

Evaluation of a Public Dialogue on Stratified Medicine

Final Evaluation Report

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Executive Summary

This report sets out the findings of an evaluation of a public dialogue on the topic of stratified medicine, commissioned by the Technology Strategy Board¹ in 2013 with support and part-funding from Sciencewise². The dialogue was delivered by the OPM Group and evaluated by 3KQ.

Context and Aims. The Technology Strategy Board (the Board) is the UK innovation agency working to stimulate innovation and economic growth in the UK. A significant part of their funding is being used to promote the development and uptake of stratified medicine, which is the science of identifying the right treatment for the right patient at the right time. There are significant questions about how the public, patients and healthcare professionals might receive the possible changes implied by the introduction of stratified medicine: for example, about awareness, patient recruitment, and data sharing. In light of these questions the Board and Sciencewise decided that the right way to explore these questions was through a process of public dialogue: *“A process during which members of the public interact with scientists, stakeholders... and policy makers to deliberate on issues relevant to future policy decisions”*.

Activities and Content of Dialogue. The dialogue consisted of 19 public workshops held over a 4-month period, with 180 members of the public and 40 stakeholders. The methodology used comprised five strands:

- Public workshops: held in 2 locations (London, Glasgow) with each group meeting twice for a full day.
- Targeted workshops: four groups (adult patients, young patients, young people, medical students), mostly meeting twice for about 2.5 hours in the evening.
- Self-facilitated workshops: variety of community groups including two with black and minority ethnic (BME) groups.
- Stakeholder workshop: held after the above three strands to discuss the findings.
- Oversight and governance arrangements, in particular an Oversight Group (OG).

The public workshop sessions provided an introduction to stratified medicine via a simple video animation, poster displays to support participants' learning, a video of a patient who had been successfully treated with stratified medicine, and various other case studies and scenarios that helped participants explore the questions and choices that arise from the technologies. The other events with the public used the same basic materials.

Evaluation. A range of data was gathered via direct observation, telephone interviews, participant questionnaires (70% public response rate, 74% stakeholder response rate) in all strands. The evaluators also reviewed the majority of written correspondence and documents that were circulated such as minutes, Terms of Reference, dialogue stimulus materials, process plans and the Dialogue Report.

Meeting the objectives. All the objectives of the dialogue were very well met. The Oversight Group members, as well as the funders, were pleased with the process and outputs against the objectives, with one Oversight Group member summarising it by

¹ Now named Innovate UK (formerly the Technology Strategy Board).

² Sciencewise 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. www.sciencewise-erc.org.uk

saying: *"If anything, the dialogue exceeded what could have been expected"*.

Good practice standards. The Sciencewise guiding principles were very well met. There was a wide range of contributing factors here. The dialogue was well timed in terms of being *"upstream enough that all the major decisions haven't yet been made, but not so upstream that there's nothing to talk about"* as one Oversight Group (OG) member described it. There was adequate time given at the start of the project to discuss and agree what the project was trying to achieve. There was a scoping report written as part of this early stage, researching the work already done on the topic and the issues arising. This scoping report helped set out a common baseline for the project and informed the design of the dialogue accordingly. The dialogue used a wide range of methods to reach different parts of the public, which was valued by the OG members and gave credibility to the dialogue in the eyes of stakeholders. The stimulus materials used in the workshop sessions were effective, accessible, and helpfully set stratified medicine in the wider context of the overall development of medical practice over thousands of years, not just the 'here and now'. The Dialogue Report was clear, accessible and comprehensive, although the reporting process perhaps could have involved the public participants more along the way.

Self-facilitated groups. The use of self-facilitated groups was particular in this project, being seen as an innovation alongside the more traditional dialogue methods. There were 7 sessions run by volunteer facilitators within existing community groups or patients groups. The outputs were seen as rich and important, for example highlighting a concern that stratified medicine could lead to more discrimination on ethnic grounds. There were challenges particular to this strand too. Drumming up interest was relatively difficult, as was ensuring a consistent quality standard across all the groups in terms of facilitation and reporting.

Satisfaction levels. Satisfaction levels were high. 97% of public participants said that they were *"overall satisfied with the events"*, and the majority of these agreed strongly, which does indicate high satisfaction levels from a participant perspective. OG members were also satisfied with the dialogue, citing four main ways in which the project had been valuable to them:

- Building understanding of how people "out there" perceive what people in the stratified medicine sector are doing. An OG member remarked *"It has provided a perspective that would have been impossible to get otherwise"*.
- Providing and summarising evidence on the range of public views. One OG member said *"The dialogue sets out evidence in a more robust way about the range of views. I can point to this when meeting stakeholders"*.
- Learning about the potential of public dialogue in a new environment. This was seen by some OG members as a *"Good enough process to act as an exemplar dialogue on similar topics"*.
- Contributing to democratic legitimacy in a more general sense. One OG member remarked that this kind of public dialogue process was *"part of securing democratic legitimacy for a new technology or practice"*.

Governance. The governance of the dialogue, including the operation of the OG, was very successful. Factors contributing to this were varied. The role of the external OG was clear, and the group agreed Terms of Reference early on. Once appointed, the delivery contractor took a firm managerial role of the OG, ensuring an effective connection between the OG's role and the evolving needs of the project. The Sciencewise Dialogue and Engagement Specialist role was welcomed and well received by the Board and OG, and was particularly valuable during the set-up phase of the

project before the delivery contractor was appointed.

Achievements and Impact. Stratified medicine is a complex topic to communicate to public participants who generally start with very little understanding of how the healthcare sector works, how conditions are diagnosed, how treatments are developed, and how regulation works. A major achievement therefore, of this dialogue, was providing the information, support and time to enable participants to learn about and deliberate on the issues in a productive way. Impacts arose in the following areas:

- **The Technology Strategy Board** cited various impacts of the dialogue. It has changed the way that the staff involved communicate about stratified medicine, in particular assuming a lot less about what people know, and also emphasising sensitivity to ethnicity. Particular findings of the dialogue were useful to the Board, such as the differing levels of trust the public had in different institutions (government and industry), and the use and sharing of data. The impact of these findings though has not yet arisen as it is still at an early stage following the dialogue. One OG member remarked *“The benefit of this is not today or tomorrow, but in 18 months time”*.
- **Public participants** said their views had been affected on the topic (82%), and that they had learned something new (97%). Some participants also said that they were likely to change something that they do as a result of taking part (43%), including one participant who said: *“Since the first session, I have changed my diet and added 'exercise' to my routine - more encouraged to lead a healthier lifestyle”*.
- **Stakeholders** - including those on the OG - said that the dialogue had *“reaffirmed what is already out there about what people think”* and the new information enriched the evidence base available. Stakeholders talked about the dialogue having had an effect on them regarding how they communicate around stratified medicine, including *“using the term stratified medicine less and talking about how it works instead”*. Some of the OG members saw the dialogue process as an exemplar in how public dialogue should be run and what it can deliver, one of them saying: *“I was always of the view that it is possible to have a well conducted dialogue - I just hadn't seen it in any of those I was involved with”*.

Learning. There is a variety of learning to take from this dialogue, much of it positive and stemming from what worked well. Specific lessons include:

- The value of setting up the Oversight Group before the contractor is procured.
- Funding approval can take a long time.
- The value of allowing time to really explore what the dialogue is aiming to achieve, and including a Scoping Review to assist with this stage of the process.
- The value of targeting groups that will be affected by the technologies under discussion, such as young people, BME groups, patients, or future healthcare professionals.
- Self-facilitated groups are a useful but challenging method. The advantages need carefully weighing against the logistical challenges of running the sessions and ensuring quality and consistency.
- If reporting is aggregated into one Dialogue Report, it can lead to participants being less involved than they might otherwise be, firstly because it takes a long time for them to see the report, and secondly because the output from their event is merged with so many other events.

- A stakeholder workshop at the end to discuss the findings can be particularly valuable in effectively disseminating the results of the public dialogue to interested parties.

Overall, this dialogue was a success. It met its objectives very well, and fulfilled Sciencewise's guiding principles that set out good practice. The governance arrangements worked effectively, and participants were satisfied with the value the dialogue provided. It is still early to judge the impact of the dialogue but there are already changes in the way some staff at the Technology Strategy Board communicate about stratified medicine, and various particular findings that they intend to take forward over the coming months and years.

The evaluators thank everyone who contributed their views and time to the evaluation: it would not have been possible without their generous and honest participation.

1 - Introduction

This report sets out the findings of an evaluation of a public dialogue on the topic of stratified medicine, commissioned by the Technology Strategy Board in 2013 with support and part-funding from Sciencewise³.

The evaluation presents evidence on the quality of the public dialogue process, and its impacts. It also identifies lessons to help develop good practice in public dialogue on science and technology issues.

2 - Background

Healthcare is currently the most highly funded priority area for the Technology Strategy Board (the Board), which is the UK innovation agency working to stimulate innovation and economic growth in the UK. Part of that funding is being used to promote the development and uptake of stratified medicine, which is the science of identifying the right treatment for the right patient at the right time. The Technology Strategy Board is working with partners including NICE⁴, the Medical Research Council, Arthritis Research UK, Cancer Research UK, the Department of Health and the Scottish Government Health and Social Care Directorate to invest a combined total of £200million over five years.

In 2011 these partners put together a roadmap highlighting nine areas they saw as vital to support uptake of stratified medicine; in many of these areas, such as increasing awareness, patient recruitment and data collection, management and use, there were clear questions to be answered about how the public, patients and healthcare professionals would receive the proposed changes. In light of these knowledge gaps the Board began to discuss the possibility of a public engagement project with Sciencewise, the Government programme on public dialogue on policy involving science and technology.

The Board and Sciencewise decided that the right way to explore these questions was through a process of public dialogue. The phrase 'public dialogue' is used in this report to mean *"A process during which members of the public interact with scientists, stakeholders... and policy makers to deliberate on issues relevant to future policy decisions"*, taken from the Sciencewise definition in their Guiding Principles⁵.

An Oversight Group (OG) was set up for the project; a range of people with specialist knowledge who could help ensure the process was fairly, objectively and sensitively conducted. This group included experts from medical research and bio-ethics, alongside representation from medical charities, patient groups and the pharmaceutical industry (full membership in Appendix 1). The OG was charged primarily with ensuring good governance of the project throughout, from commissioning to final reporting. Over the progress of the dialogue, the group was invited to undertake the following tasks:

- Input to and agree the specification for the public dialogue
- Interview and help appoint the delivery contractor

³ Sciencewise 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. www.sciencewise-erc.org.uk

⁴ NICE is the National Institute of Clinical Excellence

⁵ Sciencewise (2013). *The Government's approach to public dialogue on science and technology*. <http://www.sciencewise-erc.org.uk/cms/guiding-principles/>, containing the guiding principles

- Review the proposed methodology
- Advise on technical content as well as specialist involvement
- Attend and support at dialogue events
- Review the Dialogue Report

The public dialogue was commissioned by the Board via competitive tender in June 2013 and ran for around 9 months. OPM Group was appointed as delivery contractor for the dialogue, and 3KQ was appointed as independent evaluators.

The public dialogue was funded jointly by the Board (£105,930) and Sciencewise (£130,500, comprising £108,000 funding and £22,500 in support and guidance costs) with total funding of £236,430 including VAT. This includes project design and delivery and the independent evaluation. A calculation of the costs of the time given to the Oversight Group and specialist input to the dialogue events are an additional £39,000 (estimated at 60 days @ £650 per day). This makes a total project cost of £275,430.

The full Dialogue Report of the findings can be found online⁶, together with the materials used during the dialogue and also a summary video.

⁶ www.stratifiedmedicine.wordpress.com and <http://www.sciencewise-erc.org.uk/cms/assets/Uploads/Stratified-medicine-a-public-dialogue-Final-report.pdf> and on the Technology Strategy Board's website at <https://www.innovateuk.org/documents/1524978/2138994/Stratified%20medicine%20-%20a%20public%20dialogue%20-%20Final%20report>

3 – The Public Dialogue

The overall aim of the public dialogue was to understand how a selection of the public would understand and view stratified medicine. Specific purposes of the public dialogue included:

- **Purpose 1:** To discover the diversity of public opinion about stratified medicine and in the process also to discover how best to explain what it involves, and which terms are least likely to cause confusion, misinterpretation or misunderstanding, so that stratified medicine and the issues it raises can be discussed effectively with patients, their families, and members of the public generally.
- **Purpose 2:** To explore the possibilities of stratified medicine through a process that enables patients and members of the public to identify advantages and disadvantages that developers and healthcare providers may be overlooking, and to think creatively about ways to amplify the former and mitigate the latter.
- **Purpose 3:** To identify what steps practitioners and other healthcare providers will have to take to communicate the complex information that patients and their families will need about the testing processes that stratified medicine requires, and the support that different strata of patients will require before, during and after treatment.
- **Purpose 4:** To establish what sort of ethical framework and practical approaches to consent for trials that will build patient and public confidence to support the sharing of the personal data necessary to ensure the effectiveness of stratified medicine.

Scoping Report

The dialogue began with a Scoping Report that researched the key issues in the area, and information on the different perspectives held by stakeholders and the public. This Scoping Report was conducted by the delivery contractor, via desk research and interviews with OG members and a few wider stakeholders. The Scoping Report was discussed at an OG meeting, and subsequently it helped frame the dialogue during the design process. This Scoping Report was seen as very useful by the OG in terms of establishing a common baseline from which the dialogue was starting.

Stimulus materials for the public workshops were then compiled (details provided in section 6) and tested in a short pilot workshop, allowing improvements to be made before going live.

The dialogue then entered its main phase, during which 19 public workshops were held over a four month period and with 180 members of the public and 40 stakeholders. The methodology used comprised five strands:

- Public workshops
- Targeted workshops
- Self-facilitated workshops
- Stakeholder workshop: held after the above three strands to discuss the findings
- Oversight and governance arrangements.

The key aspects of these workshops are set out below, and more detail is contained in Appendix 2.

	Public workshops	Targeted workshops	Self-facilitated workshops	Stakeholder workshop
Aim	To understand diversity of public views	To understand views of specific sub-sets of public	To understand public views of pre-existing groups	To present public findings and discuss them with stakeholders
Number of locations/groups	2 locations, each met twice	4 groups, each met twice	7 groups, each met once ⁷	Met once
Number of participants	24-27 participants per session	5-15 participants per session	5-8 participants per session ⁸	40 stakeholders
Total numbers	51	38	63	50 (includes OG members and public participants)
Recruitment	Purposive sampling	Via intermediary groups	Pre-existing groups	Self-selecting by invitation from the Board
Timing	Two full day sessions, 2 weeks apart for each location	Two evenings, 2 weeks apart	One session per group, 2 hours long	Full day workshop
Incentives	£40 each day 1 £60 each day 2	£25 session 1 £40 session 2	£80 per group	No financial incentive paid

The first three of these strands were conducted largely in parallel (exact dates are in Appendix 2), exploring the same issues with similar materials, but with different subsets of the public. This enabled a cross-comparison and triangulation of findings to be made between strands, before the headline results were drawn together and presented to a stakeholder workshop (the fourth strand above).

A summary of the dialogue methodology used is below.

Public workshops: (October 2013)

- **Purpose and targets.** The aim of these workshops was to engage a diverse group of the public who would not be expected to have any prior knowledge of the topic. Two locations were used; London and Glasgow. There was a target attendance of up to 30 participants at each of the two locations i.e. a total of 60, and ultimately 51 completed the full two sessions.

⁷ With the exception of one group of 25 young people, who met twice.

⁸ With the exception of one group of 25 young people.

- **Recruitment.** The participants were recruited by a recruitment agency to meet a quota broadly reflective of the UK population, including screening criteria covering age, gender, and socio-economic class. This was the only strand which purposively sampled in this way, aiming to get a diversity of participant views in the room at the same time. Recruitment was conducted on the street. Participants were incentivised by a thank you payment of £40 for workshop 1 and £60 for workshop 2.
- **Facilitated and structured.** A team of at least four facilitators and/or note-takers from the delivery contractor staffed these events. Additional specialists observed the events and assisted by answering questions when appropriate (see Appendix 2 for details of which specialists attended). Participants were taken through a schedule of activities that enabled them to learn about stratified medicine, ask questions, discuss the issues, and also give their views (Appendix 2 has more detail, including a process plan of the workshops).
- **Recording.** Data was captured in a variety of ways: audio-recording, the facilitators took notes, and occasionally the participants were asked to generate their own outputs such as a ranking of the social issues that stratified medicine raises.
- **Full days, reconvened.** Both workshops at each location were a full day long, held on Saturdays with a fortnight between event 1 and event 2 to allow some time for reflection between the two.

Targeted workshops: (October and November 2013)

- **Purpose.** The aim of these sessions was to understand the views of specific sub-sets of public, rather than getting a diversity of views in the room. Four subsets of the public were therefore identified, based on the fact that they would be most affected by the development of stratified medicine: adult and young patients, young people and future healthcare professionals (medical students).
- **Recruitment.** There was no specific target of participant numbers for these groups, although they were expected to be relatively small groups from the outset. Recruitment was conducted by the delivery contractor, via research into possible groups (some via prior contacts) that could provide willing participants to attend a session. No screening was undertaken as the views of the participants within each group were seen to be equally valid. Each group ultimately had between four and fifteen people.
- **Evening sessions, reconvened.** Each targeted group was invited to meet twice for about 2 hours each time, with time in-between to consider the issues they had discussed. The exception was the medical students whose schedule only allowed for one session (their total incentive payment was still £40).
- **Flexible process.** The delivery contractor facilitated these sessions, and there was no specialist support apart from at the session for medical students (where a member of the Oversight Group attended and helped to answer questions). More flexibility was allowed as to which topics each group covered. This enabled each group to focus on what it had most to say about. For example, patient groups spent more time on care implications than the public. Appendix 2 sets out which topics were covered in which workshops.
- **Recording.** Data was captured by the facilitator taking notes, and audio-recording of discussions.

Self-facilitated groups: (November and December 2013)

- **Purpose.** The aim of these sessions was to understand public views within pre-existing groups, in particular where the materials and information are not supported by specialist input. This was in part to mimic more closely the way in which members of the public at large might engage with communications material regarding stratified medicine in an everyday situation.
- **Recruitment.** For these workshops groups were chosen that had not been represented in large numbers in the other strands, including people with chronic health conditions and minority ethnic groups. There was no specific target of numbers of participants or groups, although budget had been allocated to support up to 18 sessions. Seven workshops were held, with an average of eight participants at each session.
- **Self-facilitated.** The self-facilitated groups were provided with the same materials as the other groups but one group member was asked to facilitate the discussion after a briefing with the delivery contractor. There was no facilitator from the delivery contractor, and no specialist to answer questions. The aim was to explore how people interpreted stratified medicine outside of the more managed process of the main dialogue, as they might encounter it in the real world.
- **Single sessions, individual follow up.** The self-facilitated groups had the shortest discussions, just one session of around two hours. This reflected both the more limited nature of debate that might naturally occur in an everyday setting. The delivery contractor followed up each session with a telephone interview with the group's facilitator.
- **Recording.** Data was captured by the convenor of the discussion taking notes. The delivery contractor interviewed the convenor over the phone after the event to get a fuller description of the session.

Stakeholder workshop (January 2014)

After the three strands of dialogue above were complete, the findings were drawn together into a headline report, and discussed at a stakeholder workshop. This workshop aimed to involve stakeholders in reviewing the findings and exploring the implications for the future development of stratified medicine. Invitations were sent by the Board to over 100 organisations across industry, academia, government and the third sector. Around 40 stakeholders attended, in addition to representatives from the Board and project Oversight Group and two public participants from earlier stages of the dialogue (50 people in total). The workshop was a full day event, facilitated by the delivery contractor. The process used on the day is included in Appendix 2. There are aspects of these stakeholder discussions that are incorporated into the Dialogue Report.

Governance and Oversight

An Oversight Group (OG) was set up for the project; a range of people with specialist knowledge who could help ensure the process was fairly, objectively and sensitively conducted. This group included experts from medical research and bio-ethics, alongside representation from medical charities, patient groups and the pharmaceutical industry (full membership in Appendix 1). The OG was charged primarily with ensuring good governance of the project throughout, from commissioning to final reporting. The group agreed formal Terms of Reference that did not change throughout the project. Over the progress of the dialogue, the group was invited to undertake the following tasks:

- Input to and agree the specification for the public dialogue
- Interview and help appoint the delivery contractor
- Review the proposed methodology
- Advise on technical content as well as specialist involvement
- Attend and support at dialogue events
- Review the Dialogue Report

The OG first met in mid-2012, and was at that time convened by the Sciencewise Dialogue and Engagement Specialist (DES). Once the delivery contractor was appointed, convening the group became their responsibility although it was also chaired in a light touch way by the Sciencewise DES. The group met three times during the dialogue process, ending in February 2014. There was no formal management group within the OG, although occasionally the Board and the delivery contractor met informally to discuss project details in between OG meetings.

4 - Evaluation Aims and Methodology

The aim of this evaluation is to provide an independent assessment of the public dialogue's credibility, and its effectiveness against its objectives, including an assessment of impacts.

The key questions asked in the evaluation are:

- Objectives: has the dialogue met its objectives? Were they the right ones?
- Good practice: has the dialogue met the Sciencewise principles of good practice?
- Satisfaction: have those involved been satisfied with the dialogue and its value?
- Governance: how successful has the governance of the project been, including the role of the Oversight Group, the Board and the Sciencewise support role?
- Costs/Benefits: what was the balance overall of the costs and benefits of the dialogue?
- Impact: what difference or impact has the dialogue made?
- Lessons: what are the lessons for the future?

This evaluation report is based on the following data collection and assessment methods, conducted between 8th July 2013 (the inception meeting) and March 2014:

- **Observation.** The evaluators directly observed a variety of events and meetings: Oversight Group meetings⁹, two public events¹⁰, two targeted workshops, and the stakeholder workshop¹¹ towards the end of the process.
- **Interviews.** Stakeholder interviews were conducted at key points throughout the dialogue. A limited round of interviews before any of the events had happened established the context for the dialogue events to baseline the evaluation. Around eight brief participant interviews were carried out in the margins of the public events themselves. A second round of seven interviews was conducted of OG members at the end of the project, to assess learning and impact.
- **Questionnaires.** Written self-assessment questionnaire data was gathered from all four of the public events, all the seven targeted workshops, and four out of seven of the self-facilitated groups. This represents an *overall* response rate of 70% from public participants. A summary of the data gathered from these public events is provided in Appendix 3. Gathering evaluation data from the participants at the self-facilitated groups was not always possible or effective. An online survey was used for the first group, and participants did not complete the survey. Hard copy evaluation forms were provided to the facilitators for the subsequent six groups: four out of the six groups completed them. Questionnaires were also used at the stakeholder workshop, with a response rate of 74%. The evaluation report from this event is provided in Appendix 4.
- **Document review.** The evaluators reviewed the majority of written correspondence¹² and documents that were circulated such as minutes, Terms of Reference, stimulus materials, process plans and the Dialogue Report.
- **Website review.** A brief review of the project website www.stratifiedmedicine.wordpress.com was carried out both in terms of the content and also the traffic that it has attracted.

⁹ Oversight Group meetings took place on 13th August 2013, 25th November 2013 and 24th February 2014

¹⁰ The evaluators observed both the London events, on 5th and 19th October 2013

¹¹ The stakeholder workshop took place on 22nd January 2014

¹² Over 350 emails were read and reviewed as part of the evaluation.

5 – Objectives

“Has the dialogue met its objectives? Were they the right ones?”

The evaluation aims to address seven main questions (as shown in section 4), of which the one above is the first, focussing on objectives or purposes.

There were four purposes for the public dialogue. These are below for ease of reference:

- **Purpose 1:** To discover the diversity of public opinion about stratified medicine and in the process also to discover how best to explain what it involves, and which terms are least likely to cause confusion, misinterpretation or misunderstanding, so that stratified medicine and the issues it raises can be discussed effectively with patients, their families, and members of the public generally.
- **Purpose 2:** To explore the possibilities of stratified medicine through a process that enables patients and members of the public to identify advantages and disadvantages that developers and healthcare providers may be overlooking, and to think creatively about ways to amplify the former and mitigate the latter.
- **Purpose 3:** To identify what steps practitioners and other healthcare providers will have to take to communicate the complex information that patients and their families will need about the testing processes that stratified medicine requires, and the support that different strata of patients will require before, during and after treatment.
- **Purpose 4:** To establish what sort of ethical framework and practical approaches to consent for trials that will build patient and public confidence to support the sharing of the personal data necessary to ensure the effectiveness of stratified medicine.

Once the Scoping Report had been completed, the delivery contractor regrouped these four purposes into four dialogue topics, to optimise the focus and design during the workshops. These were:

- Definition and communication
- Implications for patients and care
- Social issues and consequences
- Research, testing and data sharing

The identification of these four topics also allowed a distinct list of outputs to be developed for each, which brought more clarity to what was expected of the dialogue. Given this live restructuring that occurred, the purposes are taken as a whole in this evaluation, with comment below.

The purposes were **very well** met. Note that a definition of ‘very well met’ is included in Appendix 5.

Evidence for this comes from direct observations, interviews with OG members, review of the Dialogue Report, and participant questionnaires. Specifically, OG members said that:

“The dialogue achieved what we set out to do.”

“If anything, the dialogue exceeded what could have been expected.”

“The objectives were really well met.”

The Dialogue Report offers a breadth and depth of detail of participant views against each one of the four dialogue topics, which all relate to the purposes of the project. All the purposes appear to have been addressed in the Dialogue Report, although there are inevitably some areas that could have been probed further had more time allowed or if priorities had been ordered differently by the Board and the OG. For example, one OG member observed that:

“The dialogue didn’t delve too much into how specific groups of healthcare professionals should communicate stratified medicine, but then we [the OG] weren’t particularly clear about which professionals we were talking about: that may come later.”

The Board, Sciencewise and the OG generally saw this dialogue as a ‘start point’ rather than an ‘end point’ in terms of building a more robust understanding of public views. Therefore it is not surprising if some objectives were not fully fleshed out. OG members felt that there is plenty of time and opportunities in future to build on what has been achieved in this dialogue to go into more depth on specifics where useful (for example, the involvement of carers, or exploring in more depth the views of ethnic minorities). The overriding sense is one of the dialogue having achieved all it set out to do.

Participants across the public events had a very high satisfaction rating of the events overall: 97% agreed that they were satisfied with the events they attended. Of these, 72% agreed strongly and 25% tended to agree (see Appendix 3 for data). Overall participants found the events enjoyable, as well as having enough time and balanced information to explore the topic:

“Loved it start to finish.” Public participant, London

“Enjoyable experience hearing experts views and other people’s opinions.” Public participant, Glasgow

Factors that contributed to the purposes being met are varied. They include:

- Seeking regular comment from the OG from the very earliest stages and then throughout the project. The OG were invited to comment on the framing of the overall Invitation to Tender for the dialogue, and also the purposes and topics for discussion, as well as the specific facilitation plans, materials and eventual reports emerging.
- The time and budget available to do the Scoping Report allowed a very clear understanding of the territory to be developed in terms of work already completed in the literature, uncertainties identified, and possible questions to ask of the public. This provided a sound foundation of knowledge on which to build the dialogue.
- The re-mapping of the initial ‘purposes’ across into specific topics and outputs near the start of the project. Whilst this created quite a complex audit trail if a reader wishes to track back from an output to the initial purpose, it was essential to ensure that all the original purposes were going to be addressed in a logical,

complete and coherent way without something being overlooked.

- Facilitation plans were designed explicitly around the topics, including a very clear awareness of how each session (Appendix 2) supported a particular topic and purpose.
- Facilitators followed the facilitation plans during the events, and asked consistent questions between sub-groups, aided by printed materials and prompt sheets.
- Stimulus materials were clear, useful and varied in their format: they supported participants well. The video animation gave a good introduction and overview to the whole topic to orientate people, then followed up by the much more detailed information covering how medicine has changed over time, and how stratified medicine fits in. This in particular helped participants explore what stratified medicine is: a real challenge given the lack of clarity that exists about definitions in the field. The case studies brought the topic to life for participants and helped them understand how the issues were important in a practical sense: important for the objectives to be achieved.
- Recording and data capture tools were appropriate (see more in later section).
- The attendance of the more engaged OG members at the public events and stakeholder workshop. This allowed a very good understanding of the dialogue to be built up in the minds of at least some of the OG members.
- The use of various different methods of engaging different publics. This meant that the objectives could be met from a variety of different public perspectives, which in turn gave reassurance to OG members that the objectives had been properly met.

6 – Good Practice

“Has the dialogue met the Sciencewise principles of good practice?”

Sciencewise principles of good practice¹³ combine theoretical understandings and practical experience to frame the essential elements of good public dialogue on policy involving science and technology. There are five broad principles:

- **Context:** The conditions leading to the dialogue process are conducive to the best outcomes.
- **Scope:** The range of issues and policy options covered in the dialogue reflects the participants’ interests.
- **Delivery:** The dialogue process itself represents best practice in design and execution.
- **Impact:** The dialogue can deliver the desired outcomes.
- **Evaluation:** The process is shown to be robust and contributes to learning.

Each principle is taken in turn below. We provide an assessment of how well the principle has been met, what evidence this assessment relies on, and what contributed to the principle being met or otherwise.

Context Principle: The conditions leading to the dialogue process are conducive to the best outcomes.
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This principle was **very well met**.

Purpose. The purposes of the dialogue were stated from the outset. It is probably fair to say that as originally phrased, the purposes were quite complex, slightly overlapping, and tackled different levels of what different players wanted to achieve. However, the purposes got the project off the ground after quite a long process of negotiation, with a collective agreement about broadly what it needed to achieve. The process of reformulating the original purposes to optimise them for framing the public dialogue was timely, useful and provided a clear - if rather complex - audit trail for how the dialogue would achieve what was originally planned.

Policy route and timing. This dialogue was not planned to specifically feed into a time-bound policy decision. Whilst there are risks attached to this approach - the dialogue could drift with no direction - it was ultimately seen as a clear advantage in this case. Specifically, the dialogue was seen as being:

“Upstream enough that all the major decisions haven’t yet been made, but not so upstream that there’s nothing to talk about.” OG member

This was seen as a major factor in the success of the dialogue. The ‘upstream’ nature of the policy area means there is still a lot of flexibility in the way stratified medicine technologies and processes are applied. In turn, this means that public discussion

¹³ Sciencewise (2013). *The Government’s approach to public dialogue on science and technology*. <http://www.sciencewise-erc.org.uk/cms/guiding-principles/>

hadn't already been framed by competing interests in the public domain, as some on the OG believed had happened to issues like GM crops or other high profile contentious issues.

"In this case, I think the timing was about right - we can have a fairly good idea of what kinds of innovation are likely to emerge from the stratified medicine area and what might reasonably be the issues for various stakeholder groups, and so can have a reasonably well informed conversation with members of the public and other stakeholders". OG member

Despite there being no specific policy hook for the dialogue, there were various relevant contextual programmes and initiatives progressing that can and possibly will pick up the findings of the dialogue. As well as the Board's Stratified Medicine Implementation Platform and all the research that they fund and oversee, there are other linked policy initiatives such as the debate¹⁴ about how to increase sharing of data, and how to gain public consent for it. Data sharing was one of the key topics of focus for the public dialogue.

Governance. The governance of the project was effective. The Board initially took a fairly hands-off approach to governing the project, leaving Sciencewise and then the delivery contractor to lead on driving activity forward. Over time a very productive relationship developed between these parties which benefitted the dialogue greatly: the delivery contractor driving the practicalities and intellectual effort of the dialogue, gaining input and signoff where needed from the Board, and receiving advice from Sciencewise where needed. The Oversight Group also operated effectively and transparently, and is explored later in this report in section 8.

Resources. Resources appeared to be adequate for the demands of the project. Extra funds were required for the stakeholder workshop, which was added as an extra element to the original dialogue design. There is separate comment on resources for the evaluation later in the report.

Hard to reach groups. The purposive sampling of the public dialogue sessions (not the targeted or self-facilitated sessions) provided a broad based cross-section of the public. In addition, the dialogue did take account of the fact that some groups of society were likely to be affected by stratified medicine more than others. The targeted sessions and the self-facilitated sessions focussed on groups that either had a particular reason to be affected (e.g. adult patient support group for rheumatoid arthritis), or a particular view on stratified medicine beyond the general public (e.g. medical students, who are likely to continue into professional roles within healthcare).

Two self-facilitated sessions were held specifically with people from Black and Minority Ethnic (BME) communities, to ensure that any issues relating to ethnicity were explicitly covered. A key finding emerging from these sessions was the belief that stratified medicine held the potential to further discriminate against BME people, in a society where they already believed there to be institutionalised inequality in the healthcare system. This finding was cited by a few OG members as particularly interesting to them, and warranted further consideration.

¹⁴ Around the closure of this dialogue, NHS England delivered a leaflet to households to inform patients about plans to share the data on their patient records, called "care.data". It was – and still is – a controversial scheme.

A few stakeholders at the final stakeholder workshop felt that the methodology did not adequately cover the issue of ethnicity for the dialogue to be credible for them:

“Not representative. BME groups? Foreign languages? Hard to reach groups?”
Stakeholder, final workshop

However, other stakeholders felt that this was not problematic given the wider efforts to engage:

“The results are credible because of the wide range of ages, ethnicities, socio-economic groups and education levels etc. involved.” Stakeholder, final workshop

On balance, the evaluators conclude that the dialogue did make efforts to reach BME groups and thus ensure that ethnicity issues were covered, although more can always be done. Every shift in emphasis in design involves a trade off, and more effort spent on involving more BME groups would have risked unbalancing the overall dialogue results in a disproportionate way. The OG explicitly recognises that the dialogue was a start point for exploring these issues with the public, and not the final word. There is plenty of time to explore and build on all the findings with specific groups of the public, including more BME groups.

The one group that the OG and delivery contractor decided at an early stage not to pursue was carers. Whilst there is a clear reason why carers may have a greater interest in stratified medicine than the general public, it was felt too difficult to involve them given everything else that the dialogue was trying to do. Carers are notoriously difficult to engage in processes like these for obvious reasons: they are busy people with clear priorities in life that makes it difficult for them to be available for several hours in a day. This was decided consciously as something that could be explored later in a potential ‘next phase’ if needed.

One OG member observed that the very elderly (75+) were not included as part of the recruitment specification. They were not specifically targeted partly because this wasn’t identified at the start as a particular focus or recruitment bracket¹⁵, and for practical reasons engaging the over 75s can have a different set of requirements that were seen to be outside the remit of this dialogue. Although mentioned, the lack of over 75s wasn’t seen as problematic. Again it can be picked up at a later stage if required.

Scope Principle: The range of issues and policy options covered in the dialogue reflects all the participants’ interests (the public, scientists and policy makers).

This principle was **very well met**. Factors for this are explained below.

Framing. The purposes of the dialogue were clearly set out, and followed throughout the dialogue. The fact that the OG were involved in framing the original purposes of the dialogue – as opposed to the commissioning body agreeing them before the OG were on the scene – seemed to add to the sense that stakeholder interests were being met through the dialogue more widely.

Participants. There was a very good return rate for participants across all strands of dialogue, in that the vast majority of people who attended their first event did return for their second event, and nearly all of these stayed to the end and completed an

¹⁵ The usual recruitment bracket used was 65+, which is relatively standard practice.

evaluation questionnaire. If one accepts a high return rate as a proxy indicator for participants' interest, then this implies they were interested and engaged in the topic. From the evaluators' observations, participants were also largely very engaged in the events, albeit with 'low energy patches' which are not uncommon or unreasonable. When asked which three words best described their experience of the public events, the majority of participants from the public workshops clearly found the dialogue interesting and informative (see graphic below¹⁶) with very few negative comments.



Diversity of perspectives. The OG brought a range of perspectives to the framing of the dialogue from the start (see Appendix 1 for the organisations represented). It is fair to say that everyone on the OG was “pro” stratified medicine: there was nobody on the OG who thought that stratified medicine was fundamentally a bad idea. This seems to reflect the views published in the public domain, in that where organisations have a view on stratified medicine, it is a positive one. Campaign groups do not exist to prevent the expansion of stratified medicine. To this extent, the dialogue included a diversity of perspectives in its framing.

There was an implicit line of discussion throughout the design of the dialogue about how supportive the framing of the materials should be. Whilst the materials were largely balanced, some of the ‘pro’ flavour in the project did flow through to the materials used. This is perhaps most notable in the video animation¹⁷ which described stratified medicine as a ‘ground-breaking approach’ and generally left viewers with a positive sense of the topic. However, as the findings of the dialogue emerged, it became clear that this positive framing of stratified medicine was not so much about an unfair lack of

¹⁶ This graphic is compiled at www.wordle.net The size of the word is proportional to the frequency it was used by participants.

¹⁷ <http://stratifiedmedicine.wordpress.com/the-basics/>

balance, but the internal struggle that the whole sector has to explain to the public what it is, and how it is different from “normal medicine”. Indeed, a key finding from the dialogue is that the terminology of “stratified medicine” is unhelpful from a public perspective, as is the reference to it being “ground-breaking”.

The specialists that attended the public dialogue events (see Appendix 2 for their details) were well informed and helpful when answering questions. The evaluators saw no evidence of specialists trying to persuade the public participants of their view, and the specialists seemed open to listening to public views. The attendance of the specialists was essential for the public to get answers to their questions that in turn informed their deliberations.

“The experts were approachable, knowledgeable and enthusiastic.”
Public participant, Glasgow

97% of the public participants said they could ask questions easily and get appropriate answers, from either the specialists or facilitators.

Delivery Principle: The dialogue process itself represents best practice in design and execution.
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This principle was **very well met**. Factors for this are described below.

Appropriateness of methods. The dialogue employed a wide range of methods: public dialogue sessions with a cross section of participants, targeted sessions with specific groups, and self-facilitated sessions for pre-existing groups. This was supported by an information website and a final stakeholder workshop to draw the strands together, prior to final reporting. These methods all seemed appropriate and proportionate.

Specifically, OG members tended to value the methods equally, and could not identify a particular strand that delivered less or more value than another. They valued the potential of drawing on different methods to provide richer findings. The strands were analogous to a jigsaw in that *together* they provided a picture of views of the public, and removing any of the strands would have weakened the picture commensurately. The methods were seen as credible by the majority (87%) of the stakeholders at the final workshop because:

“The range of groups engaged with.” Stakeholder, final workshop

“Used multiple ways of finding opinions.” Stakeholder, final workshop

“Focussed on what the patient needs to know, rather than what the professionals could deliver.” Stakeholder, final workshop

The issue of credibility is discussed further in section 11.

Organisation. The practical organisation of the dialogue seemed smooth and professional. Deadlines were met, suitable venues booked, people sent to the right place at the right time, and given quality materials to prompt their thinking. The only

visible logistical issue was broadband technology, when the live streaming of the video animation and some of the stimulus videos did not download as expected to the public audience. This was resolved each time without a problem, but it was noticeable that it happened a few times. Overall though, organisation of the project was very well received by the OG, the Board and participants alike:

“The delivery contractor did an excellent job.” OG member

This is consistent with the evaluators’ experience of the organisation of the dialogue.

Clear objectives communicated. The OG had a clear sense of what the dialogue was trying to achieve, as represented by the original purposes agreed and included in the Invitation to Tender for the contractor. These purposes were then reformulated so the design of the dialogue could be optimised. A simplified version of these topics was clearly briefed to the participants at the public events. There is no evidence that participants misunderstood what they were participating in, or were dissatisfied with the objectives in any way, apart from one public participant in London who felt that there was *“too much focus on invented ethical issues, and not enough focus on cost and implementation risks”*. However, this was not a widely held view and it can be said that the objectives were clearly communicated all the way through the process, both in a direct way but also via the constant reiteration in different verbal ways by facilitators.

Involvement of external stakeholders. The OG was the first main conduit for external stakeholder interests to be involved in the dialogue. The OG was convened to scope out and help the Board set up the project, as well as provide advice and feedback throughout. This is covered above and also later under governance (section 8). OG members were also invited to attend the events themselves, which some accepted:

“It was wonderful to actually attend the events in person.” OG member

The second main conduit for external stakeholder interests to be involved was the stakeholder workshop towards the end of the process. This was a fairly large event: over 100 were invited and around 50 attended. The event was deliberately framed and designed by the contractor as a ‘discussion about the findings’ rather than a ‘presentation of the findings’ in order to engage stakeholders as constructively as possible. This seemed to work well. It was a clear and effective opportunity for a wide variety of stakeholders to attend, get involved, and take on board the findings of the public dialogue.

A couple of interviewees mentioned that they were slightly disappointed that although invited, industry representatives and the Department of Health were not able to be more actively involved in the public dialogue. Everybody acknowledged the pressures on workloads in particular with budget cuts and reorganisations. It is fair to say that both parties had plenty of opportunities to be more involved – both on the OG and also at the events – but struggled to prioritise regular and active participation.

Non-biased. The dialogue design, materials and reporting seemed to achieve good balance and neutrality overall.

“Extremely good at giving enough information without biasing perceptions.” OG member

As mentioned above, just occasionally a 'pro' stratified medicine emphasis seemed to show through, namely the video animation that framed stratified medicine as a 'ground-breaking approach' and similarly positive descriptions. Whilst it did not obviously unbalance the discussions that followed, a few stakeholders at the final workshop did identify it when sharing what factors reduced the dialogue's credibility.

"An underlying assumption that stratified medicine is a 'good thing' which perhaps biases the discussion in one direction?" Stakeholder, final workshop

"FAR too positive about stratified medicine and this influenced the answers participants gave." Stakeholder, final workshop

Public participants on the other hand predominantly found the information fair and balanced (93%).

"As well as can be expected - I'm a bit cynical of the medical industry and government." Young patient

The OG were also content with the balance of the analysis and reporting:

"I was impressed at the balance of process including the analysis." OG member

Be deliberative. The events offered a good opportunity for members of the public to deliberate on the issues, with time, information and specialist support to assist them. Participants largely agreed that they had enough time (81%), they could ask questions easily and get appropriate answers (97%), that they could contribute their views (98%) and that they felt comfortable with the specialists answering questions (99%).

"Just the right amount of time given". Public participant, Glasgow

"We could have carried on for a long time, so it was good to have a cut off time."
Public participant, London

"We all listened to each other and the facilitator made sure we all had a chance to speak". Public participant, Glasgow

"Specialists were excellent. Docs and Prof were fab." Public participant, Glasgow

It was also noticeable that public participants were very comfortable with the presence of observers (Sciencewise, evaluators, the Board) where they were present (91%). The *most negative* comment from public participants was:

"Not really comfortable but I accept it as part of the process." Public participant, London

Role of specialists. Only the public workshops had specialists supporting the events. These were usually two professionals from the stratified medicine sector who brought a practical and technical understanding of how stratified medicine is implemented, and what opportunities it brings alongside the challenges it faces. The specialists did not attend the targeted or self-facilitated workshops. This was not seen as problematic as the facilitators were entrusted to answer questions in the targeted workshops, whilst the self-facilitated workshops were in part designed to understand where the participants saw the gaps in information (so specialist attendance would have likely been counter-productive).

Mapping out views vs consensus. In line with the purposes of the dialogue, the process prioritised mapping out the divergent views of the public participants, rather than trying to move to a consensual position on specific questions. The dialogue sessions were designed, facilitated and recorded accordingly, and all strands followed roughly the same format and stimulus materials, albeit with more depth provided in the public workshops. For the majority of the findings this was entirely appropriate and worked very well, generating a large amount of qualitative data which was subsequently analysed and reported in the Dialogue Report.

The one area for reflection is the overall conclusion initially drawn in the Headline Findings report (provided to the stakeholder workshop as an input to the day) that there was ‘majority support for stratified medicine’. The design of the purposively sampled public workshops did not initially contain a specific question that elicited a direct answer about this from participants. Instead, participants’ overall levels of support for stratified medicine were to be inferred from the totality of discussions. Whilst this is not necessarily an invalid way of reaching a conclusion, the late addition of a specific question to the end of the workshops: “How do you feel overall towards stratified medicine?”, along a scale from positive to negative, provided more quantifiable evidence that supported the conclusion. This was important to maximise the robustness of any overall conclusion that might be drawn about participants’ support. This was illustrated in the London public workshops where the overall discussions felt very positive throughout the two days, but when asked the specific question to calibrate and capture their degree of positivity/negativity, participants were much more mixed about their views, with explanations as to why. This question was then carried across into the other events.

Facilitation. The facilitation was friendly, effective, independent and professional across the three strands which the delivery contractor facilitated (public, targeted and stakeholder – not self-facilitated). Public participants agreed (97%).

“Facilitation was very effective.” Public participant, Glasgow

“Facilitator was brilliant and supportive throughout.” Public participant, London

A one-to-one briefing session was held with the facilitators of the seven self-facilitated sessions, either face to face or over the phone. Initially group training sessions had been planned, but it was logistically difficult to arrange this so the idea of individual briefings was introduced as more pragmatic. See more on the self-facilitated groups below.

It was noticeable that some of the facilitators had developed a very strong understanding of the technical content regarding stratified medicine. This greatly aided their ability to ‘speak the language’ firstly with the OG and stakeholders in the final workshop, and also to answer questions that the public raised if there wasn’t a specialist sitting in on their small group discussion in the public events. This was cited by a couple of OG members as a real advantage, which made the delivery of the project smoother and more effective. There is the risk of content knowledge developing to the point that the facilitator is contributing more than process management, and this is worth bearing in mind in future. However, the facilitation clearly benefitted from this technical knowledge in this case.

“Thank you, very well facilitated and interesting event.”
Stakeholder, commenting on the stakeholder workshop

Materials. All of the dialogue strands used the same stimulus materials where time allowed, maintaining consistency between the strands as far as possible. Appendix 2 details the materials that were used at each of the specific workshops, but in summary the following existed and were widely used:

- Animation. A five minute introduction to what stratified medicine is, the opportunities it offers, and some of the challenging questions it raises. Viewed in plenary.
- Timeline poster. Setting out the origins of medicine and its development to modern medicine, and the possible future progress to stratified medicine. Viewed by individuals as they browsed around the room in an 'open' session.
- Discovery posters. Four posters, each one setting out the disease factors and possible tests in four areas: environmental, genetics, physical, and infection factors. Viewed by individuals alongside the timeline poster above.
- Video from a patient's perspective. A five minute video covering one leukemia patient's experience of being treated successfully with a stratified approach. Viewed in plenary.
- Case study of Angela and Suzie. A4 handout setting out the hypothetical case of two sisters both diagnosed with breast cancer. One can benefit from a stratified approach, whilst the other cannot. Handout was read out by table facilitator and then discussed in table groups.
- Social issues cards. A series of A5 cards each with individual 'social issues' printed on them. Participants discussed them and arranged them in order of importance in their table groups.
- Video of bio-bank manager. A short description of how patient data and tissues are sampled, archived and used in future research. Viewed in plenary.
- Consent scenarios. A4 case studies setting out four different situations in which patients might be asked for consent to share data. Read out at table groups and then discussed in groups before feeding back key points to plenary session.

All these materials were written and produced by the delivery contractor either directly or indirectly, for example the videos and animation were produced under their guidance by a sub-contractor. All the materials worked well in supporting participants through the learning process and prompting their deliberations. In particular, the timeline poster was very effective in placing stratified medicine in the wider context of how medicine has developed over the past two millennia, rather than simply talking about stratified medicine as 'new'.

Self-facilitated groups. This dialogue made an explicit choice from the start to have one strand to targeted existing groups and invite them to run their own dialogue sessions with the materials developed for the other strands. The intention was to run up to 18 sessions, split roughly equally between young person groups and patient groups. Although OG members saw the strand as a success, there are various practical difficulties¹⁸ that were experienced that are worth commenting on:

- *Difficulty holding anticipated number of sessions.* It proved harder than expected to access groups that had the time and energy, as well as someone in their group who was willing to volunteer to facilitate and take notes. Despite a

¹⁸ These are also covered in the Dialogue Report, p66.

significant effort by the delivery contractor to drum up interest, only seven dialogue sessions were ultimately held: significantly less than the 18 initially planned.

- *Difficulty holding training sessions for volunteer facilitators.* Three training sessions were planned to bring together the volunteer facilitators from the relevant groups, but this was found to be logistically difficult and the volunteer facilitators were reluctant to make the time available. Instead, individual briefings were held either face to face or over the phone between the delivery contractor and the volunteer facilitators. This was more effective.
- *Difficulty in recording discussions and feeding the outputs into the analysis.* The volunteer facilitators were asked to take notes during the sessions. This happened to varying degrees, with some volunteers taking no notes at all whilst others took more extensive and useful notes which could be passed on to the delivery contractor. To ensure that substantive feedback was gained from the sessions, the delivery contractor debriefed each of the volunteer facilitators and made their own version of the outputs, which was fed into the overall analysis of findings in the project. This debrief interview was seen as useful by the delivery contractor.
- *Difficulty in evaluating the sessions.* The volunteer facilitators did not always circulate the evaluation form provided (four out of seven were circulated and completed), and participants did not complete the online evaluation form when emailed it after the session if they had forgotten to circulate the hard copy form. Although there was still a fairly good response rate overall, it did result in a gap in the evaluation data.

This strand was the subject of some discussion amongst the project team and OG, in part due to its unfamiliar aspect, and in part due to its logistically difficult format to deliver. Below we set out some of the advantages and disadvantages of the method.

Advantages/Positives	Disadvantages/Negatives
Potentially reaching people that would not otherwise be involved.	Difficult to drum up interest even with a small financial incentive offered, and a flexible timescale available.
Able to minimise 'response bias' where participants say what they think the delivery contractor facilitator wants them to say.	Impossible to manage or assess the degree of bias introduced by the volunteer facilitators - or other participants - as the delivery contractor is not present.
Potentially cost-effective way of reaching a large number of interested people (if the topic is immediately attention-grabbing and relevant to them).	Potentially an expensive way of reaching relatively few participants (if the topic is not appealing enough to boost numbers).
Empowering people to take control of their own learning and deliberations.	Data collection variable and potentially unreliable.
	Little control over the mechanism for evaluation: volunteer facilitators do not always use the evaluation forms provided.

Appropriate scale and diversity. The dialogue engaged over 180 public participants via 19 workshops over a four month period.

The Sciencewise Guiding Principles say that public dialogue should “*be of appropriate scale and be appropriately ‘representative’*. *The range of participants may need to reflect both the range of relevant interests, and pertinent socio-demographic characteristics, including geographical coverage*”. The principles also say that “*public dialogue does not claim to be fully representative, rather it is a group of the public, who, after adequate information, discussion, access to specialists and time to deliberate, form considered advice which gives strong indications of how the public at large feels about certain issues*”.

In the light of this and the evidence gathered via observations, interviews and questionnaires, the dialogue does appear to have been conducted with appropriate scale and diversity. As covered in section 3, the public workshop strand was purposively sampled to reflect a cross section of ages, genders and socio-economic classes and hence understand the diversity of views likely to exist amongst the public. The targeted strand, and the self-facilitated strand, accessed more homogenous groups that the OG wanted to understand the specific views of, for example young patients, or BME views. This seemed to allow specific issues to arise that may not have arisen so clearly otherwise, in particular a sensitive perception that stratified medicine could lead to discrimination on ethnic grounds.

The delivery contractor had a rationale (beyond budget constraints) for the choices made about scale and diversity of participants targeted across the different strands of dialogue, which was important for OG members and stakeholders alike. Although this is discussed as part of ‘credibility’ in section 11 later, stakeholders said:

“[It was credible because a] wide group of people have been involved in serious dialogue.” Stakeholder, final workshop

It was appropriate and important that specific efforts were made to engage groups of the public that had specific reason to have a view on stratified medicine, either because they were patients, or would work in the healthcare profession in future.

Two locations were used for the public workshops, London and Glasgow. Few significant differences emerged between these two groups of public participants. On the one hand, this questions whether both locations were really needed given the extra budget required – although of course this is only known with hindsight and could not have been predicted. On the other hand, the consistency of messages between the two locations provides some reassurance that the findings give “*a strong indication of how the public at large feels*” about stratified medicine, as described in Sciencewise’ guiding principles. The choice of two locations was seen as appropriate and proportionate.

Involve participants in reporting. All public participants, and the stakeholders at the final workshop, were emailed (where contact details allowed) and thanked for their participation, and informed that they would be contacted again with a link to the Dialogue Report when it is published.

It is worth the Board considering how participants might hear about how their views are being communicated and used in policy making in future, as implementation of stratified medicine develops.

It is debateable whether participants were really ‘involved in reporting’ as mentioned in the Sciencewise guiding principles. The ways in which participants were involved in reporting include:

- Being able to hear what their small-group facilitator verbally fed back to the wider group in the plenary sessions of the public workshops (during work sessions where this happened).
- Being able to see what others wrote on Post-its and sometimes on note-taking sheets, as well as browsing round the materials Blu-tacked to the walls that were generated by participants earlier in the day.
- A handful of participants attending the stakeholder workshop, with one of them being asked to provide a verbal update on their experience of the dialogue.

However, they did not see or review any kind of summary report from their sessions until the Dialogue Report was published.

Although there are practical challenges to involving participants in what gets reported, one might have more confidence that comments have been captured to the participants' satisfaction if they had a chance to check or review them somehow. The detailed practicalities of eliciting views from 8-10 people at once in a small discussion group places a lot of emphasis on the facilitator/note-takers, as well as making assumptions about what people believe who choose to remain silent or quiet. The ability of public participants to constructively review what has gone forward in their name is severely limited if all they see is a finalised Dialogue Report six months later, in particular when it summarises 19 workshops. This is something to consider in future public dialogues: how can participants be more involved in what goes forward in their name? It is noted, however, that there aren't any easy answers to this methodologically. Reflection and discussion across the Sciencewise programme and elsewhere may prove fruitful.

Website. The dialogue website - <http://stratifiedmedicine.wordpress.com/> - was launched on 23rd September 2013, a couple of weeks before the first public workshop. The site is simple in structure, with four pages as follows:

- *About* – an introduction to the topic of stratified medicine and the public dialogue project.
- *Project diary* – updates on progress from the project team.
- *The materials* – including five sub-pages with a range of videos and written material used at the facilitated public and targeted workshops, and also for use by the self-facilitated groups.
- *More information* – links to another website for more information on stratified medicine, and to the contractor's and dialogue funders' websites.

The *About* and *Materials* pages contain well-written background and stimulus material reflective of that used in the dialogue workshops. This content was potentially useful in different ways depending on the visitor. For example, a member of the public who had been involved in a workshop might have found it useful to visit the website and reflect further on some of the material they had seen in the workshop; an Oversight Group member might have looked here to check what was being shared with the public; a stakeholder might have viewed these pages to get some background information on the project. In this sense it fulfilled a variety of needs of a range of potential audiences.

The *Project Diary* page has four entries – from September 2013, October 2013, December 2013, and March 2014. While these entries track the overall arc of the dialogue, there was perhaps potential for them to be both more regular and more interactive – for example inviting comments and questions. However, given a limited budget, not providing these additional functions was an understandable choice.

The *More Information* page contained the basic links one might expect – a link to funder and contractor websites, and a link to more information on stratified medicine. There was perhaps an opportunity to, fairly easily, link to further background material, with a brief description of each link, in order to provide visitors (in particular members of the public involved in the workshops potentially looking for further information) with a range of information outside the materials they had already seen at the workshops, and to explore the context of the topic in their own time in greater depth.

Across the six month period measured (mid-September to mid-March), the website received a total of 313 visits¹⁹. This number breaks down as follows:

- Visits per week ranged from 1 to 30, with an average of 13 people visiting the website each week. Out of these 13 per week, it is perhaps realistic to assume that at least 2 or 3 were project staff, funders, evaluators, Sciencewise or OG members.
- Across the period, the average number of pages viewed by each visitor was 4.8 (5).
- There tended to be peaks in the number of visitors and more significant peaks in the number of page views around key events such as the public workshops, Oversight Group meetings, and stakeholder workshop.

The number of visits per week was not very high. The highest numbers of people tended to visit the website around the time of the public dialogue workshops, and numbers did appear to cluster around significant events. This suggests that the website fulfilled an important purpose as a back up to existing materials and a place where people could go to re-read materials, find out more through the linked websites, or refresh their memory to prepare for key meetings. It did not appear to act as a place for wider public engagement, to draw in larger numbers of people not directly involved in the dialogue project – but equally it was not intended to fulfil this purpose.

Overall, the website appeared to do a good job of providing a simple, low maintenance, one-stop shop for dialogue background and materials.

Impact Principle: The dialogue can deliver the desired outcomes.

This is covered under section 9.

Evaluation Principle: The process is shown to be robust and contributes to learning.

The principle appears to be **very well met**. Others are invited to judge this from their perspective too, and feedback to the evaluators is welcome.

Factors addressing this principle include:

¹⁹ A “visit” is defined as a unique visitor per week, so if one person logs on twice in a fortnight, it counts as 2 visits.

- There was an independent evaluation.
- The evaluation was adequately resourced, approximately 10% of the delivery project budget.
- The evaluation was commissioned by competitive tender.
- The evaluation started early: at the same time as detailed design and delivery started.
- The evaluation addressed the objectives and expectations of stakeholders including the Board, as well as standards of good practice set by Sciencewise.
- The evaluation gathered both qualitative and quantitative data so that conclusions could be evidence-based.
- The dialogue process ended with an open discussion of learning at a 'wash-up' meeting, as well as planned publication of a case study to share learning more widely.

OG members commented that:

"I didn't even know there was an independent evaluation at the start! The evaluation has really strengthened the process though."

"At first I thought that the evaluation was adding an unnecessary layer of complexity, but in hindsight it's been useful."

The evaluators welcome feedback on any aspect of the evaluation.

A note on procurement administration

The evaluators thank all those involved in the setting up and administering the contracts in place during the dialogue, including specifically for the evaluation. We recognise that administration is rarely at the top of many peoples' priority list, and often gets delayed due to staff changes and other unavoidable logistical problems. In the spirit of wider learning, we note two points that are worth considering across the Sciencewise programme, in particular for the management of evaluation contracts.

First, any extension of the budget for the delivery contract could usefully *automatically* factor in a commensurate extension to the evaluation contract, rather than it needing to be subject to a separate negotiation and justification process. In the case of the stratified medicine dialogue, the addition of the stakeholder workshop to the process effectively made the process larger, longer and more expensive. This necessitated a longer, larger evaluation. Also, the overall dialogue process designed was significantly more complex than anticipated on the basis of the Invitation to Tender. A rather protracted process of re-negotiation occurred to align the needs of the project with the budget availability of the evaluation. This was eventually agreed – and we thank the Board again for this and believe the evaluation is much more robust as a result. However, it could be made more streamlined if all budget extensions were automatically seen as comprising two components, delivery and evaluation, rather than the evaluation extension being bolted on separately at a later date.

Second, the rapid agreement of formal financial administration is essential if the evaluation of the project is to be optimised. In this case, the confirmation of the

appointment of the evaluators took over five months²⁰, which was well over half way through the delivery of the dialogue. There are tangible impacts on the evaluation here that are worth highlighting. In this case, the evaluators held back conducting a full round of initial interviews with the full OG because administration was not in place. As a result the baseline established was not as robust or full as it might have been. Beyond this, the evaluators conducted the evaluation in good faith as if contracts *had* been agreed: but this is not an ideal way to operate.

²⁰ 3KQ were notified of their appointment on 5th June, and the contract was issued on 13th November.

7 - Satisfaction Levels

“Satisfaction: have those involved been satisfied with the dialogue, and its value and benefits to them?”

Satisfaction levels appear **high**.

The public participants were certainly satisfied with the dialogue, with 97% of public participants saying that they were “overall satisfied with the events”. The majority of these agreed strongly, which does indicate high satisfaction levels from a participant perspective.

“I am pleased to have been part of this research.” Public participant, London

“I still don’t understand what stratified medicine is, but hearing the opinions was interesting.” Young patient workshop

“It was fun.” Young people workshop

OG members were also satisfied with the dialogue, as judged by the debrief conversation held on 24th February 2014 and subsequent interviews with the majority of OG members. No particular dissatisfactions have arisen, beyond the constraints to the dialogue process as explored elsewhere in this report. For example, the lack of engagement with carers, over 75s, and further ethnic diversity. None of these things were seen as problematic, rather they pointed towards future work that might be required at some point.

“I’m very satisfied with the process.” OG member

“10 out of 10.” OG member

“If anything it did more than could be expected.” OG member

Value and Benefits

OG members cited four main ways in which the project had been valuable to them.

- Building understanding of how people “out there” perceive what people in the stratified medicine sector are doing. An OG member remarked: *“It has provided a perspective that would have been impossible to get otherwise”*.
- Providing and summarising evidence on the range of public views. One OG member said: *“The dialogue sets out evidence in a more robust way about the range of views. I can point to this when meeting stakeholders.”*
- Learning about the potential of public dialogue in a new environment. This was seen by some OG members as a *“good enough process to act as an exemplar dialogue on similar topics”*.
- Contributing to democratic legitimacy in a more general sense. One OG member remarked that this kind of public dialogue process was *“part of securing*

democratic legitimacy for a new technology or practice". In the same vein, another said: *"If public dialogue is a good thing in a democracy, arguably we don't spend enough on it as a country"*.

More benefits and ways in which the dialogue delivered value are covered under Impacts, in section 9.

8 - Governance

“How successful has the governance of the project been, including the role of advisory panels, stakeholder groups and the Sciencewise support role?”

The governance of the dialogue was **very successful**. Factors contributing to this are set out below, mainly focussing around the role of the Oversight Group as the key governance structure in place. See section 3 for details of how the OG worked.

Governance clarity. The role of the external Oversight Group was clear, and the group agreed Terms of Reference (ToRs) early on. The group focussed on advising on the dialogue process, with decisions being taken by the Board when sign off was required. The ToRs were clear on this. However, OG members commented that getting involved in this kind of group is always slightly uncertain:

“The ToRs were clear, but I didn’t really know how it would turn out: if it had been another ‘yes committee’ I couldn’t have prioritised it.” OG member

Whilst the OG members weren’t particularly clear on why the specific individuals had been invited to join the OG and that more transparency around this might have been useful, they felt that the individuals had worked well.

“Structure worked well, and the people were good too: honest but not unnecessarily contentious in the way they participated.” OG member

Management of the Oversight Group. Once appointed, the delivery contractor took a firm managerial role of the Oversight Group. They set the OG meeting dates, set the agendas, and took the record of actions and decisions. This ensured an effective connection between the OG’s role and the evolving needs of the project. The OG was asked to comment on the right things at the right time.

“The delivery contractor was good at providing us with information at the right times. I never felt I was being harassed, but I did feel I was being kept in the loop.” OG member

The Board role. After initially being keen to oversee the project at arms length, the Board were increasingly involved in working with the delivery contractor on specific choices in the dialogue design, as well as with the materials development. This was welcome by both parties and was seen as a valuable development of a working relationship that improved the effectiveness of the overall dialogue.

Sciencewise. The OG members, and in particular the Board, were very supportive of the Sciencewise Dialogue and Engagement Specialist’s (DES) input. The DES was effectively treated by OG members as a member of the OG. This appeared helpful from the evaluators’ viewpoint. However, the value of Sciencewise’s input on this project appeared primarily about helping to get the project off the ground in the first place:

“The Sciencewise DES was essential in helping us see how we at the Board might approach this differently: listening, instead of telling.” The Board

“For various reasons this project took a long time to get off the ground and this limited my capacity to be as actively involved as I would have liked in the later stages. On the other hand, I think investment in thinking and designing at the front end is the most important way that Sciencewise can contribute to such projects.” Sciencewise DES

This may explain one OG member’s view which, although positive overall, illustrated a shift in roles upon inception of delivery:

“I wasn’t particularly clear how Sciencewise fitted in once the delivery contractor was appointed.” OG member

To summarise though, the continuing role of Sciencewise as advisor throughout was seen as important and productive.

9 - Costs and Benefits

“What was the balance overall of the costs and benefits of the dialogue?”

Judging the cost/benefit trade off of public dialogue is notoriously difficult. This is for various reasons, including:

- Benefits are often intangible and so hard to quantify in a meaningful way. How does one quantify a benefit such as, “I’ve become more open-minded about what the public have to say”?
- Benefits arise down the track instead of at the close of the dialogue, so risk being left out of a traditional cost/benefit analysis.
- Benefits are often difficult to attribute in isolation to the public dialogue alone. For example, “The dialogue was one part of the evidence that led us to X”.
- There is no counterfactual to assess against. One can only speculate as to what “might have happened without the dialogue”.

Despite this, the benefits that have arisen already are listed in section 9 above, although we do not attempt to quantify or monetise them.

The costs of public dialogue on the other hand are easier to quantify. Funding is agreed, invoices are paid and recorded, and people’s time can be tracked or at least fairly easily and accurately estimated. Below we list the costs of the dialogue so that a full picture is on record:

Technology Strategy Board contribution	105,930
Sciencewise contribution ²¹	130,500
Time of OG members, Board and specialists ²²	39,000
<u>Total</u>	<u>£ 275,430</u>

Perhaps the best indicator of relative value of a dialogue process is the view of the funders upon closure. In this context, the funding for the project was just about right:

“Very worthwhile.”

“Very good value for money, relatively cheap with wide overarching significance.”

When reflecting specifically on whether the dialogue could have been delivered almost as well with slightly less funds, funders said:

“Possible with less funding? Not really, the project would have suffered.”

“Possible I suppose, but the extras like the video case study would have been chopped which are the tools that are getting the messages out there.”

²¹ £108,000 funding plus £22,500 in support and guidance costs = £130,500

²² The time of OG members is estimated based on the number of OG meetings held, attendance at the dialogue events themselves, and the number of specialists that assisted with the events. This does not include attendance of any of the 40 wider stakeholder attendees at the final stakeholder workshop. A total of around 60 days is estimated. A nominal day rate of £650 plus VAT has been used to monetise the value of time in this context. All figures include VAT.

And when reflecting on whether a little more funding would have added significant value:

“More funding? Might have been useful, but we could have done a lot more without much extra value at this point.”

We can conclude, therefore, that the benefits outweigh the costs in the eyes of the funders.

10 – Impacts

“What difference or impact has the dialogue made?”

Stratified medicine is a complex topic to communicate to public participants who generally start with very little understanding of how the healthcare sector works, how treatments are diagnosed, how treatments are developed, and how regulation works. The main **achievement** therefore of this dialogue as cited by various OG members was the dialogue’s success in providing the information, support and time to enable participants to learn and deliberate on the issues in a productive way.

“Confirmation that people are capable of making sense of complex information and given time, that they can do it and come up with sensible opinions.” OG member

“It is possible for public to form opinion if given time, information and support.” OG member

Impacts on public participants

Public participants said their views had been affected on the topic (82%), and that they had learned something new (97%).

“I’ve learned what stratified medicine is.” Public participant, London

Some participants also said that they were likely to change something that they do as a result of taking part (43%). Most of these participants did not say what they might do differently, or gave only very general changes such as “be more interested”, but some did give specifics:

“Get more involved, and ask more questions of my GP.” Public participant, London

One public participant in particular had clearly been quite motivated by the workshops:

“Since the first session, I have changed my diet and added 'exercise' to my routine - more encouraged to lead a healthier lifestyle.” Public participant, London

Impacts on Stakeholders

Various impacts were identified by stakeholders including the OG. These are listed below (and see section 7 for more on the value and benefits of the project to stakeholders).

Some stakeholders felt they might talk about stratified medicine differently:

“I might use the term strat med less, and focus on talking about how it works and use other phrases like personalized or tailored.” OG member

Some stakeholders felt the dialogue had confirmed in a robust way what they already believed:

“There aren’t any surprises, it reaffirms what is already out there about what people think: it’s useful.” OG member

"It is a useful exercise to enrich the evidence base." OG member

Some stakeholders gained insights and learning about the dialogue process itself:

"It's good to see that public dialogue can be done in a balanced way. I may suggest this model to another committee that I sit on." OG member

More specifically for one OG member, the dialogue project provided an excellent example of quality delivery for the first time in their experience:

"I was always of the view that it is possible to have a well conducted dialogue - I just hadn't seen it in any of those I was involved with." OG member

In addition to these categories of impacts, stakeholders at the final workshop suggested ways in which they might take forward the findings personally:

"Join a biobank." Stakeholder at final workshop

"Report the side effects of medicines that I take." Stakeholder at final workshop

"Consider a public lecture on stratified medicine at the university I work at." Stakeholder at final workshop

These and others listed in the evaluation data from the final stakeholder workshop (Appendix 4) could usefully be followed up in coming months to assess the extent to which the commitments have been followed through.

Impacts on the Board

The Technology Strategy Board commissioned this public dialogue, so arguably the most important area of impact is on their thinking and actions.

Some learning and changes to thinking within the Board were personal:

"I've grown as an individual through being involved in this dialogue."

"It's been really informative."

Other specific changes were identified in the ways the Board staff involved intended to take stratified medicine forward including:

- Insights in relation to the use of the terminology of stratified medicine (it was one of the aims of the project to test these - see section 3).
- Differing levels of trust the public had in different institutions (e.g. Government and industry).
- Sensitivity around issues of ethnicity and the need to ensure the focus is on increasing access to appropriate treatments.
- The use and sharing of data.
- The importance of understanding what affects the adoption of new technologies like stratified medicine.

Comments from the Board included:

"It's changed the way in which I talk about stratified medicine: I assume a lot less about what people know or believe."

"I will very much stress that it is not a new concept but an evolution of established practice and try to communicate that there is no intention to ethnic stratification."

"We can look at this project as a model for public engagement in future to understand where trust and distrust lies with the public."

"I will now push for more PR to communicate the positives more clearly – industry need to improve this, as the public pay for developments one way or another."

The Board cited the fact that some of their colleagues had also been interested in the outputs and process of the public dialogue:

"The animation video has gone right round the Board."

"Our colleagues are now talking about the merit of public dialogue on other topics."

"Our [the Board's] stakeholders are now talking about it."

One OG member captured a widespread but not openly voiced feeling well when they said in interview that:

"The Board seem to have recognized that the public do have interesting things to say. It wasn't too frightening, they may do more dialogue on other topics". OG member

Impacts on policy now and in future

The impacts of a public dialogue project cannot often be fully identified and quantified immediately upon the close of the dialogue. Impacts take time to emerge, especially when there is no specific policy decision point that the dialogue is feeding into. This appears to be at least partly the case here:

"The benefit of this is not today or tomorrow, but in 18 months time." OG member

It is worth noting that although public participants overall felt fairly confident that the dialogue would make a difference to how stratified medicine would be implemented (71%), their confidence was less definitive than nearly all other areas of their feedback, with 14% not knowing, and 5% disagreeing. Whilst not particularly unusual, this is worth the Board and others bearing in mind.

A few OG members highlighted the need for the Board to consciously take on board the findings in a clear way, and that there was some lack of confidence that this would happen:

"I would certainly hope that the Board will pick up on it, but I'm not fully confident." OG member

"the Board should announce their response to the key findings. Not hugely confident that the Board will do this publicly." OG member

In the meantime, the Board has disseminated the dialogue results widely. It is a measure of the success of the project for the Board that they see the results as sufficiently important to actively share them.

The stakeholder workshop at the end of the project was seen as a particularly useful mechanism for widening awareness of the project and its findings, and is being considered for inclusion in future projects co-funded by Sciencewise.

“The inclusion of a stakeholder workshop at the end of a dialogue process worked really well: I am already including this in other similar projects as a result” Sciencewise DES

The results have also been disseminated to organisations working closely with the Board including the Association of the British Pharmaceutical Industry (ABPI) and the Academy of Medical Sciences (AMS) as well as articles covering the dialogue published (e.g. in *Mental Health Today* on 25th April 2014) and blogs on the Sciencewise and British Science Association website. There are plans for wider dissemination including further articles in periodicals (e.g. the *Health Service Journal*) as well as to those interested in data issues (e.g. Genomics England and the Department of Health).

11 - Credibility

The perception of credibility depends on who is making the judgement, and what their expectations are for the public dialogue. In the context of this dialogue on stratified medicine, there are two main groups of people that formed a judgement (either explicitly or implicitly). First, the OG and those close to the delivery of the project. Second, stakeholders who were not involved in the delivery of the dialogue but attended the final stakeholder workshop. These are taken in turn below.

Oversight Group

Without exception, the OG members saw the dialogue process as a credible way of understanding the range of public views on stratified medicine.

“A credible model. The workshops and report are robust.” OG member

OG members were realistic about the limitations of public dialogue, as well as its benefits, and listed various constraints that they were aware of and comfortable with. They explicitly did *not* see this as reducing its credibility in their eyes though – they were aware of these limitations when they set the project up. Specifically, they identified the following limitations:

- The dialogue had not produced statistically representative findings
- The public workshops were largely a very ‘managed’ environment
- The dialogue did not attempt to elicit views of *every* sub-sector of the public (carers, over 75s, every ethnic group, people with mental health issues, and so on)
- The dialogue could not explore every aspect of stratified medicine in depth.

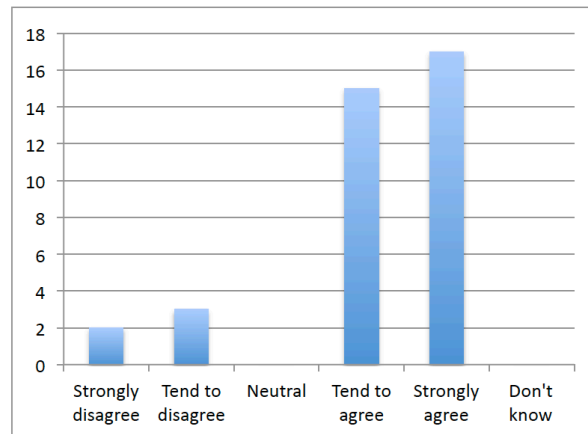
The OG accepted these constraints both at the start and during the process. They emphasised that the dialogue was more of a start point than an end point, so the constraints were to be expected.

Wider Stakeholders

The final stakeholder workshop was the second group of people who formed a view on the credibility or otherwise of the dialogue. An illustration of attendee views is below, with full detail in Appendix 4:

**Q2 - "I believe that the public dialogue has credibility"
i.e. the process and outputs appear valid and convincing**

Participants selected one answer that best represented their response.



There was a minority of attendees (5 out of 37, see above) at this final workshop who felt that the dialogue was not credible due to the sample not being representative, the use of incentives, and the lack of 'full' ethnic inclusion.

"Are the people who chose to be part of the dialogue truly representative of the public? I am not convinced they are." Stakeholder, final workshop

However, the majority of attendees (32 out of 37) did feel the dialogue was credible. Reasons cited included the range and diversity of the findings (some expressed this as "representativeness"), the methodology used, and the use of incentives to reach people who had not previously been involved.

"Broad and inclusive process to ensure demographic representation." Stakeholder, final workshop

Interestingly, the issue of representativeness, and the use of incentives, were raised by some attendees as factors that made the dialogue *more* credible, and by others that made it *less* credible. It is hard to know exactly what underlies the difference, but one might speculate that it is likely that stakeholders had varying expectations and aspirations for this kind of dialogue process – some of them not necessarily realistic, but important to them all the same.

So, in summary, the dialogue was seen as a very credible process, by those who commissioned it, the OG, and the majority of the stakeholders. The evaluation only saw evidence of a few wider stakeholders who questioned the credibility of the process, on grounds that perhaps weren't entirely fair given the limitations of the dialogue. However, the OG did make the point quite strongly that the main limitation – that of not claiming representativeness – needs keeping in the front of mind when interpreting and communicating the dialogue results.

12 - Lessons

“What are the lessons for the future (what worked well and less well, and more widely)?”

There is a variety of learning to take from this dialogue, most of it arising out of successes in the project. Each area of learning is taken in turn.

Setting up the Oversight Group before the contractor is procured

In this project, the OG was set up months before the Invitation to Tender for a delivery contractor was released into the procurement process. The OG helped the Board scope the challenge, identify questions to be answered, and generally define the purposes of the project with Sciencewise’s help. Importantly, the OG inputted to and agreed the Invitation To Tender, so that when the contract was let, the specification did not immediately need to be changed or discussed in detail. Equally, the OG was invited to read the competing tenders and attend the contractor interviews, so had the opportunity to be involved in the selection process all the way along. This seemed to pay dividends further into the project, with the OG having a relatively strong and clear ownership of the project.

Funding approval takes a long time

Overall, the project took about two years to go from conception to inception. The nature of funding discussions, including the requirement for the Board to provide some of the funding (as opposed to it being fully funded by Sciencewise), means that it simply takes a long time for all the sequential hurdles to be ‘jumped through’. They do, however, serve an important purpose. We are not suggesting they are bypassed in any way, simply highlighting explicitly that it took far longer than anyone expected. One specific aspect that took a while to become clear was who was expected to actually run and oversee the dialogue. The Board initially thought it was for Sciencewise to run, whereas the reality is that the commissioning body – in this case the Board – was expected to own and run the project, with the assistance of a delivery contractor. Although this is a relatively minor point in this case, there is potentially scope to clarify this at an earlier point on future projects, including on the questions the commissioning body want to ask the public, and what they want and expect from the process.

Allowing time, and including a Scoping Review

It was noticeable that this dialogue project had a good amount of time available: 10 months from appointment (early June) to closure (end March). This allowed the space and freedom to discuss things properly amongst the delivery team, the Board and the OG. It allowed the delivery contractor to hold a public pilot of the materials and make subsequent improvements, and also try out a slightly different process via the targeted groups and self-facilitated groups. One main way in which the looser time constraints assisted was by allowing the Scoping Review to take place early in the project. The Scoping Report emerging was seen as a really important product in its own right. As well as setting out the technical issues clearly for the OG in one place, the Scoping Review helped frame the whole dialogue process and accelerate materials development, as well as immerse the facilitator team in the technical content that in turn afforded them more dexterity later on.

Targeting groups that will be affected by the technologies under discussion

There was clear reason to suspect that some sections of the public could have more reason to be affected by stratified medicine than others. The inclusion of workshops for patients (young and adult), medical students, BME and patient support groups helped enormously with triangulating the findings, as well as building the credibility of the findings overall. It is worth explicitly saying that these could not have *replaced* the purposively sampled public sessions, and were useful as an *addition* to them.

Self-facilitated groups are a useful but challenging method

The dialogue focussed one strand of discussions on pre-existing groups, for example patient support groups or youth groups. A volunteer from each group, who was briefed in advance by the delivery contractor, facilitated each discussion. This volunteer then ran their discussion and took notes. It was uncertain from the start how many groups would take up this offer or request for a discussion.

Experience showed that the OG valued the strand as it accessed members of the public that would not otherwise be reached (in particular BME communities), and this helped triangulate the data from other strands. However, it was quite difficult²³ to persuade a range of groups to hold a discussion, as there were many factors that had to come into alignment: the group needed to be willing to physically meet; not be too busy; be content to deal with complex material; do it within the timescale; do it almost for free; and have a volunteer facilitator. This is quite a lot to ask of a group, and therefore understandably it took a while to secure even the seven groups that did happen. Specifically, the delivery contractor found that the following things helped, or may help in future:

- Invite the volunteer facilitators to the public events if possible, so they are well briefed and immersed in the technical content themselves.
- Target groups who have a clear interest in the benefits and implications of the technologies under discussion. In this case, patient groups offered the best return.
- Be ready to offer a financial incentive that is comparable to the public workshops.
- It is hard for volunteer facilitators to capture a full and accurate set of notes. Following up with a debrief interview soon after the event to hear about discussions can help make the data more robust.

Aggregated nature of reporting

One of the Sciencewise principles is to involve participants in the reporting of their views. This is partly about the ethical requirement to keep them updated on how their input has been passed on and used, and partly so that everybody can be reassured that participant views have been captured, summarised and reported accurately. This dialogue process had 4 strands of workshops²⁴ in all, and one Dialogue Report. No strand reports or interim reports existed. The consequence of this is two-fold:

- *Long lead time.* The Dialogue Report is emerging between two to six months after the participants attended their events. This is a long time for participants to remember what was said and how their event/s felt. Equally, it is a long time for facilitators to remember proceedings too, when they analyse the data and write the Dialogue Report.
- *Loss of traceability.* The fact that all public and stakeholder input is aggregated in one Dialogue Report, rather than being set out in individual event reports or

²³ Up to 18 sessions were planned, and 7 happened.

²⁴ 4 strands: public sessions, targeted sessions, self-facilitated sessions, and the final stakeholder workshop.

strand reports means that it is very difficult for participants to see where their input is, and how it has been recorded, analysed and reported (beyond the selection of quotations used). Whilst there is no particular reason to doubt the capture and analysis methods of the delivery contractor, the use of only one report at the end does place significant reliance and trust in these procedures, and prevents participants confirming their comfort with how their views have been presented.

In summary, it is probably unrealistic for participants to be able to judge whether their views are accurately recorded or not within one report issued six months after the first event. There are few easy answers to how methodologically this could be remedied, but brief reports on each event, together with more rapid reporting, may be something worth considering. However, the final report was considered to be concise, accessible and readable (including by public participants) which, given the complexity of the topic and process, was a significant achievement.

Stakeholder workshop at the end to discuss the findings

With no specific policy hook to hang this dialogue on, there was a danger that the dialogue results could drift, with everybody finding it *interesting* but nobody really *doing* anything as a result of the findings. Whilst strictly speaking this risk remains, the inclusion of a stakeholder workshop after the dialogue events (but before the full Dialogue Report was written) was very useful in 'spreading the word' about the dialogue's existence and findings. However, the views of the stakeholders were also included in the Dialogue Report, with little clarity about how they had affected the findings themselves. In future, consideration would need to be given as to whether the stakeholder workshop is defined explicitly as 'part of' the public dialogue, or whether this would start to blur the definition of public dialogue and the clarity of what the Dialogue Report is reporting: public views, or a mix of public and stakeholder views?

13 - Conclusions

Overall, this dialogue was a success. It met its objectives well, and fulfilled Sciencewise's guiding principles that set out good practice. The governance arrangements worked effectively, and participants were satisfied with the value the dialogue provided. It is still early to judge the impact of the dialogue but there are already changes in the way some staff at the Board communicate about stratified medicine, and various particular findings that they intend to take forward over the coming months and years.

The evaluators thank everyone who contributed their views and time to the evaluation: it would not have been possible without their generous and honest participation.

END

Appendix 1 – Membership of the Oversight Group

Academy of Medical Sciences	Dr Naho Yamazaki
Association of the British Pharmaceutical Industry	Dr Louise Leong
Department of Health	Colin Pavelin
Genetic Alliance	Alastair Kent
Involve	Simon Denegri
Kings College London	Prof Nikolas Rose
Sciencewise	Andrew Acland
Technology Strategy Board	Alasdair Gaw and Penny Wilson
University of Edinburgh	Prof Joyce Tait