Social values and health priority setting: an international comparative analysis

Report of a NICE workshop held in London on February 17/18, 2011

The world's health systems differ as much as the nations in which they're set: differences in resources, organisation, and culture. But there are some problems and dilemmas that all health systems, in one way or another, have to confront. One such is that irrespective of a country's wealth or level of development it will be faced by a demand for medical resources that exceeds supply. Choices have to be made. Judgements of what to give and what to withhold; about who is or is not deserving of most help; and which activities or interventions should take priority. No matter what economic formulae may be contrived to help those who devise and implement a nation's health policies, at some level those policies have to be rooted in a complex and occasionally contradictory set of social values.

Given this diversity, is it possible not only to compare the decisions made by different countries, but to decipher the differing social values that shape those choices? And in the light of such an analysis - even if incomplete - might it further be possible to generate a set of principles that policy makers in any country would find helpful when framing health policy?

It was with this ambitious agenda in mind that NICE, in association with UCL and supported by the Wellcome and the Nuffield Trusts, organised an international workshop on social values and the setting of health priorities. The intention was not to answer these questions in a mere day and a half, but rather to discern whether there was an appetite among researchers to pursue them further. And, if so, whether the group of 30 or so people who attended the London meeting and those attending a second meeting in Rio in Rio might be interested in contributing to the development of a research programme on the topic.

Introducing the topic

Albert Weale, professor of political theory and public policy at UCL, began by suggesting that we need to explore the cultural context of social values, how they are institutionalised, and their practical effect on priority setting in health. There is no one right way of doing things; but exchanging ideas and experiences should be illuminating.

Peter Littlejohns, NICE's director of clinical and public health, described the background to the meeting. Although the number and variety of available healthcare interventions are on the increase, and public expectations are rising, current levels of growth are unsustainable. So prioritisation is unavoidable. The issue is not *should* you prioritise, but *how*. Governments may not like to admit that this is the case, but they are increasingly having to accept the need to do so. And this means paying due attention to the social values involved: equity, justice, beneficence and the like. We need to know how they do affect, and how they should affect, decision making. Bringing together like-minded potential collaborators is an important first step towards setting up a research programme with this goal in mind.

A background paper had been prepared by Albert Weale and his colleague Sarah Clark. The presentation, given by Sarah Clark, was intended to provoke further thought on the nature of the social values the pair had described in the paper(see addendum), and to explore the range of possible interpretations of those values. Process values are, in essence, the "how" of decision making, content values the "what" and "why". As they say in the background paper, "There are many values that may be involved in priority setting in specific contexts, including legality, faithfulness to constitutional provisions and respect for international obligations. However, this paper focuses on three general process values which can be seen and assessed in any system: transparency, accountability and participation. In terms of content, there are also a number of values, but here we identify: clinical effectiveness, cost effectiveness, justice/equity, solidarity and autonomy."

For the purposes of the meeting Sarah Clark had configured their reasoning in the form of a grid (slides are appended, and should be viewed in conjunction with this commentary) which became a reference point throughout the coming day and half. She began with transparency, the range of interpretations of the term being presented as three scenarios on the left of the slide. The terms "who", and "by what processes" are not to be taken too narrowly. The answer to "who" might just be "clinicians"; the answer to "by what processes" might be "using experts". The column on the right of the slide indicates the level of transparency that correlates with each scenario. Only the fullest level of transparency allows people to judge the fairness of decision making (and, perhaps, accept those decisions even when they themselves are losing out).

The next value, accountability, is closely linked to transparency. The key questions here are “To whom is accountability owed” and “Accountability for what?” Different elements of accountability will be owed to different groups: clinical effectiveness to patients, for example, and cost effectiveness to the payers. Participation involves many groups from patients in particular to citizens in general. There are a great many reasons for valuing participation; the slide itemises just four. The more reasons one adds, the more compelling the case for moving participation from playing a consultative to a controlling role in decision making.

Moving on to content values, Sarah Clark began with clinical effectiveness: the capacity of an intervention to achieve a given end. But this too has a range of interpretations, presented again on the left of the slide layout. As shown on the right, the different interpretations have differing implications for patient care, and for patients’ autonomy. AZT is an example of a drug in the top category; it was introduced before evidence of benefit was firm.

The importance of cost effectiveness relative to other values again has three gradations from being “one factor among several”, through “one of the most important”, to “not just important but decisive”. This gradation affects the focus (in the central column of the slide) of the system’s values: are they to stress the needs of the individual or the group as a whole. This may also have implications for who is to benefit from an intervention; should it be directed at particular patient subgroups, or does it not matter so long as the most overall benefit is being obtained from the resource?

The third content value is justice and equity. This has three interpretations: that all patients should be treated the same; that some, on account of poverty, vulnerability or whatever, should be positively prioritised; and that some people with, for example, an irresponsible lifestyle, should be “negatively prioritised”. The central column of the slide shows what these three prioritisations imply for the importance of health – as the only relevant factor or one of several. And these in turn place an emphasis on, respectively, health solidarity, socioeconomic solidarity and autonomy.

Solidarity can be thought of as a commitment by society that all within it should stand together: to be “all in it together”, to borrow a phrase much used by Britain’s governing coalition. When it comes to health provision, the corresponding arrangements lie on a spectrum running from comprehensive care for all, through a basic package for all, and on to

entirely private arrangements. As far as health solidarity is concerned the spectrum runs from full through partial to weak.

The final content value is autonomy and, once again, Sarah Clark presented three variants of what autonomy – understood here in terms of personal preference and personal responsibility - might mean. Where individual preferences and responsibilities are not emphasised, priorities can be set collectively. Where people are fully responsible for making their own healthcare arrangements, they also set their own priorities.

Sarah Clark said she recognised that there were values other than those she had covered (such as dignity and compassion) that people might want to take account of. In the end she left her audience with what she described as the $64,000 question: what might lead countries to prioritise some values over others?

Initial thoughts and responses

The opening presentations were followed by a session in which delegates had the opportunity to mention issues that had not been raised but which they felt merited consideration, and to put questions on what they had heard. Albert Weale initiated the session by reflecting on the balance between process and content. Some commentators feel that process is the more important element to focus on because even if people disagree about content and the importance of particular social values, a discussion on process and especially on transparency enables all concerned to see how decisions were reached.

On the range of different interpretations that can be placed on many of the terms - from transparency to the very nature of good health - he reminded his audience that these can differ not only from place to place, but from time to time in the same place. He went on to point out that while there is an understandable tendency to focus on the culture of society when studying the influences that determine social values, the influence of the family should not be neglected.

The first delegate to comment remarked that there had been no mention of the “rule of rescue”. It is paradoxical that a society prepared to spend millions on saving people who put their own lives in jeopardy through the pursuit of dangerous pastimes will nonetheless cavil at a similar expenditure to prevent the death of someone with an illness for which they bore no responsibility. (In fact the rule of rescue did not figure in later considerations, partly on the advice of Peter Littlejohns who had had

previous experience of group discussions on the topic, and felt it likely to prove an unhelpful distraction from more general issues.)

Another comment drew attention to the distinction between social values in the context of public as opposed to individual health. They posed different problems, it was suggested. There is also the question of the range of policies the meeting should aim to consider: health policy alone; or wider social policy?

The consideration of social values demands a degree of wariness - perhaps even humility. These values are not intellectual abstractions, but feelings and beliefs that are lived out in peoples' experiences. They may conflict with each other and with the pursuit of cost-effectiveness. Some people who are happy about a ban on smoking in public places are equally opposed to a ban in the home, in spite of the effect of passive smoking on children. Social values, it appears, can trump health values. And social values are sometimes traded one against another.

Is cost-effectiveness just a methodology designed to achieve certain values; or is it a value in itself? There seemed to be some uncertainty on this point, and it was raised several times more during the course of the meeting. It was also pointed out that while cost effectiveness is a central plank of NICE's activities, it is not explicitally used l in some country's deliberations.

Thinking on the issue of social values and health priority setting is unavoidably affected by wider social change. Parts of the Western world in particular are generally perceived as having come to place much greater emphasis on individualism. If true this surely has an influence on thinking about social values. Individualism can be seen, for example, as making cost effectiveness more difficult to calculate. Institutional influences too have an effect. Could the very existence of the NHS create particular ways of looking at cost effectiveness that don't reflect social values in general, but the manner in which the NHS functions as an organisation?

Country sessions

Moving from the general to the particular, the meeting heard a series of presentations by delegates from different countries. Each had been asked to explain briefly how their nation's health system operated, and then to give some account of the place of social values in setting the country's health priorities. Much of the finer detail of these presentations, particularly of the structure of the health systems, can be found in the

slide sets appended to this document, which should be read in conjunction with it.

Thailand

The Thai people have access to one of three health care schemes; the Universal Coverage (UC) scheme and the Civil Servant Medical Benefit Scheme are entirely funded out of taxation, while the Social Security Scheme is partly funded by employers and employees. The packages of benefits to which members of these various schemes have access are drawn up by responsible health plan committees. Benefit packages of three health plans share the National List of Essential Medicines (NLEM) developed by the Subcommittee for the Development of NLEM who explicitly employs evidence of safety, effectiveness and cost-effectiveness as criteria for including medicines into the list. The case of benefit package management under the UC scheme which is taken care by the Subcommittee for Development of Benefit Package and Service Delivery at the National Health Security Office is on focus. The Subcommittee considers similar evidences used by the NLEM committee, plus budget impact. The evidence partly comes from the Health Intervention and Technology Assessment Program (HITAP), and the International Health Policy Program

The process of compiling the benefit package was originally not systematic. New arrangements introduced in 2009 were designed to be systematic, transparent and evidence-based. Thus a variety of stakeholders, including lay people and patients as well as health professionals, decision makers, industry, NGOs and academics, can propose (though not select) technologies for scrutiny with a view to having them added to the benefit package. Selection criteria for topic to be assessed include the number of potential beneficiaries, the severity of the condition, the effectiveness of the technology, the financial impact of the disease on households, variation in practice, and its ethical and social implications. These last include giving a higher priority to rare diseases and to people in lower socio-economic groups. These are agreed by all stakeholders. Apart from appeal process against decisions, criteria and procedures used are publicised.

On the balance between preventive and curative interventions, it is intended that each stakeholder group making proposals for assessment will have to ensure that at least a third of them are preventive.

France

French healthcare relies on mandatory insurance for the entire population. Sixty per cent of the expenditure goes on the 13 per cent of the population with chronic conditions. There is also optional supplementary insurance (taken out by 90 per cent of people) to cover benefits excluded from the basic package. There is a list of reimbursed drugs and, again, supplementary insurance to cover full reimbursement for all drugs.

Priority setting is deemed unacceptable in France; although there is rationing of health care provision, it is not explicit. Efforts have been made to change these arrangements and move towards a system of set financial targets. A 1995 attempt by a member of the French parliament to limit the rate of increase of health expenditure cost him his job. ONDAM (Objectif National Dépenses d'Assurance Maladie, the body that regulates health insurance) has targets, but they are only indicative and often overspent. Public health services are not linked to the overall health spending target, and different agencies compete to set priorities.

In answer to her own question, "What have we learned?" the speaker referred to the Government's increased accountability to Parliament through tighter monitoring and a move away from the traditionally open ended French system. But she added that there is still little acceptance by either doctors or patients that resources are limited, because targets and priority setting are seen as rationing. To her further question "What should be done now ?" she suggested: the introduction of true prioritisation mechanisms to 'verticalise' the 100 public health priorities; the use of full evidence, including economics, when assessing health care strategies; the systematic evaluation of public policy to learn from mistakes; and a reconciliation between overall financial constraints and everyday individual behaviour by encouraging the generation of evidence, the production of guidelines, and the evaluation of health care technologies.

One organisation that could contribute to this last endeavour is HAS (Haute Autorité de Santé), a body set up in 2004 to evaluate drugs, medical devices and procedures scientifically, to authorise their reimbursement by health insurance, and to promote the use of best practice by health professionals. Economic evaluation was originally excluded from its activities. But new legislation in 2007 changed this, and HAS now produces guidance and recommendations on the most effective strategies. One contribution to this has been the creation of CEESP, the Economic and Public Health Specialist Committee, comprising 25 members including economists, social scientists and patient

representatives as well as doctors. It gives advice, but final decisions are made by the minister of health. Reconciling science with economics has proved a struggle, because the prevailing view sees the two disciplines as in conflict.

HAS has produced a guide to its methods of economic assessment. Its principles include: being transparent about assumptions and methodological choices; being explicit about the level of uncertainty and the robustness of results; justifying departures from standard cases and being explicit about the reasons for such departures; and reconsidering results when more evidence becomes available. HAS is now trying to make social values more explicit.

The presentation finished with a brief account of the issue of payment for growth hormone treatment in France. (The topic was revisited at greater length in a later session.)

China

China has three medical insurance schemes: one for urban employees; a more recent one for children, students, and the elderly; and a third for its rural population. For urban dwellers the money comes mainly from employers and employees, but in the less developed rural areas there are government subsidies for hospital charges and for medical expenses incurred in dealing with certain critical diseases. There is much variation across the nation. There are also three drug formularies in use, one for the urban population, one for the rural population, and a third, the essential medicine formulary, comprising Chinese as well as western drugs.

The development of thinking about social values and prioritisation is still at an early stage in China. Standards of clinical effectiveness are at the discretion of physicians, and criteria used to judge cost effectiveness are less than rigorous ("spend within budget"). Social values are implicit in decision making, but there is much disagreement about matters such as justice and equity, the comprehensiveness of coverage, and what constitutes a basic level of security. The system is biased towards major diseases and inpatients.

A number of other social values are the subject of controversy. They include: insurance coverage, especially whether it should be for minor as well as catastrophic disease; whether prevention should be included; the meaning of "basic" in "basic benefit"; and the provision of orphan drugs. The country needs a new drug list that will make the most effective use of

limited resources. But how to reconcile social values with economic judgements is still an open question in China.

England and Wales

The NHS covers the whole of UK, and offers comprehensive health care that is funded out of taxation and largely free at the point of use. But since the advent of devolved administrations, some of the detail varies a little in Scotland and in Northern Ireland. The country's new coalition government is intending to introduce major changes to the organisation of the system, and how this will affect its performance remains to be seen.

The presentation followed Sarah Clark's framework for the analysis of social values and health care priority setting, and can mostly be read straight from the relevant slides. The presentation responds to each of the questions posed in that framework, in some cases by quoting the words of NICE's constitution. In response to the question under heading 1A, although NICE is generally thought of as the pre-eminent body in health priority setting in the UK, it is not alone. Other government advisory committees play a role, as do the bodies that actually commission health care. NICE influences these decisions, but does not determine them. Over the years its role has expanded - to cover disease prevention and health promotion, for example. It will soon be expanding its territory again, this time to cover the cost effectiveness of social as well as medical care.

The question under 1B concerns rules of decision making. From the outset NICE was expected to take account of the availability of resources – though without guidance on how. Although the Secretary of State has the right to direct NICE to undertake tasks of the Government's choosing, it has made little use of this right. Section (d) of the Directions to NICE speaks of "potential for long term benefits to the NHS of innovation". This was originally intended as a spur to doctors to make greater use of the fruits of industrial innovation; nowadays it is more often interpreted to mean encouraging the industry itself to be innovative.

Accountability for decisions (question 1C) takes three forms: the topics chosen by NICE for appraisal have to agreed by the Secretary of State; its technology appraisals can be appealed by professionals, patients or by industry; and its actions are subject to judicial review. On the last point, court decisions have lead to modifications of guidance, but not actually changed it. Participation in decision making (question 1D) takes several forms: stakeholder involvement at all stages in the process; the close involvement of patients; and a council comprising citizens who meet periodically to discuss issues of particular concern to NICE.

Moving to the content of decision making, question 2A refers to cost and clinical effectiveness, 2B to social value judgements. These matters are covered in the NICE document *Social value judgements*. This takes the form of a series of eight principles, subject to judicial review, based on the deliberations of various advisory committees, a group of ethicists, and the Citizens' Council. Cost sharing (question 2C) has only a limited relevance to the UK because of its free-to-all NHS. But it has been decided that patients can themselves pay for drugs not approved by NICE for use in the NHS. At one time people buying and using unauthorised drugs would have jeopardised their right to NHS treatment.

The presentation finished with a glimpse of what the current reorganisation of the NHS might mean for NICE. The new system will see a devolution of responsibility to lower levels of the system where decision making will be lead by professionals. Precisely how this will affect the work of NICE remains to be seen.

Korea

Korea has a national health insurance scheme covering almost 97 per cent of its population. The remainder are covered by arrangements akin to those of Medicaid in the US. For reimbursement of the cost of newly introduced drugs the government operates a positive listing system under which each is subjected to a cost effectiveness value judgement. Existing drugs are covered by a negative listing system; but there is a plan to switch this also to a positive one. Non-drug health technologies are covered by a negative system; once they are approved for safety and submitted for reimbursement decision, they are automatically listed.

Decision making for drugs, medical devices, diagnostics and procedures is handled by a number of bodies including the NECA (the National Evidence-based healthcare Collaborating Agency) and KFDA (a Korean equivalent of the US FDA). Cost-effectiveness is a factor in making decisions about new drugs, but there is insufficiency of transparency in the process, and it is not always clear why a drug is or is not accepted for reimbursement. The ministry of health has a final say, but accepts most of the recommendations passed to it by HIRA. Decision-making is governed by a Medical Services Act, and a National Health Insurance Act. Cost-effectiveness is specified in the second of these acts.

The relative effectiveness assessment of drugs in Korea has undergone some recent changes. From 2007, new drugs have to have undergone a cost effectiveness analysis to be reimbursed by the country's national

health insurance. In 2008 Korea began to evaluate the drugs already listed, with the intention of stopping reimbursement for less effective ones. But this precipitated a political debate, and cost-effective analyses of already listed drugs was abandoned in 2010.

Decisions on coverage are based on a number of principles including clinical value, disease severity and budget impact as well as cost effectiveness. Clinical value and cost effectiveness are the decisive factors, but can be over-ruled on various grounds such as the lack of any alternative treatment or the severity of the disease. The cost effectiveness threshold for reimbursement was set following a comparison with levels adopted by other countries including the US, the UK, Canada, Australia and Japan. Cost sharing arrangements depend on the patient groups and the diseases in question.

The afternoon session began with a brief departure from individual country experiences. Dan Chisholm and Ole Norheim offered the meeting their account of the development of a checklist for priority setting. Like others with an interest in the topic, they have found it a difficult issue to grapple with. Their aim has been to produce an equity orientated list to be used alongside the results of economic analysis. Their starting point was a systematic review of how people have thought about equity criteria in previous studies.

They pointed out that if you change the mix of interventions for a particular population with a view to making things more equitable, you may find that you have also changed the net health benefit to the population as a whole. In other words there are tradeoffs to be negotiated, and a “mess” of themes and issues to be tackled (see slide).

In the hope of finding some way by which equity and priority setting could be considered together and in a standardised way they embarked on a series of meetings, workshops and reviews to put together a potentially usable checklist. The process sought input from a range of disciplines from economics to philosophy – one aim of this eclectic mix being to force people to reconsider all the issues involved. Agreement cannot be instantaneous because there are legitimate differences in viewpoint that point to different conclusions and ways of doing things.

The two speakers put some practical flesh on the theoretical bones by illustrating the kind of checklist question that can be asked. They began with question related to the disease itself, such as the severity of the condition, its rarity and its capacity to benefit from treatment. Relevant to

this last category are empirical studies which have shown that most people wish to include everyone in treatment packages; even individuals who can't benefit much from treatment shouldn't be left with no services. Each checklist question was illustrated with examples drawn from actual diseases.

The next group of questions relates to the characteristics of different social groups: whether, for example, the intervention tends to reduce disparities in heath associated with unfair inequalities in wealth, income or level of education. The third group of questions concerns non-health benefits and burdens: whether the intervention has a special value because it boosts the population's productivity or reduces the likelihood of later catastrophic health expenditure.

Other issues that might feature in a checklist of would be the risk of assigning responsibility for their illness to individuals who were not in a position to have avoided it, and the temptation to discount the value of an intervention because its benefits would not be felt immediately.

Fairness is an important but difficult issue. A checklist cannot replace deliberation about fair and efficient priority setting. But it could form a useful input to that process, not least by encouraging decision makers to think about things to which they don't always give due consideration. The present list, the speakers emphasised, is still a work in progress

USA - I

The presentation started with an overview of US health policy decision making, using a slide graphically illustrating its complexity. Seventeen per cent of the population do not have health insurance. Although the Medicare system operates over the entire country, only 15 per cent of coverage decisions are taken nationally. The rest are local to the seven regions into which the system is divided. Decisions on Medicaid are taken at state level.

One celebrated American example of priority setting is the Oregon Health Plan (OHP), Oregon being the only state which has attempted to ration not by people but by services provided. It was launched in 1989 using telephone surveys to establish the views of Oregonians on various states of health. This was used to rank all treatments available through Medicaid, a line being drawn where the money ran out. Treatments below this line in the rank order were not to be funded. The experiment is regarded by most commentators as having in large measure failed, but a version of the list is still in use.

The Oregon Health Services Commission is the body in charge of the list. The 11 commissioners, who include four consumer representatives, receive information on which to base decisions about the list from various expert subcommittees and task forces. The OHP follows an explicit algorhythm in making it prioritisation list. It uses health care categories, of which there were originally 17. This number has since been reduced to nine, with “Maternity and newborn care (100)” at the top and “Inconsequential care (1)” at the base. The revised system better encapsulates the views of the Oregonians originally consulted. The numbers in brackets indicate the weight to be given to each category in the algorhythm. Examples of high and low scoring items are schizophrenia and sprains of joints or muscles respectively. The system is low on rigour but high on transparency. All rankings are made public, and anyone who objects to a ranking can appeal. Cost plays no part in the system except as a tie breaker when two competing treatments score equally.

The system can claim legitimacy as reflecting the values of Oregonians because it undergoes continuous reassessment. It has not, however, stemmed the rise of health care costs, and the number of uninsured people in the state remains a problem.

The presentation also featured the Effective Health Care Program of the Agency for Healthcare Research and Quality (AHRQ). This aims to provide patients, professionals and policy makers with the kind of evidence of effectiveness that they most need. AHRQ values public engagement, and welcomes suggestions from the public about what to research; but the process by which it decides what topic to consider is not clear.

AHRQ is trying to improve stakeholder engagement in its Effective Health Care Program by helping end users to ask the questions that are most relevant to their intentions. It is also setting up a randomised controlled trial to discover the best method of seeking relevant views from the public.

The current move to reform US healthcare is centred around the new Affordable Care Act, which commits to an entitlement of care for all. It also aims to reduce the overall cost of the system, which has become a burden to the economy as a whole. This Act was only passed because the Presidency and both Houses of Congress were controlled by the Democratic Party. The Republicans have a different view, and their

recent advances allow them to dispute both the means and the goal of the Act.

Germany

The German Institute for Quality and Efficiency in Health Care (IQWIG) was established in 2004 following the model pioneered by NICE. The country has a system of statutory health insurance serving 90 per cent of the population. Cost-effectiveness was a relatively late arrival, not having been introduced into the system until 2007. Before that cost-effectiveness was already included as one of the basic tenets of the SHI system, however, that meant that certain therapeutic alternatives were not reimbursed. An example would be golden inlays that are considered a not cost-effective alternative over amalgam fillings. The country is also a latecomer to prioritisation and rationing. Solidarity, by contrast, has a long history in Germany. The statutory health insurance (SHI) system is administered by the Federal Joint Committee (FJC= Gemeinsamer Bundesausschuss, GBA). Its decisions are transparent and made public including the reasons why a particular decision was taken. Nevertheless, it remains unclear why individual members/ representatives take a certain position and how issues and topics are prioritized within the committee. FJC as the parliament of representatives from the national hospital association, the nationl association of physicians in office, and the national association of SHI funds makes decisions on what technologies to be covered in the SHI system. FJC primarily, but also the department of health commission IQWIG to compile evidence-based information on health technologies. But its recommendations are not binding.Neither can IQWiG's recommendations be appealed, yet the FJC decisions can be held accountable in a legal sense. Again the decision making process per se is transparent, but the moral and ethical values held by individual representatives may not be known, as there is no agenda on how to weight different values.

Delegates heard about the sequence of events by which IQWIG collects evidence and produces its reports. This part of the process follows defined procedures and is entirely transparent. IQWIG has to perform cost effectiveness analysis according to "international standards" but is not allowed to perform it across diseases. It is charged only with doing such analysis as the national association of SHI funds according to the old law (before Jan 1st, 2011) is required to set an appropriate and reasonable price. According to the new law health economic evalution will be performed by the manufacturer and submitted in a dossier that IQWiG will assess. On the basis of IQWiG's assessment of this dossier and the

subsequent appraisal by FJC negotiations between the national association of SHI funds and the manufacturer will take place. Yet, health economic evaluation will only take place after a process of negotiations solely based on a benefit assessment fails. So economic information is used in a way very different from that in most other parts of the world.

Germany does not use the QALY, about which it has many ethical and other doubts as has just been laid out by the National Ethics Council. There is also a legal issue arising from a high court ruling that people who have even a slight chance of benefitting from a service should get it.

More recently Germany has introduced early benefit assessment under which a manufacturer compiles a dossier of evidence that a new drug has advantages over a comparator. FJC has three months to decide how to respond to the dossier in making a decision on the reimbursable price. But the negotiations and the reasons for the decision are not made public.

USA – II

The final presentation took the form not of a country perspective but of the working of accountable care organisations (ACOs). Priority setting in the US is difficult. Ron Keren, who gave the presentation, said that if change is to come it will probably be at local level. ACOs are a new idea and could be a new locus for priority setting and the consideration of social values. Reform in US healthcare is focussed on coverage, gaps in quality, and rising costs. This involves reforming a payment system that currently promotes high volume and high intensity care regardless of quality, but not coordinated or preventive care. He listed a number of previously attempted solutions from public reporting to pay for performance. The concept of accountable care organisations features in the 2010 Affordable Care Act.

The speaker went on to list the characteristics of these organisations (see slide). He described it as a radical approach that moves away from the idea of one clinician taking care of one patient to that of a group of clinicians taking care of a panel of patients. Shared responsibility for quality and cost require decision making about health priorities if it is to work and to save money. This in turn requires discussions of the implicit and explicit social values involved.

There will need to be transparency on guidelines, quality measures, outcomes and any financial gains made by participants. There will also need to be accountability to patients, payers and providers, and also their

participation. The new arrangements will probably have to be built on what is currently in existence because it is not feasible to scrap the existing system and start again.

The need for clinical effectiveness data will be essential for meeting quality benchmarks – and difficult issues will have to confronted. What to do when the evidence is limited or conflicting? And what should be the effectiveness threshold for warranting prioritisation? Realigning financial incentives should reduce unnecessary care, promote preventive care, and so increase cost effectiveness. This will also be promoted by the need to consider value for money.

Issues of justice and equity will need to be considered given that different panels of patients could have very different socioeconomic, age and other make ups. There would probably need to be a law to prevent, for example, the cherry picking of the most healthy patients. Solidarity would be served by ACO panel members lobbying together for resources.

Ron Keren sees ACOs as a marketplace for social values. Patients are free to choose their physicians, payers can contract with ACOs that share their values, and ACOs can use their social values as selling points to attract patients and payers.

Themes to consider…

The presentations complete, Albert Weale kicked off the next session of the afternoon by expressing the hope that the meeting would sow the seeds of a research project that would be useful to policy makers. To facilitate further thought and discussion he presented a list of topics that he'd compiled, based on what he'd heard thus far during the presentations and the preliminary discussion of the morning. He presented his thoughts - themes to consider - on a series of slides, ordered according to the familiar sub headings used by Sarah Clark.

Transparency

All systems have many actors involved in making decisions that affect priorities. But while some of the organisations involved are explicit, others play more of a background role, which may be overlooked. Then there is the transparency of the means by which decisions are made. The Korean case in which initially it was somewhat unclear how new drugs came to be recommended . Some decisions are the outcome of a bargaining process between industry and those setting expenditure priorities. What are the ethics of bargaining or negotiating under these circumstances, and how much of what goes on is apparent? There can be

transparency of process but not of appraisal, as in the German example. Can there be a conflict between transparency and negotiation?

Accountability
This can involve complicated sets of actors, with different decision making processes. And there can be different sorts of accountability to different actors; you might be accountable to taxpayers for costs and to patients for benefits. There is also the issue of non-decisions: things that don't appear on the agenda. Does someone benefit from them?

Participation
The obvious point to be considered is the make-up of any participative groups: citizens, patients, stakeholders, providers or others. Their differing interests mean that they cannot simply be grouped together. How are stakeholder representatives selected? Are there particular groups, patients for example, who might be regarded as key stakeholders? In the Thai example, stakeholders can propose the balance between preventive and curative activities, picking priorities from the list. And what of the role of professional associations in recommending members for assessment committees? This has obvious links with broader principles of government in society, and with the specific example of the importance in Germany of the constitutional principle of self-government.

Who is part of the crucial institution, and so gets directly involved in decision making? Are they professional public servants or unpaid volunteers or others? Policy may be devised by policy planners thinking about cost-effectiveness, and then modified to take account of other considerations. Or policy may be devised in a bottom-up manner with priorities set through, for example, deliberative participation. Does it make a difference which process is adopted? The WHO check list raises this question. Our understanding of the comparative functioning of different methods of participation is weak.

Clinical effectiveness/evidence
Who generates the evidence, how is it brought together and what decision strategies do policy makers adopt when using it? It has to be borne in mind that new information comes in all the time; risks need to be reassessed. For many people, getting to grips with risk information is difficult.

Cost effectiveness

A basic question that cropped up more than once is whether cost effectiveness should be seen as a value in its own right, or as a vehicle for considering values that we care about – of which one might be the sustainability of the system over time. NICE is legally required to look at it; does this make a difference?

The use of a threshold approach allows comparisons across disease groups but defining its value is difficult We also need to avoid confusing high intensity care with high quality care; it shouldn't be assumed that high quality care is necessarily more expensive.

Finally there is the cost effectiveness of displaced care – in particular if certain conditions such as cancer get privileged treatment. What sort of care is this displacing? This is about thinking of cost effectiveness not as a goal for policy makers but as a prompt to encourage the prudent use of resources.

Equity/Justice

Some countries – notably China and Thailand in this meeting – have different schemes for different groups of people. One role of HTA in this context could be to help to reduce disparities between these schemes. The choice of prioritisation criteria – severity of disease, for example – is also a factor here in trying to promote equity and justice. So too are fixed budget schemes in which equity/justice are perpetually on the agenda because meeting one need usually means denying some other.

One aspect of appraisal that can easily be overlooked is the time taken to complete it. ("Justice delayed is justice denied.") Delay may, of course, be necessary for safety reasons. One has to think about the implications for people who are having to wait for a decision on something that affects their health if not their life.

Inter-generational issues of justice. If your aim is to create a sustainable system, the present generation has a duty to maintain the viability of the system for future ones. There is, of course, an element of self-interest in this, neatly summed by the thought that one should be nice to one's children because they'll eventually be choosing your care home!

Solidarity

The Chinese presentation brought out the clear distinction between those things which were matters of social pooling and those that were down to the individual. Cost-sharing is an issue in all systems, but its basis may

differ: cost-sharing implications for high cost patients, for example. Five per cent of a low cost is not the same as five per cent of a large cost. Differential packages are one remedy of tackling this.

Autonomy
Autonomy attracted relatively little comment during the meeting. Use of co-payment regimes to allow greater autonomy for those who want better benefits is one instance.

Social Values
Is the problem how to balance equity and cost assessment, or is it how to structure a prudently financed but adequate health care system? These may look like the same question but they are not, because cost effectiveness is playing a different role in the two cases.

Institutions and levels of decision making
All these decisions take place in specific institutions. The issues here include reconciling the macro and the micro, the national and local. (This is the source of the UK's "post-code rationing" debate.) It is noteworthy that American ACOs seem to face some problems similar to those of national systems. The European Union has faced arguments about the right to cross-border care.

Devolved decision making has clear implications for accountability.

Practical Reasoning
Issues here include: the requirement for empirical evidence; scoping the decision making process in values and empirical evidence; attempts to systematise the decision making process; the "rule and exemption" approach in NICE's use of ICERs (there is a rule, but it can be broken, given certain circumstances); the unhelpful distinction between the scientific and non-scientific; the scope of evidence needed for social care intervention; the value of learning through a study of comparative evidence; and the desirability of avoiding a mechanistic approach.

Defining Benefit
Consideration must be given to the broader and longer term benefit of developing arrangements that support innovation; to the assessment of community benefit in circumstances involving a range of interventions; to the pros and cons of the value-based purchasing of drugs; and to the distinction between setting priorities for healthcare services as opposed to wider public action of the kind required in supporting public health

services. The last of these might even include topics (such as transport) that wouldn't normally be considered as part of health care policy.

Measurement/operationalisation
Data reduction is always involved in making decisions. If it's equity we are interested in, how do we know that we are achieving what we are aiming for?

Research question
Having run through the lengthy list of issues and questions raised by the presentations and discussions ("a modest agenda"), Albert Weale suggested that it was time to begin thinking how a research project could be framed around them. We have to talk about values and priorities within the context of the institutions responsible for dealing with these matters, he said. They shouldn't be discussed as if institutions didn't exist or didn't matter. Research has to connect with the real world. He thought we should be asking what policy makers would find useful to help them with their decisions? What would they like to know about other systems, either as good models or as awful warnings? He wondered if these questions might be the place to start the discussion. He was struck by how far, despite great differences between health systems and values, there seemed to be shared agendas. If there is indeed this convergence, the way forward may lie in concentrating less on content than on process: less on what needs to be done than on how you do it.

The first issue raised by a delegate concerned the fixing of priorities not for new interventions and technologies but for existing ones. Focussing solely on the new was tantamount to tinkering around the edges; the real difficulty lay in trying to introduce more rational priority setting into existing expenditure. In the context of UK public health, the speaker said, what counted was a broad balance between resources allocated to prevention as against treatment. Germany has a similar problem – but it is not an issue that engages that country's politicians. Another delegate suggested, more optimistically, that international interest in risk factors for disease was currently on the increase.

Experience shows that while health systems often find it hard to deny access to new technologies, they find harder still to withdraw existing ones for which there is little evidence of benefit. Disinvestment, it was pointed out, is always hard - and not necessarily easier even when budgets, as at present, are likely to be dwindling.

On the issue of transparency it was pointed out that many decisions depended on technical and economic arguments with which much of the public might have some difficulty in getting to grips. For another delegate the key issue was finding ways of getting the people most directly affected by decision making - the patients - to play a greater role in the making of those decisions. Someone else raised what he viewed as key questions about health care systems. What is actually driving the development of the priority setting process? What do the people designing the process really care about? Are they looking for ethical or political legitimacy, do they want some sense that the public agree with the processes they have set up? An understanding of the drivers involved might reveal a lot about the ways in which different countries approach these questions and what they really care about. The case studies that delegates had listened to often seemed to be trying to achieve different things.

Albert Weale suggested that a research project into the question of participation might look at the comparative functioning of different methods of participation. In the UK, where public engagement is much in vogue in policy making, it's possible to buy off-the-shelf remedies which don't do the job well. We need to indentify appropriate methodologies. One size is unlikely to fit all.

Delegates heard that the WHO check list described earlier had been prompted by the fact that while a great deal of cost effectiveness data are available, they are not much used. The hope is that a check list, if meaningful and practical, will encourage a greater use of these data. But someone else raised an even more basic issue: why start with cost-effectiveness? Why not justice and equity, for example? Perhaps it's the obvious link between health care and money that often tends to place cost effectiveness in its central position. Non-economist might well think that some other starting point would be more appropriate. But it matters, because where you start from inevitably creates a bias.

Does the appeal of cost-effectiveness as a starting point stem from the fact that the data are quantifiable and so less "woolly" than those of other possible choices? Possibly - though woolly cost effectiveness data are not unknown! An alternative explanation is that what people are looking for is consistency in comparison, and this is what cost effectiveness seems to offer.

Rejoining the discussion Albert Weale recalled a warning delivered earlier in the day about the hazards of being too "mechanistic" in our

judgements. He felt that cost effectiveness is important because it can guard against wasting resources. Taking it seriously represents a kind of collective prudence – which is not necessarily the same as asking decision makers to maximise some numerical quantity. He went on to wonder if simply gathering and balancing evidence of very different kinds - clinical trials, economic data, public engagement exercises and the like - is of itself an issue for policy makers.

Delegates heard a German perspective on cost effectiveness and decision making. Politicians, it was suggested, like cost effectiveness because it's a valuable tool for justifying decisions, something to hide behind. And is health economics scientific? This has been much discussed in Germany. It can be seen as no more than a way of accounting for decisions that may in truth have had some other origin. Another delegate highlighted the difference between creating a new system as opposed to adding to an existing one. The process of priority setting does not necessarily pose the same problems in both cases. This raised the question of training packages to help policy makers get to grips with issues of this kind. Such packages do exist. It was suggested that capacity building should be considered in the context of any research project that might emerge from the meeting.

The day finished with a discussion of the possible benefits of setting up a website to bring together information and experiences of the kind discussed at the meeting, and to serve as a focus for future developments.

Small groups

Day two of the meeting began with the division of delegates into small groups based, as far as practicable, on single countries. The aim was for each group to consider a recent piece of guidance or a drug evaluation, and then use the Sarah Clark framework to judge them on the extent to which the decision reached did or did not take account of social values.

China

The group felt that it wasn't relevant to use a particular example, so instead tackled the framework question with respect to the workings of health policy and decision making institutions generally in China. The body concerned with compiling the national formulary comprises a collection of experts from hospital and drug companies brought together by the Government. Its decisions are the product of health technology appraisal and a consideration of what is valued in Chinese society. The formulary itself is in two parts; drugs in one section merit 100 per cent reimbursement but drugs in the other receive only 60 per cent. In theory

the allocation is based on evidence, but in practice evidence can be trumped by unspecified expert opinion.

There are no explicit and publically declared rules of decision making. Accountably of the experts is limited to a declaration that they have no conflicts of interest and will act with honesty. There are procedures for public comment on decisions, but they are not much used. Press conferences called to launch new formularies constitute the main forum for public discussion.

Social values appear to be implicit rather than explicit in the sense that people making the decisions have their own cultural values. But cost effectiveness seems to trump everything else. Because treatment and prevention are handled by different agencies, they tend not to be brought into conflict when priorities are being set.

Although there is apparently a thirst for more explicitness about the basis of many of these decision, it remains for the present the domain of expert committees.

Korea

The Korean case study featured glucosamine, often used for osteoarthritis. This comes in two forms: the sulphate, available in Korea as a prescription drug (a small market); and the hydrochloride, categorised as a health supplement (a large market). But is glucosamine effective?

Several agencies are involved in drug decisions. HIRA makes recommendations to the ministry of health about which drugs should be covered for insurance purposes in the formulary. KFDA is accountable to the public, the president and the congress. NECA is responsible for collecting evidence, assessing it and making policy recommendations. It holds closed meetings with ~~manufacturers~~ policymakers and other bodies, and also open meeting for public hearings. The main stakeholder is the manufacturing sector, because the market is so large.

Effectiveness and safety are the main determinants of decisions. Cost effectiveness is not yet a consideration. In the case of glucosamine there was some concern about safety, and a big debate about its effectiveness. The debate drew peoples' attention because glucosamine is a frequent gift to mothers or mothers-in-law, especially if they are suffering from bad knees! Participation included patient surveys of patient views, and also open hearings.

In the case of the sulphate there was a little evidence to suggest a beneficial effect of using it; for the hydrochloride there was no evidence at all. The only outcome was a minor modification by KFDA to the package insert and Ministry of Health and Welfare announced that they will make a decision whether or not to reimburse glucosamine when used as a health supplement based on NECA's evidence and KFDA's re-evaluation. Social value judgement took account of glucosamine's importance as a gift.

In the end there was some reduction in the use of the glucosamine on account of a greater public awareness of the paucity of evidence. But there was no change in its legal status. As a test of evidence-based decision making it was only partially successful. Efforts will continue to integrate evidence into decision making.

France

The issue considered was payment for expensive growth hormone treatments for a number of conditions including infants who are small for gestational age. The cost of treatment is fully covered in France. The benefits of treatment include achieving normal adult height and a better quality of life. But there are uncertainties about the efficacy of treatment, and the possibility of an increased risk of diabetes and cancer.

The institutions involved in making the decisions in cases like this are HAS (Haute Autorité de Santé) and the Transparency Committee, both accountable to the ministry of health which makes the final decision on reimbursement. It often follows the recommendations it is given, but does not have to. (There is a debate in France over whether the ministry should be able to exercise this power.) HAS's main responsibility is establish the clinical effectiveness of the hormone and its cost, together with various other factors, none of which are explicit and are currently being debated.

Social values not only inform the content of the decisions made, but have also influenced the way the process has been set up. For France this is a political rather than a technical decision - which is why the ministry is responsible for taking it. The process is relatively transparent by comparison with other systems in France, and in this sense operates against the grain of traditional French values. It is even possible to sue if it is felt that the committees have not followed their own procedures correctly.

There is no public element in consideration of medical efficacy, but the broader assessment can include patients' views. There is also a period in which decisions can be contested. Decisions are informed by a consideration of the clinical benefits and a full cost utility analysis – though the definition of benefit in the case of growth hormones (number of centimetres of extra height) is the subject of disagreement. Is an extra 2cms of height part of what it means to be a healthy person? And who should decide? There are social values being discussed here, but in the guise of judgements on effectiveness.

Issues covered in a brief general discussion of the first three country presentations ranged from the severely practical (how to measure social values) to the deeply philosophical (do we really want health care values to mirror social values if the social values in question might themselves be regarded as undesirable).

Thailand

The institution featured in the Thai example was the National Health Security Office. Its decision making body is the Subcommittee for Development of Benefit Package and Service Delivery and it relies mainly on evidence of cost effectiveness and budget impact. Participation in topic proposals involves seven groups of stakeholders. The process of selection is carried out by a narrower group from which both lay people and industry representatives are excluded. While this committee takes account of the health technology analyses with which it is presented, it is under no legal obligation to follow them.

The first case study was the prevention of cervical cancer, the second most common cause of cancer in Thai women. The choice was between screening and vaccination against the causative virus, Human Papilloma Virus (HPV). Following an economic analysis the subcommittee chose to recommend a strengthening of the existing screening programme and the introduction of a comprehensive approach rather than offering the vaccine.

The second case study was of the provision of adult diapers for people with disabilities. There was an assessment of the effect of diaper use on quality of life and household expenditure, and also a cost utility analysis. Preliminary results suggest that diapers improve quality life by 10-15 percent and significantly reduce household expenditure. The recommendation presented to the decision makers (though not yet agreed) is to include diapers in the universal benefit package, and so protect the

poor from a financial burden. However, further studies on cost-utility and feasibility are being undertaken.

The social value judgement at decision making level was described as "formal" and "informal" criteria. The difference is that only with formal decisions are reasons given in the meetings, and announced to the public.

Germany

The chosen example was the problem faced by IQWIG in choosing a set of patient-relevant outcomes for a group of oncology drugs that have already passed the first hurdle by having been shown to possess at least minimal clinical effectiveness as judged by the European Medicines Evaluation Agency (EMEA). From IQWIG the issue moves to a federal joint committee charged with making decisions on cost, but not on cost effectiveness. This committee has to decide if the new drug is better than an existing one. On the issue of patient-related outcomes, three parameters are taken into account: morbidity; mortality; and quality of life. IQWIG has found itself struggling with judgements based on morbidity, not least when reviewing a drug in terms of the way that patients perceive its effects.

The insistence on patient-relevant criteria means that, for example, a small reduction in tumour size which might be relevant to the EMEA might not be relevant to IQWIG unless it was perceived as beneficial by patients. This leaves the decision making system with some delicate balancing acts to negotiate.

Germany does accept cost sharing, but only up to a set maximum, which depends on the condition. For chronic conditions people have to cost share up to a level of one per cent of gross income. For acute conditions the figure is two per cent. But there is a debate about the boundaries of acute and chronic. Limiting the extent of co-payment is seen as backing the idea of solidarity, which is important in Germany. IQWIG can't itself explicitly factor in social values; this is the role of the government.

England

The group assessing an English example chose the NICE technology appraisal guidance TA 187 on the treatment of Crohn's disease. The rules make it clear without clinical effectiveness there can be no cost effectiveness. Both these factors along with cost and severity of the disease are taken in account when reaching a decision. NICE also relies in considerable measure on QALY calculations.

Insiders tend to view NICE's processes as rational and transparent. But although NICE has general principles on social values, exactly how they get incorporated in a final decision can be quite opaque to members of the public. Accountability includes the possibility of taking NICE to court to contest a decision. But how does the public perceive this accountability? A reading of press reports of what NICE does, or is believed to do, suggest that there is a communication problem between it and the public. Appeals against NICE tend to be on technical grounds. It would be more difficult to appeal on the basis of some alleged disregard of social values.

In the TA 187 example the drug was calculated to cost £30,300 per QALY gained – which is above NICE's threshold. But having considered the severity of the disease and noted that there were few treatment options available to Crohn's patients, the committee decided to recommend it anyway. This demonstrates that social values were being taken into account.

Under some circumstances cost sharing is a possibility.

A future research agenda….

Albert Weale kicked of the final discussion session of the meeting by thanking everyone for the richness of the insights that had emerged from this and the previous day's presentations. He then went on to make a couple of general points on the thinking behind the meeting. By way of illustration he used Sarah Clark's third slide, headed "Process values: transparency". The idea of using a framework or template was to offer a means by which people could explore a range of interpretations of particular values. There are, for example, many possible interpretations of transparency. The idea of the template is to capture the range of interpretations as they occur in different systems. Using the definitions suggested on the slide you could even score transparency from 0-4 (where 0 means that transparency is not seen as a relevant value). But there is no assumption that everyone will assign the same importance to it.

His second point was that when it comes to social values, never mind the broad cultural context, it's difficult to gather relevant information. The case studies had illustrated this. He instanced the role of the gift in the Korean example.

From what Albert Weale had head it seemed to him that setting up a website would be a good idea. This would serve not only to collect the

information already available, but to act as a repository for further information and other material. A body of case studies of decision making, for example, would demonstrates the range of what is happening, and could be updated over time. The next stage is find out what policy makers really need to know.

It is possible to consider the role of values in decision making in two ways: you can think about those things which cause values to have the influence they do; alternatively you can think about the consequences of those values, and their influence on decision processes. It seemed to Albert Weale that the reasons why value changes take place is an interesting one, but should not be the primary business of a group of this kind. The focus should rather be on improving decision making, if this is feasible.

He finished by reminding his audience that Sarah Clark's template is not a design sent down from on high, but more of a questionnaire to be filled in.

The first suggested research question, designed to fill a knowledge gap, was how social values currently feed into decisions on coverage made by different health systems. Mapping processes and discerning how social values feed into those process would be both useful and do-able. Another suggestion was to select a handful drugs which are only marginally beneficial in terms of clinical or cost effectiveness, see how different health systems have dealt with them, and try to tease out the reasons for the various decisions.

A rather broader suggestion was to try linking the social climate to the nature of the decisions made. Someone warned of the dangers of taking on too big a task. Having himself carried a lot cross national comparative research Albert Weale commented that one of the disappointing features of such work is that it always seems to end up confirming national stereotypes!

Someone else pointed out that the manner in which social value judgements are communicated to the public merits further study, not least in the hope of improving it. Another thought concerned the distinction between conscious and unconscious consideration of social values. Some health systems make explicit attempts to introduce them; others do not. But this does not mean that social values have played no part in the decision making process. A case controlled comparative approach might cast light on this.

At this point Peter Littlejohns took the microphone to admit that he had begun the day wondering if any research was feasible. The case studies and the subsequent discussion had persuaded him that his fears had been groundless. There was plenty of material and ideas on which to work. He also drew attention to the difference between the information that policy makers want, and that which perhaps they *should* want. Another task for the group could be to identify the latter category more clearly. He said he was also much attracted by the idea of building up a portfolio of case studies.

One delegate wondered how this work might link up with other attempts at identifying the sources of the differences in the decisions that are already made by other health technology assessment bodies. She also wondered how it might link up with WHO's check list research project. One the authors of that work agreed that there was an overlap, although his project was more concerned with developing a practical tool that could be used by different health systems rather than with accounting for the source of the differences between those systems. He added that a new version of the checklist would soon be available and that it would be good to circulate it around the members of this group. If people wanted to test it for themselves in decision making processes he would be more than happy for them to do so.

In response to a delegate who wondered what was in the minds of the meeting's organisers as far as an objective for the event was concerned, Peter Littlejohns replied that the general aim was to build on the networks that had already been established, mainly through NICE International. For him the key issue was to improve the quality of decision making - and he believed that this could be helped by research linked to actual experience and born out of an interaction been academics and policy makers.

Albert Weale offered one example of the kind of project that he could foresee exploiting the group's resources: the issue of copayment. The incremental cost effectiveness ratio (ICER), he pointed out, aggregates the costs and aggregates the benefits. What a consideration of co-payment can do is force you consider on whom the costs actually fall. Research on this distributive element would have considerable practical significance.

Thinking ahead to the kind of article he'd like to read, one delegate said he'd really appreciate a comparative analysis of the kind of values other than cost effectiveness that are taken into consideration in the political

process. Cost effectiveness, he observed, is still the dominant paradigm. What about impact on household income? What about age? To read about experiences of using these and other values would be useful.

Conclusion

It was clear that all attendees were minded to continue with the potential collaboration that had begun to emerge during the day and a half of the meeting. The creation of a website is one obvious next step; but Peter Littlejohns was already trying to think beyond this. Funding is one severely practical issue that has to be considered – but this can't be tackled until the way forward has been more fully clarified, and agreed. Suggestions for funding sources would be welcome. He thought it unlikely that a single country would be enthusiastic about paying the entire cost of a project with such an international dimensions; funding by a portfolio of funders represented a more realistic possibility.