



Academy of Medical Sciences

Using evidence to judge the benefits and harms of medicine

Evaluation of public dialogue

Final report October 2017

Executive Summary



Introduction

The public dialogue run by Ipsos MORI sat within the Academy of Medical Sciences' ("the Academy") policy workstream on medical evidence, 'How can we all best use evidence to judge the potential benefits and harms of medicines?'. The study looked at:

1. The strengths and limitations of different sources of evidence used to evaluate the risks and benefits of medicines.
2. The ways in which conflicts of interest impact on the validity (or perception of validity) of evidence.
3. The communication of evidence to support discussion and decision-making.
4. The perceptions and perspectives of society on scientific evidence (including in the context of shared decision making between patients and their clinicians).

The study began with a call for evidence. The final project comprised four strands:

- a '[Methods of evaluating evidence](#)' Working Group project
- the '[Conflicts of interest](#)' workshop
- two '[Communicating evidence about medicines](#)' workshops
- the public dialogue.

The three sub-projects address themes that informed and were raised during the public dialogue and point to some of the social factors that underlie this topic.

The Academy also commissioned an online survey. ComRes interviewed 2,041 members of the British public online between 18 and 20 March 2016 in the UK, and 1,013 GPs online between 16 and 26 March 2016. General public data were weighted to be nationally representative of all British adults aged 18+, by age, gender, region and socioeconomic group. GPs data were representative by former SHA region.

Following a procurement process involving invitations to tender and the submission of proposals, the Academy appointed Ipsos-MORI to design, manage, run and report on the dialogue. The central question of the dialogue was 'how can we all use medical evidence¹ to judge the potential benefits and harms of medicines'? The dialogue objectives were to:

1. Provide opportunities for members of the public, patients, researchers and healthcare professionals to come together to discuss and explore their aspirations and concerns about the use of evidence to judge the benefits and harms of medicines
2. Identify areas of consensus, disagreement and uncertainty.
3. Where possible, explore public views on ideas emerging from the methods for evaluating evidence working group, conflicts of interest workshop and the communicating evidence workshop.

¹ The Academy of Medical Sciences defines medical evidence in the [full study report](#): "We define good scientific evidence as data or information derived from research that uses robust and reliable scientific methodologies, and seeks as far as possible to eliminate or minimise biases."



4. To inform the development of the final report and any recommendations made by the oversight group
5. To enable the Academy to build on previous experience in public dialogue to inform policy advice and recommendations.

The Academy of Medical Sciences

The Academy of Medical Sciences ('The Academy') was founded in 1998 as an independent body in the UK representing the diversity of medical science, with the express purpose of promoting the translation of advances in medical science into benefits for patients and the population at large. The Academy has six objectives:

1. Promoting excellence
2. Influencing policy to improve health and wealth
3. Nurturing the next generation of medical researchers
4. Linking academia, industry and the NHS
5. Seizing international opportunities
6. Encouraging dialogue about medical science.

The Academy carries out a broad range of engagement and communication activities, including public lectures for academic and non-academic audiences and social and mainstream media channel. The Academy aims explicitly to bring the voices of public and patients into its policy advice and in 2006, it carried out its first public dialogue, [drugsfutures](#), as part of a major policy project on [Brain Sciences, Addiction and Drugs](#). Since then, two further policy projects have included a public dialogue strand: [Animals Containing Human Materials](#) and [Health of the Public in 2040](#). The views expressed in these dialogues have informed the recommendations of the oversight groups on these projects and been integrated into the final reports.

Public dialogue

Public dialogue has increasingly become an expected feature in the policy making landscape and political awareness of the specific characteristics and value of dialogic engagement - as opposed to purely communicative or educative approaches - seems to be growing. In evidence sessions held as part of a [recent inquiry on science communication](#) by the [Science and Technology Select Committee](#), questions explored some of the complexities of engaging the public on uncertainty - scientific and political; scientific method; the precautionary principle; the relationship between the purpose of engagement and the approach used, and; building engagement skills amongst scientists and science skills amongst special advisers. One recurrent question was how to evaluate the impact of engaging publics in science and technology.

Sciencewise², the UK government's programme for public dialogue in policy making on emerging science and technology was re-launched in April 2017, following a brief hiatus. The Sciencewise programme is funded by the Department for Business, Energy and Industrial Strategy and has

² Declaration of interest: the writer is lead Dialogue and Engagement Specialist and Lead Evaluator for the current Sciencewise programme.



supported 55 public dialogues since its inception in 2005. Sciencewise dialogues have established standards for engaging publics on science and technology, and the Sciencewise programme has developed a set of principles to which good dialogue should adhere. In its call for tenders on this project the Academy stated its support for the Sciencewise guiding principles and required applicants to accord with these principles in their tender proposals and implementation of the dialogue.

The Sciencewise principles address the following:

1. Context: the conditions leading to the dialogue process are conducive to the best outcomes
2. Scope: the range of issues and policy opinions covered in the dialogue reflects the participants' interests
3. Delivery: the dialogue process itself represents best practice in design and execution (Delivery)
4. Impact: the outputs of dialogue can deliver the desired outcomes
5. Evaluation: the process is shown to be robust and contributes to learning

Independent evaluation has been a requirement of Sciencewise projects since its start. In addition to learning from specific dialogue projects, Sciencewise has explored the theoretical and practical challenges associated with evaluating dialogue, responding to the increasing scrutiny of this growing area of publicly-funded activity. In March 2016, it published a [Framework for Assessing the Quality of Public Dialogue](#). This sets out a definition of public dialogue:

“Public dialogue is a process during which members of the public interact with scientists, stakeholders (for example, research funders, businesses and pressure groups) and policy makers to deliberate on issues relevant to future policy decisions.”

In assessing the quality and impact of public dialogue, the Framework advises a pragmatic approach. It notes that each public dialogue is bespoke and that evaluation should explore not just the delivery of a dialogue, but the political, organisational, cultural and behavioural context in which it is taking place.



Overall aim of the evaluation

The aim of this evaluation has not been to judge the performance of the delivery contractor or of any individuals from the Academy or of members of the group overseeing the study as a whole. The success or otherwise of a dialogue is a consequence of many factors, including the initial question, its scope and framing; governance and project management arrangements; relationships and quality of communication between commissioner and contractor, and oversight group members and contractor; timelines and budgets. The work of the delivery agency - in this case, Ipsos-MORI - has to be seen within this broader context.

In the absence of impact, however, a dialogue has little purpose. So the focus of the evaluation has been on factors other than its immediate delivery through the workshops. It looks more broadly at the things that have contributed to its success and that offer lessons for future dialogue projects run by the Academy as part of policy workstreams. To this extent, it prioritises the voices of those who had most power in the process: oversight group members. Their understanding of the role of the dialogue as one strand amongst others, and their views on its status as evidence-generating or not will have informed the way in which it was integrated into the final study report.

Six key questions

The Sciencewise guidance on evaluation,³ which provided an overarching framework for this evaluation, specifies six key questions.

1. Has the dialogue met its objectives?
2. Has the dialogue met standards of good practice (Sciencewise principles)?
3. Have those involved been satisfied with the dialogue (value to them)?
4. What difference/impact has the dialogue made?
5. What was the balance overall of the costs and benefits of the dialogue?
6. What are the lessons for the future (for good practice and more widely)?

Questions 2, 3 and 4 are addressed throughout this report, though not in the form of explicit responses to each question. Question 6 is addressed narrowly, in a separate chapter, that looks at what the Academy itself has learned from this dialogue and might consider in future dialogues. Question 5 is notoriously difficult to assess: the budget assigned to public dialogues is rarely sufficient to cover the resources required, particularly from staff. This is generally true for both the commissioner and commissioned side of a project. Evaluating the long term benefits is also very difficult: extracting the specific contribution made by a public dialogue to the eventual impact that a study such as this is likely to have would be impossible. For that reason, we have not attempted to answer question five, beyond saying that those people interviewed for this evaluation learned and gained value from in their participation and from the outputs and it is clear that the Academy is taking steps to make the most of what it has learned. Question 1 is answered explicitly in chapter 6.

³ [SWP:08 - Evaluation in Sciencewise](#) and [Quality in Public Dialogue](#).



Data collection

This report is based on the following data sources:

- Telephone interviews lasting approximately 45 minutes, with members of the oversight group (OG) and of the Ipsos-MORI delivery team: interviews were digitally recorded and transcribed
 - 6 baseline interviews
 - 6 final interviews
- Questionnaires completed by publics and patients, healthcare professionals (HCP) and observers attending workshops designed and run by Ipsos-MORI
- Observation at three workshops (two in London, one in Glasgow)
- A workshop with the Academy of Medical Sciences staff team.

Interviews were recorded and transcribed. Observation notes were made during events and photographs were taken of the outputs of the Academy workshop: these have informed the diagrams shown in chapter 5.

Reading this report

Chapter one looks at some of the wider themes raised during the evaluation interviews. These describe the context in which the study as a whole took place and were factors that arose explicitly or were implicit in public participants' discussions during the dialogue. They include issues of trust and conflicts of interest; changes in the information available to publics as a result of information technologies; new medical technologies and treatments; and, the increasing emphasis on preventive, rather than reactive medicine.

Chapter two looks at why a public dialogue was seen as a valuable element in the study as a whole and at the governance and management of the dialogue. This includes an overview of oversight group members' expectations of the contribution that the dialogue would make to the study as a whole; the contribution made by the oversight group to the development of the project and members' participation in workshops; and, the contribution of the Academy staff team to the dialogue.

Chapter three In this chapter, looks at the dialogue events. The chapter draws primarily on data gathered on self-completion questionnaires filled out by public participants, healthcare professionals and observers. It includes observations made by the evaluator and concludes with a summary of what worked well and what worked less well during the workshops.

Chapter four looks at the immediate impacts of the dialogue project. Unfortunately, only one participant was available for an interview following the events: their comments are integrated with those of oversight group members and Academy staff. This chapter draws for its evidence on the interviews with oversight group members and the workshop and a subsequent meeting with staff at the Academy of Medical Sciences.



concludes this report by looking in detail at the fifth dialogue objective in more detail. Objective 5 concerns what the Academy of Medical Sciences might learn from this dialogue and what this means for how it integrates dialogue activities into future policy projects.

Chapter five looks at what the Academy team learned from the project and how it might use this learning to inform future dialogue projects. The data on which this chapter is based come from a workshop held with Academy staff involved with the project. The main focus of the workshop was to describe the project process as a whole, and identify places where it might be improved.

Chapter six answers the question: has the dialogue met its objectives? We look at each objective in turn. The assessment draws on the data gathered in interviews, in the staff workshop, from the participant feedback questionnaires and on the evaluator's own experience of designing and running dialogue and of evaluating them. It concludes by reflecting briefly on oversight group members' views on the value of including the public dialogue in this study.

A note on language

Quotes used in this report are taken verbatim from respondents' comments, without correction.

We use the terms "publics" and "public" interchangeably, to refer to the people whose role in the dialogue project was defined as either public or patient. The terms "publics" is used to emphasise that "the public" is not homogeneous.



Chapter 1: Context and scope

Summary

Introduction

In this chapter, we look at some of the wider themes raised during the evaluation interviews. These describe the context in which the study as a whole took place and were factors that arose explicitly or were implicit in public participants' discussions during the dialogue. These include issues of trust and conflicts of interest, changes in the information available to publics as a result of information technologies, new medical technologies and treatments and the increasing emphasis on preventive, rather than reactive medicine.

Trust

Public trust in institutions and professional expertise has been a hot topic for many years, though some evidence suggests some consistency across the years. For example, [Ipsos MORI's Veracity Index](#) looks at trust in different professions. Between 1993 and 2015, levels of trust in doctors' veracity increased from 84% to 89%. Over that same period, trust in the veracity of politicians, the government and journalists - who are amongst the sources and communicators of medical information for the public - was consistently low, generally hovering between 20% and 25%, but dropping at times to 10% (journalists). Trust in scientists was considerably higher, though not quite at the level of doctors: in 1993 it stood at 63%, rising to 83% by 2014, with a drop in 2015 to 79%.

Whilst not comparable with the Ipsos MORI findings, because of methodological differences, a [YouGov report](#) on research from 2013 found very low levels of trust in the pharmaceutical industry: 19% of respondents agreed the industry was 'trustworthy' and 18% agreed it has 'high ethical and moral standards'. Interestingly, though, a much higher proportion - 50% - thought that the industry 'is socially useful and improves people's lives'. This tension in views between the contribution big pharma makes to society and individuals and the level of trust placed in it was played out in the public dialogue and the themes of trust and trustworthiness recur throughout the final dialogue report.

Conflicts of interest

One of the main factors that appears to undermine trust in the pharmaceutical industry is the perception that the industry profit seeks, and that prescribing health care professionals are one of the channels through which it does this. A quote from the YouGov report suggests:

"Doctors should be forced to put up prominent notices in their practices if they have ANY links with pharmaceutical companies." Female, aged 64, East of England



The importance of public trust in sources of information about medical evidence and the potential for perceived or actual conflicts of interest to undermine trust was highlighted in discussions at a workshop held by the Academy as a part of its Communicating evidence about medicines work: “*conflicts of interests (both real and perceived) can have a significant impact on how trustworthy information is thought to be*”.⁴ As the [report on this workshop](#) notes, attitudes towards the source of medical evidence can affect perceptions of that information and how it is ‘*ultimately used in decision-making*’.⁵ One speaker at the workshop noted that the view that financial interests can undermine trust in evidence sources and raise questions of conflicts of interest does not apply to the pharmaceutical industry alone: “*NICE may be perceived to be a mechanism for saving money*”⁶, potentially raising public concerns about a conflict between clinical and financial need.

The Conflicts of Interest sub-project draws out the complexity involved in identifying what constitutes a conflict of interest, how to determine whether or not there is a conflict of interest in any given case, where in the system this happens, what its impact might be (for example, the potential for conflicts of interest to lead to biased research or reporting of medical trials), and what action to take. In her introduction to the workshop, Baroness O’Nora O’Neill highlighted too that managing conflicts arising from financial interests will not eliminate the sources of all bias in the production of medical evidence, pointing to researchers’ unconscious cognitive biases - or ‘wishful thinking’ - as a further source.

Sources of medical information

Communication technologies have given us access to a vast range of information of widely varying trustworthiness: some of this information might be underpinned by medical evidence, some is anecdotal or experiential and some is straightforwardly misleading or wrong. We are increasingly using the internet to carry out our own research on health conditions and medicines, to check, or marshal arguments against, advice given to us by healthcare professionals, to identify potential treatments, to source medicines outside formal prescribing channels and to discuss with others the efficacy or otherwise of the medicines we use. One interviewee for this evaluation described the effect of this as the “*democratisation of knowledge*”. This has been part of our changing relationships with healthcare professionals, giving us resources to challenge them and requiring them to take the time to explain why personal research findings might be misleading or why some treatments are not available. In other words, access to information has changed the nature of the decision-making process between patient and healthcare professional.

Changing approaches to decision-making

In parallel with our ability to gather information from multiple sources with ease, there has been a move over the past 20 - 30 years towards shared or informed decision-making in health policy

⁴ [Perspectives on 'Communicating evidence about medicines'](#) A report of a one-day workshop held by the Academy of Medical Sciences on 6 June 2016, p16

⁵ Ibid., p5

⁶ Ibid., p19



and practice.⁷ One person interviewed for this evaluation mapped out some of the questions that arise when seeking to define shared decision-making:

“Is it a decision which seeks to get some form of consensus or is it a decision which is about demarcating who we think is responsible for what?... Is it about the clinician trying to persuade their patient that the right thing to do would be to rely on this piece of evidence or are we saying that what we get out of it is that the clinician should say, well I think there’s a percentage chance that it will work with these side-effects and then hand the whole decision over to the patient to decide, maybe in conjunction with their social support networks, which might include user groups?” (OG member)

However defined, shared decision-making brings with it questions of the relationship between medical evidence and the personal values, beliefs and behaviours of both the patient *and* the healthcare professional. Healthcare professionals can be seen as the “objective” partner in the patient-doctor relationship and the values and beliefs they bring to the table discounted but, as noted above, we are all - researchers, healthcare professionals, publics and patients - subject to unconscious cognitive biases and wishful thinking. Healthcare professionals tread a difficult line, having to recognise their own values and how to use medical evidence in such a way that takes a patient’s own values into account whilst also providing the best possible care that they can. This difference between HCPs clarifying the import of medical evidence and understanding how this evidence plays into a patient’s values was noted by an oversight group members in an evaluation interview:

“there’s something around engaging with people to help them take informed decisions and not make what you might describe as reasoning mistakes, by which I mean if I believe I’m taking a decision on the basis of scientific evidence, but I misunderstand that, then I think that’s a reasoning mistake, but if on the other hand it doesn’t matter very much what the scientific evidence is because I want to prioritise something different then I’m not actually making a mistake, I’m just adopting different set of values.”

This interviewee’s view was that HCPs can legitimately intervene to correct errors in a patient’s reasoning about medical evidence, but that they should not seek to undermine the values on which a patient draws in making decisions about their own treatment.

⁷ Whilst these terms are sometimes used as if interchangeable, they are not: a [paper from the BMJ](#) provides a useful introduction, and pulls out the relationship between shared decision making, seen as a process, and concordance, seen as an outcome. For discussion of concordance and how it differs from associated concepts such as adherence and compliance, see Horne et al, *Concordance, adherence and compliance in medicine taking*, 2005, at http://www.netscc.ac.uk/hsdr/files/project/SDO_FR_08-1412-076_V01.pdf (accessed 14 July 2017)



Medical research and innovation

New preventive medicines, such as statins, and the potential of ongoing research in single-cell genomics and gene editing are just two ways in which medical research and innovation are changing the conditions it may be possible to treat and the outcomes of those conditions for patients. We are focusing increasingly on prevention (the debate on statins gives stark relief to some of the debates surrounding the use of preventive medicines) and big data are enabling us to move rapidly towards precision medicine. These changes will impact on what our health services can provide and on our expectations of it, and on the relationships on which effective delivery of these services depend. More philosophically, new health technologies raise questions about what it means to be human, and whether there are or should be limits to the nature and extent of interventions made in the name of healthcare.

As medicine becomes increasingly data driven, understanding what those data are telling us - what evidence they provide - becomes ever more critical. Whilst at present most medicines are prescribed in the absence of bio-data, precision medicine holds the promise of diagnostic tests that will allow healthcare professionals to predict and prevent conditions, and to tailor medicines to the needs of individual patients. Some patients' bio-data might suggest that no drug will be effective in treating their condition. The potential of precision (sometimes called stratified or personalised medicine) brings to the fore the relationship between patient and healthcare professional, and the ability of the latter to communicate evidence effectively and in an accessible way. As one oversight group member said:

“if we’re struggling now with conventional treatment, once these approaches become more generally available we will fail to adopt and use them effectively” (OG member)

‘Statin wars’

The Academy’s project on using medical evidence was directly prompted by the chief medical officer, Dame Sally Davies, who wrote to the Academy in June 2015 citing the need for an [“authoritative independent report looking at how society should judge the safety and efficacy of drugs as an intervention.”](#)

In the 18 months prior to this request, there was an ongoing and heated debate about the advantages and disadvantages of prescribing statins to people at low risk of heart disease. Hostilities broke out following the publication in the BMJ of two papers. *Should people at low risk of cardiovascular disease take a statin?*⁸, by John Abramson *et al* and *Saturated fat is not the major issue*,⁹ by Aseem Malhotra. The Abramson *et al* paper was prompted by an updated Cochrane review, in 2013, on the use of statins by people with low risk of cardiovascular disease. The authors suggested that under the proposed updated standards “no level of risk would

⁸ [Abramson John D, Rosenberg Harriet G, Jewell Nicholas, Wright James M. Should people at low risk of cardiovascular disease take a statin? BMJ2013; 347 :f6123](#): paywall. The paper can be read at: <https://www.ndph.ox.ac.uk/files/forms/abramson-paper.pdf/@@download>

⁹ [Malhotra Aseem. Saturated fat is not the major issue BMJ 2013; 347 :f6340](#): paywall. The paper can be read at: <https://www.ndph.ox.ac.uk/files/forms/malhotra-paper.pdf/@@download>



*preclude statin therapy, raising the question whether all people over the age of 50 should be treated.*¹⁰ They argued that there is no evidential basis to support the claim that the benefits of the extension of statins to use on low risk patients would outweigh the harms. The challenge to these two papers was led by Professor Rory Collins, who [argued publicly that they were flawed and misleading and had done great harm](#).

The initial dispute, its continuation and extensive coverage across the press and on social media raised questions about the nature of evidence - for example, the quality of evidence from observational studies was challenged, as was the reliability of patient reports of side effects. The reporting of side effects in RCTs was questioned. Accusations of conflicts of interest were made, there were suggestions that GPs' own interests informed their advice to patients and questions were asked about over-medication.

In June 2016, one month after Dame Sally Davies' letter to the Academy the media reported substantial reductions in the number of people taking statins, attributing this to the controversy and drawing on a study funded by the British Heart Foundation (BHF) and [published in the BMJ](#). In their conclusion to the BHF study, the authors note:

“This research highlights the potential for widely covered health stories in the media to have an effect on real world behaviour related to healthcare...”

¹⁰ Abramson John D, Rosenberg Harriet G, Jewell Nicholas, Wright James M. Should people at low risk of cardiovascular disease take a statin? *BMJ*2013; 347 :f6123, p1



Chapter 2. The dialogue as part of a wider study

Summary

Introduction

In this chapter, we look at why a public dialogue was seen as a valuable element in the study as a whole and at the governance and management of the dialogue. This includes an overview of oversight group members' expectations of the contribution that the dialogue would make to the study as a whole; the contribution made by the oversight group to the development of the project and members' participation in workshops; and, the contribution of the Academy staff team to the dialogue.

The quotes in this chapter are taken from interviews with oversight group members.

Why include a public dialogue in this project?

As should be evident from the discussion above, the context for the dialogue was ripe. The project as a whole met a specific request made at a high level, addressed live questions and added momentum and complemented ongoing work elsewhere in the health system - for example, on patient information provision and shared (or informed) decision-making. The oversight group chair, some OG members, the Academy team and the Academy as a whole had a commitment to public dialogue. This commitment, together with the thorough planning of the Academy team and the targeted and creative communication of the outputs would help to ensure that the dialogue had impact within the study as a whole and that this impact was reflected in wider dissemination of the work.

The decision to include a public dialogue strand in the medical evidence study was based on the recognition that specialists - researchers, academics, healthcare professionals, for example - bring a particular perspective to the questions being asked. In the absence of public voice, the report risked speaking to informed audiences only, and being seen as a voice from the ivory tower. This point was made by all those interviewed for this evaluation. The public dialogue provided insight into the reasoning processes used by the public in using medical evidence, the different ways in which evidence and values interact and some of the consequences of this interaction on levels of trust in different sources of medical information.

"I would regard any expert group trying to derive recommendations and advice as being ... as really needing to delve as much as possible into what public views might be about the things they're discussing."

"if we didn't have a public dialogue I think we could really be accused of being in an ivory tower, and indeed, I think it won't just give it external credibility, it may raise questions that we might not have anticipated or public concerns that we might not



think about so I think it could give genuine steer in direction of where things are going.”

Convening and managing an oversight group with the appropriate spread of knowledge and expertise required for this project could result in an unwieldy and divisive structure. However, the oversight group was, as one member put it “*working far better than I’d dared hope*”. The range of views and the technical and experiential knowledge brought to the Group was seen as “*about as diverse as it reasonably could be and still be effective*”.

There was some question about whether the balance on the Group might be skewed towards the “*somewhat detached business of evaluation of evidence or discussion of ethics rather than the functional aspects of what it feels like to have a conversation with a patient about medicine*”. For some members of the group, this was seen as something that could be addressed through the public dialogue:

“[we could] get the viewpoints of that constituency through another route rather than trying to have everything in the meeting, so I think that’s why the dialogue is quite a good way of doing that because it will ensure that we get some input from patient’s representatives and from jobbing GPs and so on”

Oversight group members’ expectations of the public dialogue

The OG members interviewed thought that the public dialogue would bring richness to their final report, enabling them to flesh out and illustrate technical or theoretical content with case studies and examples.

“there might be the possibility of using examples if people give their permission for that and where communication has been good and where it’s been bad and what sorts of information people find difficult or easy to understand and what matters to them.”

More broadly, OG members interviewed expected that the dialogue would give them some understanding of how effective this type of engagement is at bringing public perspectives to bear on the judgements of specialists, and of the guidelines and frameworks that might be appropriate when addressing similar questions in the future.

Increased acceptance of the need to allocate sufficient resource to educating or informing the public about medicines was seen as an important further outcome of the dialogue and of the project more widely.

Oversight group involvement in the dialogue process

The oversight group was involved in drafting and approving the final invitation to tender and in reviewing submitted proposals and selecting the delivery agency, Ipsos-MORI. They had some discussion of the dialogue during meetings, though this was limited. Academy staff played the leading role in working with Ipsos-MORI to develop and shape the project. Ipsos-MORI was not



invited to attend oversight group meetings, other than presenting their proposed approach, and the discussion following their presentation was very brief.

A delivery agency can gain huge value from hearing a dialogue topic being discussed by specialists, both narrowly, in terms of the framing of questions or checking where the priorities lie, and broadly, in terms of the wider contextual factors and other current and related work. Understanding an oversight group's expectations of a dialogue, its attitude towards the process, the language used to discuss the topic and the balance and weight of different debates can all inform the design of the dialogue process and stimulus materials, the selection of information to provide to participants and the choice of how best to present that information.

Dialogue design and delivery is invariably stronger and more able to meet the objectives set if the delivery team is viewed as a partner in the process. In this project, being part of these wider oversight group discussions would have helped Ipsos-MORI to get more from the initial stakeholder workshop and to draw more from it when designing the dialogue process. It might also have given them more clarity about the overriding question for the project.

“Is it a project around patient choice or about weighing up the pros and cons of evidence?”

Project management

The strong and very knowledgeable Academy team responsible for the project meant that some of the disadvantages to the delivery contractor of limited contact with the OG could be overcome. Initial weekly meetings helped to give the project a dynamic from the start and regular, though less frequent meetings throughout helped to maintain this. The pace slowed somewhat towards the conclusion of the project, in part because of changes to the Ipsos-MORI team, which slowed delivery of the final version, as new team members were not familiar with the project, and in part because the process of signing off the final dialogue report took some time.

The Academy team included policy, project management, communications and dialogue expertise. This breadth of knowledge and level of commitment throughout the project is noteworthy and unusual: more typically, senior colleagues will assign responsibility for ensuring delivery of a dialogue to more junior staff and take a definite step back. On this project, senior staff remained actively involved, giving up Saturdays and evenings to attend events, for example, and attending the final staff workshop with the evaluator. Their contribution to and clear enthusiasm for the dialogue project was a main factor in its overall success.



Chapter 3. Design and delivery

Summary

Introduction

In this chapter, we look at the dialogue events. The chapter draws primarily on data gathered on self-completion questionnaires filled out by public participants, healthcare professionals and observers. It includes observations made by the evaluator and concludes with a summary of what worked well and what worked less well during the workshops.

Dialogue events

The events are the most visible element of a dialogue project and their quality is a result of many factors. The importance of the wider context has been noted earlier. More focused factors include include the way in which the initial question is divided into manageable sub themes that are accessible to non-expert publics; how these sub-themes inform the process design and the choice and variety of stimulus materials and tools; the balance of educative, deliberative and reflective sessions; recruiters' success in achieving the desired range and number of participants; input from relevant specialists with the appropriate skills; the skill of lead and table facilitators; the transparency and openness of intent behind the dialogue, and the use of, and audience for the project outputs. The ambiance of the venue and the quality and quantity of refreshments are also important: dialogue participants often comment when these are not seen as up to scratch. The success of public dialogue events rests on combining these and more elements in the best interests of both the participating publics and stakeholders and of the commissioning body awaiting the results and hoping to have real impacts in the world.

The appropriate balance of these factors - which will differ from project to project - maximises the potential for publics to explore, discover and deliberate freely on a topic without feeling pressured to arrive at a 'right' answer. It gives them the confidence to ask questions, of specialists, facilitators and each other and to disagree with these same groups. It should provide them with the space to introduce themes and perspectives on a topic: this is difficult for a contractor, who has set objectives and often a tight schedule. It shouldn't collapse into question and answer sessions. Achieving the appropriate balance of very different factors means satisfying a project commissioner, public and stakeholder participants, the contractor's team, possibly an oversight or advisory group and, in the end, the audience assessing the credibility or otherwise of the process.

A detailed evaluation of all these factors would be hugely time consuming - and costly. In this chapter, we use feedback from those taking part in or observing events, observation data recorded by the evaluator during the event and interview data gathered gathered from oversight group members following events.



Overview of dialogue events

The project comprised both public and stakeholder events. The public strand consisted of face-to-face workshops in London and Leeds, held in June 2016. In both locations, the first day-long workshop was followed by an shorter, evening event, which reconvened the same participants. Thirty-two people attended the London workshops and thirty attended the Leeds workshops (two people did not return to the second Leeds event).

There were three elements in the stakeholder work. The first was a workshop with stakeholders, held in London, in April 2016. The purpose of this event was to help the Ipsos-MORI team scope the project more fully and gain insight into the range and diversity of current debates. The second element was a workshop with general practitioners (GPs), research nurses and pharmacists, held in Glasgow in May 2016. This workshop had two aims:

- I. To seek views on the question which the dialogue sought to answer: “how can we all use evidence to judge the potential benefits and harms of medical evidence?”; and
- II. To help the Ipsos MORI team devise the most effective way of bringing together the public and healthcare professionals (HCPs) in the main public dialogue events.

The third element ran before the reconvened dialogue events in London and Leeds. Healthcare professionals with a range of different roles spent three hours discussing the Academy’s question about using evidence. Following this, they joined the public participants for further discussion.

Public participants in the workshops were recruited to reflect the population of the two locations, with quota set for age, gender, life stages and sociodemographic characteristics. A subset of the public participants, described as “patients” was defined as people taking more than one (prescribed) medicine. They received a ‘thank you’ payment for their participation.

Two approaches were used to recruit healthcare professionals. Most were recruited through Ipsos MORI’s panel of GPs and consulted. An online screener was used to ensure a mix of gender and years of professional practice. Other HCPs, including hospital consultants, nurses, pharmacists and more GPs were recruited through Academy of Medical Sciences networks.

Participants’ views

Publics and patients

Ipsos-MORI recruited members of the general public and people with specific health conditions to take part in the workshops held in London and Leeds. The evaluation questionnaire did not distinguish between these two groups, so what follows includes the views of both of these constituencies.



Table 1. Evaluation questionnaires returned by public participants¹¹

Location	Workshop 1	Workshop 2
London	30	27
Leeds	27	28

Questionnaire feedback was overwhelmingly positive and participants' comments reinforced the quantitative data (see Appendix 1 for collated questionnaire data). The comments illustrate the range of different benefits participants attributed to their involvement in the workshops: some focused more strongly on the social aspects (*"meeting & discussing with all different people"*); some on what they learned - for example, *"[F]inding out about how research is carried out"*; some gained reassurance (*"Being reassured that drugs are screened & processed correctly before made public"*). A number of participants focused on the delivery of the workshop process and the facilitation: for example *"The information given, the delivery was clear and accessible for which could be a jargonated [sic] topic"* and *"It was told so I could understand"*.

The few negative comments related primarily to the length of the first Saturday workshops: these were more prevalent amongst Leeds participants. In London, some participants remarked on the absence of natural light: as noted earlier, the quality of a venue is important to participants.

At the close of the second, shorter workshop, participants were asked how their views had changed. Many comments relate to increased knowledge and understanding, with no specific details provided. Asked what, if anything, they would do differently as a result of taking part in the workshop, a number of people said they would ask their GPs more questions and for some, this was linked clearly to confidence gained increased understanding: *"I need to engage in a discussion with my GP in regards to my health & any treatment"* and *"I believed completely in my doctor and my mother. Now I can trust in myself to ask necessary and relevant questions to better understand what I'm doing to myself"*. Others points made include reading information on medicines with more care and making changes to diet.

Participants valued greatly being able to listen to and discuss the topic with health care professionals. Fifteen of the 22 responses to the open question *"what was the best thing about the event today"* mentioned the involvement of GPs, or HCPs or doctors.

Stakeholders

The first event run by Ipsos-MORI in this project was a stakeholder workshop in London. Ten evaluation questionnaires were returned and stakeholders' feedback was very positive (see Appendix 1 for collated data). In comments about what they had learned from the event, stakeholders pointed to a range of things, including how patients respond to information about medicines, how open discussions can be in public dialogues and the *"value of stories over facts"*

¹¹ A few respondents did not complete every question: the numbers provided are the total number of people returning a questionnaire.



in making the case". A number of participants commented on the value of the event as a networking opportunity.

The five people who responded to questions about the 'worst thing' about the event or about what might be improved in future suggested more time or a shorter agenda: one respondent felt that discussions were not always kept on focus. This perception may have been driven by the Ipsos-MORI's early uncertainty about the oversight group's priorities for their work and the main driver, noted earlier in this report.

Healthcare professionals

Healthcare professionals (HCP), including general practitioners, nurses, pharmacists and consultants with a number of different specialisms, took part in the project. In Glasgow, a workshop was held with HCP only. In London and Leeds, HCP joined the public participants during the second workshop. Recruitment of HCP was more challenging than recruitment of publics and patients, but the combined resources of the Academy's networks and Ipsos-MORI's contacts helped to ensure a good level of participation from a people with a range of specialisms and roles.

Glasgow

Sixteen evaluation questionnaires were returned, and feedback was strongly positive (see Appendix 1 for collated data).

HCP's comments on what they had learned from the workshop ranged from learning about public dialogue and the Academy of Medical Sciences; the different perspectives on the use of medical evidence and the cross-disciplinary and multi-level nature of the problem of how best to communicate medical evidence. One person noted that discussions such as this encourage reflection on one's own practice.

HCP participants valued the lively discussion ("*Good discussion and mix of opinion*") and having an opportunity both to air their own views and hear what others thought. Two people commented on the good facilitation.

London and Leeds

Seven evaluation questionnaires were returned from the London workshop and five from Leeds: these small numbers should be kept in mind when reading the summary on responses provided below.¹² Ipsos-MORI also amended the process of involving HCPs in the workshop discussions slightly, following the London event and discussion with the Academy of Medical Sciences and some initial feedback from the evaluator.

Feedback from HCP participants in London was positive. Five of the seven questionnaires returned included comments: these related primarily to the value of hearing from and talking with

¹² Two Leeds HCP completed a specific HCP evaluation questionnaire and the other three completed a 'public' questionnaire, so data cannot be collated across all five questionnaires.



patients. One respondent felt that better time management and more effective chairing and facilitating would improve future events.

Feedback was positive from the five Leeds HCPs who returned an evaluation questionnaire. Those who included comments in their feedback remarked on the value of open discussion and the interaction between the public and healthcare professionals. Asked what they learned from taking part in the event, one wrote “*patient’s expectations!*” and another noted that “*the ‘public’ is encouragingly interested & concerned about taking medicines and being involved in the process*”. Asked how their views had changed, one respondent wrote that more public engagement is needed: asked what they might do differently in future, one wrote “*Involving patients in decision-making*”.

Interview and observation data

The Sciencewise publication [Quality in Public Dialogue: A framework for assessing the quality of public dialogue](#) sets out a range of appraisal questions to ask of the delivery stage of a public dialogue. These questions cover a different aspects of dialogue delivery, including how well the project met its original objectives, its fairness and the absence of in-built bias, the appropriateness of the sample recruited to participate and onto the quality of facilitation, data collection, recording and analysis.

For any project, there is a balance between these different factors. In this section, we focus broadly, on what went well and what went less well, from the perspective of the oversight group members and Academy staff who both attended dialogue events and took part in this evaluation. In the interests of not identifying individuals, this section combines their observations with those of the evaluator. All those who contributed to the data used to inform this section are referred to as ‘observers’ and quotes are not attributed to an individual’s role on the project.

What worked well?

Views on the spread of participants in the dialogue workshops tended to differ according to the sub-group being observed. Some observers were surprised at the number of patients present but reflected on having listened to only one table session at any length. Others noted a breadth of participation.

“I thought they seemed to have got themselves a reasonable selection of people. I don’t know quite how they did it, but there was a certain, certainly a diversity of voices there.”

The facilitation at events was, overall, seen as friendly, welcoming, respectful and businesslike. The topic was complex and most public participants arrived in the room with little or no prior knowledge of what medical evidence is and how it is generated. In the absence of input from specialists at tables, facilitators did at times seek to explain technical matters. This can blur their role as process leads. However, for the most part, facilitators were able to re-direct such questions effectively. As noted earlier, some participants valued in particular the absence of jargon.



At some events - and notably in the Glasgow workshop for HCPs - more vocal participants were at times in danger of monopolising the discussion, but the skilled facilitator brought the group back together and invited contributions from others.

“I thought they did a fair job of drafting provocations whilst not leading the discussion too much, which is always difficult, I think - I want you to talk about this, but I want you to talk about it in your own way is a tricky one”

Given the complexity of the topic and the breadth of different areas to be covered, the discussions were, as a whole, rich and wide-ranging.

There was limited input from specialists - for example, in providing technical information. At the London event there was one impromptu contribution from an oversight group member. Prompted by questions arising in the discussions he had taken part in, he gave a short talk covering study design, the approaches taken by the pharmaceutical industry and the regulation of medical research. This was very positively received and the ability of the Ipsos-MORI team to incorporate this on-the-spot change demonstrates flexibility and quick thinking in response to the immediate demands of the day, though it did run slightly longer than scheduled.

Some of the materials used in the course of the dialogue were praised highly, particularly the pop-up pharmacy, designed by Ipsos-MORI's partner in this project, (INSERT NAME). This type of stimulus material enables participants some time-off from sitting round a table with a facilitator or listening to presentations from the front, adding variety and a less formal means to explore the topic. The pop-up pharmacy also has a use beyond the project: considering the legacy of stimulus materials in this way helps to ensure that the value extracted from the budget extends beyond the lifetime of the dialogue project itself. Other stimulus materials included two videos, one of which brought the voices of HCPs involved in the Glasgow workshop into the room; 'drug fact boxes', used to prompt discussion about the value to patients of different types of evidence; and pen portraits, used to prompt consideration of some of the difficult choices patients have to make about using medicines.

“I thought that the pop-up pharmacy thing worked really well.”

The Ipsos-MORI team learned from the first event in London, modifying the process for the event in Leeds to address some of the aspects that had worked less well - notably, the involvement of healthcare professionals. This is less straightforward than it might seem. It requires facilitators to carry out their core task of holding the group together and on topic, whilst also taking mental notes of how the design of the process is contributing to the ease of discussion, the quality of the information generated, the interaction between those involved and to modify their facilitation style appropriately, on the hoof. The facilitators' feedback, together with that of observers at events, is used in the decision about whether and how to change the process for subsequent events. Those attending both the London and Leeds events noted improvements in the latter, with the session involving HCPs seen as notably better.



What worked less well?

It is a truism of dialogue projects that there is never enough time to explore every topic in every session to the depth desired. Facilitators can do things to make the best use of the time that is available. Two points to note from this project are the importance of asking only one question at a time: there were occasions on which it was not clear what question was being posed, with facilitators tending to confuse participants with several different conjoined questions. This tends to lead first to participants needing to clarify what they have heard and second, to different participants hearing different questions - and responding to these. This can use up time but generates little valuable data. Asking an effective question means that everyone hears the same thing and more time can be given to exploring responses.

This is connected with a second observation, about effective probing questions. Again, time is always an issue here and facilitators are continually balancing their desire to dig deeper into participants' views against the clock ticking towards the next session. For the most part, facilitators' probes appear to have been effective: for example, participants were asked to explain the link between different comments they had made or asked a sub-question to encourage them to explore their views further. However, observers felt on occasion that *"we didn't get as far through some of the discussions as might have been ideal"* though they did recognise the time pressures placed on facilitators.

"The facilitator allowed them to say, well 'we went to Google' but it felt important to understand which things. For example, did they take the top search on google, did they look out user groups? I asked that question although I didn't get much further, so maybe the facilitator just judged that that wasn't going to get much further."

Specialist involvement, from people able to provide information on the more technical aspects of the topic, would have added a more deliberative quality to the process. Whilst oversight group members were on hand, they did not have a defined role as technical specialists. If they were present in this capacity, providing them with a briefing of how to play this role effectively and ensuring that public participants understood them as playing it would have been helpful.

Dialogue projects are always a journey, in which the interplay of information on a topic - in this case, medical evidence - with the values and views of publics participating moves the process forward, though not in a linear fashion. Having nominated specialists on hand to answer questions at the time they arise can add greatly to this process, minimising the pressure on facilitators to try to respond, keeping different roles clear and reducing the need to rely on pre-prepared materials.



“There were clearly some questions that the group had that needed people who were involved in the area to answer and the facilitators didn’t feel comfortable in answering all those questions but I don’t know whether that undermined or not the richness of the data that came out.”

“[T]here was obviously a bit of a thirst for knowledge - it would have been good to have someone built in.”

As noted above, the way in which HCPs were involved in the patient and public workshops changed between the London and Leeds event. In London, the interactive session between HCPs and publics and patients became a question and answer session, rather than a dialogue. The power dynamics round the table were at times stark, with HCPs tending to embrace their role as specialists and publics and patients becoming more passive.

Finally, as noted by some participants, the London venue lacked natural daylight. The acoustics were also difficult at times, particularly in small table discussions, because the room was slightly too small.



Figure 1. The pop-up pharmacy designed by



Chapter 4. Impact

Summary

Introduction

The impact of a dialogue project is a fundamental aspect of determining its overall success. In the absence of any impact on the topics being discussing there is little value in taking up the time and intellectual energy of those who take part. As with design and delivery, the impact of a project is a consequence of many factors, including the timing and relevance of the dialogue topic in relation to policy decisions or public debates; the profile and status of oversight group members and the commissioning organisation; how external audiences view the credibility, robustness and quality of the approach and delivery of events; the preparedness of the commissioning body to consider the dialogue outputs against other strands of enquiry and their ability to communicate and disseminate the findings widely, as well as to particular target audiences; the quality of these communications; the readiness, capacity and capability of those with a role to play in acting on the findings and - as ever - many other factors.

In this chapter, we look at the immediate impacts of the dialogue project. Unfortunately, only one participant was available for an interview following the events: their comments are integrated with those of oversight group members and Academy staff. This chapter draws for its evidence on the interviews with oversight group members and the workshop and a subsequent meeting with staff at the Academy of Medical Sciences.

All quotes in this chapter are from interviews with oversight group members.

What value did the public dialogue bring to the project as a whole?

All of the interviewees and workshop attendees felt that the dialogue brought value to the project as a whole. The final dialogue report is seen as well-evidenced and detailed and, interviewees felt, it will resonate with both professional and public audiences.

“I think it’s opened up a perspective which is outside the rather closed professional expertise that we have.”

“It has both validity, but it’s nuanced and important information.”

However, there were differences in views on the weight that can be attributed to the dialogue findings. Those who were more cautious tended to focus on what they saw as limitations in the methodology, which they felt arose either from the time and resource available for the dialogue or are inherent to dialogue as a process. These interviewees tended to characterise the public



dialogue as illustrative, rather than evidential, and as providing a lively and engaging confirmation of what is known already through more reliable data gathering processes.

“It’s mainly confirmed things - you have to be careful not to over imbue the public consultation with a degree of scientific quality that it can’t have because of the nature of the exercise.”

Others noted that the discussions on the oversight group about the status of the dialogue as evidence reflected wider debates:

“I think there’s a whole set of issues which are battles within the system that’s apparent, battles within the scientific community about qualitative versus quantitative and it could be that we’re caught up in that. So I think there’s an attempt in the process to identify a richer set of what counts as evidence but there’s quite a few people who think that there’s a hierarchy of evidence still, despite what the report seems to be trying to say.”

Despite having some caveats about the dialogue as evidence-producing, those who were more cautious felt that the dialogue had “enable[d] us to ask some very specific questions that are relevant to this particular review”, particularly when taken with other strands of evidence informing the study.

The status of the dialogue was debated by the oversight group in the course of the project. One of these debates, referred to in the evaluation interviews, concerned situational information. It was noted that this has a bearing on how people respond to and use medical evidence. Findings from the dialogue - a social process taking place in a hotel - cannot, it was argued, be used to say anything about how real people might respond. The latter are likely to have real and sometimes serious health conditions and their response to medical evidence takes place in the context of what is usually a private conversation with a healthcare professional.

The view that the report findings were a function of the dialogue process and hence without wider validity was not unanimous. The primary counter-response was pragmatic. It was acknowledged that people with a serious or life-threatening condition might well have different views on the topic to those taking part in the dialogue. Nonetheless, taken on its own terms and recognising that all research methods have their shortcomings and flaws, the dialogue was seen as having raised new questions, and to have provided insight into different forms of reasoning that specialists can often either not notice, discount or just ignore.

“My take on public dialogue generally is that it helps us realise that we’re asking not quite the right questions and to step back a bit and be aware of our own biases and blindspots. I think it’s been pretty helpful on that.”

“I think what we picked up in the public dialogue was that there was a slightly different type of reasoning process and that actually what we needed to do was stop thinking about it as if the users of medicines were lay professionals, but



actually start thinking that they have a different world view that they were operating on.”

A second response was that the public participants’ response to information provided in the course of the dialogue and, in particular, their enthusiasm for questioning the healthcare professionals at events, demonstrated a set of *“interests and behaviours that were not just created by the event, albeit they might have been shed light on by the event”*. This observer reflected on a dissonance, during the events themselves, between what people said and how they behaved. This point was made with particular reference to what was described as a paradoxical combination of expressed cynicism about healthcare services and pharmaceutical industry products, with a strong desire to use these products and to learn more about them and their production and use.

“There was a strong sense on the one hand of them thinking that they knew more about it than the doctors ...? And yet still valuing the discussion with the doctor, which I thought was interesting and perplexing.”

Interviewees’ discussions of the debates that took place in the oversight group suggest that the dialogue had value not just to the final project outputs, but that they helped to enrich thinking - or at least debate - on the group itself. This echoes a view of the dialogue itself, which suggests that its value lies in the thought processes of those involved, as much as in the final outputs, and it is the former that need to be interrogated.

The extent to which debates about the dialogue changed the views of oversight group members was questioned. It was suggested that people who found the dialogue insightful were likely to have had more positive attitudes towards this approach from the start, whilst those who questioned its value initially were not felt to have shifted their view.

“[It] stopped people thinking in terms of evidence being a single thing, which despite best efforts round the table, I think people still were on that sort of -- not quite tramlines, but relatively narrow perspective.”

“I think it’s reinforced some of the things that some people round the group were already very aware of but I’d be slightly doubtful whether anyone’s really moved that far, I suspect that people who have found it insightful and it’s influenced their thinking are probably people already in that sort of place already.”

For the most part, data gathered for this evaluation suggest the following: an oversight group with different views on the value of a dialogue, different views on the status of the evidence gathered, as discussed already in this section. Another perspective offered was that the Academy needs to develop its understanding of deliberative practice. Whilst doing this would not, necessarily, have any impact on the debates outlined here, it suggests that there might be value in the Academy taking stock of how it understands what it does in this field, how it describes this in commissioning projects that involve public dialogue and what its expectations are of any outputs.



"I don't think the Academy people are particularly sophisticated users of deliberative events, I've been to a few and I've heard people talk about what they're trying to get out of it and I'm not sure thatwhat it was hoping to get and therefore how to work out what the best methods were."

The dialogue report and its impact on the study report

Interviewees thought that the dialogue added power to the conclusions and recommendations of the final study report. The study report integrates the findings from the public dialogue with the wider evidence gathering strands, foregrounding the former at the start of each chapter. It is written in accessible and straightforward language and the design and layout enable the reader to skim the main points, or dive more deeply into the work. The dialogue was described as influential on both the report and the process of developing it. One interviewee felt that the study report echoed the dialogic process, presenting a conversation between patient and public views in the main narrative.

"Some of the perceptions we gained were instrumental in terms of the way we constructed and weighted the final report - incredibly important for the way the report came out."

To this extent, it *"puts a gauntlet down that the professions have to respond to"*, or risk being accused of ignoring public views.

"We've actually got the public dialogue speaking very loudly within the document."

"I thought that the way that the patients and public views fed into the final report was absolutely fantastic."

It is too soon after publication of the report to determine what concrete impacts the dialogue project might have on the topics it covered or whether the recommendations made are followed. Its initial impact was seen as influenced primarily by the quality and extent of the Academy's communication and dissemination activities. The high profile given to the public dialogue findings in the final report was seen, at least in part, as motivated by the Academy's recognition that public views would be attractive to mainstream media in particular, and hence contribute to its overall impact. The Academy's analysis of media coverage of the final report shows that, of 38 reviewed media mentions, in outlets as diverse as The European Pharmaceutical Review, BBC Nottingham, The Carer and the Financial Times, 37 included something that came out of the public dialogue.¹³

The Academy's early decision was that the project should *"harness and endorse what was beginning to gain traction already"*. Rather than seeking to *"invent lots of new stuff"*, the work was seen as a way of adding to, and perhaps accelerating - progress on topics already being discussed, such as patient information leaflets. So, whilst the media coverage of the report had great value, the real impact of the project as a whole is seen as being on more specialist

¹³ See Appendix xx for more detail of the Academy of Medical Science analysis of media coverage.



audiences. To this extent, the dialogue and the other strands of the work are strongly complementary and the integrated report presents this complementarity in a single document. The dialogue element helps to widen awareness of the work amongst a general audience whilst the other elements - seen by some as more credible - addresses the needs of specialists.

“One of the difficulties of a report like this is that you’re always trying to address two audiences: you’re addressing the audience of scientists and experts who are immersed in the topic, but also trying to say something to the public directly, and it’s that second purpose which is probably more strongly fitting with this particular exercise [the public dialogue].”



Chapter 5. Learning from the project

Summary

Introduction

In this chapter, we look at what the Academy team learned from the project and how it might use this learning to inform future dialogue projects. The data on which this chapter is based come from a workshop held with Academy staff involved with the project, held during development of the final study report but prior to the final Ipsos-MORI report being signed off. The main focus of the workshop was to describe the project process as a whole, and identify lessons for improving future projects including a public dialogue.

Planning and shaping

The organisational context in which public dialogue takes place is an important factor in its success, not just at the planning stages but throughout. Staff need sufficient time for what is often a very resource intensive process. Support from senior staff, who can champion dialogue internally and externally, is crucial. The Academy of Medical Sciences strategy includes a commitment to public dialogue. And, as was evident from their attendance at dialogue workshops, which took place out of normal working hours, this strategic commitment is embedded in practice. Director level staff bring substantial experience of dialogue too, having led similar projects on previous studies. This is perhaps particularly important when Academy staff are working with oversight groups in which some members are less convinced about the value of dialogue.

Staff attending the workshop mapped out the early stages of planning a dialogue, identifying where in the process improvements could be made and the specific value of some of the elements.

In the early planning stages, the following were seen as particularly important:

1. Some oversight group members having understanding/experience of public dialogue,
2. Allowing sufficient time at the first OG meeting for comprehensive discussion of the invitation to tender (ITT) for the dialogue.
3. Providing enough of the right type of information in briefing papers on dialogue and the Academy's previous work and successes: staff felt that, in this project, more might have been useful.
4. Presenting information on dialogue at the appropriate time: staff felt that this might have been done slightly too early on this project.

Figure 2 below shows the early stages of a project, as mapped out by staff at the workshop.



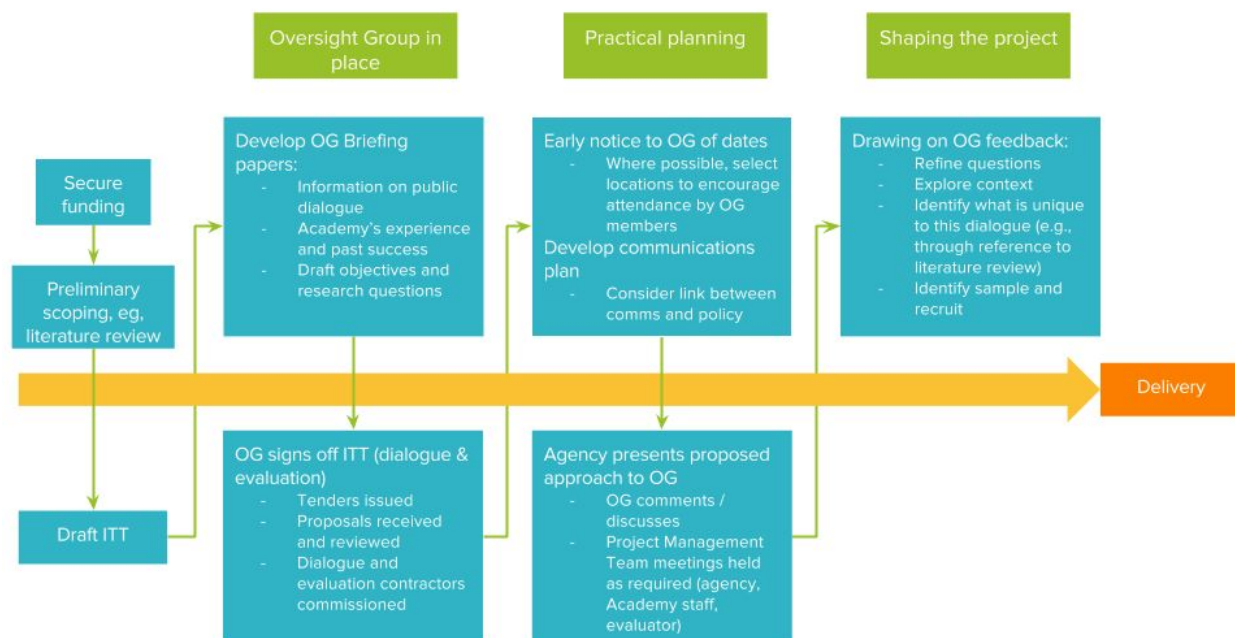


Figure 2. Planning and shaping the dialogue

Additional things to consider for future dialogue included:

1. Including a public dialogue 'champion' on oversight groups: on this project, the OG Chair played this role, but this might not always be possible in future projects.
2. Having a public dialogue sub-group, comprising OG members able to commit more time to this element of a project, and having the experience required:
 - Alternatively, have more regular OG meetings during the planning and shaping stages of a dialogue.
3. More involvement of the delivery agency in oversight group meetings:
 - The discussions can be very useful in helping the agency team to get under the skin of the topic, understand the language and nuances of current debates and gain direct insight into the range of views and expectations of OG members.
4. Reviewing the tendering process: discussions continue during the proposal writing stage and by the time an agency is appointed, requirements for the dialogue might have been modified:
 - Understanding proposals submitted as a starting point for a conversation about how best to shape the dialogue to meet the needs of a project, rather than as the recipe for delivery is important.
5. Giving more thought to the role of specialists (for example, healthcare professionals, scientists, other experts), and how different roles and levels of involvement can impact on the dialogue process.
6. Considering the data access implications of re-contacting public participants following project at an early stage, and what value re-contact might have.
7. Involving more Academy staff in future projects, to increase resource and widen understanding of dialogue.



Delivery and reporting

For the most part, Academy staff felt that both the delivery and reporting process were good. Those who had observed events found them useful and enjoyable: seeing the discussions covered in the final report gave them a life that they would not otherwise have and enabled the Academy to refer to particular conversations or points raised when reviewing a first draft of the dialogue report. The analysis process was inclusive, involving the whole Ipsos-MORI team, the Academy of Medical Science project manager and the evaluator. This helped to ensure that different perspectives were brought to bear on the data.

In the staff workshop, participants noted in particular:

1. Some surprise at public participants' limited understanding of science and of how evidence is generated: one staff member described this as an "eye opener".
2. The great value of the Action Report on the public dialogue, produced by the Academy.
3. Disappointment at the OG discussion on the public dialogue report, which was seen as both too short and, at some points, some OG members reverted to talking about the final report, which resulted in a generally confused conversation.
4. Lateness in delivery of the final report, principally as because of changes in the Ipsos-MORI team shortly after the events concluded.

Figure 3 below shows the delivery and reporting stages of a project, as mapped out by staff at the workshop.

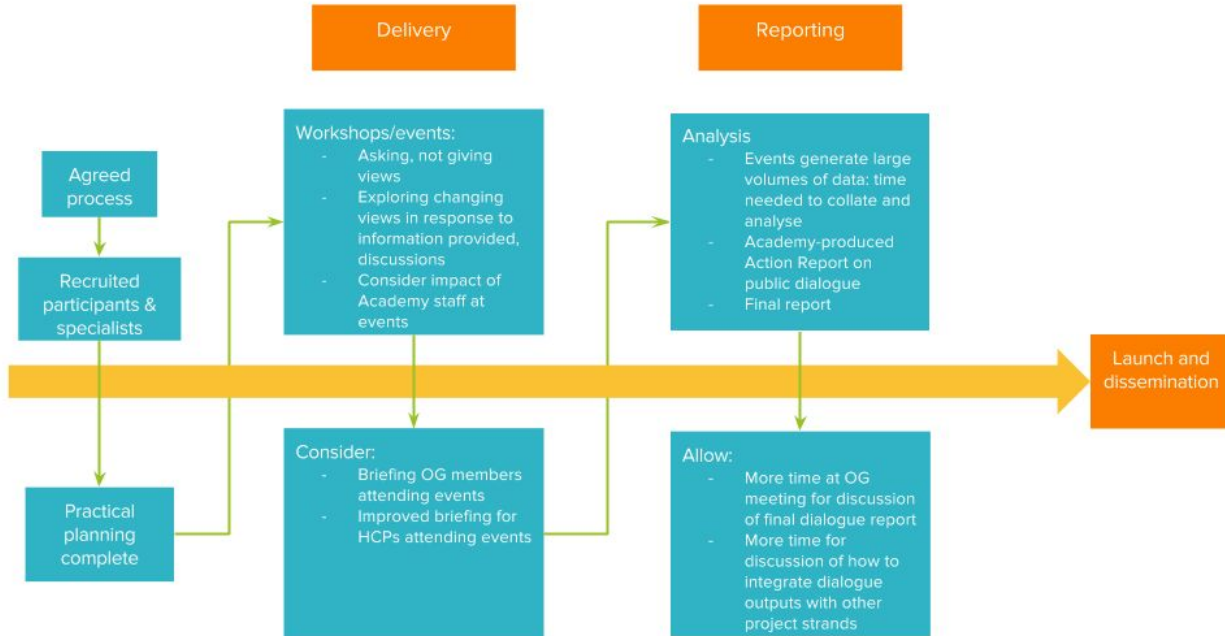


Figure 3. Delivery and reporting of the dialogue

One thing to consider for future dialogue was:



1. Having a public dialogue champion on the OG might help the group to focus its attention more fully to reviewing the final dialogue report, and ensure it receives sufficient time in the agenda: one OG member did take on this role to some extent, which was seen as helpful
 - At this stage of the process, which involves the OG as a whole making decisions about how best to use the findings from the dialogue in their full report, it is perhaps less appropriate to assign responsibility for this strand of the work to a sub-group

Communications and launch

The staff workshop took place when communication and dissemination plans were at an early stage, and a lot of work took place afterwards. Shortly prior to the launch event, held in June 2017, the Academy hired a new communications officer. This additional resource helped to ensure that the media coverage of the study and report was widespread, both in reach and range of publication.

Attention to communication started prior to the launch, however, with oversight group members visiting key stakeholders to discuss the early recommendations and the Chair of the group [blogging on the Academy's website](#). In July 2017, the Academy held an Implementation Workshop, to explore the implementation of the report's recommendations. This included discussion of the recommendation to continue dialogue and engagement with patients and the public. See [Appendix xx](#) for the Academy's list of media coverage mentioning the public dialogue.

The outputs from the project included a series of animations and a patient question leaflet, which drew on the study, and included a set of questions that patients might ask when visiting their HCP. These, together with the other outputs (with the exception of the final dialogue report) are held on the [Academy of Medical Sciences project mini-site](#).

In the staff workshop, the focus was primarily on plans for this stage of the project. These included:

1. A breakfast session for the dialogue community, to share learning from the project
2. Inclusion in the final study report of visuals developed from data gathered during the public dialogue.
3. How best to use the Pop-Up Pharmacy in future.
4. How best to report back to participants in the public dialogue - for example, by means of a summary of the full study report:
 - This conversation led to a discussion about the importance of considering these questions at the earliest stage of a project, to avoid difficulties in accessing participant data arising from data protection regulations.
5. Inviting participants to the launch event:
 - This was done, and some participants did attend.



Figure 4 below shows the launch and dissemination stages of a project, as mapped out by staff at the workshop.



Figure 4. Launch and dissemination of the final study report



Chapter 6. Conclusion

Summary

Introduction

In this chapter, we look briefly at question 1 of the six key questions evaluators are asked in Sciencewise guidance to address: has the dialogue met its objectives? We look at each objective in turn. The assessment draws on the data gathered in interviews, in the staff workshop, from the participant feedback questionnaires and on the evaluator's own experience of designing and running dialogue and of evaluating them. The chapter concludes with a list of the main lessons captured elsewhere in the report.

Has the dialogue met its objectives?

Objective 1. Provide opportunities for members of the public, patients, researchers and healthcare professionals to come together to discuss and explore their aspirations and concerns about the use of evidence to judge the benefits and harms of medicines

Observation and informal conversations with participants at the London event and observer reports on the mix of people at the Leeds event suggest that the events brought together a diverse and inclusive group of publics and patients. However, it is not possible to compare the actual sample with the sample agreed with the Academy: Ipsos-MORI was not able to provide demographic details of those attending events.

HCPs involved in the workshop in Scotland included nurses, GPs, pharmacists, and researchers. In the London and Leeds events, HCPs were primarily either GPs or consultants.

The design of the event included opportunities for patients and publics to interact with HCPs. However, as noted earlier in the report, and in London in particular, this interaction took the form of a question and answer session, rather than being deliberative.

Learning:

1. Carry out comprehensive individual briefings with specialists prior to events and provide briefing notes that explain and reinforce the most important features of their role.
2. Consider how power differentials and assumptions of role are likely to affect interactions between different participants in a dialogue event and seek to mitigate the impact of these through process design and clear advance briefings for specialists.



- This might be particularly important in the case of relationships between publics and HCPs, where the latter are recognised as “the experts” and the former as “the patients”: in these roles, there is a tendency for HCPs to adopt the role of information provider and for publics to act as questioners.¹⁴

Objective 1 was achieved.

Objective 2. Identify areas of consensus, disagreement and uncertainty.

The Ipsos-MORI report draws out the range of views expressed during the workshop, noting what publics and patients found complex or difficult. For example, in a section on responses to the pop-up pharmacy, the authors describe the range of concerns generated by information on the mock-up drug packages. They highlight where views were held in common across a large number of participants, and the issues on which there were disagreement.

The analysis session run by Ipsos-MORI brought together people with different perspectives, including table facilitators, the evaluator and the Academy project manager. This helped to ensure that some of the finer details of discussions at workshops were considered during the analysis and reflected in the report.

Objective 2 was achieved.

Objective 3. Where possible, explore public views on ideas emerging from the methods for evaluating evidence working group, conflicts of interest workshop and the communicating evidence workshop.

The timing of the Academy-run workshops precluded direct input to the dialogue of ideas from these events. However, these issues were explored during the public workshops in some depth. Themes discussed that related to communicating evidence included understanding where participants source information about medicines; how trustworthy the different sources are perceived to be; what type of information is sourced and the accessibility of available information. Stimulus material - notably, the drugs fact box, but also the pop-up pharmacy - enabled exploration of a particular approach to presenting medical evidence. Participants also discussed the role played by big pharma and the extent to which they felt there is a conflict of interest between the commercial requirement to maximise profit and the development of socially valuable and medically evidenced drugs.

Objective 3 was not achieved, but this did not appear to be to the detriment of the project. This is in part because, as discussed above, these issues were explored in the dialogue and also because the integration of findings from the dialogue into the full study report was thoughtful and the dialogue outputs were covered comprehensively.

¹⁴ A related point is made in the final chapter of the Ipsos-MORI report, which notes the “quite natural behavioural biases and heuristics that have developed in a healthcare system that takes so much of the responsibility away from the patient”. (p74)



Objective 4. To inform the development of the final report and any recommendations made by the oversight group

As discussed earlier in the report, views on the public dialogue differed across the oversight group. Group members were not equally convinced of its value or of the status of the outputs and whether or not they could be described as evidence.

Despite this, however, the final study report makes extensive use of the public dialogue findings, presenting them clearly and in conversation with the other strands of the project. Recommendation 12 of the report is to continue public and patient engagement.

Interviews carried out for this evaluation suggest that the visibility of the public dialogue findings in the final study report is the result of two main features of this project:

1. The Chair of the oversight group having a strong and vocal commitment to the public dialogue
2. The ongoing and dogged work of the Academy team.

Learning:

- In projects involving public dialogue, include oversight group members who are able to champion the work and support the Academy staff in making arguments for its value.

Objective 4 was achieved.

Objective 5. To enable the Academy to build on previous experience in public dialogue to inform policy advice and recommendations.

The Academy team involved in the dialogue attended a workshop to draw out the main lessons of the project (see chapter 5), and is clearly committed to applying what it has learned to future projects. There is an ambition to share knowledge within the Academy of the value and practical work involved in public dialogue projects. This is vital if the practice of dialogue is to be institutionally embedded. First because it ensures that staff turnover does not disrupt this practice and second because it protects the more knowledgeable members of staff from the need to be the only 'go to' person for information about dialogue, which can be onerous.

Objective 5 was achieved.

Concluding remarks

In summary, the main lessons from this dialogue are:

- Oversight groups have a valuable and critical role to play in a dialogue project such as this: their familiarity with dialogue as a process, their understanding of the status of the outputs, and their commitment to ensuring that dialogue findings inform the final report, including its recommendations, contribute significantly to its impact.
 - Including dialogue champions or establishing a sub group with responsibility for guiding the dialogue throughout will help to ensure that the OG contribution is not squeezed out by other pressing agenda items and give it the time it deserves.



- Providing a comprehensive briefing on public dialogue to OG members proved valuable, but thought needs to be given to when and how it is most appropriate to present this briefing.
- The value of a strong and informed staff team in the commissioning agency (in this case the Academy), should not be under-estimated:
 - Widening practical experience of dialogue within the Academy will help to ensure that their knowledge becomes embedded more widely.
- Ensure sufficient time is available following the tendering process and appointment of an agency to review their proposal and identify where discussions have moved on and whether the proposed approach needs revision.
- Involving the delivery agency in oversight group meetings helps them to become familiar with the topic, the language used to discuss it and the current debates, as well as with the expectations of the OG. Where possible, the delivery agency should attend OG meetings.
- Decide at an early stage in the process whether public participants are to be re-contacted following a project: this will allow time to consider data access and data protection.
- Visit venues beforehand, or ask for photographs, to make sure natural light is available: spending all day in a basement room is likely to be tiring for all those involved.
- Existing power dynamics between specialist and publics - for example, as in the “doctor/patient” relationships will be transferred into the dialogue context: process design should consider how these might be mitigated.
 - Comprehensive advance briefing sessions will help specialists to understand their role on the day.
- Provide briefing notes to event observers: their behaviour on the day can impact on participants and on the process as a whole (for example, taking notes of particular points, particularly if done on a mobile phone).
- Facilitators can make the most of the time available to them with clear questioning: they should ensure that they ask only one question at a time.

Finally, to pick up a point raised briefly in chapter 4, the Academy might consider carrying out a short review of current deliberative practice.

At the end of their interviews, oversight group members summarised their thoughts on the dialogue:

“This was a really good model and they should replicate it for other projects and other reports and other things that they're thinking about. I think it worked really really well.”

“It was exactly the right thing to do for a project of this nature and I hope it will be embraced on future projects.”

