

Appraising options for addressing the 'Kidney Gap'

Overview

Deliberative Mapping is a two-year project (2001-3) funded by the Wellcome Trust under a programme to develop innovative methods for public engagement in the biosciences. The Deliberative Mapping methodology is also applicable to other complex technological and environmental policy appraisals.

The multi-disciplinary research team for Deliberative Mapping is based at SPRU (University of Sussex), ESRU (University

College London) and the Policy Studies Institute (PSI). A broad-based Project Advisory Committee supported the research team throughout the project. The PAC membership is listed on the project web-site.

This Executive Summary describes the main features of the Deliberative Mapping project. Key findings are presented. The full report is available from the project web site or from members of the research team.

Aims

Deliberative Mapping is an appraisal process which integrates expert and citizen assessments through a transparent and auditable framework. Emphasising diversity, DM enhances social learning to support more robust, democratic and accountable decision-making.

The aims of the project were to:

- examine how far scientific, expert-driven risk assessment techniques can be reconciled with deliberative

approaches to public engagement;

- develop and test the DM process through a full-scale public engagement exercise. A range of specialists and citizens' panels assessed alternative policy options for addressing a complex medical issue.

The medical issue selected for the study was **how best to reduce or close 'the kidney gap'**.

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Focus

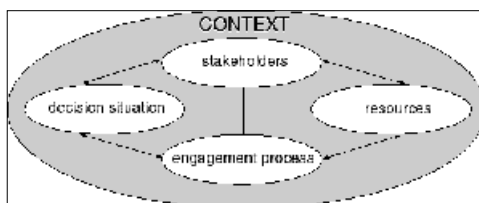
Current developments in the bio-sciences hold out hope for the effective treatment of many intractable illnesses, but never without controversy on economic, social, political or ethical grounds. The widely recognised crisis of public confidence in the regulation of scientific and technological innovations challenges decision-makers as never before. In response, new governance strategies are urgently required to deal effectively with the uncertainties posed by the introduction of new technologies into complex, plural and unequal societies.

Deliberative approaches in participatory technology assessment (PTA) require social relations based on trust and mutual respect. Weighing evidence through argument to reach a decision broadly acceptable to all parties depends fundamentally on co-operation. Without a commitment to working together, it is not possible to share knowledge and values, nor to debate and reach a judgement on the strengths of different claims.

The quality of facilitation is thus a critical factor when bringing citizens into a complex PTA. Done well, deliberative and inclusive engagement processes can widen the social base for the appraisal of policy options and help legitimate the basis of future policy making.

Good practice PTA is growing across Europe, as greater attention is being given to evaluation of choices made at each stage of the decision process identified in Figure 1.

Figure 1 **Fitness-for-purpose**



What are the important contextual factors and how do they frame the specific decision situation? Who are the stakeholders and how should they be engaged in the decision-process? What kind of engagement process is best fit-for-purpose? What is the level of resource available and is it adequate?

Deliberative Mapping is a PTA methodology which sits alongside citizens' juries and consensus conferences in its aims of promoting debate between experts, stakeholders and citizens from a wide range of social groups. DM differs from juries and conferences in that it facilitates quantitative and qualitative appraisal, based in both individual and group-based deliberations. Both specialists and citizens completed the appraisal process, providing a unique opportunity for comparative assessment of criteria selection and option performance.

Closing 'the kidney gap'.

The problem addressed in the study is the 'kidney gap'. Kidney transplantation is an established treatment for patients with end-stage renal failure. However, there is a growing disparity between the number of donor organs available and the number of patients awaiting transplants. The gap will continue to grow as demand for organ transplants increases in the future.

Options for reducing or eliminating the kidney gap range from sophisticated biotechnological innovations such as stem cell based therapies and xenotransplantation, to changes in organ donation practices and improved health education. However, all options are characterised by scientific and technical uncertainties and/or raise social, economic, cultural or ethical difficulties. In this context, there is a particular value in approaches to public engagement, which provide for effective integration and mutual learning between different specialists, stakeholders and citizen perspectives.

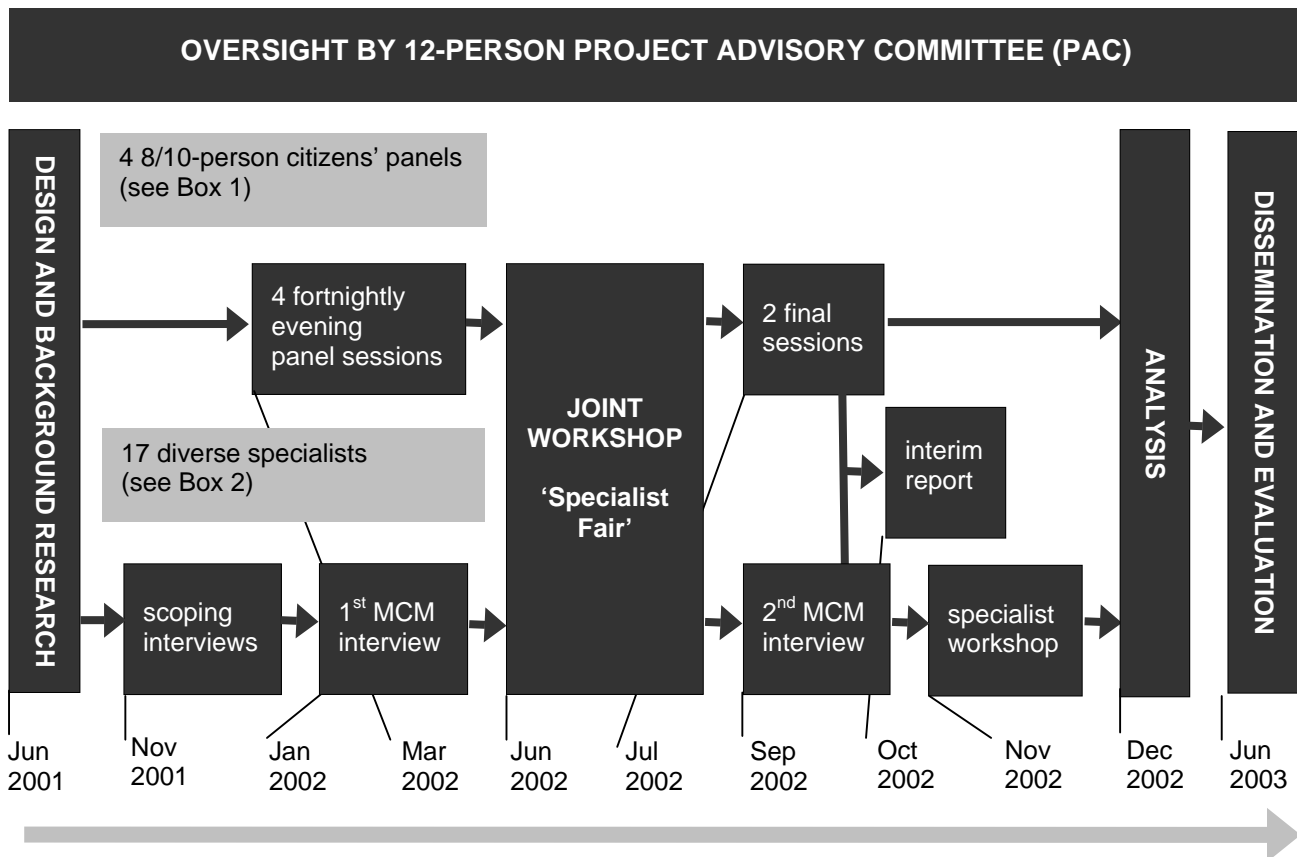
Framework

The Deliberative Mapping approach integrates a number of methodologies:

- **open-ended scoping interviews** with specialists and stakeholders.
- **facilitated group deliberation** in a series of citizens' panels, a joint citizen/specialist workshop and a specialists meeting.
- **structured quantitative appraisal** using a scoring and weighting framework based on paper-based MCM in the citizens' process; and sophisticated MCM software in the specialist process.
- **a Joint Workshop** with an agenda set by the citizens' panels; and '**specialists fair**' allowing free association and focused dialogue between citizens and specialists.

Figure 2 shows how these methodologies were integrated in the DM process. Citizens (see Box 1 overleaf) and specialists (Box 2) followed the same basic framework for appraisal. A set of common **options** (Box 3) are each assigned a **score** to reflect performance under freely defined **criteria**. These are then **weighted** to reflect their importance. This allows determination of a set of **ranks**, indicating the overall performance of each option. The result is a 'map' of the way performance varies under different perspectives, which is further interpreted through qualitative analysis of transcripts which record the deliberations of individual specialists, and the citizens' panels.

FIGURE 2. Schematic summary of structure and timeline for the Deliberative Mapping project. This shows an iterative and interactive structure, subject to stakeholder oversight.



Box 1: CITIZEN PERSPECTIVES

Thirty-four citizens from Camden, North London were recruited by stratified sampling using a questionnaire-based approach. Individuals were selected to include a wide range of ages, occupations, ethnic backgrounds, and family circumstances. Potential recruits were screened to exclude patients, and carers of patients.

To promote effective deliberation and allow analysis of social, economic, cultural and demographic differences, the 4 panels (8-10 members) were differentiated by gender and socio-economic class (BC1 men/ women; C2D men/women). Panellists were paid £300 for attending 6 evening meetings, and the one day Workshop.

BOX 2: SPECIALIST PERSPECTIVES

17 specialists were recruited to span a wide range of perspectives, disciplines and institutional affiliations, summarised below.

Transplant Policy

- senior civil servant at Health Department
- senior executive at UK Transplant
- professor of nephrology, medical school

Healthcare Policy

- ethnic health specialist, NHS Executive
- public health physician
- government health economist

Medical Research

- academic stem cell researcher
- immunologist at medical school

Industry

- medical equipment industry executive
- pharmaceutical company executive
- commercial xenotransplant researcher

Ethics

- academic ethics committee member
- medical ethicist, doctor's organisation

Other Stakeholders

- kidney transplant patient
- complementary medicine practitioner
- religious doctor's organisation
- animal welfare organisation

BOX 3: A COMMON SET OF OPTIONS

To ensure comparability between the different perspectives of citizens, specialists and stakeholders, six '**core options**' were identified by the research team for appraisal by all participants. Four '**prompted options**' could also be appraised if participants wished. To ensure consistency, balance and appropriate scope, the ten options were defined in consultation with the PAC. Citizens received a booklet, which described each option in some detail.

Specialist participants were invited to define further options if they wished. Shorthand characterisations of the core and prompted options are given below in the sequence used throughout the DM process.

Core Options

- 1 Improved transplant services.** Improving existing transplant services: learning from national and international best practice.
- 2 Altruistic living donation.** Increasing the number of donors through voluntary unpaid living donation.
- 3 Presumed consent.** Increasing the number of donors by giving the medical profession a greater role in making decisions about organ donation.
- 4 Xenotransplantation.** Cross-species transplantation using organs from genetically modified pigs.
- 5 Embryonic stem cells.** Human tissue engineering using human embryonic stem cells to repair or build kidneys.
- 6 Encouraging healthier living.** A preventative approach.

Prompted Options

- 7 Improved kidney machines.** Building bio-artificial machines that function more like a real kidney.
- 8 Adult stem cells.** Human tissue engineering using stem cells from adult humans to repair or build kidneys.
- 9 Rewarded giving.** Providing a small economic incentive for consenting to organ donation after a person's death.
- 10 Accepting death.** Placing greater emphasis on dying with dignity.

Process

Citizens' Strand

Each citizens' panel met for six 1.5 hour evening meetings, with a joint workshop with specialists between meeting 4 and 5. Each panel followed the same programme:

Session 1. Introduce panellists and facilitation team; agree ground rules; discuss initial thoughts about transplantation; provide information about the 'kidney gap.'

Session 2. Clarify, discuss and then agree meanings, definitions and implications of the 10 common options that might solve the 'kidney gap'.

Session 3. Discuss and agree a shared set of criteria to be used by the panel to judge the pros and cons of the different options.

Session 4. Panellists score six core options and any prompted options under chosen criteria; panel reviews performance patterns; decided what issue to take to Workshop.

Joint Workshop. All four panels join specialists to discuss issues raised in their deliberations.

Session 5. Discuss workshop outcomes; panellists re-score options; weight criteria to reflect priorities.

Session 6. Discuss individual & full panel results. Evaluate the DM process.

Provision of Information to Citizens

Great care was taken in preparing clear, balanced and informative briefing materials for the citizens' panels. Subject to oversight by the PAC, the Citizens Booklet outlined the general issues bearing on the 'kidney gap', and spelled out the common options from different perspectives.

Technical queries arising in the early sessions were discussed with individual specialists by one of the facilitation team, and then reported back to the panel. Beyond this, further detailed information was exchanged at the Joint Workshop. (See project website for all written materials).

Specialist Strand

To inform the definition of core options, the specialist process began before the Citizens' Panel process and took the following form:

Scoping interview by phone to discuss project and views about the kidney gap.

First MCM interview conducted at place of work using MCM software to structure the appraisal of common and additional options under weighted criteria.

Joint Workshop. All specialists were invited to participate with citizens' panel members to exchange views and respond to questions.

Second MCM interview conducted at place of work using MCM process to elicit any changes in their own appraisals.

Specialist Workshop all specialists invited to reflect on the various perspectives, the emerging findings and process as a whole.

Joint Workshop

Citizens and specialists came together in a one day Joint Workshop. The citizens' panels set the agenda for the morning plenary session. Two people from each panel, chosen by their peers, made a short presentation on an issue from their deliberations. Specialists then responded briefly to these issues, and gave their own additional perspectives.

The afternoon session took the form of a 'specialist fair'. Specialists were seated individually at desks spaced out around the hall, with publicity material if available. The citizens were invited to 'visit' whomever they wished and raise whatever they wished in discussion with each other and their chosen specialists. This allowed citizens freely to associate and take control of their interaction with the specialists. The result was a delicate balance between the effective exchange of citizen concerns, technical information and stakeholder perspectives.

Results

The Overall Performance of the Core Options

Despite many differences in perspective, there is a remarkable degree of consistency between the appraisals made by the four citizens' panels, and the 17 specialists.

Of the six core options, two perform markedly better overall:

- ***improved transplant services***
- ***encouraging healthier living***

Two further options are generally ranked highly, but slightly lower or with more qualifications than the two 'lead options':

- ***presumed consent***
- ***altruistic living donation***

Finally, the two 'technology-based' options perform markedly worse than the others overall:

- ***xenotransplantation***
- ***embryonic stem cells***

The picture for the four discretionary options is, for various reasons, more ambiguous:

- ***adult stem cells***
- ***improved kidney machine technology***
- ***rewarded giving***
- ***accepting death***

Figures 3-5 (at the end of this Executive Summary) provide a snapshot of the patterns lying behind this overall picture. They show the extent of the convergence between the citizens' panels and the various groupings of specialists, as well as indicating the areas of difference.

Qualitative analysis of the panel discussions shows that citizens used many different kinds of 'public reasons' rather than purely personal preferences to reach their judgements about the options. All took their responsibilities as representatives of wider society in the Deliberative Mapping project very seriously, as the extended analysis in the Final Report demonstrates.

The Nature and Importance of the Appraisal Criteria

The criteria used to appraise the options were defined, selected and weighted by the participants themselves. The four citizens' panels developed 14 distinct criteria. The seventeen specialists produced 111 criteria. Three of these were introduced as issues of principle, under which certain options were ruled out of appraisal. Based on these criteria, specialists also identified a number of ***additional options*** for appraisal. These refined or introduced new features not present in the core options.

What kinds of criteria were thought important? Eleven broad categories may be identified. The extent to which the more detailed specialist criteria fitted the categories was discussed with each individual. The relative importance of the criteria groups to citizens and specialists is revealed through analysis of criteria weighting and analysis of the discussions between the citizens. Many areas of agreement emerged from this analysis, as well as some differences in terms of interpretation and priority between citizens and specialists.

Priorities for citizens and specialists

Feasibility. Includes issues of scientific, technical, legal, institutional and political viability. Asks how well an option will work in practice and the timeliness with which it will become practically available.

Ethical acceptability. Includes moral questions about consent (donor and family), coercion (of donors), animal welfare, nature/culture boundaries, other socio-political issues and general notions of the 'good society'.

Economic. Includes the cost of the option in broad monetary terms. Various accounted for at the level of the NHS, extended to include the research system or others on whom explicit costs fall, or encompassing hidden costs for society as a whole.

Patient outcomes. Includes issues of medical success and patient quality of life, sometimes based on established clinical quality of life scales and sometimes more broadly defined, including 'quality of dying'.

Capacity. Addresses the contribution made to increasing the number of organs available (or reducing the need) for transplant. It excludes wider issues of success.

Public safety. Addresses implications for the safety of non-patients. Includes issues such as infection risks or other unintended or unanticipated public health impacts and health effects of surgery on living donors.

Wider Benefits. Includes benefits that may be gained from an option that are wider than organ donation itself. For example, information about more healthy lifestyles will protect against other illnesses; scientific research may produce results that are more widely applicable.

Generally lower priority issues

Equity. Includes the extent to which organs will be supplied to those in greatest medical need rather than on some other basis, such as ability to pay.

Information and transparency. Addresses the extent to which good quality information is available to support public judgements.

Socio-political motivation. Considers the underlying economic, social or political interests that might benefit from particular options.

Other social impacts. Addresses wider issues such as emotional impacts on families and carers, and consequences for society as a whole of becoming increasingly dependent on the products of scientific and technical expertise.

Reflections on Deliberative Mapping

One aim of the DM project was to trial this novel public engagement process. Reflections from the specialists and citizens are, therefore, important results. These are the headlines; full details are provided in the Final Report.

- **Reflections on the DM process**

All the panellists took pride in having completed this complex task. Their success was attributed to the sequencing of tasks over several sessions; different modes of working together; being in-groups with similar people; and high quality facilitation.

Specialists appreciated the novelty, scope and potential of DM. Some thought the process protracted; others were concerned about definitions of 'expertise' in this context; a few were worried about potential issue framing problems for the citizens' panels.

- **Reflections on learning**

The panellists expressed a sense of empowerment and strong feelings of ownership over the results of the appraisal. Having sufficient information provided to engage with the issues; working through a structured decision-making process; and meeting specialists were all highly valued learning experiences.

Specialist learning was social rather than technical. They were all genuinely surprised by the quality of the citizens' deliberations, their willingness to engage with, and challenge specialist views. When tensions exist in policy circles about the ability of the public to participate in scientific and technical decision-making, this was an important lesson.

- **Reflections on policy impacts**

The citizens had mixed opinions about the potential impacts of the DM project on policy. The BC1 panels, especially the men, were more optimistic that policy-makers would take note of the findings than either of the C2D panels.

Specialists welcomed the project and thought it offered a worthwhile public engagement strategy for policy makers. A few were worried about how the richness of discussions could be communicated successfully to decision-makers; and, more generally, there were concerns about how to scale up from the local to the national level.

Evaluation

The DM project was guided by an explicit set of evaluative criteria at all stages of its design, implementation and analysis. The final report includes detailed critical reflections on the lessons learned by the research team. These reflections will be augmented in the light of further comments at the dissemination workshop. Evaluative comments by project participants so far have been strongly positive. The deliberative mapping approach combines **inclusiveness** and **openness** to divergent perspectives, **specificity** and **robustness** in its policy implications, **transparency** and **auditability** for third parties, and **efficiency** and **added value** for sponsoring policy institutions.

One particular observation concerns the way in which the convergence in option rankings is underlain by a rich diversity in the detailed perspectives. Taking the integration of quantitative and qualitative assessment seriously is important. Purely discursive analysis would likely have been dominated by a picture of contrasts and tensions. By the same token, quantitative analysis alone would have missed important nuances of difference.

However, there are also important constraints and limitations to be acknowledged. One key issue that arises in any appraisal process – whether deliberative or analytic – concerns the degree to which outcomes may be subject to invisible

contingencies. The DM process was designed both to minimise and provide a check on such factors. However, this does not preclude the possibility that certain aspects of the findings may be artefacts of the process. For instance, there is some evidence that inter-personal encounters between specialists and citizens at the Joint Workshop may have affected appraisals for certain options. If a specialist was felt to be friendly, open and approachable, some of the citizens responded more positively to 'their' option in subsequent discussion.

It also seems that the process of weighting may actually be conducted by specialists in a rather different fashion than is assumed in the theoretical framework for decision analysis. Reflecting other PTA research findings, there are also questions around strategic behaviour in the assessment of the options – a factor addressed by the high auditability of the MCM procedure.

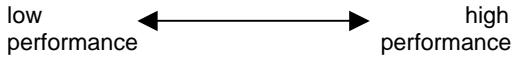
Finally, although it may be seen as efficient in relation to the added value of the outputs, Deliberative Mapping is quite complex, time consuming and expensive. It needs strong project management and high quality facilitation. This places significant demands on sponsors, practitioners and participants alike. Such investments of time, effort and resources are not possible or appropriate in every context and should not be undertaken lightly.

Conclusions

This process has identified a number of specific and concrete policy implications for closing the 'kidney gap'. In particular, these are strongly favourable for organisational options **improved transplant services** and **encouraging healthier living**. There are correspondingly negative implications for technology-based options like **xenotransplantation** and **embryonic stem cells**.

In conclusion, Deliberative Mapping offers a practical means to inform technical policy decisions in a robust and accountable fashion. It shows that quantitative and qualitative appraisal techniques and individual and group-based methods can work together effectively as part of a deliberative and inclusive process. By balancing a variety of specialist, stakeholder and citizen perspectives, DM may help to foster more co-operative policy dialogues.

In all the charts below, option performance ranges from low on the left to high on the right



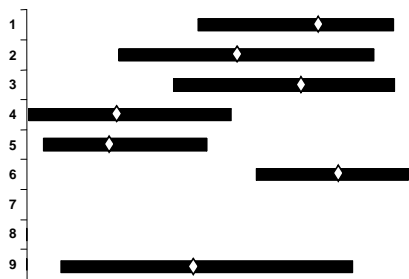
KEY TO OPTIONS

- 1 improved transplant services
- 2 altruistic living donation
- 3 presumed consent
- 4 xenotransplantation
- 5 embryonic stem cells
- 6 encouraging healthier living
- 7 improved kidney machines
- 8 adult stem cells
- 9 rewarded giving
- 10 accepting death

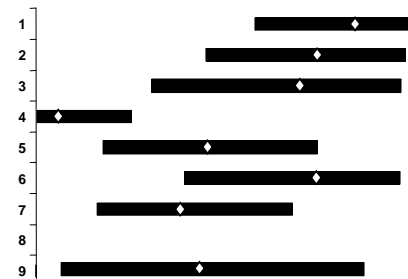
FIGURE 3: Citizens' Panel Rankings

key range of rankings across all members mean ranking over all members

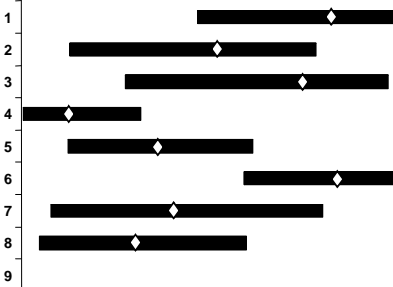
women's panel (BC1)



men's panel (BC1)



women's panel (C2D)



men's panel (C2D)

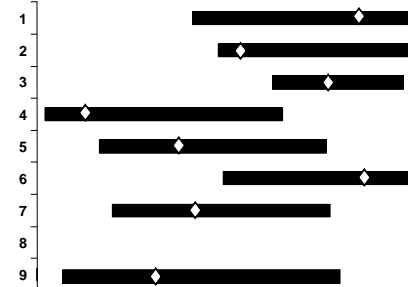


FIGURE 4: Specialist's Rankings

mean ranges for 17 participants

key Ranges show combination of individual uncertainties and variability across individuals.

- option appraised by all participants
- option appraised by all participants and ruled out by some
- option not appraised by all participants

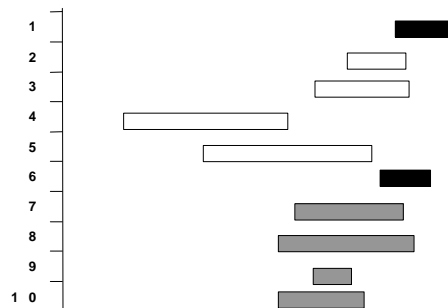

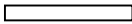



FIGURE 5: Mean ranking ranges for sub-groups of specialists

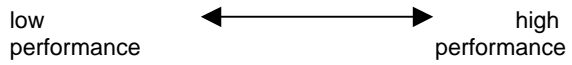
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- 10 accepting death

KEY TO CHARTS

-  option appraised by all participants
-  option appraised by all participants and ruled out by some
-  option not appraised by all participants

All the charts below show means of performance ranges, from low on the left to high on the right. Ranges show combination of individual uncertainties and variability across individuals.



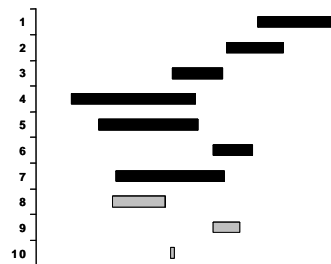
Three Industry Specialists



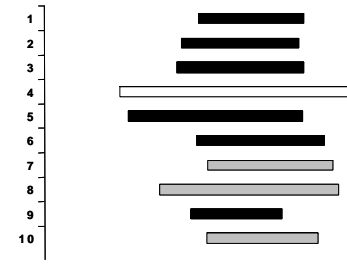
Two Medical Research Specialists



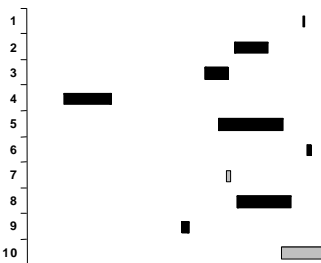
Three Transplant Policy Specialists



Three Healthcare Policy Specialists



Two Ethics Specialists



Four Stakeholder Specialists

