quality of community support available has varied tremendously between the regions, and often individuals have had to rely on informal support from their families. Re-engaging with the community also requires continued efforts to change public perceptions. The public may have a misleading, unwarranted fear that most individuals discharged into the community represent a danger to others, when in fact the vast majority of people with mental health disorders pose no such risk.\(^6\)

Another phenomenon, long present, but only now receiving greater attention are inequalities in the mental health of ethnic minority groups, and asylum seekers. Between 1989 and 1998 alone there were more than four million asylum applications to EU countries, with a large proportion originating from the former Yugoslavia. Many of these people arrive suffering from post traumatic stress disorder caused by conflict, and/or from high levels of distress experienced during their flight from persecution. A recent survey of mental healthcare services for these individuals and ethnic minority groups in 16 countries in
western Europe, suggests that services often do not meet their needs, and where services do exist they are concentrated in large urban areas. The survey also found that there were marked differences across countries. In the Netherlands for instance, while services for minority groups were evident, little was available for refugees. In contrast, Sweden appears to have a wide range of different interventions specifically aimed at refugees who may have experienced trauma or torture.

**Increasing the use of cost-effectiveness information**

Tackling inequalities in mental health and improving access to mental healthcare systems fundamentally requires the much greater collection of baseline social and epidemiological data, and the increased use of case controlled and cohort studies. However resources within mental healthcare budgets may not be used in either their most efficient or equitable manner, treatments may not be effective or very costly, available services may not be targeted to those in most need, and transaction costs may be too high, i.e. there may be too many managers involved in administering a mental healthcare service.

Economic evaluation techniques can be used to help inform decision makers about the relative costs and outcomes associated with different uses of resources. While it will not be possible to conduct economic evaluation in all circumstances, every effort should be made to present policy makers with information from previous published economic evaluations, taking into account any differences in the structure of health and social care systems as well as other contextual information.

These evaluations ideally should be conducted from a broad perspective reflecting the multi sectoral impact of mental health disorders. An intervention which may increase costs to the healthcare service may reduce the costs to the criminal justice system, or allow an individual to maintain productive employment. A recent study looking at behavioural disorders in children argued that the economic and social costs of exclusion in later life might have been avoided through the use of effective low cost interventions in childhood.

**The way forward?**

Although mental health and psychiatry reforms have been on the agenda of European policy makers for more than twenty years, the pace of reform has varied markedly, and there have been many missed opportunities. In many cases plans and aspirations have not been backed by sufficient action, and mental healthcare continues to retain its ‘Cinderella’ status.

More can be done to build up knowledge on the causes and consequences of inequalities in mental health, an area of research which has been neglected in comparison to the evaluation of mental healthcare treatments. Target groups might be identified who can best benefit from pre-emptive actions to promote good mental health. While evidence on such target groups is weak, there is even now a reasonable degree of confidence that social and economic disorders, poor educational attainment, and social isolation may be linked to mental health disorders, but longitudinal evidence is required to confirm these relationships. Other potential target groups may be ethnic minorities, who may suffer from cultural and environmental isolation, and asylum seekers, who may suffer from trauma experienced in areas of conflict.

Existing resources for mental healthcare need to be used to maximise the benefits afforded to populations, and economic evaluation techniques are a useful aid to decision making in this respect. The benefits of good mental health promotion schemes and effective treatments will have many consequences, evaluation therefore needs to consider the impact of interventions on a wide range of services outside health, including social care, education, housing and the criminal justice system. Equally, evaluations should also be made of non healthcare interventions, such as supported employment schemes.

Adopting a common, harmonised approach to psychiatry and mental healthcare across Europe may help to create the impetus for fundamental change in attitudes towards mental health and in the provision of mental health services. An important aspect of this process will be reducing the level of stigma and discrimination experienced by people with mental health disorders. The WHO, and other organisations, both national and pan European, can do much to raise awareness of these issues, and educate the public as to the nature of mental health. In particular the erroneous perception fuelled by the media that most people with mental health problems are a danger to the community needs to be dispelled, as this can act as a powerful barrier to the development of community based mental healthcare services.

**REFERENCES**


Social inclusion and mental health

The role of the European Foundation for the Improvement of Living and Working Conditions

Set up by the European Council in 1975, the European Foundation for the Improvement of Living and Working Conditions (E.Found) is an EU agency that operates to advise and inform social policies of the European Union. Health figures are an important element in the Foundation’s programmes, particularly with regard to measures for monitoring and improving the health of workers, but also through EU-wide research that looks into the quality of life for Europe’s citizens, developments in health and care services, and measures to combat social exclusion. Mental health is beginning to be tackled as an issue at European level through the work of the Foundation, and in the broader context of chronic illnesses and the obstacles to successful employment and social inclusion.

The purpose of E.Found

The Foundation undertakes research and other information projects, and organises debate through conferences and workshops across the European Union in order to fulfil its mandate of improving living and working conditions through the dissemination of knowledge.

The Foundation acts as a policy instigator by providing policy makers with good quality information about relevant issues. The Foundation works in the framework of four year programmes, involving both monitoring activities and strategic research, which is both proactive – carrying out investigations which are driven by changes on the ground – as well as reactive – responding to the information needs of target audiences. The Foundation also promotes and manages cooperation, meetings and exchange of information between research teams, experts, economic and social actors; and it aims to develop its role as a platform for dialogue and discussion among policy makers, social partners and researchers by continuing to host a wide range of meetings.

Health and the 2001 to 2004 programme

Health, understood in its wider sense as physical, mental and social well being, has been a major focus of attention in the four year programmes of the Foundation. The Foundation has had dedicated programmes of research, for example from 1977 to 1980 on physical and psychological constraints at work, from 1981 to 1984 on physical and psychological stress, from 1989 to 1992 and from 1993 to 1996 on promoting health and safety at work, from 1997 to 2000 on health and well being. A series of research and policy debates on health promotion at work ran through the 90s. During the four year programme 2001–2004, the Foundation is launching a new research initiative on “Illness and Social Inclusion”.

The main purpose of this new activity is to examine how to drive forward the social inclusion of people with long term physical or mental illnesses. The term ‘illness’ refers broadly to chronic illness and disability due to a range of conditions such as depression or heart disease. This first overview will:

– collect information, documents and studies on links between illness and social inclusion;

– document and assess the place of people with chronic mental or physical illness in current policies for the promotion of social inclusion;

– examine measures for integration through inclusion in the labour market.

Chronic illness and to a greater extent mental illness are still taboo subjects. As a result, people who are ill or disabled may be stigmatised and experience a lack of understanding in many aspects of social and public policy, as well as in the labour market.

Although the problems of citizens with chronic illness and disability have become

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clearer, explicit examination of the links between illness and inclusion have not been developed. Previous research in the Foundation has looked at some aspects of disability and at issues regarding both social inclusion and disadvantaged groups and access to employment, but the new programme represents an essentially new research direction, which links these different areas of interest of the Foundation in order to achieve a better understanding of how illness and exclusion intertwine.

Towards social inclusion?
People with chronic illness and disability, and in particular mental illness, can fall into a vicious circle of decreasing job opportunities and increasing poverty, which becomes harder to escape as they become more disconnected from the working environment. Furthermore, the public sector tends to tackle the issue only from one hook (public health) or another (social affairs) or in a fragmented way (physical illness but not mental illness, social assistance but not inclusion).

Towards social inclusion?

A broad range of policies
The development of policies and the delivery of services to promote the social inclusion of people with chronic illnesses and their integration into working life is receiving more attention at EU and national levels. However, the values and concepts underlying this issue need to be clearer. The project will address this and examine how those concepts are being made operational. It will review the nature and scale of the problems facing different groups with chronic illness. The project aims to identify measures in employment, education, housing, transport and other areas which facilitate social and economic integration.

During this year, the project will focus on the following:
To conduct a review with three aims:
– to realise a glossary of key concepts;
– to collect documents and produce a bibliography of studies on the relationship between chronic illness and social inclusion;
– to give an overview of relevant public policies and measures for social and economic integration.

To organise a roundtable:
– to discuss the results of the research;
– to help the Foundation determine new actions;
– to highlight the Foundation’s work on the issue.

The first sentence of point 28 of the Presidency conclusions of the European Council Meeting in Laeken in December 2001 reinforces the relevance of working on illness and social inclusion. It states, “The first joint report on social inclusion and the establishment of a set of common indicators constitute important elements in the policy defined at Lisbon for eradicating poverty and promoting social inclusion, taking in health and housing.”

The Foundation aims to be a significant actor in the achievement of the ambitious goal set out in the Lisbon summit in 2001 that the EU should become “the most competitive and dynamic knowledge-based economy in the world, capable of sustainable economic growth with more and better jobs and greater social cohesion.”

I would like to thank Robert Anderson, Research Manager and Coordinator of the Living Conditions Team at E.Found for his constructive and helpful comments.

For more information on the Foundation or its work see website: www.eurofound.ie
Evaluating innovative mental health services
Lessons from a systematic review of home treatment

Jocelyn Catty

Since the beginning of the deinstitutionalisation movement across many countries in the 1960s, a wide variety of models of community based service have been developed to offer care to people with mental health problems outside the hospital environment. While there is widespread consensus that treatment in the community is a valuable goal, there is far less consensus about the relative effectiveness of such service models or their resource implications. The difficulties of evaluating them, however, are legion. While mental health interventions are themselves by no means easy to evaluate, service models – structures for the delivery of a variety of interventions – are still less so. The more components they contain, the harder it may be to ascertain which have been key to their success, if any.

Moreover, as different models emerge and become established, they may undergo a shift from being seen as innovative to being part of ‘standard’ practice. This may result in the standard service to which innovative ones are routinely compared, increasingly containing some of the same components. This makes it difficult to evaluate such services and, of course, difficult to develop policy and build better practice.

This article draws on our recent experience of conducting a systematic review looking at the effectiveness and cost effectiveness of home treatment for mental health problems.

Home treatment: a systematic review

In response to the need to ascertain the effectiveness of ‘home treatment’ over other forms of care for people with mental health problems, we conducted a systematic review, with colleagues, utilising Cochrane Collaboration methodology. We defined ‘home treatment’ as any community based non-residential service, but found that most services qualifying for inclusion also included a commitment to home visiting. The systematic literature search found 91 studies conducted over a thirty year period, the majority from North America (59) and Europe (25). This included both randomised and non-randomised comparative studies, which were analysed separately to test the sensitivity of the analysis to this methodological difference. Using data on service components collected through follow-up, we conducted a series of regression analyses to determine whether any of them was associated with the outcome of days spent in hospital. Two features were found to be significantly associated with reducing hospital days, notwithstanding international variations in services and contexts: regularly visiting patients at home and taking responsibility for both health and social care within the team.

The findings of this study are reported elsewhere. Here, we focus on our particular attempts to deal with the difficulties posed by mental health service evaluation, particularly regarding international variations and cost analysis, and the lessons to be learned from this project in these regards.

Interpreting service labels

Interpreting the results of innovative mental health service evaluations is made more complicated by the difficulty of identifying precisely what each different service model comprises. A proliferation of labels for community based services, often sounding very similar (for instance, Assertive Community Treatment, Programme for Assertive Community Treatment, Assertive Case Management, Assertive Outreach), creates confusion as to which labels are synonyms for one clearly defined service model and which should be taken to denote discrete sets of service components – or at least meaningfully different variations upon a theme. Published papers frequently fail to detail all the components of the services so that the label given can be reliably interpreted. This makes problematic both the interpretation of individual studies and the meta-analysis of groups of related studies through systematic review.

In our review, an extensive follow-up of the studies’ authors was conducted (with a

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Despite the pitfalls involved in evaluating innovative mental health services, the need to do so is clearly paramount.

Even where different services adhere closely to the same model, their effectiveness may be crucially affected by the context in which they operate. Contextual factors such as methods of providing psychiatric and social care or differences on organisational and financing structures need to be fully understood and taken into consideration in interpreting the success or otherwise of an evaluated service and assessing its potential for adoption or translation into different contexts. Given that the services used as controls are generally even less well defined than the experimental services, the differences between comparators internationally may be both more pronounced and less easy to ascertain, potentially leading to a distortion of the study findings or of the clinical significance attributed to them.

A secondary objective of our review was to identify international differences in home treatment services and find a way of interpreting any differences between studies in their international contexts. Our analysis was based on a comparison of European to North American studies, as we found so few studies from other countries (seven out of 91), but in practice even these were largely from the US (55) and UK (21). There may have been an English language bias in our search strategy; several studies without English abstracts were found and translated, however, but did not meet the inclusion criteria for ‘home treatment’. Nevertheless, it is of concern that so little is known about home treatment services elsewhere. It is difficult to determine from this whether home treatment services do not exist elsewhere, or whether they are not being reported in comparative studies, or whether studies reporting them are not published in the kinds of journals drawn on by the databases used for systematic reviews.

The evidence of our analysis by location – Europe or North America – was that service context may indeed have a meaningful impact on study findings. Our conventional meta-analysis found that North American studies were likely to find a greater reduction in hospitalisation than European ones. An alternative analysis, however, using data only for the experimental services, found there to be no difference in hospitalisation between North American and European experimental services. This suggests either that the control services in the two locations were different in a way meaningful enough to have an impact on these findings – that is, that the European control services were closer to their experimental counterparts – or that other, untested, differences in service context had made an impact.

Innovative services

The caveats and difficulties involved in evaluating mental health services outlined so far would apply as much to the evaluation of longer standing services as to the evaluation of innovative ones. Services evaluated, however, tend to be innovative ones, and this poses additional problems. New services may be under study in the first year or years of their existence, so that their results derive from a phase of their operation which may not be representative of its later development. This is supported by data from our review: when we followed up the authors of the studies, only 44 per cent of the 60 per cent who responded reported that their experimental service was ‘still identifiable’ (27 services), while ten services had ended when or even before the study was published. The frequent association between innovative services and academic departments is another likely complication, along with the additional enthusiasm of clinicians for a new initiative or a high profile study. Both of these factors may decrease the applicability of the findings to other services.

In the present review, we attempted to control for such factors by performing an analysis based on experimental service data alone. This, it was hoped, would to some degree control for such features as the service being connected to an academic department and its clinicians being ‘product champions’ for a newly developing service or research project. The regression analyses mentioned above, testing for associations between service components and hospital days, were performed both in the conventional way (testing the difference in hospital days against the difference in the service component) and using experimental data alone.

This was, of course, a relatively crude way of controlling for the innovative nature of the service. In practice, it was of limited utility, particularly for the components analysis, as some of the components (such
as visiting patients at home) were present in all the services for which we had data. It did produce some interesting findings, however. For instance, caseload size was found to be associated with increased days in hospital, even though in our conventional analysis (comparing experimental to control data) there had been no association with reducing hospital days; this counter intuitive finding might be because services with lower caseloads cater for more difficult patients. More importantly, this ‘experimental services analysis’ also enabled us to interrogate the idea of service context, as described above, in analysing the impact of the location of the study.

**Costing innovative services**

Despite the pitfalls involved in evaluating innovative mental health services, the need to do so is clearly paramount. In particular, it is vital that their cost effectiveness be assessed so as to inform reliably the decisions of service providers and policy makers. To this end, data needs to be available on the utilisation of a wide range of health and social services. The need for a comprehensive service profile is particularly pronounced in the mental health field because of the wide ranging impact of psychiatric disorders on individual abilities and needs, and because many people with mental health problems are supported by a variety of healthcare and other agencies.

The cost analysis in our review was intended to mirror its main analyses, which comprised a conventional meta-analysis (pooling all findings for days in hospital), along with the two types of regression (components) analysis. The cost analysis was intended to develop this by including detailed service utilisation data, attaching UK unit costs and costing the findings of the regression analyses. There were, however, insufficient data to conduct such analyses comprehensively. The authors of only 46 studies (51 per cent) responded to our questionnaire concerning service utilisation and while they reported collecting fairly comprehensive data, only 12 of them were able to provide it (even in aggregate form). We were able to cost the difference between experimental and community based control services using inpatient and outpatient data, but this finding (£41 per patient per month in favour of the experimental services) was based on data from only 12 studies. There were insufficient data to cost the other analyses.

An unexpected additional finding of the study was that, judging by what authors reported to us that they had originally collected, many published papers did not report data that had been collected. It must be of concern that so many data are collected but either not analysed or not published. This raises ethical issues and procedural questions as to whether far reaching policy and practice decisions based on the results of these studies are as well informed as they could be.

One important remit for this review was to ascertain the cost effectiveness of home treatment for people with mental health problems. Despite the scale of our study, we found little evidence for this. This is particularly alarming given the breadth of inclusion criteria for the review, the large number of studies found and the intensive follow-up to authors conducted, and has wider implications for mental health service evaluation more generally.

**Implications**

Mental health policy is at present built on data that is less robust than it could be, in terms of both the extent and the uniformity of the data collected and the degree to which it is interpreted meaningfully in context. This paucity of data, for costing and more generally, is likely to remain a problem for mental health service evaluation until those evaluating services engage in a detailed theoretical discussion about what data needs to be collected. Meaningful debate needs to take place about the collection and interpretation of data in order to evaluate services effectively, with reference to both their components and their wider contexts.

We have already argued for the prospective collection and reporting of process variables such as service components, for both experimental and control services, and the need to collect outcome data using standard, well validated measures has also been indicated. These recommendations could valuably be extended to incorporate a close examination of the wider service context, particularly where international comparisons are to be made.

**Note**

The systematic review from which this article draws its conclusions was funded by the National Coordinating Centre for Health Technology Assessment. Views expressed here do not necessarily reflect those of the NHS Executive. Thanks are also due to the rest of the research team for the review: Chris Wright, Hilary Watt, Juliet Henderson and Andrew Healey.

**References**

The decisions of the European Court of Justice (ECJ) concerning the free movement of goods and services in healthcare have kindled a rigorous debate among experts across Europe about the possible repercussions for national healthcare systems and the implications for cross border care. Though challenging and necessary from a theoretical point of view, this debate frequently neglects one important aspect: the views of patients. Would patients actually appreciate the option of free access to providers in another Member State? What will be the likely future trends in demand for cross border healthcare in Europe?

Following the ECJ decisions, the Techniker Krankenkasse (TK), a German not-for-profit sickness fund, has conducted a customer survey on different aspects of cross border healthcare. Sickness funds in Germany operate in a competitive environment. Over 300 sickness funds cover almost 90 per cent of the German population within the statutory health insurance system (SHI). The insured have a free choice of sickness fund, and the funds are obliged to contract regardless of gender, age or medical precondition. People with income above the compulsory insurance limit may opt for a private insurance scheme. In order to achieve and sustain a competitive advantage, sickness funds are required to tailor their services so as to meet the demands of the insured. Thus customer orientation is a critical success factor.

From the perspective of a German sickness fund one further question is relevant: Would the Single Market rules allow improvement to the services of health insurance carriers?

Although the customer survey was conducted with a sample of the over five million insured under the TK, the results allow a number of general conclusions about:
- the current and future use of urgent care during a temporary stay in another Member State;
- the motives of patients seeking healthcare abroad for non-urgent treatments and thus likely future developments of cross border care for patients from Germany;
- the range of services the insured expect from their statutory sickness funds regarding insurance coverage and healthcare within Europe.

The results must be interpreted with regard to the German healthcare system: a benefit in kind system, that is financed by an income related contribution shared between the insured and their employers. Provision of health services is free for patients except for small co-payments for selected benefits such as drugs and dental prosthetics. Patients have free access to all contracted providers. One of the main reasons for Germany’s soaring healthcare costs is overcapacity, particularly for inpatient care. As a result, Germany is one of the few EU-countries without any waiting lists.

The role of cross border healthcare
The financial impact of cross border care is marginal. The TK spends under 0.4 per cent of total expenses on treatments abroad. This is largely in line with the EU average.1 Urgent treatments during temporary stays in other Member States account for the vast majority of cross border care used by German patients within Europe. However, the financial value underestimates the actual volume of cross border care. Almost six per cent of the insured use medical services abroad each year but these

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* The customer survey was designed in cooperation with the Gesellschaft für Versicherungswissenschaft and -gestaltung e.V. (Cologne). The survey included two separate samples and questionnaires to cover two aspects of cross border healthcare: Patients experience (3,296 respondents who have used cross border care) and the expectations of the insured (2,447 respondents in a representative sample of all insured). A research report is available in German and can be ordered via email: sagasi@tk-online.net
are often low value treatments such as drugs and outpatient services and inpatient stays are far shorter when abroad. In addition, many people neglect to claim the small sums of money involved from their insurer.

Demand for cross border healthcare concentrates on the popular holiday resorts rather than the border regions. Health service providers in tourist areas in Spain and Austria see a significant demand from German patients that are insured with the TK.

Current problems with urgent treatments

Under the EU system of coordinating social security systems (Directive 1408/71 EEC), the right of access to healthcare in the country of stay is certified by an E111 form issued by the competent insurer. As an exception, i.e. when the formalities of the E111-process cannot be completed during the stay abroad, the patient is entitled to cost reimbursement on his return home. In theory, the E111-procedure entitles the insured to care as if they were covered by the healthcare system of the host country. In practice, the exception has become the rule and over 60 per cent of cases are dealt with by cost reimbursement, usually based on German rates as the vast majority of bills do not exceed the 1000 euro limit.

The E111 procedure fails because only 40 per cent of people carry E111 forms, believing they can use their German health card, and because in one third of cases the provider does not accept the E111 form – it is more attractive to bill patients directly. For outpatient care, patients are prepared to pay the comparatively low amounts in cash. Therefore, problems with the E111 procedure are more pronounced where the percentage of outpatient care is relatively high, such as Spain. Here the E111 procedure leads to satisfactory results only in 18 per cent of cases. Whereas in Austria, where the share of inpatient care is comparatively high, the E111 procedure was successfully used in 37 per cent of cases.

Cost reimbursement leaves patients with a financial risk as they have to pay the differences between the invoices and the German reimbursement rates. Not surprisingly complementary private insurance products covering the full costs of treatment are very popular in Germany. Forty per cent of insured people bought such a complementary insurance scheme for their last trip abroad.

It is interesting to note that besides the widespread problems with the E111 procedure, only a minority of patients encounters problems when using health services abroad. Problems of access to appropriate services, such as finding a suitable provider, occur in six per cent of cases. Problems relating to the quality of care arise in less than five per cent of cases. Even language problems are far less significant than could be expected. Only 13 per cent of patients that used cross border care reported communication problems because of language barriers.

Mobility of the insured

The more the insured travel the more likely they will require a medical treatment abroad and the more important EU-wide health insurance coverage becomes. Mobility within Europe is very high. Almost 80 per cent of the insured travel to another Member State at least once per year for a holiday (see Figure 1).

In addition, many people, particularly high income earners, travel for business reasons. In the group of high income earners, over 50 per cent of the insured travel at least twice per year for professional reasons and it can be expected that mobility within Europe will increase further.

With already high and increasing mobility, demand for urgent care in other Member States will also rise, in particular in tourist areas where providers are already specialising in the treatment of foreign patients. In addition, people will increasingly expect a level of service from their sickness fund similar to that offered by other service related industries such as the banking sector. The insured will not accept the

“Demand for cross border healthcare concentrates on the popular holiday resorts rather than the border regions.”

Figure 1

FREQUENCY OF PRIVATE TRAVEL WITHIN THE EU AS PER CENT OF THE INSURED

<table>
<thead>
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<tbody>
<tr>
<td>More</td>
<td>2%</td>
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<tr>
<td>Once per month</td>
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<td>Once in three months</td>
<td>8%</td>
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<td>29%</td>
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<td>Once per year</td>
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“As yet, the German government has been reluctant to fully implement the free movement of goods and services for healthcare.”

The administrative burden of the E111-procedure but will expect a comprehensive EU-wide health insurance coverage by their statutory sickness fund.

The mobility of patients

In addition to the EU coordinating system, the Single Market regulations give patients access in principle to non-urgent treatments within the EU. As yet, the German government has been reluctant to fully implement the free movement of goods and services for healthcare. However, people expect free access to healthcare providers throughout Europe. Almost 80 per cent of the insured agree that patients should be free to choose whichever provider they prefer, irrespective of residence, suggesting significant interest in cross border care. However, the experience gained in healthcare projects in border regions shows that the use of cross border treatments is limited. It is only attractive if the benefits derived from travelling for treatment outweigh the additional efforts necessary.

There are a number of potential benefits of cross border care for patients:

(Perceived) increased quality: The most attractive advantage of cross border care for patients from Germany is to gain access to high quality care. For the insured, access to innovative treatments provided in other Member States (73 per cent) and access to the best medical experts throughout Europe (67 per cent) are the most highly ranked advantages.

Reduced cost: Sixty-two per cent of the insured would consider a treatment abroad if they were able to reduce co-payments.

Improved availability: As there are no waiting lists, issues of availability are not significant for German patients. However, for almost one third of the insured it is a potential advantage of cross border treatment, if a planned treatment can be organised during a holiday.

Furthermore, the increasing experience of health services abroad for urgent treatment will encourage people to use them for non-urgent treatments. Whereas, on average, people believe that the German system provides the highest quality of healthcare, those insured that have already used healthcare, particularly in Austria, the Netherlands and France, believe that in these countries healthcare services are at least of equal standard or of better quality.

On the other hand there are obstacles when patients use health services abroad:

Travel expenses: Almost 60 per cent of the insured see the additional travel expenses and the risk that the cost of treatment might exceed the amount reimbursed by the insurer as a major disadvantage of planned cross border care.

Language barrier: For 40 per cent of the insured, language problems are a drawback. However, young people expect far fewer language problems.

Risk: Almost 60 per cent of the insured consider the uncertainty regarding warranties and follow-up treatments as a major disadvantage of cross border care.

Future trends in non-urgent cross border care

Considering the reasons patients use cross border care (see Figure 2), it can be concluded that demand from German patients for non-urgent care within Europe will rise in three areas:

1. Highly specialised care: The market for highly specialised care based on advanced technologies and expensive innovations will become increasingly international. Firstly, this is the result of the growing interest of patients. Secondly, it is attractive for providers to realise economies of scale and improve efficiency through access to a broader market. The use of telematics and remote consultations will provide additional momentum.

2. Pharmaceuticals and medical devices: These medical products can be imported, so patients have no travel time and cost. In addition, quality risks are low – some products are marketed under the same brand name across Europe. The advantages arising from price differentials within the EU can be significant. In conjunction
with innovative distribution channels and e-commerce demand is likely to increase.

3. Rehabilitation and spa-treatments: For some rehabilitative treatments, going abroad may produce an added value for patients when climate conditions are favourable or the location is attractive. With EU enlargement, the traditional health resorts in eastern Europe are likely to see a rising demand from German patients.

In general, it can be expected that demand for cross border healthcare from German patients will not increase dramatically unless it is actively promoted. In addition, a liberalisation of healthcare markets in Europe will bring more patients from other European countries to Germany, enabling more efficient use of capacity by German providers.

**The role of statutory sickness funds**

With the high mobility of the insured, sickness funds can provide added value:

**Insurance coverage**: The insured expect to be covered by their German sickness fund according to their national conditions when they travel within Europe. Over 80 per cent of the insured would prefer to use their German health card throughout the EU. In addition, over 60 per cent of the insured would welcome the option to buy a supplementary insurance package with their sickness fund and not with a private insurance company.

**Information**: In particular, the insured would turn to their sickness fund for information on healthcare systems (85 per cent) and advice on access to providers abroad (78 per cent). The effort for patients to make a deliberate and informed decision to select a healthcare provider, e.g. for a specialised treatment, is huge. The use of information technology and the internet will certainly improve the dissemination of information but availability is still very limited. European healthcare markets will, therefore, benefit from more transparency achieved by a framework for common quality standards and best practices.²

**Contracts with providers** The insured support the view that the insurer should accredit providers in other Member States (67 per cent). A contract between the service provider and the sickness fund would reassure patients about the quality of care and reimbursement procedures.

In practice, there is still a wide gap between the expectations of the insured and the services actually provided. Statutory sickness funds are restricted by the limitations set out in the legal framework for the SHI system. As a result, the statutory system as a whole is far less attractive than it could be. Many insured with incomes above the compulsory insurance limit opt for a private insurance coverage. A negative side effect is that these insured will no longer contribute to the solidarity system of the SHI.

**Conclusion**

The liberalisation of healthcare markets in Europe provides opportunities rather than threats. It will not result in an uncontrollable stream of patients leaving Germany. In fact it has potential advantages for all players in the German healthcare market:

- The insured who are already used to travelling within Europe could benefit from a EU-wide health insurance coverage.
- A major benefit would be created for patients – not only those who are willing to travel for treatment. The international competition of health service providers would increase transparency in the healthcare market and raise quality and efficiency.
- Health service providers would benefit by gaining a broader market access with the potential of realising economies of scale and improving efficiency.
- Sickness funds could improve their competitive position and offer services according to the requirements of their insured. In addition, international procurement policies could allow exploitation of price differentials within Europe.

As the organisation of health services remains a matter of national competence it is now the task of policy makers in Germany to make the Single Market rules an integral part of national healthcare policy.

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EU Ministers discuss cross border movement of patients

Member State Health Ministers met in Malaga on 8 February for a wide ranging discussion on the free movement of patients in Europe. Ministers recognised the new European dimension to healthcare in the light of rulings from the European Court of Justice, which brought health services within the domain of the European Single Market. Importantly, they called for more information on the quality and cost of healthcare, the content of a basic package of European healthcare services and a review of healthcare projects in border regions.

The conclusions of the Malaga meeting are available at the Spanish presidency website: www.ue2002.es

Dutch court rejects Smits-Peerbooms cases

Following the European Court of Justice (ECJ) rulings in July in the Smits/Peerbooms cases concerning the right to reimbursement for hospital treatment provided in other EU Member States (see Eurohealth 7:4), the local Dutch court has issued its final judgement, after taking the ECJ judgement into account. It ruled that the Dutch sickness funds were correct in refusing to pay for treatment abroad in these two cases.

In the Peerbooms case, the Roermond Court decided that the neurostimulation treatment provided in Austria was not considered common practice by international medical standards, a criteria established by the ECJ; in the Smits case, the Dutch court ruled that the treatment could be obtained in the Netherlands without ‘undue delay’, a condition laid down in the ECJ ruling, by a medical establishment that has a contractual arrangement with the patient’s sickness insurance fund. While the treatment may differ from that available in Germany, the Dutch treatment was considered equally effective from a medical point of view and so the request to have the treatment paid for in Germany was refused.

EU moves towards Health Card as key to work mobility plans

The European Commission is proposing an action plan to remove obstacles to EU citizens moving across borders to work. One key, visible initiative is a plan to introduce an EU health insurance card. This is intended to replace the current E111 health form with an electronic card that will cut down on paperwork and provide proof of entitlement to healthcare and appropriate national reimbursement throughout the EU. It will not contain any health records.

This initiative has long been suggested but has faced objections from opponents who fear violations of civil liberties and the erosion of national health systems. The action plan, which would require strong political support from Member States, contains 25 specific measures with a target of 2005 for implementation. Measures include EU quality marks for information systems, effective access to residence and employment for public sector workers in other countries, the creation of portable supplementary pension rights and clearer rules for recognition of professional qualifications.

Further practical information is available from the ‘Europe Direct’ service: www.europa.eu.int/europedirect/index.html

MEETING OF EU HEALTH MINISTERS WITH EXPERTS ON CELLS AND TISSUES

European Health Ministers met in Malaga in February to consider potential changes to regulations concerning the therapeutic use of human cells and tissues.

With exchanges of tissues and cells between different Member States increasing, ministers received expert opinion that regulatory homogenisation would be needed to protect recipients and donors.

It has been estimated that over 300,000 EU citizens receive cell and tissue implants each year, including bone, tendon, cartilage, skin, blood vessels, heart valves and corneas, and that the number of procedures in use has multiplied rapidly. Spain has prioritised the issue during its EU Council Presidency as it has the highest rate of organ donation in the world, more than double the EU average of 15 donations per million inhabitants.

Article 152 of the EU Treaty specifies European competence in this respect and the European Commission has indicated that proposals are being prepared for relevant regulations, although agreement is not anticipated before the next Health Council on 26 June.

Further information about this and other priorities for health is available on the Presidency website: www.ue2002.es
COMMISSIONER SEeks “BALANCE AND CONSENSUS” IN PHARMACEUTICAL REVIEW

European Commissioner for Enterprise, Erkki Liikanen, has set out his approach to the controversial current review of EU pharmaceutical legislation.

Speaking at the Eighth Annual Pharmaceuticals Conference in London on 14th February, he described the challenges he faced, to improve competitiveness of the European industry, to prepare for an enlarged EU, to develop the EU science base and to meet citizens‘ expectations regarding access, quality and safety. He stated that the first objective is “the need to continue to guarantee a high level of health protection for citizens”, but that he sought a balance including “rationalisation and simplification of the regulatory process” and meeting the “challenges of globalisation by completing the EU internal market for pharmaceutical products”.

Following a consultation with stakeholders, he proposed to seek greater cooperation between national scientific experts, to introduce a ‘fast track’ registration for products of significant therapeutic interest and an international system to make new medicinal products available in advance of authorisation on a ‘compassionate use’ basis. Mr Liikanen announced that he was seeking to test validated and patient orientated information for three diseases: diabetes, AIDS and asthma.

Full copies of the speech are available from the EU press service at: http://europa.eu.int

Note: The European Parliament has begun its scrutiny of the Commission proposals under the co-decision procedure. It is expected to be debated at first reading between April and September 2002, and the Rapporteur will be Francoise Grosstete MEP.

Commission report on Internal Market and Health Services

The report of the EU High Level Health Committee on ‘Internal Market and Health Services’ is now available for downloading at http://europa.eu.int/comm/health/ph/key_doc/key06_en.pdf.

The High Level Committee created a working group on the Internal Market and Health in April 1999, chaired by German representative Dr Hans Stein with a mandate to:

– collect information on the impact of Community provisions on health systems;
– collect information on cross border health care and service arrangements; and
– identify the nature and degree of problems arising and consider options for Community and national actions to resolve them.

The report draws on findings of the EU funded BIOMED research project undertaken by the European Health Management Association which explored the impact of EU legislation on national health systems.

Further details about this project are available at: www.ehma.org/pubsummary.html

EU PUBLIC HEALTH PROGRAMME: THE FINAL HURDLE

The Council and European Parliament could not agree on the second reading of the EU public health programme and have therefore started a conciliation procedure to resolve their differences. They hope to adopt the programme at the Health Council under the Spanish Presidency in June 2002. The European Commission has published its opinion on the European Parliament’s second reading.

When adopted, the EU public health programme will herald a new step in European health policy with a move to a more coherent public health policy. The main sticking point is the budget with the European Parliament requesting 380 million euro for six years and the Council suggesting 280 million euro.

Vaccination strategy, genetic determinants of health, quality guidelines for health systems and patient information have all been added to the programme in the second reading and will need to be discussed in the conciliation procedure.

EU LICENSING PROPOSED FOR HERBAL MEDICINES

The European Commission is to propose a specific European licensing procedure for herbal medicinal products with a long standing traditional use.

The aim is to improve quality checks and market surveillance of such products. Quality requirements would be the same as for other medicinal products, but safety and efficacy could be assessed from information gathered from at least 30 years of traditional use.

The proposal also provides for a new scientific committee on herbal medicine experts to be established at the London based European Agency for the Evaluation of Medicinal Products to draw up monographs to further harmonise and facilitate registration applications for herbal medicinal products.

Farm Commissioner bemoans Europe’s “biotech muddle”

EU Agriculture Commissioner Franz Fischler has warned of his fears that European food producers are at risk of being left behind in global markets because of consumer confusion about safety of products containing GMOs.

Arguing that the EC has presented a clear approach called ‘Life Science and Biotechnology Strategy of the European Commission’, Mr Fischler stressed that the Community had to stop making decisions on a purely emotional basis. He praised organic farming practices and demanded that proponents be protected from contamination so that labelling provisions are reliable.

“Agriculture today is demand driven,” he concluded, “and the role of consumers is absolutely paramount.”

For further information from DG Agriculture see website: www.europa.eu.int

MEPs disagree on tobacco taxes compromise

In a second vote on a Commission proposal to set a minimum excise duty of 57 per cent of the retail sale price of tobacco and €70 for 1000 cigarettes, the European Parliament has adopted amendments that are again at odds with a ‘political compromise’ agreed between ministers and Commissioners.

In setting a lower EU minimum rate of €60, MEPs were warned by Commissioner Bolkestein that they risked encouraging some Member States to lower their national rates.

A number of pro-health amendments were also rejected in the report by Georgos Katiforis, which was adopted overall by 325 votes to 151 with 50 abstentions in Strasbourg in February and now goes back to consideration in the Council.

LAEKEN EUROPEAN COUNCIL

EU leaders met in Laeken, Belgium, on 14-15 December for a European Council summit which reached agreement on a range of issues, including the counter-terrorist campaign, the Middle East crisis and the shape of talks on Europe’s long term future.

In the health field, the Belgian Government succeeded in introducing into the Council Conclusions a call for particular attention to be given in future to the impact of European integration on Member States’ healthcare systems. The Conclusions note that concrete results must be achieved at EU level in a range of areas including better quality health care.

The need to better divide and define EU and national responsibilities and the possibility of Treaty reform are highlighted as issues which should be addressed in order to intensify cooperation in fields such as social inclusion, the environment, health and food safety.

The need to revise Article 152 on Public Health was raised in November at the European Health Policy Forum by the EU Health Commissioner David Byrne and is also contained in the conclusions to the European Health Forum (Gastein) session on Health and the EU Internal Market.

The European Council conclusions are available at: http://europa.eu.int/rapid/start/cgi/guesten.ksh?p_action.gettxt=gt&doc=D0C/01/18|0|AGED&lg=EN&display=

2002 COMMISSION WORK PROGRAMME

In his ‘State of the Union’ address on 11 December, European Commission President Romano Prodi outlined the major challenges ahead for the EU and presented the Commission’s priorities for 2002. The Commission work programme announces actions next year in the following seven areas:

Promote a new European governance and institutional reform: A key action in this area will be the presentation of proposals to simplify and streamline rules on mutual recognition of professional qualifications.

Safety and security of European citizens: Including appropriate measures to enhance transport security and safety, civil protection and public health.

Launch of the Euro and financial integration: This will include continuing efforts to modernise the framework for public procurement.

Implement the EU’s sustainable development strategy: Key actions include the presentation of a Communication for a Community Strategy on health and safety at work and develop an adequate capacity to respond to communicable disease threats.

Deliver concrete results on the EU’s enlargement negotiations: The Commission will help the Union to achieve the goal of completing negotiations with up to 10 candidate countries during 2002 and assess whether they meet the accession criteria.

Reinforce Europe’s relationship with Mediterranean partners: The Commission will propose ways to improve cooperation in a wide range of policy areas including social affairs.

Strengthen EU development policy: Including implementation of the programme of action aimed at decreasing the spread of communicable diseases and contribute to the new Global Fund to fight HIV/AIDS, tuberculosis and malaria.

The work programme is available on website: http://europa.eu.int/commission/programme/index_en.htm
**EU Health Commissioner launches new website**

Commissioner Byrne has launched the first part of his new look web pages which provide an overview of key issues under his responsibility, an overview of his speeches, press releases, internet chats as well as a presentation of his private office, his biography and photographic materials.


**Influenza: a European response**

The European Commission has published information about national and European responses to influenza. It reports that not all Member States have National Pandemic Preparedness Plans in place. It also highlights vaccine shortage as a potential problem which might benefit from EU level coordination. The Commission has identified influenza as a priority area within the Community Network for communicable diseases and is currently drawing up a Community Influenza Preparedness Plan.


**Osteoporosis prevention**

Following the publication of a report critical of national approaches to osteoporosis prevention, a new cross party group has been set up in the European Parliament to address related issues. Its chair will be Mel Read MEP, from whom further information is available at: [mread@europarl.eu.int](mailto:mread@europarl.eu.int)

**HIA at the HDA**

The Health Development Agency for England has launched a new site to help professionals carry out health impact assessments, at: [www.hiagateway.org.uk](http://www.hiagateway.org.uk)

**EU enlargement and healthcare – new study**

The Standing Committee of European Doctors (CP) has issued a number of urgent wake-up calls to policy-makers in a study on the impact of enlargement on healthcare.

In particular, it claims that EU enlargement will lead to a brain drain of doctors from Eastern Europe unless urgent action is taken to improve their pay and social status. The Committee also fears that recent European Court judgements on cross border healthcare may lead to large flows of patients from the new Member States to neighbouring states of the existing European Union. Enlargement will also highlight existing problems with EU legislation on medical qualifications, says the report, particularly concerning training periods, recognition of sub-specialisms and third-country diplomas.

Further information on the Standing Committee of European Doctors is available at: [www.cpme.be](http://www.cpme.be)

**Updated information on EU enlargement process**

The European Commission has updated its information on how the EU enlargement process is proceeding with regard to the free movement of people. It highlights the question of how the EU should apply EU Directives on medical qualifications for citizens from the candidate countries who completed their education in ‘third countries’ when individual candidate countries were part of the Soviet Union (in the case of the Baltics), Yugoslavia (in the case of Slovenia), and the Czech Republic and Slovakia if these countries accede at different times. Information on the EU enlargement process is available at: [http://europa.eu.int/comm/enlargement/negotiations/chapters/chap2/index.htm](http://europa.eu.int/comm/enlargement/negotiations/chapters/chap2/index.htm)

**Transport and health**


The report complements the Commission’s white paper on transport policy published in September 2001, which is currently going through the EU institutions’ decision making process. Dr Lucas’ report calls for health impact assessments to be carried out by the Commission in the field of transport policy by the end of 2003. She also calls for the commission to produce proposals on exchanging good practice on walking and cycling schemes between Member States.