Evaluation of the project:

"Mitochondria Replacement Consultation"

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Executive Summary

This document presents an evaluation of the *Mitochondria Replacement Consultation'* project, funded by the Human Fertilisation and Embryology Authority (HFEA) and Sciencewise[1]. It begins by describing the project objectives, and then goes on to describe the evaluation approach adopted. This approach is based upon the criterion of *translation quality*, which is concerned with the efficiency of information/ knowledge gathering, recording, transmission and interpretation between the various stages of the activity, and involving various parties (including the sponsors and stakeholders/participants), and its comprehensiveness and appropriateness. Use of the translation criterion by necessity requires the consideration of the sponsor objectives (in this case, both project objectives and Sciencewise principles of good practice in public dialogue), as these specify the initial information/knowledge targets for the project to achieve.

The original aims of the project, as stated in the Invitation to Tender for the evaluation, were to assist the HFEA in understanding:

- The ethical issues entailed in licensing techniques to avoid mitochondrial disease;
- How people comprehend ethical issues involved in techniques to avoid mitochondrial disease;
- The deliberative process people go through to form views on techniques to avoid mitochondrial disease;
- The difference between informed and uninformed views on techniques to avoid mitochondrial disease;
- Interested stakeholders' arguments for and against techniques to avoid mitochondrial disease.

The project was comprised of five discrete yet, in part, inter-linking strands – the first two best defined as engagement, the remaining three as consultation, approaches:

- Reconvened deliberative public workshops, occurring across 3 geographical locations (Newcastle, Cardiff and London) and involving approximately 30 participants in each workshop.
- Open consultation meetings involving interested stakeholders and members of the public across two locations: London (n= 53 participants) and Manchester (n= 39 participants)
- A public representative survey involving 979 public participants
- Patient focus group with individuals directly or indirectly affected by mitochondrial disease involving 7 participants (including 1 telephone interview)
- An open consultation questionnaire with interested stakeholders and members of the public – returning a response of 1,836

Figure 1 is a schematic representation of the HFEA project. This diagram highlights the inter-relation of project strands that took place.

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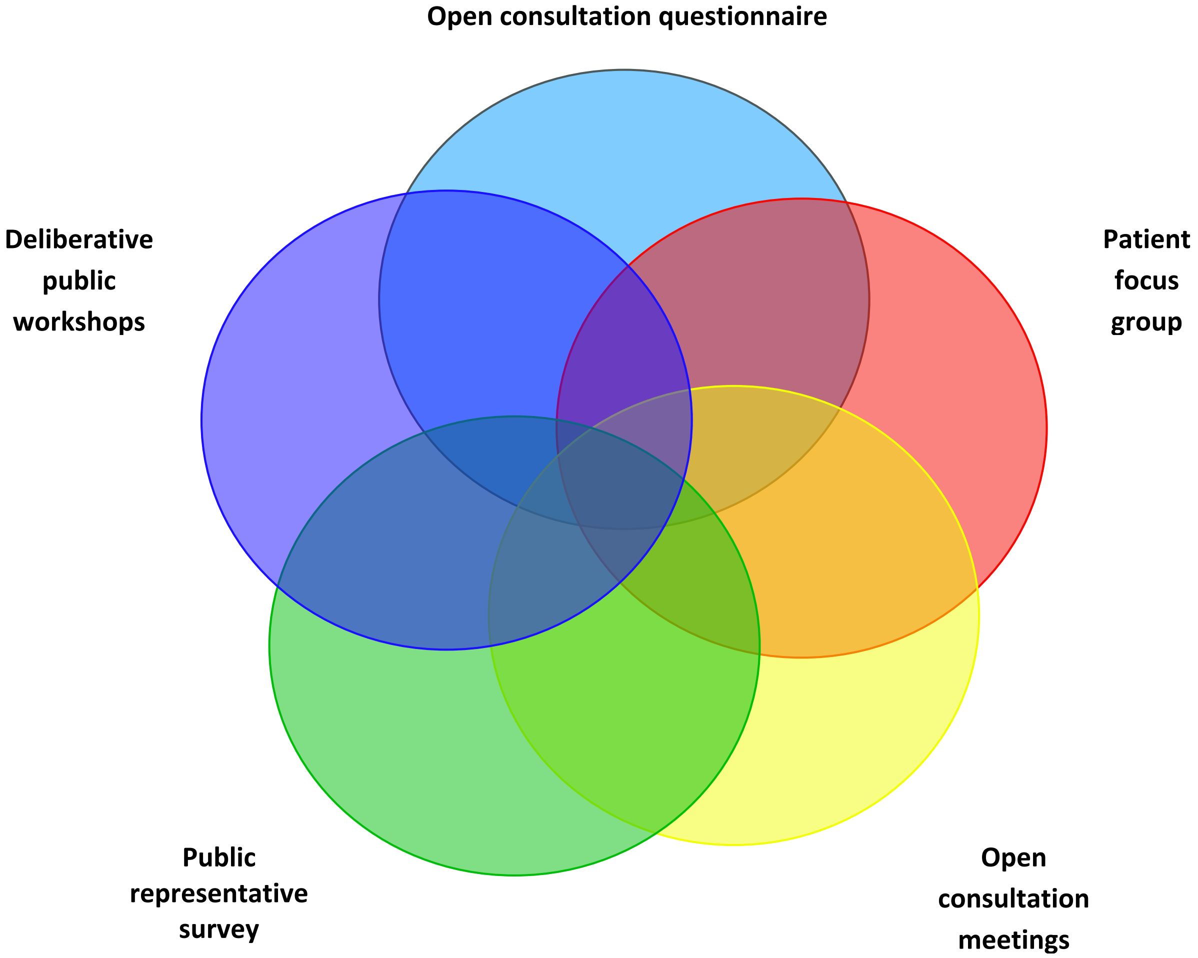
[1] Sciencewise is the UK's national centre for public dialogue in policy making involving science and technology issues.

Figure 1: A schematic representation of the project strands



The project also benefitted from an Oversight Group, membership of which was eclectic and comprising a heterogeneous assortment of prominent stakeholders recruited to provide substantive commentary, steer and advice on the multiple phases of the project. An expert group of stakeholders was also assembled in the early stages of the project – on a one-off basis – providing early guidance in the production of project tools/materials.

Our approach to evaluating the process and impact of the project was informed by a combination of four methods: a) participant questionnaires; b) observation of events according to an observation protocol; c) interviews with various participants involved in the process; d) documentary analysis. In turn,

- **Participant questionnaires:** we designed a bespoke questionnaire, distributed at both reconvened deliberative workshops and the open consultation meetings.
- **Observation of events**: we designed an observational protocol which was used to guide the formation of a critical record of deliberative workshops; open consultation meetings; oversight group meetings; an expert advisory group meeting; and the HFEA's open authority meeting.
- **Interviews with stakeholders**: we undertook interviews with key project stakeholders comprising members of the HFEA's project team; the contractor's project manager; members of the project oversight group; an Authority member; and a Sciencewise representative.
- **Documentary analysis:** we consulted a variety of written materials throughout the multiple stages of our evaluation ranging from stimulus materials incorporated into dialogue events, to the final report.

As the following chapters articulate in greater detail, our overall conclusion is that the project has been a success, not least when considered in the context of having:

- Produced a credible corpus of evidence facilitating, and what we can only infer as, enhancing and enriching, the capacity of government to make an informed decision based on public intervention/input regarding the regulation of techniques to avoid mitochondrial disease in clinical treatment.
- Successfully triangulated multiple research and consultation methods: as a basis for excellence in public engagement activity; in situating a viable platform for expert and non-expert interface; in raising awareness of the ethical, scientific and social implications of mitochondrial disease in the context of the techniques under discussion; as an experience in capacity building consolidating an investment in public engagement practice for the participating organisations and stakeholders; and in producing a corpus of evidence which espouses the attitudes, views and opinions of diverse public and stakeholder constituencies.

However it would seem that engagement strands of the project were stronger in design and execution, perhaps attracting greater investment, emphasis and focus, and concurrently advice, than the consultation elements. As the headline summary table reveals below, there were more frequent issues of information translation evidenced among consultation than engagement activities. Many of these issues in our opinion stem from a lack of precision and poise in the formation and sequencing of questions. There is also a suggestion that engagement and consultation strands might have more profitably interlinked and been executed in more co-informing ways.

Engagement strand	Headline summary
1. **Reconvened deliberative public workshops**	highly successful: well-facilitated, with good ‘information translation’ throughout
2. **Open consultation meetings**	largely successful in the sense of providing an open, unbiased presentation of the key issues to participants who were largely already engaged in the issue in some manner though compromised in part by issues of information translation

Consultation strand	Headline summary
3. **Public representative survey**	Relatively meaningful survey of public opinion, which might have benefitted from greater precision in terms of question formatting, sequencing etc.
4. **Open consultation questionnaire**	A comprehensive survey which managed to engage with a broad cross-section of stakeholders and public groups
5. **Focus group**	A significant aspect of the consultation which appeared somewhat limited in scope, if satisfactorily managed

Translation quality

In Table 2 we have summarised our assessment of the effectiveness of various stages of the project against our meta-criterion of translation quality.

Table 2: Summary of results of the assessment of translation quality

Stage	Source	Translation quality
Deliberative public workshops	Critical observations and participant questionnaire	Largely excellent
Open consultation meetings	Critical observations and participant questionnaire	Largely excellent
Public representative survey	Final report; oversight group and final report	Good
Patient focus groups	Final report	Adequate
Open consultation questionnaire	Final report; oversight group; email correspondence	Good
Oversight Group	Observations and email correspondence	Largely excellent
Authority Open Meeting	Observation	Largely excellent

To conclude, the evidence we have collected suggests that some aspects of the project were largely excellent in particular the impressive participation of a large number of high-profile people in diverse organisations. However, there were a number of shortcomings with respect to translation quality, as outlined in the table above.

Sciencewise evaluation questions

We were also specifically asked to assess whether the project had answered a number of ‘key questions’ that are standard to public dialogue projects funded by Sciencewise. These questions were:

- Has the dialogue met its objectives?
- Has the dialogue met (Sciencewise) standards of good practice?
- Have those involved been satisfied with the dialogue (of value to them)?
- What difference/impact has been made by the dialogue?
- What was the overall balance of costs and benefits for the dialogue?
- What are the lessons for the future? What worked well and less well, and more widely?

The second key question asks whether the exercise reflected good dialogue practice according to Sciencewise. The Sciencewise principles are (in summary):

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

To address these in turn:

- In terms of 'context' (as defined by Sciencewise), the project has been, bar initial 'teething issues' mainly related to embedding sound communication protocol and clear understanding of expectations between the HFEA as the contracting authority and the contractor consortium, arranged and implemented in such a way as to yield a fertile and dynamic dialogue ecosystem.
- Regarding 'scope', the project has covered a myriad of social, cultural, ethical and scientific concerns related to the treatments under scrutiny. Ostensibly, there might always be other areas for consideration, but certainly, we would suggest that the use of stimulus material was appropriate and in the main served to stimulate and facilitate conversation which tended to be successfully facilitated – given to freedom of expression among all participants, who were as much as time provided able to elicit opinions, ask questions and seek clarification. One significant aspect related to the scope of the project, focused on participants' attitudes to the dialogue process itself, with some sense of apathy manifest among members of the public dialogue workshop held in Cardiff. At root was a concern regarding the legitimacy of the dialogue as an exercise in genuine public consultation, where the results of the public being consulted would have a discernible impact on decision-making processes in policy contexts.
- Regarding 'delivery', the dialogue process should first be regarded as experimental – not so much in terms of the forms of dialogue processes used, but for the manner in which the technologies were successfully orchestrated together and in ways which were at least in part, cumulative and/or co-informing.
- Regarding 'impact', for the HFEA and the contractor, the project had reinforced and/or revitalized their understandings of the importance of public engagement of this kind and in thinking about how to manage a project of such detail and variety. The dialogue had in this way made a direct impression in terms of their professional thinking and methods/channels for delivery of project-work. A similar sense of the project increasing the validity of public engagement activity was reported among members of the oversight group. From our own evaluation perspective, the project provided a template for collaboration between multiple agencies, with distinct agendas.
- And regarding 'evaluation', the sponsors have clearly made efforts to ensure a thorough assessment has taken place by commissioning this independent evaluation.

Regarding the third Sciencewise overall evaluation question, 'satisfaction', the vast majority of public participants provided testimony which demonstrates they had enjoyed and taken some sense of personal fulfilment from the dialogue process. In a similar vein, our interviews with the full range of project contributors: the HFEA project team, OPM, Sciencewise, the oversight group – revealed a sense that the project had provided an enjoyable and satisfying experience.

Turning to whether the project will make a 'difference' (the fourth question) we can state, that the project has made a difference in terms of attitudes and praxis related specifically to public engagement in science and technology and of course as has more recently emerged, impact on Government decision-making (see bullet points above for more on impacts).

Regarding costs and benefits (the fifth question), it is always enormously difficult to determine the monetary value of an activity whose impacts are essentially diffuse and are in ways quite abstract – related more to behaviour or culture change than any monetary gain. Similarly, our interviews with stakeholders presented an opinion that any cost/benefit analysis would be largely predicated on the outcome of the decision of the Secretary of State for Health. Nevertheless, we might and should infer that the cost of public inclusion within policy-(in)forming discussion is negligible in the context of the potential benefit gained immediately by participating organisations and public groups – both proximal and distal. Furthermore associated costs are made almost an irrelevancy where activity which is focused on the preservation and perpetuation of social and scientific democracy: serves to enlarge the public sphere, increase the fluency and frequency of participatory deliberation in matters of ethical and scientific complexity, and provides an exemplar of the achievement and success of democratic science governance.

Regarding 'lessons' (the sixth question), these are discussed throughout this report.

Taken in its totality however, it is our summation that the project has contributed to the capacity, authority and credibility of the HFEA as an agency now able to report on the basis of a sound evidence base to the Secretary of State for Health on:

- ✓ The process of deliberation people use to form views on techniques to avoid mitochondrial disease
- ✓ The informed public views on these techniques
- ✓ Analysis of the ethical and regulatory issues involved

Concurrently the project has largely succeeded in capturing:

- ✓ The ethical issues entailed in licensing techniques to avoid mitochondrial disease;
- ✓ How people comprehend ethical issues involved in techniques to avoid mitochondrial disease;
- ✓ The deliberative process people go through to form views on techniques to avoid mitochondrial disease;
- ✓ The difference between informed and uninformed views on techniques to avoid mitochondrial disease;
- ✓ Interested stakeholders' arguments for and against techniques to avoid mitochondrial disease.

Furthermore the project has positively impacted on the individual and institutional perspectives of those involved in its implementation and steer, on the value of public engagement as a catalyst for scientific transparency, accountability and democratic decision-making for policy: regulatory and legislative purposes.

In responding to the underpinning Sciencewise dialogue evaluation criteria we are concurrently able to confirm that the project, as an exercise in public dialogue, has:

1. Met, if not exceeded, its objectives
2. Met standards of good practice (Sciencewise principles: context; scope; delivery; impact; evaluation)
3. Been a valuable and beneficial exercise for all those participating

4. Enjoyed successful governance and benefitted from effective working relations between the HFEA, the project Oversight Group, Sciencewise, the contractor and the evaluator.
5. Produced short-term impacts in terms of ameliorating and consolidating the value attributed to public engagement in policy contexts; longer-term impacts in embedding 'best-practice' in scientific transparency-making and the democratization of science governance. The project has also produced impacts directly related to new forms of regulation and legislation in respect of the two techniques. The Department of Health announced on 28th June 2013 a decision to publish draft regulations later in the year on innovative IVF techniques to help prevent serious mitochondrial diseases. This followed advice from the Human Fertilisation and Embryology Authority based on these public consultations activities supported by Sciencewise. This was preceded by a debate in parliament on 25th June when the Health Minister, Anna Soubry, mentioned the Sciencewise support and followed by a written ministerial statement on 1st July
6. Shown excellent value for money, in terms of a cost/benefit analysis. However we should note that this determination is an awkward calculus and ostensibly open to challenge. We make this determination on the basis of the high-esteem with which the consultation is held by all participating stakeholders and on the basis of its fulfilment and surpassing of many of its stated aims/objectives.
7. Provided numerous lessons not least in triangulating multiple methodologies.

As a caveat, it is necessary to mention that the strength of our conclusions is ostensibly greatest where we gained direct access as non-participating observers of 'live' public events, or where our own analysis is born of direct consultation with stakeholder groups. It occurs therefore that our commentary is more substantive when commentating on the dialogue, less on the consultation successes of the project, which we might differentiate as the deliberative (public workshops and open consultation meetings) and the survey (consultation questionnaire, public representative survey) modes, respectively. This is not however, to in anyway undermine the significance or merit of the survey work conducted by the contractor, only that in terms of evaluation, the latter is premised more or less solely on analysis of secondary materials i.e. final report, and is consequently constrained by being further distanced and less immersive than those accounts forged through direct and first-hand experience. Furthermore, there is ostensibly far greater depth and richness in the accounts garnered through bi- or multi-lateral dialogue than responses elicited in isolation and text; and thereafter more for an evaluator to comment on. In this context, and in the context of the project as an exercise in engaging publics in participatory deliberation, the greater accent of our analysis and reported findings, lie in our consideration of its energy and efforts in translating scientific and ethical complexity in ways conducive to meaningful, productive and ultimately, for the purpose of policy, influential dialogue across a broad spectrum of 'publics'.

We should also at this point make reference to what some have regarded as the competing and/or conflictual nature of project findings: while the dialogue strands of the project reported approval for legislative change supporting the techniques, aspects of the consultation strands, principally, the open consultation revealed slightly more people opposing than supporting the techniques, often arguing that their use would amount to inappropriate interference with the natural or spiritual aspect of reproduction, or that any artificial or in vitro manipulation of embryos is unethical. We would argue that the polarity of these two conclusions should be understood in reference to the method of their elicitation and/or context of production. Whilst we must interpret both conclusions as valid and legitimate responses to the over-arching question at hand, we must be cognisant of how the question is posed and worked through in each respective format. In the context of a poll, the potential for effective information translation is constrained by its proscriptive environment, where information is provided in a uni-directional and transmissional form, and where an opportunity to ask questions; to probe deeper; and for collective 'workshopping' and problematization and concurrently prolonged deliberation is for the most part, off-limits. Where the survey, as a method in canvassing opinion is inherently inclined to produce more reflex or instantaneous responses, engagement methods are conversely focused on lengthier, more challenging, penetrative and complex negotiations of attitudes, values and behaviours. Dialogue thus produces conclusions which, we would argue, are the culmination of more committed, immersive and involved interface with a series of questions; where also, respondents own questions may be (re)posed – where clarification is sought; and where the contribution of multiple and heterogeneous parties, with potentially diverse ethical/social/cultural frameworks enrich the quality of the decision-making process and the robustness of final answers. It is in this context that the meshing and weighting of the various competing data sets ought to be understood and for the readership of the HFEA's recommendations, interpreted.

1. Introduction: the 'Mitochondria Replacement Consultation' project and its assessment

The Government asked the Human Fertilisation and Embryology Authority (HFEA: the UK's independent regulator of assisted reproduction and research involving human embryos) to engage with the public on emerging – but currently prohibited - IVF techniques designed to prevent mitochondrial disease. The stated purpose of the consequent project was to "review the ethical, social and regulatory issues, if techniques to avoid mitochondrial disease were to be permitted in clinical treatment, and to contribute to HFEA advice to the Secretary of State for Health." In particular, the HFEA wished to report on: "The process of deliberation people use to form views on techniques to avoid mitochondrial disease; the informed public views on these techniques; analysis of the ethical and regulatory issues involved".

The HFEA – in collaboration with co-funder and advisor, the Sciencewise[2] Expert Resource Centre (Sciencewise) – determined that the project would:

- Have two strands: the first involving a *public dialogue process* and the second a *broader public consultation exercise*.
- Be aimed at assisting the HFEA in understanding: a) the ethical issues entailed in licensing techniques to avoid mitochondrial disease; b) how people comprehend ethical issues involved in techniques to avoid mitochondrial disease; c) the deliberative process people go through to form views on techniques to avoid mitochondrial disease; d) the difference between informed and uninformed views on techniques to avoid mitochondrial disease; e) interested stakeholders' arguments for and against techniques to avoid mitochondrial disease.
- Be managed by the HFEA and advised by an *independent Oversight Group* (OG) on the *content* and *process* of the dialogue.
- Follow the government's approach to public dialogue on science and technology (as described in *Sciencewise Guiding Principles*[3]).
- Involve the following elements:
  a) Testing – to discover what special interest groups and lay members of the public see as the ethical and social issues involved in techniques to avoid mitochondrial disease, and how their views may be influenced by different framings of the issues;
  b) Qualitative research – to discover what people think when they have the opportunity to deliberate on the issues, and discover how their views are formed and what influences them;
  c) Quantitative research – to discover what randomly-selected lay members of the public think of the acceptability of techniques to avoid mitochondrial disease, in the absence of detailed information or deliberation, and which key pieces of information or argument have the most influence on their views;

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[2] The Sciencewise programme is funded by the Department for Business, Innovation and Skills (BIS). Sciencewise aims to improve policy making involving science and technology across Government by increasing the effectiveness with which public dialogue is used, and encouraging its wider use where appropriate to ensure public views are considered as part of the evidence base. It provides a wide range of information, advice, guidance and support services aimed at policy makers and all the different stakeholders involved in science and technology policy making, including the public. Sciencewise also provides co-funding to Government departments and agencies to develop and commission public dialogue activities. www.sciencewise-erc.org.uk

[3] The Government's Approach to Public Dialogue on Science and Technology. Available at http://www.sciencewise-erc.org.uk/cms/guiding-principles/

d) Web-based public consultation – giving interested stakeholders and self-selecting members of the public the opportunity to express their views, and;
e) Public consultation events – allowing interested stakeholders and self-selecting members of the public the opportunity to voice and debate their views.

It was stipulated that all elements of the project would be informed by the testing phase, and that the findings from the qualitative and quantitative phases would be used in the design of the materials and process for the wider consultation elements.

An evaluation was thence sought to consider *the project as a whole*, covering both the process of the project (e.g. what was done and how well did that work?) and the impacts of the project (e.g. what difference did the project make?). The objectives for the evaluation were stated to be:

- To provide an independent assessment of the project's credibility, effectiveness and success against its objectives;
- To contribute to the overall Sciencewise aim of creating excellence in public dialogue to inspire and inform better policy making in science and technology (through gathering and presenting objective and robust evidence of the activities, achievements and impacts of the overall project, and identifying lessons from practice to support Sciencewise work in capacity building across Government, and the development of good practice in public dialogue);
- To identify how well the project has worked in order to identify clear lessons to feed into future HFEA engagement work;
- To identify how well the different elements of the project have interacted with each other and contributed to the overall aims of the HFEA review
- The impact of the project on the HFEA’s advice to Government.

Additionally it was noted that the evaluation should include consideration of seven key questions:

- Has the project met its objectives?
- Has the project met standards of good practice (Sciencewise principles)?
- Have those involved been satisfied with the project (value to them)?
- How successful has the governance of the project been, including the role of the Oversight Group, the HFEA and the Sciencewise support role?
- What difference/impact has the project made?
- What was the balance overall of the costs and benefits of the project?
- What are the lessons for the future (what worked well and less well, and more widely)?

This report describes the evaluation of the ‘Mitochondria Replacement Consultation’ project. The next section describes the precise approach taken in this evaluation, in which the various aims and questions above are incorporated.

2. The nature of the evaluation

Just as there are uncertainties as to how best to conduct stakeholder engagement processes, there are uncertainties as to how best to evaluate these. One major area of debate in this area is whether it is possible to derive a generic evaluation framework that can be used to evaluate *all* instances of stakeholder engagement, or whether each instance of engagement is so specific in its aims that this is infeasible. Rowe and Frewer (2004) have argued for the former: they contest that, though the aims of any particular event might differ at one level, they are similar at a higher level. That is, all instances of 'stakeholder engagement', and its relative, 'public engagement', seek to achieve similar goals, and that similarity is part of what defines them. Various authors have sought, then, to stipulate what those common goals might be, defining 'evaluation criteria' against which the success or otherwise of any event might be judged.

This is not the place to go into a review of different evaluative frameworks (although there are relatively few *coherent* examples of these). One framework, elaborated in Horlick-Jones, Rowe and Walls (2007), sees engagement events (whether involving stakeholders or the public) as *information systems*. They conceptualise the fundamental purpose of engagement as the efficient elicitation and combination of information from all parties involved to produce a comprehensive and accurate output (which may then be used by the event's 'sponsors' in whichever way they please). Thus, they suggest that one way to view the effectiveness of *any* engagement event is according to the efficiency with which information enters, travels through, and emerges from it, and their concern is with recording barriers – structural, behavioural (etc.) – that can lead to 'information loss' (where some of the entirety of *theoretically relevant* information is omitted, corrupted, mistranslated). The theoretically relevant information comprises all that which might have a bearing on understanding (and potentially resolving) the issue about which the engagement is concerned. The emphasis on identifying places of information loss (poor '*information translation'*) emerges because the full nature of theoretically relevant information cannot practically be known (i.e. and hence, they do not suggest attempting to detail it – for to detail it would essentially be to solve the problem that the engagement is addressing).

This theoretical system assumes that efficient information translation relies upon the presence in an engagement event of all appropriate stakeholders (who may or may not include the public) that potentially have information relevant to the problem. It requires a clear presentation of the problem, and all associated facts, to those participants from the 'sponsors' (or the 'organisers', when these are contractors for the sponsors). It requires the availability of a suitable environment in which dialogue can take place between the relevant stakeholders (suitable in terms of physical and time resources, and in terms of efficient process management, such as by one or more facilitators). And it requires suitable methods and resources to record, combine, analyse and report the output from the dialogue between the stakeholders. Furthermore, the translation framework can be extended to the larger project in which any particular engagement is included, in which case it compels interest in the way in which results are disseminated and used. Thus, if results go no further than a final report, and have no further influence upon events, one might consider information loss to be total, and the project to be a failure.

Horlick-Jones *et al* have subsequently referred to information translation as a *meta-criterion* (though *higher-order criterion* is perhaps a more appropriate expression), in the sense that it essentially subsumes many of the other 'normative' criteria found in the literature. For example, it subsumes most of the nine evaluation criteria from Rowe and Frewer (2000) (one of the best-known evaluation frameworks): thus, 'task definition' (one of the nine criteria) is important for participants to ensure that they understand and are focussed on the appropriate question; 'transparency' is important in many ways, throughout the system, as any instance of non-transparency clearly represents a case in which information that is relevant is being filtered from the process; 'resource efficiency' is important, because an absence of time or physical resources would entail the premature completion of an event before all information, options (etc.) could be explored; 'structured decision making' relates to the need to ensure the accurate and structured recording and combination of participant information; 'representativeness' is critical, because the absence of a relevant party ensures that their theoretically relevant information is absent the process… and so on. In short, Horlick-Jones et al (2007) (within this paper, and in a number of subsequent evaluations), have argued that most normative criteria can be easily transformed into criteria that concern *information*.

Having made an argument for the existence and use of 'normative criteria', applicable to the evaluation of all engagement events, it is still worth considering other, more precise criteria related to a particular event being evaluated – if only for pragmatic and political reasons. Horlick-Jones and colleagues (e.g. Horlick-Jones *et al*, 2006), in evaluating a major UK public engagement initiative ('GM Nation?'), therefore used three sets of evaluation criteria. These comprised a) a set of normative criteria (those of Rowe and Frewer, 2000), b) the sponsor's criteria, as indicated by their stated aims, and c) a set of criteria inferred from the participants' answers to a number of open questions in a participant questionnaire. Clearly, it is important to take into account a sponsor's specific aims when conducting an evaluation (even though Horlick-Jones *et al* might argue that these are often easily translatable into criteria concerning information). But why – some might ask – are these not sufficient? The reason for this is essentially two-fold. First, sponsors' criteria are often badly phrased and vague (and arguably, this may even be deliberate), making evaluation difficult, as the more vague a concept, the more difficult it is to operationalize. A typical aim, for example, might be 'to engage with the public'. In this case, the sponsors might argue that any event held in which 20 people 'came through the door' would equate to 'engaging' with 'the public' and hence be a 'success'. Clearly, this is an unsatisfactory and trite way to evaluate success. Second, although the sponsors might themselves be content with a limited evaluation, it is important to recognise that most significant events will have many interested *observers* – from other stakeholder groups, political parties, nations, academia, and so on – who would *not* be satisfied with such an evaluation, and would contest it. Using a 'normative' evaluation, conducted by an independent evaluator, can overcome some of these problems (but not all). On top of this, evaluating the success of an event according to those who took part would seem equally pertinent – not least for the participants themselves, who might not understand the language of the normative evaluation. This justifies the consideration of implicit participant evaluation criteria.

In the current evaluation, this three-legged scheme is the one that is adopted. That is, the main part of the evaluation will be based upon the normative criterion of 'information translation', while the various declared aims of the appropriate parties (HFEA and Sciencewise) will be considered as a second (and third?) perspective, and the views of various public participants involved in the different events will act as a third (and fourth and fifth…?) perspective. Table 1 shows our interpretation of the various criteria from the different parties – some of which have been noted in section 1.

Table 1: A summary of the various aims of the project (criteria against which 'success' is determined)

Normative	**Project aims (HFEA)**	**Sciencewise - 7 evaluation questions**	**Other stakeholders**
Information translation efficiency (TRANSLATION)	a) The ethical issues entailed in licensing techniques to avoid mitochondrial disease (INTENT) b) How people comprehend ethical issues involved in techniques to avoid mitochondrial disease (INTENT)	Has the project met its objectives? (see left) Has the project met standards of good practice (Sciencewise principles)? (TRANSLATION +) Have those involved been satisfied with the project (value to them)?	Public – inferred from questionnaire responses (SATISFACTION +) 'Other' stakeholders – inferred from interview responses (SATISFACTION +)

	c) The deliberative process people go through to form views on techniques to avoid mitochondrial disease (INTENT) d) The difference between informed and uninformed views on techniques to avoid mitochondrial disease (INTENT) e) Interested stakeholders' arguments for and against techniques to avoid mitochondrial disease (INTENT)	(SATISFACTION) How successful has the governance of the project been, including the role of the Oversight Group, the HFEA and the Sciencewise support role? (MANAGEMENT) What difference/impact has the project made? (TRANSLATION: IMPACT) What was the balance overall of the costs and benefits of the project? (COST-BENEFIT) What are the lessons for the future (what *worked well* and *less well*, and more widely)? (TRANSLATION)	

There are a number of points to note about this table. First, most of the 'sponsor' (HFEA) objectives are instrumental, or 'aims of intent'. Establishing the achievement or otherwise of these is relatively straightforward: the expected elements will have either happened or not. One of these objectives, however, speaks to the translation issue, and hence it has been classified as both an 'intent' and 'translation' criterion (the name of the relevant criteria being given in brackets). There is more overlap evident in the table: one of the other Sciencewise questions is actually a rather broad one, which in itself appears to involve a variety of sub-criteria, which is 'has the project met good practice according to Sciencewise principles'. In the Table this has been nominated 'Translation +', since many of these 'sub-criteria' are related to good translation in a similar way that, it was previously argued, many of the criteria in the literature also relate to this concept, while others may be worth considering as extras (hence the '+' sign). The criterion of 'satisfaction' is also replicated: it is a specific Sciencewise question, but it is also a criterion of other stakeholders (the public and 'others'). This criterion is labelled 'Satisfaction +' in the fourth column, because satisfaction is likely to be just one element of how others judge the quality of this project, and those other elements (criteria) cannot be known until those others are asked (and their criteria are inferred, from questionnaire responses and interviews). Two other criteria are evident in the 'Sciencewise 7' that appear to be somewhat independent, labelled here as 'governance' and 'cost-benefit'. This evaluation will speak to all of these criteria in the end; the main purpose of Table 1 is to clarify these criteria and to emphasize that there is considerable overlap between the different sets.

Beyond the evaluation *per se*, and as noted in the first section, the evaluation has its own objectives that need to be met, including: providing an independent assessment of the project's credibility, effectiveness and success against its objectives; contributing to the Sciencewise aim of creating excellence in public dialogue to inspire and inform better policy making in science and technology; identifying how well the project has worked in order to identify clear lessons to feed into future HFEA engagement work; identifying how well the different elements of the project have interacted with each other and contributed to the overall aims of the HFEA review; considering the impact of the project on the HFEA's advice to Government. Conducting and presenting the evaluation well, in an appropriate way (e.g. clearly specifying recommendations), should enable these objectives to be achieved. However, whether the evaluation is seen to successfully achieve these objectives will be for the evaluation funders (and perhaps other external observers) to decide.

The evaluation relies upon several information sources: a) documentary evidence (e.g. details of the project sponsors' criteria may be ascertained from project documents); b) participant questionnaires (given to those attending events); c) evaluator observation of various public events, using an 'observation protocol' to record pertinent issues related to information translation, and d) interviews with relevant parties, to fill in missing gaps. Copies of the observation protocol and the participant questionnaire can be found in Annex A and B respectively.

Finally, a brief word is needed here on how to *translate* this report. What this report is *not* intended to be is a critical piece, attempting to apportion *blame* for *failures*. Instead it should be seen as providing a more cautious critique, indicating areas where there may be issues (such as potential mistranslation), and providing lessons for alternative ways of proceeding in future projects, involving similar elements, to this. Thus, in places, graphs are presented showing comparisons of responses from participants to various events: the reader should not over-interpret these graphs, or assume that, because participants rated one event 'higher' than another with respect to a certain question, that this means that the former event is necessarily 'better' than the latter. *Context* is important to recognise, and differences in the contexts of the events might explain (less favourable) outcomes as much as differences in the relative structures of events or the ways in which they have been implemented. For example, something as simple as bad weather can completely undermine an event, while the nature of participants – their range and personalities – can have a major impact on how an event proceeds (in addition to aspects that are under the control of the organisers, such as the quality of facilitation). Furthermore, the reader needs to recognise that participants are not omniscient or always fair in their assessments. People can be short-sighted, opinionated, distracted, ignorant, political, and even just unpleasant. Thus, to read too much into negative responses from one or two individuals would be inappropriate. However, when a number of participants come up with similar arguments, then it is as least worth considering what their issues are and what might be done about them. And finally, as noted at the start of this section, there is no universal acceptance as to the best and only way to evaluate engagement, and as such, it would be wrong to adopt one scheme and be overly dogmatic about the outcomes from using it. In short, this report should rather be seen as a story, perhaps, in places, a cautionary tale, that discusses and analyses the Mitochondrial Disease project, hopefully in a thought-provoking way from which some lessons might be learned.

Evaluation of the evaluation activity

Finally, we turn to 'self-evaluation' of the evaluation work itself. As will be mentioned elsewhere in this report, not least in our commentary of the informational and communicative successes of the project, our capacity to engage in various evaluation activity, freely and without hindrance, was greatly aided by the overall openness and willingness of the delivery team: the HFEA and OPM, to engage with the evaluation process positively, proactively and without hesitation. Where evaluators are on occasion unnecessarily or unreasonably viewed suspiciously and as obstructive and/or intrusive to the dialogue process, by delivery contractors or those contracted to implement dialogue, the experience of this project demonstrated that evaluators and facilitators can work harmoniously and synchronously – yet importantly without losing credibility and authority born of impartiality and critical distance - in the delivery of a dialogue project's objectives. We explicitly stated from the beginning of the dialogue, and repeatedly thereafter throughout, that our modus operandi as an evaluation team centred not as is often erroneously perceived, in an assessment of the contractor's and commissioning body's performance but in identifying, as a process of formative learning, evidence from evaluation research on the value and merits in the different methodologies deployed throughout the project; and the extent to which these combined to fulfil the project's remit. This distinction we believe is an important feature in building a relationship of 'trust' with contractors, facilitating open lines of communication and access for data collection. In this way and in this instance, our evaluation was built in as a continuous and ubiquitous, yet tacit aspect of the dialogue process. The agreeability of the dialogue delivery contractor to our evaluation also meant, that we were able more fluently, openly and less hesitantly than might usually be the case, to research, review and comment directly on aspects of the project, particularly those events we attended and observed.

The ease with which we were able to undertake evaluation was also significantly boosted by the spirit of co-operation and collegiality shown not only by the contractor but all those within and/or associated with the HFEA project team, members of Sciencewise, who as we have come to know are integral to scaffolding the evaluation process, and the wider project community, especially those among the oversight group who were not only interested in what we were doing as evaluators but receptive and obliging in our requests to draw on their own experiences of the project. Considering the populousness of project members, the wealth of materials (and their inherent complexity) and the complexity in their co-ordination, we have been especially impressed by the general mood of good-will and the helpfulness of project members in supporting and in some ways enhancing our efforts in evaluation.

Where we might have had slight initial concerns regards the multi-modality of the dialogue process and potential difficulties in accessing various data, these were largely deflated, where information flow and messaging was regular, consistent and transparent. In terms of our being able to directly comment on the various processes of the dialogue, the only aspect to which our account is a little more cursory is that pertaining to survey work- for which our commentary might only be fairly generic.

Conducting evaluations of public engagement projects is always potentially difficult, and it is necessary for us to elaborate on the nature of the difficulties we faced in order to assess the limitations that these have placed upon our analysis. There are essentially two classes of evaluation difficulties; those related to the theoretical question of 'what makes an engagement exercise/project good or effective', and those related to the data collection and interpretation and other practical aspects of the implementation of the evaluation. Elsewhere we have discussed these difficulties in detail (Rowe *et al*, 2005).

We now turn to the objectives for our evaluation work that were specified at the outset. Those objectives were to:

- Provide an independent assessment of the project's credibility, effectiveness and success against its deliverables and objectives, throughout and at the end of the project.
- Contribute to the overall Sciencewise aim of creating excellence in public dialogue to inspire and inform better policy-making in science and technology through
  - gathering and presenting objective and robust evidence of the activities, achievements and impacts of the overall project
  - identifying lessons from practice to support Sciencewise work in capacity building across Government, and the development of good practice in public dialogue.
- Contribute to the development of mechanisms throughout the project to aid reflection and learning in relation to the project's own engagement processes.
- Gather and present objective and robust evidence of activities, achievements and impacts to support Sciencewise work in increasing wider understanding and awareness of the value of this work.
- Identify lessons for the project to support Sciencewise work in capacity-building across Government, and the development of future good practice.

This report concludes our independent review of the HFEA dialogue project's credibility, effectiveness and success. The work we conducted has been rigorous and evidence-based and informed by personal attendance by at least one of the evaluation team at every 'public' facing/involving event.

On the whole, we have been largely impressed in the manner of the project's conceptual and applied approach to public dialogue in a particularly complex and sensitive scientific arena. Aside from the kinds of teething problems to be associated and anticipated with any dialogue project, most of all, one of this scale, we are able to report according to Sciencewise's own overarching evaluation framework and our own meta-criterion of 'translation', that the various dialogue components were individually successful and collectively more so, in substantiating a series of recommendations, the basis for which has been shown to be equitable, fair, impartial, transparent and with sufficient opportunity for broad contribution/meaningful involvement, time for deliberation, reflection and advisement.

Finally, we turn to the topic of capacity-building and future good practice. This dialogue project ought to be seen we believe, certainly by way of comparison to previous or on-going public dialogues in emergent or controversial science for policy purposes in UK and perhaps even European contexts, as an exemplar of good practice. Whilst we would advocate certain refinements to the process for future use and/or replication, the project has been successful in translating information and knowledge in ways that has stimulated a range of valuable debate; an efficacious and potentially sustainable expert/public interface consolidating and ostensibly strengthening a 'science and society' nexus/democratic science governance; and in mobilising public opinion for the explicit purpose of the social and ethical problematization of Pro-Nuclear Transfer (PNT) and Maternal Spindle Transfer (MST) and by extension the presentation of this to government.

As an exercise in professional capacity building, we have identified that all those involved in the dialogue process have in many ways benefitted: in improving attitudes, ideas, and strategic approaches for working collaboratively, creatively and imaginatively in public engagement contexts.

A sense prevalent throughout the project was the extent to which all those involved went the 'extra-mile' in ensuring the dialogue's success. In this context, we believe that all those externally contracted went considerably beyond their remit in terms of a time and labour commitment. From the perspective of our own evaluation we have significantly exceeded what we had previously allocated as a time contribution to the project – in what has ultimately transpired to be nearly thrice that of our initial projection. Whilst work of this kind nearly always results in an under-estimation of time, a slightly more generous allocation of budget for evaluation, not least in the context of dialogue which is 'pan-UK' would we believe augment the capacity of future evaluators in responding to contracts of this nature.

Evaluation Timeline

An evaluation timeline responded to the agreed timeline for project deliverables and complemented many of the activities specified within the project brief.

Evaluation Activity	**Date of Activity /Evaluator present: Watermeyer (RW), Rowe (GR)**
Inception meeting	21st May 2012 (RW & GR)
Development of participant questionnaire and evaluation materials for public workshops and consultation meetings	June-July 2012
Attendance at deliberative public workshops	July 2012
Attendance at open consultation meetings	13th November (London); 22nd November (Manchester)
Attendance at oversight group meetings	20th August 2012; 30th January 2013;
Evaluators/HFEA teleconference	Fortnightly throughout duration of project (RW)
Interim evaluation meeting with HFEA and Sciencewise	14th December 2012 attended by RW, GR, HFEA and Sciencewise
Attendance at HFEA Authority Open Meeting	20th March 2013 (RW)
Interviewing of key project stakeholders	25th March 2013- 10th April 2013 (RW)
Delivery of draft evaluation report	23rd April 2013
Attendance at project 'wash-up' meeting	26th April 2013
Delivery of final report	Tbc

3. Deliberative Public Workshops

a) Description of the Workshop Process

This chapter provides an evaluation of the 'deliberative public workshop' component of the project. This element comprised six events: two run in each of three locations: London, Cardiff and Newcastle. The first set of events were largely concerned with providing participants the rudimentary knowledge needed to engage with the mitochondrial disease issue; the second (reconvened with the same participants from the first series) were concerned with debating the social and ethical aspects of this issue. These five-hour events involved the use of videos; presentations from experts; facilitated small group discussions among tables of participants (chosen to be broadly representative of the population); plenary discussions, and some voting processes (in the second series of events). The evaluation is based *primarily* on an analysis of *participant responses to an evaluation questionnaire*, completed by all participants at the end of the workshops, complemented with additional insights provided from our own observations (following a structured observation protocol and informal conversations with the commissioning authority and contractor).

Results suggest these events were highly successful: they were well-facilitated, with good 'information translation' throughout. Participants were highly engaged, took the task seriously, and were satisfied with the events. Negatives were rather minimal (mostly concerning the lunch!); nevertheless, a few recommendations for improvements are made at the conclusion to this chapter.

As noted, there were a total of six workshops, all of which were run on Saturdays (as convenient for working participants). The first series of three were run in July, 2012: London and Cardiff were run on the same day, while an event was run in Newcastle a week later. The second series was run two weeks after the first – thus, the London and Cardiff workshops were 'reconvened' on the same day (with the same participants who had previously attended them) and the Newcastle event was reconvened a week later.

Thirty participants were recruited for each event (in anticipation that some would not turn up: between 26 and 29 actually turned up for both sessions at the different workshops). Participants were recruited to be broadly representative of the population, in terms of sex, age, ethnicity and socio-economic group. Two other criteria were used to help select participants: the first was according to the number of children they had, and the second was whether they occasionally or never followed science issues in the media. Religion was not a selection criterion *per se*.

The first series of workshops was largely concerned with providing the scientific background to the issue of mitochondrial disease and novel potential treatments, that is, to provide participants with the knowledge necessary to allow them to consider the merits or otherwise of the proposed innovations. Participants attending the workshops were seated at three tables (pre-designated). Some of the events during the day (which went from 10a.m. to 3p.m.) occurred in plenary, though many took place in three smaller groups (of up to 10). Each table had a professional facilitator. Information was provided to participants through a number of means: handouts, posters, videos, and through presentations and responses from a scientific expert.

The first workshops essentially followed a similar schedule. Between 9.30 and 10.00, participants arrived, registered, and completed an initial questionnaire. Coffee was available. Participants then sat around three tables. The events began with plenary presentations, during which there were introductions to the parties involved; the aims of the day were described; and 'housekeeping' issues were raised (by the organisers). The context of the issue was then presented by an HFEA representative.

There then followed a short session in which the groups at separate tables discussed their initial views and knowledge. This session varied in specifics according to event and facilitator (all tables having one facilitator). In some cases, some sort of introductory task took place (e.g. individuals being asked to chat with their neighbour and then introduce them to the group), while in others the facilitator stood beside a flip chart and simply asked the group what they knew about assisted reproduction. A coffee break followed.

There were then four more elements to the rest of the morning: first, there was a small group 'discovery session' called by the organisers 'bluff your way in biology'. During this, each participant was given 15-20 minutes to answer a short quiz on the basic biology associated with mitochondrial replacement, drawing on information posters that were placed around the room (there were also handouts, and the expert was around as a resource to be quizzed). Participants were split into small groups for this. The answers subsequently emerged on a handout and were discussed at the tables.

Next, there was a video describing mitochondrial disease. This used cartoon-style animation to give a simple explanation of the problem and potential solutions (this was shown more than once at one event). The experts (scientist and HFEA person) were available to answer any questions following the video, and there were slides showing the two different proposed options for dealing with mitochondrial disease. Some group discussion followed on mitochondrial disease and the ways of avoiding/dealing with it. Finally, there was a plenary round-up, and this was then followed by lunch.

The afternoon session started with an expert question-and-answer session or the re-showing of the video (at one event). There were table discussions focussing on 'What is new about these techniques? How are they different from assisted reproduction techniques that are currently permitted?' There were then further table discussions on the issues: 'What have you discovered today and what more do you need to know? What will you tell your friends and family about today?' Questions were collected for the expert to answer.

There was then a plenary summing up of the day and looking forward to the next event, with the issue of ethics introduced. The organisers' report suggests that there was also a quiz and a chance to win a box of chocolates, although we did not observe this take place. Finally, the event closed; participants were thanked, and asked to complete a short evaluation questionnaire. After this, as they were leaving, participants got 'thank you' payments. Close time was officially 3p.m.

The second series of events was somewhat different in emphasis. These broadly followed a similar process (some events were conducted in plenary, some conducted at three facilitated tables with up to 10 persons at each – generally in the same groups as before, though some effort was made in one of the events to mix the groups up). Again, an HFEA representative was present to cover regulatory (etc.) issues, as was an expert. On this occasion, however, the experts involved were bioethicists, since the workshops now moved on (after initial re-familiarisation of participants with the science) to discuss the ethical issues of allowing (or not) the novel treatments being discussed. Additionally during these workshops, participants' views on the desirability of allowing the new approaches were collected at three times during the day.

More precisely, these workshops proceeded as follows. There was again a half-hour period at the start, to allow for arrivals, registration and completion of an ethics questionnaire. Coffee was available. The day started at about 10a.m. with introductions again by the organisers and the HFEA, a description of the agenda, ground rules, and so on. In at least one event there was then a brief episode in which people were asked to chat to their neighbour about what they remembered from last time. To recap the issues, the video from the first event was shown again. Now in small groups, participants were asked to introduce themselves (and in Newcastle say what they would be doing today if they weren't here). They were then given spots (stickers) and asked to put these on a 10-point scale on a poster on a wall noting where they were on the question of the new techniques. This was the first of three voting occasions. There was some slight divergence then between the events, with those at the London event discussing 'five key questions from last time', at others, participants discussed their views (ratings). And then there was a second video, showing the issue from a sufferer's perspective (an emotive video), followed by more discussion at the tables (more or less, depending on the event).

After a coffee break, the rest of the morning session involved small table discussions on identifying social and ethical issues. The groups considered scenarios and deliberated on two specific issues: DNA from 3 people, and the issues of germ line therapy. After discussing the first scenario (with again, variation between events – from group discussions in general, to discussions in pairs, writing on post-its), there was another video – this about the nature of 'identity'. This was followed by a presentation by the bioethicist. Discussion followed in groups and plenary (a chance for the ethicist to answer questions).

Then the groups considered the second ('germline') scenario. A second round of voting (using the stickers) took place. Then there was another segment of video, in which various experts discussed the germline problem, and then the bioethicist spoke again. (The sequence of these events did vary somewhat across the three events.)

After a lunch break, there was more video (a third part showing experts' views, and then all the previous parts together). More questions were taken from the audience, and answered by the ethicist. Next there were small table discussions reviewing the issues, and thinking about 'What's most important?' and further 'What messages do we want to give to the Secretaries of State?' A third round of voting took place, with discussions in the groups. The event then ended with a plenary debriefing, discussing what would be done with the participants' contributions and how they might stay involved. Once more, then event ended with the distribution of the participant evaluation questionnaire and the honorarium payment.

In all workshops, over both series, tape recorders were used to collect data from the different tables. The facilitators also collected a lot of information on participant views, questions, and concerns, from post-its (on which participants were asked to write down any questions they had through the day) and information written on flip charts. A questionnaire was also used to collect the views of participants at the end of the second of the workshops.

Aside from the questionnaire data from the evaluation questionnaires, other data was collected by evaluators (one evaluator having attended each of the six events), following an observation protocol. The purpose of the observation was to assess the conduct and process of the event, and in particular, to look at process issues about which the participants might not be aware and on which they would not be able to comment. The results from the observations are not recorded in detail here, but important insights are raised when appropriate. Copies of the questionnaire and observation protocol are provided in Appendix A and B.

b) The Results

i) Information provision

The questions in the questionnaire were largely designed to address the quality of 'information translation' (see the introductory chapter), as well as to address issues to do with participant satisfaction and event impact.

The idea of good translation is that all relevant information is efficiently, fully, and in a non-biased way, presented to participants, who are then given ample opportunity to reflect upon and explore that information, and then to express their opinions, again, in a full and non-biased way (with such information then being comprehensively recorded, coded, and summarised by the event organisers). The first set of questions therefore asked participants whether they believed that they had received important information of various types, such as 'what the workshop was about' (question 2), whether the aims were clearly specified (question 3), whether it was made clear to participants as to why they were invited (question 4), and whether it had been made clear how the participants in general were selected (question 5), and relatedly, whether participants believed that those attending were appropriate for the event (question 6). All of these are important issues, in the sense of providing participants with information about their roles and what is expected of them.

The answers to the five questions noted are shown in Tables 1-5. Along with each Table, Figures show the relative responses from across the workshops on the two occasions, as well as summary pie charts showing the combined total 'scores'. There are three figures with each table, i.e. Figures 1a, 1b and 1c are associated with Table 1; Figures 2a, 2b and 2c are associated with Table 2, and so on. These first tables show that there was good agreement by participants across the three venues and over the two different series of events that they were clear as to the purpose of the workshops (80-90% agreed). By and large the Newcastle event was scored best in this regards (over 90%), while around 20% of respondents to the two London and Cardiff event indicated that were in some way unsure about the workshop's purpose (see Table 1).

Participants were in strong agreement (over 90%) that the aims of the workshops were clearly specified at the different events (see Table 2) – indeed, only two participants from Cardiff (in each of the events) claimed to be unsure of aims.

In terms of why participants had been invited, again, there was general agreement that this had been made clear to participants. Table 3 shows that between 80-90 percent (and up to 96% in the case of the second Newcastle event) agreed that this was so. As previously, there was slightly more disagreement on this issue from Cardiff participants.

In terms of how participants for the events were selected, there was somewhat less agreement than for the previous issues. Table 4 shows that approximately one third of participants were unclear about the selection process, or claimed categorically not to know how participants were selected (while about two-thirds were more positive). However, around 80% of Newcastle participants claimed that they were aware of the selection process (while the percentage in the Cardiff event increased on the second round). It is possible that the improvements may have followed from this issue being made more explicit by the event organisers following commentary on this in an evaluation précis that was circulated between the London/Cardiff and Newcastle events (recall that the Newcastle event took place a week after the other two) – perhaps indicating a positive role of formative evaluation.

Finally here, there was large agreement that the participants to these events were somehow 'appropriate' (see Table 5) – with full, or near full agreement from participants attending the Cardiff and London events (from both occasions), although with slightly less agreement from those attending the Newcastle events. Indeed, the relevant question (6) asked participants to say whether there were any notable absences. From the first workshop, one Newcastle participant wondered whether there ought to have been a religious representative, and another wondered about whether there ought to have been present someone who knew about (had) the disease. Three Cardiff participants also noted the possibility of having a clinician, a government representative, and 'people of a scientific background'. From the second event, although there was only a slightly greater uncertainty about this issue expressed in response to the closed question, participants indicated a greater number of others who might be included. This included people from a religious background (suggested by two from Cardiff), having a scientist/medic at the second session (noted by two from Cardiff, one from London and one from Newcastle), having someone with the disease in their family (one from London), having someone who had been adopted (one from London), having a decision maker (one from Newcastle), having 'Chinese and… other ethnic minorities' (one from Newcastle), and having 'more younger women' (one from London). Naturally, logistics limits the number of possible participants, although the absence of a suitable scientist (as well as bioethicist) in the second set of workshops was something that was noted as a slight difficulty (by the observers) – and this will be discussed later.

In summary, participants appeared to be quite clear on the purpose of the events and their place within these, suggesting good information translation. The issue of how they were selected was perhaps less clear, although observers at the events did notice this issue receiving special attention in the first Newcastle event following the discussion of this in the interim evaluation précis. These findings were generally fairly consistent across the three different locations and across the two different events within each of these.

Table 1: Participant responses from the three workshop locations, over the two events, to Question 2: Was it clear from the information you were sent before the event what the workshop would be about?

1st Workshop	London (N=30)	Cardiff (N=30)	Newcastle(N=29)	Total (N=89)
Yes	24 (80.0%)	24 (80.0%)	27 (93.1%)	75 (84.3%)
Unsure	5 (16.7%)	1 (3.3%)	1 (3.4%)	7 (7.9%)
No	1 (3.3%)	5 (16.7%)	1 (3.4%)	7 (7.9%)

2nd Workshop	London (N=26)	Cardiff (N=29)	Newcastle(N=28)	Total (N=83)
Yes	21 (80.8%)	24 (82.8%)	27 (96.4%)	72 (86.7%)
Unsure	2 (7.7%)	3 (10.3%)	0 (0.0%)	5 (6.0%)
No	3 (11.5%)	2 (6.9%)	1 (3.6%)	6 (7.2%)

Figure 1a: Answers to Question 2 "was it clear... what the workshop would be about?"

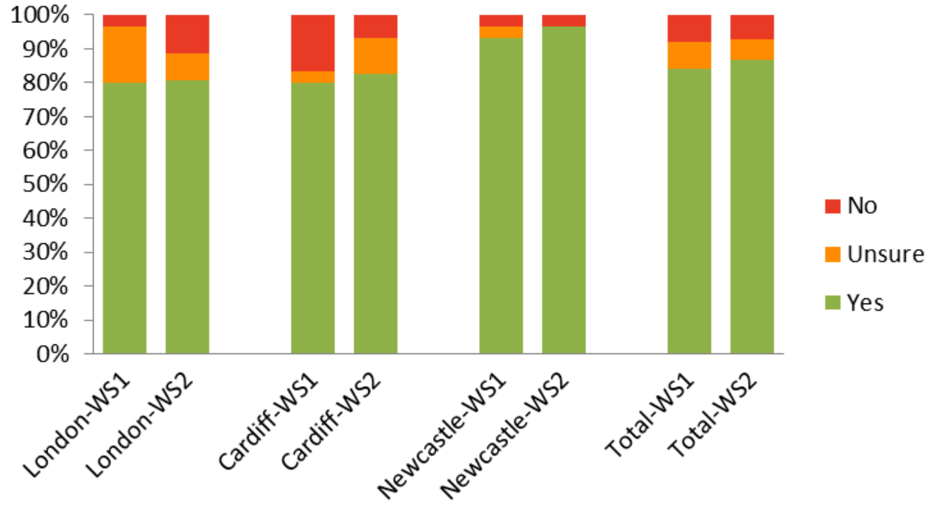


Figure 1b: Summary of all responses to Q2 from workshop series 1

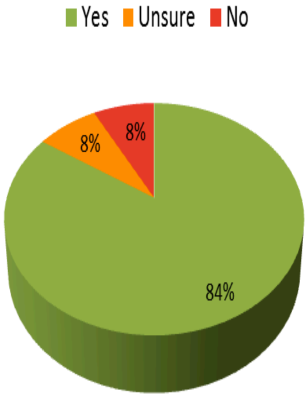


Figure 1c: Summary of all reponses to Q2 from workshop series 2

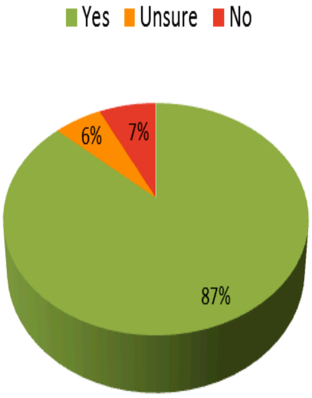
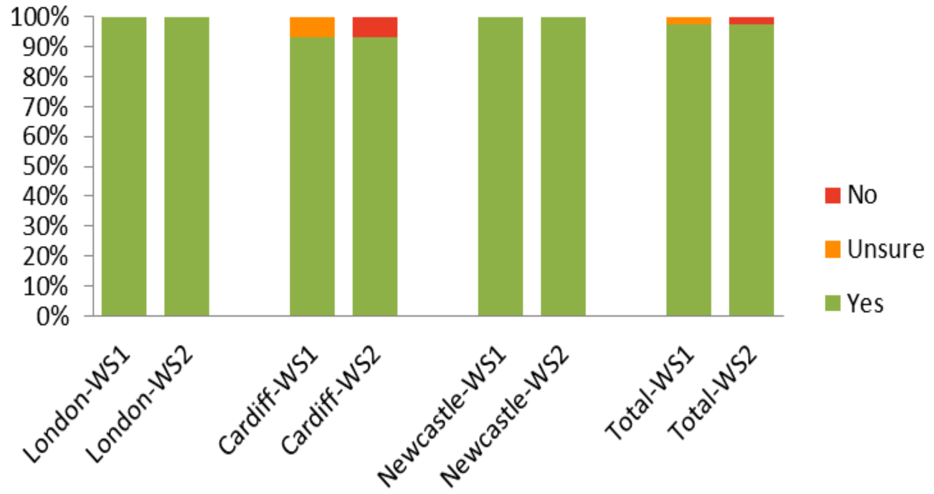


Table 2: Participant responses from the three workshop locations, over the two events, to Question 3: At the start of the workshop, were the aims clearly specified?

1st Workshop	London (N=30)	Cardiff (N=30)	Newcastle(N=29)	Total (N=89)
Yes	30 (100.0%)	28 (93.3%)	29 (100.0%)	87 (97.8%)
Unsure	0 (0.0%)	2 (6.7%)	0 (0.0%)	2 (2.2%)
No	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)

2nd Workshop	London (N=26)	Cardiff (N=29)	Newcastle(N=28)	Total (N=83)
Yes	26 (100.0%)	27 (93.1%)	28 (100.0%)	81 (97.6%)
Unsure	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
No	0 (0.0%)	2 (6.9%)	0 (0.0%)	2 (2.4%)

Figure 2a: Answers to Question 3 "were the aims clearly specified?"



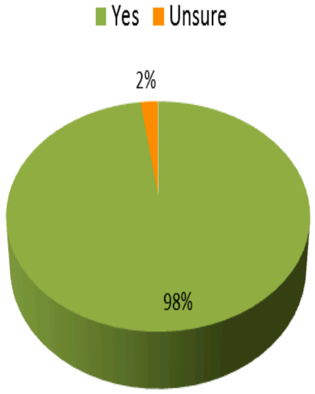


Figure 2b: Summary of all responses to Q3 from workshop series 1

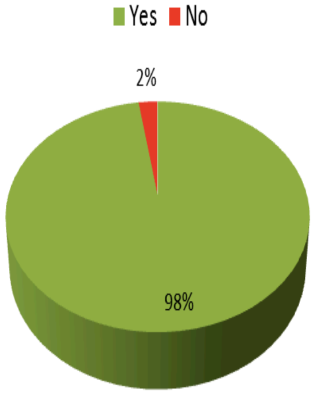


Figure 2c: Summary of all responses to Q3 from workshop series 2

Table 3: Participant responses from the three workshop locations, over the two events, to Question 4: Was it clear to you from the information you were sent before the event why you were invited?

1st Workshop	London (N=30)	Cardiff (N=30)	Newcastle(N=29)	Total (N=89)
Yes	26 (86.7%)	24 (80.0%)	27 (93.1%)	77 (86.5%)
Unsure	4 (13.3%)	3 (10.0%)	2 (6.9%)	9 (10.1%)
No	0 (0.0%)	3 (10.0%)	0 (0.0%)	3 (3.4%)

2nd Workshop	London (N=26)	Cardiff (N=29)	Newcastle(N=28)	Total (N=83)
Yes	24 (92.3%)	24 (82.8%)	27 (96.4%)	75 (90.4%)
Unsure	2 (7.7%)	1 (3.4%)	0 (0.0%)	3 (3.6%)
No	0 (0.0%)	4 (13.8%)	1 (3.6%)	5 (6.0%)

Figure 3a: Answers to Question 4 "was it clear... why you were invited?"

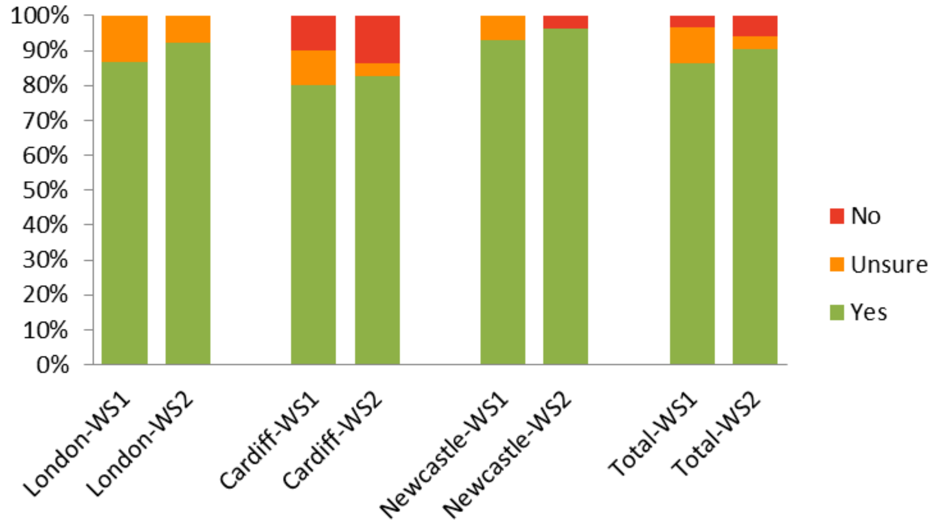


Figure 3b: Summary of all responses to Q4 from workshop series 1

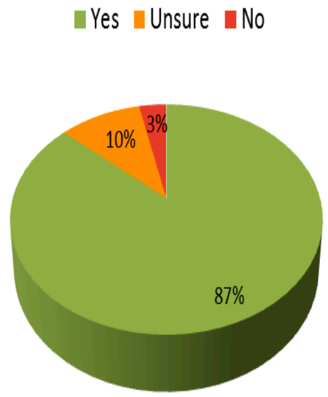


Figure 3c: Summary of all responses to Q4 from workshop series 2

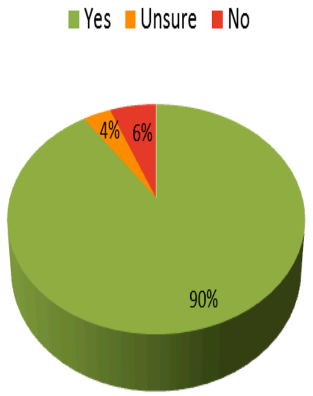


Table 4: Participant responses from the three workshop locations, over the two events, to Question 5: Was it made clear to you how the participants for this event were selected?

1st Workshop	London (N=30)	Cardiff (N=30)	Newcastle(N=29)	Total (N=89)
Yes	20 (66.7%)	19 (63.3%)	23 (79.3%)	62 (69.7%)
Unsure	4 (13.3%)	5 (16.7%)	2 (6.9%)	11 (12.4%)
No	6 (20.0%)	6 (20.0%)	4 (13.8%)	16 (18.0%)

2nd Workshop	London (N=26)	Cardiff (N=29)	Newcastle(N=28)	Total (N=83)
Yes	17 (65.4%)	24 (82.8%)	23 (82.1%)	64 (77.1%)
Unsure	1 (3.8%)	1 (3.4%)	2 (7.1%)	4 (4.8%)
No	8 (30.8%)	4 (13.8%)	3 (10.7%)	15 (18.1%)

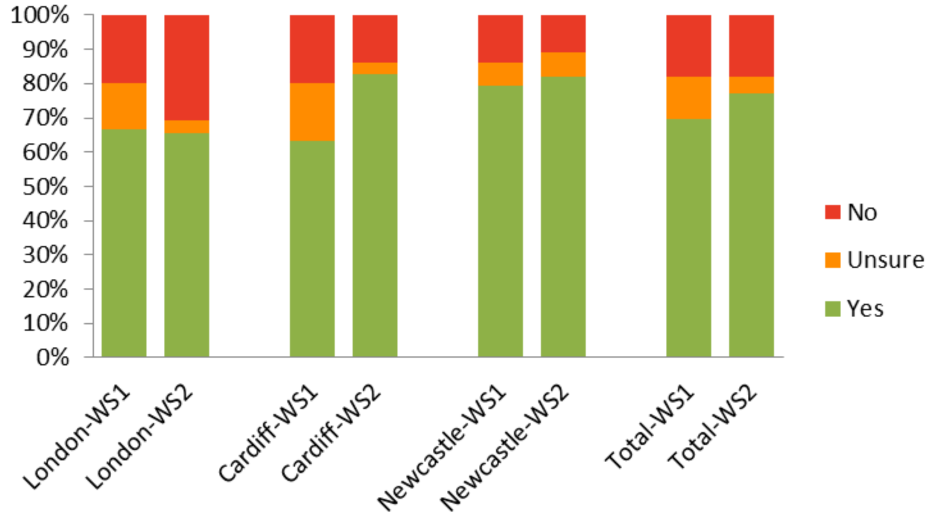


Figure 4a: Answera to Question 5 "was it clear how participants... were selected?"

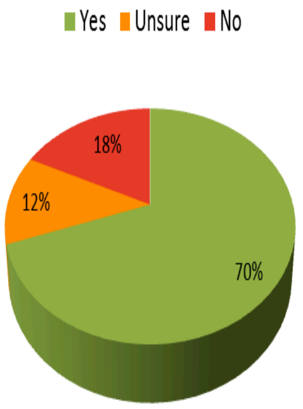


Figure 4b: Summary of all responses to Q5 from workshop series 1

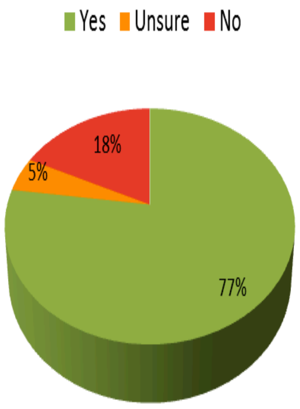


Figure 4c: Summary of all responses to Q5 from workshop series 2

Table 5: Participant responses from the three workshop locations, over the two events, to Question 6: Do you think the public participants involved were appropriate for this event?

1st Workshop	London (N=30)	Cardiff (N=30)	Newcastle(N=29)	Total (N=89)
Yes	30 (100.0%)	30 (100.0%)	26 (89.7%)	86 (96.6%)

Unsure	0 (0.0%)	0 (0.0%)	3 (10.3%)	3 (3.4%)
No	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)

2nd Workshop	London (N=26)	Cardiff (N=29)	Newcastle(N=28)	Total (N=83)
Yes	26 (100.0%)	28 (96.6%)	24 (85.7%)	78 (94.0%)
Unsure	0 (0.0%)	1 (3.4%)	4 (14.3%)	5 (6.0%)
No	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)

Figure 5a: Answers to Question 6 "do you think the participants... were appropriate?"

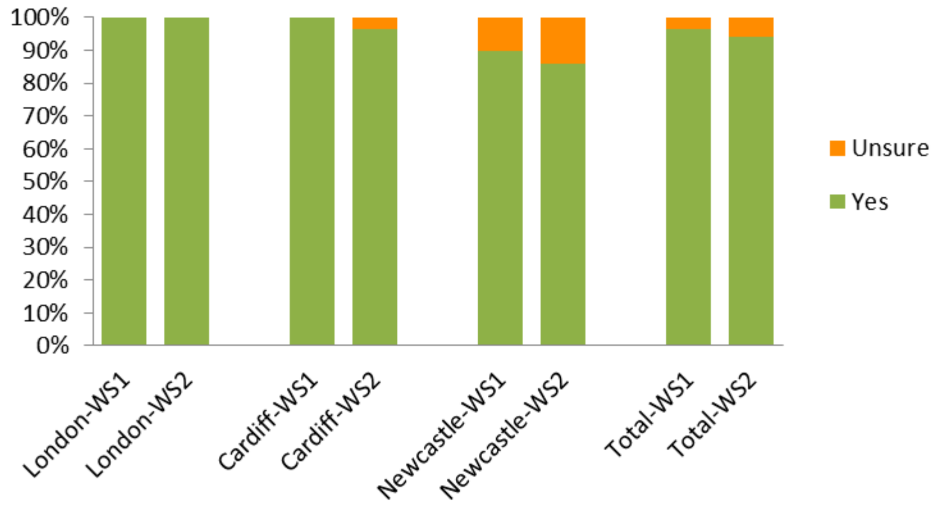


Figure 5b: Summary of all responses to Q6 from workshop series 1

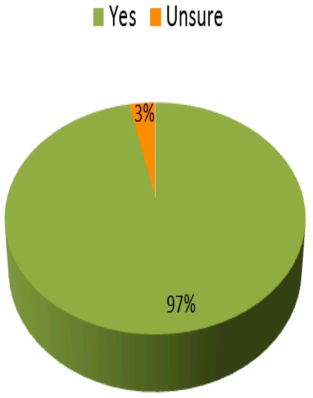
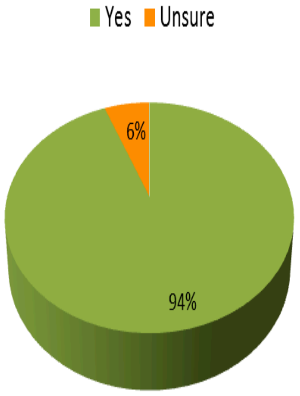


Figure 5c: Summary of all responses to Q6 from workshop series 2



ii) Information elicitation

Two questions asked participants their views on whether they had been given adequate opportunity to talk – i.e. to provide the information to the organisers/sponsors in return for (and in response to) the information that they had previously received. Table 6 (Figures 6a, 6b, 6c) shows answers to the question of 'did you have the opportunity to have your say?' This reveals a good general agreement, across locations, and over the two different workshop series, that participants did feel that they had been given sufficient opportunity to speak: all but two participants from the first series of workshops, and one from the second, either indicated that they had 'said all (they) wanted to say' or 'said most of what (they) wanted to say'. This finding matched well with observations from the evaluators, who generally identified good facilitation across the different events, with positive atmospheres produced that were conducive to encouraging open discussions, and good facilitation practice enacted to ensure non-speakers were encouraged to have their say too.

A second question on this broad issue asked whether participants felt that there was sufficient time to discuss all that needed to be discussed. This is an important issue as time limitations can potentially undermine dialogue processes by preventing discussions reaching their conclusions or denying the opportunity to discuss all relevant aspects of an issue (reducing translation efficiency). Table 7 (Figures 7a, 7b, 7c) summarises the participant responses. It is clear that the first series of workshops were deemed to have had sufficient time: all but four of the 89 participants over the three locations agreed that this was so (three of these four having attended the Newcastle event). However, the picture is less clear with regards the second series of workshops: although over 80% still agreed that time was sufficient, nearly 20% said it was not or that they were 'unsure' that there was sufficient time (14 out of 82), and these participants were spread about equally over the three different events. Indeed, it seemed clear to the evaluation observers that the topic addressed in the first workshop (largely summarising the science) was more bounded than that in the second, that is, the ethical issues raised in the second series were more open-ended, and could have been discussed further.

In fact, an additional open question (question 9) asked participants to record any 'significant issues that were NOT discussed, but which should have been'. From the first series of workshops, most participants either did not respond to this question or said 'none'. The few issues raised included: ethics (six respondents, all of whom noted that they thought this would be covered next time); financial aspects (one participant); animal suffering (one); side-effects case studies (one); impact on human evolution (one); and 'current options and the scientific background to those' (one).

From the second series of workshops, again, many respondents didn't provide an answer or said 'none'. Of the topics that were identified, 'religion' was the main one, identified by six as an omission. Other topics mentioned included 'costs' (two participants), possible health risks (two), animal rights (one), timescale for introduction (to NHS) (two), international relations (one), the decision making process and who is accountable (two), 'exactly which techniques were being focussed on in Britain' (one), the issue of cultures getting rid of embryos with small mitochondrial faults to try and have designer or perfect babies (one), and the debate on whether an embryo is a life or a mass of cells (one). Two more mentioned a specific issue that was raised in video in the second workshop series, in which one scientist talked of 'cytoplasm' in the egg that might have an impact on the developing person (which seemed at odds to initial presentations in the first workshop, which focused only on the minimal effects of the mitochondria lost in the spindle/pronuclear transfers from the two advocated techniques). This latter issue is a significant one, as will be discussed in our analysis of the deliberative public workshops (Chapter 3): several participants (among them the most vocal) spotted this in each of the locations, and were concerned that this was new information sprung on them at the last minute (as one from Cardiff wrote: '...This was not mentioned in the science presentation. I do not feel that all the potential drawbacks in the treatment were properly identified and explained', and as one declared at the London event: 'this is a game-changer!').

Finally in this section, there was one further question (13) that addressed how the discussions had been summed up by the organisers. This is an important issue in that it reflects the accuracy of translation of participant viewpoints by the organisers, particularly as 'summaries' may have significant influence on the 'take home' message by the organisers (irrespective of whatever other information is subsequently collected and described by them). Results are shown in Table 8 (Figures 8a, 8b, 8c). Over 90% of respondents in both the first and second series of workshops agreed that the summing up had been accurate.

To summarise, the events were largely well organised and facilitated, although a number of issues did subsequently emerge that might have been discussed more fully, had there been time. The 'cytoplasm' issue will be considered shortly.

Table 6: Participant responses from the three workshop locations, over the two events, to Question 7: During the event, did you have the opportunity to have your say?

1st Workshop	London (N=29)*	Cardiff (N=30)	Newcastle(N=29)	Total (N=88)
I said all I wanted to say	23 (79.3%)	27 (90.0%)	22 (75.9%)	72 (81.8%)
I said most of what I wanted to say	6 (20.7%)	2 (6.7%)	6 (20.7%)	14 (15.9%)
I was only able to say a little…	0 (0.0%)	1 (3.3%)	1 (3.4%)	2 (2.3%)
I didn't get a chance to say anything	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)

*There was one missing response from London

2nd Workshop	London (N=26)	Cardiff (N=29)	Newcastle(N=28)	Total (N=83)
I said all I wanted to say	22 (84.6%)	24 (82.8%)	23 (82.1%)	69 (83.1%)
I said most of what I wanted to say	4 (15.4%)	4 (13.8%)	5 (17.9%)	13 (15.7%)
I was only able to say a little…	0 (0.0%)	1 (3.4%)	0 (0.0%)	1 (1.2%)
I didn't get a chance to say anything	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)

Figure 6a: Answers to Question 7 "...did you have the opportunity to have your say?"

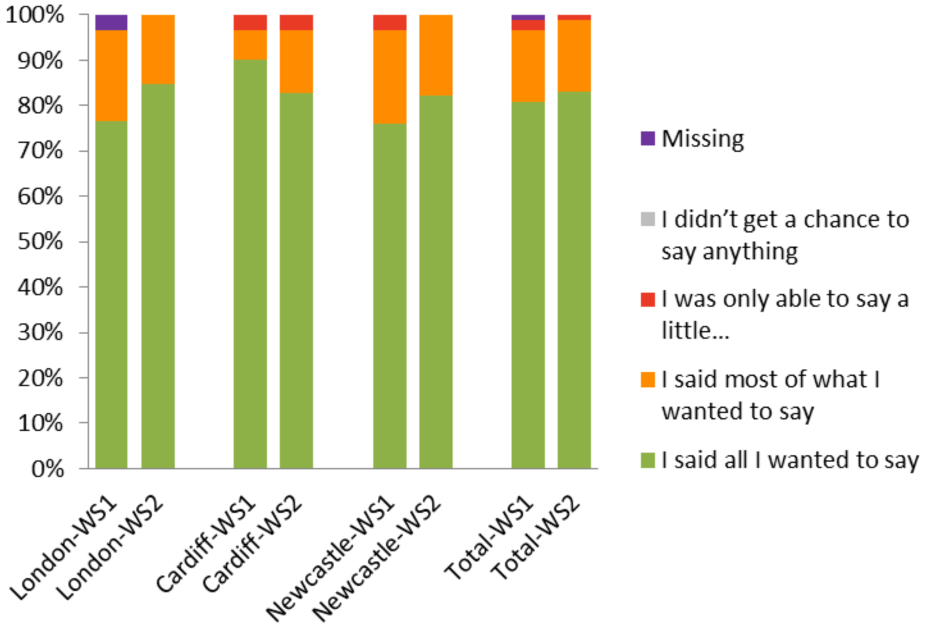


Figure 6b: Summary of all responses to Q7 from workshop series 1

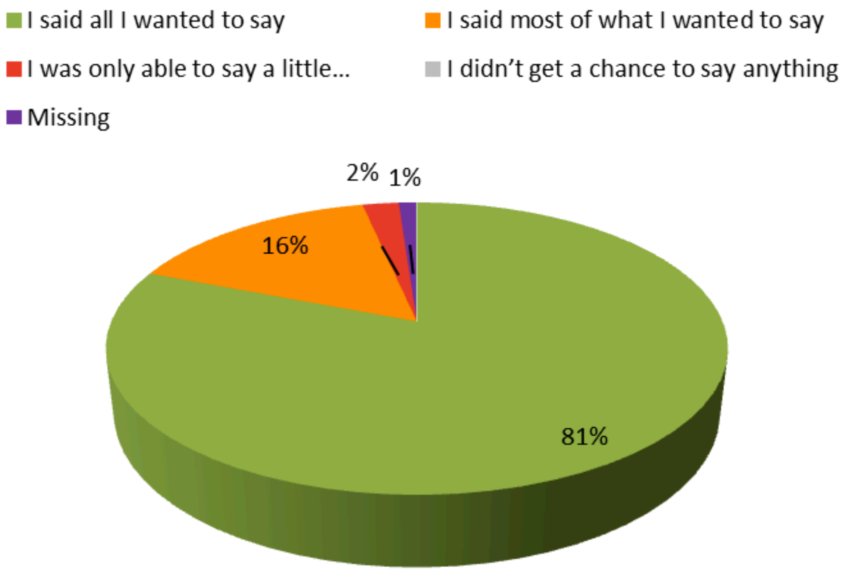


Figure 6c: Summary of all responses to Q7 from workshop series 2

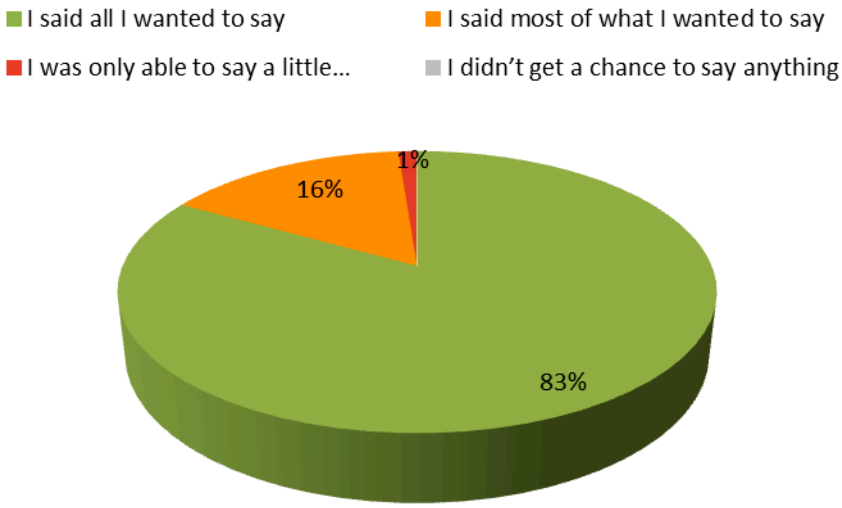


Table 7: Participant responses from the three workshop locations, over the two events, to Question 8: Was there sufficient time to discuss all that needed to be discussed?

1st Workshop	London (N=30)	Cardiff (N=30)	Newcastle(N=29)	Total (N=89)
Yes	30 (100.0%)	29 (96.7%)	26 (89.7%)	85 (95.5%)
Unsure	0 (0.0%)	0 (0.0%)	1 (3.4%)	1 (1.1%)
No	0 (0.0%)	1 (3.3%)	2 (6.9%)	3 (3.3%)

2nd Workshop	London (N=25)*	Cardiff (N=29)	Newcastle(N=28)	Total (N=82)
Yes	21 (84.0%)	25 (86.2%)	22 (78.6%)	68 (82.9%)
Unsure	3 (12.0%)	2 (6.9%)	1 (3.6%)	6 (7.3%)
No	1 (4.0%)	2 (6.9%)	5 (17.9%)	8 (9.8%)

*There was one missing response from London

Figure 7a: Answer to Question 8 "was there sufficient time...?"

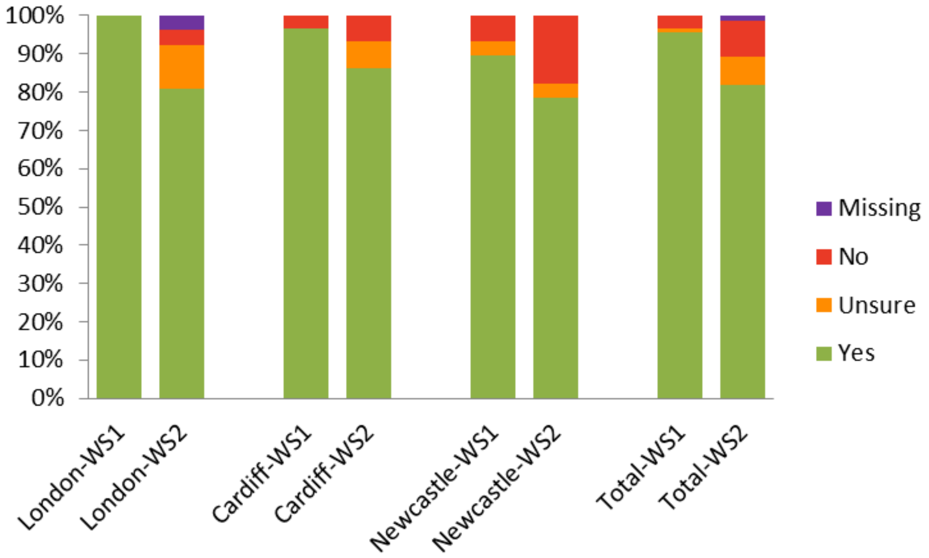


Figure 7b: Summary of all responses to Q8 from workshop series 1

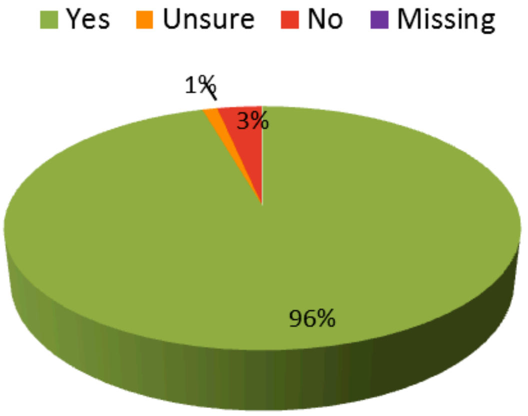


Figure 7c: Summary of all responses to Q8 from workshop series 2

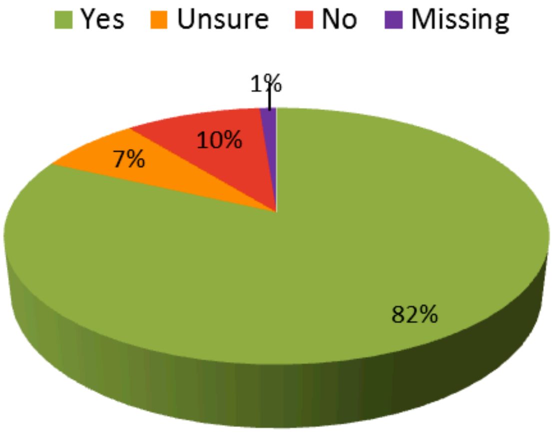


Table 8: Participant responses from the three workshop locations, over the two events, to Question 13: Do you think the summing-up accurately reflected what was discussed at the workshop?

1st Workshop	London (N=30)	Cardiff (N=30)	Newcastle(N=29)	Total (N=89)
Yes	26 (86.7%)	30 (100.0%)	28 (96.6%)	84 (94.4%)
Unsure	3 (10.0%)	0 (0.0%)	1 (3.4%)	4 (4.5%)
No	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
There was no summing up	1 (3.3%)	0 (0.0%)	0 (0.0%)	1 (1.1%)

2nd Workshop	London (N=26)	Cardiff (N=29)	Newcastle(N=28)	Total (N=83)
Yes	24 (92.3%)	27 (93.1%)	26 (92.9%)	77 (92.8%)
Unsure	1 (3.8%)	0 (0.0%)	1 (3.6%)	2 (2.4%)
No	1 (3.8%)	2 (6.9%)	1 (3.6%)	4 (4.8%)
There was no summing up	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)

Figure 8a: Answers to Question 13 "(did the) summing up accurately (reflect discussion)...?"

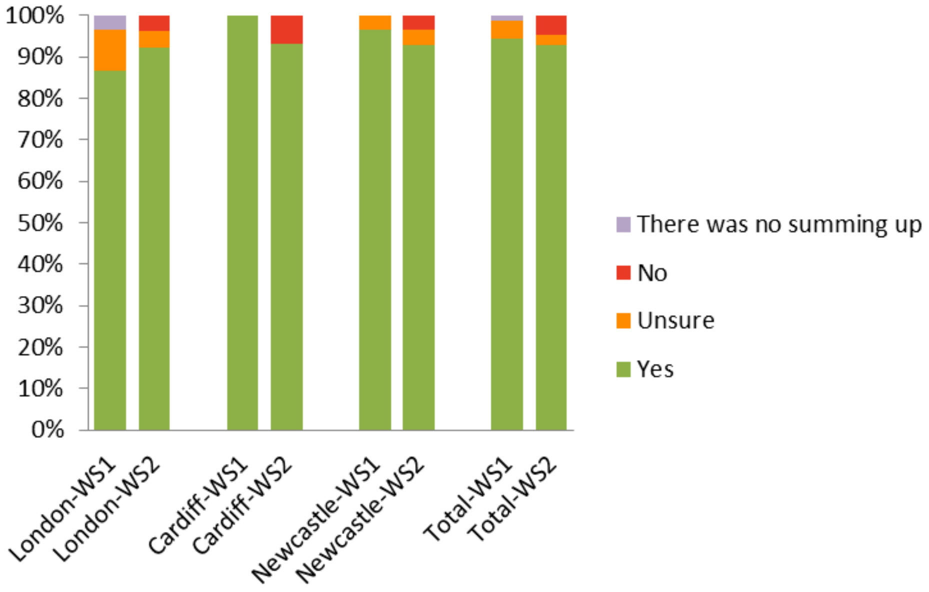


Figure 8b: Summary of all responses to Question 13 from workshop series 1

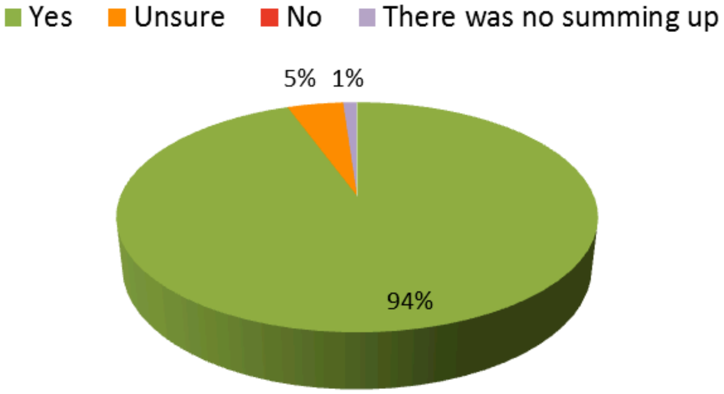
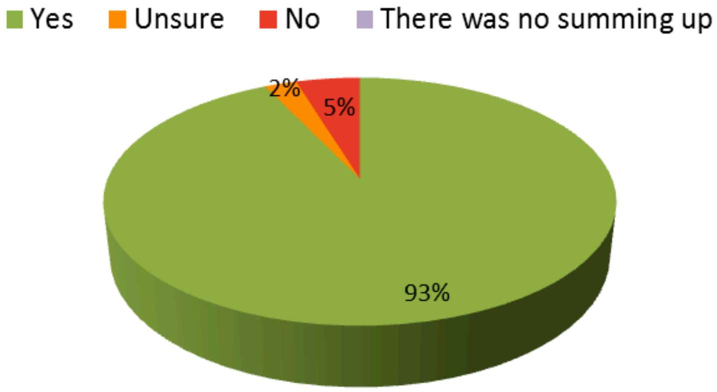


Figure 8c: Summary of all responses to Question 13 from workshop series 2



iii) Impact of the workshops

An important issue is the nature of the impacts of the workshop on and according to participants. That is, how did participation affect them, and what other effects did they see as likely to result from the events. Various questions looked at a number of related issues: some of these speak to translation issues (e.g. the efficiency of the information communicating process). First, one question (10) asked ‘did you learn much from the workshops’. Table 9 (Figure 9a, 9b, 9c) shows that the majority, from all three locations, and in each of the two events (one addressing science, the other bioethics), overwhelming agreed that they had. Nearly 90% in total from each series said they had ‘learnt a lot of new things’, and almost all of the remainder said that they had at least learnt ‘a few new things’. Just one person (from London) said, on each occasion, that they had not learnt anything new (and this was almost certainly untrue).

Perhaps more interestingly, another question (11) asked whether participation in the event had changed participants’ views in anyway. Table 10 (Figure 10a, 10b, 10c) summarises the answers to this question. The data show a wide range of responses. By and large, more people said they changed their views after the second series of workshops than after the first (about 65% indicated some change after the first workshop, summed over the three locations, as opposed to about 47% after the second workshop), which is perhaps to be expected, given the nature of ethical issues that were brought up in those second workshops. Generally, those attending the London events said that they changed their minds to a greater extent than those attending Cardiff, with even fewer of those attending Newcastle saying that they changed their minds. This is difficult to interpret: in the first place, the impact of the workshops on people’s opinions is clear, and this may be seen to be positive (if few had admitted to changing their minds, one might wonder at the potency of the information they had received), although lack of impact on opinion is not necessarily a sign of failure: some participants didn’t change their minds in workshop one because (as they noted) they had had no prior opinion; some did not change in workshop two because they had developed an opinion in the first workshop (e.g. that the techniques were hopeful) and felt that the information in the second was not enough to change this position.

Table 9: Participant responses from the three workshop locations, over the two events, to Question 10: Did you learn much from the workshop?

1st Workshop	London (N=30)	Cardiff (N=30)	Newcastle(N=29)	Total (N=89)
I learnt a lot of new things	28 (93.3%)	25 (83.3%)	27 (93.1%)	80 (89.9%)
I learnt a few new things	1 (3.3%)	5 (16.7%)	2 (6.9%)	8 (9.0%)
I'm not sure I learnt anything…	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
No, I did not learn anything new	1 (3.3%)	0 (0.0%)	0 (0.0%)	1 (1.1%)

2nd Workshop	London (N=26)	Cardiff (N=29)	Newcastle(N=28)	Total (N=83)
I learnt a lot of new things	25 (96.2%)	21 (72.4%)	25 (89.3%)	71 (85.5%)
I learnt a few new things	0 (0.0%)	8 (27.6%)	3 (10.7%)	11 (13.3%)
I'm not sure I learnt anything…	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
No, I did not learn anything new	1 (3.8%)	0 (0.0%)	0 (0.0%)	1 (1.2%)

Figure 9a: Answers to Question 10 "did you learn much...?"

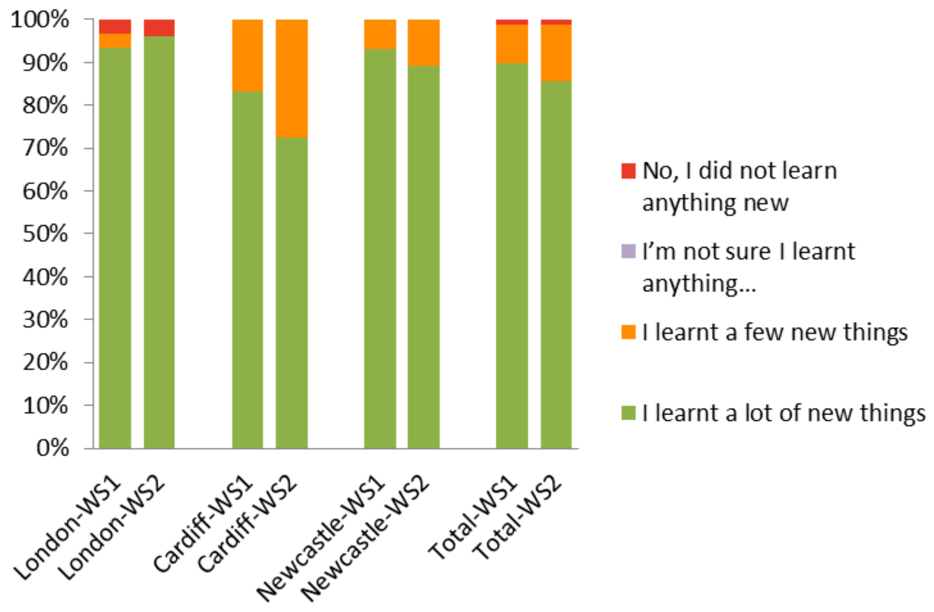


Figure 9b: Summary of all responses to Q10 from workshop series 1

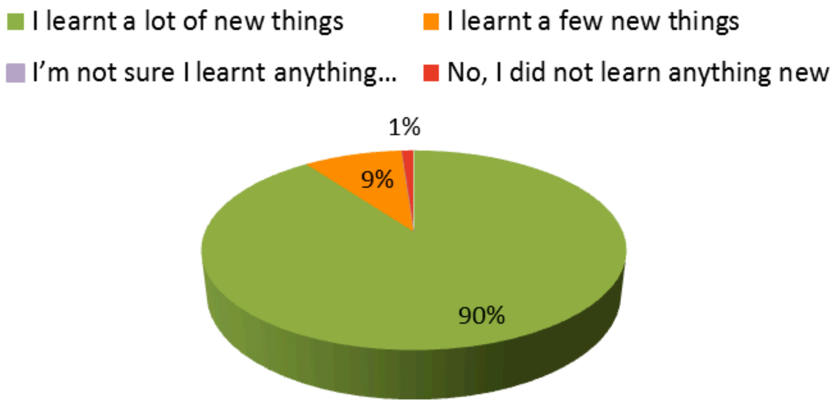


Figure 9c: Summary of all responses to Q10 from workshop series 2

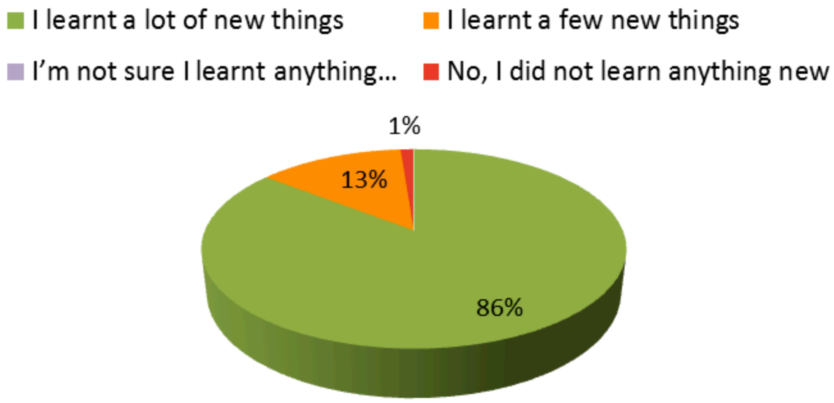


Table 10: Participant responses from the three workshop locations, over the two events, to Question 11: Did participation in this event change your views on the issues in any way?

1st Workshop	London (N=30)	Cardiff (N=30)	Newcastle(N=29)	Total (N=89)
Yes, I changed my views considerably	7 (23.3%)	8 (26.7%)	3 (10.3%)	18 (20.2%)
Yes, I changed my views to some degree	9 (30.0%)	8 (26.7%)	7 (24.1%)	24 (27.0%)

I'm not sure whether I changed my views or not	7 (23.3%)	7 (23.3%)	8 (27.6%)	22 (24.7%)
No, I did not change my views in any way	7 (23.3%)	7 (23.3%)	11 (37.9%)	25 (28.1%)

2nd Workshop	London (N=26)	Cardiff (N=29)	Newcastle(N=28)	Total (N=83)
Yes, I changed my views considerably	7 (26.9%)	9 (31.0%)	3 (10.7%)	19 (22.9%)
Yes, I changed my views to some degree	14 (53.8%)	12 (41.4%)	9 (32.1%)	35 (42.2%)
I'm not sure whether I changed my views or not	1 (3.8%)	3 (10.3%)	4 (14.3%)	8 (9.6%)
No, I did not change my views in any way	4 (15.4%)	5 (17.2%)	12 (42.9%)	21 (25.3%)

Figure 10a: Answers to Question 11 "did participation... change your views...?"

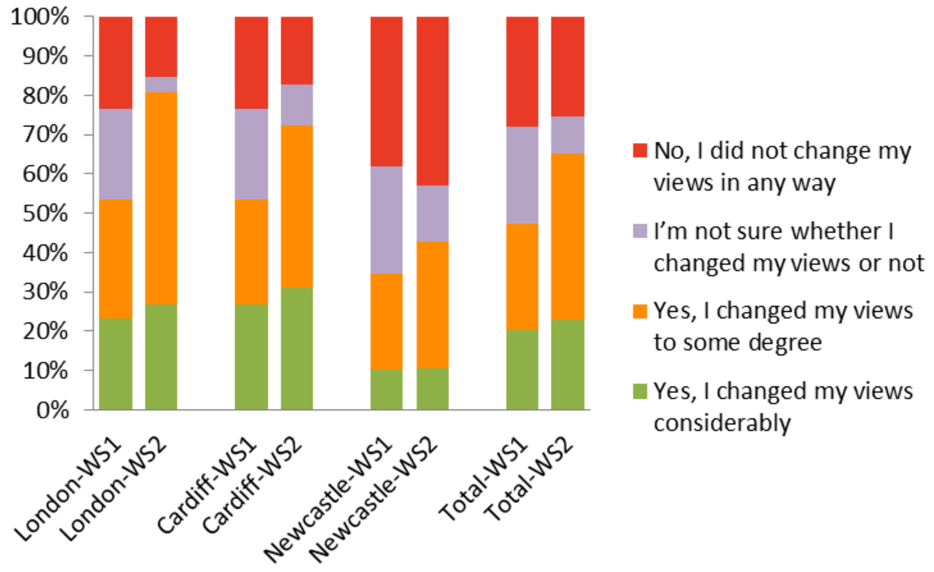


Figure 10b: Summary of all responses to Q11 from workshop series 1

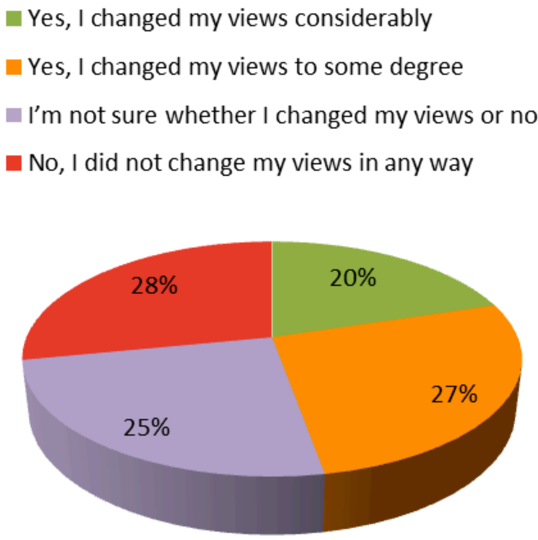
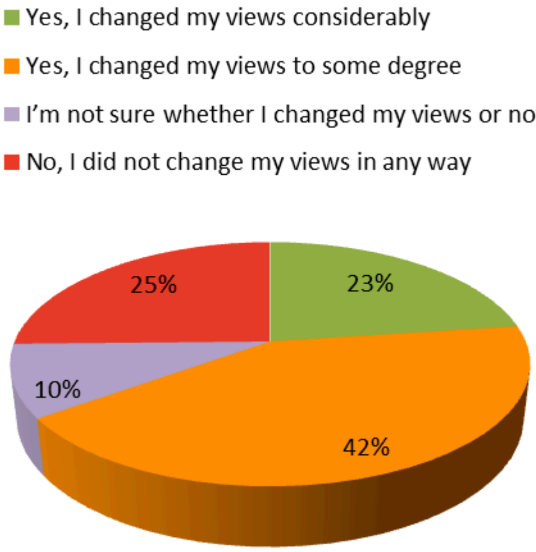


Figure 10c: Summary of all responses to Q11 from workshop series 2



An open question (12), asked participants specifically 'what information (from speakers, from written material, from other participants, etc.) did you think was potentially influential on your views?' Responses from participants after the first series of workshops tended to fall into two types: some participants noted a specific fact or issue that they had learnt; some reported the most influential information source (medium). Regarding the former, participants from the three locations identified a range a facts about IVF, genetics, the nature of mitochondrial disease, the nature of the treatments and research, and the potential benefits of treatment, that were influential. Regarding the latter, the scientist speakers were the most frequently noted ‘medium’ that were found to be influential (by seven from London, six from Newcastle and two from Cardiff). Beyond this, the video was mentioned (four from Cardiff, two from Newcastle, but none from London), and the written material/handouts (four from Cardiff, and by one each from London and Newcastle).

Turning to the second series of workshops, again, there was some difference in answering, with a relatively small number citing specific scientific facts or answering ‘all of it’. This time, more respondents identified the specific media that were of influence, with a clear winner being the two videos shown – one of a sufferer, and one showing various commentators giving their views on aspects on the problem. The videos were specifically mentioned by ten respondents from Cardiff, nine from London, and nine from Newcastle. Besides this, the expert speakers (bioethicists) were also identified as a significant influence, though there was some variety across locations: 14 of those in London mentioned the expert bioethicist, compared to six from Cardiff and two from Newcastle. Aside from this, written material/handouts were only cited as a main influence by one person from London and one from Cardiff – which might be because it was the most neutral information (designed to be so, over various iterations), or most bland (without the tone, nuance or emotion of the spoken word).

From our observation of events, it was clear that the participants appreciated the experts, who were by and large effective communicators, and personable. The three videos were also clearly quite powerful – the one showing the sufferer was seen to cause some powerful emotions among some participants, while one revelation in the video of experts talking (mentioned previously, regarding the ‘cytoplasm’ issue) was also seen to have powerful influences, as will be described shortly. As an aside, although the posters and handouts were not well cited by participants as a source of influence, the observers noted that most of the written material was well used by the facilitators.

Aside from the utility of the different information sources, and their potency with regards participants’ opinions, we also asked participants their opinion on how well the workshop was run (i.e. their views on the facilitation and activities of the organisers) and their overall level of satisfaction. These questions both speak, to some extent, to the perceived efficiency of translation in the events.

Question 14 asked ‘overall, do you think the workshop was well run?’ Table 11 (Figure 11a, 11b, 11c) summarises the results from this. These results give a resounding vote of confidence in the organisers/facilitators – in all three locations and in both series of workshops. From the first workshops, not a single participant said the event was not well run, and only one was ‘unsure’; from the second workshops, only two suggested that the workshops were not well run (one from Cardiff and one from Newcastle), with one being ‘unsure’. It should be noted that this concern largely seemed to stem from the apparently new information about the ‘cytoplasm’ issue that emerged in the video of the experts. Question 14 allowed participants space to say what was wrong with the workshop. One wrote:

“There were questions from the science portion of the group that I feel were avoided deliberately. This came to light with information on the second day. The sudden revelation of possible spinal

problems so late in the discussion really knocked my confidence in the info given to me. It made it very difficult to focus on the ethical issues. I feel I have been manoeuvred to a decision somewhat."

A second said:

"But not all the information was given e.g. video told us different/extra to what we were first told"

Of course, this issue speaks less to how the workshop was actually run on the day, as to a problem with the pre-defined content.

Question 15 asked simply 'how satisfied were you with the event?' Table 12 (Figure 12a, 12b, 12c) summarises the answers. These results confirm those just discussed: from the first round of workshops, all but two indicated that they were either 'very' or 'fairly' satisfied (one, from London, was 'neither satisfied nor dissatisfied' and one was 'unsure'); from the second round all but three were either 'very' or 'fairly' satisfied (one, from Cardiff, being 'neither satisfied nor dissatisfied', while one each from London and Cardiff were 'not very satisfied'). There was, of course, overlap between those not satisfied and those who were concerned with how the workshop was run (see previously).

Indeed, our observations confirmed that there were general good atmospheres at the events and although some participants were clearly less engaged than others (and one at London appeared to almost deliberately disengage, being concerned with animal rights issues and therefore being against almost any sort of experimentation), none seemed dissatisfied with the overall process.

Table 11: Participant responses from the three workshop locations, over the two events, to Question 14: Overall, do you think the workshop was well run?

1st Workshop	London (N=30)	Cardiff (N=30)	Newcastle(N=29)	Total (N=89)
Yes	29 (96.7%)	30 (100.0%)	29 (100.0%)	88 (98.9%)
Unsure	1 (3.3%)	0 (0.0%)	0 (0.0%)	1 (1.1%)
No	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)

2nd Workshop	London (N=26)	Cardiff (N=29)	Newcastle(N=28)	Total (N=83)
Yes	26 (100.0%)	28 (96.6%)	26 (92.9%)	80 (96.4%)
Unsure	0 (0.0%)	0 (0.0%)	1 (3.6%)	1 (1.2%)
No	0 (0.0%)	1 (3.4%)	1 (3.6%)	2 (2.4%)

Figure 11a: Answers to Question 14 "... overall, do you think the workshop was well run?"

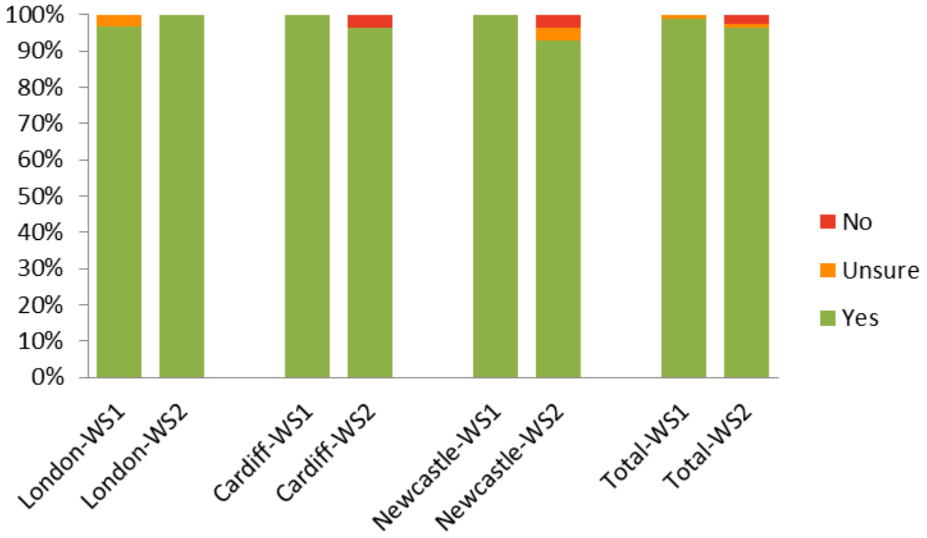
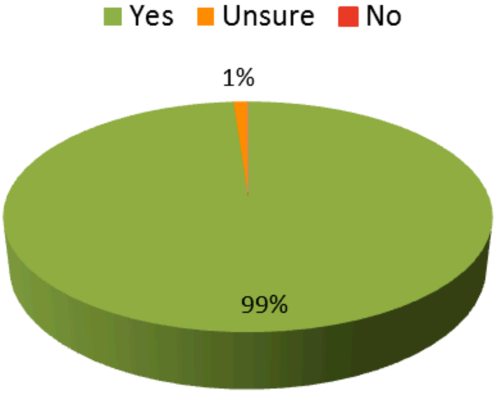


Figure 11b: Summary of all responses to Q14 from workshop series 1



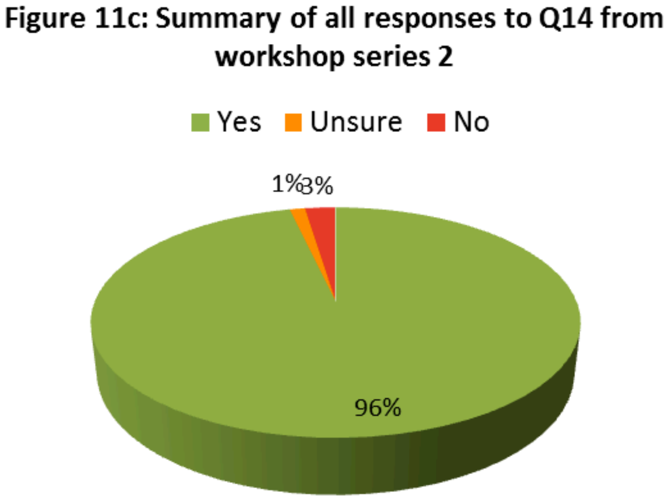


Table 12: Participant responses from the three workshop locations, over the two events, to Question 15: How satisfied were you with the event overall?

1st Workshop	London (N=30)	Cardiff (N=30)	Newcastle(N=29)	Total (N=89)
Very satisfied	20 (66.7%)	28 (93.3%)	22 (75.9%)	70 (78.7%)
Fairly satisfied	8 (26.7%)	2 (6.7%)	7 (24.1%)	17 (19.1%)
Neither satisfied nor dissatisfied	1 (3.3%)	0 (0.0%)	0 (0.0%)	1 (1.1%)
Not very satisfied	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
Not at all satisfied	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
Unsure	1 (3.3%)	0 (0.0%)	0 (0.0%)	1 (1.1%)

2nd Workshop	London (N=26)	Cardiff (N=29)	Newcastle(N=28)	Total (N=83)
Very satisfied	19 (73.1%)	22 (75.9%)	23 (82.1%)	64 (77.1%)
Fairly satisfied	6 (23.1%)	5 (17.2 %)	5 (17.9%)	16 (19.3%)
Neither satisfied nor dissatisfied	0 (0.0%)	1 (3.4%)	0 (0.0%)	1 (1.2%)
Not very satisfied	1 (3.8%)	1 (3.4%)	0 (0.0%)	2 (2.4%)
Not at all satisfied	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
Unsure	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)

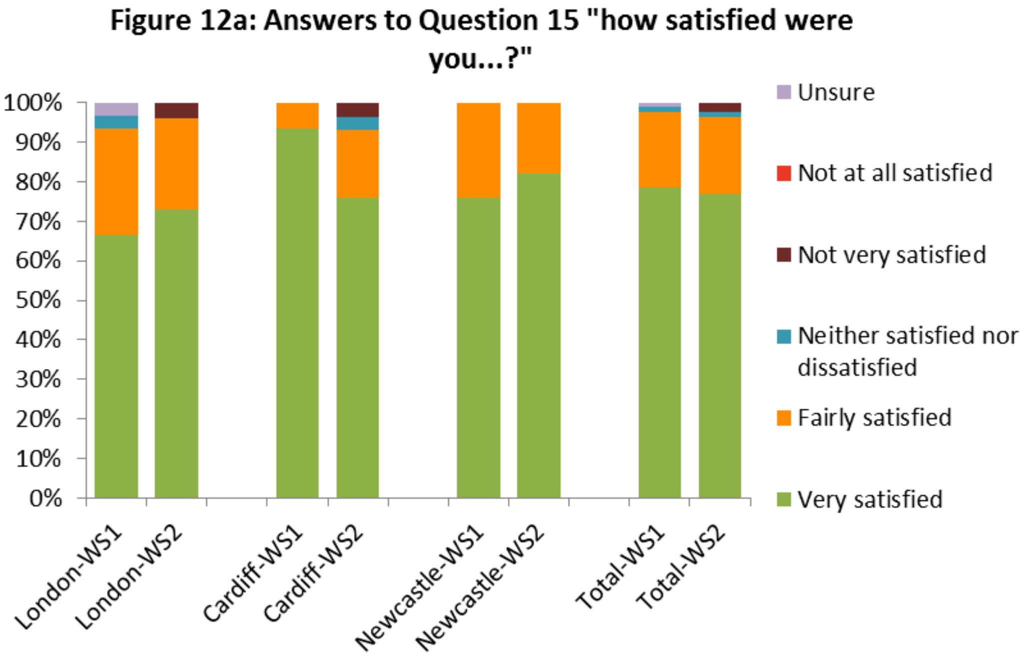


Figure 12a: Answers to Question 15 "how satisfied were you...?"
100%
90%
80%
70%
60%
50%
40%
30%
20%
10%
0%
London-WS1
London-WS2
Cardiff-WS1
Cardiff-WS2
Newcastle-WS1
Newcastle-WS2
Total-WS1
Total-WS2
Unsure
Not at all satisfied
Not very satisfied
Neither satisfied nor dissatisfied
Fairly satisfied
Very satisfied

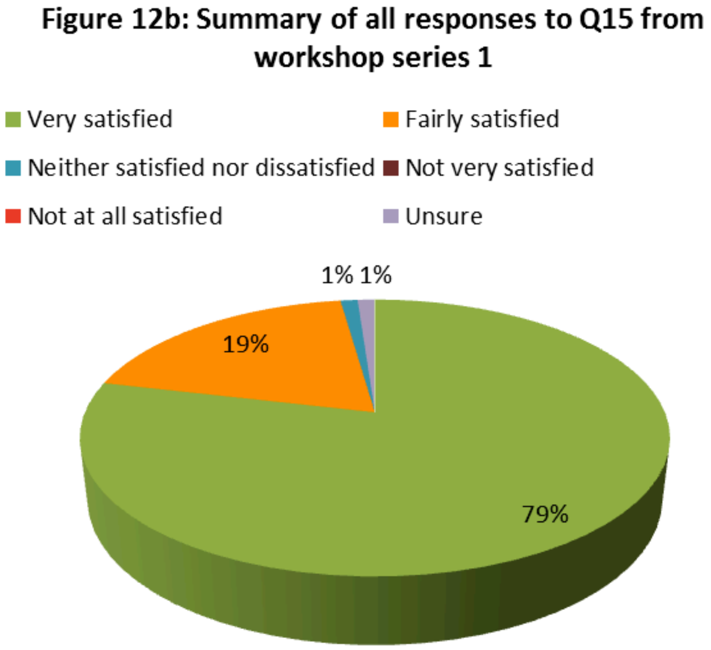
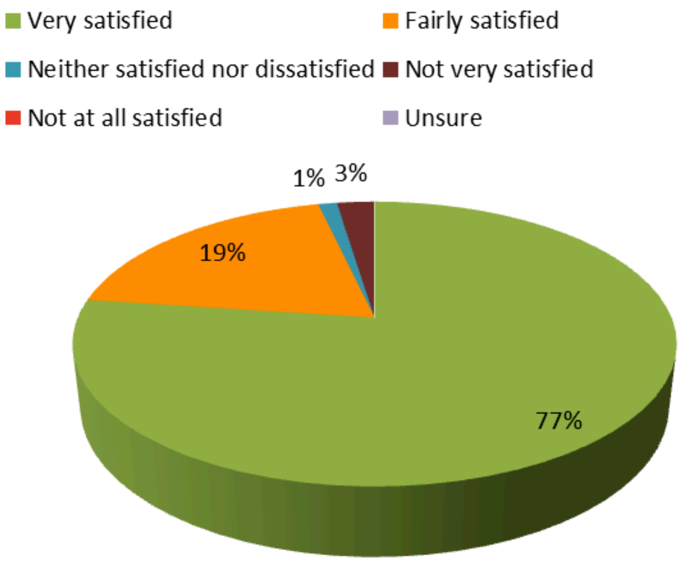


Figure 12b: Summary of all responses to Q15 from workshop series 1
Very satisfied
Fairly satisfied
Neither satisfied nor dissatisfied
Not very satisfied
Not at all satisfied
Unsure
1%
1%
19%
79%

Figure 12c: Summary of all responses to Q15 from workshop series 2



Another couplet of questions looked at the impact issue from the perspective of whether participants thought the workshops would or should influence government policy. These were asked to get a sense of participants' convictions about the process, as a degree of public cynicism can often be found in those engaged in events such as this. It is notable that in these workshops, at the very outset, HFEA representatives (as well as the organisers) discussed the place of the workshops in the overall consultation on this issue, and emphasized the importance of these workshops. Participants were also asked, at the end, specifically for their messages to the relevant Secretaries of State. Given all this, the question arises: how believable did participants find this? Were they convinced, or were they sceptical?

Question 16 asked 'do you think the event is likely to have any influence on government policy?' Table 13 (Figure 13a, 13b, 13c) summarises the participants' answers. Answers were roughly similar across the two series of workshops (i.e. participants became no more, or less, persuaded about potential influence as a result of attending a second event), and showed that approximately half thought that there would be influence, while another half were either unsure or thought there wouldn't be an influence (although these were mostly 'unsure'). There were, however, some differences across the locations, with those at London seemingly more convinced of influence and those in Cardiff seemingly least convinced (with those in Newcastle more alike those in London). Indeed, over two-thirds of those in Cardiff were uncertain about influence after the first workshop (although this did reduce slightly after the second). It is unclear to us why this is so; could it be down to a national effect, with people in Cardiff being less trustful of the UK government in London?

Participants were asked to explain their responses to this question. There were a range of responses, from those that thought the government would listen (as it had initiated in this event), to others who asserted that government 'ought' to listen, to others who simply expressed a 'hope' that it would. Of those showing doubt, perhaps a dozen in total over each series of events, suggested that, effectively, the government do what they want to/ don't listen to the public/ already has its mind made up. Some thought there would be no influence because the numbers involved were too small. Others thought that influence would 'depend' – on what the majority thought, on financial matters, on expert views, and indeed, on religious views.

Following this question, we also asked whether participants thought the events *should* have influence on government policy. Table 14 (Figure 14a, 14b, 14c) summarises the results. Unsurprisingly, more thought that the events *should* have an impact than thought they *would* have an impact. Around 85% answered 'yes', and this was fairly consistent across locations and the different workshop series. Only two participants, from London, attending the second workshop, actually suggested the events *should not* influence policy. Answers to the associated open question were dominated by responses along the lines of 'we are the public, and the government should listen to the public'. There were few dissenting opinions to this line, although several participants did suggest that the event showed that informed opinions were needed to judge on the matter, and that appropriate experts perhaps ought to 'decide such issues'.

Table 13: Participant responses from the three workshop locations, over the two events, to Question 16: Do you think the event is likely to have any influence on government policy?

1st Workshop	London (N=30)	Cardiff (N=30)	Newcastle(N=29)	Total (N=89)
Yes	20 (66.7%)	8 (26.7%)	17 (58.6%)	45 (50.6%)
Unsure	7 (23.3%)	20 (66.7%)	11 (37.9%)	38 (42.7%)
No	3 (10.0%)	2 (6.7%)	1 (3.4%)	6 (6.7%)

2nd Workshop	London (N=26)	Cardiff (N=29)	Newcastle(N=28)	Total (N=83)
Yes	16 (61.5%)	11 (37.9%)	15 (53.6%)	42 (50.6%)
Unsure	8 (30.8%)	14 (48.3%)	11 (39.3%)	33 (39.8%)
No	2 (7.7%)	4 (13.8%)	2 (7.1%)	8 (9.6%)

Figure 13a: Answers to Question 16 "do you think the event is likely to influence... government policy?"

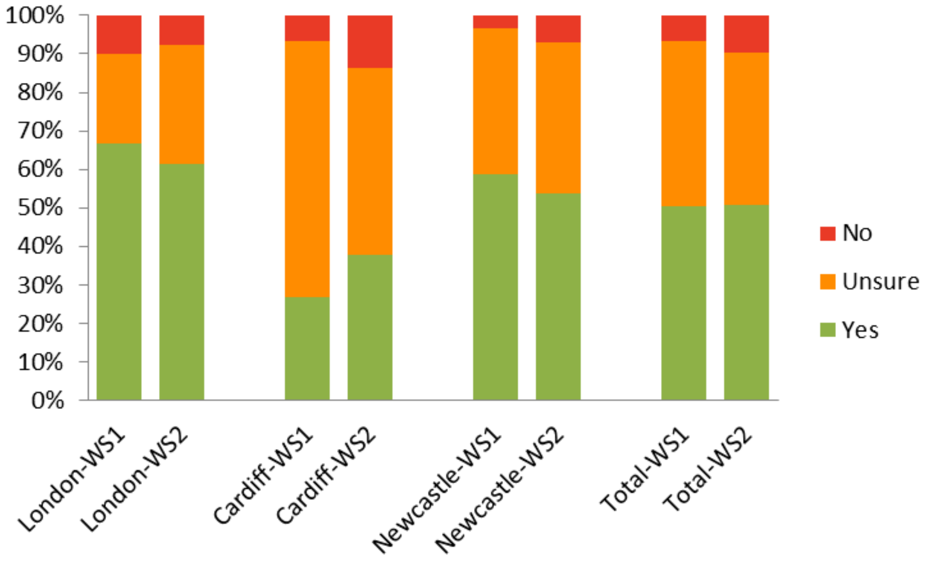


Figure 13b: Summary of all responses to Q16 from workshop series 1

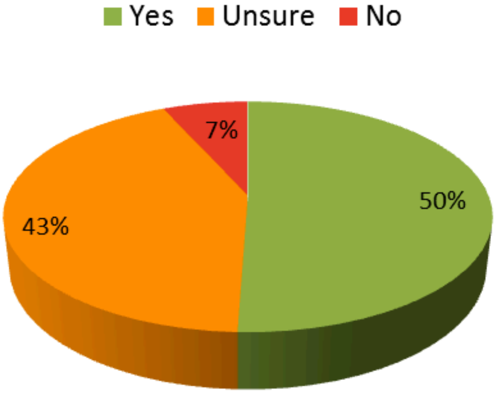


Figure 13c: Summary of all responses to Q16 from workshop series 2

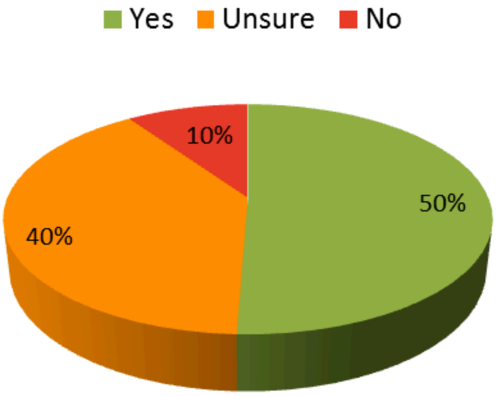


Table 14: Participant responses from the three workshop locations, over the two events, to Question 17: Do you think the event *should* have any influence on government policy?

1st Workshop	London (N=30)	Cardiff (N=30)	Newcastle(N=28)*	Total (N=88)
Yes	26 (86.7%)	23 (76.7%)	25 (89.3%)	74 (84.1%)
Unsure	4 (13.3%)	7 (23.3%)	3 (10.7%)	14 (15.9%)
No	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)

*There was one missing response from Newcastle

2nd Workshop	London (N=26)	Cardiff (N=29)	Newcastle(N=27)*	Total (N=82)
Yes	21 (80.8%)	23 (79.3%)	26 (96.3%)	70 (85.4%)
Unsure	3 (11.5%)	6 (20.7%)	1 (3.7%)	10 (12.2%)
No	2 (7.7%)	0 (0.0%)	0 (0.0%)	2 (2.4%)

*There was one missing response from Newcastle

Figure 14a: Answers to Question 17 "do you think the event should... influence government policy?"

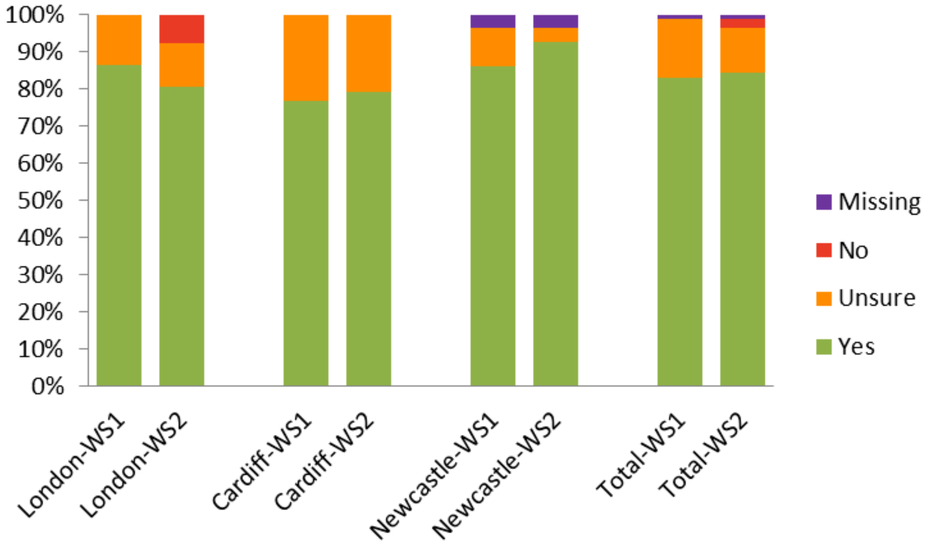


Figure 14b: Summary of all responses to Q17 from workshop series 1

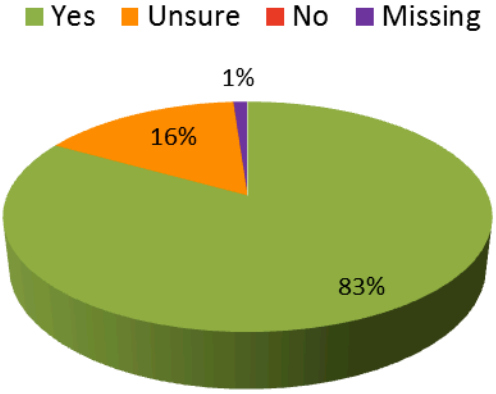
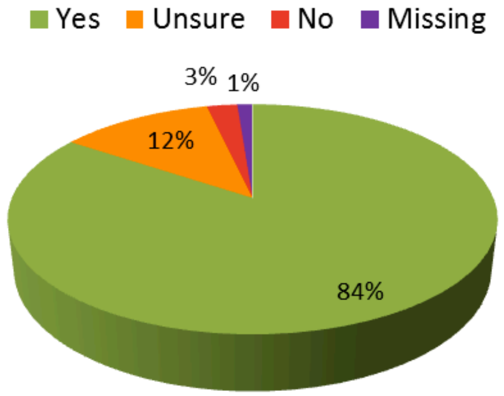


Figure 14c: Summary of all responses to Q17 from workshop series 2



Finally, regarding impact, participants were asked whether they thought that their participation in the workshops would likely lead them to change their behaviour in one of three ways. The results are shown in Table 15 and in Figures 15a, 15b, 15c, and 15d (for the three separate events, and then across all events, respectively). Bearing in mind that answers to questions about future behaviour are not always accurate, participants still foresaw the events having some tangible effects: over three quarters (on average) thought that they were 'more likely to get involved in events like this in future' (a gratifying result, suggesting some increase in political self-efficacy), and this was a fairly consistent result across locations (and largely similar across the two workshop series). Around half of participants also suggested that they were more likely to 'talk to friends and family about this issue', and around 40% suggested that they were more likely to 'follow news stories on this issue'. (Note: multiple responses were allowed, so the total across all three options can sum to over 100%.)

In summary, then, participants were satisfied by the workshops, thought they were well run, thought they would have a number of influences on their own behaviour in the future, and thought the results from the workshops ought to influence government policy – although roughly half were uncertain that they would.

Table 15: Participant responses from the three workshop locations, over the two events, to Question18: As a result of this event, which of the following impacts, if any, do you think it is likely to have?

1st Workshop I will be more likely to:	London (N=30)	Cardiff (N=30)	Newcastle(N=29)	Total (N=89)
Get involved in events like this in future	23 (76.7%)	26 (86.7%)	22 (75.9%)	71 (79.8%)

Talk to friends and family about this issue	16 (53.3%)	17 (56.7%)	20 (69.0%)	53 (59.6%)
To follow news stories on this issue	10 (33.3%)	15 (50.0%)	15 (51.7%)	40 (44.9%)

2nd Workshop I will be more likely to:	London (N=26)	Cardiff (N=29)	Newcastle(N=28)	Total (N=83)
Get involved in events like this in future	23 (88.5%)	22 (75.9%)	21 (75.0%)	66 (79.5%)
Talk to friends and family about this issue	11 (42.3%)	12 (41.4%)	16 (57.1%)	39 (47.0%)
To follow news stories on this issue	11 (42.3%)	10 (34.5%)	11 (39.3%)	32 (38.6%)

Note: multiple answers allowed so sums of column entries may exceed 100%

Table 15a: Answers to Question 18 on perceived impacts (London events)

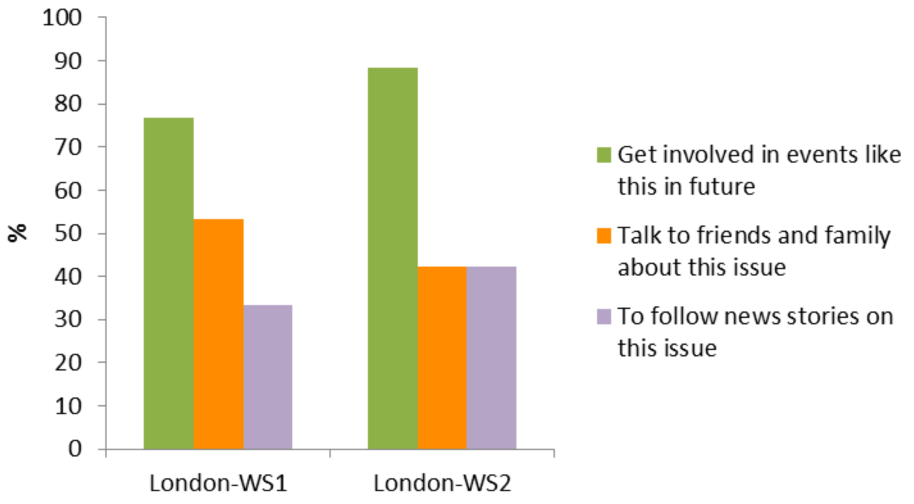


Table 15b: Answers to Question 18 on perceived impacts (Cardiff events)

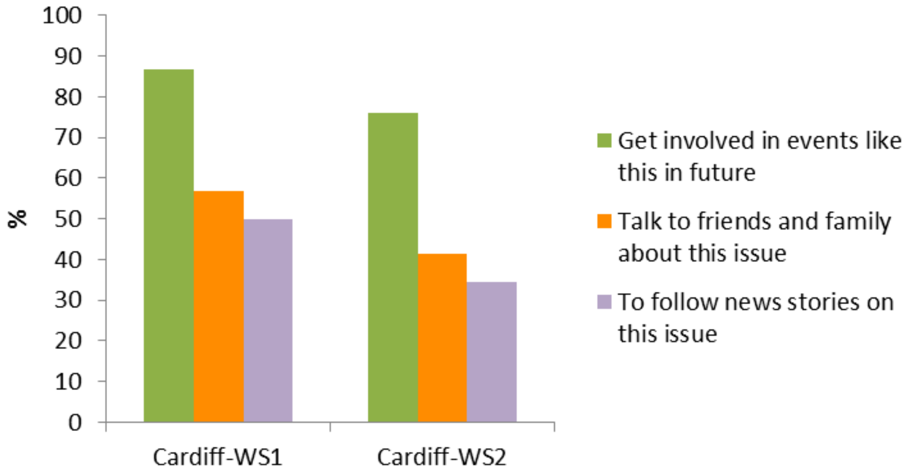


Table 15c: Answers to Question 18 on perceived impacts (Newcastle events)

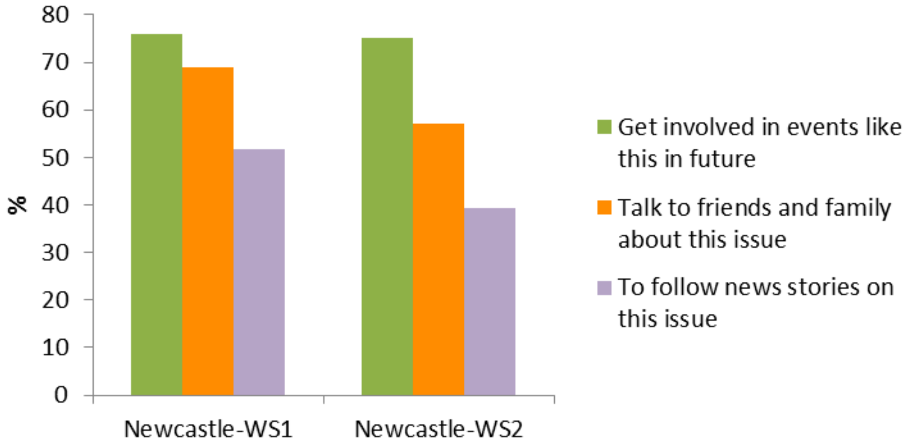
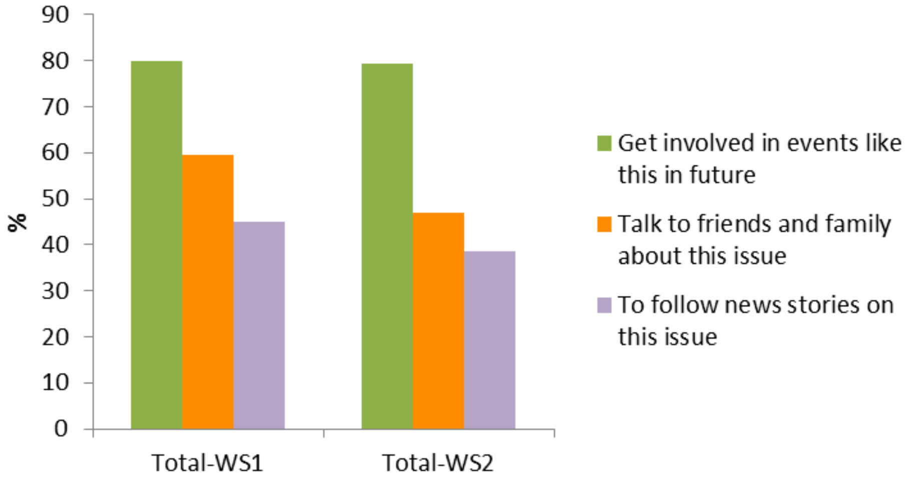


Table 15d: Answers to Question 18 on perceived imapcts (all events)



iv) In their own words: the pros and cons of the workshops

Most of the questions in the questionnaire are informed by a theoretical concept as to what makes good public dialogue, essentially, good information translation, in addition to event influence (which is seen as the necessary outcome of good translation of public dialogue aims). However, it is useful to ask participants in their own words what they have found good and bad about an event, as this can reveal alternative conceptualisations of the ‘effectiveness’ issue. The questionnaire therefore included three additional open questions that asked (19) ‘overall, what was the best thing about the workshop?’, (20) ‘overall, what was the worst thing about the workshop?’, and (21) ‘how do you think an event like this could be improved if something similar was run in the future?’

There were a number of very common themes in response to the ‘pros’ question. The pros given in response to attending the first workshops were very similar to those given in response to the second, and these were:

- Having learnt new things about an interesting/important topic
- Interaction between (and meeting other) participants and hearing others’ views (the table discussions)
- Interaction with, and hearing from, the experts (including the HFEA representatives)
- Well organised events/good moderators
- Ability to contribute to the issue/discuss concerns/air views
- The videos
- The informal approach/atmosphere/’laughs’/’freedom to air your views, without fear of offending’
- Meeting friendly people
- The lunch/cakes (three persons only)
- The money (one person only)

Of these responses, by far the most frequent was ‘having learnt something’, which arguably would be a great outcome if the event were merely one of public science communication. Although many liked the discussion aspects – talking to others (including the experts) – it is notable that there were no real responses concerned with, for example, having an opportunity to influence policy (the nearest to this was perhaps from a few people who were positive about having the chance to 'air their views'). It might be that participants were uncertain that they would have any actual influence on policy (in spite of assurances to the contrary). Logistical issues – such as food and money – played very little role in people's satisfaction.

Regarding the cons, these were expressed by far fewer participants. Indeed, the most common response to this question was either to leave it blank, or to write 'n/a' or 'no/none'. The main themes (noted by at least two participants) that did emerge were as follows, in descending order of frequency, with the number of responses of each type in brackets (with the first number being the number of participants raising this issue from the first workshop series, followed by the number from the second):

- The lunch (no hot meal or vegetarian option; coffee not ready on time) (10 from first series, 6 from second series)
- Unbalanced contributions by participants (some saying too much, some too little) (3,6)
- The incompleteness of the science information (0,6)
- Watching a video 3 times (seen as a little condescending) (4,2) (note, this was solely a Newcastle phenomenon: in the first event the video was shown three times, then once more at the start of the second event)
- Too long (3,2)
- Not fully understanding the subject/too complex/confusing (1,3)
- Not enough table discussion time (1,2)
- Noisy because tables too close (room layout) (3,0)
- A bit repetitive (1,1)
- The location (could have been out of the city?) (0,2)
- Hot room (1,1)
- Some people didn't listen (to others' opinions) (0,2)

As can be seen, the lunch was by far the biggest concern of participants, mentioned on 16 different occasions. Room layout (closeness of tables) and room temperature were other logistic difficulties. (Interestingly, the importance of these more basic concerns seems to correspond nicely with Maslow's ideas from his 'Hierarchy of Needs' – in which more basic needs can act as de-motivators, but not motivators, i.e. cause dissatisfaction, but not necessarily be a source of satisfaction.) Regarding the nature of other participants, some noted how some of their colleagues spoke too much or too little or didn't listen. Regarding the process itself, for some it was too long, while for others it was too short. The one major issue that emerged specifically in the second series of workshops was the apparently new and contradictory information that emerged in the video of experts (the 'cytoplasm' issue), which caused six to write of their concerns, and which also caused some voiced concerns by participants at the events themselves (as observed by the evaluators).

The final question concerned how the event might be improved. Again, the majority of answers were that it could not be, or no answers were provided. The answers that were provided tended, perhaps predictably, to follow on from the previously noted 'cons' ('provide better lunch', once ‘lunch’ had been identified as the worst part of the workshops; ‘have separate rooms’, when noise and closeness of tables was identified as a problem; have more or fewer sessions, when the events were perceived as too long or too short, etc.). One extra issue that did emerge, however, was the need to have a scientific expert available in the second round of workshops, as well as the first, as there were still scientific questions that needed answering that the bioethicists (etc.) could not answer (an issue identified by five respondents to the second series of events). Indeed, this was an issue noted by an evaluator at one of the events, during which a series of scientific questions were raised, which the available staff could not answer. There was also a call for more information of various types, including more on animal testing, more on figures/numbers/statistics, and perhaps more videos. A number of participants suggested having smaller groups, or more groups, and perhaps having mitochondrial disease sufferers in attendance.

v) Conclusion

This section of the report focuses on the results from the participant questionnaires, largely because the gist of our observations backed up the perceptions of participants, which is to say that the events were very competently run and facilitated, that there was a good use of information materials, that small discussions were well facilitated and – we hope – comprehensively recorded (tape recorders were used at all events). See also the section on stakeholder views, for wider insights beyond those of the public participants (section 11). If we were to draw a number of lessons at this stage, we would advocate:

- Ensuring information consistency, as the one real issue that seemed to cause consternation among participants was the apparently new information that was presented in one of the videos in the second session (re the ‘cytoplasm’ issue).
- Related to this, it was clear from the second series of events that participants often still had questions about the basic science around the issue – but these could not be specifically answered without the presence of a relevant expert. Thus, we would advocate having an appropriate scientific expert at both sessions. Presence of such an expert might also have helped to explain the ‘cytoplasm’ problem to participants and potentially ameliorate concerns.
- Taking issues of participant comfort more seriously – especially in ensuring a good lunch for those willing to give up their Saturdays!
- Consider using smaller groups and potentially multiple rooms to enable better participation of those attending (we noted, as did participants, how noisy it could become and difficult to hear discussions at tables). Possibly, the organisers were victims of their own success in this respect, as attendance was excellent at all events, and probably higher than expected.

Of course, some of the issues noted above would require greater staff or monetary resources, and so may not be achievable. Regardless, and in conclusion, we would suggest that the workshops were highly successful events from a variety of perspectives.

4. Open consultation meetings

a) Description of the Public Open Meeting Process

This chapter provides an evaluation of the 'public meeting' component of the project. The public meetings, one held in London and the other in Manchester, were designed to expose participants to the full gamut of possible views about mitochondria replacement techniques. They established a forum for informed debate about the issues. . These two-hour events involved the use of an explanatory video; statements from panel members in plenary; self-facilitated discussions among tables of participants; and plenary answering of questions by the panel members. The evaluation is primarily based upon evaluator observation, with other details added from a number of interviews with the organisers and a commentary provided upon the resulting report compiled by the contractors.

Observation suggests that the meetings were largely successful in the sense of providing an open, unbiased presentation of the key issues to participants who were largely already engaged in the issue in some manner. With respect to 'information translation', however, there were a number of matters that undermined the processes somewhat, often related to the natural (resource) constraints of events such as this, as well as the unfolding of events somewhat beyond the organisers' control (e.g. turn-out rate; missing expert panellist; presentational styles of panellists). These issues are elaborated in this chapter, with lessons for the future conduct of events like this made at the end.

i) *London*

The 'public meeting' took place at Hamilton House in London on 13th November 2012. Registration took place from 6pm (tea/coffee and finger food were provided in the main meeting room), with the event proper running from 6.30 to 8.30 (the event started about 5 minutes late, and over-ran by a similar time).

According to one of the organising team, over 60 people had registered an interest in attending. The total actual turn out of participants was 53; it is difficult to be precise because, in addition to the participants, there were various members of the contractors (OPM), the HFEA, the oversight committee, and the present evaluator.

The evaluator was told by an HFEA representative that, on registering, participants were asked to go to a particular numbered table (allocated in order to ensure a mix of people from different types of affiliations at each). Participants however did not always strictly adhere to this rule. There were seven numbered tables, plus an additional unnumbered one; participants sat around the tables numbered one to six (but not seven, which suggests that participants did not all follow instructions, unless it just happened that all participants allocated to table seven did not turn up), with a number of late arrivals sitting at the unnumbered table at the back and then being dispersed amongst tables one to six by the organisers once the table discussions began. On these tables were, first, a set of questions on several A3 sheets, with room for answers to be written, second, a set of A4 pages describing the mitochondrial disease issues and the novel treatments being considered, and third, blocks of coloured post-its.

The event began with one of the organising team (from OPM) welcoming participants. This presenter introduced himself and described to participants how this event was one of several strands being used by HFEA to address the mitochondrial disease issue that was being discussed. He continued by explaining the contractor's role, and then outlined a rough agenda for the evening, notably, that there would be a video, brief presentations from the panellists who were sat on the stage, '30 minutes' of table discussions in which they would be asked to 'facilitate themselves' and write answers to the questions on the A3 sheets (doing the top sheet first), and then they would open up into 'public debate' with free-ranging questions from the floor. We noted that digital recorders were present on all the tables and these would be turned on during the table discussions.

The presenter then introduced the evaluator (who was sat at the back, taking notes), briefly describing his role (to check that the event was open and unbiased), and also highlighted that there were other HFEA people and members of an oversight group who would be 'wandering around as well'. Finally, he directed participants to the HFEA consultation on its website and made a plea for participants to look into this when they got home.

The Chair of the event (BF) then took over. She began by noting that one of the intended panellists had had to pull out at the last moment for personal reasons, but that they had managed to find a replacement (a member of the oversight committee). The four other panellists on the days were then introduced in turn, and these included an HFEA Executive member, who was also included late in the day to add further scientific expertise to make up for the lost panellist.

After these introductions, the video was shown. This was an animated/ cartoon-like video explaining the issue of mitochondrial disease and the nature of the new treatments that might address this. The video was the same one as was shown in the previous public dialogue events held in London, Newcastle and Cardiff (and which was generally well-appreciated by participants – see previous chapter).

Following this, the Chair invited the four panellists, in turn, to speak for '3-5 minutes maximum' on the issue. The two 'replacement' panellists went first, followed by a speaker who might be broadly characterised as against the new interventions. While the first two speakers had generally kept to describing the science issues in a generally neutral manner, this speaker was more direct in opposition, using 'blunt' language and deliberately eschewing 'euphemisms'. The speaker used emotive terms: 'harvesting'; 'kills embryos'; 'spare parts'. The Chair questioned her at the end on her use of the term 'cloning', and asked one of the other panellists (the HFEA representative) if they were comfortable with the way the word was being used. She responded that it was 'not factually correct' to use the term as had the other speaker, although the latter continued to insist on the correctness of the term ('a different type of cloning'). At this point, a confident member of the audience spoke up and had a brief exchange with the HFEA panellist, until the Chair diplomatically intervened to move the event on because of the 'little time' available.

The fourth presentation was also somewhat emotive, with the representative of a patient charity, who had lost a daughter to the disease, giving a description of the progress and effects of the disease. In short, this presentation provided an emotive plea for the new approaches in counter-point to the emotive negative advocacy of the third speaker.

The Chair now thanked the speakers and passed the microphone (metaphorically) over to the chief OPM representative, who told the participants 'for the next 20 minutes…' to discuss the questions on the A3 sheets at their tables. He suggested that one person at each table act as chair and another as scribe. The instructions did not provide detail regarding how to do this. OPM representatives were then instructed to turn on the digital recorders at the tables.

The different tables then embarked on discussions of the questions. HFEA, OPM and oversight committee members sometimes circulated amongst the tables (as did the evaluator) and sometimes stayed at single tables to hear discussions (and sometimes contribute). More will be said on the process of these shortly.

After sometime (at least 30 minutes) the Chair gave a five minute warning and asked participants to write down some questions for the panel (the post-its were never mentioned, though some participants did now begin to write on these).

The Chair now announced to the audience that they would 'come together as a group' and move to the final session (beginning 7.45). Questions had been collected by the OPM staff, and some of these (although it is not clear how many, and/or how these were sieved) were now passed by the Chair to the panellists. Subsequently, the first two questions went to the HFEA panellist; the next two went to the patient charity representative, and two more were given to the 'anti' panellist and the stand-in panellist together (each taking the lead for one of these). Around 8.10 the stand-in panellist had to leave (to applause). During the answering of these questions, audience members occasionally came in to clarify (if the question had been theirs) or seek further answers from the panel. During this process it became clear that several in the audience were more expert in certain respects than the panellists and, recognising this, the Chair occasionally directed scientific questions to them.

The final act involved the Chair attempting to 'sum up' the discussion, and essentially ask the question as to whether the new research and techniques truly represented a 'sea change' or a 'big leap forward' – or not. Another 20-25 minutes of discussion followed, with questions/comments coming from about half-a-dozen audience members, and occasionally, from oversight committee members in the audience.

Around 8.35 the Chair brought proceedings to a close and thanked the audience.

Finally, another HFEA representative stood up, thanked the audience, talked of next steps, and again alerted participants to the HFEA online consultation.

The meeting broke up slightly later than planned, but it was notable that there was no great rush for the door, and perhaps half of the participants remained for some minutes after, discussing issues in pairs and small groups.

ii) Manchester

This meeting took place at *The Studio* in Manchester on 22nd November 2012. Participants were met by a receptionist and directed to a first floor room, where coffee and snacks were available, while name badges were present on another table. A member of staff gave participants their name badge plus a pack of information to take home.

Appendix 1 provides a sketch of room. This comprised a relatively large screen placed on the furthest wall, a table for a laptop, a collection of tables with four seats behind them for the panellists, and a flipchart (not used in the event). In front of the main screen were seven tables with eight chairs around each. On each table were glasses, pencils, bottles of water, a numbered sign (with numbers 1-8), an A3 sheet of paper containing questions, a pen, blank sheets of paper, post-it notes, a Dictaphone, eight copies of an A4 sheet of paper explaining the scientific steps for Pronuclear Transfer (PNT), and eight more explaining the scientific steps for Maternal Spindle Transfer (MST).

The event largely proceeded in the same way as London, although there were a few differences, largely consequent on the nature of interactions between participants and panellists, as will be discussed.

The event started at 18:38 (eight minutes behind schedule). One of the organising team from OPM (RC) asked everyone to sit at the table number corresponding to a number on their name badge. As people took their seats, it was clear that there were fewer than the 53 people present at the London meeting. The evaluator initially counted 40, including all panel members and HFEA staff. RC then asked individuals sat on scarcely populated tables to move to join another. Tables 4, 5, and 6 then filled-up (7/8 attendees), while Tables 1 and 3 had only 5 members on them (initially, though they filled as more arrived during the event). The participants appeared to range in age from their early 20s to mid 50's, was predominantly Caucasian, and entailed a mix of both men and women (although with slightly more of the latter).

RC welcomed all attendees and thanked them for coming when the rain/traffic was so heavy (a possible deterrent). He introduced himself and his organisation; explained that this was the second of two similar events (first in London); told the room about the HFEA website on this issue, and urged participants to articulate their views there before the deadline passes. (During this introduction, a few more people filtered into the room.) He then explained that there would be three parts to the evening: an introduction to mitochondrial transfer using a video and brief presentations from panel members ('about how they feel , which will provide a range of views'); group discussions, in which the A3 size sheets of paper and digital recorders would be used to record the issues raised; and a debate using an open floor style format to allow participants to ask questions. RC then introduced members of the HFEA and the evaluator (explaining that the latter was here to ensure the process was open and transparent).

RC then handed over to the Chair of the event (MB), who highlighted the importance of the topic being addressed and the difficulties surrounding it. She introduced all members of the panel by name and followed this by stating that the room would first watch a film explaining mitochondrial transfer in its current guise.

The video was started as more people filtered into the room. The video is as described earlier (see London event). The video ended with the question: 'What we want to know is that if this technique is safe, how do you feel about it being offered to women whose children might have mitochondrial disease?' When the video finished, one participant called out that she had a question; the Chair responded by saying that they would allow the panel members to present their perspective first, and allow questions after this.

The Chair asked the first panellist to speak. This was SR, a paediatrician, who explained more of 'the science side'. (This speaker had a soft voice, and no microphone, but she checked that those at the back of the room could hear her.) During her presentation, one of the participants (who turned out to be vocal through the event) shouted out a question, at which the Chair interceded and asked the room to leave questions until the end. This speaker had a number of slides depicting aspects of the science (the use of slides being a difference from the first event). Following this, the Chair suggested that they now move on to the implications that this technology might have for society, and welcomed the next panellist to speak (JQ) – founder of Comment on Reproductive Ethics. This speaker began by stating that part of her job was making things simpler for the public to understand. This speaker emphasized the controversial aspect of the new approach, queried whether mitochondrial transfer was in fact a 'cure', wondered whether PNT was a form of cloning, and so on. Her position can be characterised as against the technology. The Chair then asked the third panellist to speak. This panellist (MP) – Director of Research at the Muscular Dystrophy Campaign – introduced herself as working for a patient organisation on muscular dystrophy; she said she would provide the patient view on mitochondrial disease. Her position can be characterised as for the technology.

Following this, the Chair asked panellists for any immediate reactions to what other panel members had said. MP stated that she disagreed with JQs observation that this approach is a form of cloning – a statement that was vocally supported by several members of the audience (who murmured 'yes', 'that's right', and 'definitely', with a few more applauding). One of the participants at this stage shouted out "Why is one panel member throwing out these red herrings then?" (appearing agitated by the cloning claim of JQ). The Chair summarised that all could agree that the issues at hand were very difficult, and then handed over to RC to introduce the next section.

RC explained that this part of the evening involved looking at the different social and ethical implications of the techniques (stressing how some of these were discussed further on the website if participants wanted to look at them afterwards). As in the London event, on one sheet, there was a list of some of the main social/ethical concerns surrounding mitochondrial replacement including the notion of 'three-parent IVF', concepts of identity, affecting future generations, and the status of the donor. He asked attendees to discuss these issues by using the A3 sheet of paper, assigning one person to write with another person to chair. He urged participants to include as much detail as they could, including 'juicy quotes' where necessary. He said that staff would walk around the room and sit with groups to see how they were getting on. He concluded by indicating that the room would engage in debate in 20 minutes time (it being approximately 19:10 at this time). The Dictaphones were now switched on by the OPM staff.

The participants began to talk at the various tables, while some of the organisers and panellists walked around the room, stopping at different tables to eavesdrop and/or engage with attendees about their thoughts regarding the social and ethical implications of mitochondrial transfer. After about 25 minutes of discussion, RC announces that groups had one more minute to record their views on paper.

After a few minutes, RC then took the floor and announced that 50 minutes of the event remained. He passed over to the Chair to run the open forum. There was a notable difference at this stage to the London event. In London, participants had written questions on post-its, which were then collected and passed to the Chair, who chose a number from these to pass to the panellists for answering. Here, the Chair allowed the audience to ask questions directly without any unseen filtering. According to one of the HFEA project team, questioned by the evaluator beforehand, this was intended to allow the audience more airtime to articulate their views.

The Chair started by stating that attendees, should they have a question, were free to identify themselves but that they should not feel that they had to do this. The Chair stated that, before they took questions for the panel, she would like to ask attendees who had questions about the video to ask them now. The participant who had earlier raised her hand after the video (and been told to wait), now raised a point criticising part of the video as insensitive. A brief discussion addressed whether the video had been properly screened or not – it was clarified that the video had been presented to the project oversight group prior to use at events.

The Chair now moved on, and fielded various questions from participants. One queried the statistics in SR's presentation, which led to a discussion between the panellist and this audience member on prevalence and screening, with another participant (who has had a child/children with the disease) entering the debate, and broadening it (to include the issue of '3 parent IVF'). The latter's speech was emotive, passionate, and supportive of the innovations, and was greeted with applause from most members of the audience and panel. (This speech was often supplemented with reassuring utterances and quiet cries of support from other attendees.)

The Chair thanked this speaker and suggested that any other questions about the procedures/ science should be addressed now before JQ (the sceptical panellist) responded to the points of the last speaker. One point was raised from another audience member, answered by SR, and then the Chair asked JQ for a response. JQ began by talking about safety of the process, then moved on to dispute an analogy she had heard at one table likening the process to blood donation, saying 'quite clearly [they are] not the same. We are talking about creating life here so I think you need to get real'. At this point, one participant called out brusquely 'No, I think you need to get real'. This participant then continued that JQ was 'throwing red herrings all over the place.' As the debate began to get more heated, the Chair intervened, stating 'I think we can all agree that no-one is saying there are no risks with this technology'. The discussion on safety was continued by one of the previous participants and a panellist (MP), with further contributions by SR and a riposte by JQ (concerning which of the two transfer techniques is safer). The Chair then asked the room to provide further questions pertaining to the social and ethical issues surrounding these technologies.

One participant stated that his group struggled to find any ethical obstacles associated with mitochondrial replacement. A broader discussion then developed involving several audience members along with MP, JQ and one of the HFEA attendees. Some of this involved the interpretation of international and national laws and the possibility of changing these. At one point the Chair interceded, reading out an extract from an international agreement, after which she claimed that, although she should be neutral, she would speak out of turn in stating that these laws/conventions can mean whatever you want them to mean: 'To one person, they can mean X but to another, it means Y.' Further discussion continued, touching on issues such as 'identity', usually involving a number of the most out-spoken participants and a couple of panellists. Much of this debate was characterised by participants contesting assertions from JQ (who appeared to receive little if any support), sometimes quite strenuously (e.g. shouting out ‘that’s just your opinion though’), and often with disapproving murmuring.

The Chair then concluded, suggesting that many of the issues presented that night did not have yes/no answers. She then handed over to the chief executive of the HFEA to finish the session. The latter spoke for a couple of minutes, thanking all, suggesting that the contributions from this night would be useful, and urging attendees to go online to the HFEA website and provide any views they had. The event concluded at 20:32. Participants started to leave, though many individuals hung around at the end of the event to chat with one another.

b) The Evaluation Approach

The focus of the evaluation throughout the entirety of this current project is on the quality of ‘information translation’, that is, the extent to which comprehensive and unbiased information is transmitted from the information holders (e.g. sponsors, experts) to participants (the public etc.), and the extent to which information (opinions etc.) are then communicated between participants and from them to the sponsors. Our interest is in the efficiency of this process, and in particular, in documenting where there may be information gaps or loss, through inefficient processes (both in presenting, explaining and recording information). Although this perspective is central to the overall evaluation, it is important to recognise that this project has involved a variety of processes, and that some of these processes may have additional aspects that also need to be considered from our evaluative perspective that is based on assessing participatory elements. The ‘public meetings’ are arguably one such process.

‘Public meetings’ are problematic as models of participation being evaluated from a ‘stakeholder engagement’ perspective. Academics have occasionally criticised their concept, and some have suggested that they be better considered as ‘communication’ rather than ‘participation’ or ‘engagement’ approaches, in that they are generally set up to provide information to interested participants (often ‘the public’), rather than to collect (and respond to) such information. Furthermore, they can be problematic in the sense that participants are often self-selected, and hence may not truly be ‘the public’ but other stakeholders. From an ‘information translation’ perspective, this is problematic as audiences to such events can often be ‘biased’ in some manner (for example, attracting many members from specific interest groups, occasionally organised to flood an event), and hence information from ALL perspectives is not available or is drowned out by vociferous voices (i.e. there is information loss). Nevertheless, processes such as public meetings may be statutory requirements or organisational requirements (for better or worse). Their aim may be to be open, inclusive and responsive, even if there are limitations in terms of what they can conceivably gain from an information frame. In the current project, this is at least implicitly recognised, with stakeholder dialogue events and an opinion poll being used to ensure that, *overall*, the project gains the full range of perspectives on the mitochondrial disease issue.

Given the above, it would be unfair to assess the two public meetings from a purely information translation perspective (in isolation they would be extremely problematic; as part of the whole process less-so). Furthermore, these ‘public meetings’ are more responsive than many, with much greater effort made to *collect* as well as *transmit* information. Therefore, for this current evaluation, though the process WAS considered in terms of translation efficiency, it was also considered from a wider perspective as having other clear aims related to issues of openness and lack of bias.

The basis of this evaluation is also, admittedly, limited, relying upon the observations of a single evaluator at each event. Further evaluative claims may be made subsequently by referring to additional documentary evidence around the process, but we did not attain participant perspectives, as we might otherwise like. Observations have been broadly based on following an observation protocol discussed elsewhere, but with broader considerations of the additional aims noted. The evaluators took contemporaneous notes throughout the events, and, during the group discussions, migrated between all of the separate tables to get a sense of the process. They also informally discussed matters at the events with various participants when opportunities arose. As with all note-taking, there is potential for transcription errors (i.e. poor information translation!), and the following claims are open to response from others at the event and may subsequently be revised.

c) Results of Evaluation

To begin it is worth briefly revisiting the purpose of these meetings as one component of a multi-stage methodology, in order to provide contextualization as to what we identified as pertinent aspects for evaluative consideration. Accordingly, the meetings should be understood as being designed to expose participants to the full spectrum of possible views about mitochondria replacement techniques and to provide a forum for informed debate about the issues.

In this context, the first issue to consider is the extent to which the events appeared to be open and unbiased attempts to engage with stakeholders and members of the public about the mitochondrial disease topic. To the evaluators, there appeared to be a serious and diligent attempt to maintain an even-handed approach. In London, the panel comprised two members who attempted to cover most of the scientific evidence, and generally discussed matters in a considered and respectful manner. Two other panel members represented opposite ends of the spectrum on the position, and these gave more emotive presentations. The Chair performed well in mediating between the panellists without any sense of preference between these, refraining from expressing a personal opinion on the topic. There was no clear evidence of any position being given preferential treatment, and from wandering around the room and listening to conversations during and after the event, the evaluator caught no hint of participant dissatisfaction (though this evidence is weak compared to what may have been achieved via participant questionnaires). In Manchester, there were three panellists, one that focussed upon the science, and two others who might be broadly characterised as for and against the use of the novel methods. As in London, the Chair was highly professional, mediating the event with poise and without being dictatorial, doing well at pacifying potentially difficult situations. This Chair did at one point venture a personal opinion, which she recognised was perhaps against her remit, although this opinion was a balanced one, and involved noting the way that laws can be interpreted differently by different readers.

Regarding the issue of ‘information translation’, there were a number of occasions where some information loss seemed evident in both events. However, it is important to note that at the beginning of the events, the key aims were clearly stated, provisional agendas were established, and the expectations of attendees were plainly outlined (all positives). The magnitude of the public’s contribution to the day was established and reiterated throughout. There were sufficient resources to enable full output of the event to be recorded (audio tapes, plenty of pens/paper, etc.) and although the attendance was lower than expected in Manchester (the consequence of inclement weather), the amount of individuals involved in group discussions was sufficient to ensure that each member had the freedom to contribute in some capacity. The organisers also appear to have thought about improvements between the two events, deciding, for example, to allow the public to directly question the panel in Manchester, rather than having comments filtered as in London. Beyond this, the organisational team were engaging, professional and calm in their approach, whilst panel members were knowledgeable, passionate, and composed during their presentations and throughout the entire consultation.

The first of the main issues impacting 'translation' concerns panellist selection. In London, as noted, the 'scientist' had to withdraw at the last moment, and though the two replacements did well in trying to fill the gap, the unusual circumstance arose that several audience members were clearly more knowledgeable about certain topics than the panellists – the evaluator was subsequently informed that among the audience members were professors in mitochondria biology. It is credit to the Chair that she recognised this and took advantage of the situation rather than trying to deny or hide the matter. The tone of the presentations by the panellists did, however, differ, and the affects that they had on participants is likely to have varied. One panellist had a particularly emotive presentation that couldn't help but induce sympathy, while another was emotive in a different way and seemed to antagonise some in the audience (this panellist was directly challenged later by an angry participant during the plenary discussion). It is difficult to know how to equalise such presentations to enable a level playing field where the 'facts' are the sole focus rather than being partially filtered through emotional lenses. If the event were conducted as a social science experiment, then the different presentations might have been tested beforehand for consistency of timing, and content, and tone, but this is perhaps an expectation too far (and too costly) for an event such as this. Regarding the Manchester event, one speaker did have the advantage of using slides (information rich), as this speaker discussed more factual issues, rather than interpretations of social and ethical issues, this did not appear to be an unbalancing advantage (i.e. there was no bias for or against the novel methods). The two panellists here that did have opposing views were fairly well-matched, in the sense of tone – unlike in London, where the 'anti' speaker appeared quite strident and unsympathetic (the 'anti' speaker here was more measured – although the nature of the audience was such as to disadvantage her).

Another potential source of information loss may have arisen from the unbalanced nature of the participants. As noted, these were self-selecting (as expected/ intended) and so formed a rather mixed set. Many – particularly from the London event - would be better described as 'stakeholders' rather than 'public'. In contrast, in Manchester, the majority of attendees appeared not to be from stakeholder organizations, but to be students (in their early-to-mid-twenties) from different fields (e.g. law and medicine). It is perhaps of no surprise that fewer stakeholder groups would be represented in a meeting held away from the capital, since many stakeholder organisations are based in London, and this may in part reflect differences in the tones of the respective audiences: while the 'anti' speaker in London provoked some hostility, she nevertheless did have some support in the audience, whereas in Manchester, the 'anti' speaker appeared to be completely isolated (to the extent that a number of participants who were positive about the new treatments, told the evaluator after the event that they felt sorry for her).

This mix in participants can be problematic in itself, particularly in small group tasks, in which confident individuals with greater knowledge might easily overbear. It would also appear less likely that a public member (rather than a 'stakeholder') would have the confidence to ask a question at the plenary stage for fear of appearing ignorant in the eyes of the rest of the audience. Indeed, in observing events at the six tables in London, it was clear that, at each, there were one or two fairly vocal members who dominated the discussions and one or two who contributed little or nothing. In Manchester, it was notable that, at the final plenary stage (and indeed throughout), there were only a relatively few participants from the audience who spoke out and asked questions, and at least two of these appeared to be people with direct experience of the condition (i.e. having had children with the condition). The evaluator also observed that, around each of the tables he observed, there were one or two prominent speakers (though most participants he observed managed to have a say).

To counter such inequalities, stakeholder dialogue events often have professional facilitators (for this and other reasons) or, in the absence of these, often attempt to set ground rules for behaviour (e.g. be respectful of the opinions of others; do not interrupt; allow everyone to have a say). No such ground rules were set at the outset of the London event, nor at Manchester (although the evaluator did hear the lead contractor suggest to the Chair, when talking beforehand, that she ask participants during her discussion of 'housekeeping' to abide by some rules, such as being respectful and not talking over others). Thus, it is probable that the output from the audience did not reflect the views of all present, but primarily the views of a dozen or so of the most extrovert. This is not to say that the views gathered are not (qualitatively) important, but rather to emphasize that there may well have been some interesting views that were not elicited because of the nature of the process – an important issue from the information translation perspective, though perhaps less important given the precise aims of these particular events.

An additional activity that might have at least got participants into the mood of speaking would have been to have started with some sort of ice breaker exercise – if nothing more than asking all participants to go around and say who they were and why they were there. The evaluator in London was only able to observe the start of one group task, in which the participants (driven by a dominant individual) did just this. However, it is uncertain that this was done at each table as this was not a specific requirement made by the organisers. It was the impression of the evaluators that in most cases the groups had jumped straight into answering the key questions on the A3 paper.

Also related to the small group tasks, the instruction for the groups to choose their own chairs and scribes is perhaps not ideal. Chairing – or facilitating – a group requires certain skills, and indeed, note-taking is also a non-trivial skill. As such, it is quite easy for groups instructed to self-manage to somehow go awry. Amongst the London evaluator's observations were that, at one table, a dominant individual appeared to have taken on both roles (leading to clear information deficit – as when he spoke he waved the pen around rather than writing); at another, a scribe was instructed to ensure he wrote down the 'group's' views, and not just his own (a natural inclination!); at another, the Chair role was taken by one of the organising team (which might not have been a bad thing, though it suggests an inconsistency in process). In Manchester, the evaluator noted a similar situation, in which an HFEA project team member essentially governed the process at one table. The behaviour of one or two of the participants in London was also somewhat patronising (although the group discussions seemed much more respectful in Manchester): a professional facilitator is unlikely to have allowed some of the behaviour witnessed by that evaluator.

The role of the various people associated with the running of the event also raised issues. Amongst the audience were a fair number of oversight committee members, HFEA Authority members and executive, and OPM staff, and their approach to the two events varied. Some actively became involved in the small group discussions, while others seemed to take on an observer role. Neither approach is necessarily problematic, though consistency is important, and it was not clear to the evaluators what instructions had (or had not) been given to these people[4]. Active involvement may have been beneficial in encouraging the groups to think on alternative topics… though it should also be remembered that with such a small amount of time (about half an hour), a significant discussion by a 'non-participant' could have severely reduced the time for the others (averaging five or six per table) to speak.

The use of materials was also perhaps not optimal. On each table were placed A4 sheets with information about the issue being discussed. However, the evaluator in London only noticed one person during the evening actually pick up one of these sets and leaf through it. The Manchester evaluator noted that the information packs given to participants at the outset were generally left unopened. Participants were given no instructions with regards to these sheets or other information and no time to read them. This is not necessarily a problem, in the sense that the information was present as a back-up if needed, and is unlikely to have been very costly to produce. However, the general principle remains that, if information or material is provided, it is generally good for organisers to note this and enable sufficient opportunity for its use. Likewise, the role of the post-its was never described at either event: it might seem self-evident, but these were only really picked up by (some) participants in London after the Chair's five minute warning, when she asked for participants to think of questions for the panel (the evaluator noted one exchange where a participant asked '…what on?' and then dismissed the post-its shown to him by a colleague as they were 'too small'). In Manchester, though post-its were available they weren't required because of the change in process (in which participants were asked to ask questions from their groups, rather than relying upon a sifting of questions by the Chair/ contractors).

One other simple factor related to information loss was that of time. Indeed, the London Chair herself noted that the final question from the floor was on a topic that could, in itself, have been talked about all evening. Clearly – and as is often the case in events such as this - there was much

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[4] The evaluators were subsequently informed that specific instructions were provided to the oversight group and authority members as follows: "We would like Authority and Oversight Group members to spread themselves evenly throughout the tables – we will allocate you to a table. The group discussions will be self-facilitated (and OPM & HFEA staff will be floating to collect questions and ensure the discussions run smoothly and the panel members will be on hand to answer questions). However, as you are likely to be more familiar with the issues the consultation raises than others round the table, we would be grateful if you could prompt discussion and question/challenge views to help to ensure the reasons for people's views are recorded and that the discussions, as far as possible, cover a range of different views. We would also appreciate it if you could address any questions about the consultation process or call someone over from OPM/HFEA if needed. Your name badge will show that you are an Authority member or Oversight Group member but please mention that at your table. Please also declare this if you wish to make a comment during the plenary debate."

more to say on the general topic of discussion, and this may have been reflected in the after-event conversations that continued for some time at both venues.

In Manchester, there was a feeling that the event ended prematurely with some issues not being addressed. If participants had longer to discuss the issues at hand, potentially in another group discussion - as this often proved to be a rich forum for avid debate among audience members - this may have resulted in greater attention being paid toward the social and ethical issues of mitochondrial replacement, which at times seemed to be overshadowed by conversations about the science itself. Indeed, this biasing towards the science was seen as problematic by a number of organisers (expressed in discussion with the evaluator afterwards), which may have been driven by the emphasis on the science in the video and the presentation of one of the speakers. We subsequently learnt that the scientific panel member focused on explaining the techniques so as to pre-empt questions which might surface at the beginning of discussion and with the hope of maintaining a focus on the ethical, less scientific, issues.

A response to this lack of engagement with the social and ethical dilemmas is tricky. Organisers should be careful not to spoon-feed or lead discussions given that they want an organic public (and/ or stakeholder) opinion but, during this consultation, a lack of intervention resulted in some audience members being unable to establish *any* key social and ethical issues. A solution to this might be the introduction of fictional, 'real-world' scenarios like those which proved popular in previous events. Another option would be to provide newspaper headlines which discuss mitochondrial transfer in some capacity (e.g. 'I've got two mums and a dad'; 'Scientists win right to play with our genetic future'; 'Are we opening the door to designer babies?'; 'Is this another medical science adventure which benefits only a few?' etc.). As a potential alternative, these could have been written on the flipchart that was not utilised throughout the consultation (this may have helped to synthesise views as well, although it was very clear what side most, if not all, of the public were on). This may have helped the public identify some of the key ethical and social concerns without excessive interference from the organisers. The general plea made by the HFEA representative at the close (as well as the organisers throughout) for participants to complete the online consultation may have allowed an opportunity for the unstated opinions to be aired.

There were a few other minor issues noted by evaluators at both events, which might have had some impact on 'information translation'. One of these was the lack of microphone for panel members – though we note microphones were provided for London panel members (this would be a problem at other events for more softly-spoken panel members and organisers), while in Manchester the main doors were open when the video played so outside noise may have disturbed some audience members.

d) Conclusions and lessons

To remind, these meetings were designed to expose participants to the full spectrum of possible views about mitochondria replacement techniques and to provide a forum for informed debate about the issues.

There were clearly a number of positive aspects to the events in London and Manchester, not least that the events appeared to be run in an open manner that clearly sought to be fair and unbiased – in terms of their selection of panellists, and in how opinions were enabled to be heard. The discussions were professionally facilitated and provided a means through which members of the public interested in mitochondrial transfer could articulate their perceptions, concerns, and understandings. The two Chairs were also impressive, displaying balance throughout and doing well to control potentially difficult exchanges. It is also notable that the atmosphere at both events was welcoming, with coffee and snacks provided (and the food was good!), and a friendly aura. From this perspective, it is likely that that the audience went away relatively positive regarding HFEA's efforts (though lack of evaluation data on participant opinions precludes making this statement strongly).

In terms of lessons for the future, it is first necessary to note that in the present case, some of the translation difficulties noted are largely countered by other elements of the overall program (e.g. gaining views from representative public samples), while some of the difficulties that arose can simply be lain at the door of bad luck (the withdrawn scientist in London; bad weather in Manchester)) or largely uncontrollable events (having decided to allow participants to self-select, it is then down to those registering to actually turn up!). Beyond this, however, a number of lessons for the future can be identified. These are:

- At the outset, give participants 'ground rules' for behaviour in small group and plenary sessions
- In the small group task, ask participants to introduce themselves and note their affiliation (i.e. use some sort of ice breaker exercise)
- Chair, facilitator and scribe are non-trivial tasks: try to avoid placing these roles on participants in group exercises if you can at all avoid it (perhaps using slightly bigger groups to enable these to be facilitated by the contractor team)
- Consider the implications of mixing people with different levels of knowledge, confidence etc., to ensure everyone feels equally able to speak and contribute (e.g. beware mixing highly knowledgeable stakeholders and uninformed members of the public)
- If information or material (e.g. post-its) is provided, ensure that the participants are clear on their use and that they have the opportunity to use these (otherwise they are a redundant cost)
- Be clearer as to the aim of the small group tasks and the role of 'home team' members (are they expected to contribute, to clarify points only, or to remain silent observers?)
- Provide a mechanism whereby participants can get their opinions to the organisers – such as through a post-event questionnaire
- Consider allocating each group an allotted amount of time (5-10 minutes) to voice their perspectives in order to ensure a fairer distribution of airtime in the open forum element (e.g. at Manchester)
- Think more carefully about desired audiences and if necessary take steps to encourage certain parties to attend (e.g. at Manchester it was notable that the 'anti' panellist was outnumbered, while one of the 'pro' participants with direct knowledge also complained that the preponderance of students in the audience didn't have relevant experience to contribute and that more people personally affected by the condition ought to be present)
- Consider utilising alternative approaches (e.g. using scenarios or fictional newspaper headlines) to help focus participant thinking on the key topics of the event (here, the social and ethical issues, rather than the nature and adequacy of the science)

6. Public representative survey

a) Description of process

This element involved a general public opinion survey of public attitudes towards the genetic treatment of mitochondrial disease.

The survey was included in a UK omnibus survey. Respondents were selected using a random location methodology (i.e. a random selection of 175 sample points was created, covering the UK, for each of which demographic quotas were set to ensure that the selected sample was representative). Respondents were contacted by interviewers in these sample points, with interviews carried out in August 2012. In total, 979 face-to-face interviews were completed.

The survey comprised 10 'questions' (listed below), although some of these comprised several actual questions (e.g. the first 'question' asks to what extent respondents agreed or disagreed with three different statements about medical research).

Q1. To what extent you agree or disagree with the following statements?
Medical research can do a lot to reduce human suffering
Medical research creates new knowledge and treatments which will benefit the wider healthcare system
The application of medical research leads to unforeseen negative side effects

Q2. To what extent you agree or disagree with the following statements?
There should be free and accessible healthcare and treatment for people with serious genetic diseases
There should be free and accessible genetic testing to help families avoid having a child with serious genetic disease

Q3. IVF is where a couple having difficulties conceiving have eggs and sperm mixed in a laboratory to create an embryo. The embryo is then grown for a few days and placed into the woman's womb where it has a reasonable chance of leading to a normal pregnancy. Have you heard of IVF (in-vitro fertilisation) before?

Q4. Techniques are already available to test embryos during IVF for a specific genetic disease. Couples who know they have a high chance of having a child with a serious genetic disease can use this technique to have a child without that disease and not use the embryos that have tested positive. How would you describe your attitude to this?

Q5 Can I just check if you, a member of your family or your immediate circle of friends have any direct experience of inherited genetic disorders such as cystic fibrosis, Huntington's disease, muscular dystrophy or sickle cell anaemia?

Q6. Some people are born with, or develop, genetic diseases – such as cystic fibrosis, Huntington's disease, muscular dystrophy or sickle cell anaemia – which they inherit from one or both of their parents. These diseases are caused by an alteration in an individual's genetic material that leads to a variety of physical or learning impairments. A small proportion of these genetic diseases are inherited just from the mother and are difficult to avoid. These are called mitochondrial disease and can often be severe. Have you heard of mitochondrial disease before today?
Have you heard of mitochondrial disease before today?

Q7. Scientists are developing techniques which could remove the chance of these mitochondrial diseases by altering the genetic make-up of an egg or embryo during IVF. What is your initial reaction to this?

Q8. In order for this to happen, you would need to replace abnormal mitochondria in the intended parent's egg or embryo with healthy mitochondria from a donor egg or embryo. This means that any resulting egg or embryo will contain a small amount of genetic material in its mitochondria from a third person (other than the mother and father). What is your reaction to this?

Q9. As I said before, the techniques to avoid mitochondrial disease would involve altering the make-up of an egg or embryo, specifically the mitochondria. The donated healthy mitochondria would replace the intended mother's faulty mitochondria and would then be passed down to the child and, in turn, to that child's children and beyond. This is called germline gene therapy, because the change goes down through the generations (the germline). Assuming that scientists could show that this is safe, what is your reaction to this?

Q10. Currently, these techniques cannot be offered to couples as the law only allows them to be carried out in research. However, Parliament may have an opportunity to change the law to allow these techniques to be offered to couples. If Parliament did change the law, who do you think should decide whether individual couples should have the treatment?

As can be seen above, several of the questions required respondents to answer yes/no/don't know, although the majority required responses on scales (usually 5-point, with an 'unsure' option) indicating the degree to which a statement was agreed with (either stated as from 'strongly agree' to 'strongly disagree' or from 'very positive' to 'very negative'). The final question presented respondents with three policy options ('if Parliament did change the law'), from which to choose.

b) Commentary on information inputs (the questions, and their development)

Questions were developed with input from the HFEA, OPM and the project oversight group. They were subsequently trialled on a focus group, much in the same way as the dialogue materials.

By and large the questions were neutrally framed, with balanced scales. Where there is a positive framing in any one question, there is also a negative framing to ensure balance (for example, 'question 1' has three statement: while one asks about 'reducing human suffering' another asks about 'negative side effects', i.e. questions are asked about both positive and negative aspects of medical research). Some of the questions are perhaps imperfectly phrased (e.g. question 2 asks respondents to what extent they agree with 'free and accessible healthcare and treatment for people with serious genetic diseases', which causes problems if one thinks that healthcare should be free but not accessible, or vice versa (i.e. accessible/available, but at a cost)). It is also to be hoped that respondents to this question knew what 'serious genetic diseases' entailed, as the term is not defined. Subsequent questions, however, do premise their questions with definitions or explanations of the issues being discussed (e.g. IVF, mitochondrial disease).

Q10 asked participants to choose one of three options regarding who should decide whether a couple could have treatment 'if' Parliament did change the law to allow this (expert regulators; medical specialists; the couple themselves). Methodologically there would appear a slight problem with this question, in the sense that it is necessary for the three options presented to be fully inclusive, that is, for there to be no other conceivable options (or combinations), otherwise respondents would be being denied an opportunity to choose something else, and forced by the question to choose amongst options with which they did not really agree. If inclusiveness could not be guaranteed, it might have been best to include an ‘other’ option (even though it is difficult for people to necessarily think beyond framing presented to them). Care should also be taken in the sense that the question asks respondents to make a choice ‘if’ there is a change to law… without allowing them to say they do not think there should be such a change, i.e. taking the answering of the question for implicit agreement that the law should be changed.

c) Commentary on information outputs

First, given the nature of the recruitment method, following a clear procedure to attain a representative national sample, it appears that comprehensive access to relevant information sources was achieved. Where certain differences exist between desired and achieved samples, a weighting approach has been taken, with analysis based on the weighted figures.

Following this, the analysis in the report – which shows responses to the questions asked as the percentage of the overall sample – also seems fairly complete. Although the analysis contains few comparisons between sub-groups this is stated as because “views were held relatively consistently between sub-groups, or because variations were relatively small and lacked consistency” (p.3). However, the specific socio-demographic factors tested for effects should be noted (e.g. male-female; age; region). (Ideally, evidence ought to also be provided for ‘null results’ – such as in an appendix - to allow the reader to see that factors such as age had no consistent influence on opinions, but this would clutter the report perhaps and make it difficult for an audience to read.) The factors of ‘education’ and 'faith’ were highlighted as ones producing more consistent variations, and the analysis subsequently describes these differences in results numerically in the text when they occurred (although it might be easier to see the nature of differences if such results were presented in figures, as are most of the general sample results).

6. Open consultation questionnaire

a) Description of process

An open written consultation: ‘Medical Frontiers: debating mitochondria replacement’ ran from 17th September 2012 to 7th December 2012. Respondents were asked to engage with information presented online within the consultation website and provide answers to seven questions.

The purpose of the written consultation was to gather public views on the social and ethical impact of making the proposed techniques available to patients.

The consultation generated a total of 1,836 responses the majority of which, as noted by Dialogue-by-Design who administered the consultation, were returned via the consultation website (n=1,260). In addition, a further 524 letters and e-mails were received; and 45 respondents completed a response form. Respondents are reported as being made up of stakeholder organisations, individuals with personal experience of mitochondrial disease and undifferentiated members of the public. A caveat is included in the report of the process which makes explicit and emboldened reference to the views expressed as not necessarily being representative of the wider population.

b) Commentary on information inputs

As with the variety of other consultation materials and apparatus used in the course of project, the questions in the open consultation questionnaire, received the scrutiny, input and advice of the oversight group and HFEA project team.

c) Commentary on information outputs

The results of the open consultation questionnaire are unique among the multiple strands of the project for invoking, if only by a small margin (just over 500 respondents), greater numbers in opposition to the introduction of both techniques than in favour.

d) Conclusion

The findings of the open consultation questionnaire ought to be viewed cautiously and mindful of the lack of profiling data of significant numbers of those responding. Of 1260 completing the online survey, 917 aligned themselves with the profile category ‘other’. A further breakdown of the ‘other’ respondent type reveals a clump of respondents’ self-identifying with ‘member of the public’, which is not altogether revelatory. However, we are able to discern that the second highest sub-category to ‘other’ (n=143) consists of those claiming ‘professional expertise in science, medicine, bioethics etc.’, in other words, those who might be aligned with a scientific investment or at least, interest, in the techniques. A further, 61 respondents identified with the sub-category ‘concerned about mitochondria replacement’. The majority of opposition to the two techniques emanated from this cohort. In contrast, those most likely to be in favour of the two techniques were drawn from less well represented cohorts: those personally affected by mitochondrial disease (n=57) and those described as a family member/friend of someone affected by mitochondrial disease (n=151). This trend correlates to the findings of *Chapter 11. Media Representation of, and Responses to, the Consultation*, where the public’s ethical uncertainty and ambiguity towards the two techniques tends to increase where direct experience and emotional investment in respect of mitochondrial disease is limited.

A final caveat to interpreting the findings of this strand of the consultation again refers to respondent type, this time focusing on a respondent classified as: an individual responding of his/her own volition; organisations or membership bodies; and finally individuals responding as representatives of a particular organisation/group and therefore that body's ideological stand-point. In conclusion, we would suggest that the findings of the open consultation questionnaire are not representative of attitudes attributed to the 'general public' but a variety of sub-publics – some with specific ideological/ethical investments.

7. Focus group with people affected by mitochondrial disease

a) Description of process

A focus group was conducted in London in December 2012 with six participants, all of whom had been affected by mitochondrial disease in different ways. One telephone interview was also conducted by the dialogue delivery contractors, in January 2013, with a participant who was unable to attend the focus group.

b) Commentary on information inputs (the questions, and their development)

We can say little about the development of the focus group protocol from the report, as it contains few methodological details. For example, it does not explain how the six participants were selected, nor does it discuss the questions asked in detail (as opposed to under broad headings), whether the event was tape/digitally recorded, or describe the analysis process. However further to inquiry, the HFEA has confirmed that participants were recruited through patient groups – the Lily Foundation, the Muscular Dystrophy Campaign and the Children's Mitochondrial Disease Network, who were also asked by the HFEA to advertise the focus group through their networks. We understand that patients were also approached at the open meetings.

c) Commentary on information outputs

The outputs from this process are qualitative rather than quantitative. It is unclear how the analysis was done. The process of having participants write down thoughts on post-its seems sensible, and allows a verifiable record of participants' views (recommendations to government). Qualitative data was fed into both OPM's global report and HFEA's own.

d) Conclusion

This was a relatively minor – though important – element of the overall process, deliberately engaging with people with a very direct stake in the problem, i.e. sufferers. The only possibly negative issue here is that there was just a single focus group – and more groups might have uncovered other issues (i.e. data saturation cannot be confirmed). However, other views from this important group were also collected through the consultation and expressed by panel members (who were sufferers) in the two public meetings.

8. Media representations of, and responses to, the consultation

a) Overview

This chapter provides an account of the consultation from its inception to the point of presentation of its results as viewed through the lens of the UK online-media – the majority of the following excerpts take their origin from electronic versions of UK newspapers and online news outlets such as BBC online. The chapter accordingly seeks to situate a perspective on the consultation drawn from external commentators: science reporters/writers and public groups responding to their articles: ‘distal’ stakeholders i.e. those not directly participating in the consultation yet invested in its commentary. This focus and intention of this chapter is in presenting the various media representations and responses to the consultation and therefore its wider public contextualization. It should not be assumed to be a fine-grained, critical analysis of media constructions of the consultation. It is not. We do however provide, in the following section a summary of key points.

Accordingly, this chapter should be treated as a selection of ‘sound-bites’ which elicit attitudes/opinions to the consultation. These are represented within the various articles as ‘expert commentators’ and reader responses to specific articles and as organised through online commentary forums. Our hope is that as a repository of media reportage, this chapter will provide the reader with a more lucid sense of the way the consultation and its findings were received and represented by UK science journalists and their readers.

b) Key points

- The vast majority of articles made reference to, or included in their title, ‘three parent’ babies
- Whilst the majority of articles represented the polarity of ethical opinion on the techniques, the focus of opposition appeared habitually solitary, with David Kind routinely exclusively presented as the voice of dissent.
- Some of the articles have confused the words ‘advise’ and ‘recommends’.
- The majority of articles accurately outlined the advice and wording used in the HFEA’s press release: www.hfea.gov.uk/7790.html
- Articles with online forums generated a significant volume of reader responses.
- Other articles featured relatively high-numbers of online ‘shares’, ‘forwards’ and ‘re-tweets’.
- Many reader responses were premised on first-hand experience of IVF and mitochondrial related disease.
- Reader responses reflected a contrast of views between those who interpreted the techniques as ‘unnatural’ intervention, and those who felt that the benefits of the techniques were such that ethical deliberation was largely unwarranted and redundant.

c) Key dates

The HFEA launched the public consultation into the ethics of the novel IVF-based mitochondria transfer techniques on 17th September 2012.

Press briefing was held on 14th September 2012. The HFEA press officer has commented that this briefing was one of the most highly attended.

Press briefing: 19th March 2013 with Professor Neva Haites (Chair of the project Oversight Group), Professor Robin Lovell-Badge, Juliet Tizzard (HFEA) and Hannah Darby (HFEA)

Authority decision provided on the 20th March 2013

In piecing together this chapter we have identified and reviewed a large number of online media sources, including: electronic versions of daily UK broadsheets; one tabloid newspaper; news-sites such as that provided by the *BBC*, *Reuters* and *Sky News*; regional news-outlets; and more specialist stakeholder/interest-group sites. The breadth and diversity of sources reveals, as might be expected, significant media interest in the consultation.

The following lists should be read as comprehensive but a non-definitive inventory of media coverage, and provide recommended additional reading:

d) Media Coverage following announcement of the consultation

Source	URL
BBC News	http://www.bbc.co.uk/news/health-19597856
BBC Blog	http://www.bbc.co.uk/news/health-19604004
ITV News	http://www.itv.com/news/2012-09-17/are-you-comfortable-with-a-baby-having-three-parents/ & http://www.itv.com/news/update/2012-09-17/choosing-babies-genetic-make-up-is-unchartered-territory/
The Independent	http://www.independent.co.uk/life-style/health-and-families/health-news/regulator-asks-public-whether-to-allow-three-parent-families-8143333.html
The Guardian	http://www.guardian.co.uk/science/2012/sep/17/genetics-embryo-dna-mitochondrial-disease
The Telegraph ***(front page)***	http://www.telegraph.co.uk/science/science-news/9546214/Three-parent-baby-fertility-technique-could-be-made-legal.html
The Mail Online	http://www.dailymail.co.uk/health/article-2204291/Dawn-GM-baby-Technique-gives-children-parents-year-away.html
The Daily Star	http://www.dailystar.co.uk/latestnews/view/272615/Public-opinion-sought-on-GM-babies/
Reuters	http://uk.reuters.com/article/2012/09/17/uk-ivf-3parent-idUKBRE88F0IA20120917
The Wellcome Trust	http://www.wellcome.ac.uk/News/Media-office/Press-releases/2012/WTVM056294.htm

The Scotsman	http://www.scotsman.com/the-scotsman/health/views-wanted-on-creation-of-ivf-babies-from-genes-of-three-parents-1-2530418
Wessex FM	http://www.wessexfm.com/news/national/767980/three-parent-babies-could-be-made-legal/
London and South East News	http://www.lse.co.uk/FinanceNews.asp?ArticleCode=l43ln0jr63xnx80&ArticleHeadline=RPTBritain_asks_Should_3parent_IVF_be_allowed_to_avoid_disease
Herts and Essex Observer	http://www.hertsandessexobserver.co.uk/News/National-News/Public-opinion-sought-on-GM-babies-2-1254095.xnf
Channel 4 News	http://www.channel4.com/news/public-to-get-its-say-on-babies-with-three-parents
BBC Today Show (edited)	http://news.bbc.co.uk/today/hi/today/newsid_9752000/9752373.stm
International Business Times	http://www.ibtimes.co.uk/articles/385029/20120917/britain-asks-shouldparent-ivf-be-allowed-to-avoid-disease.htm
The First Post	http://www.theweek.co.uk/health-science/49066/ethics-debate-opens-three-parent-ivf-technique
The Crosby Herald	http://www.crosbyherald.co.uk/news/uk-world-news/2012/09/17/public-opinion-sought-on-gm-babies-68459-31848826/
Expatica	http://www.expatica.co.uk//news/british-news/-three-parent-baby--fertility-technique-mulled-in-britain_244178.html
Medical Express	http://medicalxpress.com/news/2012-09-three-parent-babies.html
Net Doctor	http://www.netdoctor.co.uk/interactive/news/consultation-launched-on-three-person-ivf-id801450239-t116.html
Red Online	http://www.redonline.co.uk/news/in-the-news/three-person-ivf-consultation-begins
Bionews	http://www.bionews.org.uk/page_177705.asp

e) Media coverage following announcement of the results of the consultation

Source	URL
The Telegraph	http://www.telegraph.co.uk/science/science-news/9942873/Britain-on-course-for-three-parent-babies.html
Sky News	http://news.sky.com/story/1067007/ivf-three-parent-

	babies-hurdle-cleared
BBC News Online (video)	http://www.bbc.co.uk/news/health-21856436
BBC News Online (article):	http://www.bbc.co.uk/news/health-21806911
Nature	http://www.nature.com/news/wide-support-in-uk-for-novel-dna-transplants-in-human-egg-cells-1.12649
The Guardian:	http://www.guardian.co.uk/science/2013/mar/20/britain-three-person-embryos-genetic
The Independent:	http://www.independent.co.uk/life-style/health-and-families/health-news/three-parent-babies-one-step-closer-survey-reveals-support-for-radical-ivf-therapy-8542476.html
The Mail	http://www.dailymail.co.uk/health/article-2296286/Plans-parent-IVF-babies-step-closer-fertility-watchdog-gives-ahead.html
The Times (behind pay wall)	refers to a letter sent by Nobel Laureates to the Government asking them to legalise the techniques for treatment

In addition to these sources, it is worth noting 7 further media presentations on the consultation provided by Lisa Jardine as HFEA Chair: BBC Today programme; BBC News 24, BBC World, BBC Scotland and Channel 5; and HFEA CEO, Peter Thompson on Drive Time on Radio 5 and Sky News.

f) INITIAL RESPONSE to CONSULTATION ANNOUNCEMENT

1. 'Three people, one baby' public consultation begins' – James Gallagher 17th September 2012
This article generated 413 responses: among those of the **'Editor's Picks'**:

"Nature has created this problem, and it's a step forward to be able to help some parents in a meaningful way. If the gene is "bred" out of the line, then the savings in stress, emotion, worry, and ultimately financial savings will surely make it worth it. . .No-one should see their child die for want of a bit of science."

"To people who don't agree with this technology: if your child had a severe disease leading to pain, disability and death before the age of 5, and you had the opportunity to prevent this for your next child, would you take it?"

"I don't believe that there is a right to have a child, however, I do believe that there is a right to have a healthy child. Anything we can do to rectify or remedy genetic defects should be permitted."

"Given that IVF is already available I do not see any additional ethical issues that should hinder

this. In fact, I think it's wonderful that biomedics have developed techniques that would enable this kind of treatment in a few years. Yes, there are ethical issues and there are financial issues, but these are no different to those we already have for IVF. You can't put the genie back in the lamp."

". . . if this treatment becomes available it should be within the grasp of anybody that needs it, not just for the privileged few who can afford it as that would obviously be grossly unfair."

"Natural Selection should be Natural (not contrived, not enhanced, not circumvented).Yes, it is sad not to have perfect anything, yet people do live with limitations, disabilities, wishes denied (poverty, education limits, social circumstances).Society not obligated to give Anyone (much less Everyone) 100% of all they may wish for including perfect health. Accept you can't have it all & Adapt. Adopt."

"I have Mitochondrial disease and cannot believe anyone would be against this treatment. Myself and my twin brother were diagnosed two years ago and suffer greatly from the resulting effects of the disease. How this can be linked to designer babies is beyond me. Meddling with nature? It really makes me sad hearing these comments from someone who obviously doesn't understand genetic diseases."

"If one understands the science, one cannot find reason to object. This is not 'engineering' - no genetic material will be altered or mutated and no genetic traits will be selected for, apart from lack of mitochondrial disease. It's simply replacing mitochondria. And for the record, it is NOT a small step from replacing nuclear (genomic) DNA."

"How this can be linked to designer babies is beyond me. Meddling with nature? It really makes me sad hearing these comments from someone who obviously doesn't understand genetic diseases."

2. 'Ethics of using three people's DNA to create one baby' Fergus Walsh (BBC Medical Correspondent) 17th September 2012:

[Comparison to transplantation as] a 'medical technique . . . of fundamental significance to medicine and society'

"Unlike transplantation and fertility treatment, it would benefit very few couples. Those it could help would be able to have healthy children free of a potentially fatal genetic disease. Future generations of those families would also be free of the genetic fault. But it also has huge potential significance for society because for the first time children would be born with DNA from three people – what has frequently been dubbed 'three-parent IVF."

"The technique raises many [ethical] issues: what is the legal status of the woman who donates her DNA? How might any child that is born feel about having DNA from three people? When should they be told? But this is not just an issue for the couples involved. For the first time it will mean that scientists are altering human genetic inheritance."

Comments to Article

“I think that as long as all parties are satisfied, there should be no reason why not.”

“I think medical advances nowadays are contributing vastly to the overpopulation problem worldwide . . . if the body is naturally not able to conceive/produce a viable baby due to a disorder or condition, surely it is simply natural selection. We can’t keep aiming to produce ‘perfect’ human beings.”

“Mad scientists is the term that comes to mind . . . Every action has a re-action and a baby made in a laboratory is an unnatural process which will have an effect.”

3. Regulator asks public whether to allow 'three parent families', Jeremy Laurance, *The Independent, 17th September 2012*

Josephine Quintavalle of Comment on Reproductive Ethics, which is against the manipulation of embryos, is a member of the HFEA committee overseeing the consultation. She said: "The HFEA has tried extremely hard to pull the issues together. The challenge now is to sell it to the public – this is about your future, not just the future of disease. There is not just ethical opposition, there are scientific worries about germ line modification."

David King, director of Human Genetics Alert, said the proposed technique was "unnecessary" and "highly dangerous . . . That it is even being considered is a reflection of medical consumerism and scientists' fetish for employing the most hi-tech methods," he said.

Dr King added “The proposed techniques are both unnecessary, and highly dangerous in the medium term, since they set a precedent for allowing the creation of genetically modified designer babies. Since there is a safe alternative option in these cases, standard egg donation, the minor benefit of satisfying the mother's wish to be genetically related cannot justify the risks that the techniques create for the child or to society.”

The Society for the Protection of Unborn Children rejected the consultation as a "sham".

4. Daily Star: ‘Public opinion sought on GM babies’ (no author listed)

5. 17th September 2012, incumbent Wellcome Trust Director, Sir Mark Walport stated, perhaps unsurprisingly, in reference to the Wellcome Trust Centre for Mitochondrial Research at Newcastle:

“The work of Professor Turnbull and colleagues holds great promise for preventing previously incurable diseases and giving families affected by these diseases the chance to have healthy children, something most of us take for granted. The HFEA consultation provides an important opportunity for us to discuss with the public why we believe this technique is essential and to listen to any concerns they may have.”

6. 'Three-parent baby' fertility technique could be made legal' Nick Collins, Science Correspondent, *The Telegraph*, 17th September 2012

"The panel appointed to oversee the consultation includes scientists as well as leading voices opposed to the treatment including Josephine Quintavalle, of the Comment on Reproductive Ethics campaign group. She said, 'This is not about curing disease in an existing human being, it is creating a new kind of embryo and the alterations you have made will pass on to future generations. You are playing around with the building blocks and restructuring how human life is created."

Dr Marita Pohlschmidt, of the Muscular Dystrophy Campaign, said: "For women who have been dealt the heavy blow of living with mitochondrial disease, the prospect of bearing healthy children is of immeasurable value. We believe that this technique could open up the possibility of motherhood untainted by the fear of passing on a painful, debilitating condition to their future children."

"A survey of 800 people by the Progress Educational Trust found that two thirds supported the use of the technique while a third opposed it, while a report by the Nuffield Council on Bioethics last year claimed the approach would be ethical."

g) RESPONSE to CONSULTATION FINDINGS

A press briefing was held by the HFEA on March 19 with Professor Neva Haites, Professor Robin Lovell-Badge, Juliet Tizzard and Hannah Darby on hand to explain the consultation outcomes. A press briefing was also held at the Authority meeting where Lisa summarised the agreed advice.

1. 'Britain on course for 'three parent babies'. Nick Collins, *The Telegraph*, 20th March 2013. Resulting in 246 reader comments

"Britain is on course to become the first country in the world to legalise the creation of IVF babies with three biological 'parents' after the fertility watchdog announced that the public is in favour of the controversial technology"

"The Human Fertilisation and Embryology Authority (HFEA) has advised the government that there is 'general support' for the treatment and there is no scientific evidence to suggest it is unsafe. Although many people registered ethical concerns about the process, most of those who responded to the consultation said it was justified if further tests prove the technique is safe and can eliminate the risk of genetic conditions like muscular dystrophy. The Department of Health, which ordered the consultation last year, must now decide whether to make Britain the first country in the world to permit the treatment, paving the way for its use in clinics".

1.1 Persons cited by Nick Collins (Telegraph):

"Given the broad public support and the advice from the HFEA we urge the Government to make changes to the legislation so that these techniques can be used in the clinic, provided that further research continues to demonstrate their safety and accuracy" Professor, Sir John Tooke, President

of the Academy of Medical Sciences.

“This report shows that the public is broadly in support of this research because of its potential to provide families with a history of mitochondria disease with the opportunity to have healthy children” Ted Bianco, Acting Director of the Wellcome Trust.

“Historians of the future will point to this as the moment when technocrats crossed the crucial line, the decision that led inexorably to the disaster of genetically engineered babies and consumer eugenics”. Dr David King, Director of Human Genetics Alert.

2. ‘IVF: ‘Three-Parent’ Babies Hurdle Cleared’ Thomas Moore, Health Correspondent, *Sky News*

‘It (HFEA) dismissed fears of critics, who say it is a slippery slope towards designer babies’

3. ‘Three-person IVF moves closer in UK’ James Gallagher, Health and Science reporter, *BBC News* 20th March. Generated 327 reader comments.

On the HFEA’s Open Meeting, Gallagher comments on Mr Hossam Abdalla, clinical director of the Lister Fertility clinic in London on identity: “If a child wants to know about that, why are we so restrictive. . . why are we telling them they can’t have access”.

Reports on Lisa Jardine citing: “Other countries are astounded that we’re this far on in discussions . . . This is not a Rubicon or a slippery slope.

3.1 Reader Comments (Editors’ Picks)

I will pray for this each day each hour each minute. I have a 4 year old son who lives with mitochondrial disease. This is really a hope for us . . .

When are we going to accept that childless parents are childless for a reason? It is very sad, but necessary. We should not offer IVF to anyone.

I fully support this as I am someone who has a mitochondrial disease. Why shouldn’t I have the chance to try for a family in a controlled way to prevent the heartbreak of losing a child, or having a child with a life affecting disability and watching them suffer and then still die.

To those of you arguing against funded IVF as it’s not considered essential, I assume you wouldn’t expect NHS treatment for anything that happened to you caused by non-essential activities such as smoking, skiing etc.

IVF should be for private paying patients only, like cosmetic surgery, it is a luxury not a necessity’

Three parents is misleading, as it suggests the child will be the equal genetic product of three people . . . Mitochondrial DNA accounts for a ‘tiny’ proportion of our genome. Frankly the fuss isn’t worth it.

This sort of science is incredible but must be monitored carefully

If we have the technology to ensure that parents and their children can live a normal life without the pain of loss, or a reduced quality of life, then who are we to deny that?

4. 'Britain ponders 'three-person embryos' to combat genetic disease', Ian Sample, Science Correspondent, *The Guardian*, 20th March 2013. Generated 263 comments

We understand that more research is required but believe it is crucial that the government moves now to draft the regulations so that mitochondrial patients in the UK will have access to this treatment," said Doug Turnbull, director of the Wellcome Trust centre for mitochondrial research at Newcastle University.

Sarah Norcross, director of Progress Educational Trust, said: "Techniques to prevent inherited mitochondrial disease received the green light from the Nuffield Council on Bioethics last year, and have now received the green light from the general public. We urge the government not to create unnecessary roadblocks, and to pass legislation so that families blighted by mitochondrial disease can benefit from these techniques."

5. 'Three parent babies' one step closer: survey reveals support for radical IVF therapy', Steve Connor, Science Editor, *The Independent*, 20th March

[Refers to an} "exhaustive survey of public attitudes to the replacement of an affected mother's mitochondria . . . has found broad support for the technique."

Cites Lisa Jardine: " . . . although some people have concerns about the safety of these techniques, we found that they trust scientific experts and the regulator to know when it is appropriate to make them available to patients."

Reports that "David King, director of the pressure group Human Genetics Alert, criticised the HFEA for ignoring the potential risks associated with the technique: . . . These techniques go far beyond anything existing in both invasiveness to the embryo and complexity so it's not surprising that they pose serious health risks to the child, risks that the HFEA refuses to properly address."

6. 'Plans for three-parent IVF babies a step closer after fertility watchdog gives the go-ahead . . . But critics have labelled it 'Frankenscience', with unknown science effects. Fiona Macrae and Nick McDermot, *Daily Mail ONLINE*, 20th March – received 97 comments

7. 'Three parents? Five parents? All that really matters is healthy babies: For families touched by the miseries of mitochondrial disease, help may be at hand. Anjana Ahuja, *The Telegraph*, 21st March – shared 194 times; Facebook 132; twitter 62

"What has given rise to talk of a third parent – 'is a distraction'".

[Referencing herself] "So who was the original sourced of the Ahuja mtDNA? Not me, nor my mother, nor my maternal grandmother. We are all, in this lineage, carriers of the same mtDNA (except for chance mutations among generations). I can hardly claim ownership of it, and it is therefore illogical to argue that my identity is uniquely bound up with it. Grateful though I am to

the ‘ancestral mum’ who bequeathed her daughters the mitochondrial tool-kit for survival, it is not to her that I look for my identity.”

“Children created using donated sperm or eggs are normal, healthy, well-adjusted and even show surprisingly little interest in tracing their biological parents. Maybe we shouldn’t find it strange: these children are loved by parents who have triumphed over adversity to have them. That is surely what the best parenting is about – unconditional love.”

9. Governance and wider engagement

a) Overview

Given the multiple components and phases of the consultation, fluent inter-communication between the contractors, the HFEA project team, and those providing independent advice and steer (in addition to precise information signposting, exchange, transfer, recording and reportage) was essential for ensuring the successful transition between the various phases; their inter-relatedness and complementarity; and the integration of their respective emergent findings into a cohesive series of recommendations.

In our estimation, the channels of communication between all parties responsible for the design and delivery of project elements were, in the main, successfully managed. Whilst we observed some slight initial miscontruance between certain parties in terms of the project brief, this appeared no more than an issue of calibration, quickly resolved by explicit clarification (and acceptance) of aims/objectives, desired outcomes and expectations of personnel roles. Some disruption to the fluency of communication between contributors was also reported, if only by a few, caused by changes in personnel. However, while these changes – which were largely unavoidable and difficult to pre-empt in any project of substantive duration (i.e. 12 months+) - might have proved seriously injurious to the project's progress, any serious disruption or disconnect was generally contained and bypassed, facilitated in large part by the professionalism and efficiency of those 'stepping-into-the-breach'. As a multi-modal/dimensional project involving a large number of contributors, the fluency and erudition of communication should be seen, in this case, as a particular achievement, especially when considering the potential for miscommunication, misunderstanding and information loss.

In this section we will look at the various communication and information devices used within the governance and wider engagement in the project, which in our opinion, contributed to sound translation across project strands, and also importantly, a clarity among those involved in their implementation, scrutiny and steer. We consider the role of the project's oversight group; the HFEA expert stakeholder meeting; HFEA teleconferences; and the HFEA Open Authority Meeting.

b) Oversight group

The oversight group was an enormously important aspect in the overall design of the project whose members contributed willingly and handsomely in offering expert steer, commentary and a multitude of advices drawn from their own diverse professional contexts. The heterogeneity of the group was especially significant in establishing as near as possible a universal spectrum in critiquing aspects of the project from scientific, theological, journalistic, secular, scholarly and patient perspectives. Managing what sometimes were rather polarised opinions in terms of project direction was not always easy and presented a special challenge to the delivery team, which nevertheless seemed to incorporate and synthesize split-opinion to good effect, without dilution. The oversight group met on five separate occasions, with each meeting following an agenda involving an information update on the project's progress by members of the HFEA, the dialogue delivery contractor, and on one occasion, the evaluation team. These updates were open to questions, discussion and further interrogation by the group, which provided expert feedback both within the context of the meetings and also, frequently, via e-mail correspondence. The latter was especially true where members of the oversight group were tasked to comment on informational/stimulus materials for use in the dialogue workshops and public meetings.

An issue, without much in the way of solution, for the oversight group - and characteristic of all such other similar advice forums - was the stricture of time in the group being presented with a comprehensive review of emergent findings and progress and, thereafter, opportunity for its own commentary. Lines of questioning - from oversight group members seeking clarification - would sometimes be cut short and/or be re-routed and continued through e-mail conversation.

The members of the oversight group were themselves largely complimentary of project management, and the way they saw themselves and their own contributions managed and incorporated into project design and execution. In this sense particularly, the oversight group was clearly influential and persuasive in terms of directing and improving upon aspects of the project design, with advices clearly heeded and embedded by the delivery team. In this context we can draw on two such examples:

- A meeting of the oversight group on 26.06.2012 at the Royal Statistical Society, where, in reflecting on the design of the public dialogues, the oversight group provided broad and specific advice in terms of:
    - the format of survey questions (in terms of wording, relevancy, duplication);
    - dialogue workshop materials (in terms of accuracy of language, clarity of meaning in illustrative examples; sequencing and complementarity of component parts).
- The final meeting of the oversight group 30.01.13 provided critical commentary of the draft final project report. The contractor in this instance was privy to a plethora of advices regards the framing and general presentation of arguments: contextualisation, clarification; the timbre of narrative as dispassionate and devoid of ‘judgement-statements’; typographical consistency; the sequencing and naming of chapters, and so on.

c) HFEA expert stakeholder meeting – 19.06.2012

An expert panel was assembled by the HFEA at the HFEA offices as: an opportunity to receive direct input and critical insight from stakeholders on the ambitions, aims/objectives and strategy of the project; an opportunity to identify what kinds of information were needed and what kinds of information ought to be posed to public groups; and an opportunity for informed debate. Attending members of the group were provided by the HFEA project manager with an overview of the project methodology (reconvened dialogue events, public meetings, survey etc.) and an overview of key personnel (HFEA team, the contractor, the oversight group, and Sciencewise – though with no mention of the evaluation team).

Members of the group were then asked by the dialogue delivery contractor to consider what range of issues were at stake; what kinds of topics ought to be discussed; what kinds of informational/educational material was required to bring non-expert groups ‘up-to-speed’; and what were the building-blocks needed for meaningful discussion? This generated a myriad of impressions, concerns and caveats from stakeholders:

- Concerns were raised as to the exact intention motivating the consultation, with questions focused on the extent to which the consultation was designed, and/or for that matter would be interpreted, as a legitimizing process focused on producing consensus and less a critical debate with potential radical uncertainty.

- Accuracy, precision and neutrality were deemed to be pre-conditional to an efficacious and equitable dialogue platform – with plain language seen as essential in circumventing confusion and bias born of the topic's complexity (as one participant noted '. . . it's really important not to use words that are likely to polarise or prejudice views').

- A question was raised as to why this group and not a group of communication experts was being asked to contribute to discussions around the dialogue process.

Self-reservations about the suitability of the group as experts able to comment on the design of the *public engagement processes* appeared to us valid, yet in thinking about the *content* of the dialogue and thereafter how it might be received, the group raised many significant points.

d) HFEA teleconferences

A key facet of continuous information exchange, specifically enabling our contribution as evaluators to the project's formative learning, and at a more rudimentary level allowing us to keep abreast of any developments, were regular teleconferences with the HFEA project team (usually the project manager and project officer). We happily developed positive lines of communication and a co-supportive, collaborative interface with the HFEA's team, which remained consistent throughout the duration of the project, even when there was change or reshuffling of personnel. Fortnightly teleconferences provided a useful channel with which to feed into/ comment upon process; a window onto the HFEA's own strategic thinking, approach and concerns with regards to the multiple project elements; a means for critical reflection and projection (which served to bridge project strands and crystallize our own interpretation and vision of the project as a whole); and ultimately served, much like the oversight group, as another opportunity for internal dialogue designed to facilitate and safeguard the quality of process.

In addition to regular teleconference with the HFEA, as evaluators we also participated in:

- an inception meeting, which was useful in framing in detail at a preparatory stage the various parties contributing to the project's delivery and providing an overall sense of the methodologies to be used both by the delivery and evaluation team, as well as uncovering hopes and aspirations;

- an interim evaluation meeting with members of the HFEA team and a Sciencewise representative;

- regular debriefings with Sciencewise (particularly its evaluation manager).

e) The HFEA open Authority Meeting – 20.03.2013

The HFEA's open Authority meeting at Hatton Garden, London, was the final stage of deliberative and informational translation within the project, drawing together the various strands of the consultation; its conclusions; and those of Authority members tasked with agreeing advice they wish to provide to the Government

The meeting gathered together the entirety of the Authority's members, which - much like the project's oversight group - comprised an heterogeneous membership, and also featured two of the same individuals. Also attending were members of the HFEA's project team, the HFEA Chief Executive, and Chair. The meeting was conducted in front of a public audience – whose demographic is unknown. The Authority meet regularly throughout the year to discuss and determine HFEA policy and practice, often publicly, and all papers are publicly available.

The 'openness' of the meeting was significant for demonstrating transparency of process and, to a limited degree, public accountability – while the extent of public participation was limited to observation, the Chair did advertise an opportunity for audience questions following completion of all agenda items. The meeting was not in this context exclusively fixed on discussion of the consultation: in fact, the discussion and decisions on what to advise government was demarcated by an hour and fifty-five minutes slot, preceding a lunch to which all attendees were invited.

The Chair was helpful in initially welcoming the public audience, in explaining the nature of the meeting, and in relating certain house rules, such as an embargo on *tweeting*. Explicit reference to the meeting as an exercise in *democratic deliberation* was made by the Chair who emphasised that it was 'genuinely the decision-making of the Authority via the collection of evidence into mitochondrial replacement'. What then followed was a presentation provided by the HFEA's senior policy manager – who had latterly been our main point of contact at the Authority - of the key evidences and recommendations, deliberated and then elected on by members.

Authority members appeared largely impressed with the manner in which the project had been co-ordinated and managed, with plaudits issued for the consultation's bravery and creativity in using a variety of methods that successfully chaperoned non-expert audiences through intensely complex scientific and ethical issues. One Authority member for instance commented:

> *. . . it's very impressive the way the study has been shaped . . . I'm impressed with the way different groups were brought together.*

However, and in the context of the safety and efficacy of the techniques, members were united in emphasising the importance of seeing developments in the science of mitochondrial replacement as a work-in-process and as neither final nor conclusive:

> *Our recommendations need to let ministers and the public know there is some way to go.*

Issues of concern and of discussion between Authority members therein centred on aspects of the mitochondrial treatment that had previously occupied centre-stage in oversight group meetings, such as issues of identity, and demonstrated that many of the ethical conundrums obfuscating consensus remained problematic. In this respect it was noted by the HFEA's Chief Executive that 'this is up for discussion' and persisting concerns and reservations would be addressed in the advice to government.

The meeting resulted in various decisions which are available to view at: http://www.hfea.gov.uk/docs/2013-03-20_Authority_minutes.pdf. Overall, members largely agreed on the suggested advice for government.

f) Integration of consultation results into internal decision making

Suggested advice was presented to the Authority board which incorporated outcomes/views expressed from all strands of the dialogue work. There were two additional non-public dialogue strands which also fed into this advice – a scientific report and a regulatory considerations report.

g) HFEA internal learning

As part of the HFEA's programme management, the Authority undertook an internal lessons learnt exercise (implemented in two stages), in conjunction with the contractors, Sciencewise and the evaluation team

h) HFEA final recommendations.

The results of the public dialogue were fully incorporated into the HFEA's advice to Government. Further information may be found at: http://www.hfea.gov.uk/6896.html

i) Next steps.

The Department of Health's time-frame apropos consultation on the draft regulations remains unclear. The last public statement in such respect was published 28th June 2013. Further information may be found at: https://www.gov.uk/government/news/innovative-genetic-treatment-to-prevent-mitochondrial-disease

j) Feedback to participants

The HFEA plans to e-mail all participants who signed up to the mitochondria e-mail inbox to update them and alert them to the Department of Health consultation on the regulations (when launched). The Authority itself maintained regular e-mail contact throughout the duration of the consultation. The contractor also distributed letters of thanks to participants.

10. Impacts and lessons for the future

a) Evaluation approach

A latter stage and significant aspect of this evaluation focused on what immediate stakeholders to the project, that is, those directly contributing to the conceptualisation, implementation and steer of its various elements, opined as the relative success, shortcomings and merits of the project as a public dialogue intended to facilitate governmental decision-making regards the regulation and potential legalisation of the two 'techniques'.

In conjunction with both the HFEA project team and Sciencewise we established a target-list of interviewees, which included members of the HFEA's project team, including the Authority's Chief Executive; six members of the project oversight group; two members of the contractor team – including the overall project manager; a representative from Sciencewise; and a single Authority member. An interview schedule, developed in conjunction with Sciencewise, focused on aspects of 'process and impact': the effectiveness and efficacy of the 'dialogue' as an exercise in the democratic governance of emergent and controversial technoscience; the effect of the dialogue in influencing, shaping and changing participant and stakeholder perceptions and attitudes informing the scientific and ethical construction of PNT and MST. Among a twenty-point interview schedule (with a final commentary/final reflections prompt) respondents were asked:

- to critically reflect on the strength of the project design and the alignment and/or complementarity of its various strands;
- to identify what aspects of the project approach they might - with the vantage of hindsight - have altered;
- to identify what they perceived to be the most significant contribution(s) of the project
- to consider the project's legacy for the HFEA; the ethical and scientific future of mitochondrial treatments (PNT, MST); for public engagement in policy contexts
- to comment on the overall success of the project and through a cost-benefit analysis

An interview timeframe was developed to coincide with the release of the final report and not long after the HFEA's formal decision-making public meeting, where the terms of recommendation were voted upon by Authority members, in front of a public audience. Interviews were slated at such point to allow both sufficient time for stakeholders to digest the various findings of the delivery contractor's report, yet allow a freshness to their interpretation. Interviews subsequently commenced the week of the 25th March and ran to the 9th April.

Stakeholders on the whole were largely supportive and complimentary of the process. Those interviewed belonging to the oversight group were especially forthcoming in their praise of the process and the professionalism of the project delivery teams, particularly the HFEA team in managing the process; some among the interview cohort recommending the project as an exemplar in how to engage the public in complex and controversial science. However, in terms of what respondents identified as the impacts of the project, a consensus prevailed, that it was too early to tell, with most correlating the overall impact of the project with the Government's final decision.

b) What was special and interesting about the project?

Respondents verged on consensus in locating the ethical and scientific complexity of the overarching topic of discussion – variously characterised as a ‘niche and technical area susceptible to big controversy’; a ‘*crossing the Rubicon* kind of issue’ with ‘big ramifications’ and ‘real bite’ – and thereby the richness, diversity and plurality of ethical and scientific conversations which ensued, as distinguishing the project as an especially noteworthy exercise in publics’ bioethical deliberations. For those among the stakeholders interviewed with nominal or nil working/prior knowledge of PNT/MST, the science under discussion was felt to be especially fascinating – matched equally by the relative ‘exoticism’ of the incumbent ethical dilemmas.

Secondly, stakeholders were in total agreement that the project’s multi-method approach was - in the context of public consultation - ‘something of a rarity’ and whilst the elements were ‘individually… nothing new’ they were ‘collectively striking’ and provided for the most extensive and exhaustive form of public opinion evidence collection in their own professional experience.

Another significant feature seen to distinguish the project and reported by stakeholders was a focus on the information journey and the pathway to information acquisition and application, or in other words how information provision impacted and influenced the production and/or refinement/recalculation of non-expert views within the public dialogue workshops.

It was to be noted in this context, that the consultation was never intended as a kind of plebiscite but an opportunity for participatory deliberation via multiple methods of public consultation.

c) Strengths of the overall project approach

Stakeholders were unanimous in identifying the respective breadth of the project’s methodology or ‘technologies of elicitation’ employed and the heterogeneity of professional identities involved in its implementation and oversight. In terms of the latter, stakeholders reflected that the oversight group itself, populated by an eclectic mix of interested, expert and invested parties, including members of the clergy, scientific, legal and of course medical constituencies was a tremendously valuable resource in considering, visualising and informing the project’s trajectory. The contribution of the oversight group was especially significant in providing critical commentary and expert advice across a plethora of issues, and concurrently raising important if difficult questions, which facilitated both the core HFEA team and the dialogue contractors in their preparation and execution of the project’s various strands. The oversight group was, in this way, especially helpful in pre-empting potential ‘landmines’ which might albeit inadvertently, jeopardise the integrity, credibility and legitimacy of the project process and thereafter its outputs/outcomes. The wealth of expert perspectives, gained through the oversight group, matched with what was seen to be the amenability and responsiveness of the contractor and core-team in assimilating and acting upon its advice, was seen by respondents as a core component of quality assurance, maximising the efficacy of the process and the extent to which its findings might be confidently disseminated.

Members of the oversight group were especially complimentary in this regard of the contractor, who at all stages was seen to be ‘considerate, resourceful and responsive and undeterred by criticism’. Complementing this finding, and from our own critical reflections, a highlight of evaluating this project has been the ease of working with the contractor and establishing a relationship governed by the principle of evaluation as a paradigm of ‘formative learning’ and an understanding that the contribution of the evaluation team was not to assess performance but to analyse and where possible, expedite and/or ameliorate, process through open communication and shared findings. The degree of synergy and willingness to collaborate across the project appears both in the opinion of stakeholders and via our own numerous observations, to have been a hallmark of the project in its totality and in a sense that it provides a benchmark in effective translation.

Happily, our own contribution in terms of reporting interim evaluation findings was also welcomed by stakeholders and identified as another instance of the project’s success in interweaving rather fluently a multitude of collaborators.

The receptivity of the contractors and their willingness to listen, learn from and take on board the counsel of experts was clearly recognised by members of the oversight group, whose own role was, by default, further validated, and whose own willingness to contribute to the conceptual and applied orientation of the project appeared to consequently enlarge.

In synthesising the various strands of the project, stakeholders commented that the project team and contractor performed admirably and ‘did an excellent job of covering most bases’. Stakeholders commented that by observing attention to detail and sound project-management, and with not a little creativity, the various and often competing elements of the project were managed harmoniously, and to some extent in a manner which though not quite co-informing, was nonetheless complementary in the generation of an holistic vision.

Some among the stakeholders claimed some initial degree of concern that the project’s methodological approach was - though admirable - overly ambitious. However, in a final analysis, stakeholders commented that the multi-modality of dialogue/consultation environments and elicitation techniques, for instance online and virtual forms of consultation and offline and face-to-face, was a necessary condition for negotiating the density of ethical and scientific debate. It was also felt that the majority of project strands were well rationalised and designed with a clear purpose. Whilst the individual strands were not especially novel, the manner in which they were integrated provided a particularly effective platform with which to approach questions in creative and imaginative ways, whilst the triangulation of methods provided a validity check and quality assurance as to the credibility and legitimacy of findings.

The dialogue events were seen to be especially revealing – a sentiment that these provided a unique and unparalleled opportunity to gauge a faithful and ‘authentic’ expression of public opinion.

The project was deemed by many as a unique event in public consultation when experienced as the interface between a highly innovative, ‘state-of-the-art’ science and its emotional and ethical interpretation and public construction. The success of the multi-phase and largely qualitative methodology, it was felt by some, provided an opportunity to engage with ‘the human-side’ of science, in ways in which other consultations have not.

One member of the oversight group commented specifically on the service of *Dialogue by Design* and also complimented the role of the evaluator in feeding into the formative learning surrounding the dialogue workshops and reporting this back to the oversight group.

Stakeholders (outwith the HFEA project team and contractors) tended towards a multi-lateral endorsement of the project as a perfect example of how to pull together various methodological strands successfully and relatively seamlessly into an over-arching consultation, which unveiled new angles, new forms or interpretation; and manage (if not altogether reconcile) various, polar and antithetical opinions.

Stakeholders drawn from the oversight group were especially flattering of the HFEA project team, who it was felt responded to the projects' various anticipated and unanticipated challenges with aplomb – providing excellent signposting for all those involved who remained well scaffolded throughout the entirety of the process.

One stakeholder in particular stressed that the consultation had been managed objectively, impartially, without prejudice or agenda-setting and provided a fair and just series of recommendations. This outcome was viewed especially favourably and as a unique triumph where the personal (or institutional) views of those involved were bound to run at odds and where the passion of personal conviction might run high.

It was widely perceived among those interviewed that a seemingly complex methodology, harnessing multiple conduits/platforms for invoking and capturing public opinion, was a necessary condition of the project's success in disentangling the ethical and scientific complexity of the treatments.

In summary, stakeholders were impressed with:

- The way that people with little or no knowledge coalesced and contributed to meaningful and deliberative discussion with those with expert authority.
- The emotional influence of patient/public-testimony
- The wide range of stakeholders in the oversight group representing the full spectrum of opinion from those advocating or broadly supportive of MST/PNT to those implacably resistant to embryo research of any kind.

d) Concerns about and weaknesses of the project overall

Whilst the project gained from the heterogeneity of the oversight group's membership and thereby the plurality of its insight, the triangulation and synthesis of opinion especially diverse or divergent, was not always easy or possible. Balancing fixed positions and opinions was seen to be a particular challenge for the project team.

Whilst linkage between the various elements of the project was fairly efficient, some stakeholders commented that a better job might have been made in terms of meshing the outcomes of discrete parts in formative and/or informing ways. For instance, it was felt that some (if not all) of the learning gained from the dialogue workshops could and ought to have been used in more purposeful ways in educating and influencing the development of strategy and materials used elsewhere and at later stages of the project. Transitions between the various elements or stages of the project could, in this regard, it was felt, have been made more fluid had there been a more consistent approach to continuous critical reflection informing onward planning. As it was, certain elements of the project occurred in isolation.

Another aspect seen to slightly impact the fluency of transition between project parts was the numerousness of the parties involved in the various stages of implementation: from the facilitation of dialogue workshops/public meetings; development of stimulus and informational materials; administering of an online and on-street consultation etc. Clear communication and clarity regarding 'who does what and when' was reportedly compromised, yet only occasionally, where the populousness of those involved – 'a lot of players on the same pitch' – and the diversity of competing tasks caused information loss, slippage or misconstrual. It was however noted, that the project's timetable, intentionally plotted and spaced to maximise the opportunity for learning between project stages, had helped to orient all involved and provided a sense of what had come and what was to come.

The issue of time was articulated by a number of stakeholders as a factor impinging on process and quality assurance. In this context, a few stakeholders commented that the project's public meetings would have benefitted from more generous lead-in and an opportunity to secure the most appropriate speakers and arguably a more cosmopolitan audience. A number of others felt that the public meetings were the weakest component of the project overall, a conviction based on a sense of 'trying to do too much', of 'time pressures', 'no press coverage', an opinion that 'presentations from the front were not all that helpful', and in at least one of the meetings, a 'failure to get a high profile Chair'. Achieving productive dialogue and dialogue-conducive environments, is a time and labour intensive challenge, which was seen in part to be incompatible with the urgency and speed of the project's respective timeframe and turn-around.

In terms of commenting on specific aspects of the project, one other stakeholder stated that the patient focus group seemed something of an unnecessary 'add-on' and afterthought, which contributed little in the way of fresh insight and resembled nothing more than a tick-box exercise.

Some pointed to the irony that the findings of the consultation might now become *log-jammed*, whilst government assiduously if languidly contemplates regulatory/legislative action. The log-jam effect would thereafter have direct implications in terms of considering the consultation as one influential, and integrated less isolated, aspect of the policy-making process and thereby also, depending on the degree of separation – time lapse – between the dissemination of the consultation's recommendations and any action taken as a direct consequence, lessen the perceived impact of the consultation in informing policy, where indiscriminate delay might obfuscate lines of causality and attribution.

One significant weakness reported by a number of stakeholders was that of expectations, or at least a shortcoming in appropriately forecasting and thereafter in marshalling expectations. Some among those interviewed from the oversight group advised that the recommendations and advice imparted by the HFEA should NOT (but may well) be treated as conclusive and/or final. Some concern was registered that the dialogue project would be erroneously interpreted as an open-and-closed case where instead it represents a first step among many, potentially culminating in new regulatory and legislative actions involving mitochondrial treatments.

Another sense in terms of managing expectations was focused on what one stakeholder saw as an underestimation in terms of the complexity of the issues under discussion – both ethical and scientific – and an overestimation in terms of the capacity of the public groups to make sense and return meaningful comment on these. Furthermore, one or two stakeholders were manifestly concerned that a diagnosis of the extent or reach of the consultation on public constituencies, would reveal that the broader or majority public remained disengaged, and that those who had been consulted may be discerned as the self-appointed, pre-invested, or 'likely-candidates' seen to habitually dominate these sorts of activities. It was in this context that one stakeholder suggested that PNT/MST would continue to be articulated in the public sphere/imagination as 'three-people-one-baby'.

Whilst stakeholders were unified in identifying the benefits of the project in raising public awareness around mitochondrial disease, some questioned the value and efficacy of consulting publics who knew nothing of, or more specifically, had no direct experience of mitochondrial disease and whose response/opinion was framed by speculation and conjecture and/or bite-sized knowledge accrued throughout the consultation process. In this sense, where the consultation constituted a legitimate exercise in engaging lay-publics in an ethically and scientifically complex issue, it was felt by a few, that the opinions of those without lived experience or exposure to the effects of mitochondrial disease on children and their families, should not be weighted with the same degree of significance and status, certainly when accumulated into a corpus of evidence designed to influence policy-decisions, as those with a record or personal history of such experience. The argument therein followed, that the project might well have occurred as a *closed*, less *open* consultation where 'public' advice correlated to the views of laypersons with direct experience of the effects of mitochondrial disease. In this context, the paucity of consultation with 'patient' groups and a perceived imbalance between 'patient' and 'public' consultation, with only one 'patient' run focus group – was seen to undermine the credibility and weight of significance to be inferred from the consultation as a conduit of reliable and valuable 'public' testimony. Of course, by means of counter-argument, one of the very purposes of the consultation was to invoke the perceptions and attitudes of those without direct experience and personal investment, working so to speak, from a blank canvas, as an exercise intended to provide a corpus of critical, objective and dispassionately sourced evidence and concurrently an opportunity to discern the ways with which those without expertise or experience, formulate value-systems in such contexts. Nevertheless in pursuit of balance and commensurability, this concern raises an important issue of participant recruitment to public dialogue: who is recruited, why and for what purpose? It is also pertinent to ask, and demonstrate transparency in, how views, particularly where disparate in nature or unequally informed by underpinning scientific, ethical and/or experiential knowledge, are subsequently weighted, prioritised and infused or amalgamated into an evidence-based finding.

Despite the various platforms and methods of engagement employed within the project, one or two stakeholders determined that the fullness of the complexity of the issues was albeit understandably, not thoroughly enough communicated.

Finally, and despite the project’s explicit focus on mining qualitative data, one stakeholder cautioned against attributing and overly stating the significance and reliability of statistical findings, such as those excavated through the online consultation, though feared that the readership of the final report would demonstrate bias to numbers as the seal of credibility, with statistical findings having a ‘mesmerising effect’ even when random and/or unsupported by qualitative contextualization.

Stakeholders reported a number of concerns taking root from and as extraneous to the project process. These were individual accounts which focused around:

- A perception of the fragility of public confidence in science enterprise.
- A sense that the final results of the online consultation as one constituent part of the overall dialogue was not synchronous with the overall recommendations put forward.
- A concern that - despite the very best attention for dialogue to be pluralistic and diverse - question marks remained over the audience selection related to the public meetings, where (as one stakeholder identified) the audience seemed uniformly and unapologetically partisan.
- A concern that whilst much of the consultation findings focused on public's concerns regards the safety of the techniques, the only proof of risk is through practice and by committing to the licensing of either/both techniques.
- A need for precision, especially in terms of terminology as represented to public groups within informational materials.

e) Lessons for the future

More public meetings and more financial investment were endorsed as a means for advancing and further securing the legitimacy and credibility of project findings. A weakness often attributed to public engagement in science and technology (PEST) is that the extent of engagement, defined as the number of public participants involved, is always limited, restricted not least by the high cost of assembling and co-ordinating public dialogues/meetings. However, the extent of engagement, defined as the impact and/or affect of the dialogue on its participants, is nearly always if not constantly, broad and high, with participants generally reporting a high degree of personal fulfilment and satisfaction – not least by having been asked important questions and having had an opportunity to be heard. The HFEA consultation in this respect was a case-in-point of how PEST can be mobilised as a bridging device: linking the electorate, if only a fragment, with the government and high-level/decision-making processes. This consultation therefore represents a valiant attempt in engendering not only a more meaningful, credible and profitable science and society nexus; but a more authentic expression of democratic science governance.

Where numerical data is habitually vaunted, it was felt it would have been beneficial to have discussed the significance of not only the science but the consultation itself, where the number of affected individuals is so small.

As may be the case in any context guided by individuals with differing epistemological and methodological orientations, there was some level of disagreement with regards to the specifics of project design; in the main revolving around the extent to which questions in the online consultation should have been closed or open, with the suggestion from some being that closed rather than open-text questions are more likely to secure a healthy, and potentially more statistically significant return from respondents. However, whilst ostensibly simpler and more direct lines of questioning might return a higher response-rate, the responses returned may follow-suit in being less than revelatory. In other words, where breadth is gained, depth may be lost.

f) Impacts on stakeholders

Many stakeholders commented on being slightly more reassured of the legitimacy of the science – and moderately assured that 'techniques' were not harmful.

They commented on how the project had generated key evidential materials illuminating how the public thinks and responds to fresh insight and knowledge catalysed via public engagement/consultation.

The consultation was seen in this regard to reinforce views on the necessity of public engagement/consultation in generating 'depth of evidence' in aspects of science – particularly medical science, where cognate ethical and social deliberations requires an investment of time and thought that goes beyond 'scratching the surface' of an issue.

The consultation informed

- Sciencewise practice: the message from the project is that dialogue is both a purpose and a method
- the dialogue delivery contractors' practice: a sense that the project generated significant amounts of internal interest and that the project as a multi-faceted engagement, offering a blue-print for future consultation work of a similar ilk.
- the HFEA's own engagement practice, moreover increasing knowledge of the client-provider relationship in consultation exercises.

One concern directly related to stakeholder engagement, was where there had been changes in the core project team, lines of communication had altered, and the personal rapports and methods of communication established between stakeholders and the project team were lost. Whilst it may be enormously difficult if not impossible to prevent personnel change in the life of any project, particularly one of significant duration, it is important to recognise the importance of establishing and thereafter maintaining consistency in communication protocols, so to ensure continuity in information dissemination and receipt and avoid information loss, which might result in certain stakeholders feeling cut-off, marginalised or unable to satisfactorily participate. Investing in and generating a successful collaborative basis and 'team' dynamic, is fundamental to any large-scale, multi-method and multi-agency project – which was however generally well observed in this instance.

Among the scientific constituency of stakeholders, and concurrently, those with limited appreciation of PEST, came a suggestion that the project had altered and invigorated their enthusiasm and recognition of the value of PEST as a precursor or catalyst to decisions involving bio-medical regulation.

Not one among the stakeholders interviewed failed to recognise the project as a genuinely informative and educational experience, which to some degree and in some way impacted their views, perhaps not so much on the issues discussed – certainly true of oversight group members who remained faithful to their initial opinions – but in opening their eyes to the value, or consolidating their appreciation of, public engagement for policy purposes in technoscientific domains.

g) Wider impacts

Stakeholders identified the following short-term impacts:

- Scientists' confidence that the translation goal is achievable – transferral to clinical practice is achievable
- Generation of a credible body of evidence
- The value of the consultation as a means of reassuring politicians for whom the scientific and ethical complexity of the techniques represents too great a risk in the policy context.

Stakeholders also identified the following longer term impacts:

- For those working in gene therapy dealing specifically with modifications to the nucleus, the recommendations of the project will represent a 'chink of light'.
- Scientists will identify the UK as leading the way – setting a precedent difficult for other countries to ignore or oppose.
- Government must realise that continued and long-term investment in dialogue/consultation of this sort is essential in the generation of the most robust evidence-informed policy.
- Of recommendations on regulation/legislation of PNT and MST and how this might/will ultimately affect the lives of those children conceived by such means.
- Are contingent upon the final decision of the Secretary of State for Health – in making the 'right' decision.
- The consultation it was felt would provide a basis for the HFEA's future public consultation work.
- In their own critical reflections of the project experience, members of the HFEA's project team commented that the consultation had provided a rich source of learning in best practice in public engagement; in effective working with a range of external and contracted parties in fulfilling the objectives and aspiration of public consultation in emergent and controversial science; and an overall template for use in future work.
- Finally, stakeholders were keen to identify the educational quality of the project as a whole on all participating groups, and emphatically not only the lay-publics habitually characterised as 'empty vessels'. Concurrently, as one stakeholder elucidated, the consultation was not just about developing an attitudinal baseline or poll – it was 'not just engaging what people

think but informing the public and policy-makers to the complexity of the issues and paths through the complexity'. The consultation in this sense was seen to be about co-opting the public in locating potential solutions or in posing new problems, respectively alleviating or extending the ethical conundrums informing the body of evidence influencing the prospective regulation/legislation of PNT/MST.

Stakeholders were also impressed with:

- The way that people with little or no knowledge coalesced and contributed to meaningful and deliberative discussion with those with expert authority.
- The emotional influence of patient/public-testimony
- The wide range of stakeholders in the oversight group representing the full spectrum of opinion from those advocating or broadly supportive of MST/PNT to those implacably resistant to embryo research of any kind.

Stakeholders also elicited the following ideas concerning the project's legacy:

- Increased credibility for the HFEA – ought to provide greater confidence in mobilising for and managing public engagement/ involvement in ethical and scientific deliberations in controversial issues.
- The greater value or impact of the dialogue is yet to be determined and is seen to rest on what the government ultimately decides.
- For the HFEA, the project 'reinforces' a sense of value for public engagement activity.
- Legacy for the treatments remains to be seen, but one feeling was that should either/both techniques be approved, then this would open the doors for 'scientists to do good'.
- Great insight was attained into how a quality consultation should be arranged, with the consultation providing an 'off-the-peg' model of public engagement.
- It was felt by some that the consultation will have an impact on the Department for Health for whom knowledge of public views is essential and integral to the development/pursuit of evidence-informed policy.
- In thinking along the lines of the consultation as an exercise in evidence collection, stakeholders reflected that it provided a set of views that will be relied upon for years to come. Of course, so much of the legacy of the project is indeterminable and contingent upon the outcome of government decision-making. In this context, stakeholders observed that were Parliament to act on the HFEA's recommendations then the consultation would have 'got the ball rolling on social acceptance of the treatment', with the consultation becoming a reference point and basis for educational and policy announcements based on evidence, and a model for regulation in other national contexts.
- For the public, the project was viewed as a potential gateway to future and further involvement in participatory deliberations. It was also felt by a number of stakeholders that

> the project would hopefully/likely furnish lay-participants with the confidence to get involved in other forms of engagement/consultation activities.

h) Overall success

There was a general, pervasive feeling among stakeholders that the project met – but did not exceed - its objectives. Some suggested that it would be difficult to exceed the generation of a corpus of quality evidence, though others claimed that the project had exceeded its remit in producing evidence of interest to the legislatures of other countries.

A frank assessment of success was issued by a few who commented that given the complexity, controversialism and emotionalism of the subject material and the ambitiousness of the project methodology, arriving at the final recommendations was in itself a significant achievement:

> It could have been a car crash. The fact that it happened at all and in a fairly measured way – is itself an achievement.

Many among those interviewed attributed the success in seeing through the project to the professionalism and personability of all those involved in its implementation, and the capacity for all contributing stakeholders – drawn from varying professional contexts and for some, ideological positions – to work respectfully, harmoniously and in co-supporting ways.

Stakeholders articulated that whilst the project had presented unique challenges and difficulties, involvement in its design, steer and implementation had proved to be genuinely satisfying and fulfilling with one respondent stating they were sorry to see the end of it.

There was an overall feeling that the cost of the dialogue was worth the economic cost: certainly for having shown to engage in processes of democratic science governance; and in generating a comprehensive and reliable body of evidence. However for the majority of stakeholders, not least those among the oversight group, their estimation of value was obscured by not being either fully aware of the total cost of the project, or how such a cost might be measured against what most understood as the inherent value of public engagement to policy generation.

From the HFEA's perspective the project represents a milestone as 'the most thorough project (of its sort) we've ever done . . . with no stone left unturned'.

Of course the overall success of the project differed with the varying outlooks and personal convictions of each stakeholder towards the prospect of new regulation/legislation for the techniques. The overall sense however, is that the consultation has been treated as a success in testing public approval necessary for expediting regulatory policy, potentially advancing the translation of the techniques into clinical practice. In this sense, and for those advocating one or the other or both techniques, the consultation is a success in so much as it is portentous of 'the techniques being put in place and applied appropriately and in establishing a set of regulations that would work'.

Finally, the project was largely greeted as an example of how to communicate complex science to an inexpert audience in accurate and unbiased ways.

i) Final comments

Interviewees were invited at the end of each interview to provide any further or follow comments. The vast majority responded that they had already said most of what they had wanted to say and/or referred back to prior comments. Two respondents however provided two specific accounts worth mentioning.

One member of the oversight group commented that they were aware of the significant commitment and undertaking of the HFEA’s policy team - a lot unobserved - which was of particularly high standard. The HFEA were commended by the continuous involvement/ collaboration with the various contractors, which was seen to ease the load of the oversight group – who were enabled to keep-on-task.

Another member of the oversight group stated that the exercise had provided an invaluable opportunity to plot where public groups are in terms of an individually and collectively motivated moral compass.

11. Conclusions

Through the various strands of evaluation activity grafted onto and responding to the multi-methodological approach undertaken in this project, and thereby the evaluation evidence gleaned via non-participant observation; participant questionnaire; stakeholder interview; and documentary analysis, we are able, by means of critical and impartial determination to recommend this HFEA and Sciencewise collaboration as a credible and efficacious exercise in public engagement and public consultation for policy purposes.

The project and thereby its co-ordinators both at the HFEA and OPM, should be commended and credited for delivering a high-quality engagement/consultation activity, which satisfied, in the main, indicators of best practice in dialogue activity, promulgated by Sciencewise and additionally, for the most part, met the quality threshold for 'translation'.

Whilst no project of this sort may ever be said to be completely perfect – our own minor criticisms have been articulated – this project is conspicuous, in our opinion, for managing to satisfy all those with whom it came to contact; in some part impact upon individual and collective thinking – if only in terms of reinforcing the efficacy of public engagement as an important and necessary component in policy formation in technoscientific domains. Furthermore, it has proven especially successful for combining experimentality and creativity with practicality and a common-sense approach- the latter as ingredients surely preconditional to navigating public deliberations around a topic of such scientific and ethical complexity and sensitivity.

The professionalism and commitment that we observed of all those involved, and of whom there were many, ought also to be noted, for without which, the general momentum, enthusiasm and sheer determination in achieving the best outcome; and most credible, defensible body of evidence and series of recommendations, might not have materialised.

Watermeyer and Rowe, July 2013.

12. References

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Horlick-Jones, T., Walls, J., Rowe, G., Pidgeon, N., Poortinga, W., Murdock, G. and O’Riordan, T. (2007b) *The GM Debate: Risk, Politics and Public Engagement*, Abingdon: Routledge.

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Annex A: The Observation Schedule

Observational Schedule

NB The following schedule suggests aspects to observe that are related to the 'translation' concept. The schedule is expressed in the form of various questions: the observer should seek to answer the questions and provide explanation/ evidence for their answers.

Information Comprehensiveness *(Do the sponsors provide full information to participants?)*

- Do the sponsors clearly state the aims of the event at the outset?
- Do the sponsors clearly elaborate on an agenda?
- Do the sponsors clearly explain to participants what is expected of them (defining their task)?
- Do the sponsors explain how they have selected participants/ why they are there?
- Do the sponsors explain what will follow from the event (i.e. what feedback they might expect and what will happen with the output from the event)?

Information Appropriateness/Fairness *(Do the sponsors fairly frame the problem or is there any evidence of bias in terms of information provision/ recording/ translation?)*

- At the outset, do the sponsors provide a fair summary of the subject being considered, or do they provide a particular slant, bias or frame that might lead some perspectives to be focused upon at the expense of others?
- Does the way in which information is collected suggest any particular bias (beyond, say, randomness)?
- Is the process managed in such a way that bias is introduced in terms of the information that is considered or recorded (e.g. participants with one position allowed to speak at the expense of those with another position)?
- In any summing up, is there any bias in the reporting of the output from participants?
- Is participation fair, or do some participants have much greater opportunity to speak and influence than others (whether due to facilitator bias or event logistics)?

Process Limitations to Effective Translation

- Is there sufficient time for participants to consider all the necessary information, provide all necessary information, and think about this information? Are certain debates unneccessarily cut short because of time limits?
- Are there any information resource limitations that hinder the effective consideration of the topic of debate? That is, are participants asked to discuss an issue or solve a problem on which it is clear that extra information might have been made available (report findings, academic evidence)?
- Are there sufficient resources (personnel, tape recorders etc.) to enable the full output from the event to be recorded, or do such resource/logistic deficiencies ensure that there is only a partial recording of output, or imperfect recording of information?

Information synthesis

- How is the various information outputs synthesized, and are there any apparent inefficiencies? For example, how are competing priorities compared and contrasted? How are pro and con arguments set against each other? How is such information displayed to participants – and is it in a way that may help or hinder them from synthesizing different points of view? [For example, are there whiteboard or computer screen displays of pro and con lists? Are accurate 'minutes' taken? Is there any form of voting process to confirm participants' aggregate views?]

Annex B: The Participant Questionnaire

Evaluation Questionnaire

Dear Participant,

Thank you for having taken part in the workshop. We would now like to ask you a few questions about it as part of our evaluation of this project. We would therefore be extremely grateful if you could complete this questionnaire as soon as possible, and return it to us in the FREEPOST envelope supplied with it (on the train home might be a good time!). The questionnaire should not take too long, and would be of great help to the project team (and others) in terms of helping to improve events like this in future.

Finally, please be assured that your responses will be treated anonymously. Although we ask for your name and organization below, these are so that we can characterize those that respond to this questionnaire. Your name will not be cited in any evaluation report or associated with any comment you make herein.

Thanks for your cooperation.

Dr Richard Watermeyer and Dr Gene Rowe (evaluators)

1. What is your name? ……………………………………………………………………………………………………….
2. Was it clear from the information you were sent prior to the event what the workshop would be about?
   Yes ☐
   No ☐
   Unsure ☐
3. At the start of the workshop, were the aims clearly specified?
   Yes ☐
   No ☐
   Unsure ☐
4. Was it clear to you from the information you were sent prior to the event why YOU were invited?
   Yes ☐
   No ☐
   Unsure ☐
5. Was it made clear to you how the participants for this event were selected?
   Yes ☐
   No ☐

Unsure ☐

6. Do you think the audience was appropriate for this event?

   Yes ☐
   No ☐
   Unsure ☐

   If there were there any notable absentees, who were these?

   ……
   ……
   ……
   ……

7. During the event, did you have the opportunity to have your say?

I said all I wanted to say ☐

I said most of what I wanted to say ☐

I was only able to say a little of what I wanted to say ☐

I didn't get a chance to say anything ☐

8. Was there sufficient time to discuss all that needed to be discussed?

   Yes ☐
   No ☐
   Unsure ☐

9. Do you think there were any significant issues that were NOT discussed, but which should have been? What were these?

   ……
   ……
   ……
   ……

10. Were there any significant issues raised at the workshop that were not resolved? If so, what issues were these?

   ……
   ……
   ……

………

11. Did you learn much from the workshop?
    I learnt a lot of new things ☐
    I learnt a few new things ☐
    I'm not sure I learnt anything new ☐
    No, I did not learn anything new ☐

12. Did participation in this event change your views on the issues in any way?
    Yes, I changed my views considerably ☐
    Yes, I changed my views to some degree ☐
    I'm not sure whether I changed my views or not ☐
    No, I did not change my views in any way ☐

13. Do you think the summing-up accurately reflected what was discussed at the workshop?
    Yes ☐
    No ☐
    Unsure ☐
    There was no summing up ☐
    If not, what do you think was missed or misconstrued?

    ………
    ………
    ………
    ………

14. Overall, do you think the workshop was well run?
    Yes ☐
    No ☐
    Unsure ☐
    If you said 'no', what was the main problem?

    ………
    ………
    ………
    ………

15. How satisfied were you with the event overall?
    Very satisfied ☐
    Fairly satisfied ☐
    Neither satisfied nor dissatisfied ☐

Not very satisfied ☐
Not at all satisfied ☐
Unsure ☐

16. Did the event live up to your expectations?
Yes ☐
No ☐
Unsure ☐
If not, why not?

……
……
……
……

17. Do you think this event is likely to have any influence on government policy?
Yes ☐
No ☐
Unsure ☐
Please explain your response.

……
……
……
……

18. Overall, what was the best thing about the workshop?

……
……
……
……

19. Overall, what was the worst thing about the workshop?

……
……
……
……

20. How do you think an event like this could be improved if something similar was run in the future?

………

………

………

………

Finally, we would like to phone a few people afterwards to ask them some more detailed questions about the event. Would you be prepared to talk to us again in a short 30 min. telephone interview?

Yes ☐
No ☐

If you said ‘yes’, please provide the details below:

Home phone number (including area code): ……………………………………………………………………….

What is the best time to phone you (e.g. weekends, after 6pm):

………

Once again, thank you for your time. Now please place this questionnaire in the FREEPOST envelope and post it (you do not need a stamp).

Annex C: Interview schedule: project stakeholders

Interview schedule: Project stakeholders

- What do you think was most special and interesting about this public dialogue project?
- What do you identify as the strengths in the project approach?
- What do you identify as the weaknesses in the project approach?
- Was there anything about the way this public dialogue project was designed that led to outcomes that could not have been achieved through other public consultation methods? Please give details.
- Was there anything that could have been done to change the dialogue project that would have increased the credibility and legitimacy of the results with those making recommendations / decisions on the issues?
- How well did the different parts of the projects - the dialogue events, the public meeting, the focus group, the survey, the oversight group - link together to meet the objectives?
- Has taking part affected your own views on: a) the issues discussed and b) public engagement in policy on these sorts of issues? Please say why / how.
- What did the public say that was most influential on your thinking?
- At what point in the development of thinking on the policy decision / recommendations did the dialogue results have most impact?
- How has the dialogue affected / improved what you were going to do / recommend (or not)? Please give details.
- Will you use the results of the project in your own work in future? Yes/No. Please say how [as specific as possible].
- What do you identify as the main short-term impacts of this project?
- What do you identify as the likely main long-term impacts of this project?

- What is the legacy of this project: for the HFEA; for the ethical and scientific future of mitochondrial treatments (PNT, MST); for public engagement in policy contexts/for policy purposes; for the other funders and other stakeholders involved; for the public?

- What do you think was the single most valuable achievement of the project?

- In your opinion has the project met (or exceeded) its stated aims and objectives, or not?

- Do you have a sense of how much the project cost overall, and do you think that matters? [if interviewee is a long way out on cost, tell them the budget]

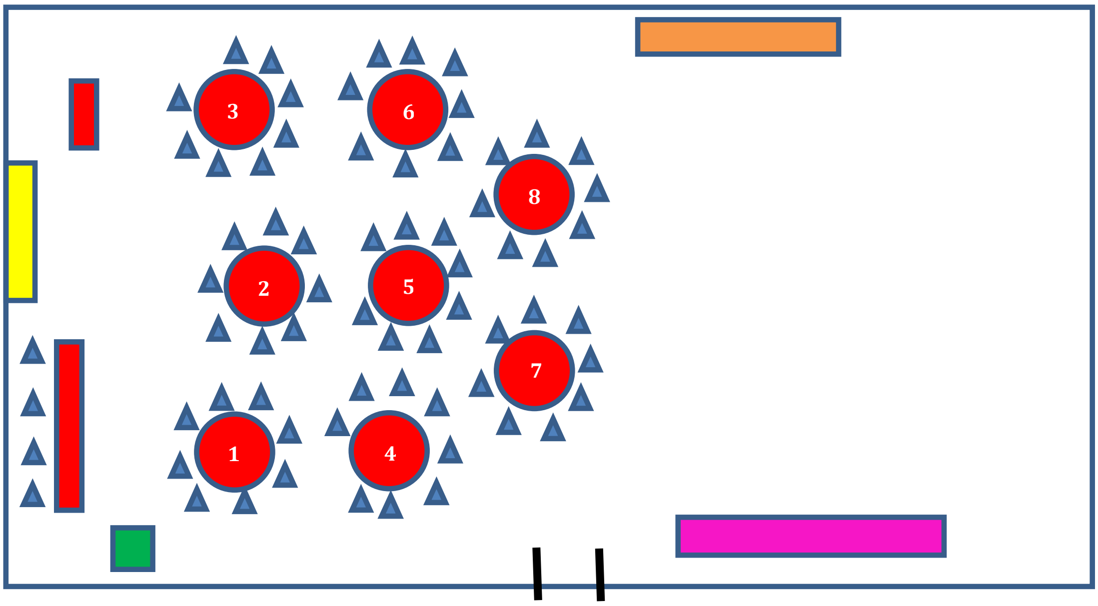
- Do you think there were any ways that the project could have been done just as well but where costs could have been saved? And is there anything that would have been really useful to do if there had been just a little more money?

- Do you think the project's achievements and impacts were worth the costs?

- As a whole, do you think the project has been a success? Please say why or why not.

- Finally, is there anything else you would like to say about this project?

Annex E: Layout of the room at the Manchester open consultation meeting



Key

Red = tables

Blue = chairs

Yellow = screen

Green = flipchart

Orange = food tables

Pink = hanging rail for coats/umbrellas

Black = entrance