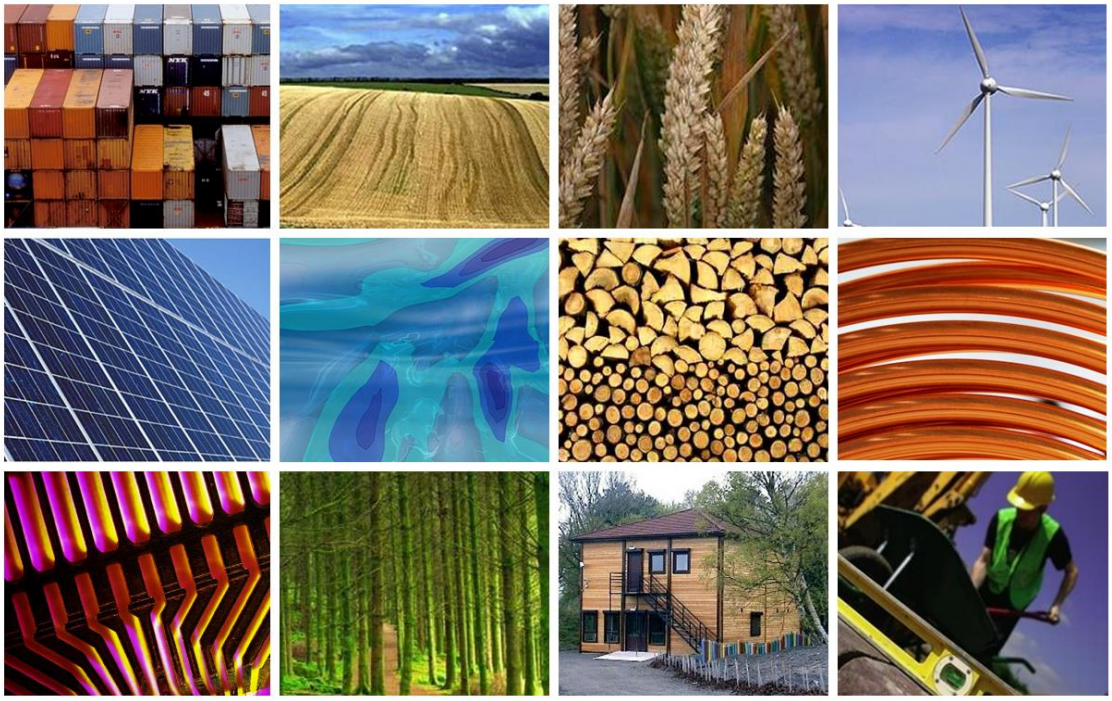
Genomics England and Sciencewise

Evaluation of a public dialogue on Genomic Medicine: Time for a new social contract?

Evaluation report
June 2019



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Glossary of Acronyms

ABI	Association of British Insurers
AI	Artificial Intelligence
APBI	Association of British Pharmaceutical Industry
BEIS	(Department of) Business, Energy and Industrial Strategy
BME	Black and Minority Ethnic
CMO	Chief Medical Officer
CSO	(NHS) Chief Scientific Officer
DA	Devolved Administration
DHSC	Department of Health and Social Care
FTE	Full Time Equivalent
GDPR	General Data Protection Regulation
GE	Genomics England
GG	Generation Genome report
GMS	Genomic medicine service
GMC	General Medical Council
NHS	National Health Service
OG	Oversight Group
REA	Rapid Evidence Assessment
SEG	Socio economic group
SGP	Scottish Genomes Partnership
SoS	Secretary of State
SSAC	Scottish Science Advisory Committee
SLT	Senior Leadership Team
UKRI	UK Research and Innovation
WGS	Whole Genome Sequencing

EXECUTIVE SUMMARY

Introduction

This report of the independent evaluation of a public dialogue on Genomic Medicine: Time for a new social contract? has been prepared by URSUS Consulting Ltd on behalf of Genomics England (GE) and Sciencewise[1]. The public dialogue was designed in response to the Generation Genome report (2016) which called for a public dialogue and consideration of whether the nature of genomic medicine, and the societal issues it raises, imply a need for a new 'social contract'. The process was designed to fit with the completion of Genomics England's 100,000 Genomes Project and to help inform the roll out of NHS's genomic medicine service from 2019 onwards. Originally only intended to cover England, at the request of the Scottish Genomes Partnership, a Scottish location was also added in order to explore whether attitudes would be different in the light of the slightly different policy decisions to be taken in Scotland.

Objectives

The dialogue had the following eight objectives:

1. To establish current knowledge and understanding on public views and attitudes to i) genomic medicine, ii) whole genome sequencing (WGS) iii) the concept of a 'social contract' between the public and the NHS and iv) safeguards/'red lines' essential to public support/trust for genomic medicine, through a review of previous dialogue, engagement, consultation and related research projects involving the public.
2. To understand participants' aspirations and concerns around the use of genomic data and other personal information.
3. To understand how participants 'trade off' concerns about data, privacy and use of their information against potential health and other benefits that may come from genomic medicine, and what safeguards need to be in place.
4. To explore understanding of the idea of a 'social contract' as applied to the NHS and the principles by which it is understood to, or should, operate.
5. To explore what expectations and understanding are shared between patients, the public, clinicians, academics, industry and other stakeholder groups around the ambitions and outcomes for genomics and genomic medicine in the UK.
6. To contribute to and inform the ongoing policy, political and ethical environment for genomic medicine to flourish, as the benefits and opportunities presented by the technology are realised.
7. To contribute to the wider policy, political and ethical environment about the collection and use of data by government beyond healthcare and genomics.
8. To develop an understanding of the language and terms that the public and other stakeholders use in association with genomic medicine in order to inform communications for and about genomic medicine activities and services in the UK.

Framing of the design and delivery

The final report summarises potential changes which will be needed in the interactions between patients and their families, clinicians, counsellors, researchers and commercial companies involved with delivering genomic medicine and using, holding and sharing genomics data. The findings are organised around the underlying principles of solidarity, reciprocity and altruism and presented as a

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

visual 'model' showing the current relationships between each principle and actor and how these will be changed in genomic medicine. The foreword to the report concludes that there is a strong case for some of the implied changes to be inscribed in the NHS Constitution when it comes up for review. The report has been endorsed by Dame Sally, Chief Medical Officer as a valuable and timely report.

Dialogue and Evaluation Methodology

The dialogue process was delivered by Ipsos MORI between July 2018 and May 2019 and was steered by a large and diverse Oversight Group (OG) of 19 members.

The process involved a Rapid Evidence Assessment (REA), a stakeholder workshop (19 participants), reconvened dialogue workshops in four locations involving nearly 100 participants (97 at workshops one and 92 at workshops two), and a final summit involving 21 participants and 16 experts. The workshops (in London, Leeds, Coventry and Edinburgh) were held on a week-day evening (three hours) and a full Saturday, two weeks apart. The dialogue locations and participant recruitment quotas were designed to reflect the average age, gender and socio-economic profile of their locations. They groups included strong participation from groups expected to be both less (BME groups) and more enthusiastic (heavy users of the NHS) about genomics and data sharing.

The participants were able to access information through an engaging mix of PowerPoint, video, handouts, quizzes and small table discussions co-produced by the contractors and Genomics England. Over the two workshops participants were first introduced to the how NHS health services are delivered, how their data is currently used and shared, and to existing and potential uses of genomic medicine and the 100,000 Genomes Project. Over the two days they explored their aspirations for genomic medicine, their potential concerns and red lines around their data being used and shared, and what a 'social contract' making clear the roles of all those involved in genomic medicine delivery might look like. At workshop two participants were able to explore issues in both the short term/personal and longer-term/societal level through a set of three family tree scenarios. At the summit a smaller group of reconvened participants explored the issues underlying a social contract and how genomics medicine service roll out should be communicated in greater depth at five 'workstations' each dealing with a different aspect of data privacy and security and use by researchers and commercial businesses.

Contributions from the OG, inputs from a large group of stakeholders and more than 40 days of specialist input (covering clinical, research, ethical, data management and 100,000 Genomes Project participant panel expertise) during the two workshop days played an important role in ensuring that participants were exposed to a wide range of views and the dialogue was fair and balanced.

Scenarios and probing by facilitators helped to prompt rich discussions around the complex issues. The mix of experience levels and facilitation styles, and team continuity across events resulted in very positive group dynamics. Almost everyone participated very actively in discussions and all felt they had made a valuable contribution and had their voices heard.

The evaluation process ran between August 2018 and May 2019 and involved desk review, observation of events (stakeholder workshop, six out of eight dialogue workshops, the final summit and the launch), analysis of participant and specialist feedback questionnaires and survey results, review of the draft final report and one to one interviews with 14 individuals drawn from the Oversight Group, Genomics England and the contractors.

Project governance and management

The large, senior and diverse OG played a significant role in the success of the dialogue. While resource-intensive to manage, the group included all key stakeholder points of view and brought considerable experience in qualitative research, and expertise in genomics, health data and ethics. The group were instrumental in constantly refocusing the dialogue on its objectives, ensuring stimulus materials were balanced and accessible, and in contributing as specialists to the dialogue workshops, the summit event and the launch. Almost all the OG members interviewed had disseminated the findings and identified ways in which they now expect to use the insights gained in policy processes or future research.

The study also benefited from having a dedicated Genomics England project manager (0.4 FTE). Both he and the Ipsos MORI senior team had valuable experience in running complex public dialogues and in the genomics and health data areas. A flexible design approach, helpful advice from the Sciencewise team, and very collegiate relationships established in the core project management team all contributed to the success of the dialogue.

Key Evaluation Findings

Meeting the objectives

The sequencing, careful attention to framing and the active engagement of the OG, who felt a strong ownership of the process, meant that six out of eight objectives of the research were very well met providing: a comprehensive understanding of the publics' views on issues around genomics (objective 1); an understanding of dialogue participants' views on genomics, data sharing, the social contract (objectives 2, 3 and 4); potentially significant impacts on policy for the future development of genomics medicine (objective 6); and some practical suggestions on a communications strategy and the language which can be used to describe genomics to the wider public (objective 8). Two other objectives – exploring shared expectations (objective 5) and contributing to wider policy (objective 7) – were not really expected to be fully met by this dialogue, but most interviewees felt they had been partially met.

Satisfaction with the process

Participants were unanimous in their satisfaction with the overall process, reporting that it had been interesting, informative, enjoyable and thought-provoking. Almost all felt they had learnt something new about genomic medicine, its potential for making a difference, potential concerns around data use and what they thought a social contract for genomic medicine service roll out should look like. Specialists, commissioners and specialists also described themselves as very satisfied with the quality of the process and the usefulness of its outputs.

Policy impacts

The process produced a final report organised around the concepts underlying a social contract which all those interviewed founded very helpful in moving the discussions forward. The timeliness of the process and the large number of potential policies and practices that the report can feed into meant that the dialogue is likely to have significant impacts.

The report has been praised by both the Chief Medical Office (CMO) and NHS Chief Scientific Officer (CSO) and is expected to directly influence roll out of genomic medicine in the NHS in terms of expectations of clinicians, researchers and genetic counsellors and feed into Genomics England's advice to government. New understanding on the implied social contract could eventually be inscribed in the NHS constitution when it comes up for review. The findings will also feed into related genomics policy processes involving commercial stakeholders such as the National Genomics Healthcare Strategy 2019, led by Baroness Blackwood, and the Science and Technology Committee

Inquiry into Commercial Genomic Testing. Sponsors hope it will also be taken forward by the Genomic Leadership Group in Scotland and will help to encourage public dialogue approaches within the EU initiative for leveraging European infrastructures to access one million human genomes by 2022.

Both Genomics England and Wellcome expect to commission follow on qualitative and quantitative research for instance on attitudes amongst specific BME groups, or in exploring issues such as what people expect in exchange for sharing their anonymised data with commercial users, or their views on the emerging concept of 'genomic volunteers'. The findings are also expected to resonate with wider policy processes involving the collection, holding and sharing of personal data.

Costs and Potential Benefits

A highly experienced contractor was able to deliver this large public dialogue to a high standard, on time and within budget. Additional value added was provided through the contractor's flexibility in adding an extra location at marginal cost and significant in-kind contributions of senior time by Genomics England, OG members and other stakeholders (as specialists at workshops and the summit). Based on conservative estimates in kind contributions added 50% over and above the financial budget. Some flexibility in the design also allowed an underspend in one area (under-recruitment in Coventry) to be reallocated to other policy briefings, dissemination events and increasing participant number in another location.

It is too early to quantify the potential economic impacts of the dialogue process, but early indications are that they could be considerable. For instance, in the short term a better understanding of the wider publics' views and redlines and a clear communication strategy which stresses the benefits of many people opting in to the genomic medicine service, while highlighting how potential concerns about data privacy, security and sharing can be managed could help to avoid the wasted investment in previous failed big data collection projects such as care.data. In the longer term the dialogue may also contribute to helping reduce NHS costs through the following: better tailored cancer treatments; prevention of common avoidable conditions through predictive testing; access to cheaper pharmaceutical treatments or earning revenues by sharing data with commercial businesses. Successful roll out of genomic medicine could also generate significant opportunities for other UK business sectors including Artificial Intelligence (AI) and big data, genomic diagnostics, and pharmaceuticals.

Key lessons learnt on design and delivery

- The buy-in of senior management and a large OG, representative of a diverse range of stakeholders and viewpoints, were critical in maximising the likely impact of the dialogue.
- On-street recruitment against demanding recruitment quotas worked well for large cities but was a challenge for smaller ones: alternative approaches would have been to choose **all** large city locations or to deliberately recruit smaller **groups in more challenging locations**.
- **Across the four locations the** ideal table size **was** eight participants supported by one or two experts **and** one facilitator. **Achieving this ratio for all locations would have** required an extra group/facilitator **in London and Leeds,** with budget**ary** implications.
- Scheduling reconvened workshops two-weeks apart worked well to allow those that wished to do their own research between sessions to do so, without losing momentum and keeping drop-out rates to an acceptable 5%.
- Scheduling of a joint participant/specialist summit on a weekday did not prevent a suitably diverse and inclusive group of participants from attending. Those invited were keen **to attend** because they already knew what was involved and that they would enjoy it**: they were enabled**

to attend because they received an incentive and travel costs. Scheduling on a weekday also made it easier to get a good turnout of stakeholders, specialists and OG members.

- This process reinforced the findings of previous dialogues that participants actually need very little **background information on th**e science of genomics in order to make a valuable contribution to the debate.
- Projective techniques helped to stimulate deliberation**. Three** family tree scenarios **were very effective in eliciting views on both** short-term**,** practical **issues** and longer-term less likely scenarios and **on** both personal and societal perspectives.
- A large cast of specialists and stakeholders across a mix of disciplines, and including those with lived experience of genomic medicine, added great value to the workshops. The recruitment process was more time-consuming than **expected but** could perhaps be streamlined by starting early (as soon as the workshop locations were fixed) and delegating day to day **communication and** briefing to **the** contractors**.**
- Where dialogues seek to involve patient representatives as OG members or specialists then it is important to provide one to one briefing to ensure they feel fully briefed**, supported** and confident in their roles.
- Commissioning bodies should consider whether there would be benefits of being able to re-engage with participants for follow-up research. If so this will require making provision to seek GDPR-compliant permissions through evaluation or consent forms **during the dialogue workshops**.

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1 INTRODUCTION

This report has been prepared by URSUS Consulting Ltd and presents the findings of an evaluation of a public dialogue on Genomic Medicine: Time for a new social contract? undertaken for Genomics England (GE) and Sciencewise[2].

1.1 BACKGROUND CONTEXT

In 2012 the Department of Health and Social Care (DHSC) launched the 100,000 Genome Project and set up Genomics England to work with the National Health Service (NHS) England to achieve its aim of Whole Genome Sequencing (WGS) of patients and their families with rare diseases, and sequencing of patients and their cancers by the end of 2018. The 100,000 Genomes Project was able to learn from the experience of NHS's Care.data[3] programme, launched in 2014, which failed to communicate the benefits of sharing data to the wider public, with the result that more than a million people chose to opt-out. Following a review into safeguards around the sharing of patient data by the National Data Guardian, the conclusion was that the NHS had lost people's trust in the scheme. In mid-2016 the Minister for Life Sciences announced the scheme would be closed. Since it was set up Genomics England has been committed to embedding ethical considerations into its work. This has been done through an Ethics Advisory Committee and by directly involving participants of the 100,000 Genomes Project in a Participants Panel which has been involved in decision-making about delivery. The panel was set up with guidance from ethicists and has been closely involved in shaping the 100,000 Genomes Project e.g. by suggesting schemes such as "track my sample", which have been well received by patients.

Many of the issues which have already surfaced around genomics are shared with other new and emerging technologies. The issues include the public's attitudes to big data, trust in commercial involvement in R&D and data handling, equity, priority setting, transparency and oversight. However, genomics also raises specific issues including the following:

- Individuals may feel that their genomic data is personal and seen as sensitive and its release could potentially lead to an individual being stigmatised and that it therefore needs to be kept very private;
- The best clinical care for patients can only come from a large number of people having donated their data;
- The boundaries between clinical and research use of data become blurred with clinicians needing access to research databases to provide the best clinical care and researchers (both academic and commercial) needing access to de-identified clinical data to identify the causes of rare diseases or to develop more effective treatments. This puts more onus on researchers to feedback results to patients;

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

[3] A big data initiative designed to link health care data from hospitals and general practitioners in a central database that would allow researchers to develop new treatments and improve the monitoring of performance. Despite wide support from charities and researchers (who would have had access to largely anonymized data), NHS England was criticised for poorly understanding the public's views to data sharing and poorly explaining the potential benefits of the scheme, how data would be secured and who it might be shared with.

- The pace of research means that future opportunities will arise to revisit data for purposes not yet envisaged: current individual treatment consents (effectively a license) will need to become less transactional and more like an ongoing, informed, consent process for data donors.

Mindful of past experiences with sharing conventional healthcare data and what makes genomic medicine different, in her Annual Report, Generation Genome[4], (2016) the Chief Medical Officer (CMO) commissioned a group of ethicists and clinicians to prepare a chapter on what principles should underpin a so called 'social contract' after the completion of the 100,000 Genomes Project. This was intended to cover both how research and clinical data might be used, and to underpin mutual expectations of the NHS, patients and the private sector in delivering a genomic medicine service. The possibility of inscribing any findings in the NHS Constitution[5] when it was up for renewal was also mooted.

With the completion of the 100,000 Genomes Project NHS England is now committed to embedding genomic medicine into mainstream NHS delivery through the roll-out of a national Genomic Medicine Service, which will become part of routine care and treatment so that everyone can eventually benefit. Through the Participant Panel and work by the Wellcome Genome Campus and patient organisations such as the Genetic Alliance, the views of genomics patients on the use and sharing of their data for research is relatively well understood. Clinicians reported that more than 90% of patients seen in genetics clinics see the benefits of providing researchers with access to very broad data sets, are willing to share their data, and do not want to have to keep signing limited. individual consent forms. What was missing was an understanding of what **potential** patients (i.e. the wider public) might think about genomics, their data use and what safeguards or redlines they would like to see in place.

In Scotland the 1,000 Genomes project[6] contributed data to the 100,000 Genomes Project but only for rare diseases, not cancer. This was partly a financial decision and partly because cancer tumour genomics is less developed than genomic sequencing for rare diseases. It was also felt that creating a bioinformatics approach for fast screening might be cheaper, quicker and applicable across all types of samples than whole genome sequencing (WGS). The desire for the dialogue to be finished by around the time the 100,000 Genomes Project came to an end - which meant starting promptly - precluded Scotland from being involved right at the start. However, as the dialogue progressed the Scottish Genomes Partnership was keen to explore the Scottish public's views in the context of the different roll out options in Scotland. Resources were therefore allocated to add a Scottish location.

1.2 FRAMING

Genomics England and DHSC were keen to commission a public dialogue to explore how people's implicit understanding of what the NHS is for might be affected by their views on how their genomic data should be used and stored. A large opinion survey by Ipsos MORI (29th May 2018) of nearly

[4] Annual report of the Chief Medical Officer 2016: generation genome

[5] The **NHS Constitution for England,** first published in January 2009 in response to Lord Darzi's report 'High Quality Care for All' sets out the objectives of the NHS, the rights and responsibilities of the various parties involved in health care, (patients, staff, trust boards) and the guiding principles which govern the service. There is a commitment to review the constitution and accompanying handbook every 10 years.

[6] The Scottish Genomes Partnership is funded by the Chief Scientist Office of the Scottish Government Health Directorates [SGP/1] and The Medical Research Council Whole Genome Sequencing for Health and Wealth Initiative (MC/PC/15080).

2,000 adults (16-75 year olds) had found that 66% of respondents "*knew not a lot or nothing at all about genomics*" before being interviewed. It was therefore clear that in order to grapple with the practical and ethical implications of genomic data use, some initial understanding of the potential of genomic medicine would be required.

The overall objective of the dialogue was to understand the public's aspirations and concerns about the use of their genetic data through informed, deliberative discussions with groups chosen as reflective of - but not statistically representative of - the wider public. The design of the dialogue needed to provide enough, balanced background information so that participants would be confident that they were equipped to explore the principles underlying a social contract.

The tender for the dialogue included 17 questions that the commissioners were keen to see answered, which could be grouped broadly as:

- Awareness of and support for genomic medicine;
- Views on a social contract, deal, or relationship between actors, for genomic medicine;
- The factors influencing public acceptability of genomic medicine, trade-offs and red lines;
- Overall perceptions of the benefits and disbenefits and how these should be addressed; and
- Insight into future communication, including how aspirations and concerns should be addressed.

These were expressed as eight objectives for the dialogue as follows:

1. To establish current knowledge and understanding on public views and attitudes to i) genomic medicine, ii) whole genome sequencing (WGS) iii) the concept of a 'social contract' between the public and the NHS and iv) safeguards/'red lines' essential to public support/trust for genomic medicine, through a review of previous dialogue, engagement, consultation and related research projects involving the public.
2. To understand participants' aspirations and concerns around the use of genomic data and other personal information.
3. To understand how participants 'trade off' concerns about data, privacy and use of their information against potential health and other benefits that may come from genomic medicine, and what safeguards need to be in place.
4. To explore understanding of the idea of a 'social contract' as applied to the NHS and the principles by which it is understood to, or should, operate.
5. To explore what expectations and understanding are shared between patients, the public, clinicians, academics, industry and other stakeholder groups around the ambitions and outcomes for genomics and genomic medicine in the UK.
6. To contribute to and inform the ongoing policy, political and ethical environment for genomic medicine to flourish, as the benefits and opportunities presented by the technology are realised.
7. To contribute to the wider policy, political and ethical environment about the collection and use of data by government beyond healthcare and genomics.
8. To develop an understanding of the language and terms that the public and other stakeholders use in association with genomic medicine in order to inform communications for and about genomic medicine activities and services in the UK.

This is a large number of objectives for a dialogue process and, as discussed in *Section 5* meant that it was not possible to address all to the same extent.

Genomics England and Sciencewise were keen to establish a diverse Oversight Group (OG) representing the commissioners and all the different perspectives in the field. From the outset all OG members were clear that the dialogue should be framed in the context of the CMO's call for an extensive public dialogue on genomic medicine and the implications for a social contract. Genomics England and those that had been involved in the Generation Genome report saw this as the core objective. As one OG member put it:

> "*As a society we are at a tipping point - data must be donated and shared and we all need to be in this together to improve human health. A partnership is needed. The question is: are our participants ready to embrace this partnership. THIS is at the heart of the social contract*".

Other stakeholder organisations including ethicists, data privacy and patient organisations also had broader interests. Some were keen to understand the differences between patient and general public views:

> "*We are hoping for a better conversation which shows whether and how the public views genomic medicine differently from other strands of medicine– is there anything different or is it part and parcel?*".

While other OG members, such as the 100,000 Genomes Project Participants Panel and Genetic Alliance, were keen to ensure that work they have already done on the patient voice was reflected in the evidence assessment, framing of the potential benefits and the discussions around data sharing.

Several OG members were also very keen to ensure that the roll-out of the genetic medicine service by Genomics England and NHS is considered and cautious – managing expectations about the speed that benefits might be delivered, ensuring the consents process is clear, and ensuring that data can be safeguarded so that the public does not lose trust in the process. As one OG member put it: "*In the next few years we're told that genomic data will be the biggest data set available. How do we use and manage it securely and get it right? We only have one chance"*.

OG members were keen to stress that participants should be exposed to a wide set of views and materials and be able to express their own aspirations and red lines and feel free to 'dissent' and be heard. Although one dialogue objective focused on understanding how views were shared across different stakeholder groups, the dialogue process was not intended to reach a consensus on what a new social contract might look like.

1.3 LAYOUT OF THE REPORT

- *Section 2* describes the methods for the dialogue delivery and the evaluation;
- *Section 3* describes impacts (to date and anticipated) on policy, practice and research;
- *Section 4* assesses the governance and management arrangements for the project;
- *Section 5* assesses how far the dialogue has met its eight objectives;
- *Section 6* describes how far the dialogue has met Sciencewise best practice standards for design and delivery;
- *Section 7* describes overall satisfaction with the process by participants and its impact on them;
- *Section 8* compares the financial and in-kind costs and potential economic benefits of the dialogue; and
- *Section 9* summarises findings and lessons learnt for Genomics England and Sciencewise.

2 METHODS

This section describes the methods for the dialogue delivery (*Section 2.1*) and for the evaluation (*Section 2.2*).

The dialogue process was designed and delivered by Ipsos MORI between June 2018 and April 2019 and was steered by an Oversight Group with representation from the commissioners (Genomics England and Sciencewise) and wider stakeholders. The process involved a Rapid Evidence Assessment (REA), stakeholder workshop (15 participants), dialogue workshops in four locations involving a weekday evening (97 participants) and a full Saturday (88 participants). A mix of participants (21) and specialists was reconvened for a one-day summit in London.

2.1 DIALOGUE METHODS

2.1.1 Setting up the Oversight Group

Genomics England was responsible for convening a large Oversight Group (OG) comprising 19 members[7]. The OG was tasked with advising on the overall framing of the project, helping to inform and shape the dialogue design and ensuring that the dialogue was far-reaching, accessible, involved all relevant stakeholder groups and appropriately selected members of the public. It was also tasked with ensuring that all materials used were appropriately comprehensive, balanced and accessible to lay participants. The OG was expected to comment on: a rapid evidence assessment; dialogue and stakeholder engagement strategies; dialogue questions; composition of events; stimulus materials; outputs from the dialogue exercises; and the draft final report. All OG members were invited to comment on the draft materials for the workshops. Most feedback received was from a small self-selected group of five or six OG members who were more closely involved. The group met four times over the course of the dialogues. The OG membership is shown at *Annex A*.

2.1.2 Rapid Evidence Assessment including qualitative and quantitative review of what is known

The Rapid Evidence Assessment (REA) aimed to ensure that the dialogue built on what is already known by summarising evidence across a wide spread of generic literature covering attitudes to both health and wider data issue including privacy and perceived risks, as well as genomics-specific literature on attitudes to potential benefits, risks and uncertainties about the roll out of genomic medicine. The REA covered 26 documents including qualitative and quantitative research from a long list of some 50 sources suggested by Genomics England, Ipsos MORI and members of the OG. Comments from the OG were incorporated and the REA was published on Genomics England and Ipsos MORI's websites in September 2018.

2.1.3 Stakeholder engagement

A three-hour stakeholder workshop was held in London in September with the objective of getting a range of views and inputs to: the REA; the issues and information participants would need to know in order to express opinions on how genomic medicine is rolled out; and suggestions for case studies, stimulus materials and individuals who might be involved as specialists. One to one interviews were also carried out with stakeholders who could not attend including medConfidential, Open Privacy Group and Ethics and Genetics. Stakeholder engagement was intended to ensure a full range of views were heard and reflected in framing the dialogues and in stimulus materials. A

[7] The membership of the OG was fluid in terms of the representation from some organisations, with more than one representative from Genomics England, NHS and Wellcome Trust and some change in the individuals representing other organisations over the course of the dialogue.

handful of stakeholders were also invited back to the summit: two attended as specialists. The list of attendees is shown at *Annex B*.

2.1.4 Workshop design and stimulus materials

In the initial bid the contractors offered reconvened events in three locations for 30 participants and exploratory focus groups in two locations, with specialist audiences (people with rare diseases, and people from a black and minority ethnic (BME) background) and three-hour communications-focused workshop with public participants, specialists and OG members. Based on the findings of REA and their own experience, the core team and OG agreed, instead, to incorporate BME groups in the main workshops and bring in 100,000 Genome Project Participant's panel members as specialists. Resources were reallocated to allow a larger summit event focusing on the social contract and communications. Additional funds were also found from Sciencewise and Genomics England for a small reconvened workshop (15 participants) in Edinburgh.

Workshop designs and stimulus materials were developed by Ipsos MORI and reviewed electronically before each set of events by the core team and the Oversight Group and amended for accuracy. *Table 2.1* summarises the workshop design by sessions and stimulus materials presented.

Table 2.1: Summary of workshop and summit design and stimulus materials

Workshop one (18.15-21.15)	Workshop two (10.00-16.00)	Summit (12.00-4.00)
Slides on overview, objectives, other events, housekeeping	PowerPoint recap on objectives and event one and discussion on homework (hopes and fears for genomics)	PowerPoint on headline findings from workshops one and two Reflections from GE and a specialist Vox pop video (7 minutes) of participant journeys
Discussion about hopes and priorities for healthcare	Presentations at small tables by specialists on their jobs, hopes and fears for genomics	Picture sort exercise – selecting image that reflects hopes and concerns for the future of genomics
PowerPoint table quiz on uses of health data	Initial probe on the social contract (expectations, partnerships, fears etc)	Table discussions on the founding principles of the NHS and values that the social contract is based on
Video – Understanding Patient Data	Three family trees in different SEG and ethnic contexts. Each new character introduced a new scenario including: • Current possibilities for WGS, infant screening and genetic tests for rare conditions and cancers • More extreme scenarios projecting longer term societal concerns. Initially envisaged that each table would cover all three scenarios, then adapted so they would consider just one.	5 workstations with visual prompts on: • Where is our data? – giving and using genomic data, assurances needed • The patient of the future – expectations of different actors • One big family – confidentiality, consent and counselling support needs • Show me the money – expectations around business access and use of data • Blurred lines – expectations of researchers (acad & comm) & clinicians
PowerPoint introducing genomics, 100,000 Genomes Project and health data	'Washing line' to gauge how participants felt about the likely success of genomics in ten years' time	Summary of the most important principles each group thinks should guide genomics rollout in the NHS
Specialists share different points of view on hopes and concerns about genetic medicine	Discussions on the social contract based on expectations of what different actors should, could and mustn't do.	Plenary presentation back from each group (planned)
(Homework – talking about genomics with family + friends and online search	Voluntary insurance code – discussion based around handouts	Feedback from commissioners on what they had learnt and what they would do with it (planned)
	Discussion on use of data using 'Talking Heads' handouts highlighting concerns of campaigning organisations	
	Final post-it exercises on social contract (priorities and gaps)	

Workshop designs and materials were slightly amended for flow and timing after feedback sessions on the pilot workshops in London.

2.1.5 Public dialogues workshops

The REA highlighted marked differences in awareness and attitudes towards genomic medicine amongst younger/older people, amongst the BME community and existing patients. The OG and core team agreed that all four locations would aim for a similar demographic mix. In addition, inter-sectional BME quotas to reflect the size of the BME population in each location (about 40% in London, 21% in Leeds, 26% in Coventry and 8% in Edinburgh) and with a mix reflective of gender, age and socio-economic segments (SEGs) within these populations. The brief for on-street recruitment also included questions to screen out individuals who worked in healthcare or the NHS or where they, or their families, had taken part in the 100,000 Genomes Project. Questions on medical conditions ensured the involvement of a range of different types of NHS patients (to include some 'heavy' users including those with long term conditions and cancer).

Slight over-recruitment (32 for 30 in London, Leeds and Coventry) and 18 (for 16) in Edinburgh resulted in workshops involving 97 members of the public (for workshop one) and 91 for workshop two. Evening events were held on 16th, 18th and 25th October and 15th November: full day events on Saturdays on the 3rd, 10th, 17th and 24th November. Participants received staged incentive payments of £65 for the first evening, £100 for event two and £5 if they completed the homework task.

For each event a lead facilitator was responsible for overall timekeeping and flow and facilitating a small table, supported by two additional table facilitators with a ratio of 1:8-10 facilitator: participants. In order to ensure that all participants were able to hear a balance of expert views some 25 clinicians, researchers, patients in the 100,000 Genome Project and ethicists were invited to take part as specialists for workshops one and two. This resulted in 40 specialist days across the four locations (see *Table 2.2)* with more than half the specialists attending several workshops. For every workshop there was at least one specialist per table, and sometimes two or three.

Table 2.2: Specialists taking part by location

	London	Leeds	Coventry	Edinburgh
Event 1	4	6	3	3
Event 2	4	8	4	6

2.1.6 Summit

A reconvened summit held in London brought back half a dozen participants from each of the three English locations, together with a mix of ten specialists and six OG members. The summit aimed to build on the outcomes from the eight workshops and explore the values, principles and red lines underlying participant expectations of a social contract. It also aimed to help inform a communications strategy around mainstreaming genomic medicine in the NHS and identify the type of language that should be used in public communications. Workshops participants involved in the summit were selected to provide a broad spread of gender, age, BME and SEG mix, with a focus on those who had seemed most engaged during workshops one and two. An additional incentive of £100 and travel expenses to London were offered to ensure that all those invited could attend, regardless of their financial circumstances. Specialists were given distinct roles: either to answer questions at five workstations around the room; or to stay with a small group of public participants and help them to frame their questions at each workstation.

2.1.7 Analysis and reporting

For each of the workshops all substantive discussions in plenary and at small tables were recorded by a note-taker (one for each table) and with audio recording. A film maker also attended most workshops and recorded vox pop interviews with up to ten participants in each location. The transcribed notes from the nine sessions were analysed manually by the core Ipsos MORI team around an agreed set of themes and proposed report outline at a planning workshop also attended by Genomics England and the evaluator.

The outputs from the public dialogue process included the final report (including workshop discussion flows and stimulus materials in annexes), a short video describing participant views and journeys, and slide decks for dissemination events. Permissions were sought so that the transcript evidence from the public dialogues could be shared with the National Archive for other academic research.

2.1.8 Dissemination events

A flexible design allowed for up to five policy briefing events, as opportunities arose, to share early findings and disseminate final report findings with different stakeholder groups. The final report (including dialogue designs and stimulus materials) and a summary of the findings are available on the Ipsos MORI and Genomics England websites.

2.2 EVALUATION METHODS

The objectives of the evaluation were the following:

- To gather and present objective and robust evidence of the nature and quality of the impacts, achievements and activities of the project in order to come to conclusions; and
- To identify lessons from the project to support the design and delivery of future public dialogue projects.

The evaluation took place between July 2018 and May 2019 and involved the following key tasks:

- **Phase 1: Baseline Assessment.** Working alongside the delivery team to ensure that research framing and overall process design reflected what was already known about public understanding and attitudes to data and that the framing reflected the expectations of the OG and stakeholders. Input was provided on workshop design, recruitment of participants and the development of stimulus materials to the core team. Feedback was provided to the core team through a short inception report covering the REA and stakeholder event (see Annex B).

- **Phase 2: Interim assessment of design and delivery** Evidence collection from participants, specialists and observers taking part in dialogue workshops and the summit. Evidence was collected through questionnaires and informal interviews during the events and findings were fed back to the core team immediately after events and to the OG through a brief report.

- **Phase 3: Final assessment of the project overall** summative evaluation of the project based on data collated from phases one and two and qualitative data collected during phase three. This included 14 semi-structured interviews with stakeholders who have been involved with the process (as members of the OG, specialists or stakeholders) or who will be the main users of the outcomes, and the core Genomics England, Ipsos MORI and Sciencewise teams.

Evidence from the evaluation is included throughout the following chapters. The source of evidence is identified by the following symbols:

- Formal feedback from participants through post-event questionnaires (91 for workshop one; 88 for workshop two; and 16 for the summit) and quotes from participants;
- Specialist and stakeholder feedback in post-event questionnaires and informal discussions (40);
- One to one interviews with OG members, policy makers and the core team (14); and
- Evaluator observation at meetings, events and workshops and independent assessment.

Lessons learnt were shared at a wash-up meeting with Genomics England, Sciencewise and the delivery contractors in late May and their feedback has been incorporated in this final report which is available on the Sciencewise and Genomics England websites.

3 IMPACTS

This section assesses the impacts of this dialogue process on policy, practice and research that have already been identified or are anticipated. It is arranged as follows:

- *Section 3.1* summarises activities to disseminate and communicate the findings of the dialogue;
- *Section 3.2* summarises the potential impacts on genomics medicine and data use policy;
- *Section 3.3* describes the potential wider policy impacts; and
- *Section 3.4* summarises lessons learnt.

The active involvement of a large and very senior stakeholder group, senior buy-in within Genomics England and flexibility in including dialogue workshops in Scotland means that the findings are likely to have significant policy impacts. A flexible approach to programming of policy briefings and dissemination events, and a very well attended launch event, have meant that the final report and key findings have been widely disseminated.

The report has been praised by both the Chief Medical Office and NHS Chief Scientific Officer and is expected to directly influence the roll out of genomic medicine in the NHS in terms of expectations of clinicians, researchers and genetic counsellors. New understanding on the implied social contract could eventually be inscribed in the NHS constitution when it comes up for review. The findings will also feed into related genomics policy processes involving commercial stakeholders such as the **National Genomics Healthcare Strategy 2019**, led by Baroness Blackwood, and the **Science and Technology Committee Inquiry into Commercial Genomic Testing**. Sponsors hope it will also be taken forward by the **Genomic Leadership Group in Scotland** and will help to encourage public dialogue approaches within the **EU initiative for leveraging European infrastructures to access one million human genomes by 2022**. Both Genomics England and Wellcome Genome Campus expect to commission follow on qualitative and quantitative research on attitudes amongst specific BME groups, or in areas such as attitudes to sharing data with commercial companies. The findings are also expected to resonate with wider policy processes involving the collection, holding and sharing of personal data.

3.1 DISSEMINATION AND COMMUNICATION OF THE RESULTS

The process design allowed for dissemination of findings from the earliest stages, with the REA published on the Genomics England and Ipsos MORI websites, and provision for five policy briefing events by the contractors throughout the process. These have included sessions with key stakeholder groups (the 100,000 Genomes Project Participants' Panel), the Association of British Insurers (ABI) and the Genomics England senior leadership team.

During the project some concerns were raised at Genomics England about how reflective the outputs would be of the wider public's views. In particular, Genomics England wanted to be reassured that some of the intended audiences of the dialogue, particularly politicians and policy makers, would be confident of the robustness and validity of the dialogue given the sample size. Sciencewise, Ipsos MORI and the project manager were able to allay concerns by spending time explaining the benefits of the approach taken. The final report also includes, in the introduction, a discussion on the choice and relative strengths of this methodology. This has strengthened the report and will also help other readers, unfamiliar with public dialogue, to understand how they can apply the results.

The final report has been very well received by commissioners, OG members and wider policy makers (see *Box 3.1*). A shared view was that this was a good piece of work, delivered in a very collaborative way, with the delivery contractors open to advice and re-focusing back on the social contract question. A number of evaluation interviewees told us that the final report would be a major contribution to the literature in the field and that it is set to become a key reference point for future public dialogue on this topic, helping to broaden discussion about the key issues and how to tackle them. As one OG member described it, the report was a starting place in understanding the wider publics' views: *"a cracking place to start – not yet the definitive work*". The report was also seen as accessible to a non-practitioner or academic audience: *"[the report was] very well written from the point of view of an audience not immersed in the subject".*

Box 3.1: Specialist and decision maker views on the process and the outputs

Commissioners:

- *"Excellent. A worthwhile project which delivered some context we didn't already have".*
- *"Very pleased with the project – a lot riding on it – everyone involved has been very collegiate".*
- *"Gives us a sure foundation that we aren't misreading the public and we're going in the right direction. Very clear red lines but also encouragement …"*
- *"Really good basis for more work on policy developments and bringing industry into discussions".*
- *"A very positive and well-run dialogue which adds to what has been done – beginning to get a good understanding of what the public thinks across a broad area".*
- *"The workshops in Scotland were very useful indeed and I learned a lot listening to the participants".*

Other OG members:

- *"By and large happy with the final report – a good, fair, coherent representation".*
- *"Even the first version of the report was pretty good – just needed a bit of sharpening on the language and a few concepts".*
- *"A difficult ask - would have been difficult for other contractors with less background in Genomics to deliver this process".*
- *"In general, a good public dialogue that seemed to deliver what the commissioners wanted".*

The timing of the dialogues and the publication of the findings have been timely, coinciding – as planned - with the completion of the 100,000 Genomes Project in December 2018, the Secretary of State (SoS) for Health announcements of targets for future WGS and genetic tests, and before the roll out of the Genomic Medicine Service (GMS) in the NHS. *Table 3.1* summarises dissemination activities to date.

The report was launched on 25th April 2019 at an event hosted by Genomics England, with findings presented by Ipsos MORI and 'in-conversation' responses from two members of the OG (one author of the Generation Genome chapter on the social contract and a 100,000 Genomes Project Participant Panel member) and the Sciencewise Programme Director, Simon Burall. The Chief Medical Officer provided a response. The launch brought ringing endorsements from the CMO: "*its' brought us some very rich information about what people think and moves us forward a bit….I think it's ended up not far distant from where I hoped it would*" (Dame Sally Davis) and from the NHS Chief Scientific Officer (CSO):

> "*The NHS welcomes the report today and what it sets out. The framework linking solidarity, reciprocity and altruism gives a good way of going forward with genomic medicine as part of personalised and individualised treatment*" (Dame Sue Hill).

A further policy briefing may be carried out with other interested organisations over the next few months. This might include, for instance, presenting the implications of the dialogue for communications around the NHS roll out of the genomic medicine service, or with industry groups.

Table 3.1: Examples of dissemination of dialogue findings by core team and stakeholders

Dialogue partner	Dissemination and Comms activities
Ipsos MORI	• 100,000 Genomes Project participant's panel – with about 30 participants • Association of British Insurers (ABI) – implications for insurers to about 50 participants • Genomics England senior leadership team – draft final report to about 15 participants. • Press release 25th April and Full report, key findings and conclusions and REA all available on Ipsos MORI website
Genomics England	• Launch Event - 25th April at Science Gallery London (10am – 1pm). From an invited audience of 300 stakeholders a mix of 100 attended (Genomics England, NHS, academics, industry, NGOs and patient's groups). Discussions were hosted by Vivienne Parry (GE) "in conversation" with a panel including OG members (Mike Parker and Rebecca Middleton) and Dame Sally Davies (CMO) with dialogue findings presented by Ipsos MORI • Press release and social media (tweets) for the launch on 25th April: "*A major new dialogue has found the public are enthusiastic and optimistic about the potential for genomic medicine but have clear red lines on use of data*". • Report available to download from Genomics England's website. • Learning session delivered for Genomics England staff on the dialogue and its implications for Genomics England
Scotland Genome Partnership (SGP)	• Retweeted GE twitter announcements and commentary from the launch day. • Report circulated to SGP Management team and funders (Scottish Government's Chief Scientist Office and the Health Policy team). • Will be highlighted as a key achievement in SGP report to funders (June 2019). • Report will be posted at SGP website in late May.
Wellcome Genome Campus	• Press and media attended launch • Findings and report will be disseminated through the website and social media

Genomic Medicine Service	• OG members will share reports through their networks including:
	  ○ Association of Genetic Nurses and Counsellors
	  ○ British Society of Genomic Medicine
	  ○ Scottish Genomic SGP's Genomic Rare Disease Implementation Group

Oxford University Ethics	• Feed into 100,000 Genomes Project through membership of the board • Feed into big data ethics discussions
100,000 Genomes Project Participant's Panel	• Early findings were shared through a presentation at the panel by Ipsos MORI (see above) • Panel members attended the launch and the OG member participated on the discussion panel responding to the report • Findings have been shared with the panel via social media and will be discussed at future meetings
Genetic Alliance	• Will share announcement of the dialogue with its 220 members and 350 voluntary organisations, classed as supporters, via a news item in the newsletter • Will post a link to the final report on website
UKRI	• Shared launch press release on social media and invited potential public dialogue users to the launch.
Others	• Deloitte UK Centre for Health Solutions, requested permission to cite the report in 'Shaping the future of digital health care' (2019) which will highlight the current challenges, opportunities, and future potential, in accelerating the adoption of digital technologies to help tackle some of health care's most intractable challenges. • ResearchProfessional ran an article (29/3/2019) leading with the finding "*Researchers need 'genomic literacy*", highlighting findings that researchers will need to be equipped with the communication skills to better support patients and donors who are participating in genomic research. • The launch and report were also picked up by *Research Fortnight* and Progress' *Bionews*

3.2 POTENTIAL IMPACTS ON GENOMIC MEDICINE AND DATA USE POLICY

3.2.1 Overall impact

Genomics England were very pleased with the quality and findings of the final report and the core team's success in including a foreword signed by the Chief Medical Officer: "*One of the great strengths was that it was able to respond to the CMO's Generation Genome report and come up with very strong recommendations*". (Genomics England)

> "*I am delighted to see the publication of this important and timely report. It is increasingly clear that developments in genomics have the potential to significantly improve human health. Furthermore, the ability to provide the best care for patients can be greatly enhanced by comparing their data with that of many others. These benefits, which depend upon the safe collection, secure storage, and controlled use of patient information, are only fully achievable and sustainable in the context of well-founded public trust and confidence*". (CMO, Professor Dame Sally Davies)

The report recommendations included a very clear depiction of the underlying values for a social contract – reciprocity, solidarity and altruism – and how these might be changed by aspirations and concerns amongst participants about genomic medicine and their data use. The report also included a recommendation to inscribe some of these changes in the NHS constitution. Many of those interviewed for the evaluation found the clear graphic 'model' which summarised how genomics changes the underlying relationships between principles and stakeholders very helpful in moving discussions forwards.

The findings about the public's red lines also resonated strongly. Since the findings of the dialogue were first shared (but after the public workshops were completed) four of areas where dialogue participants identified strong red lines in relation to their genomic data use (by insurers, for state surveillance, by profiteering businesses, or for genome editing) emerged as live issues in the media. Examples included: a legal test case on sharing of predictive test results within families; Chinese state surveillance; Vertex's pricing of Orkambi, a cystic fibrosis medication to the NHS; and a Chinese academic's announcement of the success of (illegal) germline editing of twin embryos. For Genomics England this reinforces the report's message: "*we really cannot drift into these decisions…they really need to be linked into the social contract and NHS strategy"* and that "*the findings should be openly discussed with politicians and more broadly. They suggest the opportunity for a big conversation about genomic medicine*".

There is an expectation amongst the policy makers and OG members interviewed that the findings could start to have an impact on discussions about how the ambitious targets for genomic medicine will be rolled out. In his recent speech at the Royal Society (20th March 2019) the Secretary of State (SoS) for Health talked about goals for WGS and predictive tests and the ethical implications of genomics, privacy, consent, insurance, how and with whom data is shared. He recognised that not only patients but the views of the 'worried well' need to be reflected and that "*we need to take people with us"* and address the new concerns and fears that genomic medicine raises: "*Understanding the human genome raises profound new ethical questions, and we need to get the ethical rules right, both for diagnostic and predictive genomics*". (Matt Hancock MP, Secretary of State for Health).

The report is also seen as very valuable from the perspective of those representing families with rare conditions on the practicalities of rolling out genomic medicine, for instance in terms of knowledge of clinicians and support provided through counsellors. One OG member told us: "*the whole report will be so valuable to influence policy on a practical basis – what can we do to support patients and make the genetic medicine service work?*" (OG Member).

3.3 SPECIFIC IMPACTS ON POLICY, PROCESSES AND PRACTICE

Interviews with the commissioners and OG members following the publication of the report have identified numerous ways in which the findings on the social contract and participants red lines may potentially be integrated into policy and practice.

National policy:

- **Feeding into the National (UK-wide) Genomics Healthcare Strategy,** led by Baroness Blackwood, and involving the National Genomics Board, Genomics England, NHS, UKRI, academics, small and large pharma industry and patients' groups during 2019.
- **Informing the Science and Technology Committee Inquiry into commercial genomic testing** (launched March 2019) to establish what safeguards need to be put in place to protect those who get tested. The Inquiry closed for submissions shortly after the launch.
- In Scotland, the sponsors hope the findings will be taken forward by the **new Genomic Leadership Group**, which has been established following the publication of the **Scottish Science Advisory Committee (SSAC)'s Report on Genomic Medicine** (February 2019) which highlighted the importance of involving and engaging the public.
- **Feeding into ongoing discussions on creating an Ethics Committee for the NHS,** currently being discussed by academic ethicists and Dame Sue Hill (CSO, NHS).

Informing practice:

- **Informing practitioners**. The report highlighted the need for more genetic counsellors, and patient representatives felt that the findings also helped to endorse the need for much greater awareness of genomics amongst clinicians: "*so that they know at least as much as patients"*. In Scotland the SGP also expect the findings to be a useful reference point for clinicians and genetic counsellors. From the point of view of patient bodies (such as Rare Disease UK) the report is seen as showing that the views expressed by the public (in Scotland) are broadly in line with those of rare disease patients and their families.
- **Changing expectations of researcher roles.** The findings suggest that, instead of the current easy default for researchers of not sharing findings with data donors, the default assumption for genomics in the future will need to be that research findings will be shared. The onus will be on researchers to do so. This might require more targeted follow-up dialogues on what researchers should be doing in the light of the ambitious targets announced by the SoS for Health. The findings will also feed into ongoing discussions that research funders across the health landscape are having about supporting researchers to communicate with the public.

Reinforcing the case for public dialogue in genomic policy making and initiatives:

- **In Scotland, feeding into the SSAC report chapter** on the importance of Patient and Public Involvement and Engagement, which until now has mainly been led by academics.
- **Feeding into the EU initiative for leveraging European infrastructures to access one million human genomes by 2022**. The report will be shared with the Ethical, Legal and Social Group and the overarching group. Genomics England would like to make a very strong case for involvement of the public and patients in decision making. "*We would like to see public dialogue as a major plank of all work in this area*".

Changing the NHS Constitution

- A number of OG members that we interviewed would also like to see the implications of changed relationships between the factors underlying a social contract inscribed in the NHS Constitution. Several interviewees were very enthusiastic about this potential result, one commenting that "*a change to the NHS constitution would show that a public dialogue on very*

complex issues could help to inform changes in policy" and another that "*that would be an incredible result*". Views on what would be involved in making these changes varied widely. At one extreme authors of the Generation Genome chapter felt that this might simply involve changes in wording and prefacing the constitution with what is new and/or different about genomic medicine. At the other extreme interviewees felt that, from a data privacy perspective, opening up the discussions on underlying concepts in this dialogue has been very useful, but any changes to the NHS Constitution and the implied social contract would need to be taken forward cautiously as part of a much longer dialogue process.

3.3.1 Scope for further research work

Building on the findings, evaluation interviewees suggested they would like to follow through with further research in the following areas:

- **Smaller scale public dialogues** by Genomics England with groups that the research has highlighted as more sceptical about the potential benefits of genomics and their data use, such as Afro-Caribbean communities and Pakistani men. This could be by Genomics England themselves or by Genomics England playing a facilitative role in enabling local actors to undertake these dialogues at a more regional / community level.
- **More qualitative research on data donors or 'genomic volunteers' and what they can expect to get back**. This might take the form of joint work with others in the field including Genomics England, NHS, National Data Centre, Alan Turing Institute, Wellcome Genome Campus, Health Data Research (HDR) UK etc.
- **More quantitative research on how data donors and patients view their data use by business** such as big pharmaceutical companies and what donors might expect in return (e.g. feel good factor, expectation of first access to treatment, cash payment or contributions to the NHS etc.) through quantitative surveys was suggested by Wellcome Genome Campus.
- **New-born and infant Screening.** Feeding findings into the Genetic Alliance's planned work on new-born screening (starting June 2019) which will explore patient views on current systems, available technologies and future potential for WGS in infants; and into a Task and Finish group for the **Genomics Board on Newborn and Infant Screening**, whose ultimate policy audience will be the NHS and Public Health England (PHE).
- Further **public dialogue work around gene editing using CRISPR-cas9** and proposed changes in the legislation to allow uses in humans to correct serious defects (e.g. with Royal Society or Francis Crick Institute).

The Genomics England core team consider that, with a good contractor and a clearly defined project management role, they would be able to carry out small public dialogue processes without further assistance from Sciencewise.

3.4 POTENTIAL WIDER POLICY IMPACTS

The findings chimed with those of other Sciencewise studies in that participants were happy to accept their data being used conditional on: consent being obtained first; only de-identified data being used; safeguards to protect privacy; and data not being used for non-consented uses (such as online targeting, insurance, policing or immigration) or as the basis for profiteering by the private sector.

Beyond the health sector, the OG members will share findings and the impacts may be felt in policy work in the following sectors:

- **Big Data**. Implications for expectations and ethics in big data will be shared through the University of Oxford Big Data Institute.
- **Insurance**. Implications for predictive testing will be shared through the Association of British Insurers (ABI).
- **Other commercial sectors** who will benefit from genomics medicine roll out including artificial intelligence (AI), software, diagnostics, commercial researchers and pharmaceuticals, and other sectors covered in UKRI's Strategic Prospectus. The commissioners reported that *"[we now] genuinely have a platform to go out and talk to stakeholders about the implications".*

One unanticipated impact from the process has been in helping Sciencewise sharpen its narrative for explaining the potential benefits and robustness of public dialogue as an approach. UKRI and Sciencewise also took the opportunity to invite potentially interested policy makers, who are not yet familiar with public dialogue, to attend the launch and view an exemplar of a good dialogue process with potentially far-reaching policy impacts.

3.5 LESSONS

The evaluation has highlighted the following lessons for maximising the potential impacts of a well-run dialogue process:

- Getting senior commitment at the highest level to the project during the business case, based on tying it closely to the CMO's ask around the Generation Genome report, meant that despite unanticipated changes in senior leadership, the dialogue could have real and wide-ranging impacts.
- Involving a diverse and very senior Oversight Group created many opportunities for them to feed their expectations for how they could use the results into the design of dialogues and take the findings back into their own organisations and networks to amplify the impact.
- Including the case and methodology for public dialogue in the final report has strengthened the final report and increased understanding of the credibility of the approach. This could be included in future Sciencewise dialogue reports to contextualise findings and the value of dialogue approaches as a rich evidence source.

4 GOVERNANCE AND PROJECT MANAGEMENT

This section assesses the efficiency, effectiveness and proportionality of project governance and project management arrangements based on observation of all four OG meetings, post-dissemination interviews with OG members and interviews with core team members from Ipsos MORI and Genomics England. The findings are presented as follows:

- *Section 4.1* describes the Oversight Group and its effectiveness;
- *Section 4.2* describes the project management arrangements between the commissioners, the contractors and Sciencewise; and
- *Section 4.3* summarises lessons learnt from the evaluation.

A large (19 members), senior and engaged OG played a significant role in the success of the dialogue. While resource-intensive to manage, the group included a wide range of key stakeholder points of view and brought considerable experience in both quantitative and qualitative research (including public dialogue), and expertise in genomics, health data and ethics. The group contributed very positively to framing the dialogues, ensuring stimulus materials were balanced and accessible, and in contributing as specialists to the dialogue workshops, the summit event and the launch. Almost all the OG members that we interviewed identified ways in which they now expect to use the insights gained in policy processes or future research. The study also benefitted from having a dedicated project manager with prior experience of running similar dialogues, the experience of the Ipsos MORI team, and the highly collaborative relationships established in the core project management team.

4.1 OVERSIGHT GROUP

A large group (19) of highly qualified experts in their fields provided a diverse mix of academic, clinical, ethicists, patient representative and data science perspectives. Several members had been involved in the evolution of the project from early drafting of the chapter on the social contract in the Generation Genome report, through developing the 100,000 Genomes Project and its guiding ethics, to the design of this dialogue process. More than half the members had previous experience of qualitative research, and a small handful had direct experience of public dialogues. This helped to ensure that the OG was confident about the credibility of the approach and the robustness of the results.

The breadth of organisations involved, and the seniority of its members, meant that it was a lively group with strong opinions, sometimes expressed in rather academic language. One member described the group as "*lots of forceful characters, but it seemed to work*". Nevertheless, all interviewees agreed that the group was inclusive, that all views were welcomed, and all were heard. As one member put it: "*OG members with very different views were given equal airtime and the chance for individual discussions with the core team*" while another reported that *"I felt I'd been fully engaged – I didn't feel any less important than other members – my comments were reflected in the final report".*

A few of the individuals attending the OG changed over the course of the project, though organisational representation remained constant. For example, there were a number of members from Genomics England and NHS, not all of whom attended each meeting, and the individuals representing NHS and ABPI also changed over the course of the project. This did not appear to affect overall coherence of the group, since a large core group (about 9-12 members) attended each of the four meetings, with several participating by telephone. The project manager, Ipsos MORI and

the Sciencewise adviser took great efforts to ensure that individuals who could not attend were kept updated and that their opinions were heard. However, it would have been helpful for the OG leaders to make sure those unused to these formats, such as the participants panel and privacy campaigners, were not intimidated by academics or policymakers on the OG.

The group as a whole reported feeling fully engaged (see *Box 4.1*) and we observed that about a dozen members had a very strong sense of ownership of the process and outcomes and many shared their expectations of how they would use the results with the evaluators from the outset and followed up by disseminating the report, attending the launch and reporting how they would use the findings in their work. At least ten members attended the launch event (including two substitutes for individuals who were unable to attend).

An early redesign of the timetable - adapting timings to allow an extra month in Phase One – meant that the OG had time to meet and actively influence the Rapid Evidence Assessment (REA) coverage and the design of the stakeholder workshop. Half a dozen members took the opportunity to suggest gaps, additional sources and contacts. All OG members were also invited to attend dialogue events and the summit as specialists or observers: three attended dialogue events and six attended the final summit. A group of half a dozen OG members were also closely involved in making detailed comments on iterations of the final report. All those interviewed felt that their points had been reflected in the final version.

Those interviewed told us (see *Box 4.1*) – and we observed – that they had been able to influence the direction and nature of the dialogue, materials or outputs according to their interests.

Box 4.1: Views of those interviewed on governance and management of the dialogue process

Commissioners:

- *"[OG] seemed to work well – seemed to have a good representation and most voices seemed to get heard".*
- *"[the OG] was quite good at establishing and communicating to contractors exactly what they wanted to get out of it – hashing it out in lively debate".*
- "*I spent quite a lot of time reviewing stimulus materials and felt able to have a positive influence, particularly in shaping scenarios and ensuring they had a little more forward leaning stance".*
- *"Full of highly informed, very strong characters with very diverse views. Ipsos and the Genomics England project manager managed it beautifully and managed to keep everyone on board. I think they did really well".*

Other OG members

- *"A big group and slightly unwieldy but worked surprisingly well – it was important to have a wide range of voices in the room".*
- *"Composition was good and balanced and worked well given the size of the group".*
- *"Nicely conceived – included most organisations that have an interest in this area".*
- *"Everyone seemed broadly committed to the process and recognised the importance of being part of the project".*
- *"The process was good, and I felt properly involved and felt I contributed in helping develop the social contract concept".*
- *"First meeting was incredibly daunting to join a group of such highly qualified people and academic language".*
- *"OG was a good place to challenge the articulation of the social contract – nearly got lost but OG members kept bringing it back as they clearly felt it important to address".*

We observed that the group had a major impact on the overall dialogue framing (consistently bringing the workshop designs back to questions around the social contract), reviewing the design of

individual project components, and suggesting techniques/formats and content for the stimulus materials (such as the family tree scenarios suggested by the OG Chair). Whilst involving multiple interests in the design proved challenging, strong project management prevented the challenge from becoming a problem (see Project Management, below).

The OG was generally keen to keep the focus on the realistic, near-term potential of genomics, and known plans on how genomic medicine and data use were likely to unfurl. However, the contractors were given some freedom to explore the questions in interesting ways, including scenarios which allowed them to explore wider societal impacts (rather than just personal benefits and risks) and allowed red lines for data use to be explored fully.

As illustrated by their comments in *Box 4.1* individual members felt that the OG had played a very significant role in keeping the process focused on core objectives. All interviewees told us they felt that they had got back what they put in and that their suggestions had been heeded. One interviewee reported "*everything I was able to offer was considered seriously*". Indeed, several individuals agreed that the OG had been so useful that, if Genomics England or others plan to carry out any follow-on research, they would be happy to continue being involved in some capacity (from periodic emails to a follow-on steering group or a role in policy advocacy).

4.2 PROJECT MANAGEMENT

During the pre-procurement process Genomics England, the project Commissioners, and Sciencewise, which supported the process, worked closely in preparing the ITT and ensuring that there was buy-in for the project at the highest levels within Genomics England. The buy-in across a senior group proved vital in ensuring that the dialogue was viewed as robust and that it will have significant policy impact (see *Section 4*).

During the wash up meeting the commissioners and contractors highlighted the inflexibility of the UK Shared Business Services (SBS) bidding process and the challenges this imposes for delivery contractors in proposing novel approaches or different options for how the dialogue could be delivered within a fixed budget. However, based on prior experience of public dialogues, the commissioners had built some flexibility into the ITT by specifying a step by step approach to project design. This included kicking off with a rapid review of what is already known about public attitudes to genomics and data (the REA), and making decisions on the number, locations and length of dialogue events based on the findings. The design also included a contingency for sharing findings with others as opportunities arose.

Again, based on experience of running dialogues, Genomics England appointed an experienced project manager (0.4 FTE) who worked solely on the dialogue from July 2018 to April 2019. The Project Manager took on the main responsibility for organising OG meetings, agendas, co-chairing OG meetings and making sure that individuals were kept updated and their voices were being heard. He was also responsible for identifying and convening a large cast of specialists involved in the stakeholder workshop, public workshops and the summit. The effort in ensuring a full spread of specialists (clinicians, researchers, patients, ethicists) across nine events was the most time-consuming element for the project management team.

This flexible approach and the very collaborative relationships established amongst the core project management team were important in ensuring that a potentially unwieldy OG and a long list of expectations from the dialogue could be managed effectively. The commissioners reported that "*this flexible stepwise approach has been enormously helpful*" and the core team and the delivery

contractors felt that "*creating a really good – not too formal – relationship*" and the commitment of the project manager had been a critical factor in making this dialogue work. As noted in *Section 6* the active engagement of the right spread of specialists was a key element in the success of the dialogues, but as the project manager noted *"it required a lot of ingenuity and hard slog but, by and large, we got exactly the people we wanted there"*. Most OG members interviewed reported that the dialogue had been a well-run process, the OG a useful group and that the delivery team had been very open to the OG's suggestions.

The contractors could have taken on more of the responsibility for communicating with the OG and specialists had they been kept systematically updated with contact details and fluxes in OG membership and specialist recruitment. This caused a few minor misunderstandings and challenges in ensuring all specialists were pre-briefed and that all OG members saw all relevant documents. However, in our view this did not affect the overall quality of the process or policy impact.

Several OG interviewees commented that the Ipsos MORI team had been very responsive, flexible and adaptive, particularly in adding on additional events, within a constrained additional budget, in Scotland. This was very much appreciated by the Scottish commissioners. One OG member noted that "*the contractors were good at being responsive and alert to issues and anticipating potential sensitivities"* while another commented that "*Ipsos MORI were really good at taking on the brief and really willing to work with and listen to the OG - quite a slick process".*

Genomics England also reported that Sciencewise provided very useful support, particularly during the early stages of developing the project, and in ensuring that a full range of viewpoints were represented on the OG and any perceived gaps – such as data privacy campaigners – were included in the stakeholder workshop and interviews or through specialist inputs. One interviewee noted that *"[Sciencewise] had lots of useful experience of developing the business case, briefs, procurement, and experience that was really invaluable"* and that they were "*very good at 'keeping us honest' and suggesting ways through potentially tricky situations and making sure that the full range of stakeholders were involved*".

4.3 LESSONS

The main lessons learnt on governance and project management were the following:

- Senior buy-in within the commissioning body is vital. Appointment of a senior project manager with experience of dialogue was also very helpful, enabling effective governance structures and considerable advance preparation pre-procurement.
- It was important from the outset to have clear and realistic expectations of the time and resource required for project management, from both the commissioning body and the contractors.
- A large, diverse, very senior and well run OG was effective in framing the dialogues, advising on issues and perspectives to be covered and advising on stimulus materials. It also ensured a strong sense of ownership of the findings which have been widely disseminated and will help amplify the potential impacts of the dialogue beyond the commissioners' policy agenda. Social capital has been built for involvement in further dialogue and research in this area.
- The flexibility built into the design process (within the confines of the procurement system), the strong relationships established in the core team and the flexibility of the contractor were major strengths of this public dialogue. The flexibility in adding a location in Scotland was greatly appreciated by the Scottish commissioners.
- The commissioners and contractor need to establish the division of responsibilities within the 'political landscape' of the subject area. The commissioner is primarily responsible for

identifying the right people and persuading them to take part as OG members and volunteer experts; the contractor should then manage the resultant group.

- Recruitment of specialists for dialogues and stakeholders for workshops, summit and launches takes more time than expected. Maximising the planning time, being very clear about specialist roles and can help streamline the process.

5 ASSESSMENT OF HOW FAR THE DIALOGUE HAS MET ITS EIGHT OBJECTIVES

This section assesses how the dialogue has met its eight objectives and is organised as follows:

- *Section 5.1* describes the overall achievement of the objectives; and
- *Section 5.2* describes the credibility and robustness of the dialogue.

The commissioners and a wide range of other organisations involved in the governance and delivery, viewed the process, and therefore the findings, as credible and robust. The sequencing and careful attention to framing, together with the engagement of a large and senior Oversight Group who felt a strong ownership of the process and helped to frame the dialogues, contributed to six out of eight objectives of the research being very well met. The project as a whole provided: a comprehensive understanding of the public's views on issues around genomics (objective 1); an understanding of dialogue participants views on genomics, data sharing, the social contract (objectives 2, 3 and 4); potentially significant impacts on policy for the future development of genomics medicine (objective 6); and some practical suggestions on a communications strategy and the language which can be used to describe genomics to the wider public (objective 8). Two other objectives – exploring shared expectations (objective 5) and contributing to wider policy (objective 7) – were not really expected to be fully met by this dialogue, but most interviewees felt they had been partially met.

5.1 OVERALL ACHIEVEMENT OF OBJECTIVES

Table 5.1 shows how different components of the process were designed to meet the eight objectives and our assessment that six of these were fully met, based on evaluation interviews and our expert judgement and experience. Achieving so many objectives would be a challenge for a dialogue process and two of the objectives (5 and 7) were seen as of lesser importance by the commissioners but were included as areas where they hoped the dialogues might start to contribute.

The following paragraphs consider in greater detail how objectives have been met in relation to*:*

- understanding wider **public** views and attitudes (Objective 1);
- understanding views **of public participants in the dialogues** (Objectives 2, 3 and 4);
- understanding **shared views with other stakeholders** (Objective 5);
- **impacting on genomics and wider policy** (Objectives 6 and 7); and
- recommendations on **communications and language** (Objective 8).

5.1.1 Establish current knowledge and understanding on public views and attitudes (objective 1)

The objective was to collate what is already known about:

- the wider public's views and attitudes towards genomic medicine and WGS;
- and the concept of a 'social contract' between the public and the NHS; and
- safeguards/'red lines' essential to public support/trust for genomic medicine.

This understanding was to be gained through a review of previous dialogue, engagement, consultation and related research projects involving the public.

The objective was successfully achieved through the REA. The expectations of the OG in terms of the depth and scope of the REA were well managed by Genomics England. OG members were able to contribute additional sources for inclusion in the REA, including some unpublished research on language suitable for using by clinicians to communicate with patients and for the NHS/Genomics

England in talking about genomics with the public. The OG's inputs helped to ensure that the views of all key stakeholder groups were covered (policy, clinicians, patients and the public, and BME groups). Comments from the OG on the final draft suggested the review had been balanced, covered all the key issues and drawn valid conclusions: participants in the stakeholder workshop largely agreed with this assessment (see *Annex B*).

Table 5.1: How the objectives were addressed by different elements of the process

Objective	Success	Evidence Assessment	Stakeholder workshop	Dialogue workshops (1 and 2)	Summit, launch & final report
1. Understand current knowledge	✓	Reviewed	Reflections on REA on key issues and examples	event one: Opening discussions on aspirations for the NHS and quiz on health care data in the NHS and how it is currently shared	
2. Understand aspirations and concerns	✓	Reviewed	Input on: What info & issues participants need to know, and case studies to bring to life	event one: Sessions on aspirations and concerns for GM in the NHS and data sharing. Homework task to explore aspirations and concerns further through talking to family and friends. event two: Ranking of potential benefits (from diagnosis, prevention to cure etc.)	
3. Understand trade -offs	✓	Reviewed		event one: discussions around aspirations & risks of GM and data sharing. event two: Family tree scenarios explored benefits and risks in near and longer term & redlines. Session on insurance code of conduct explored acceptability of predictive testing.	
4.Understand idea of social contract	✓	Reviewed	Focus on what is different about GM	event two: session on general expectations and ranking of how NHS could use GM and what different stakeholders (NHS, patients, public, insurance and researchers) must/mustn't do; and on what patients and the public would ideally contribute; and what they should expect back from a GMS from NHS and researchers	Five workstations on: data, familial implications, expectations of patients and researchers and commercialisation. Final report structured around the social contract and solidarity, reciprocity and altruism
5. Explore shared expectations	A good start		Mix of 19 stakeholders, including industry	Did not focus on building consensus but did explore red lines and how widely these were shared	16 stakeholders attended the summit, but the focus was not on developing shared expectations.
6. Contribute to Genomic Medicine policy & ethics	✓				Final report highlighted lessons for GMS roll out (change to researcher/ clinician/counsellor roles, data use and storage etc.).
7. Contribute to wider policy	Starting point				Clear findings on use of WGS data in insurance, online targeting, policing and immigration etc.
8. Language & comms	✓	Lessons from Wellcome work	Reflections on helpful imagery and analogies	Testing of different language on social contract (deal, partnership, reasonable expectations ….) and genomic medicine throughout	Final report section on lessons on language and comms needs.

The findings from the REA informed the design of workshops, the recruitment approach (for instance including patient, industry and BME groups in the main workshops rather than in parallel events). The REA also highlighted some of the issues around genomic data use that the public were likely to find contentious, such as predictive testing for insurance, commercial involvement in healthcare, sharing of data with other government agencies and concerns about the NHS's capacity to roll out genomic medicine. These insights influenced workshop design, for instance leading to the inclusion of a session on the voluntary insurance code on genetic testing. It also included lessons about language use which helped informed the workshop materials.

5.1.2 Participant understanding and views (Objectives 2, 3 and 4)

These three objectives specifically aimed:

- To understand participants' aspirations and concerns around the use of genomic data and other personal information;
- To understand participants' views on potential health and other benefits of genomic medicine, the trade-offs (such as concerns about their data use and privacy) and what safeguards need to be in place; and
- To explore understanding of the idea of a 'social contract' as applied to the NHS and the principles by which it is understood to, or should, operate.

The project commissioners from Genomics England and OG members interviewed for this evaluation all agreed that these three objectives were fully met. The dialogues provided a good understanding of what the wider public (also described as 'potential patients') felt compared to the views of patients, whose views are much better understood by clinicians and patients' groups. Many of the OG group had experience of working with genomic patients (in clinical practice, or as representatives of their interests) and reported that insights which allowed them to contrast wider public with patient views were particularly useful. As one clinician noted:

> "*It is really interesting to hear wider public views as we are normally talking to the patient community who are much less concerned about data use and sharing – they are much more focused on individual or familial benefits*" while another reported that "*from my point of view the main thing was to take the temperature of where the public are at in their understanding of genomics and the social contract.*"

Scottish commissioners and representatives of patients felt that the Scottish workshop discussions had highlighted that the views of the wider public did not diverge significantly from those of genomics patients:

> *"Views expressed by the public in these workshops are broadly in line with the views of rare disease patients and their families, which means that we do not seem to be dealing with one set of views where there are specific health reasons to engage/be positive, and another where there are not. This is reassuring and helpful for future research and engagement*."

The Social Contract

Almost all OG members felt that objective four was the most important and challenging objective for the dialogues and that real headway had been made in achieving this objective, particularly during the final summit and in the way the final report was presented and written. Almost all evaluation interviewees recognised that, conceptually, it had been a real challenge to reach this point, with a need to constantly bring the dialogue back to tackling the central question of what a social contract would encompass (see *Box 4.1*). However, almost all felt that the OG had played a key role in helping the core team to think about the terminology and language, and that the way the findings were presented around a model of solidarity, reciprocity and altruism was a real breakthrough.

Interviewees recognised that the social contract was a construct developed by the authors of the Generation Genome report and that public participants could not be expected to have any prior familiarity with the term or what it might imply in terms of underlying values. OG members were, therefore, closely involved in helping provide a theoretical framework and language that might help participants to explore these issues (for instance around whether to use the term 'deal' with its associations with Brexit and commercial transactions, or whether to use 'partnership' or 'expectations' suggesting a more reciprocal relationship).

The language – of partnerships, expectations and responsibilities – was first introduced in the morning of workshop two, and concepts of a kind of 'social contract' 'deal' or 'mutual expectations' that might underpin future genomic medicine were introduced as ways of grouping underlying

principles were introduced that afternoon. When participating specialists were asked whether the language used to communicate the idea of a social contract had enabled participants to voice their views about the social contract most agreed (seven strongly agreed, 11 tended to agree, two were not sure), but many felt that much more detailed conversations were still needed.

The summit focused in more detail on issues which appear to underlie the social contract, through a process design that involved five workstations (see *Section 2)* and a final (planned) plenary, in which to pull together the key issues. When asked whether they felt like the ideas they came up with were starting to feel like a social contract, that could inform how genomic medicine is taken forward, public participants mostly agreed (six of the twelve who answered strongly agreed, six tended to agree). Specialists felt they had heard a lot about the expectations of different actors and their red lines, but were less sure that discussions had reached any consensus. Some commented that a range of different views on many specific issues had been captured but a few worried that the questions at workstations had been too granular and that the bigger picture view of the underlying principles had been lost.

All those interviewed after they had seen the final report told us that the way the findings were organised around the intersecting values of reciprocity, solidarity and altruism was a major step forward and helpful in presenting very complex relationships in an accessible way. This is reflected in the wording in the foreword to the final report signed by the CMO and an OG member:
"This report…reveals that the relationship between the NHS, patients, and the public is currently understood in terms of three core values: reciprocity, altruism, and solidarity. These values are likely to continue to inform the understanding of the appropriate relationship between medicine, research, and society as genomic medicine plays a more central role in healthcare". **(Foreword to final report, Professor Michael Parker, Wellcome Centre for Ethics and Humanities, University of Oxford and Dame Sally Davies, CMO England).**

Box 5.1: Views of OG members on Objective 4: Understanding the Social Contract

- *"It has been valuable work to try and find different terminology and ways of presenting these [social contract] concepts".*
- *"Quantitative survey or one-hour telephone interviews with individuals could not have got to this point. None of us really understood framing about social contract and NHS Constitution… [gave us] some real insights about reciprocity, solidarity and altruism and red lines".*
- *"A struggle – a difficult task because not an accepted concept outside of Generation Genome chapter - but think the final report has done this".*
- *"Was a bit of a struggle for all of us but the final report looked good".*
- *"Got there in the end but a bit of an effort to get people to answer the central question on the social contract".*
- *"Finally, …we had to keep pulling back to this central question - what do people think about the social contract? How do they feel about people using their data?".*
- *"Lots of discussion in the OG and seemed to help get to the right terminology in the end".*
- *"A start, but we would not like to see this as the sole basis for a change in the social contract – that needs longer discourse, more education and regulation, not just [changes to] wording in the NHS constitution".*
- *"People were amenable to thinking about health care in terms of solidarity …human genomics is a good emblem for this – it's what we share but also what distinguishes us, and we can share it to help each other relatively easily. By demystifying It also helps to make the divide between research and health care less frightening"*

5.1.3 Exploring shared expectations and understanding (Objective 5)

This objective was to explore whether different actors in the genomic space share expectations for and understanding of the ambitions and outcomes for genomics and genomic medicine in the UK. Those actors are patients, the public, clinicians, academics, industry and other stakeholder groups. This objective was partially met. Focusing in on the *shared* expectations, OG interviewees commented that they had heard many views of public participants, clinicians, academic researchers and other stakeholders at the summit but had no sense that the meeting had resulted in a shared understanding.

As noted in Section 1, the intention of the project was never to reach a consensus on what a social contract should look like. However, our observation was that the planned closing plenary - which did not take place because other sessions over ran - would have been the opportunity for all involved to pause and hear wider views. It would also have been an opportunity for the commissioners to reflect on what they had heard and how they would take these findings into their policy and practice. Losing the final plenary did not impact on the final reporting or overall dialogue impact but may have coloured perceptions that this objective was only partially met.

Analysis of the data generated in the dialogue showed that there were areas of common ground, as discussed in the final report: most people found genomics and use of their genomic data, broadly acceptable, subject to some widely shared red lines. However, one stakeholder interviewed commented that views still seemed quite binary amongst public participants (either wholly supportive or wholly sceptical) and another that industry had not been much involved. Further dialogue with groups that seemed most sceptical about genomic data use and further work with industry were both identified as areas for follow on work (see *Section 3*).

5.1.4 Policy impact (Objectives 6 and 7)

Objective six concerns the contribution of the dialogue to and informing the ongoing policy and ethical debates and, the political and ethical environment, to enable genomic medicine to flourish. Public participants in the dialogues were clearly informed of how their views are expected to feed into shaping the roll out of genomic medicine by the NHS. The objective was introduced at the beginning of each event by Genomics England, Ipsos MORI or an invited specialist (at the summit), and as summarised in *Box 5.2,* this was clearly understood by participants and almost all were confident that this would happen.

Box 5.2: Public participant views on policy objectives

- After workshop one almost all the 91 participants reported (71 (78.5%) strongly agreed, 17 (18.7%) tended to agree) that they were aware of and understood the purpose of the workshops and their role in participating.
- The design and feel of the workshops, which made it clear that the participants' views were highly valued, played a clear role in participants' perception that the events had achieved what they set out to do.
- By the end of workshop two, 84 participants (95% of 88) were therefore confident (58 (65.9%), strongly agreed and 27 (30.7%) tended to agree) that the events would inform how Genomics England and NHS decide about rollout of genomic medicine in the future.

As described in *Section 3* the dialogue findings are already expected to play a positive role in shaping policy processes, clinical and researcher practice and are reported as making a significant contribution to the research field. The findings will provide a starting place for further research and engagement around issues such as the attitudes of specific groups (such as BME and genomic

volunteers and commercial businesses) or areas (such as the sharing of genomic data with pharmaceutical businesses).

Objective seven concerns the contribution of the dialogue to the wider policy, political and ethical environment about the collection and use of data by government, beyond healthcare and genomics. As noted in *section 3,* the dialogue findings could feed into other policy areas which involve the collecting, using and sharing of personal data. Interviewees suggested that the final report effectively highlights 'redlines' about data uses in research and safeguarding of data which could also be relevant to other non-genomic big data discussions. However, the commissioners and OG members did not consider this objective to be as important as those focused on genomics.

5.1.5 Communications and language (Objective 8)

Objective eight concerns developing understanding of the language used by the public and other stakeholders to discuss genomic medicine. This understanding will inform communications for and about genomic medicine activities and services in the UK. Given past lessons on the need for any successful genomic medicine service to get opt-in from a critical mass of patients and citizens, this was an important objective. The commissioners and almost all OG members interviewed agreed that it had been met.

The REA and workshop one discussions underlined the very limited acquaintance that participants had with the term genomics. While workshop two discussions reinforced the conviction amongst practitioners that people needed relatively little technical information, for example on the science of DNA, in order to understand its potential benefits and risks. One OG member reported that:

> "*Our experience suggests that what people really need to know in a clinical situation is very limited…patients just want to know how does it affect you, your family, what can be done about it*."

Several OG members interviewed felt that the report supported what is already known in this area but did not yet provide a template for how to communicate about genomics to the wider public. One interviewee told us that the report presented:

> "*No major surprises but reinforces what has been done before"* while another commented that "*it gives a tone, but I don't feel that the report gives a strong understanding of the language the public uses – there was quite a lot of technical language in the final report*".

The final report suggested an approach to communications that builds on public participants' views that Genomics England and the NHS need to do more to inform people. This struck a chord with patient representatives, who raised concerns about the social implications of low genomic literacy amongst clinicians, as well as patients, one noting that there is:
"*an urgent need for genomic literacy to be addressed – what does it mean for society and within the NHS? – increasing the understanding of clinicians so that they understand more than patients*".

The approach to proposed communications in the final report included calling the public to action around 'people powered genomics' while avoiding over-hyping the short-term potential for genomic medicine-based treatments. One OG member also pointed out that any successful communications strategy will need to help break the strong link in the public imagination to the separate, but related, concepts of genetic modification.

5.2 CREDIBILITY AND ROBUSTNESS OF THE DIALOGUE

All OG members interviewed reported that the dialogue had been appropriately framed as a component of a longer discussion about the social contract underlying genomics in the NHS. There

was unanimous agreement amongst OG members interviewed that the breadth and depth of topics covered, and the richness of the findings, could not have been achieved through quantitative surveys or focus groups. The credibility and robustness of the process and its findings were a function of the project being well-thought through and well-reported on; strong governance by an engaged OG; and being timely in coinciding with the end of the 100,000 Genomes Project and the roll out the genomic medicine service. The process has also been an exemplar of how exposure to good dialogue processes can demonstrate the value of small numbers and rich, detailed discussion offered by dialogue.

Box 5.2: Commissioner and OG member's views on the credibility and robustness of the process

Commissioners:

- "*We've done a good job. We should take confidence from this work as public dialogue being something the UK does well and should encourage others to do".*
- *"A timely example of what can be achieved with good public dialogue and an example of success to strengthen the case for public engagement".*
- *"Absolutely credible – couldn't have got to this through quantitative research".*

Other OG members:

- *"A big well-thought through exercise with a significant report – will become a key reference point and footnote to other work. A good start".*
- *"A credible and robust process – when I first saw the numbers involved I was a little sceptical but as soon as we got into it I realised that the detail of discussion that public dialogue produces could not have been done on a larger scale".*
- "*I think it feels like a credible process and Ipsos MORI have managed it well – the way the report is written, and visuals work well*".

5.3 LESSONS

Six out of eight objectives were fully met. The two that were only partially met were not seen by the commissioners of OG as being as important as the other objectives. The evaluation has drawn the following lessons on what enabled this success:

- Active involvement of a large and well informed OG from the earliest stages helped to continually refocus the dialogues around the objectives and deliver a process that was considered robust.
- Time spent on ensuring that commissioners and OG members that chose to do so could make detailed comments on the draft report and ensuring that these were reflected in the next iteration resulted in strong ownership of the findings.
- Inclusion of a literature review in the process meant that the report could refer to it instead of including that evidence, and more easily demonstrated analysis rather than description.
- A relatively long final report was required in order to cover the long list of objectives and ITT questions and in order to cover all the bases within Genomics England and the OG.
- Ipsos MORI really added value to the findings by developing a 'model' which was able to organise the findings in a visual way. The report was also structured to have real world policy impact. Audiences found this framing of the outputs both novel and useful. Possibly Sciencewise should include a request for visual models that illustrate qualitative findings for future dialogues.

6 HOW DELIVERY MET SCIENCEWISE BEST PRACTICE

This section provides an assessment of how far the dialogue process has met Sciencewise principles for good practice in design and delivery based on evidence from observing workshops involved in this public dialogue and the summit, collecting formal feedback from public participants and specialists through post-event evaluation forms, and through interviews with the commissioners, delivery contractors and OG members. The findings are organised as follows:

- *Section 6.1* describes delivery across a wide range of best practices, summarised in *Table 6.1*
- *Section 6.2* looks in greater detail at three areas considered particularly pertinent to this dialogue, namely: the number and mix of participants; ensuring participants had sufficient time and information; and ensuring the dialogues were fair and balanced.
- *Section 6.3* summarises the lessons learnt.

The dialogue delivery met all Sciencewise best practice standards, and most of these very well as a result of a combination of an experienced commissioner; engaged Oversight Group (OG); and careful design by a very experienced contractor. A good mix of nearly 100 participants over four locations meant that groups of different sizes (about 15 or about 30) broadly reflected the demographic and socio-economic characteristics of their locations. They also included strong participation from groups expected to be both less (BME groups) and more enthusiastic (heavy users of the NHS) about genomics and data sharing.

Contributions from the OG, inputs from a large group of stakeholders and more than 40 days of specialist input (covering clinical, research, ethical, data management and 100,000 Genomes Project participant expertise) during the two workshop days played an important role in ensuring that participants were exposed to a wide range of views and the dialogue was fair and balanced. The participants were able to access information through an engaging mix of PowerPoint, video, handouts, quizzes, small table discussions including with specialists. Scenarios and probing by facilitators helped to prompt rich discussions around the complex issues underlying aspirations and concerns for genomic medicine and the use of genomic data. The mix of experience levels and facilitation styles, and team continuity across events resulted in very positive group dynamics. Almost everyone participated very actively in discussions and all felt they had made a valuable contribution and had their voices heard.

6.1 OVERALL DELIVERY OF BEST PRACTICE

Table 6.1 summarises our overall assessment of delivery against best practice standards. This shows that a very experienced contractor supported by an Oversight Group (OG) and Genomics England project management team with some prior experience of delivering public dialogues around complex health and data issues was able to meet all Sciencewise' s best practice standards. Most were met to a high standard.

In the sections below we have focussed in on three areas identified as particularly pertinent to this dialogue as follows:

- **Ensuring appropriate numbers and types of participants were involved**. This was important because the brief and REA had suggested that some groups (BME, patients and older people) might have different views and the OG and core team decided to recruit similar profiles across all locations, rather than running any special interest groups. The dialogue therefore needed to

ensure that such voices were well represented and heard, even if no conclusions could be drawn on whether their views differed markedly from other parts of society.

- **Ensuring participants had sufficient time and information for deliberative discussions**. A key challenge for this dialogue was designing workshops which were able to cover the large number of questions raised in the brief and by the OG; by giving participants just enough - but not too much - technical knowledge on genomics and health data as a starting point; and conveying it through an engaging mix of techniques and formats which allowed space for deliberation.

- **Ensuring the dialogue was fair and balanced**. The commissioners and OG members held generally positive views about genomics. To ensure a balanced dialogue, it was important that any missing voices – such as more sceptical data privacy campaigners or commercial businesses - were represented, through stakeholder engagement, balanced stimulus materials, and by including a range of specialist disciplines and viewpoints in the room for participants to hear.

6.2 QUALITY OF DELIVERY IN KEY AREAS

6.2.1 Representation was of an appropriate scale and mix to provide useful results

The OG agreed that the proposed English locations (London, Coventry and Leeds) would provide a mix of urban and suburban audiences. They also agreed they would be convenient for recruiting a mix of specialists to support the dialogue sessions. A Scottish location was added later in the process to explore whether the different policy context in Scotland affected participants' views. The aim was to have 25 to 30 participants in each of the English locations and 16 in Edinburgh. Actual attendance for workshop one across all locations was 97 (against a target of 106), with a 5% fall-off by workshop two to 92. *Table 6.2* summarises the characteristics of the group at each location against the gender, age, ethnicity, and socio-economic grade (SEGs) of the recruitment quotas. Evaluation questionnaires were completed by 91 participants for workshop one and 88 for workshop two.

The turnout for London, Leeds and Edinburgh was high, with very little drop out and a good spread of participants from across the recruitment sample. Recruitment numbers were low for Coventry (only 21 at workshop one) with further drop out – including the loss of three BME participants – for workshop two. On-street recruitment with participants required to make a commitment to three dates, including a weekday in December, proved difficult in a smaller city. The contractor offered to repeat the event, but the core team agreed that small numbers had not affected the quality of the discussions and that participants had been able to have more intimate, in-depth discussions. The underspend on recruitment and participant incentives was reallocated to additional dissemination events and the summit.

For the summit, on a Friday in London, the contractors invited back a mix of 21 participants, evenly spread across the three English locations, and 19 attended. Scheduling a week-day dialogue event could have had some impact on the level of participation, with those in full or part-time employment unable to attend, with the result that the group was dominated by economically inactive participants. However, analysis of the sample, our own and specialist observations suggest that a good mix was achieved. Adding in a third date to the recruitment specifications may, however, have made it more difficult to recruit the full quota in Coventry.

We observed that participants developed strong bonds within the small groups from their own locations. Those attending the summit reported that they had found it useful to hear the views of those from other locations.

Table 6.1: Assessment against good practice principles

Sciencewise Good practice principles	Achieved	Evidence and commentary
Focus on addressing agreed dialogue objectives	✓ ✓	• Design was tightly focused on delivering six of eight objectives, and the OG was able to steer the focus to the social contract.
Fair and balanced dialogue	✓ ✓ ✓	• The composition of the OG group, a diverse stakeholder workshop, involvement of many specialists (clinicians, ethicists and Participant Panel members) and inclusion of more sceptical voices who were not in the room were included via projective materials (talking heads handouts, family tree scenarios) ensured a balanced dialogue. (*Section 6.2.3)*
Appropriate number and types of participants	✓ ✓ ✓	• The number and mix of participants reflected the findings of the REA and the agreed recruitment quota and through careful design, facilitation and a mix of learning and deliberation methods were able to reflect the populations of three English and one Scottish location. (see *Section 6.2*.1)
Respect for public participants	✓ ✓ ✓	Participants seemed comfortable to share their opinions: in many cases, individuals felt safe enough in the space to share very personal stories of their own or family health issues. all 91 participants completing questionnaires agreed after workshop one that they were able to contribute their views and have their say 70 (77%) strongly, 21 (23%), tended to agree). There was also unanimous agreement that all were treated equally and respectfully. At the summit all participants completing questionnaires agreed (8 strongly, 5 tended to agree) that the facilitators made sure that the views of participants, as well as specialists, were heard. Almost all specialists attending the summit agreed (nine strongly, three tended to agree) that both participants and specialists were heard: "*some were quieter than others, but I saw everyone contribute*".
Sufficient time and information for deliberative discussions	✓ ✓	Agendas were ambitious for all events but slight amendments after London workshops one and two allowed more time in other locations by removing repetition of some exercises (family tree scenarios, summit workstations). Tight timing for larger meetings (London, Leeds and the summit) meant that opportunities to hear and pause in plenary were lost. All questions were covered, but this may have contributed to feelings that shared positions had not emerged. (see *Section 6.2.2)*
Quality and depth of facilitation	✓ ✓ ✓	A pool of 7-8 facilitators of mixed seniority ensured continuity across the nine events with a good ratio of 1:8-10 facilitators: participants. Achieving this ratio within the available resources meant that the lead facilitator was also responsible for table facilitation and admin (paying incentives) which caused challenges for time keeping for the final event. Facilitators worked from detailed workshop discussion flows and were well briefed in advance. We observed some excellent facilitation and probing to understand what underlay opinions expressed After workshop two almost all 88 participants agreed that the facilitation had been independent, professional and effective (71 (81%) strongly, 16 (18%) tended to agree). Several participants praised the style of individual facilitators and their ability to manage very wide-ranging discussions and keep participants on track: "*the organisers worked expertly as a team to deliver discussions"* and *"facilitated well, gave time for discussions*". One specialist noted "*there were some instances where discussion got bogged down in technical questions, but facilitators were able to draw them away*"

Learning from practice throughout	✓✓	👁 A very experienced contractor was able to draw on their own experience of delivery and materials in genomics and health data fields. 👁 Helpful suggestions from the OG on stimulus materials (e.g. family tree scenarios) helped participants explore both practical short-term and longer-term societal concerns and redlines. 👁 The Sciencewise DES and independent evaluator also fed in suggestions from practice.
Recording the dialogue	✓✓	👁 Simultaneous notetakers, audio recording and flip charts were used to capture all substantive discussions. Opportunities for quieter participants to write down their thoughts were also built into many sessions. 👁 At the summit individuals could make their own notes about each workstation to hand in separately (but time was tight, and we observed that not many chose to do so).
Capturing agreement, disagreement and uncertainty	✓✓✓	👁 Workshop design was mainly focused on hearing a wide range of views rather than driving for a consensus. 👁 Time spent on introductory tasks on all days meant that most groups gelled well. Across the eight workshops almost everyone contributed and although there were some louder characters most facilitators were skilful in not allowing individuals to dominate and at bringing quieter people into the discussions. 👁 Cut plenary sessions might have highlighted where the areas of agreement and disagreement lay at the end of each event. 👁 The final report illustrated red lines with anonymised quotes and highlighted where views were widely held or were outliers.
Analysis of dialogue results	✓✓	👁 Dialogue results from transcripts and written notes were analysed manually by a small senior Ipsos MORI team around a framework for analysis developed with Genomics England and the evaluator.
Clear and coherent reporting of dialogue results	✓✓✓	👁 The report structure gave a clear framework for reporting results, including anonymised quotes from participants to illustrate aspirations and redlines. 👂 The development of a visual 'model' for exploring the social contract was reported to be useful by all OG members interviewed. The report was well received by GE and NHS audiences.
Reporting of wider implications of dialogue results	✓	👁 The final report focussed on implications for policy, practice in the NHS genomic medicine service (objective 6) but did also mention wider implications for commercial data sharing (objective 7). Wider implications will be shared in future discussions between Genomics England and the commercial sector.
Participant involvement in reporting the dialogue results	✓	👁 Public participants were not much involved in reporting back on small table discussions to plenary during events. 👁 Participant journeys and their views were shared in a 7-minute vox pop video at the summit. 👁 The commissioners didn't seek permission to go back to participants for further work. This may have been an opportunity missed.
Sharing the dialogue results and final reports with those involved	✓	👁 Participants who had indicated that they were happy to be re-contacted by the evaluator were sent a copy of the report after the launch (but were not invited to the launch). 👁 OG members were actively involved in sharing the findings at the launch. 👁 100,000 Genome Project Participant Panel and patient focused NGOs and genomic medicine service practitioners have been involved in receiving and disseminating findings (see section 3).

Table 6.2: Targets and actual recruitment (with number of completed questionnaires)

Event	Total recruitment		Gender (quota 50:50)		Ethnicity (BME)		Social Economc Segment (SEG)		Age		
	Target	Actual	(# Male	Female	Quota	Actual	ABC1	C2DE	18 - 34 (25%)	35 - 54 (45%)	55+ (35%)
London 1	30	30 (29)	53	47	40.00%	40	60	40	30	43	27
London 2		30 (27)	53	47		40	60	40	30	43	27
Coventry 1	30	21 (19)	48	52	21.00%	24	59	41	19	48	33
Coventry 2		17 (18)	41	59		12	56	44	18	41	41
Leeds 1	30	31 (27)	52	48	26.00%	10	50	50	26	48	26
Leeds 2		30 (28)	50	50		10	52	48	23	50	27
Edinburgh 1	16	15 (16)	53	47	8.00%	13	50	50	13	47	40
Edinburgh 2		15 (15)	53	47		13	46	54	13	47	40
Summit	21	19 (16)	58	42	20.00%	16	45	55	21	47	32
Total Workshop 1	106	97 (91)	52	48	20.00%	23	68	3	24	46	30
Total Workshop 2		92 (88)	53	47	20%	21			30	43	27

Box 6.1: Evidence on representation and mix of participants

- There was unanimous agreement amongst the 91 respondents at workshop one (69, (76%) strongly agreed, 22, (24%) tended to agree) that the recruitment process and advance details for the workshop were handled well.
- In all locations, recruitment was largely reflective of quotas across gender, age and SEGs but with some under-representation of BME participants in Leeds (only 10% compared to quotas of 20%). Young people (18-34) were slightly under-represented in Coventry and Edinburgh, while older people (+55) were slightly over-represented in Edinburgh.
- All specialists at workshop one agreed that there was a good mix of participants that seemed to reflect the general public.
- In all locations the screening questions worked well to include some heavy users[8] of NHS services, who were happy to share their experiences, but no one who had been involved in the 100,000 Genomes Project and only a couple of participants across all groups who appeared to have worked for the NHS in the past.
- Staged incentive payments, and our observation that people were genuinely very interested in the topic, meant that overall drop-out rates between workshops one and two were acceptable (5%), except in Coventry (nearly 20%) where drop-out led to men and BME groups being under-represented at workshop two.
- Although overall group sizes in Coventry were smaller than intended, we observed that smaller groups in both Coventry and Edinburgh gelled well, and the higher ratio of specialists and facilitators to participants allowed more time for individual questions, testimony from patients and rich discussions around the issues.
- Larger workshops and table groups in London and Leeds felt lively and engaged but proved more challenging for time-keeping and managing noise levels: while larger groups managed to cover all the discussion topics, plenary sessions often had to be cut out, perhaps negatively impacting on any sense of whether the group shared common views on the key issues.
- Participants reported that they really enjoyed the mix of people and unanimously agreed, by the end of workshop two, that discussing the issues with their table was a highly successful element of the events: of 88 respondents 71, (81%) strongly agreed, and 17 (19%) tended to agree.
- Our observation was that almost all participants were fully engaged in discussions and that, as expected from the literature review, views on genomics and data use did not differ markedly between locations r devolved administrations. However, they did appear to differ by ethnicity, life-stage and general attitudes or trust or scepticism about government and big business.

[8] Those with long term conditions or cancer

Summit

- The group of 19 participants who attended was appropriately diverse with representation across all age groups, SEGs and the BME population nationally.
- All but two of the 16 participants who completed questionnaires agreed (9 strongly, five tended to agree) that it was worthwhile making alternative plans so that they could take part in the summit discussions.
- They also unanimously agreed (12 strongly, four tended to agree) that it was important to hear the views of participants from other locations.
- Our observation was that nearly all participants were engaged, most were active contributors and they were not overwhelmed or overshadowed by specialists. For the summit some tables were very small (three participants and two or three specialists) and by the end of the day discussions were a bit muted and slightly strained. It might have been helpful to remix groups into equal size after lunch.
- Due to lack of time for administrative tasks in the final session (with participants from Leeds and Coventry rushing to catch trains) only 16 summit participants completed evaluation questionnaires.

6.2.2 Sufficient time and information for deliberative discussions

The design was mainly organised around small table focus group style discussions (eight to ten participants plus one or two specialists with a table facilitator and note taker) with people staying in the same small groups on the first evening and then reorganised at workshop two around younger, older and mixed age groupings. The workshop plans included plenary sessions before lunch and before closing (workshop two and the summit) to provide opportunities for people to feed back on their table discussions, pause and hear what the larger group was thinking and where opinions were beginning to converge or diverge.

The design across the three events involved a good mix of well-tested techniques for sharing information and stimulating discussion including:

- **Audio visual** - PowerPoint, Genomics England video, a quiz on workshop one and vox pop video of participants at the summit. Introductory materials were adapted to the slightly different context in Scotland;
- **Handouts and role plays** – of slides, 'talking heads' quotes, the insurance code, picture sorts, workstation visuals etc. suitable for those with different learning styles. The materials were in accessible language and an appropriate level of content;
- **Informal presentations by specialists** explaining their roles, aspirations and concerns in relation to genomic medicine at both workshop one and workshop two; and
- **A light touch homework task** (with a small additional financial incentive for completion) which gave people a chance to discuss the issues with their friends and family, to do additional research if they wished to, and to discuss their experience as a warm-up to workshop two.

The discussion flow for all three workshops was tested with the OG and revised after the workshop one and two pilots in London. The quiz and video at workshop one, homework between events, and the family tree pen sketch scenarios and the 'washing line' exercises at workshop two proved particularly effective in sharing information and helping participants understand different views (see *Box 6.3*).

For instance, the family tree scenarios allowed participants to explore two different time frames: the immediate application of genomic medicine in the NHS as currently envisaged (the main focus for the commissioners); and projecting forwards to less probable scenarios, given current plans, which helped them think about wider societal concerns and how more vulnerable groups might be affected. This longer-term societal perspective reflected the concerns of ethicists and data privacy specialists amongst the OG members. Trying to repeat this exercise three times in one workshop proved over-ambitious: after the London pilot the flow was changed so that each group only looked

at one scenario dealing with a single family. This meant timing was more leisurely in other locations, but still tight in Leeds which had a larger number of participating specialists (see *Section 6.2.3)*. Across all the , all the questions posed by the commissioners were answered, however, more time for participants to feed-back their reflections in plenary and more opportunities to probe the underlying reasoning as a group would have been valuable in creating more sense of where the common ground was.

The summit was initially planned as 4.5 hours but reduced to four hours to allow for participants from Leeds and Coventry to travel to London and back on the same day. The planned content was ambitious including: a long introductory warm up; a vox pop video; five workstations to be visited by each group; and a final plenary session.

Box 6.2: Evidence on whether there was sufficient time for deliberative discussions

- Agendas for all three events were ambitious, particularly for workshop two and the Summit where the initial design envisaged all table groups looking at all family tree scenarios or workstations.
- The team was flexible in changing this after the London sessions (so that each table only considered one family tree) and during the summit (so that they only rotated to four rather than five workstations). Reducing the number of iterations for repeated exercises did not observably impact on the quality of the outcomes, but instead allowed more depth of discussion at each table and avoided risks of disengagement from repetitive tasks.
- Overall the 91 participants who completed questionnaires at workshop one reported that there was enough time to discuss the issues (with 50 (55%) strongly agreeing and 36 (40%) tending to agree). However, a small minority in London (three) were not sure and several commented that they "*could have done with more time*".
- Participants responding to questionnaires at workshop two (88) almost all agreed that the sessions were organised and worked well (68, 77% strongly agreed, 17, 19% tended to agree). Almost all participants at workshop two agreed that discussing the issues with their table group was very successful.
- In London a sizeable group (25%) were unsure or strongly disagreed that plenary sessions had played a useful component. After designs were tweaked to allow more time for wrap up plenary in both Coventry and Edinburgh, all participants reported finding these sessions useful.
- Workshop one participants unanimously agreed (74, 81%strongly agreed, 16, 18% tended to agree) that they were provided with enough, clear information on genomic medicine, health data and how the NHS services are delivered to enable them to contribute during workshop one.
- During workshop two there was unanimous agreement that the way information was shared was a successful element of the day: information shared by specialists was highly valued (70 (80%) thought it worked really well while eight (20%) thought it worked quite well. Information in other formats (e.g. PowerPoint, video and handouts) was also felt to have worked well with 48 (55%) strongly agreeing and 34 (39%) tending to agree.
- Specialists told us informally that, while participants seemed generally well enough informed, "*there were one or two misconceptions on data protection law*" that some were "u*naware of existing [data] sharing*" or "*did not understand the probabilistic nature of diagnosis*".

Summit

- Not all groups got through the extensive list of questions for summit workstations.
- Several specialists (those based at only one workstation) commented that questions "*were so specific that they risked losing the bigger picture discussion on the social contract"*
- We observed, however, that across the five topics and five groups all pertinent questions from the commissioners and OG members were covered and the findings were reflected in the final report.
- We also observed that cutting plenary sessions resulted in lost opportunities for both participants and specialists to hear what the whole room was thinking.
- All events finished on-time, but the final administrative tasks at the summit and larger events (London and Leeds) felt rushed and not all participants handed in an evaluation form.

Box 6.3: Evidence on effectiveness of techniques and appropriateness of information provided

Icebreakers

- The quiz (workshop one) worked well in providing participants a chance to work in smaller groups and proved a fun, but instructive, ice-breaker that put people at ease while demonstrating that most people had very little understanding of what health data is held about them, who has access to it and who it is shared with.
- The picture sort warm up activity at the summit also worked well to help people express their aspirations and concerns for genomics and data sharing.

Genomics England video on understanding genomics

- The video and three PowerPoint slides at workshop one on reading and interpreting a person's DNA, genetic testing and the importance of a large volume of genomic data were accessible to all participants and gave them enough initial understanding of genomics to form views on their aspirations and concerns about its future use in the NHS.
- In interviews with OG members a few questioned whether participants really needed this (quite limited) about of information in order to understand the issues. Our observation was that most participants felt excited to have learnt something new and - although they probably could have expressed views on data use and sharing with less background - most would have lacked the confidence to do so without this basic grounding.

Homework task

- Almost all participants we observed at workshop two events (London, Leeds, Edinburgh) completed the homework task and this seemed to have boosted their self-confidence in talking about the topics (having had to explain it to friends and family). Participants also appeared enthusiastic about the potential for genomic medicine, although it is worth noting that none of the redline issues (see *Section 3*) had appeared in the media at this point.
- Over 90% of participants who completed questionnaires at the end of workshop two (88) reported finding the homework useful: 43 (49%) strongly agreed while 37 (42%) tended to agree. Six individuals did not agree: these seemed to be mainly those who missed out on the homework.

Family trees

- Most participants found the scenarios engaging and helpful in understanding both how genomics might work in practice and in surfacing ethical issues and potential societal level harms (for instance about consent, privacy and confidentiality, counselling needs and use of data outside healthcare). They also demonstrated the importance of trust, based on a clear explanation of why and how data would be used and safeguarded.
- A few (older) participants told us informally that they found the more extreme scenarios unrealistic (e.g. fears of data being used by the police), but most seemed to find the families a useful exposure to different perspectives (e.g. of BME communities who had been identified in the REA and stakeholder discussions as more likely to be sceptical about genomics and their data being shared) and a way into talking about potential societal harms they might not have otherwise identified.

Washing line exercise

- A standing exercise after lunch at workshop two provided a change of pace and energy and a useful visual expression of sentiment about the future of genomics for all participants, specialists and the delivery team in the room. Information from this activity does not appear to have been collated or reported. More use of standing exercises during other workshops and events would have been helpful in keeping participants energised and engaged e.g. during the afternoon sessions at the summit.

Due to the large number of specific questions at each workstation, the rotations took longer than planned and the design was adapted to reduce rotations to four instead of five. In order to finish on time, the final plenary sessions were lost. We consider this meant that participants and experts did not have the chance to get a 'big picture' feel for where shared understanding or divergent views were emerging. This appears to have impacted on the perceptions of OG members and specialists

who attended the summit that Objective 5 (developing shared views) had only partially been met (see *Section 5*).

Cutting the final plenary also meant losing the opportunity for the commissioners to share their reflections on what they had heard and how they planned to use it. Fortunately, this does not appear to have reduced the participant's or OG member's confidence that Genomics England will use the results to help inform the roll out of the genomic medicine service (see *Section 7*).

6.2.3 Fair and balanced dialogue

The design and delivery of the dialogues made real attempts to involve the full range of views around genomic medicine and the use and storage of genomic data throughout the process. This included identifying diverse views and potential issues through the literature review, testing these at a stakeholder workshop and incorporating many different viewpoints in the stimulus materials developed. The Genomics England project manager put in a lot of time and energy to ensuring that participants in each location were able to engage with a balance of views and expertise including at least one clinician, researcher, ethicist and patient from the 100,000 Genome Project over the two days. Some were persuaded to participate by the suggestion of using the experience to demonstrate their involvement in public engagement for research grants. The facilitation team sent out detailed briefings on what was expected of specialists in advance and the Genomics England project manager talked to many by phone.

Specialists in the room were a really important factor in ensuring that participants in each location were able to access a range of different views over all three events. Local specialists were also able to describe the specific issues faced by local populations (such as the Pakistani community in Leeds and rural communities in Scotland). We observed that almost all specialists were happy to listen, were respectful of participant views and only contribute when asked. They did not dominate discussions.

The role played by 100,000 Genomes Project Participant Panel representatives was particularly appreciated by dialogue participants In some locations participant panel specialists felt they could have been better briefed, but their contributions gave dialogue participants real insights into the potential benefits of WGS, while also giving them a realistic understanding of the long timeframes involved in getting personal research results and for these to be translated into clinical treatments.

For the summit, the pool of specialists included OG members and individuals involved in the stakeholder workshop, including data specialists and a few industry representatives. Each specialist had a specific role: at least one was assigned to each of the five workstations and tasked with answering participants' questions; others were embedded in a participant group and rotated around the workstations with them; while commissioners floated between groups as observers. The specialist briefing for the summit only went out the day before, reflecting some uncertainty until the last minute about exactly who was attending and what role they would play. Nevertheless, all those who were expected to attend did so and played their designated roles.

Box 6.4: Evidence on whether the dialogues were fair and balanced and the role of specialists

Fair and balanced stimulus materials

- Almost all 91 participants who completed questionnaires across all four locations at workshop one felt that the information provided was fair and balanced (65 (71%) strongly agreed while 24 (28%) tended to agree). They also agreed that they could ask questions and get appropriate answers.
- By the end of workshop one there was very strong agreement amongst 87 (96%) of the 91 respondents that they had learnt something new about genomic medicine as a result of taking part. As one reported "*the presentation and facilitators helped my understanding of genomics so now I feel able to participate fully in the next event"*

Role of specialists:

- Most specialists reported that they had been well briefed and knew what was expected of them.
- Our observation was that specialists were able to work to this brief, treated participants with respect, were happy to answer questions and provide more information when prompted by the facilitators. Almost all were in learning and listening mode. We observed specialists explaining science in a very accessible way and providing useful analogies to explain difficult concepts.
- In Leeds eight specialists attended – this was too many in terms of the already large groups and also put a strain on the available time for other discussions. However, the facilitators were flexible in adapting to this challenge and the inclusion of local experts has also led to opportunities for follow on research (e.g. in attitudes of Pakistani men).
- Participant feedback from workshop one showed unanimous agreement amongst all 91 participants 83 (91%) strongly agreed while eight (9%) tended to agree, that they had found the specialists helpful in answering questions, with one noting that "*I liked the structure and rotation of specialists"* and that *"Experts were very informative".*

Role of 100,000 Genomes Project Participant Panel specialists:

- Participants informally reported finding the testimony of 100,000 Genomes Project participant panel representatives really powerful. Groups were generous in the amount of time they allowed them in discussions. In a few cases dialogue participants reported being unclear whether they were specialists or public participants like themselves. This could have been made clearer with badges and at small table introductions.
- Participant panel testimony exposed dialogue participants to very positive views about the potential benefits of WGS, but counter-balanced this by making clear the considerable uncertainty about when, or even if, research would translate to clinical results clear.
- Evaluation interviews suggested that participant panel specialists were not always clear whether they were there as experts on genomics, as advocates for the 100,000 Genomes Project or to provide personal testimony. Individual needs (such as large format text) were well met by the facilitation team. However, more time spent on individual briefing before the events would have been helpful, as this role largely fell to the OG member from the participants panel.

Specialists role at the summit

- Ideally, briefing before the summit would have been well in advance, since not all specialists had been involved before and they were expected to play very specific roles.
- Nevertheless, most specialists who completed feedback forms at the summit felt that specialists at workstations had been able to help make sure that participants' questions were answered and that specialists in small groups were able to contribute usefully to discussions.
- Participants at the summit really appreciated specialist's contribution: of the 16 respondents all agreed (13 strongly agreed, and three tended to agree) that having specialists at the workstations was helpful in getting questions answered, although one participation noted that "*there was less time to hear from them than on previous occasions*."
- In informal interviews at the summit many specialists underlined how important such dialogues were as a contribution to the wider debate. Those specialists who had not previously been involved in such events were favourably impressed by how public participants had been able to focus in on the key issues.

6.3 LESSONS

A highly experienced delivery team and commissioning body project manager ensured that the dialogue met all Sciencewise good practice standards, and most of them very well. The lessons learnt can be summarised as follows:

- **Scheduling**. Reconvening sessions with a two-week gap allowed those that wanted to do their own research to do so without losing momentum. Scheduling a mixed (participants and stakeholders) workshop on a Friday was successful in attracting a mix of participants of different work status (but may have been a contributing factor in low recruitment against quotas in Coventry). Almost all those invited were keen to attend. Scheduling on a workday also ensured that stakeholders and specialists were not required to give up more personal time and there was an impressive turn-out of OG members and specialists.
- **Timings**. It is important to be realistic about the outcomes needed from each event and what can comfortably be covered in a public dialogue session. The large number of questions identified in the ITT and within the OG meant there was a lot to cover and timings were tight for all events.
- **Group sizes.** Numbers are a trade-off between meaningful numbers across the sample and good deliberation. Comparing experiences across the four locations suggests that the ideal table size was about eight participants and one to two experts. However, this would require an extra group/facilitator which has knock-on effects on the budget.
- **Mix of techniques**. Projective techniques, such as the family tree scenarios, were effective at looking at practical and ethical issues associated with the immediate roll out of genomic medicine and potential longer-term societal harms. This included understanding the factors contributing to scepticism about genomic medicine and data sharing amongst specific groups. There would have been benefits in including a greater mix of standing and creative tasks and varying approaches for repetitive sessions (such as summit workstations) to change the pace and energy in the room.
- **Ensuring opportunities for large group deliberation**. It is important not to squeeze out opportunities for all participants to report back from small group discussions, hear each other's views, think about the big picture and reinforce the importance of the dialogue outcomes to decision-making processes. Cutting some planned plenary sessions meant losing opportunities to pause and hear the wider views in the room. This may have influenced OG member perceptions about whether one of the dialogue's objectives had been achieved.
- **Efforts in recruiting a large cast of specialists,** with attention to ensuring a mix of clinicians, ethicists, data experts and those with lived experience of Genomic Medicine really paid off. Experts can be persuaded to attend as a means of fulfilling the PE criterion on a research grant, and those that attended were enthusiastic about the use of public dialogue in their work. However, having more than two specialists per table makes it difficult for facilitators to manage the discussion and contributed to time pressures (e.g. in Leeds).
- **Individual briefing for specialists. More pre-briefing for the** 100,000 Genomes Project participants panel specialists would have been helpful to ensure they were confident in their role. With more advance notice, it would also have been helpful to pre-brief summit specialists on their individualised roles.

7 SATISFACTION AND IMPACT ON PARTICIPANTS

This section evaluates whether participants were satisfied with the dialogue process and the impact on them of taking part. The assessment is based on evaluation questionnaires from participants and specialist, informal discussion at events and formal interviews with OG members and decision makers. The findings are presented in the following sections:

- *Section 7.1* participant satisfaction;
- *Section 7.2* impact on participants;
- *Section 7.3* satisfaction of specialists and decision makers; and
- *Section 7.4* lessons learnt.

Participants were unanimous in their overall satisfaction with the process, reporting that it had been interesting, informative, enjoyable. Almost all felt they had learnt something new about genomic medicine, its potential for making a difference, and what they thought a social contract for genomic medicine service roll out should look like. Specialists, commissioners and specialists also reported being very satisfied with the quality of the process and the usefulness of its outputs.

7.1 PARTICIPANT SATISFACTION

As with any good dialogue process, participants were very enthusiastic about their overall experience and many made very positive comments about how much they had learnt and how much they had enjoyed taking part in workshops one and two (see *Figure 7.1*). Often repeated comments, as highlighted in the world cloud, were that the events were enjoyable, educational, enlightening and thought-provoking with a typical view being that "*I thoroughly enjoyed taking part and leave with the benefit of being informed about genomics*".

Figure 7.1: Word Cloud describing participant's views on taking part across four locations

Participants were not asked specifically if they would like to be involved in future dialogues with the commissioners but their responses to other questions suggest that many would have been happy to

do so, if asked. A handful of participants took the trouble to inform us that "*I would definitely like to get involved again"* or "*I would love to get involved*". In retrospect this opportunity for the commissioners and contractors to go back to an informed subset of participants on emergent issues would have been useful. For instance, Genomics England and Ipsos MORI plan some small focus group work to explore the concept of 'genomic volunteers' - a concept announced by the SoS for Health after the completion of the dialogues – and reconvening some participants with a prior understanding of genomics and data would have added value to this process.

Box 7.1: Satisfaction of participants with the process

- Positive group dynamics from the outset and the perception that they had learnt something new meant that there was unanimous agreement by the end of the first evening that participants had learned something new: 87 (96%) strongly agreed while two (2%) tended to agree.
- By the end of event two all 88 participants agreed (80, 91% strongly and 8, 9% tended to agree) that overall they had enjoyed taking part.
- This was echoed in almost unanimous agreement (76, (86%) strongly agreed and 11 (12%) tended to agree) that they were likely to get involved in these kinds of events in the future, if asked.
- The vast majority (76, 87% of the 88 who completed the questionnaire) were also happy to be re-contacted by the evaluator and 88% were also happy to have their anonymised data from the dialogues shared with the UK Data Archive.
- Several participants highlighted the personal journey they had been through, one reporting that "*I feel better about myself after taking part*" and another that "*I really enjoyed it. I gained confidence as it went ahead*".
- These views resonated with the comments people made in vox pop interviews which largely reflected on participant's positive experiences.
- The smaller group that took part in the summit all agreed (11 strongly, two tended to agree out of 16 respondents) that they were glad to have taken part, with a few describing the experience and the project as fantastic.
- If participant's permission had been sought to contact them again to continue working with Genomics England our observation is that many would have been happy to do so.

7.2 IMPACT ON PARTICIPANTS

Although it was not an explicit objective of the dialogue, taking part in the process clearly affected workshop participants. At the beginning of the process the vast majority of participants - 79 (90%), of the 88 who completed questionnaires - reported that they were neither aware of genomics, nor understood the relationship between research and clinical use of data or the existing role of the private sector in delivering NHS services or research. Only a handful (seven, 8%) reported knowing a fair amount, while only two felt they knew a lot about these issues. By the end of workshop two, there had been a dramatic reversal with about 90% of the 88 respondents to questionnaires now feeling they were better informed (see *Table 7.1* and *Box 7.2)*.

Table 7.1: Participation journey in understanding issues around genomics and data use

How much do you feel you know (by the end of event two) about?	I know a lot	I know a fair amount	I know very little	Total
How Genomic Medicine could be used in the NHS in the future?	30 (34%)	54 (61%)	4 (5%)	88
The possible benefits of using Genomic Medicine and sharing genetic data?	36 (41%)	49 (56%)	3 (3%)	88
The possible problems of using Genomic Medicine and sharing genetic data?	27 (31%)	52 (59%)	9 (10%)	88
What "the deal" should be for rolling out Genomic Medicine safely and securely for all?	24 (28%)	54 (61%)	10 (11%)	88

Box 7.2: Participant's learning journey

- By the end of workshop two, more than half of participants (55-60%) felt they knew a fair amount about the potential of genomic medicine, its possible benefits and problems, and what 'the deal' (the social contract) should be for rolling out genomic medicine safely and securely for all. More than a third (35-40%) felt they knew a lot about the first two areas, while a still sizeable group (27-30%) also felt they knew a lot about the possible problems and 'the deal' for genetic medicine roll out.
- We observed that those who had completed their homework task came back to workshop two with a greater understanding and enthusiasm (and often a very positive attitude) towards genomic medicine.
- By the end of workshop two, very few (four, 4% of 88) felt they still knew very little about how genomic medicine could be used in the NHS: only three (3%) knew little about the possible benefits of using genomic medicine and sharing genetic data. A slightly larger minority (10-12%) still felt they knew very little about the possible problems of genetic medicine and data sharing or what 'the deal' should be for rolling out genomic medicine safely and securely for all.
- The rough cut of the vox pop video shown at the summit gave a good flavour of participants' journeys to date and proved a useful reminder of the issues that had been discussed and the range of views in the room.
- Of the 16 summit participants who completed evaluation forms almost all agreed (10 strongly agreed, five tended to agree, one was unsure) that they now felt more aware of genomic medicine (via the news, social media, friends or NHS announcements). One participant reported that "*I felt informed and able to give my opinions*" while several others felt generally "*much more aware*" or that "*it has been on the news*[9] *and I have read more about this subject online and also discussed with friends*".
- Participants in the summit also unanimously agreed (10 strongly agreed, six tended to agree) that they felt well prepared to contribute to the days' discussions on their expectations and the values which should underlie the future of genomic medicine.
- Our observation was that participants seemed more confident of the value of their own opinions compared to previous sessions: a few remained quiet but, nevertheless, made valuable contributions.
- All the specialists who completed evaluation forms after the summit agreed that the public participants appeared well-enough informed to contribute to the days' discussions on a new social contract and most agreed that - even if they identified gaps in participant's knowledge on genomics and data - this did not seem to affect their ability to get to grips with the wider societal issues.
- At the end of the summit participants were asked how they would describe what they felt about the future of genomic medicine. Of the thirteen who answered the question, two reported feeling optimistic with no concerns; nine were optimistic with a few concerns; one was pessimistic with quite a few concerns; and one was pessimistic with many concerns.

7.3 SATISFACTION OF SPECIALISTS AND DECISION-MAKERS

The specialists who took part in workshops were also overwhelmingly satisfied with the events they attended. Many of those involved reported that they had some prior experience of public engagement but welcomed the chance to take part and hear what the public had to say. Several described the events as "*excellent*" or a *"great day".* Some of those interviewed informally at the workshops and the summit told us that taking part had helped to reinforce their understanding of how little knowledge of the science of genomics the public really needs in order to make a valuable contribution to the debate.

All specialists completing evaluation forms agreed about the usefulness of the summit: all agreed (nine strongly agreed, four tended to agree) that they were confident that the outcomes would be useful to Genomics England and the NHS in rolling out genomic medicine as one important part of the evidence for decision making. One interviewee stressed that the dialogue was "*very important - but [as one element] contributing to the broader debate*". Another interviewee noted that the

[9] This pre-dated the SoS announcement that healthy patients may be able to pay for whole genome sequencing through the NHS.

process itself was not particularly novel, but that it had not needed to be in order to deliver novel content. All those completing questionnaires agreed that they were convinced of the value of getting involved with public dialogues in the future (11 strongly agreed, two tended to agree).

Box 7.3 summarises the very high levels of satisfaction expressed by the commissioners and OG members interviewed with the overall public dialogue process.

Box 7.3: Views of commissioners and the OG on the overall quality of the process

- *"In general, it's been very good and it's an important body of work".*
- *"I think this was a well organised public dialogue - open to advice and communication".*
- *"Think the overall process worked really well …. I feel very positive about the whole thing".*
- *"A very positive and well-run dialogue which adds to what has been done".*
- *"Really enjoyed it, maybe not particularly novel in terms of process but really interesting in terms of substance"*

7.4 LESSONS

A well-run process in an area that the public is generally interested in (healthcare) meant that most participants enjoyed taking part and felt they had learnt something new and useful. The following lessons emerged:

- This processed reinforced practitioner understanding of how little knowledge of the science of genomics the public really needs in order to make a valuable contribution to the debate.
- However, participants may not have been happy with much less background information on the topics: learning something new was part of their enjoyment of the process and gave them confidence to contribute their views.
- Involving a large pool of specialists can help to create a pool of enthusiastic advocates for public dialogue approaches.
- A sense that Genomics England was fully committed to the process and would use the results to inform the roll out of genomic medicine was shared by both participants and specialists.
- In future Sciencewise dialogues it would be useful to consider whether it is worthwhile to include permissions to recontact willing participants for further research. In this case it would have allowed the commissioners and contractors to carry out follow on research on an emergent issue and compared attitudes of those new to the topic with those of informed members of the public.

8 COSTS AND BENEFITS OF THE DIALOGUE

This section provides a high-level assessment of the balance of overall costs and benefits of the dialogue process. The assessment is based on evaluation interviews with the commissioners, the contractors and OG members about the total financial and in-kind costs of the project and whether the resources were adequate to deliver a quality process. The findings are organised as follows:

- *Section 8.1* describes the financial and in-kind costs of the project and value for money;
- *Section 8.2* describes the potential economic benefits of the process; and
- *Section 8.3* summarises lessons learnt.

A contractor experienced in both delivering large, complex qualitative research processes and in the topic area allowed this large public dialogue (nearly 100 public participants) to be delivered to a high standard on time and within budget. Additional value added was provided through the contractor's flexibility in adding an extra location at marginal cost (and additional 10%), and significant in-kind contributions of senior time by Genomics England, OG members and other stakeholders (as specialists at workshops and the summit) equivalent to 50% over and above the financial budget. Some flexibility in the design also allowed an underspend in one area (under-recruitment in Coventry) to be reallocated to other policy briefings, dissemination events and increasing participant number in another location.

It is too early to quantify the potential economic impacts of the dialogue process, but early indications are that they could be considerable. For instance in the short term a better understanding of the wider publics' views and redlines and a clear communication strategy which stresses the benefits of wider involvement and how people's data will be protected could help to avoid the wasted investment in previous failed big data collection projects such as care.data. In the longer term the dialogue may also contribute to helping reduce NHS costs. Potential examples include: better tailored treatments; a focus on prevention by the potential patients; access to cheaper pharmaceuticals or revenues earned from commercial businesses with which anonymised data is shared. There will also be large scale opportunities from the successful roll out of genomic medicine for other UK businesses including Artificial Intelligence (AI), genomic diagnostics, big data storage and pharmaceuticals etc.

8.1 COSTS

8.1.1 Financial costs

The initial financial budget for the project was £160,000 to cover the public dialogue process and the independent evaluation. Sciencewise contributed £97,500 and Genomics England £62,500. Both organisations also provided contributions in-kind to cover staff costs (see below). The initial contract included the literature review, stakeholder workshop, six public workshops (recruitment, incentive payments, venues, food and facilitator team travel and subsistence) for up to 90 participants for reconvened workshops in three English locations. It also included provision for contractor fees and expenses for up to five dissemination events. At the request of the Scotland Genome Partnership the budget was extended by £14,500 (split equally between Sciencewise and Genomics England) to cover an evening and reconvened full day workshop for 15 participants in Scotland. Some resources from under-recruitment in Coventry were reallocated towards dissemination events. The total financial cost was £174,000.

The contractors managed to deliver all the required elements to a high standard within the agreed budget through a combination of: a large team of facilitators of mixed seniority and locally recruited note-takers; being very flexible; and investing some senior time over and above the agreed budget. For instance, the complexity and elapsed time for the project meant that significant senior staff time was needed for framing the dialogues, analysing findings, briefing OG members and senior policymakers, regular progress meetings and final reporting. The investment of senior time in weekly reporting and final drafting were probably not fully covered in the financial budget but were key elements in the success of the project.

At the wash up meeting with commissioners and contractors, Ipsos MORI noted that Sciencewise projects increasingly have expectations of a high-level reconvened summit or launch event and very high-quality reports, but that the time involved in fulfilling these expectations is not yet fully reflected in the budgets allocated or such dialogues.

8.1.2 In-Kind contributions

Contributions in kind were a key factor in the success of this dialogue. As part of its contribution to the project, Genomics England agreed to invest £35,000 in project management and supervision time and expenses. This adequately covered the 0.4 FTE input of the project manager's time, but probably did not fully cover other senior staff time spent as part of the OG or launching the final report. In addition, Sciencewise contributed the time and associated expenses of a Dialogue and Engagement Specialist (DES) and Lead Evaluator.

In-kind contributions were also made by:

- **OG members – an estimated 50 person days**. Two thirds of OG members attended three out of four. Several attended by telephone or took the opportunity to be briefed separately by telephone by the project manager, chair or Ipsos MORI. About a dozen members contributed at least 3 days each in attending OG meetings, reviewing stimulus materials and the final report and attending either a dialogue workshop or the summit. A few members spent much more time (more than five days each) while ten attended the final launch. Two OG members were part of the launch, reflecting on the findings and process on stage. Only one OG member received an honorarium, but this did not fully cover the opportunity cost of time spent. All the OG members interviewed reported that the time they had put in was commensurate with the benefits of the project, and that they had been happy to have participated. A few reported that they would even have been happy to put in more time.
- **Other specialists – an estimated 50 days**. Stakeholders (19) contributed at least half a day in attending the stakeholder workshop while 25 specialists invested about 40 days in attending Days 1 and 2 and the summit.

A very rough valuation of in-kind inputs, based on an average opportunity cost of £500 per person day, for some 100 days of specialist input implies an additional cost of £50,000 in specialist and stakeholder time. When added to the Genomics England in-kind contribution, this is equivalent to almost 50% over and above the financial costs of the project.

Given the wide scope, the extent of in-kind contributions, and widespread satisfaction with the process we consider that this dialogue has provided good value for money. This view is shared by the commissioners: "*Absolutely value for money – we know there were companies that could have done it cheaper but no one else had the experience".*

8.2 POTENTIAL BENEFITS

As described in *Section 3* the findings from this dialogue will be one input into decisions about how to roll out and communicate about the genomic medicine service in a way that is seen as trustworthy, transparent and does not over-hype the benefits. At this early stage it is difficult to quantify the potential benefits.

However, the understanding gained of 'potential patient' views on genome data will potentially help NHS England design its communications programmes before pursuing the Secretary of State's announced targets for genome sequencing and genetic testing and data sharing.

Genomics England senior management, the CMO and NHS CSO were very pleased with the quality of the dialogue and have also expressed a willingness to take on board participants' views. The dialogue report will form part of evidence submitted by Genomics England to the Minister at the Office of Life Sciences. The NHS Chief Scientific Officer has signalled that it will be an important part of the evidence on the roll out of the genetic medicine service. The final report made suggestions on the tone of any communications strategy for roll out, and how it will need to emphasise the benefits for society as a whole of UK and international clinicians and researchers having access to a large data set which most people choose to opt into. It will also need to stress the almost unique situation in the UK, where this data set can be collected through the NHS. The communications strategy will also need to be transparent about potential concerns about data use, holding and sharing and how this data will be kept private, safe and secure.

If the insights from the dialogues are taken onboard and reflected in the NHS's roll out strategy, capturing the public imagination and encouraging a high opt in rate, then at the very least this could help to avoid the communications mistakes and lost investment of the care.data exercise. When care.data was suspended in 2016, various sources[10] reported that the lack of prior understanding of the public's views on data sharing and poor communication about the benefits and potential concerns had led to lost investment of £7.5-7.7 Mn in sunk costs between 2013 and 2016. These costs related to constructing a database, printing and distributing leaflets and setting up a patient information helpline before the scheme was scrapped in 2016. While not all of these costs will have been wasted, the reported £1 Mn spent on ineffective communications certainly was. Avoiding such losses on communications alone could amount to five times the financial cost of the dialogue process.

In the longer term a genomics medicine service, which people trust to use their data, and which most are happy to opt in to, has the potential to inform and improve healthcare and to deliver economic benefits for the UK in the following ways:

- **Potential savings in the costs of treatment to the NHS** – more individualised medicine for cancers is expected to help provide savings (by eliminating the use of ineffective treatments) for the NHS. Likewise, predictive panel tests for common conditions could help individuals and their families to change their lifestyles and help reduce spending on common preventable conditions.
- **Research and treatments of rare conditions costs** could increase in the short-term but finding cures for acute and complex conditions would in the long term save lives and could help reduce treatment costs for some heavy users of NHS services.

[10] Telegraph online, 7 July 2016; www.theregister.co.uk, 27 Sep 2016

- **Capturing value from sharing a large genomic data set with commercial users**, with the public's consent, could also bring the NHS economic benefits in the form of fees for data use or access to cheaper treatments developed by big pharma on the back of these datasets.

Finally, the UK Government has identified genomics and biomedical sciences more broadly, as a major growth opportunity for the UK economy. A 2015 study estimated the UK commercial market surrounding human genome sequencing alone[11] at £0.8 billion. This estimate does not include the potential economic opportunities for big tech and data businesses in AI, data storage etc.

8.3 LESSONS

This large and complex study provided in-depth dialogue with nearly 100 participants. Additional numbers in Scotland were added at relatively low marginal cost. The process has generated the following lessons:

- Contractor flexibility in delivering a larger-than-planned summit and launch, and Genomics England's success in leveraging a large steering group, and specialist inputs and additional senior time invested by the contractors in analysis and high-quality reporting mean that the dialogue has offered very good value for money. Future Sciencewise projects may need to allocate more budget to meet increasing expectations of high-profile summits and launches and the number of iterations and analysis time required to produce top quality reports.
- It is too early to quantify the financial benefits of the study and how far changes to policy making might be attributed to the dialogue. However, project characteristics such as the seniority and diversity of the OG and the range and number of specialists and stakeholders involved provide a sound platform for policy impacts. In addition, the benefits simply in terms of avoiding the perceived communications mistakes of previous health data use and sharing programmes could be considerable.
- In the future it may be useful for commissioners to consider whether there would be value added from re-contacting a smaller group of informed participants to explore emergent issues or gaps identified in the research. This would require seeking permissions compliant with the General Data Protection Regulation (GDPR) during the recruitment process or through evaluation forms.

[11] Deloitte Monitor, 2015, Genomics in the UK: An industry study for the Office of Life Sciences, B(E)IS

9 OVERALL FINDINGS AND LESSONS LEARNT

9.1 CONCLUSIONS

An experienced contractor, Oversight Group (OG) and Genomics England project manager with experience of delivering public dialogues and in-depth knowledge of the issues allowed delivery of a large (nearly 100 public participants), complex, public dialogue, to a high standard on time and within budget, offering good value for money. The contractors were flexible in adding a Scottish location at the last minute, and reallocating resources from an underspend in one location to a larger than planned summit. Flexibility designed into the project also allowed a larger launch event and a handful of individual dissemination events to be carried out as opportunities arose.

The process itself was not novel, but it produced very useful findings presented in a novel way. The commissioners and a wide range of other organisations involved in the governance and delivery of the process ensured that the design of the process was robust and that the findings were considered credible. As a result, six out of eight dialogue objectives were fully met, and two others, seen as less important by the commissioners, were partially met.

The process and results were timely in coinciding with the completion of the 100,000 Genomes Project and will help inform the roll out of the genetic medicine service in the NHS and Genomics England's advice to policy makers. The quality of the report and the usefulness of its findings were praised by the Chief Medical Officer (CMO) and the NHS Chief Scientific Officer (CSO) for England.

The presentation of the final report around three key principles of reciprocity, solidarity and altruism was seen by the commissioners, OG members and CMO as a major advance in exploring the underlying relationships between principles and the roles of different actors – and how these will change with genomic medicine. A recommendation to inscribe these insights into the underlying principles of the NHS constitution when it comes up for review was also well received by the commissioners and strongly endorsed by the Chief Medical Officer.

A large, senior and engaged OG played a significant role in framing the dialogue questions and design. All the OG members that we interviewed identified ways in which they now expect to use the insights gained. These include building findings into policy making, informing practice (clinicians, researchers and counsellors) and shaping further research. Almost all members of the public involved participated very actively in discussions and all felt they had made a valuable contribution and that their voices had been heard. Without exception, participants and specialists who took part reported that they enjoyed the process and saw value in being involved. The process has helped create a pool of clinicians and researchers who are enthusiastic about the role of public dialogue in this area.

9.2 LESSONS FOR FUTURE DIALOGUES

Lessons learnt from the design and delivery for future dialogues included the following:

- **The buy-in of senior management and a large OG**, representative of a diverse range of stakeholders and viewpoints, were critical in maximising the impact of the dialogue. Time spent by the Project Manager in managing the diverse OG paid off in the valuable contribution they made in framing the process and polishing the outputs.
- **On-street recruitment against demanding recruitment quotas worked well for large cities** but was a challenge for smaller ones where the actual recruitment was low against quotas. Smaller

groups in some areas did not adversely affect the quality of the dialogue. Numbers are a trade-off between meaningful numbers across the sample and group sizes which allow good deliberation.

- **Group sizes.** Comparing experiences across the four locations suggests that the ideal table size was about eight participants supported by one or two experts. However, this would require an extra group/facilitator which would have implications for project budgets.
- **Reconvening dialogue workshops with a two-week gap** worked well to maintain momentum while allowing those that wished to do their own research between sessions.
- **Scheduling of the summit on a weekday** did not prevent a suitably diverse and inclusive group of participants from all three English locations from attending (all had been asked to keep this date open). Almost all those invited to attend were willing to do so reflecting the fact that they knew what they were in for and that they would enjoy it. Scheduling the summit on a weekday also made it easier to get a good turnout of stakeholders, specialists and OG members.
- **Information provision**. This process reinforced practitioner understanding of how little knowledge of the science of genomics the public really needs in order to make a valuable contribution to the debate. A greater mix of group sizes and technique styles, including standing and creative tasks and varying approaches for repetitive sessions (such as summit workstations) could have helped to change pace and maintain energy in afternoon sessions.
- **Projective techniques helped to stimulate deliberation**. Three family tree scenarios were effective at looking at practical and ethical issues associated with the immediate roll out of genomic medicine and helping to stimulate discussion of potential longer-term societal harms and views of more sceptical groups which would otherwise have been difficult to surface.
- **A large cast of specialists and stakeholders across a mix of disciplines and including those with lived experience** of genomic medicine really contributed to the quality of the dialogues. Specialist inputs played an important role in ensuring a fair and balanced dialogue, but the lead time and effort in recruiting the right mix can easily be underestimated. Core teams need to identify roles and start this process as early as possible in the process.
- **Division of responsibilities between commissioner and contractors**. The project manager should recruit OG members and specialists using their established networks. Once recruited, the day to day management and briefing should be delegated to contractors, who should be kept systematically updated on contact details.
- **Responsiveness to the individual needs of less experienced stakeholders**. Where dialogues seek to involve patient representatives as OG members or specialists then it is important to provide one to one briefing and support to ensure they feel fully briefed and confident in their roles.
- **Building in possibilities for re-engaging with participants**. Commissioning bodies should consider whether there are likely to be opportunities to add value by re-engaging with a group of informed participants to explore emergent issues or gaps identified in the research. This would require seeking permissions compliant with GDPR during the recruitment process or through evaluation forms.

Annex A: Members of the Oversight Group

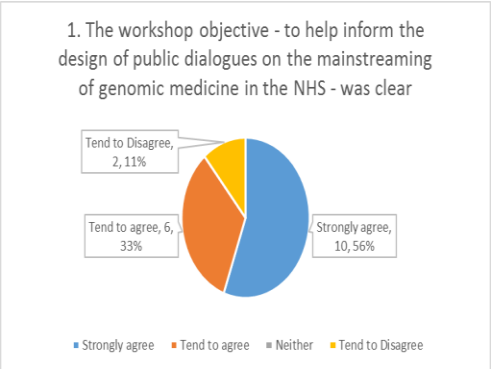
(*took part in post-dissemination evaluation interviews)

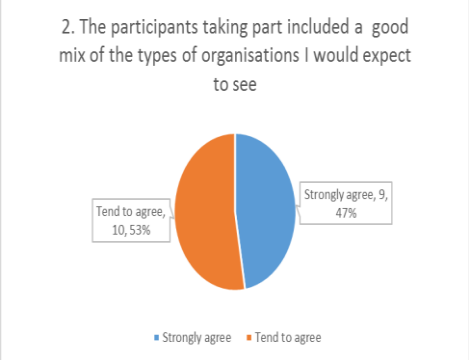
	Name	Role	Organisation
1	Vivienne Parry*	Head of Engagement	Genomics England
2	Simon Wilde*	Communications Manager	Genomics England
3	Professor Anna Middleton*	Head of Society and Ethics Research Group	Faculty of Education, University of Cambridge / Wellcome Genome Campus
4	Professor Michael Parker*	Director	Wellcome Centre For Ethics and Humanities, University of Oxford
5	Professor Jonathan Montgomery	Professor of Health Care Law	UCL Faculty of Laws, University College London
6	Professor Anneke Lucassen	Consultant in Clinical Genetics	University of Southampton
7	Professor Tim Hubbard	Professor of Bioinformatics, Head of Genome Analysis	King's College London, Genomics England
8	Dr Mark Bale*	Deputy Head of Health Science and Bioethics	Department of Health
9	Ellen Graham	Deputy Director – Genomics, Specialised Commissioning	NHS England
10	Dr Richard Scott	Consultant in Clinical Genetics, Head of Rare Disease Programme	Great Ormond Street Hospital, Genomics England
11	Nick Hillier	Director of Communications	Academy of Medical Sciences
12	Jayne Spink*	Chief Executive	Genetic Alliance
13	Dr Natalie Banner	Lead	Understanding Patient Data
14	Michael Dunn	Head of Genetics and Molecular Science	Wellcome Trust
15	Rebecca Middleton*	100,000 Genomes Project Participant	Genomics England Participants Panel
16	Phil Booth*	Coordinator	Medconfidential
17	Pete Mills*	Assistant Director	Nuffield Council on Bioethics
18	Aileen Thompson	Executive Director, Communications	ABPI
19	Sarah Norcross	Director	Progress Educational Trust

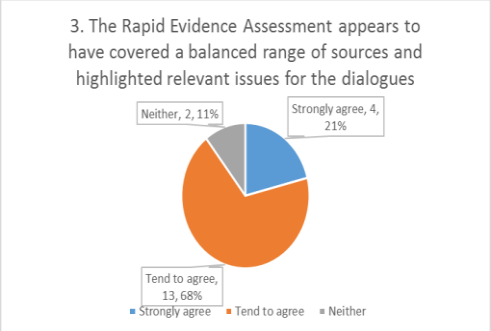
Annex B: Phase 1 evaluation feedback: Stakeholder workshop

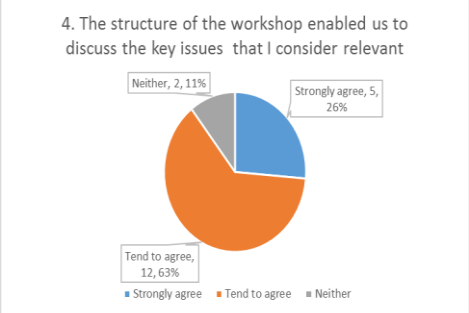
1. **Objectives** - 89% agreed (56% strongly agreed, 33% tended to agree) that the workshop objective - to help inform the design of a public dialogue on the mainstreaming of genomic medicine in the NHS - was clear.
2. **Mix of stakeholders represented** – there was unanimous agreement (47% strongly agreed, 53% tended to agree) that there was a good mix of the types of participants they would expect to see, one noting that the audience was *"even more varied than I expected",* although others pointed out that *"maybe not enough from patients"* and that it *"would be good to have participation from NHSE/NHSD".* We observed a good coverage of government departments and regulators, research funders (charity and government), institutes and academic research groups, open data/data privacy NGOs and small private research/health care companies. The sentiment in the room seemed generally very positive towards genomic medicine: although there was a lot of discussion about the potential risks as well as opportunities there were only a few voices in the room coming from a questioning perspective. This will be addressed by a few additional stakeholder telephone interviews with organisations such as Open Privacy Group.
3. **Rapid Evidence Assessment** - Although the REA was not tabled beforehand or presented in detail 89% agreed (21% strongly agreed, 68% tended to agree) that it had appeared to have covered a balanced range of sources and highlighted relevant issues. One participant noted that **"***I didn't get a sense of what it had covered*" and another that *"no info given re: sources".* Many stakeholders expressed an interest in seeing a copy of the final REA when it is published and expected it to provide a useful overview of the issues.
4. **Structure** – the majority agreed **(**26% strongly agreed, 62% tended to agree) that the structure worked wel**l.** The whole session was run in plenary by the lead facilitator. Given higher than expected numbers there was an option to split the group into two smaller tables for the afternoon session but in the interests of transparency and logistics (minimising disruption in rearranging the room) the decision was made to remain in plenary. One stakeholder felt the discussions *"Got a bit side-tracked by make-up of polling groups"* while another noted that *"smaller groups may have been useful to collect more views in the time given".*
5. **Timing** – Given the number of participants and the lively discussion the three-hour session, including a working lunch, seemed rather short. About a third of stakeholders tended to disagree (32%) or were unsure (2%) that there was enough time with individual commenting that there was *"limited time" "...never enough time"* that they *"could have done with a little more"* or *"longer would have been helpful - felt a bit rushed"* and that *"we ran out of time on the last discussion".* One commented that "*There were areas I could have commented on that were skipped over due to time* "and another that *"I think a full day might have been useful".*
6. **Facilitation** – There was unanimous agreement (79% strongly agreed, 21% tended to agree) that the facilitation was independent, effective and professional.
7. **Overall usefulness of the workshop** – there was overwhelming agreement (42% strongly agreed, 53% tended to agree) that the workshop will have helped shape the public dialogue and identify useful sources of material. However, one stakeholder felt that *"too much time was spent on earlier points rather than key questions to be answered"* while another commented that *"I think we got to all the issues, but less [on] to useful materials".* A few stakeholders made specific additional comments on issues they would like to see considered including:
    - "*Opportunities to link up messages or use of health data - lots of national initiatives, it would be good to have a consistent narrative*"

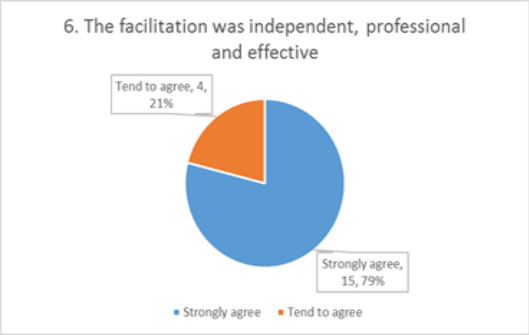
- "*Public data should touch on security - less taken for granted than in the past. See Caldicott3 for security standards and recommend the NHS working to/towards them*"

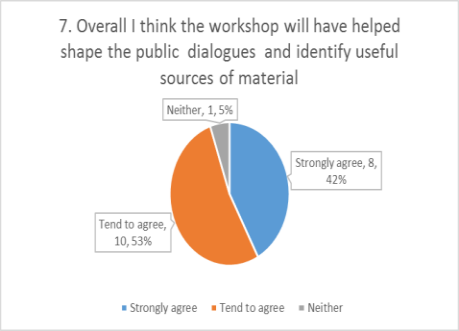












Annex C: Participant Feedback for the dialogue events

1. The recruitment process and advance details for the event were well-handled	Strongly agree	Tend to agree	Neither	Tend to Disagree	Strongly Disagree	N/A or not sure	Total
London	18	11					29
Leeds	24	3					27
Coventry	14	5					19
Edinburgh	13	3					16
Total	69	22	0	0	0	0	91
Percentage	75.8	24.2	0.0	0.0	0.0	0.0	100.0
2. I am aware of and understand the purpose of the workshops	**Strongly agree**	**Tend to agree**	**Neither**	**Tend to Disagree**	**Strongly Disagree**	**N/A or not sure**	**Total**
London	20	7	1	1			29
Leeds	22	4	1				27
Coventry	16	3					19
Edinburgh	13	3					16
Total	71	17	2	1	0	0	91
Percentage	78.0	18.7	2.2	1.1	0.0	0.0	100.0
3. I was provided with enough, clear information on genomic medicine, health data and how the NHS services are delivered to enable me to contribute to the discussions	**Strongly agree**	**Tend to agree**	**Neither**	**Tend to Disagree**	**Strongly Disagree**	**N/A or not sure**	**Total**
London	21	8					29
Leeds	23	4					27
Coventry	14	4		1			19
Edinburgh	16						16
Total	74	16	0	1	0	0	91
Percentage	81.3	17.6	0.0	1.1	0.0	0.0	100.0
4. I felt that the information provided was fair and balanced	**Strongly agree**	**Tend to agree**	**Neither**	**Tend to Disagree**	**Strongly Disagree**	**N/A or not sure**	**Total**
London	19	10					29
Leeds	20	6	1				27
Coventry	14	5					19
Edinburgh	12	4					16
Total	65	25	1	0	0	0	91
Percentage	71.4	27.5	1.1	0.0	0.0	0.0	100.0
5. I could ask questions easily and get appropriate answers	**Strongly agree**	**Tend to agree**	**Neither**	**Tend to Disagree**	**Strongly Disagree**	**N/A or not sure**	**Total**

London	15	13		1			29
Leeds	25	2					27
Coventry	18	1					19
Edinburgh	15	1					16
Total	73	17	0	1	0	0	91
Percentage	80	19	0	1	0	0	100
6. I found the specialists helpful in answering questions	**Strongly agree**	**Tend to agree**	**Neither**	**Tend to Disagree**	**Strongly Disagree**	**N/A or not sure**	**Total**
London	23	6					29
Leeds	26	1					27
Coventry	18	1					19
Edinburgh	16						16
Total	83	8	0	0	0	0	91
Percentage	91	9	0	0	0	0	100
7. I had enough time to discuss the issues	**Strongly agree**	**Tend to agree**	**Neither**	**Tend to Disagree**	**Strongly Disagree**	**N/A or not sure**	**Total**
London	15	11	3				29
Leeds	21	6					27
Coventry	9	9	1				19
Edinburgh	5	10		1			16
Total	50	36	4	1	0	0	91
Percentage	54.9	39.6	4.4	1.1	0.0	0.0	100
8. I was able to contribute my views and have my say	**Strongly agree**	**Tend to agree**	**Neither**	**Tend to Disagree**	**Strongly Disagree**	**N/A or not sure**	**Total**
London	18	11					29
Leeds	23	4					27
Coventry	16	3					19
Edinburgh	13	3					16
Total	70	21	0	0	0	0	91
Percentage	76.9	23.1	0.0	0.0	0.0	0.0	100
9. I learned something new about genomic medicine as a result of taking part today	**Strongly agree**	**Tend to agree**	**Neither**	**Tend to Disagree**	**Strongly Disagree**	**no comment**	**Total**
London	27	2					29
Leeds	25					2	27
Coventry	19						19
Edinburgh	16						16
Total	87	2	0	0	0	2	91
Percentage	95.6	2.2	0.0	0.0	0.0	2.2	100
event two: Full day Saturday Public Dialogue events: 88 participants completed questionnaires							

1. How successful do you feel different aspects of the events have been?	Worked really well	worked quite well	neither	didn't work that well	didn't work at all well	N/A or not sure	Total
London							
Amount and type of Information available							
• **Information shared by specialists**	20	7					27
• **Information presented in other ways (e.g. PowerPoints, videos, handouts)**	15	11	1				27
• **Information I collected myself (through the homework task)**	11	12	1		1	2	27
Discussing the issues							
• **Talking about the issues with friends and family**	12	13	1			2	28
• **Discussing the issues with my table**	21	6					27
• **Opportunities to discuss issues as a larger group**	12	8	5			2	27
Structure and Organisation							
• **Amount of time available**	18	7	2				27
• **How the sessions were organised**	23	3	1				27
1. Leeds	**Worked really well**	**worked quite well**	**neither**	**didn't work that well**	**didn't work at all well**	**N/A or not sure**	**Total**
Amount and type of Information available							
• **Information shared by specialists**	20	8					28
• **Information presented in other ways (e.g. PowerPoints, videos, handouts)**	15	11	2				28
• **Information I collected myself (through the homework task)**	15	11	1			1	28
Discussing the issues							
• **Talking about the issues with friends and family**	18	8	1			1	28
• **Discussing the issues with my table**	21	7					28
• **Opportunities to discuss issues as a larger group**	19	7	2				28
Structure and Organisation							
• **Amount of time available**	18	9	0	1			28
• **How the sessions were organised**	20	6	2				28

1. Coventry	Worked really well	worked quite well	neither	didn't work that well	didn't work at all well	N/A or not sure	Total
Amount and type of Information available							
• Information shared by specialists	16	2					18
• Information presented in other ways (e.g. PowerPoints, videos, handouts)	10	5	2	1			18
• Information I collected myself (through the homework task)	7	10				1	18
Discussing the issues							
• Talking about the issues with friends and family	11	7					18
• Discussing the issues with my table	15	3					18
• Opportunities to discuss issues as a larger group	15	3					18
Structure and Organisation							
• Amount of time available	12	6					18
• How the sessions were organised	13	5					18

1. Edinburgh	Worked really well	worked quite well	neither	didn't work that well	didn't work at all well	N/A or not sure	Total
Amount and type of Information available							
• Information shared by specialists	14	1					15
• Information presented in other ways (e.g. PowerPoints, videos, handouts)	8	7					15
• Information I collected myself (through the homework task)	10	4				1	15
Discussing the issues							
• Talking about the issues with friends and family	9	6					15
• Discussing the issues with my table	14	1					15
• Opportunities to discuss issues as a larger group	13	2					15
Structure and Organisation							
• Amount of time available	13	1		1			15
• How the sessions were organised	12	3					15

1. TOTAL	Worked really well	worked quite well	neither	didn't work that well	didn't work at all well	N/A or not sure	Total
Amount and type of Information available							
• **Information shared by specialists**	70	18	0	0	0	0	88
• **Information presented in other ways (e.g. PowerPoints, videos, handouts)**	48	34	5	1	0	0	88
• **Information I collected myself (through the homework task)**	43	37	2	0	1	5	88
Discussing the issues							
• **Talking about the issues with friends and family**	50	34	2	0	0	2	88
• **Discussing the issues with my table**	71	17	0	0	0	0	88
• **Opportunities to discuss issues as a larger group**	59	20	7	0	0	2	88
Structure and Organisation							
• **Amount of time available**	61	23	2	2	0	0	88
• **How the sessions were organised**	68	17	3	0	0	0	88

1. Total Percentages	Worked really well	worked quite well	neither	didn't work that well	didn't work at all well	N/A or not sure	
Amount and type of Information available							
• **Information shared by specialists**	79.5	20.5	0.0	0.0	0.0	0.0	100.0
• **Information presented in other ways (e.g. PowerPoints, videos, handouts)**	54.5	38.6	5.7	1.1	0.0	0.0	100.0
• **Information I collected myself (through the homework task)**	48.9	42.0	2.3	0.0	1.1	5.7	100.0
Discussing the issues							
• **Talking about the issues with friends and family**	56.8	38.6	2.3	0.0	0.0	2.3	100.0
• **Discussing the issues with my table**	80.7	19.3	0.0	0.0	0.0	0.0	100.0
• **Opportunities to discuss issues as a larger group**	67.0	22.7	8.0	0.0	0.0	2.3	100.0
Structure and Organisation							
• **Amount of time available**	69.3	26.1	2.3	2.3	0.0	0.0	100.0
• **How the sessions were organised**	77.3	19.3	3.4	0.0	0.0	0.0	100.0

2. The facilitation has been independent, professional and effective	Strongly agree	Tend to agree	Neither	Tend to Disagree	Strongly Disagree	N/A or not sure	Total
London	23	3	1				27
Leeds	19	9					28
Coventry	16	2					18

Edinburgh	13	2					15
Total	71	16	1	0	0	0	88
Percentage	80.7	18.2	1.1	0.0	0.0	0.0	100.0
3. All participants were treated equally and respectfully	**Strongly agree**	**Tend to agree**	**Neither**	**Tend to Disagree**	**Strongly Disagree**	**N/A or not sure**	**Total**
London	23	4					27
Leeds	24	4					28
Coventry	15	3					18
Edinburgh	15	0					15
Total	77	11	0	0	0	0	88
Percentage	87.5	12.5	0	0	0	0	100
4. How much do you feel you knew about genomic medicine before these events?	**I Knew a lot**	**I knew a fair amount**	**I knew very little**	**Total**			
London	0	0	27	27			
Leeds	1	5	22	28			
Coventry	1	2	15	18			
Edinburgh	0	0	15	15			
Total	2	7	79	88			
Percentage	2.27	7.95	89.77	100.0			
London							
5. How much do you feel you now know about the following?	**I Knew a lot**	**I knew a fair amount**	**I knew very little**	**Total**			
• **How genomic medicine could be used in the NHS in the future?**	11	16	0	27			
• **The possible benefits of using genomic medicine and sharing our genomic data?**	10	16	1	27			
• **The possible problems of using genomic medicine and sharing our genomic data?**	7	18	2	27			
• **What the deal should be for rolling out genomics medicine safely and securely for all?**	7	16	4	27			
Leeds							
5. How much do you feel you now know about the following?	**I Knew a lot**	**I knew a fair amount**	**I knew very little**	**Total**			
• **How genomic medicine could be used in the NHS in the future?**	9	17	2	28			
• **The possible benefits of using genomic medicine and sharing our genomic data?**	9	18	1	28			
• **The possible problems of using genomic medicine and sharing our genomic data?**	10	16	2	28			
• **What the deal should be for rolling out genomics medicine safely and securely for all?**	9	17	2	28			

Coventry 5. How much do you feel you now know about the following?	I Knew a lot	I knew a fair amount	I knew very little	Total
• How genomic medicine could be used in the NHS in the future?	6	12	0	18
• The possible benefits of using genomic medicine and sharing our genomic data?	11	7	0	18
• The possible problems of using genomic medicine and sharing our genomic data?	6	9	3	18
• What the deal should be for rolling out genomics medicine safely and securely for all?	5	12	1	18
Edinburgh **5. How much do you feel you now know about the following?**	**I Knew a lot**	**I knew a fair amount**	**I knew very little**	**Total**
• How genomic medicine could be used in the NHS in the future?	4	9	2	15
• The possible benefits of using genomic medicine and sharing our genomic data?	6	8	1	15
• The possible problems of using genomic medicine and sharing our genomic data?	4	9	2	15
• What the deal should be for rolling out genomics medicine safely and securely for all?	3	9	3	15
Total **5. How much do you feel you now know about the following?**	**I Knew a lot**	**I knew a fair amount**	**I knew very little**	**Total**
• How genomic medicine could be used in the NHS in the future?	30	54	4	88
• The possible benefits of using genomic medicine and sharing our genomic data?	36	49	3	88
• The possible problems of using genomic medicine and sharing our genomic data?	27	52	9	88
• What the deal should be for rolling out genomics medicine safely and securely for all?	24	54	10	88
Total Percentage **5. How much do you feel you now know about the following?**	**I Knew a lot**	**I knew a fair amount**	**I knew very little**	**Total**
• How genomic medicine could be used in the NHS in the future?	34.1	61.4	4.5	100
• The possible benefits of using genomic medicine and sharing our genomic data?	40.9	55.7	3.4	100

• **The possible problems of using genomic medicine and sharing our genomic data?**	30.7	59.1	10.2	100			
• **What the deal should be for rolling out genomics medicine safely and securely for all?**	27.3	61.4	11.4	100			
6. I feel it is important to consult the public on these issues	**Strongly agree**	**Tend to agree**	**Neither**	**Tend to Disagree**	**Strongly Disagree**	**N/A or not sure**	**Total**
London	21	5	1				27
Leeds	25	3					28
Coventry	16	2					18
Edinburgh	11	4					15
Total	73	14	1	0	0	0	88
Percentage	83.0	15.9	1.1	0.0	0.0	0.0	100
7. I am confident that these events will help inform how Genomics England and NHS decide about rollout of genomic medicine in the future	**Strongly agree**	**Tend to agree**	**Neither**	**Tend to Disagree**	**Strongly Disagree**	**N/A or not sure**	**Total**
London	19	7	1				27
Leeds	18	10					28
Coventry	10	7	1				18
Edinburgh	11	3	1				15
Total	58	27	3	0	0	0	88
Percentage	65.9	30.7	3.4	0.0	0.0	0.0	100
8. Overall I enjoyed taking part	**Strongly agree**	**Tend to agree**	**Neither**	**Tend to Disagree**	**Strongly Disagree**	**N/A or not sure**	**Total**
London	23	4					27
Leeds	28						28
Coventry	17	1					18
Edinburgh	12	3					15
Total	80	8	0	0	0	0	88
Percentage	90.9	9.1	0.0	0.0	0.0	0.0	100
9. I am likely to get involved in these kinds of events in future	**Strongly agree**	**Tend to agree**	**Neither**	**Tend to Disagree**	**Strongly Disagree**	**N/A or not sure**	**Total**
London	24	3					27
Leeds	23	4	1				28
Coventry	17	1					18
Edinburgh	12	3					15
Total	76	11	1	0	0	0	88
Percentage	86.4	12.5	1.1	0.0	0.0	0.0	100
11. Happy to be re-contacted by the evaluators	**YES**	**NO**	**Not sure**	**Total**			
London	24	3		27			
Leeds	18	1		19			
Coventry	17		1	18			
Edinburgh	10	5		15			

Total	69	9	1	79
Percentage	87.3	11.4	1.3	100.0
12. Happy to share data – anonymised to remove any identifying or personal information - from these dialogues with the UK Data Service national archive so that it can be used by other researchers in the future.	**YES**	**NO**	**Not sure**	**Total**
London	23	4		27
Leeds	19			19
Coventry	17		1	18
Edinburgh	11	4		15
Total	70	8	1	79
Percentage	88.6	10.1	1.3	100.0