



Deliberative Mapping

CITIZENS AND SPECIALISTS INFORMING DECISIONS ON SCIENCE AND TECHNOLOGY



briefing 3 **Deliberative Mapping in practice: the ‘kidney gap’**

This briefing explains the application of Deliberative Mapping – a process designed to involve specialists and citizens in decision making – to the problem of kidney shortages, and summarises how participants appraised the various options for the way forward.



The 'kidney gap' explained

This briefing is based on the application of Deliberative Mapping to the problem of the so-called 'kidney gap'. This is the disparity between the number of people who are waiting for kidney transplants, and the much lower number of donor kidneys available. There are a range of different options for how this gap could be reduced (see below), however they are all characterised by scientific and technical uncertainties and/or raise social, economic, cultural or ethical difficulties.

What is Deliberative Mapping?

Deliberative Mapping is a methodology which can be applied to a problem to judge how well different courses of action perform when appraised against a set of economic, social, ethical and scientific criteria. Fundamental to this approach is the involvement both of specialists and members of the public (see Briefing 2 in this series for more information).

Putting Deliberative Mapping into practice

The first application of Deliberative Mapping was to the problem of the kidney gap. Thirty-four citizens from north London were recruited to take part. Individuals came from a wide range of ages, occupations, ethnic backgrounds and family circumstances.¹ They were split by gender and socio-economic background into four citizens' panels: C2D women, C2D men, BC1 women, BC1 men. Seventeen specialists also took part from a number of relevant disciplines and organisations (see Figure 1).

Options for addressing the kidney gap

The task for citizens and specialists was to learn more about a series of potential options for addressing the kidney gap, and to compare their performance against a range of criteria. Participants appraised up to ten different options: six 'core options' and four 'prompted options' (see Figure 2). Individuals could elect not to appraise the prompted options if they wished; they could also introduce new options.

Figure 1: Specialist involvement in kidney gap case study

| | |
|--|---|
| <p>TRANSPLANT POLICY</p> <ul style="list-style-type: none"> ● Senior civil servant at Department of Health ● Senior executive at UK Transplant ● Professor of Nephrology at medical school | <p>INDUSTRY</p> <ul style="list-style-type: none"> ● Medical equipment industry executive ● Pharmaceutical company executive ● Commercial xenotransplantation researcher |
| <p>HEALTH CARE POLICY</p> <ul style="list-style-type: none"> ● Ethnic health specialist, NHS Executive ● Public health physician ● Government health economist | <p>ETHICS</p> <ul style="list-style-type: none"> ● Academic ethics committee member ● Medical ethicist from a doctors' organisation |
| <p>MEDICAL RESEARCH</p> <ul style="list-style-type: none"> ● Academic stem cell researcher ● Immunologist at medical school | <p>OTHER STAKEHOLDERS</p> <ul style="list-style-type: none"> ● Kidney transplant patient ● Complementary medicine practitioner ● Religious doctors' organisation ● Animal welfare organisation |

Deliberative Mapping

CITIZENS AND SPECIALISTS INFORMING DECISIONS ON SCIENCE AND TECHNOLOGY

Figure 2: Options for addressing the kidney gap

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.

The decision-making process

The citizens and specialists followed different but overlapping processes (see Figure 3).

The four citizens' panels met for six evening meetings, with a joint workshop with specialists (or 'specialist fair') between meetings 4 and 5. As part of this participants worked jointly through a paper-based multi-criteria mapping (MCM) process (see Briefing 5 in this series for more information).

Specialists took part in a scoping interview at the beginning of the process and two software-based MCM interviews, split by the joint workshop. They also attended a specialist workshop at the end of the process to reflect on the findings and approach.

Figure 3: Structure and timeline for the Deliberative Mapping project

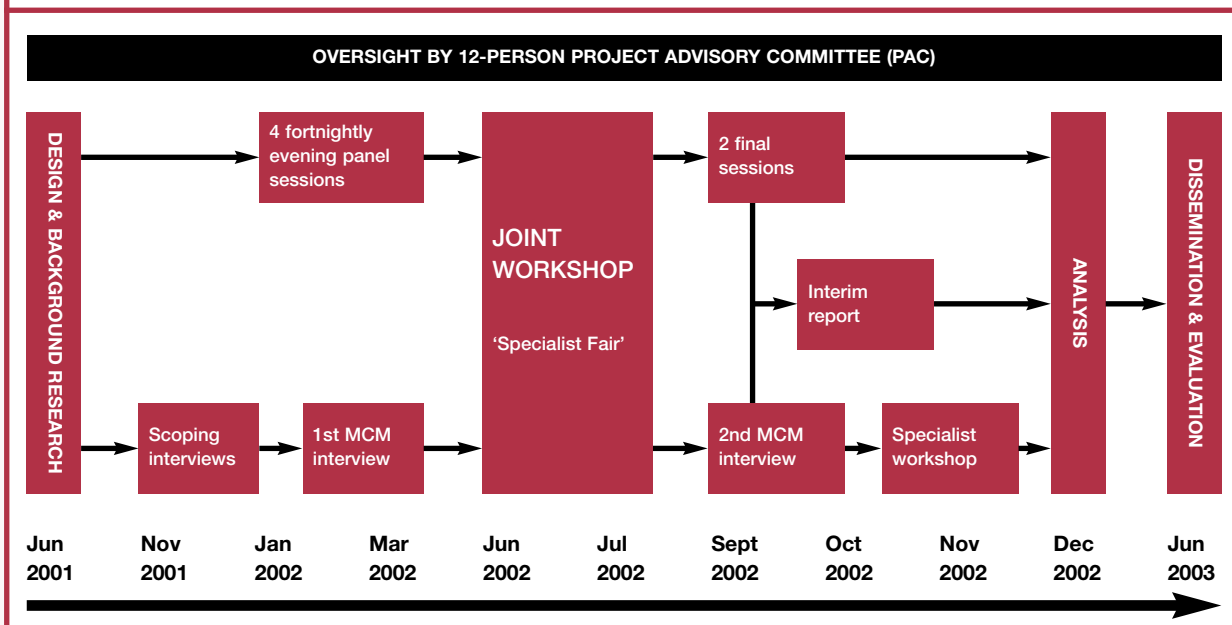




Figure 4: Appraisal themes and priorities for citizens and specialists

APPRAISAL PRIORITIES

Feasibility: includes issues of scientific, technical, legal, institutional and political viability. It considers 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 sociopolitical issues and general notions of the ‘good society’.

Economic: includes the cost of the option in broad monetary terms. This is mainly at the level of the NHS, but 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. It 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.

LOWER PRIORITY APPRAISAL 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.

Appraisal criteria

The participants scored the options against appraisal criteria that they defined.

The criteria fell into 11 broad categories (see Figure 4). Individuals weighted the criteria in each category to establish the relative importance they attached to each. Analysis of this revealed that there were many areas of agreement among citizens and specialists, as well as some differences in terms of interpretation and priority.

Findings

Despite many differences in perspective, there was a remarkable degree of consistency between the appraisals made by the citizens and specialists.

Of the six core options, two performed markedly better than the others: ‘improved transplant services’ and ‘encouraging healthier living’.

Two further options generally ranked highly, but slightly lower or with more qualifications than the two preferred options: ‘presumed consent’ and ‘altruistic living donation’.

The two technology-based options – xenotransplantation and embryonic stem cells – performed markedly worse than the others.

The picture for the four discretionary options was, for various reasons, more ambiguous.

Figures 5-7 illustrate the group 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 areas of difference.

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CITIZENS AND SPECIALISTS INFORMING DECISIONS ON SCIENCE AND TECHNOLOGY

KEY TO OPTIONS (for figures 5-7)

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

Figure 5: Citizens' panel rankings

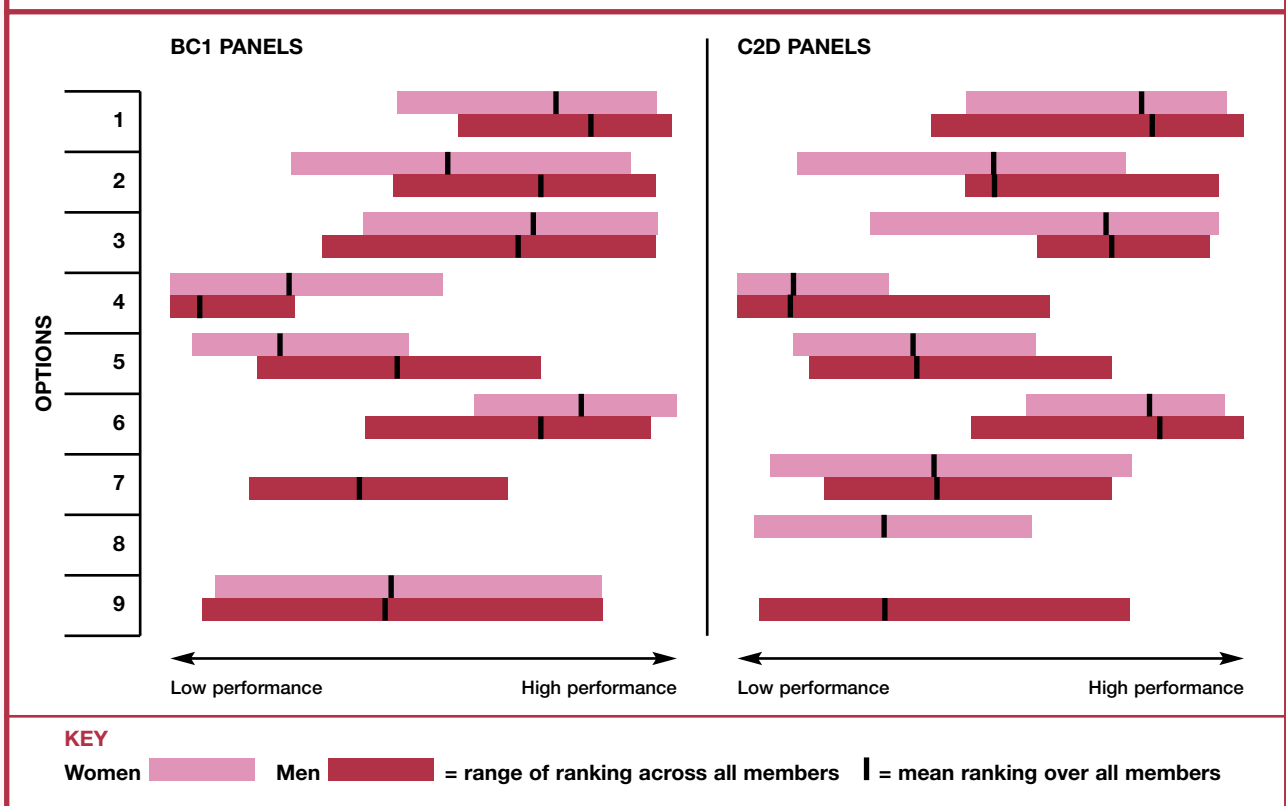
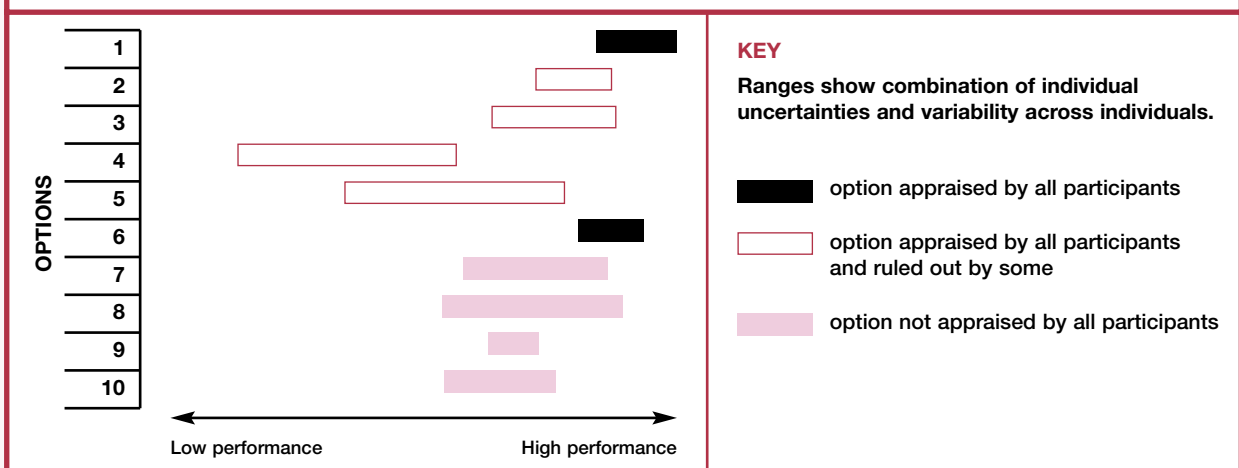


Figure 6: Specialist's rankings

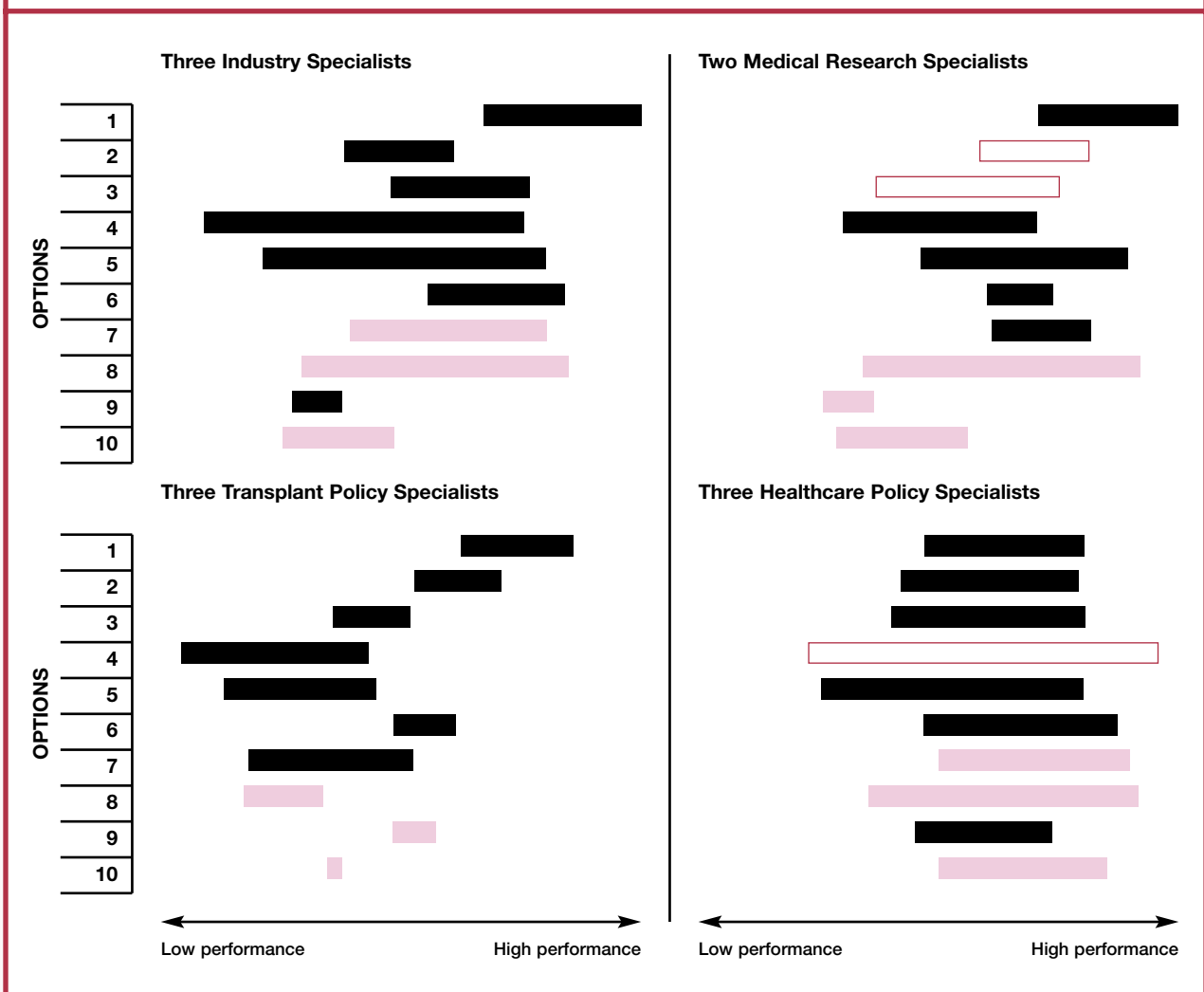
Mean ranges for 17 participants



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Figure 7: Mean ranking ranges for sub-groups of specialists



KEY

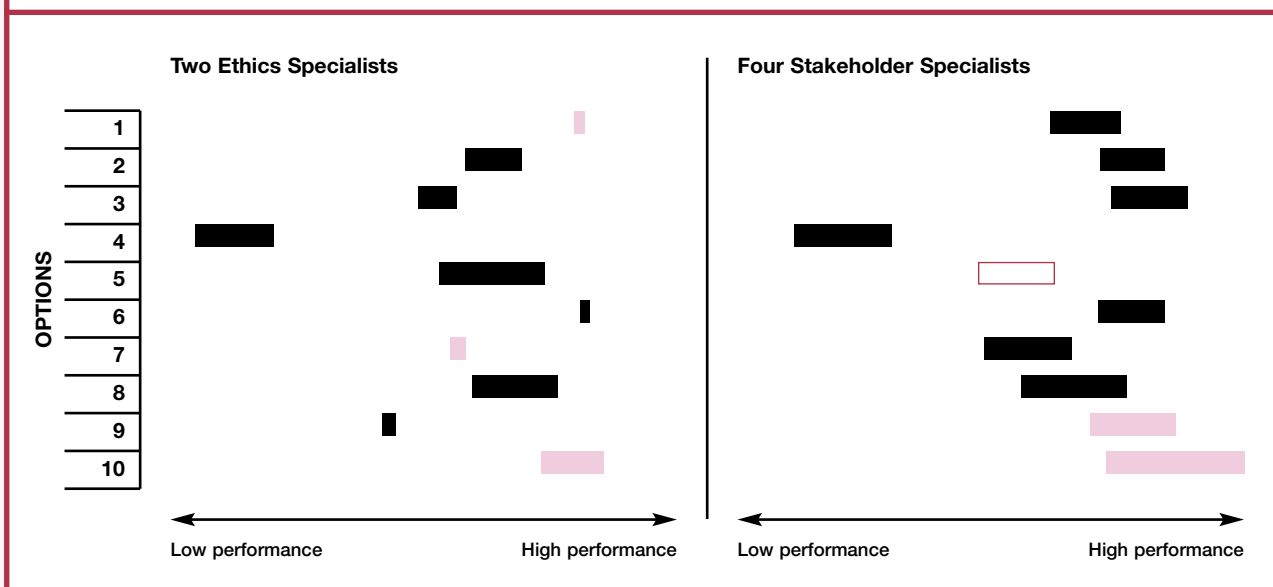
All the charts above and right show means of performance ranges, from low on the left to high on the right. Ranges show combination of individual uncertainties and variability across individuals.

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

Deliberative Mapping

CITIZENS AND SPECIALISTS INFORMING DECISIONS ON SCIENCE AND TECHNOLOGY

Figure 7: Mean ranking ranges for sub-groups of specialists *continued*



Evaluating the Deliberative Mapping process

The citizens expressed a sense of empowerment and strong feelings of ownership over the results of the Deliberative Mapping process. They valued having sufficient information to engage with the issues, working through a structured decision-making process and meeting specialists.

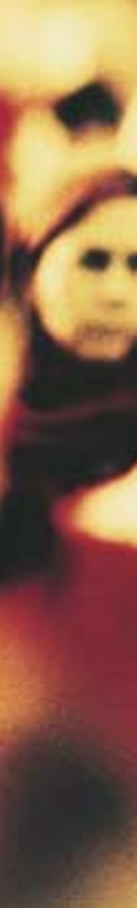
Specialists felt that their learning from the process was social rather than technical. They were all genuinely surprised by the quality of the citizens' deliberations and their willingness to engage with, and challenge, specialist views. This was an important finding given the tensions that exist in policy circles about the ability of the public to participate in scientific and technical decision making.

The impact of the process on policy making

The citizens had mixed opinions about the likely impact of the Deliberative Mapping 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. Some were worried about how the richness of discussions could be communicated successfully to decision makers. More generally, there were concerns about how to scale up from the local to the national level.

Applying Deliberative Mapping to the kidney gap demonstrated that quantitative and qualitative appraisal techniques, and individual and group-based methods, can work together effectively as part of a deliberative and inclusive process. There



may not be the same high degree of agreement every time the process is used, but the results will always provide a practical detailed picture of the relative performance of different options.

By balancing a variety of specialist and citizen perspectives, Deliberative Mapping may help to foster more productive discussions about policy, although there is no guarantee that the outcomes will be fed successfully into a policy-making process.

About the Deliberative Mapping briefing paper series

This is one of five briefings which explain Deliberative Mapping. This is an approach designed to help specialists and members of the public weigh up evidence to reach a joint decision on a complex policy issue where there is no obvious way forward.

The five briefing papers are:

1. **Opportunities and challenges for involving citizens in decision making**
2. **The Deliberative Mapping approach**
3. **Deliberative Mapping in practice: the 'kidney gap'**
4. **Citizens' panels in Deliberative Mapping: a user guide**
5. **Using the Multi-Criteria Mapping (MCM) technique.**

Further information

These briefings are available to download at **www.deliberative-mapping.org**

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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). This research was funded by the Wellcome Trust under a programme to develop innovative methods for public engagement in the biosciences, Grant no. 064492.

March 2004

Prepared by Final Draft Consultancy and designed by Sign.

Reference

1 Patients waiting for a kidney transplant and their carers were not recruited.