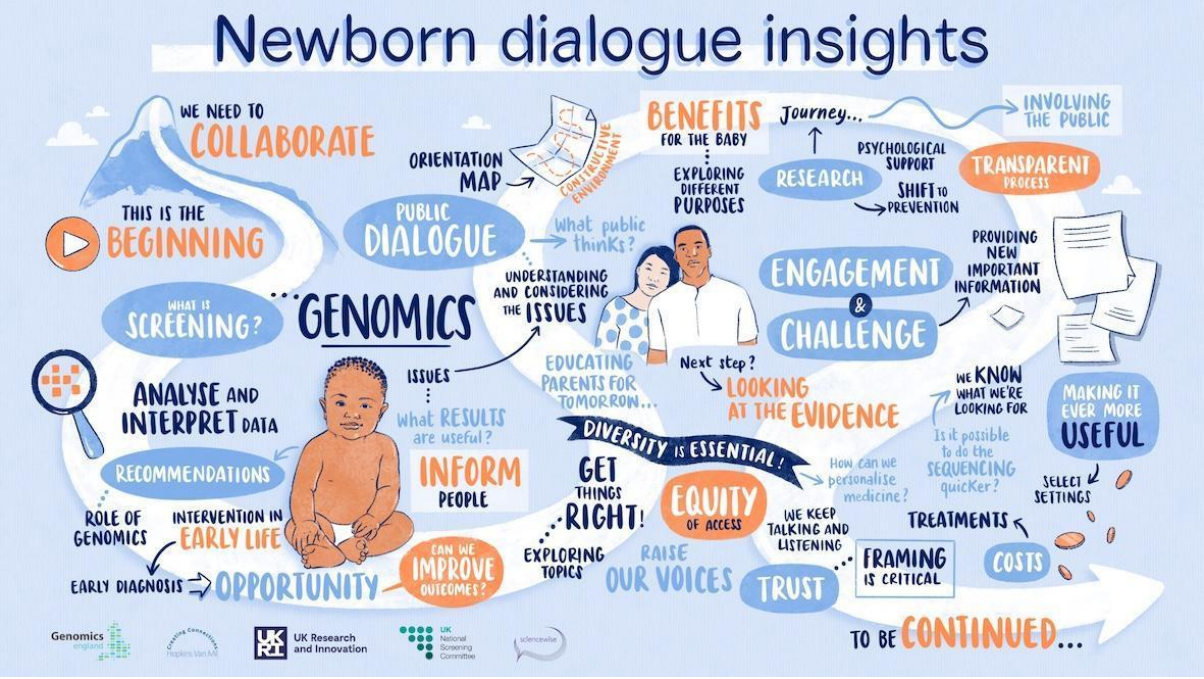
Genomics England and UK National Screening Committee

Evaluation of a Public Dialogue on the Implications of Whole Genome Sequencing for Newborn Screening

Evaluation report
January 2023



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Glossary of acronyms

CF	Cystic Fibrosis
CF SPID	CF Screen Positive Inconclusive Diagnoses
CMO	Chief Medical Officer
QALY	Quality of Life Years
DHSC	Department of Health and Social Care
EURORDIS- NBS-WG	European Rare Disease Network Newborn Screening Working Group
FH	Familial Hypercholesterolemia
HVM	Hopkins Van Mil
NBS	Newborn Screening
NGP	Newborn Genomics Programme
NHS	National Health Service
OG	Oversight Group
PHE	Public Health England
UK NSC	UK National Screening Committee
UKRI	UK Research and Innovation
WGS	Whole Genome Sequencing

1. Introduction

1.1 Introduction

URSUS Consulting Ltd has prepared this evaluation report of a public dialogue on the Implications of Whole Genome Sequencing (WGS) for Newborn Screening (NBS). The dialogue was commissioned by Genomics England[1] and the UK National Screening Committee[2] (UK NSC) with co-funding and support provided by UKRI's Sciencewise programme.[3] The public dialogue was designed and delivered by Hopkins Van Mil (HVM), independent public engagement specialists.

1.2 Policy context

In 2013, the UK government launched the 100,000 Genomes Project to investigate whether genome sequencing could help doctors better understand the causes of patients' symptoms and identify other family members who might be at risk. In 2016, the Chief Medical Officer (CMO), Dame Sally Davies, made a number of recommendations for taking forward genomic medicine in the UK in her 'Generation Genome'[4] report. One of those recommendations was for a public dialogue to explore the shared social contract between patients, the public, clinicians and academics in relation to genomic medicine. Genomics England and the UKRI Sciencewise programme commissioned the public dialogue which reported in 2019, shortly after the completion of the 100,000 Genomes Project. **The dialogue findings indicated general support for more widespread use of genomic data based on the principles of reciprocity, altruism and solidarity that underpin the NHS's values**. The NHS has since rolled out its Genomic Medicine Service,[5] which makes WGS more routinely available to patients with rare diseases and cancers.

The Generation Genome report also included recommendations that UK NSC consider population-wide screening for patients without symptoms of potential genetic conditions to help the NHS become more prevention-focused. In October 2018, the former Secretary of State for the Department of Health and Social Care (DHSC), Matt Hancock, set out a vision for sequencing five million genomes over the next five years. UK NSC and Genomics England have been encouraged to consider WGS alongside, or instead of, the current newborn screening 'heel prick' bloodspot test. Patients' groups, such as Genetic Alliance, have lobbied for the number of conditions screened for at birth in the UK to be extended beyond the current nine to something closer to the sixty regularly tested for in the US.[6]

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[1] Genomics England Ltd is a wholly owned company of the Department of Health and Social Care.

[2] The UK National Screening Committee (UKNSC) advises ministers and the NHS across the UK about all aspects of population screening and supports the implementation of screening programmes, including the blood spot test for newborns. The blood spot test screens for conditions based on a set of internationally reviewed criteria.

[3] Sciencewise helps to ensure policy is informed by the views and aspirations of the public. The programme is led and funded by UK Research and Innovation (UKRI) with support from BEIS. Involve, the UK's leading public participation charity, provides expert advice, assurance and support to the programme.

[4] https://www.gov.uk/government/publications/chief-medical-officer-annual-report-2016-generation-genome

[5] https://www.england.nhs.uk/genomics/nhs-genomic-med-service/

[6] https://geneticalliance.org.uk/our-work/reproductive-options/patient-charter-on-newborn-screening/

1.3 Aims of the public dialogue

In 2020, the Government's genomic healthcare strategy[7] committed to explore using WGS for newborn screening. UK NSC stressed that before rolling out such a service, many logistical, societal and ethical factors would need to be considered. Clinicians working with Genomics England have been collaborating with other researchers to help identify how many genetic conditions[8] could be tested for, identified early, and treated in order to help improve outcomes for the child being tested. In mid-2020, the Genomics England and UK NSC programme directors began discussions with UKRI's Sciencewise programme and decided to co-commission a public dialogue on whole genome sequencing for newborn screening (WGS for NBS). The aim was to understand whether there would be public support for a WGS for NBS pilot.[9] Delivery contractors were recruited in October 2020 with a view to completing the work by May 2021.

The relatively short timeframe for completing the dialogue was dictated by Genomics England's bid to the Treasury to fund a pilot scheme for WGS for NBS in 2021. The sequencing of the dialogue was intended to inform the design of the pilot – alongside inputs from other stakeholders – if the bid was successful. As the COVID-19 pandemic and Brexit slightly delayed the Treasury's decision, the timetable for the dialogue field work and final report was able to slip by a month, allowing more time for the process design.

UK NSC was also keen to use the dialogue as an opportunity to further its understanding of how public participants understand the existing newborn bloodspot test, and their views on the type of conditions currently screened for, the consent process and how results are shared. Genomics England also wanted to consider how WGS data collected at birth might be put to wider uses such as pharmacogenetics, conditions which might present in later life, and research.

1.4 Key challenges for the dialogue

The key challenges for this dialogue were:

- **Framing the dialogue and its objectives so that both commissioning bodies (UK NSC and Genomics England) would feel ownership of the process and treat the findings as robust, despite their different starting points.** This required effective governance and project management within each organisation to keep leaders involved and well-briefed throughout.
- **Achieving a good mix of participants reflective of the UK public while also bringing in the voices of groups with special interests** who might have different views about WGS for NBS because of their life stage or lived experience (see *Annex B*). Running a

[7] https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/920378/Genome_UK_-_the_future_of_healthcare.pdf

[8] https://pubmed.ncbi.nlm.nih.gov/33350578/ An online compendium of treatable genetic disorders – December 2020

9 Since the dialogue, the Programme is now described as a 'research study', rather than a pilot.

large number of separate groups had implications for timetabling and ensuring that participants had access to any practical or emotional support they might need.
- **Providing participants with enough, but not too much, information** across a very broad range of topics so that they felt sufficiently informed but were not overwhelmed with technical detail.
- **Ensuring that all participants had access to the same broad range of perspectives regardless of their location.** Recruiting a mix of specialists to contribute to dozens of individual workshop sessions was a logistical task that required early recruitment, careful briefing and contingency planning in case they were unable to attend due to last minute illness, work or care responsibilities during a national COVID lockdown.

1.5 Structure of this report

The findings of the evaluation are set out in the following sections of this report:
- **Section 2: Public dialogue methodology** gives an overview of the governance and management of the dialogue, how it was designed and delivered, and the outputs that were produced.
- **Section 3: Meeting the dialogue objectives** describes the objectives of the dialogue and how these were met.
- **Section 4: Dialogue impacts** describes the impacts that the dialogue has on participants, on the project commissioners, on other relevant bodies and on wider stakeholders.
- **Section 5: Design and delivery** gives an overview of certain elements of the way the dialogue was designed and delivered that have had a significant impact on its effectiveness, assesses how it has met good practice and draws lessons for future processes.
- **Section 6: Costs and benefits** provides information on the financial and in-kind costs of the dialogue and the various benefits it has provided or may contribute to.
- **Section 7: Conclusions, lessons and recommendations** summarises the key lessons on how the impacts of the dialogue have been maximised and provides recommendations for Sciencewise, for the commissioners of the dialogue, and for the delivery contractors.

The report is supplemented by three annexes which give more detail on membership of the Oversight Group, the dialogue methodology, and the evaluation findings from surveys of participants.

2. Public dialogue methodology

2.1 Governance and project management

The governance and project management arrangements contributed to the overall efficiency and effectiveness of the dialogue process.

- **Project management**. The dialogue process was managed by an experienced team of two project managers within Genomics England and UK NSC. A clear division of responsibilities and a mix of formal and 'pick up the phone' meetings between co-commissioners, contractors and UKRI Sciencewise contributed to create a warm, collegiate, effective core project team. The team was able to make timely decisions to allow efficient delivery and the productive atmosphere was a key factor in the success of the dialogue.
- **Oversight Group (OG)**. The dialogue was overseen by a large Oversight Group (OG) of about 21 members (plus alternates) managed jointly by Genomics England and UK NSC. Some members brought prior experience from Genomics England's s social contract public dialogue. The OG met online and contributed to the framing, stimulus materials, drawing from their relative specialisms. They contributed a broad range of perspectives (healthcare, geneticists, patient support and advocacy groups, ethicists and policy makers) and included individuals who were initially keen to see a WGS for NBS pilot and those that were more cautious. A full list of members is shown at *Annex A*. The project management team kept the OG members fully involved throughout and many of them championed the dialogue findings, contributing to the impact of the dialogue.
- **UKRI Sciencewise role**. A Sciencewise dialogue and engagement specialist (DES) and UKRI representative supported the process from the early business planning and contracting process through to the end publication and launch. The commissioners greatly appreciated this role.

2.2 Dialogue design and delivery

This was a rapid, intensive, online dialogue with 133 members of the public. An independently commissioned rapid evidence review and an early scheduled OG meeting allowed the contractors to make a rapid start in designing the process.

- **Workshop structure.** The design delivered just under 12 hours of online Zoom workshops spread over four evenings and one weekend session (see *Annex B*). The initial webinar (1'15") focused on sharing information. The subsequent four 2.5 or 3-hour workshops were designed around a mix of pre-filmed talking heads videos, specialist presentations (live or pre-filmed), Q+A sessions and facilitated small group (synchronous) deliberation.
- **Stimulus materials**. Stimulus materials were reviewed by the OG and piloted with 7 members of the public during January 2021. Materials were shared on the Recollective online platform and participants were also expected to share their thoughts on 'homework' tasks (30-60 minutes) on Recollective between sessions.
- **Public participants recruited**. During February 2021, workshops were held with four groups of about 21 participants each from Scotland, Northern England, Southern England, and Wales & Northern Ireland respectively (see *Annex B*). Each cohort was

recruited to be broadly reflective of the demographics of the region and to include a mix of individuals who felt more or less optimistic about the role of science in improving healthcare.

Four smaller 'special interest' groups of 7-14 individuals met in March 2021 and brought in the voices of individuals likely to think differently about WGS for NBS because of their life stage or lived experience. These groups included new or expectant parents (14), people or parents/carers of people with genetic conditions (14), individuals from Black or minority ethnic backgrounds (14), and young adults (7). To recognise and incentivise their participation, as well as to ensure that no one who wanted to take part was excluded for economic reasons, each participant received a thank-you payment of £275.

- **Specialists.** A total of 29 specialists - scientists, clinicians, ethicists and parents of or charities representing children with rare genetic conditions - took part in the workshops. Together they provided a full range of perspectives around WGS and screening. A further 23 Genomics England staff and UK NSC or OG members participated as observers.
- **Dissemination events**. The findings from the report were disseminated in two pre-launch webinars with members of royal colleges, NHS staff and academics (28th and 29th June 2021). These were well attended and the questions asked fed into the design of an online launch event (8th July 2021). Participants included: NHS and PHE managers and policy officers, scientists, genetic counsellors, midwives and doctors, charity and patient support groups for genetic conditions, the genetics industry and a few public participants. Amongst these were a handful of international health practitioners and academics from North America, Australia and Japan.

2.3 Dialogue outputs

- **Dialogue report.** A well-written and well-designed public dialogue report was simultaneously published on **Genomics England**, **UKNSC**, **Sciencewise** and **HVM** websites on 8th July 2021. Quotes from the senior leadership of Genomics England and UK NSC in the foreword underlined the importance they placed on the findings.[10] The commissioners agreed that the report "*put the citizen voice front and centre.*"
- **The executive summary** provides a succinct and coherent overview while the main report helpfully signposts how readers can dip into the detail in the main report.
- **A one-page infographic** by illustrator Giulia Coppola summarises the issues discussed at the launch event, suitable for sharing on social media.
- **A short (6 minute) video** by independent filmmaker Paul Wyatt gave a very clear description of the process. It used stimulus materials, in-meeting recordings and post-event interviews with a dozen participants to tell a compelling story of their journey. The video has been viewed about 900 times since July 2021. The material was also presented as three shorter (2 minute) videos, but these have been much less widely viewed.
- **Genomics England's website page** about the dialogue has been one of their most visited pages (with an estimated 1300 views by late July 2021).

Other key dialogue outputs included:

[10] UK NSC Independent Chair, Prof. Bob Steele and Director of Programmes, Prof. Anne Mackie and the Chief Executive of GEL, Chris Wigley

- **A slide deck** summarising the process and key findings for dissemination events.
- **Dialogue report annexes** including workshop plans, stimulus materials and the participant pack available at Genomics England's website.
- The **launch event video,** viewed more than 2,100 times on YouTube.
- Over **120 hours of audio recordings** from the Zoom workshops were transcribed for analysis using NVivo software. This data is available in the UK National Data Archive.

2.4 Independent evaluation

The evaluators observed all 36 dialogue sessions and dissemination events and collected participant evaluation feedback on the Recollective site (see *Annex C*). After the publication of the report, we interviewed the commissioners and core project team (July 2021) and OG members and policy makers in late 2021 to collect evidence on the dialogue impacts.

3. Meeting the dialogue objectives

3.1 Framing

From the first OG meeting, it was clear that the objectives of the two commissioning bodies were subtly different: UK NSC was focused more on WGS for NBS as an alternative to the existing heel prick test, while Genomics England was also interested in the wider potential to use WGS data for novel uses and later in life. As a compromise, the OG and core team suggested that the dialogue consider the following two contexts:

- **Context 1**: **The potential use of WGS as a technology in addition to, or to replace, some parts of the current NHS NBS programme (which has defined purposes and criteria).** Understanding whether public participants have an appetite to use WGS to identify a relatively small set of early onset conditions that can be easily explained by professionals and which are treatable, or where early diagnosis can improve a child's quality of life. This is the area where rollout of an NHS pilot would focus immediately, and the area where participant recommendations were expected to have the most immediate impact.

- **Context 2**: **Potential novel uses of WGS in newborns.** Understanding what public participants think about using WGS beyond traditional newborn screening for uses such as pharmacogenetics, reproductive choices and to identify risks of later onset conditions. This wider context would also include national and international research.

As shown in *Table 3.1*, all five objectives were met. **The research found a high level of support and enthusiasm for a pilot WGS for NBS programme – but with caveats. The participants suggested a clear set of principles which they wanted to see addressed before any pilot is rolled out**. Context 1 – WGS for newborn screening – was covered in greater depth within the available time. Nevertheless, the dialogue also generated valuable insights about what would be needed to enable wider uses of WGS data: several evaluation interviewees felt it would be useful to explore context 2 through further public dialogue.

The factors which helped to ensure the dialogue objectives were met included:

- **Clarity from both commissioners on what they wanted from the process**. OG members suggested that the dual framing strengthened the dialogue: "*The two different lenses on what we were doing made it better, more balanced.*"
- **The decision to commission a rapid evidence review early in the process,** which meant that the results were available to the OG and consultants to inform design.
- **Workshops designed to build towards each objective.** Each session built on previous ones with carefully chosen prompt questions.
- **Decision to convene special interest groups.** This allowed small groups with similar characteristics to make their voices heard and surfaced concerns and aspirations that might not otherwise have been heard.
- **Work behind the scenes to keep senior leadership and OG members involved.** The project management team kept their organisations and OG briefed and encouraged them to attend workshops. They developed a strong sense of ownership and confidence that the process was robust and the findings credible.

Table 3.1: How the dialogue met its objectives

1. To establish a baseline on public views and attitudes to WGS for NBS by review of previous dialogue, engagement, consultation and related research	• Based on past learning, the rapid evidence review was commissioned well in advance of the contractors starting, with findings ready to share at the first OG meeting. The findings were therefore able to influence the framing, recruitment of participants, questions asked and language used in the dialogue.
2. To understand participant views, concerns and aspirations around WGS in NBS and underlying values and principles	• Participants gradually built their understanding of screening and genomics over the initial sessions and of the potential and concerns for WGS for newborn screening and wider uses in workshops 2 and 3, respectively. • OG members and specialists praised the breadth of views participants heard. Noting that small group discussions "*covered off the issues pretty comprehensively*" and *"many of the themes addressed in this public dialogue echo our findings."* • Participants in geographic groups tended to have similar aspirations and concerns. The special interest groups brought a diversity of opinions that might not otherwise have been heard. The diversity of views from special interest groups added to the richness of the findings and made them more credible to stakeholders.
3. To understand how participants perceive potential harms and deal with uncertainty and trade these off against benefits for different parties	• Powerful testimony from those with lived experience brought both potential benefits (e.g. avoiding a diagnostic odyssey) and harms (e.g. creating patients in waiting) to light. Case studies on different use cases/conditions helped to make these tangible and bring in wider points of view. By workshop 4, interviewees felt that all participants had a good grasp of both potential benefits and limitations of WGS. "*The really difficult questions are around how predictive the results are, what conditions it would be acceptable to look for, what information to give to whom and when, and how to help parents make informed choices about tests that could have important implications for their child, themselves and maybe others in their family*." I OG member
4. Participant insights on: • **A) Safeguards to minimise harms** • **B) Information and support to help guide choices**	• Through skilled facilitation the underlying values were explored and turned into principles or criteria for a pilot roll out. Almost all participants advised Genomics England to take time and get the design right. Participants in all groups identified areas needing further work. Those in special interest groups emphasised the need to avoid discrimination and make the service available to all communities, including those currently underrepresented. • The commissioners found the emerging principles really helpful. *"The findings from this dialogue have given us an extremely valuable insight into what an ethically and publicly acceptable way of doing this might be. his is the essential first step in identifying and understanding the opportunities, risks, ethical issues and regulatory implications involved."* I Sir Mark Caulfield, Chief Scientist, Genomics England website. "*We heard loud and clear that the right level of support must be available for parents at every stage of the screening process and that any use of genome sequencing in newborn screening has to work for everyone in society*." I OG member, UK NSC
5.To explore whether expectations, understanding, ambitions and concerns for WGS for NBS are the same between the public and other stakeholders	• Through the OG and evidence, some differences in views were identified early in the dialogue. More emerged from the two pre-launch dissemination workshops and launch event (with >750 attendees) which highlighted growing support for a pilot. It also highlighted many concerns which are now being worked through via Genomics England's programme of ongoing stakeholder engagement in the Newborn Genomes Programme design process.

4. Dialogue impacts

This public dialogue has already had direct impacts on the participants, the commissioning bodies and on wider stakeholders. The full impact on policy making and NHS practice will be clear when the WGS for NBS pilot programme is rolled out, from 2023 at the earliest.

4.1 Impact on participants

The public participants enjoyed the process, which made them enthusiastic about their role (which they took seriously). Almost all attended every session and were engaged in the small group discussions and in providing additional thoughts via Recollective. Their positive experience contributed to the following impacts:

- **Most felt that it is important for the public to be involved in this type of deliberation around key public policies**. They also felt the deliberation was early enough in the decision-making process to help shape the future of NHS newborn screening.

- **Almost all participants felt confident that they had been able to contribute informed views by the end of the process**. The time and space provided for them to talk to specialists, and each other, was an important part of their growing confidence by the end of the process. Participants felt confident they had heard the full range of perspectives and had received candid answers to their questions.

Box 4.1: Quotes from public participants on how they have been impacted

- *"This is a very important piece of work … Honoured to have been a very small part of it."*
- *"Thank you for the opportunity to contribute to this important area of public health and policy. It was very challenging, but worthwhile."*
- *"It's been a wonderful experience … I'm on an 11-month stint of furlough and this has been by far one of the best experiences this past year. I really feel privileged to have taken part."*
- *"A huge responsibility, but a delight too!"*
- *"It has been a thorny subject, and my opinion has changed several times during the month, but the group discussion and time between sessions has helped me to take time to mull over the topic and make my own decisions."*
- *"I hope to see in the report that our ideas have been properly considered but I have full faith in Genomics England that this will happen."*
- *"I think it will go ahead whatever happens, but maybe we gave them some points to think about."*
- *"I have never been a part of a research panel before and I feel truly blessed to have been given the opportunity to take part and will gladly accept such an opportunity in the future.*

- **They were confident that the Genomics England and UK NSC teams would take their views on board**. The high visibility of both teams as specialists in answering questions and responding to participants' recommendations gave participants confidence that the teams were listening.

- **Most participants expressed an interest in being involved in further research**. Almost all were happy to be recontacted if an opportunity arose. Almost immediately there was a chance to take part in a UK NSC mini dialogue on cystic fibrosis. Of the 130 participants recontacted, 88 expressed an interest and 20 took part in two further workshops.

4.2 A successful launch and wide dissemination of the dialogue findings

The public dialogue launch was higher profile and more international than many Sciencewise dialogues of similar size. The dialogue messages came through clearly and have since been widely disseminated by the co-commissioners, OG members and wider stakeholders. The factors which contributed to this success included:

- **A well-thought through joint communications strategy**, which started cautiously with an announcement on co-commissioners' websites. This strategy built as Genomics England and UK NSC gained confidence in the robust process and importance of the emerging findings.

- **Providing a few well-informed journalists advance access to the findings.** Genomics England and UK NSC offered exclusive coverage and opportunities to interview senior leadership in the weeks leading up to the launch. The resulting article in The Guardian (4th July 2021) was balanced and underlined the dialogue message that participants supported a WGS for NBS pilot, but with caveats and with many issues still to work through. The article avoided the sensationalist headlines encountered in other parts of the genetics debate. The article helped to raise the dialogue's profile and led to a marked spike in interest: more than 1,000 individuals registered for the launch event on Eventbrite.

- **Attention to keeping the OG members fully engaged** ensured that most became champions for disseminating the dialogue findings.

- **A high-profile launch event supported by Genomics England and UK NSC leadership.** The event was expertly hosted by Genomics England's Head of Public Engagement, Vivienne Parry, as an online 'in conversation' style webinar with prominent panellists. The event drew on lessons learnt by the Genomics England team in running large dissemination events. The live event was attended by 539 in-person attendees; 619 individuals watched all, or part of, the stream on YouTube.[11]

- **The launch event design – which brought in public participants' voices – proved engaging for attendees.** Participant voices were heard via the short film of the process and via live testimony from a few participants. The dialogue messages came across powerfully and many attendees particularly enjoyed these parts of the webinar.

- **Being able to anticipate the key questions stakeholders would want answers to**. The pre-launch dissemination events put the Genomics England panel host in a position

[11] YouTube stream watched for 35 minutes on average, with 222 viewers at the peak during the live event and watched more than 1000 times since.

to weave key questions into panellists' discussions. This left space to answer many of the other frequently asked questions (FAQs) posed on chat box and on Twitter, to the satisfaction of attendees. The Genomics England engagement team reported that the atmosphere of openness generated by the event had positive knock-on impacts on subsequent stakeholder engagement.

- **Since the launch event, lively discussion has continued on social media.** After being invited to share comments, links to outputs and answers on Twitter (#newborndialogue) during the launch event, the conversation thread has continued and reached a wider audience. Genomics England's Chief Executive, Chris Wigley, has continued to share comments and the dialogue has been discussed on the organisation's podcast, The G Word, in July and October 2021.[12]

- **A national conversation about WGS for NBS has built gradually in the press**. *Box 4.2* summarises recent press coverage. Senior Genomics England staff and UK NSC members have continued to be available for interview. The coverage has been nuanced, covering both potential benefits and concerns without becoming politicised.

Box 4.2: Press coverage of the dialogue and its findings

- YouGov picked up on the pre-publication article to inform a public opinion poll (published in August 2021)[13] which showed nearly seven in ten respondents supported genetic testing for a range of early onset childhood conditions to help improve outcomes – only 13% were strongly opposed.
- Further articles in the Guardian in December 2021 explored potential pros and cons and explored the concerns from some stakeholders (including an OG member) that WGS for newborns might prove more valuable for research than in improving screening and an article in the Times, February 2022.
- Specialist press: Frontline Genomics (July), Science (Sep), Wired (Nov) and Medical Progress (Dec).

4.3 Impacts on Genomics England policy making

The public dialogue business case indicated that the dialogue findings would inform Genomics England's process for developing a pilot WGS for NBS programme. As summarised in *Figure 4.1*, there is already evidence that the findings are having the desired impact. The Genomics England team has found the dialogue report "*a very detailed and complex piece of work which will attract a lot of attention*" and the findings have been described as a "*springboard*" for designing the WGS for NBS pilot process.

The dialogue findings have so far had an impact in the following ways:

- **Endorsement of the decision to proceed with a pilot**. Genomics England's commissioning team credit the robustness of the process and findings as a key factor in the Treasury approval to go ahead with a pilot to include approximately 100,000 babies. A team at Genomics England is working on the design of a Newborn Genomes

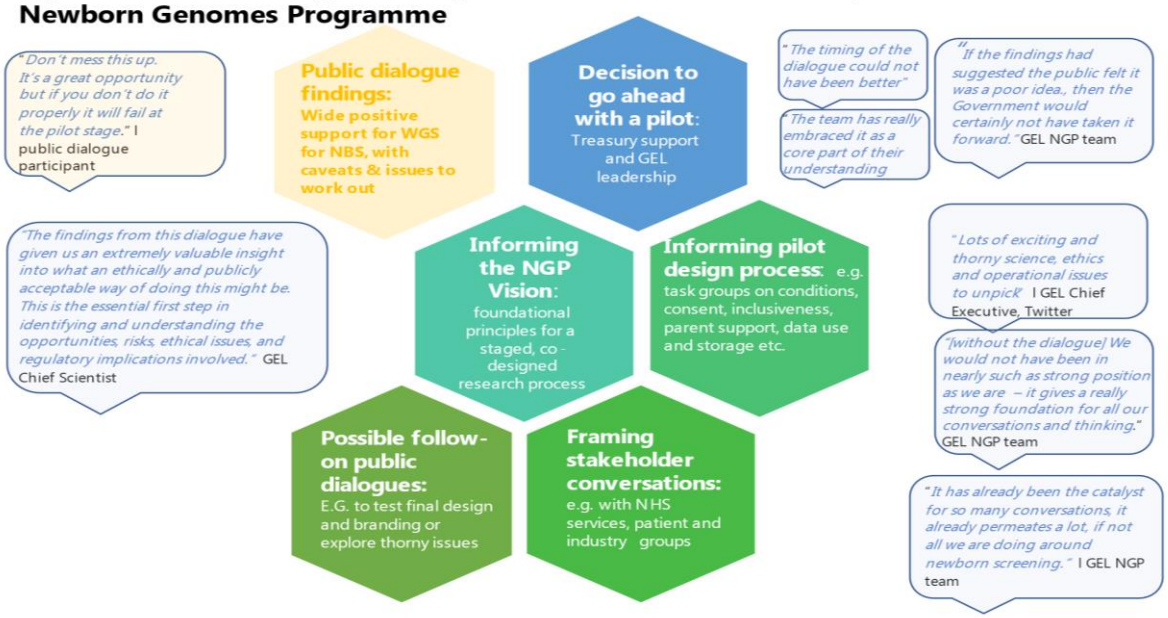
[12] 14th July interview with the HVM team about the significance of public dialogue; 8th October interview with American WGS for NBS expert, Prof. Robert Green of Harvard Medical School, on the implications of the findings.

[13] https://yougov.co.uk/topics/health/articles-reports/2021/08/16/people-support-genome-testing-newborn-babies - 1,714 members of the public

Programme (NGP). The dialogue message to take time and get the design right has influenced the team's decision to take 18 months for the design and involve many stakeholders, rather than launch quickly and adapt as they go.

- **Helping shape the NGP vision.** The findings provide the foundations for a coherent vision (December 2021) for a co-designed, ethics-approved research pilot. The vision has been shared with stakeholders through a series of online events, including a six person panel (21st October) which involved four Genomics England staff and OG members who had been involved in the dialogue. The vision highlights many of the principles first raised in the dialogue.

Figure 4.1 Public dialogue findings have influenced the development of GEL's Newborn Genomes Programme



Informing the process, task groups and topics covered during the design process. As shown in *Table 4.1*, the design process will include a mix of steering groups, task groups, specialised posts and products covering many of the key issues that participants identified as still needing to be thought through before the pilot is rolled out.

- **Providing a positive starting place for conversations with stakeholders**. As part of its wider stakeholder engagement, the Genomics England team is talking to NHS services, ethicists and patient and industry groups (who were not part of the dialogue process). The findings shared at the dissemination events and launch – and the openness with which Genomics England and UK NSC answered questions – have provided different lenses for conversations. For instance, with royal (medical) colleges the starting point is around demonstrating awareness of staffing and resource implications of a newborns programme; with rare disease patient groups it is about meeting expectations around the types of conditions that will be looked for; and with industry it is on public expectations around commercial data use.

- **Potential further public dialogue and social research**. The Genomics England team is planning to go back to dialogue participants to test their reactions to the final pilot design and ethical issues that are raised. It is also planning further small public dialogues around thorny design issues (such as an informed consent process, research and data

storage, and industry/commercial involvement). Involve (host of the Sciencewise programme) has been working with the Genomics England programme team to run consensus processes in expert groups that are developing principles for deciding what conditions the Programme will look for. The team may also use other social research methods, such as omnibus opinion polls, to track public views on WGS and genomics and public willingness to contribute WGS data to the National Genomic Research Library.

- **Informing other Genomics England initiatives.** A strong desire for equal access to genetic healthcare information came out of the geographic groups and the group of individuals from Black and minority ethnic backgrounds. This finding has helped inform Genomics England's 'Diverse Data' initiative: this will help make sure that everyone can benefit from genomic data, whatever their ancestral, socioeconomic, or geographic background.

Table 4.1: Dialogue findings reflected in tasks for designing the pilot

NGP tasks and principles	How dialogue findings have contributed
Governance and working groups	• The Steering Group (30 members) overseeing the pilot includes four OG members and so provides continuity to the dialogue.
Information and support for parents	• Dialogue findings emphasised needs for information and support for parents and NHS staff. • NGP team is working on a WGS portal for both groups to find out about genetic conditions with links to financial support and patient groups.
Co-development of principles for deciding the type of conditions to screen for	• Focusing on early onset and actionable childhood conditions – but more than the current nine – is taken as a baseline. • A 'Conditions Working Group' will review data on rare conditions and identify which conditions should be added to the Programme's screening 'panel(s)'.
Developing a person-centred consent process across screening, research and future re-analysis	• Dialogue's emphasis on the need for an informed and dynamic consent process taken as a starting point. • Appointment of a human-centred design team to engage with parent groups and design a process which empowers parents to opt into WGS as an informed choice. This includes ethnographic and other insight work.
A supportive and inclusive experience for all families	• Principle reflects the dialogue emphasis on equality of access and need for mental health support for diagnosis (or dealing with uncertainty).
Safe storage and appropriate use of data for the benefit of all NHS patients	• Dialogue principle of preventing misuse of sensitive data as a starting point for Genomics England's work with stakeholders to future-proof its Research Environment model.

4.4 UK NSC

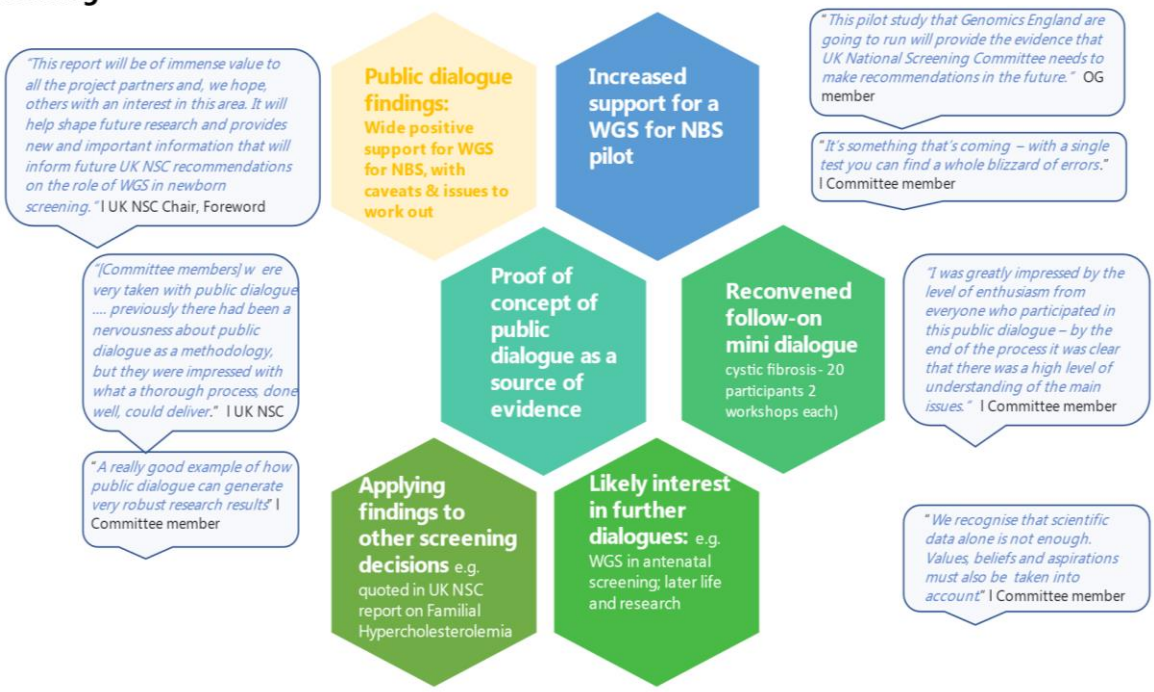
The business case anticipated that the findings would have a positive impact in helping UK NSC to provide advice to ministers and the NHS on the future use of WGS in screening. *Figure 4.2* summarises how this has already started to happen.

The dialogue findings have already started to have an impact in the following ways:

- **Proof of concept of public dialogue as a methodology**. The quality of the public dialogue process – which many Committee members had a chance to view for themselves – convinced members that it is a credible methodology which can be used to supplement evidence from large scale trials and peer reviewed articles. The UK NSC chair

considered the dialogue findings sufficiently robust to warrant a co-authored journal article in an international medical journal. The findings have been incorporated into an article by the author of the public dialogue evidence review, Professor Felicity Boardman, published in New Genetics and Society in June 2022.[14]

Figure 4.2: Public dialogue findings have influenced UK NSC's approach to decision making



- **Increased support for a WGS for NBS pilot**. The Committee members accepted the participants' overall support for WGS for NBS as the direction of travel. They were encouraged that Genomics England has decided to take more time for the design phase, and that participants appeared to support the criteria which UK NSC uses to decide which conditions should be screened for.[15]

- **Use of the findings in the decision process for a specific condition**. The findings were cited five times in the UK NSC report on familial hypercholesterolemia (FH). They will likely be quoted in other cases in the future (such as providing information on carrier status or where testing benefits families rather than babies directly).

- **Commissioning of a follow-on mini dialogue with the same cohort**. UK NSC and UKRI Sciencewise funded a small extension to allow the delivery contractors to reconvene 20 participants (15% of the original cohort) for two further workshops. They explored how wider genetic testing could be used for more accurate diagnosis for cystic fibrosis (CF) while avoiding CF screen positive inconclusive diagnosis (CF SPID). The steering group was pleased with the insights provided by this group who already had some understanding of WGS and screening issues. Evidence will be considered alongside other

[14] Expanding the notion of "benefit": comparing public, parent, and professional attitudes towards whole genome sequencing in newborns, CCA Clark and FK Boardman, June 2022.

[15] based on the principles that the benefits should outweigh harms for the population as a whole based on equitable access for all, informed choice and affordable costs.

stakeholder engagement before making their recommendations to ministers and the NHS. An article presenting the findings and lessons learnt from using public dialogue co-authored by a UK NSC member and HVM was published in the International Journal of Neonatal Screening (May 2022).[16]

- **Feeding in further evidence to the Genomics England pilot design process**. Insights from the CF/CFSPID mini dialogue (e.g. on support and information needs for parents and healthcare workers) will also feed into the Genomics England NGP workstreams.

- **Interest in further public dialogues on WGS issues.** Several Committee members told the evaluator of their interest in seeing more WGS-related work using public dialogue (e.g. on wider uses beyond birth and on antenatal WGS screening). Antenatal screening was explicitly excluded from this public dialogue, but some UK NSC members indicated it will be important to understand the public's views ahead of this technology being widely available on a commercial basis.

Box 4.3: Views of stakeholders on dialogue findings

- "*A good report and I think it will be useful in this context and definitely what was necessary when this idea began to develop – 100% useful as a basis for exploring a pilot.*" I OG member.
- "*I observed several of the dialogue workshops and was extremely impressed by the enthusiasm and thoughtfulness of all the participants, and the thoroughness of the process of engagement with these challenging ethical issues*." I OG member
- *"[Genetic counsellors] were blown away by the [launch] event, not only by the content but also by the way it was presented and constructed in a way that focused on the consultation and the society view and brought the experts in to support that rather than the focus being on the experts."* I Stakeholder launch attendee
- *"My colleague was very complimentary about the video on the actual consultation process. I think it is quite powerful to hear the participants talking about it in their own words and gives confidence about how well engaged they were."* I Stakeholder launch attendee
- *"We're seeing a lot of discussion in the general and specialist press around newborn screening. Lots of views, some strong, in many directions*." I Genomics England Chief Executive, Twitter
- "*Made people realise that UK NSC would be swimming against the tide in terms of public support and that there is a case both for using WGS and widening the number of conditions screened for (or widening the number of conditions screened for even before the pilot roll out)*." I Rare disease patient group
- "*What has really helped is that before people [had] been thinking about sequencing only – but there is so much more than that – all about the relationship with the NHS and people getting in the right pathways.*" I Genomics England team

[16] A Public Dialogue to Inform the Use of Wider Genomic Testing When Used as Part of Newborn Screening to Identify Cystic Fibrosis, Kinsella, Hopkins, Cooper and Bonham, May 2022.

4.5 Impacts on wider stakeholder attitudes and research

The dialogue findings have been widely disseminated by the OG members amongst their networks, as summarised in *Table 4.2*. The results have been cited in an article co-authored by the Genomics England team in Frontiers in Genetics (May 2022, over 1000 views).[17]Evaluation interviewees told us that by late 2021 the findings were already encouraging a wider conversation on WGS for NBS in the following circles:

- **Rare disease patient groups** are hopeful that UK NSC will consider extending the number of conditions screened for at birth.
- **The genomics industry** is starting to report on the success of the Genomics England pilot project allocation and the role of the public dialogue in informing this (Scientist Live magazine, January 2022).
- **International research and the medical community.** As the first international public dialogue on WGS for NBS, the findings have generated interest in Europe, US, and Australian research circles, and the Genomics England team has started to share findings.

Table 4.2: Dissemination of the findings and potential impact by wider stakeholders

Stakeholder	Form of dissemination and impact
OG Chair **Other OG members**	• Prof. Anne Marie Slowther UK NSC National Screening blog on dialogue findings. • Progress Educational Trust, Genetic Alliance, Med Confidential, Breaking Down Barriers, vice chairs of the Genomics England Participant Panel, Ada Lovelace and Warwick University shared links on Twitter, 8th July 2021 • Results shared by UK NSC with Scottish Screening Board and Screening Committee.
Genetic Alliance	• Shared reactions on 24th July 2021: "*Genetic Alliance UK is pleased that this public dialogue has been carried out as a first step towards harnessing the potential of genomic technology to improve health outcomes for those affected by rare, genetic and undiagnosed conditions*.". • Collaborated with Genomics England public engagement team to present findings and Genomics England's emerging vision at an online event attended by several dozen members on 26th October 2021 and with all newsletter subscribers. • Shared with the All-Party Parliamentary Group (APPG) on Rare, Genetic and Undiagnosed Conditions for which they provide the secretariat.

Progress Educational Trust (PET)	• Genomics England has sponsored and provided speakers (including dialogue OG members) for a series of events including:
	  ○ A filmed conversation between PET and Genomics England
	  ○ A series of five two-hour online workshops on key issues the GEL NGP team is working on including: the criteria for selecting conditions to be screened for and sharing results (November 2021); the consent process (December 2021); research using newborn genomes (January 2022); use of the genome as a lifetime resource (February 2022) and workforce implications (March 2022)

Genomics industry	• Public Policy Institute's report on the Genomics Revolution (October 2021). [18] Quotes the dialogue frequently (five out of 97 total references). • Key recommendation #17: "*There should be a pilot of whole genome sequencing (WGS) in newborns, conducted in line with the recommendations of the Genomics England and UK National Screening Committee public dialogue*."

[17] Developing a National Newborn Genomes Program: An Approach Driven by Ethics, Engagement and Co-design https://www.frontiersin.org/articles/10.3389/fgene.2022.866168/full

[18] Professor Gil McVean, Chief Scientific Officer, Genomics plc, chapter 3, Prevention and detection https://publicpolicyprojects.com/wp-content/uploads/sites/6/2021/10/PPP-Genomics-Revolution-Report-FINAL.pdf. The report summarises a process co-chaired by Sir John Chisholm (former Chair of Genomics England) and Professor Sir Mark Caulfield to bring together public and private-sector leaders, investors, policymakers and commentators.

	• Other recommendations reflect dialogue findings including: data protection; widening the diversity of genetic databases; sharing of international findings; and the need for independent governance and regulation of the use and storage of personal data.

International stakeholders	• Interest expressed and findings shared by the Genomics England engagement team with:
	  ○ EURORDIS (European Rare Disease Network) via its Newborn Screening Working Group (NBS-WG) which is reviewing international policy and practice in the field.
	  ○ Victoria State Health System in Australia
	  ○ Prof. Robert Green (Harvard Medical School, Brigham Women's Hospital, Boston)
	  ○ Stephen Kingsmore (CEO, Rady Children's Institute for Genomic Medicine, San Diego).
	• The UK NSC Chair suggests that the quality of research and findings would now warrant a co-authored peer reviewed article. It would be timely for the co-commissioners to discuss who might take the lead.

5. Design and delivery

5.1 Overview

The design of sessions and materials, the roles of specialists and facilitators, and logistics built on lessons learnt from what had worked in previous public dialogues, including the Genomics England and Sciencewise social contract dialogue and HVM's experience of running online dialogues since the COVID pandemic. This experience has contributed to design and delivery of a high-quality process against best practice principles as summarised in *Table 5.1*.

5.2 Emerging lessons on good practice for online delivery

The design and delivery illustrate a number of lessons for emerging best practice standards for online delivery.

- **Keeping the objectives clear for participants**. The different lens for each session, time spent setting the context, clear prompt questions and skilful facilitation helped keep the different contexts clear in what might otherwise have been a very confusing process. Refocusing on WGS for NBS in the final workshop and **enabling participants to share their thoughts with the commissioners was a vital part of a successful design**.

- **The mix of 2.5- and 3-hour live sessions felt energetic and pacy**, based around a simple formula of pre-filmed videos, short PowerPoints and case studies with specialists on hard-to-answer participants' questions. Stakeholders interviewed found the sessions "*short and punchy*" and participants found the sessions about the right length. Three-hour sessions allowed more space for participants to absorb new information, interrogate specialists and have in-depth discussions in small groups. Even with a short comfort break, the three-hour intensive sessions were probably able to cover more material than would have been possible in the equivalent half-day face-to-face workshop.

- **Sharing just the right amount of technical information**. Technical information on genetics was kept to the minimum, reflecting Genomics England's previous dialogue experience: senior input proved valuable in reinforcing this point with the OG members. The style of information sharing made the most of the online format and materials were high quality and accessible. Despite HVM's best efforts in pre-briefing, in a few cases specialist presentations were too detailed or unstructured for participants to really get what they needed for the discussions. A huge benefit of working online was in being able to record live presentations so that the best could be shared with other specialists as exemplars, with participants via the Recollective space or as films in later rounds of workshops. By the final workshop, all participants in all locations had heard the same information.

- **The design and facilitation style made the process enjoyable – which is harder online than in the room – and helped participants stay engaged.** Both specialists and participants reported they had found the process more fun than they had expected; this helped keep participants engaged and kept retention rates high despite the large number of sessions during a period of national lockdown.

Table 5.1: Assessment against good practice delivery principles

Good practice principles	Met	Summative assessment
Appropriate number and types of participants	✓	A diverse and inclusive mix of 133 participants with high retention rates over 5 sessions. **The special interest groups proved very effective in surfacing views** that might not have been heard so strongly within the more general geographically recruited groups.
Focus on addressing agreed dialogue objectives	✓	Objectives were restated for each session: the dual framing of contexts 1 and 2 may have been confusing during the middle sessions, but by the final session all participants were focused on criteria for a WGS for NBS pilot.
The framing and information presented were fair and balanced	✓	Background technical information used tried and tested short videos by the NHS and Genomics England, pre-filmed talking heads, specialist presentations and case studies which allowed participants to hear a wide range of perspectives. **They particularly valued hearing from those with lived experience**.
Clear, accessible and sufficient stimulus to enable participants to engage in informed dialogue	✓	Stimulus materials were simplified to those that work well online (videos, PowerPoints and case studies) reflecting lessons learnt from previous dialogues. **Participants grew increasingly interested in the topic as they heard from specialists** and were able to discuss the issues in depth with each other. **A few specialist contributions were unclear or too detailed**, but online recording of presentations made it possible to share between locations and ensure that all participants heard the same information by the end of the process.
Sufficient time for deliberative discussions	✓	The length of sessions (2.5 or 3 hours with a short break) allowed plenty of time for (synchronous) group deliberation. Participants also had many opportunities to review materials, explore what they had heard with friends and family in between workshops and feedback their individual reflections on the Recollective platform. This allowed individuals to express opinions more strongly than they might have felt comfortable doing in small groups.
Respect for and engagement of public participants	✓	The continuity in the facilitation team for each geographic/special interest group and the skill and style of individual facilitators meant that all participants seemed engaged and felt heard. Tech and offline support provided to those who needed it meant that there were no signs of digital exclusion amongst participants.
Quality and depth of facilitation	✓	Pilots, pre-briefing and continuity helped facilitators build a subject knowledge and contributed to excellent facilitation: carefully designed prompt questions and probing of underlying views resulted in rich findings.
Recording the dialogue	✓	All workshop sessions were recorded and small group discussions and the chat box transcribed for analysis. Simultaneous facilitator notes allowed participants to share the key points in plenary and for the lead facilitator to share back findings for each group to help frame the next workshop.
Capturing agreement, disagreement and uncertainty	✓	Facilitators took visible notes on a shared screen during small group discussions: this mostly worked well but sometimes limited how well the facilitator and group could read body language, make eye contact etc. Individual views were also captured via ePolling (Mentimeter app), via Recollective and through filmed interviews with 13 participants for the final vox pop video.
Analysis of dialogue results	✓	All data from transcripts and Recollective was coded and analysed using NVivo software with findings reflected in a detailed and nuanced final report.

- **A small, experienced facilitation team provided consistency across all locations**. This allowed the team to get to grips with the structure and content, and then focus on building cohesive small groups where everyone felt able to contribute. **As participants felt comfortable in their small groups, they were happy to challenge views they did not agree with and to report back on areas of consensus to plenary sessions.**

- **Efficient and timely recruitment of specialists, with a mix of options for how they contributed,** allowed participants in all eight groups to ask questions and get access to the information they needed. **Online delivery made it easier for specialists to take part and most found the role of presenting and answering questions in plenary and in small groups satisfying.** Many were happy to contribute to more than one group.

- **The Recollective platform added significant value.** The platform was a useful means for sharing materials and allowing individuals in special interest groups who needed to miss a workshop (e.g. new parents and individuals with conditions) to catch up and contribute in their own way. The online space also supplemented live (synchronous) deliberation with opportunities for individual (asynchronous) reflection between sessions. This added a rich layer of additional information for analysis in terms of what was similar and what was different between groups. The platform also worked well for collecting evaluation feedback and for identifying any outstanding questions or areas where participants felt they still needed answers.

- **More data was collected via Zoom and Recollective than in a typical face-to-face dialogue process.** In order to do justice to this data, the public dialogue report was also longer than usual, but commissioners were happy that all of the detail would be useful to different stakeholders.

- **Online dialogue raises new questions about the transparency and efficiency of data capture and nature of interaction between participants during small group discussions.** Facilitators took visible notes on shared screens during small group discussions. This proved a useful way of capturing headlines and gave participants time to digest each other's comments so they could return to, and build on, them. **It also made the data collection process more transparent: participants could challenge any inaccurate re-wording or interpretation of their points and gave them confidence to feedback key points to plenary.** However, there should also be space for other techniques such as facilitators taking off-screen notes or participants sharing their thoughts via the chat function or posting on virtual whiteboards as they would do in a face-to-face dialogue. This is most important during the early sessions to encourage more natural conversation flow.

Box 5.1: Specialists and observer reflections on what worked well

- *"I very much liked the way it was formulated and facilitated: people were allowed to talk, not talked at."*
- *"The convenience of joining from their own homes rather than some chilly town hall seemed to work for participants – they seemed to be genuinely engaged."*
- *"Quite good fun and that was part of the success – a challenge online but people really enjoyed taking part."*
- *"I particularly liked the exhaustive 'no stone unturned' approach [to facilitation]."*

Box 5.2: Participant reflections on the quality of the design and delivery (see also *Annex C*)

- *"The whole process was expertly and professionally facilitated from beginning to end. I know a lot of work would have gone into everything and you made it look seamless - which is testament to the efforts you all clearly go to."*
- *"The moderators were very pleasant and welcoming and they made the workshops much more fun than I expected them to be."*
- *"I have learnt so much and feel I have been able to add some personal experiences and worries and thoughts to the group."*
- *"I think this format of dialogue and homework projects is excellent. I think people are more likely to dialogue more confidently over an online format and the online homework gives you the space to bring your thoughts together and have the space to express them."*
- *"I felt very valued in this research. They made me feel like my voice truly mattered."*
- *"The facilitator did a fantastic job of including everyone, allowing us to speak when we felt we had something to contribute."*
- *"All the facilitators were excellent, thank you for helping me understand and challenge the views that I [heard] across the process."*
- *"It's very nerve-wracking speaking but I think I'm doing OK. It's great to hear people's opinions and thoughts."*
- *"It has been a really rewarding experience, listening to people and their personal stories, listening to doctors, scientists, field experts has made it relatively easy to understand it all - the thought process behind such a huge, life-altering decision process."*
- *"In particular, I would like to thank the parents of the children who have a genetic disorder for opening up. They have been very brave and may encourage others to opt into WGS when it starts. I was quite humbled by them."*

6. Costs and benefits

6.1 Costs

Financial costs

The financial budget for the dialogue delivery and independent evaluation was £226,975 split between UKRI, Genomics England and UKNSC. The budget included the costs of professional recruitment, thank you payments for the 133 participants and subscriptions for the Recollective online space. It also covered the costs of making short films as part of the stimulus materials and vox pop short videos for wider dissemination.

Based on previous experience with online dialogues, the delivery contractors had allowed for enough staff time to cover the additional preparation and analysis required for online processes. This included time for coordination of specialists, a lower facilitator: participant ratio (1:6), tech support before and during meetings and for managing the Recollective site, and additional analysis time for a greater volume of data. There was also sufficient budget for the senior team to share dialogue findings at the dissemination events. An advantage of the online budget compared to face-to-face was in the minimal costs of time and expenses for travel and subsistence costs, venues and catering and for independent notetakers in small groups.

Clarity about what the commissioners expected and constructive core team working relationships led to a smooth reporting process. The dialogue was delivered on budget, with an agreed one month no-cost extension. As one OG member noted: "*Overall I was very impressed with this as a robust way of getting public perspectives: not cheap but nevertheless great value for money.*"

In-kind costs

On top of financial costs we estimate that project partners, OG members and specialists invested a further £125-130K in kind (about 50% on top of the financial budget). This is based on estimates of their time contributed valued at an average opportunity cost of £500 per person per day. This contribution was split as follows:

- **Genomics England and UK NSC** shared project management responsibilities and each invested about two days a week over the course of the project. We estimate that, including one month's slippage in the overall schedule, they jointly spent between 165-175 days equivalent to around £82-87K on top of their financial contributions.
- **Oversight Group**. In line with their expectations most OG members contributed about two days. Online meetings were time-efficient and some members were happy to spend time they would otherwise have spent travelling contributing as specialists or observing workshops: about half attended at least one workshop. As a group they contributed an estimated £26K in time. Those interviewed felt this was commensurate with what they got out of taking part.
- **Specialists and observers** (29 including OG members) contributed an estimated 35 days of time, valued at £17K of in-kind contribution. Many were happy to contribute to more than one session or group.

6.2 Economic benefits

Unanticipated benefit

UKRI Sciencewise and UK NSC were able to commission HVM to undertake the additional mini dialogue within an allowable 10% extension on the main contract. This was a highly cost-effective approach for UK NSC. The project benefitted from admin cost savings (procurement and recruitment), reuse of some materials, and time savings in working with both participants and contractors who were well-versed in WGS for NBS. The work could be completed more quickly and at much lower cost than if it had been commissioned from scratch. The dialogue also added value to the WGS for NBS process, allowing UK NSC to feed in insights to the Genomics England pilot design team. The success of a second dialogue may also make it more likely that UK NSC goes on to commission similar research to complement its evidence gathering methods in future.

Potential longer-term economic benefits

The Generation Genome (2016) report[19] identified potential economic benefits of using WGS for newborn screening, such as allowing testing for multiple conditions and reducing the need for follow-up testing. The rapid pace of genomic discovery and dramatic fall in costs of sequencing a whole genome have now made population-wide testing an economic possibility. Widely cited figures suggest the average cost of testing - including costs of interpreting, communicating and follow-up on the results - has now fallen below 1000 pounds or dollars per person. The Government's Life Sciences Vision (July 2021)[20] anticipates that whole genome sequencing could now contribute to "*both superior healthcare and economic performance*."

Improvements to quality of life and savings in healthcare costs

- A recent US study – Project Baby Bear - shows that WGS tests for sick newborns and infants can have both clinical and economic benefits.[21]
- The application of WGS for screening the whole population of newborns – as opposed to those already showing symptoms – could also have societal benefits that outweigh costs (see *Box 6.1*).
- Genomics England's NGP design process will identify additional cost areas for a pilot that at least meets the principles which emerged from the public dialogue in terms of benefits (more actionable conditions identified at birth) and addressing potential harms (additional information and support to parents, training and NHS staff time and data security).
- If the pilot goes ahead, a full cost-benefit analysis will be carried out before a mainstream roll out. This will need to demonstrate that saved treatment costs and increased quality of life years (QALY) for patients more than outweigh the additional costs of running the service.

[19] https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/631043/CMO_annual_report_generation_genome.pdf

[20] https://www.gov.uk/government/publications/life-sciences-vision

[21] Rapid WGS for 178 sick babies sequenced provided diagnoses for 43% and resulted in 513 fewer days in hospital and an estimated saving of US$2.5 million in healthcare costs as a result of a better understanding of their illness and adapting their treatment accordingly

Box 6.1: Potential economic benefits of a successful WGS for NBS programme

- A recent compendium compiled by Bicks et al (2021)[22] identified some 600 genetic conditions which could be identified by WGS at birth. About half of these are conditions where interventions in early life would be beneficial in reducing or avoiding harm and, in some cases, avoiding death.
- Early treatment of these conditions could prevent the need for long-term hospitalisations, expensive diagnostic odysseys, and prevent life-altering, often irreversible side effects before they manifest.
- In over 90% of cases the interventions would be simple and inexpensive, involving minerals, vitamins or dietary change: only 8% of these conditions would require expensive therapies.
- Initial analysis by an expert sub-group of the Genomic Analysis in Children Task and Finish Group (2019)[23] found that 1 in 260 live births (2,612 children in 2017) were affected by a genetic condition which could be treatable.

Contribution to the UK economy

- The Genome UK report (2020), [24] notes that with the completion of the 100,000 Genomes Project and the launch of the NHS Genomic Medicine Service, the UK genomics research sector is well placed to benefit. The genomic sequencing sector is estimated to be worth £140 billion (Genomics Revolution, Dec 2021).[25]
- The Government has allocated £200m to a Life Sciences Investment Programme to deliver the objectives of the Genome UK report. Every £1 invested in genomics R&D by the Government is expected to stimulate a further £2 of private investment. Depending on the outcomes of the pilot design phase, the allocation for the Newborn Genetics Programme could be up to £100m.

[22] https://pubmed.ncbi.nlm.nih.gov/33350578/ online compendium of treatable genetic disorders, Dec 2020

[23] https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/781472/2019-update-to-the-rare-diseases-implementation-plan-for-england.pdf

[24] https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/920378/Genome_UK_-_the_future_of_healthcare.pdf

[25] https://publicpolicyprojects.com/wp-content/uploads/sites/6/2021/10/PPP-Genomics-Revolution-Report-FINAL.pdf, 2021

7. Conclusions, lessons and recommendations

7.1 Conclusions

Wider methodological learning

- Clear governance and project management arrangements are integral to the efficiency and effectiveness of dialogues of this type.
- Through the dialogue's delivery, best practice has emerged for undertaking deliberative workshops online. This includes the importance of keeping objectives clear for participants, and ensuring that sessions are not too long (optimally around 2.5-3 hours).
- Online sessions offered an opportunity to consider the transparency and efficiency of data capture. Through facilitators taking visible notes, participants could challenge inaccuracies or misinterpretations.
- The launch of the dialogue led to wide dissemination. This was supported by a well thought-through joint communications strategy.

Operational aspects and delivery of the dialogue

- The dialogue met all five of its objectives.
- Participants' consideration of how whole genome sequencing (WGS) might be used to look for a wider range of genetic conditions was covered in greater depth than deliberations on wider uses of WGS data. Several evaluation interviewees indicated that these wider uses could usefully be explored through further public dialogue.
- Participants indicated confidence that they had been able to contribute informed views; and that Genomics England and the UK National Screening Committee (UK NSC) would take their views on board.
- The dialogue has already had direct impacts on participants, wider stakeholders, and commissioning bodies (Genomics England and UK NSC) – including with respect to helping shape the vision and pilot design for the Newborn Genomes Programme.
- Participants enjoyed the process, and were enthusiastic about their role. Attendance levels were very high.
- The outputs of the dialogue, including a report of its findings, were well-produced, designed and written.
- The dialogue was delivered on budget.

7.2 Lessons on how to maximise the impact of the dialogue

The key factors which have helped this medium-sized but complex dialogue to have significant impacts include the following:

- **The sequencing of the dialogue in relation to commissioning body policy processes** so that findings have been able to feed into both organisations' decision-making processes.
- **The sphere of influence offered to public participants,** contributed to their confidence that they could make a genuine impact, and to the robustness of results for other stakeholders' reference and use.
- **The early decision to involve special interest groups** came at a point when they could be integrated into the design. This helped to build the findings' credibility and to surface views which might not otherwise have been heard.

- **The quality of the dialogue report and quotes from senior figures in the foreword** helped to give the report weight and credibility with a wide readership.
- **Careful attention to the communications and launch strategy from the outset** allowed a nuanced and open conversation on WGS for NBS to gradually build in the press, without the arguments becoming politicised.
- **The format of the high-profile launch event and efforts to socialise the findings with key audiences pre-publication** created an open and constructive environment for further conversations with stakeholders.
- **The online process created many opportunities to involve Genomics England, UK NSC and OG members as silent observers.** Seeing the workshops for themselves allowed a large group of practitioners to get a good understanding of what a public dialogue can deliver and has helped build ownership of the findings and enthusiasm for carrying out further dialogues.

7.3 Recommendations for Sciencewise

- **Encourage commissioners to convene the OG** and have a first meeting scheduled early in the process and ideally with a date for the first meeting set and included in the mini-competition document.
- **It is useful to build in more elapsed time (in this case six months) to the independent evaluation timetable** in order to gather evidence of how the commissioning bodies and others have used the findings and how it has affected their organisations.
- **Address communications, including any launch plans, throughout a project** from the inception meeting or an early dedicated comms meeting, keeping plans sufficiently flexible at an early stage so that they can adapt to opportunities.
- **When developing the business case, ensure that sufficient time and resource is allocated for analysis of the greater volume of evidence generated by online processes.**
- **Consider whether there may be a case for producing shorter report versions(s) for different audiences**: encourage commissioners to consider alternatives to a single large report (e.g. several smaller outputs or co-authored academic papers for different audiences) and factor this into the budget and timelines from the outset.

7.4 Recommendations for commissioners

- **Set out a very clear sphere of influence for participants so that they can fully invest in the process**. Sequence the dialogue process so that, even if there is some slippage, the findings can still feed into decision-making processes.
- **The scale of a dialogue can add to the perception that the results are robust and credible**. Planning for at least 100 participants allows some scope for recruiting groups who are both reflective of the general public and special interest groups.
- **Recruit senior OG members and specialists to give credibility to the process** and include them in the publication of findings (a signed report foreword, press interviews, quotes on websites).
- **Convene the OG as early as possible and ideally to coincide with the outputs of a separately commissioned literature review**. This can help to give the OG a real chance to help frame the dialogue and help the delivery contractors to hit the ground running.

- **Allow for continuous communication with the OG throughout the project** to keep them engaged so they help to disseminate findings and amplify the dialogue impact.
- **Attention to developing a comms and press strategy is worthwhile** in helping the messages to reach the right audiences. Enlisting senior support for communications activities is also useful, at an early stage and throughout.
- **Invisible working behind the scenes with senior staff is vital in creating a strong sense of ownership of the findings and enthusiasm for public dialogue as a methodology**. Consider using the opportunity of online processes to involve staff as silent observers so they can see how public dialogue works and hear directly from the public participants.
- **Care taken to socialise the findings before publication was helpful in understanding reactions from different stakeholders** and ensuring that these questions were answered at the main launch event.
- **Consider whether there are opportunities to go back to the cohort of informed participants** to test policy recommendations later in a policy process or to delve deeper into issues. For this dialogue, a 10% extension to the budget added real value in the form of a mini dialogue.

7.5 Recommendations for delivery contractors

- **Ensure that budgets and timelines are realistic** to allow for the additional volume and richness of data captured in online dialogue and for additional behind the scenes support tasks.
- **Consider a mix of workshop lengths** – slightly longer (3-hour) weekend sessions can work well to allow time for sharing information, asking questions and small group and plenary discussions. A 3-hour session with a short comfort break can cover more than the equivalent time in a face-to-face workshop. Fewer but slightly longer sessions may also be logistically more efficient, and easier to recruit participants for.
- **Plan for continuity in the facilitation team for each group.** This allows facilitators to get to grips with the structure and content of a complicated topic while building cohesive small groups.
- **Consider which elements in a project can be done without note-taking** to allow some free-flowing discussion at the beginning of the project to help form relationships and establish the tone, and then at the end when processes tend to be more reflective and final thoughts are being gathered.
- **Consider other options for participants to share their thoughts** e.g. via the chat function or posting to virtual whiteboards (e.g. on Zoom).
- **Consider when and how in a process to introduce creative elements** to prevent recourse to a standard model of "specialist presentation, discussion, Q&A".
- **An online space (such as Recollective) can add significant value to the design** allowing 'live' small group deliberations in workshops to be supplemented with 'asynchronous' individual deliberation, sharing of materials and evaluation feedback.

Annex A: Oversight Group members and roles

Members	Organisation
Chair: Anne-Marie Slowther	Professor of Clinical Ethics, Warwick Medical School, University of Warwick
Mark Bale	Head of Science Partnerships, Genomics England; Deputy Director, Science Research and Evidence Directorate, Department of Health and Social Care (DHSC)
Felicity Boardman	Prof. Medicine, Ethics and Society, University of Warwick, lead author of rapid evidence review
Jim Bonham	Laboratory Lead, Newborn Blood Spot Programme, Public Health England lead on UK NSC mini dialogue on Cystic Fibrosis
Phil Booth	Coordinator, med Confidential
David Elliman	Clinical Lead for NHS Newborn Infant Physical Examination Programme and NHS Newborn Blood Spot Screening Programme, Public Health England
Olga Ferguson	Programme clinical advisor, Sickle cell and thalassaemia screening programme, Public Health England
Joanne Harcombe	National Lead for Stakeholder Information and Professional Education and Training, NHS Screening Programmes
Kerry Leeson-Beevers	Project Lead, Breaking Down Barriers Alstrom Syndrome UK
Anneke Lucassen	Professor of Clinical Genetics, Honorary Consultant in Clinical Genetics, Wessex Clinical Genetics Service, Clinical Ethics and Law Unit, Faculty of Medicine, University of Southampton
Mavis Machirori	Research Associate, Policy, Ethics and Life Sciences (PEALS) Research Centre, University of Newcastle and Ada Lovelace Institute
Anne Mackie	Head of Screening, Public Health England
Fiona Maleady-Crowe	Head of Ethics, Genomics England
Rebecca Middleton	Vice-chair, Genomics England Participant Panel
Stuart Moat	Consultant Clinical Biochemist; Director - Wales Newborn Screening Laboratory and UK Labs Network and Welsh Infants' and Children's Genome Service (WINGS)
Sarah Norcross/Sandy Starr	Director/Deputy Director, Progress Educational Trust
Christine Patch	Clinical Lead for Genetic Counselling, Genomics England Previously on EU Genetic Public Policy Committee. Also attached to Society and Ethics Research group at Wellcome Genome Campus
Alexandra Pickard	Policy and Strategy Lead, Genomics Unit, NHS England
Jayne Spink	CEO, Genetic Alliance, and Rare Diseases UK
Bob Steele	Chair, UK National Screening Committee
Gail Walshe	Director of Participation and Regional Development, Contact – for disabled children
Vivienne Parry	Director of public engagement, Genomics England

Annex B: Methodology

B1: Locations, dates and characteristics of participant groups

Location	Dates of events	Characteristics
Scotland **Northern England** **Southern England** **Wales & Northern Ireland**	4th, 6th 11th, 27th February, and 1st March 8th, 13th, 22nd, 28th February and 3rd March	21 in each of the four regions. A mix reflective of gender, ages, ethnicity and SEGs with a range of views (hopefulness and interest) in science and health.
New or expectant parents	4th, 6th, 11th, 14th, and 18th March	14 pregnant women or their partners or new parents reflective of age, ethnicity and SEG profile for new parents. The evidence review and OG discussions highlighted a current lack of understanding about what new parents think about the existing NBS blood spot test and the current consent process – often effectively a tick box exercise carried out at a time of high emotion – and how it might need to be adapted in either of the WGS contexts being considered.
People, or parents/carers of those, with genetic conditions		14 individuals with lived experience across a range of genetic conditions routinely screened for at birth or which WGS could screen for in future. Charities represented on the OG and in stakeholder interviews stressed the importance of hearing from those with lived experience of diagnosed or undiagnosed genetic conditions. This experience might shape their views on which types of conditions should be tested for, how results should be shared, and families supported. While a number of patient groups have carried out their own research or conversations about WGS for NBS, OG members anticipated added value in bringing them into an independently run public dialogue. Participants recruited brought experience of sickle cell, familial hypercholesterolemia, lynch syndrome, BRACA, neurofibromatosis, congenital hearing loss, cardiomyopathy, and Fragile X.
Black or minority ethnic backgrounds	5th, 8th, 10th, 20th, 24th March	14 individuals from black or minority ethnic communities including a mix of gender, age and SEG. Several genetic conditions are either more prevalent in Black and minority ethnic communities (such as sickle cell anaemia or Tay-Sachs disease) or may be related to different genome glitches (Cystic Fibrosis). The 100,000 Genome Project database contains less data from minority ethnic communities meaning that individuals have less access to an accurate diagnosis. Previous Genomics England research has also shown that some communities may also have negative views about WGS and screening, shaped by past experiences of clinical research.
Young Adults		7 young adults aged 18-24 a mix of gender and ethnicity. The agreed dual contexts including WGS as a resource over an individual's lifetime pointed to the importance of involving young people to help understand their thinking about consent being given on their behalf, what information about later life risks should be shared, and at what stage, and their thoughts on long term storage of their genetic information.

B2: Purpose and content shared in each dialogue session

Focus of each session	Stimulus
Webinar 1 (1 hour 15 mins) **Introduction to the process and to population wide screening**	• Video - purpose of the dialogue and how the findings will be used • NHS videos "What is screening," "Screening tests for you and your baby" • PowerPoint – What is Screening; criteria for deciding on current blood spot testing (9 conditions) and criteria

Workshop 1 (2 hours 30 mins)
Explanations - what WGS is, what it can and can't do, and what is being explored in terms of NBS
	• Video – "Genes and WGS"
	• Specialist presentations/ talking heads videos WGS for NBS
	  • What genetic sequencing can/can't tell us now: single gene vs polygenic, role of environmental factors in health
	  • Why is WGS being considered in the context of newborn screening?
	  • Patient experience of WGS

Workshop 2 (2 hours 30 mins)
Context 1 – The potential use of WGS as a technology in addition to, or to replace some parts of, the current NHS newborn screening programme which has defined purposes and criteria
	• Specialist presentations/ talking heads:
	  • A disease currently screened for: cystic fibrosis from a parent/ patient view and a clinician perspective
	  • A disease not current screened for: Duchenne Muscular dystrophy – a parent view and clinician view on implications of WGS in newborn for such conditions
	  • Exploring issues such as uncertainty/penetrance with WGS in newborn screening
	• Case studies for NBS
	  • Cystic Fibrosis
	  • Duchenne Muscular Dystrophy

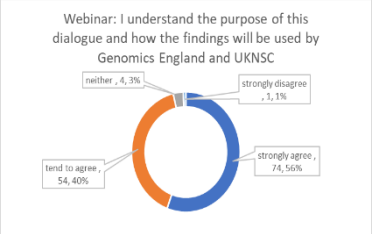
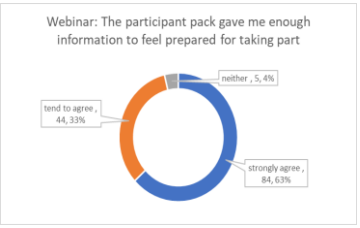
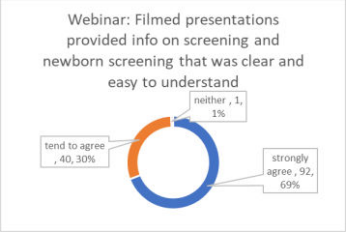
Workshop 3 (3 hours)
Context 2 – Potential novel uses of WGS in newborns beyond birth
	• Presentation /talking head video:
	  • Life course diagram
	  • Discussion on consent/informed choice
	  • Data storage and security
	• Case studies for wider scenarios:
	  • Information to personalise future drug therapies (pharmacogenomics)
	  • Condition that will not develop until later in life
	  • For wider medical and scientific research into genetic conditions.

Workshop 4 (2 hours 30 mins) **Concluding deliberations – aspirations, concerns for WGS in NBS & novel uses**	• Overview of all previous presentations, materials and case studies

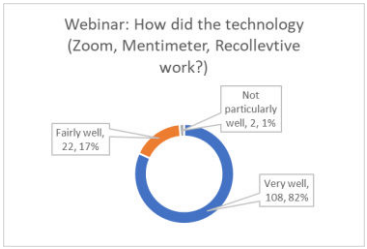
Annex C Evaluation feedback from participants

Genomics England and UKNSC public dialogue on WGS for NBS: Evaluation feedback from participants (Webinar n=133, Workshop 4 n=127)

Session 1: Webinar

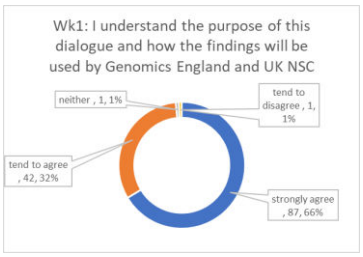
Q1	I understand the purpose of this dialogue and how the findings will be used by Genomics England and UKNSC	strongly agree	tend to agree	neither	tend to disagree	strongly disagree	
	Total	74	54	4	0	1	
	Total percentage	55.6	40.6	3.0	0.0	0.8	
	Scotland	10	10			1	
	Northern England	15	4	2			
	Southern England	14	7				
	Wales/NI	7	13	1			
	Genetic conditions	10	4				
	Pregnant women or partners	7	6	1			
	BAME	6	8				
	Young people	5	2				
Q2	The participant pack gave me enough information to feel prepared for taking part	strongly agree	tend to agree	neither	tend to disagree	strongly disagree	
	Total	84	44	5	0	0	
	Total percentage	63.2	33.1	3.8	0.0	0.0	
	Scotland	13	6	2			
	Northern England	14	6	1			
	Southern England	12	8	1			
	Wales/NI	12	9				
	Genetic conditions	9	5				
	Pregnant women or partners	7	7				
	BAME	11	2	1			
	Young people	6	1				
Q3	Filmed presentations provided info on screening and newborn screening that was clear and easy to understand	strongly agree	tend to agree	neither	tend to disagree	strongly disagree	

	Total	92	40	1	0	0
	Total percentage	69.2	30.1	0.8	0.0	0.0
	Scotland	17	4			
	Northern England	17	4			
	Southern England	12	8	1		
	Wales/NI	13	8			
	Genetic conditions	11	3			
	Pregnant women or partners	10	4			
	BAME	7	7			
	Young people	5	2			
Q4	How did the technology (Zoom, mentimeter, Recollective) work?	Very well	Fairly well	Not particularly well	Not at all well	
	Total	108	22	2	0	0
	Total percentage	81.8	16.7	1.5	0.0	0.0
	Scotland	15	5	1		
	Northern England	20	1			
	Southern England	17	4			
	Wales/NI	15	5	1		
	Genetic conditions	13	1			
	Pregnant women or partners	9	4			
	BAME	13	1			
	Young people	6	1			

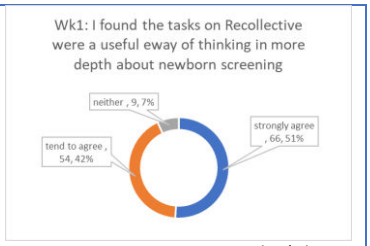


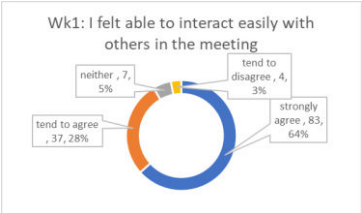
Session 2: Workshop 1 – Explanations

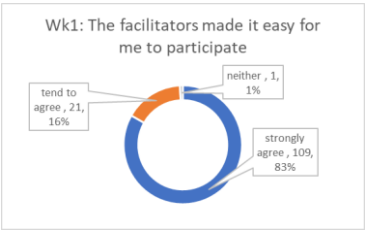
Q1 a	I understand the purpose of this dialogue and how the findings will be used by Genomics England and UKNSC	strongly agree	tend to agree	neither	tend to disagree	strongly disagree
	Total	87	42	1	1	0
	Total percentage	66.4	32.1	0.8	0.8	0.0
	Scotland	13	8			
	Northern England	15	4	1	1	
	Southern England	15	5			
	Wales/NI	11	10			
	Genetic conditions	9	4			
	Pregnant women or partners	10	4			
	BAME	9	5			
	Young people	5	2			

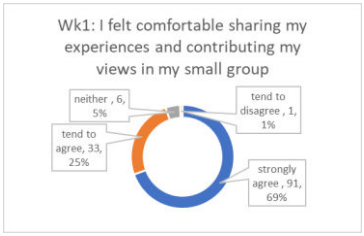
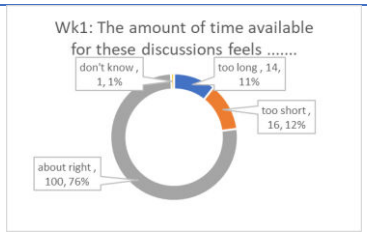


Q1	I found the task on Recollective was a useful way of thinking in more depth about newborn screening	strongly agree	tend to agree	neither	tend to disagree	strongly disagree	don't know
	Total	66	54	9	0	0	2
	Total percentage	50.4	41.2	6.9	0.0	0.0	1.5
	Scotland	12	9				
	Northern England	8	13				
	Southern England	8	11	1			
	Wales/NI	12	6	3			
	Genetic conditions	6	4	1			2
	Pregnant women or partners	9	5				
	BAME	7	3	4			
	Young people	4	3				
Q2	I felt able to interact easily with others in the meeting	strongly agree	tend to agree	neither	tend to disagree	strongly disagree	
	Total	83	37	7	4	0	
	Total percentage	63.4	28.2	5.3	3.1	0.0	
	Scotland	14	5	1	1		
	Northern England	12	6	1	2		
	Southern England	13	5	1	1		
	Wales/NI	15	5	1			
	Genetic conditions	7	6				
	Pregnant women or partners	9	3	2			
	BAME	7	6	1			
	Young people	6	1				
Q3	The facilitators made it easy for me to participate	strongly agree	tend to agree	neither	tend to disagree	strongly disagree	
	Total	109	21	1	0	0	
	Total percentage	83.2	16.0	0.8	0.0	0.0	
	Scotland	18	3				
	Northern England	16	4	1			
	Southern England	17	3				
	Wales/NI	16	5				
	Genetic conditions	12	1				
	Pregnant women or partners	14					
	BAME	10	4				
	Young people	6	1				
Q4	I felt comfortable sharing my experiences and contributing my	strongly agree	tend to agree	neither	tend to disagree	strongly disagree	

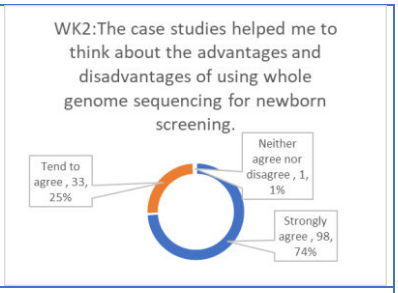




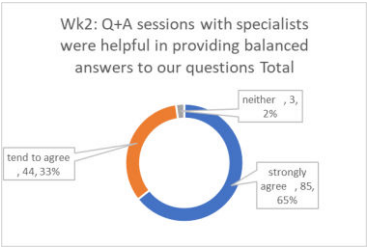


	views in my small group					
	Total	91	33	6	1	0
	Total percentage	69.5	25.2	4.6	0.8	0.0
	Scotland	13	7	1		
	Northern England	14	5	2		
	Southern England	16	3	1		
	Wales/NI	15	5	1		
	Genetic conditions	8	5			
	Pregnant women or partners	10	2	1	1	
	BAME	9	5			
	Young people	6	1			
Q5	The amount of time available for these discussions feels….	too long	too short	about right	don't know	
	Total	14	16	100	1	0
	Total percentage	10.7	12.2	76.3	0.8	0.0
	Scotland	1	4	16		
	Northern England	2	3	16		
	Southern England	1	3	16		
	Wales/NI	4		17		
	Genetic conditions	2	2	8	1	
	Pregnant women or partners	2	2	10		
	BAME	2	1	11		
	Young people		1	6		
Q7	How are you feeling about being part of this public dialogue process…?	(See box)				
Session 3: Workshop 2 - Context 1 WGS for existing NBS tests						
Q1	The case studies helped me to think about the advantages and disadvantages of using whole genome sequencing for newborn screening.	Strongly agree	Tend to agree	Neither agree nor disagree	Tend to disagree	Strongly disagree
	Total	98	33	1	0	0
	Total percentage	74.2	25.0	0.8	0.0	0.0
	Scotland	16	5			
	Northern England	17	4			

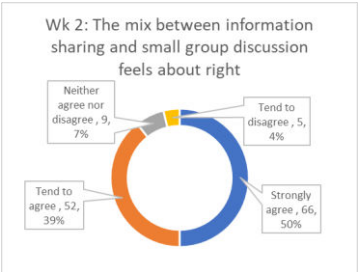
	Southern England	16	4			
	Wales/NI	14	7			
	Genetic conditions	9	4	1		
	Pregnant women or partners	8	6			
	BAME	13	1			
	Young people	5	2			



Q2	Q+A sessions with specialists were helpful in providing balanced answers to our questions	strongly agree	tend to agree	neither	tend to disagree	strongly disagree
	Total	85	44	3	0	0
	Total percentage	64.4	33.3	2.3	0.0	0.0
	Scotland	15	6			
	Northern England	9	11	1		
	Southern England	13	7			
	Wales/NI	12	8	1		
	Genetic conditions	9	4	1		
	Pregnant women or partners	10	4			
	BAME	11	3			
	Young people	6	1			

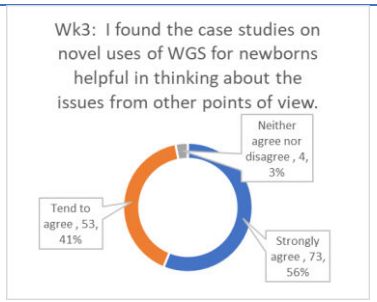
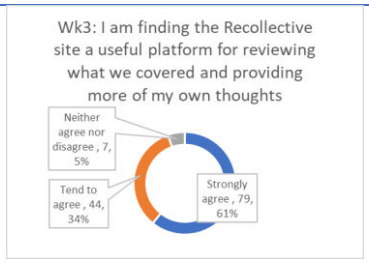


Q4	The mix between information sharing and small group discussion feels about right	Strongly agree	Tend to agree	Neither agree nor disagree	Tend to disagree	Strongly disagree
	Total	66	52	9	5	0
	Total percentage	50.0	39.4	6.8	3.8	0.0
	Scotland	15	5	1		
	Northern England	8	11	2		
	Southern England	6	10	2	2	
	Wales/NI	8	11	1	1	
	Genetic conditions	8	5	1		
	Pregnant women or partners	8	5	1		
	BAME	9	4	1		
	Young people	4	1		2	

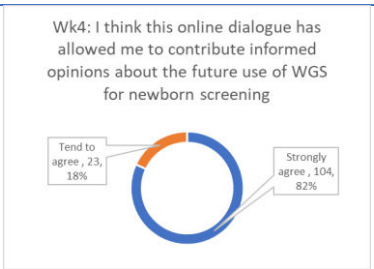


Session 4: Workshop 3 - Context 2 WGS for innovative uses or during life courses

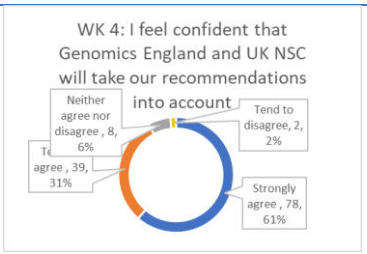
Q1	I found the case studies on novel uses of WGS for newborns helpful in thinking about the issues from	Strongly agree	Tend to agree	Neither agree nor disagree	Tend to disagree	Strongly disagree

	other points of view.					
	Total	73	53	4	0	0
	Total percentage	56.2	40.8	3.1	0.0	0.0
	Scotland	13	8			
	Northern England	9	11	1		
	Southern England	9	11			
	Wales/NI	11	9	1		
	Genetic conditions	8	4	1		
	Pregnant women or partners	9	4	1		
	BAME	9	4			
	Young people	5	2			
Q2	I am finding the Recollective site a useful platform for reviewing what we covered and providing more of my own thoughts	Strongly agree	Tend to agree	Neither agree nor disagree	Tend to disagree	Strongly disagree 
	Total	79	44	7	0	0
	Total percentage	60.8	33.8	5.4	0.0	0.0
	Scotland	13	8			
	Northern England	11	9	1		
	Southern England	16	3	1		
	Wales/NI	10	9	2		
	Genetic conditions	10	2	1		
	Pregnant women or partners	9	4	1		
	BAME	5	8			
	Young people	5	1	1		
Q3	The facilitation has been professional, independent, and effective	Strongly agree	Tend to agree	Neither agree nor disagree	Tend to disagree	Strongly disagree 
	Total	114	16	0	0	0
	Total percentage	87.7	12.3	0.0	0.0	0.0
	Scotland	18	3			
	Northern England	15	6			
	Southern England	19	1			
	Wales/NI	17	4			
	Genetic conditions	12	1			
	Pregnant women or partners	13	1			
	BAME	13				
	Young people	7				
Session 5: Workshop 4 - Final deliberation						

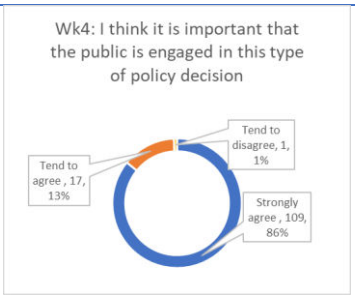
Q1	I think this online dialogue has allowed me to contribute informed opinions about the future use of WGS for newborn screening	Strongly agree	Tend to agree	Neither agree nor disagree	Tend to disagree	Strongly disagree
	Total	104	23	0	0	0
	Total percentage	81.9	18.1	0.0	0.0	0.0
	Scotland	16	4			
	Northern England	15	6			
	Southern England	17	3			
	Wales/NI	16	5			
	Genetic conditions	12	1			
	Pregnant women or partners	11	1			
	BAME	11	2			
	Young people	6	1			



Q2	I feel confident that Genomics England and UKNSC will take our recommendations into account in deciding how it is rolled out	Strongly agree	Tend to agree	Neither agree nor disagree	Tend to disagree	Strongly disagree
	Total	78	39	8	2	0
	Total percentage	61.4	30.7	6.3	1.6	0.0
	Scotland	15	4	1		
	Northern England	10	9	1	1	
	Southern England	11	9			
	Wales/NI	7	7	6	1	
	Genetic conditions	13				
	Pregnant women or partners	5	7			
	BAME	11	2			
	Young people	6	1			



Q3	I think it is important that the public is engaged in this type of policy decision	Strongly agree	Tend to agree	Neither agree nor disagree	Tend to disagree	Strongly disagree
	Total	109	17	0	1	0
	Total percentage	85.8	13.4	0.0	0.8	0.0
	Scotland	17	2	0	1	
	Northern England	19	2			
	Southern England	18	2			



	Wales/NI	17	4			
	Genetic conditions	11	2			
	Pregnant women or partners	9	3			
	BAME	12	1			
	Young people	6	1			
Q4	Overall, I am satisfied with having taken part	Strongly agree	Tend to agree	Neither agree nor disagree	Tend to disagree	Strongly disagree
	Total	119	8	0	0	0
	Total percentage	93.7	6.3	0.0	0.0	0.0
	Scotland	19	1			
	Northern England	20	1			
	Southern England	19	1			
	Wales/NI	19	2			
	Genetic conditions	13				
	Pregnant women or partners	11	1			
	BAME	12	1			
	Young people	6	1			