



April 2019

A public dialogue on genomic medicine: time for a new social contract?

Key findings and conclusions

Ipsos MORI



UK Research
and Innovation

Acknowledgments

This public dialogue on genomic medicine was co-funded by Genomics England, the Sciencewise programme¹, and by the Scottish Genomes Partnership². The authors would like to thank Genomics England, the Scottish Genomes Partnership and Sciencewise for their support and advice, and the members of the Oversight Group (OG), which was supported by Genomics England, for all their invaluable contributions throughout the study.

We would also like to thank all the public participants, clinicians, researchers, genomics counsellors, stakeholders and OG members who contributed to and reviewed materials, attended the dialogue events and were willing to discuss their hopes and priorities for genomic medicine in the NHS.

We would also like to thank Anna MacGillivray, the project evaluator, for her constructive formative feedback through the course of the study.

Our utmost thanks go to the 100,000 Genomes Project Participant Panel for their time and attendance at the dialogue workshops.

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

² The Scottish Genomes Partnership is funded by the Chief Scientist Office of the Scottish Government Health Directorates [SGP/1] and The Medical Research Council Whole Genome Sequencing for Health and Wealth Initiative (MC/PC/15080).

Executive summary

1. Introduction: a dialogue to capture public views of genomics

The NHS Constitution reminds us that our health service is founded on a common set of principles and values that bind together patients, the public and staff so that it is effective and equitable. It recognises that each party has roles and responsibilities and therefore the Constitution can be seen as a form of '**social contract**' which aims to bring the highest levels of human knowledge and skill to save lives and improve health.

The Chief Medical Officer for England's 2016 Annual Report, '**Generation Genome**' argued for a re-thinking of the wider **social contract** in healthcare today, taking into account four areas³ of medical and research practice. It also provided a public statement on the purposes and benefits of genomic data in the NHS.

The purpose of this dialogue was to take into account members of the public's priorities and concerns when considering **how genomics might alter or affect the social contract in healthcare**. This was in order to inform the way genomics should be mainstreamed in the NHS in England, as well as to inform healthcare policymaking in Scotland, and the future of genomics more broadly.

Why was a Sciencewise public dialogue the most suitable approach to canvass the public's views on a genomics future?

A Sciencewise public dialogue provides in-depth insight into citizens' views, concerns and aspirations on issues relating to science and technology⁴. These issues are often complex and unfamiliar to citizens and therefore their exploration is better suited to a qualitative approach.

How are this dialogue's findings valid?

Applying criteria used in the social science literature⁵ to determine the credibility of qualitative research findings, we can be confident that the principles and views presented here are credible and valid due to the following strategies used in this dialogue:

- a) **accounting for researcher bias** – in order to ensure the information given to the dialogue participants was balanced, we engaged with a diverse range of expert perspectives, including data privacy campaign groups, all of which fed into the development of the research materials and stimulus.
- b) **accounting for sampling bias** – the dialogue participants were recruited to be reflective of the wider UK population, using quotas informed by UK census data.
- c) **accounting for research bias** – participants were given all the information to enable them to develop their views, and given time to reflect between events. Experts rotated to each discussion group to ensure the participants were exposed to the same sort of information. Plenary sessions were built in to each event so we were able to identify a range of views including commonalities and outliers.

³ The four areas are: consent, confidentiality and the availability of the best care for patients and families, obligations of health professionals, lab staff and researchers; system responsibilities.

⁴ <https://sciencewise.org.uk/about-dialogue/what-is-public-dialogue/>

⁵ <https://ebn.bmj.com/content/18/2/34>

- d) **meticulous record keeping and systematic analysis** – a transcript was produced from each discussion group, with each one analysed using qualitative social science technique. A series of analysis sessions attended by the Ipsos MORI team, the independent evaluator and Genomics England has ensured that all the different perspectives are represented in this report.
- e) **participant and expert validation** – bringing participants back to a final genomics summit enabled us to explore key issues in further detail and thereby validate the views we noted in previous workshops. Experts who observed and participated in the dialogue discussions have reviewed the report and given feedback.
- f) **data triangulation** – the views and perspectives of the dialogue participants are supported by the rapid evidence review, and other relevant research, all of which are referenced throughout this report, where appropriate.

Are these findings representative / generalisable? This dialogue sought to understand the depth and complexity of views on a genomic medicine service and the impact of information on these views. In contrast with quantitative approaches, dialogue findings are not statistically significant. However, dialogue enables us to explore the values and reasons underlying the views expressed.

How is this public dialogue useful to decision-makers? A dialogue is a valid and robust way to inform policy, especially to inform understanding of the range of options open to policy makers which will fit with the sensibilities of the public; and why the public think the way they do. The culmination of this public dialogue is this report which provides detailed and nuanced evidence on how citizens' views, concerns and aspirations can be operationalised in a genomics future.

Ninety-seven members of the public, and thirty experts came to evening and reconvened day-long Saturday events in Coventry, Edinburgh, Leeds, and London. A proportion of each group was reconvened to a final Genomics summit event in London (n=23 in total), where the group was again joined by experts. A total of forty-three experts attended the dialogue workshops and the Genomics summit. The sessions were facilitated by a team from the Ipsos MORI Public Dialogue Centre.

A **rapid literature review** was conducted to inform the dialogue materials and to ensure that the project built on the work of previous social research on attitudes to genomics. The structure of the dialogue was developed in partnership with the Oversight Group, and materials and key questions were workshopped prior to the dialogue workshops with an external group of 15 stakeholders reflecting a range of perspectives.

2. Public views of the healthcare social contract

The dialogue participants were not familiar with the term ‘social contract’ or the explicit concept to which it refers. However, when participants discussed during the dialogue how they think healthcare works now, and how genomics should operate in society, their responses were predicated on assumptions about the **social contract** that they believe to be in place. We are therefore able to draw out the ingredients they feel this contract should have.

First, they had some clear perceptions of how they felt the social contract works today (before considering the idea of genomics). They saw it including three elements; **reciprocity, altruism, and solidarity**.

Reciprocity meant a ‘transactional relationship’ in which users “give” and “get”. Expectations were:

- The NHS will provide **evidence-based care**.
- Patients are given **diagnoses and information about their condition**, and the chance to discuss this with their **doctor**.
- Doctors are trusted to **only share patient information and data with those who are directly involved in a patient’s care**.
- The Government’s role is to **manage and deliver healthcare services efficiently**, through taxes collected centrally.
- Users (patients and the wider public) are expected to **behave well** (e.g. to not abuse NHS staff), to **value resources** (e.g. turn up for appointments on time) and **support the NHS**; understand and appreciate the value of the care given.

The social contract also requires **altruism**:

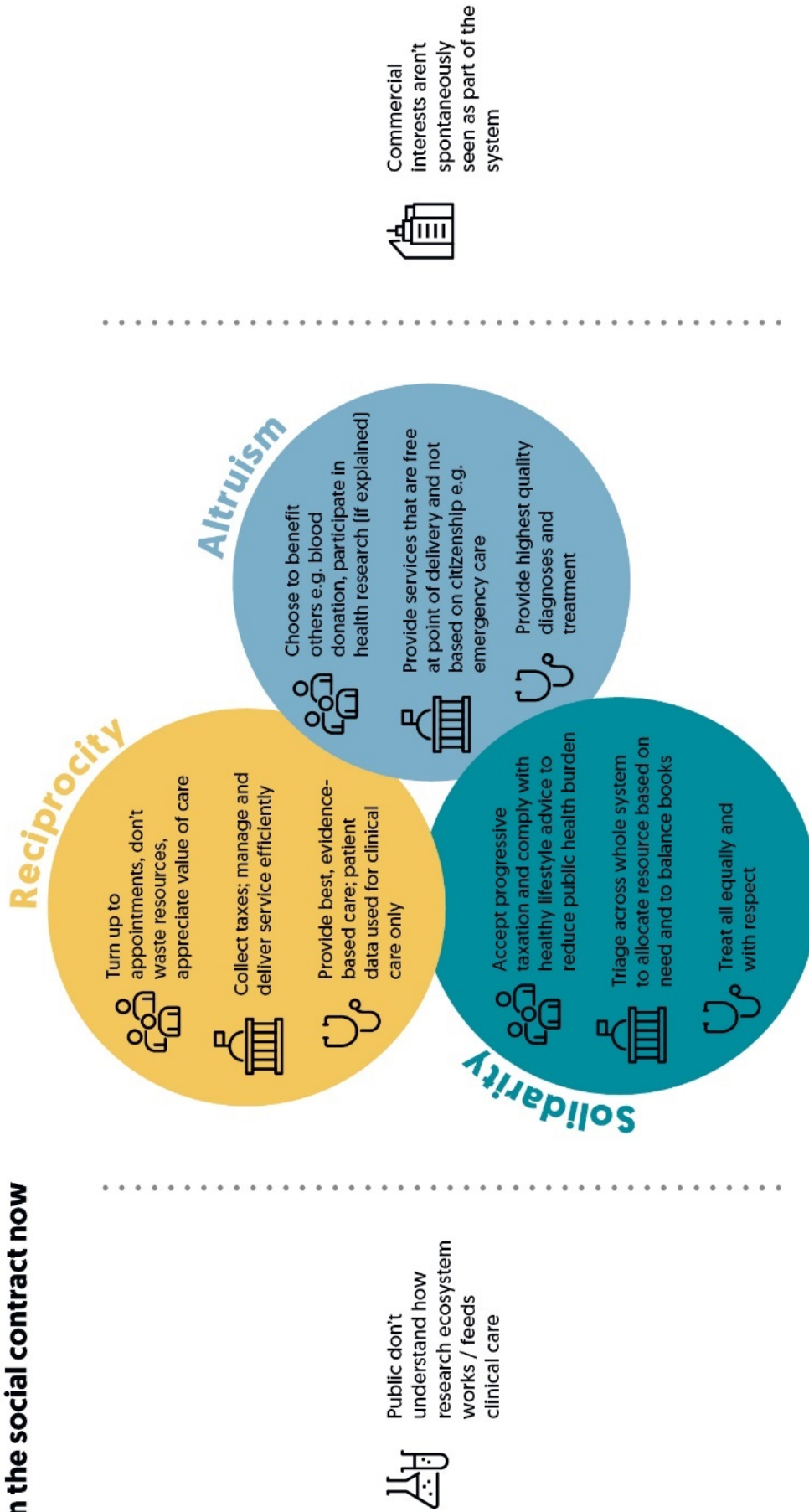
- Members of the public are expected to **want to benefit others as well as themselves**, and behave altruistically (e.g. donating blood, letting ambulances through traffic).
- Participation in health research (when understood) was seen as an altruistic act, as it often does not deliver immediate individual benefits.
- The NHS should provide healthcare services that are **free at the point of delivery**; regardless of a person having UK citizenship; there was **an inbuilt moral stance that it would be wrong to deny care to anyone**, especially emergency care.

Solidarity was the third key aspect of the social contract, requiring:

- A shared acceptance of paying for healthcare by **progressive taxation**.
- Public acceptance that individual good health contributes to the public good, and complying with health instructions (e.g. vaccinations) to reduce the public health burden.
- The NHS is expected to carry out **effective triage**, so that patients priority for treatment is based on clinical need.
- Clinicians exercising a **moral and ethical duty to treat everyone equally and with respect**.

Importantly, in dialogue participants’ conception of the social contract, **expectations of researchers were often absent; and the role of commercial companies was ignored**. This reflects the fact that the general public are generally not aware of the role biomedical research plays in the healthcare system, or the role that charities, industry, and others play in the existing system.

Public views of key behaviours in the social contract now



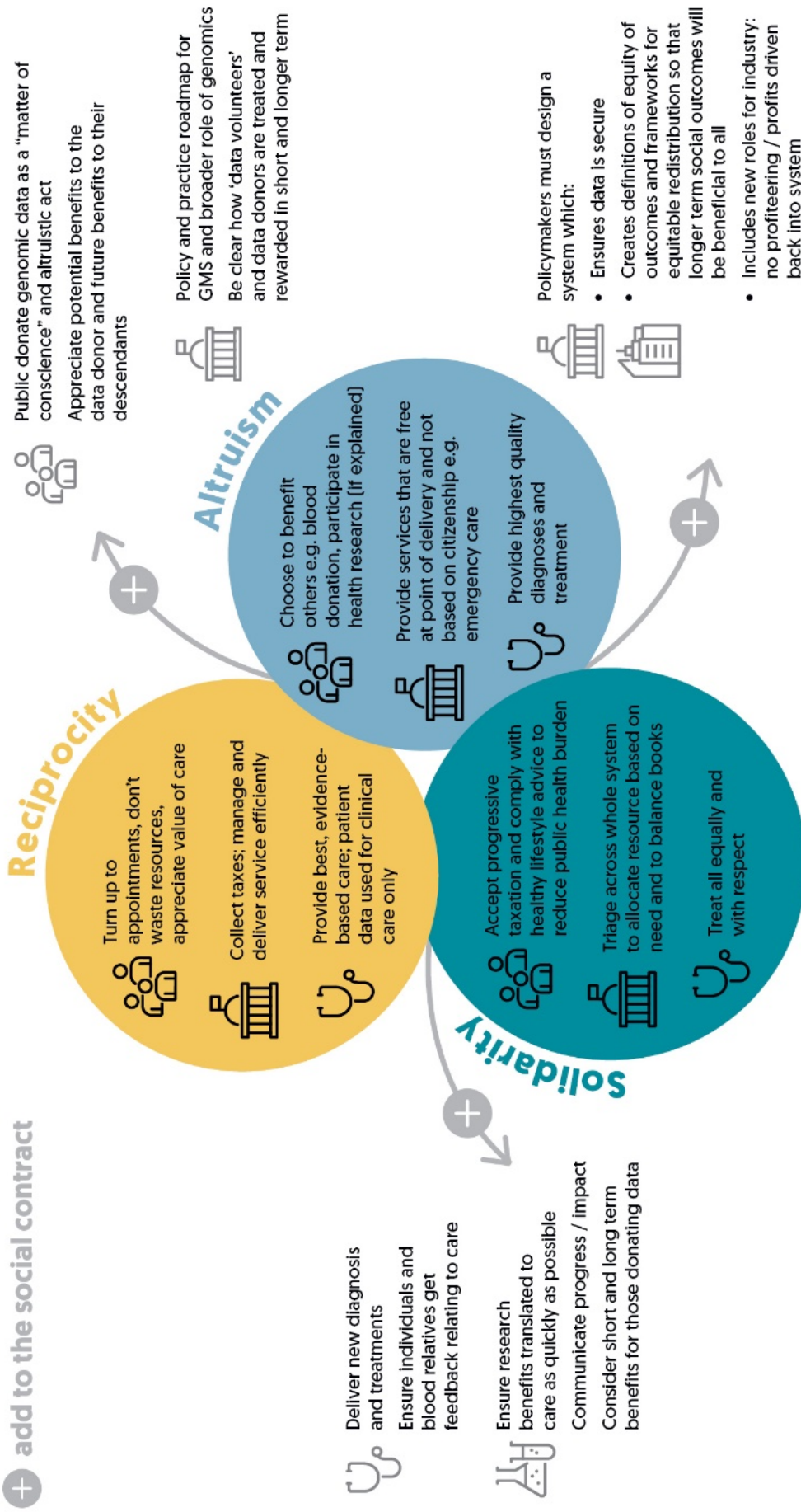
3. What genomics might add to the social contract

By the end of the dialogue, participants had discussed the implications of genomics for the social contract. Overall, in a genomics-driven healthcare of the future, they felt the principles of reciprocity, altruism and solidarity would need to remain core to the social contract, and require largely the same behaviours of all the actors.

However, the new science of genomics means that the **three elements might intersect in new ways** - leading to **new expectations of behaviours of all actors in the system**.

- **Reciprocity ↔ Altruism:** Analysing an individual's genome requires that data has been donated by many. This is because an individual's data needs to be compared against that of others to properly inform their diagnosis and treatment. This blurs the line between reciprocity and altruism. The public in the dialogue saw giving their data as an altruistic act - but also expected benefits would probably accrue to their families and descendants.
 - There would, therefore, be an increased expectation that the public would donate data, but participants felt that data donation should not be mandatory.
 - Participants thought that government and healthcare policy makers would need to create a roadmap for genomics where the status of data donors is made clear, and any rewards for them carefully worked out.
- **Reciprocity ↔ Solidarity:** Genomics can use patient data in research and clinical care at the same time, creating a feedback loop between both to increase possible learning. Participants felt that this **research/clinical blurring** brought the ideas of reciprocity and solidarity closer together.
 - Both clinicians and researchers in a genomics future would be responsible for ensuring that patients and families are informed about the progress of research.
 - They should also focus on translating the benefits of research into care, to help all of society, as quickly as possible.
 - Both researchers and clinicians should communicate to the public what they are doing with genomic data, and the link between their work and making discoveries with clinical impact; so the public can know their collective action is worthwhile and having impact.
- **Solidarity ↔ Altruism:** In the future, if large genomic datasets exist, and can potentially be accessed by new actors (such as commercial companies) social solidarity will be affected by the altruistic acts of individual donors. Dialogue participants felt that:
 - Policy makers should take the long view – design a future which prevents dystopian social outcomes. Participants emphatically did not want their donation of genomic data used outside of healthcare and research in ways that would create a stratified society which disenfranchises vulnerable members. (e.g. using predictive genomic testing when a person applies for insurance) or different racial or ethnic groups.
 - There would be a new role for industry in bringing the benefits of genomics to society; but either voluntary or external regulation will be needed. Again, participants did not want to see the altruistic data donations of individuals used to enable private sector profiteering.

Public views of what genomics will



4. What genomics might change about the social contract

As well as these additions, participants also felt there would be one change to the social contract; **genomics changes the expectation that clinicians will only share data with those involved directly in patient care.** This leads to new duties of care for both researchers and clinicians.

- Participants wanted to empower **clinicians to make the final decisions on disclosing information** (for instance, to family members affected by test results). However, participants acknowledged that this was not an easy recommendation to make, and often changed their views on whether there should be a general policy or whether clinicians should judge on a case-by-case basis. On one hand they wanted decision-making to be shared with patients and very transparent, and they wanted patients to be able to challenge decisions they did not agree with. Yet on the other hand, they did not want to add any administrative burden on clinicians from a medico-legal perspective, which making such decisions would involve.
- After deliberation, participants were broadly happy to accept the **uncertainty** of not knowing what information genomics might reveal, and **trade off complete confidentiality** against potential benefits for themselves and others, as part of their broad consent to participate in genomics research.

Participants felt both clinicians and researchers should be equipped with “**genomic literacy**” to support the informational, emotional and practical needs of patients and data donors; giving more information and support than has been necessary in the past when communicating with research participants.

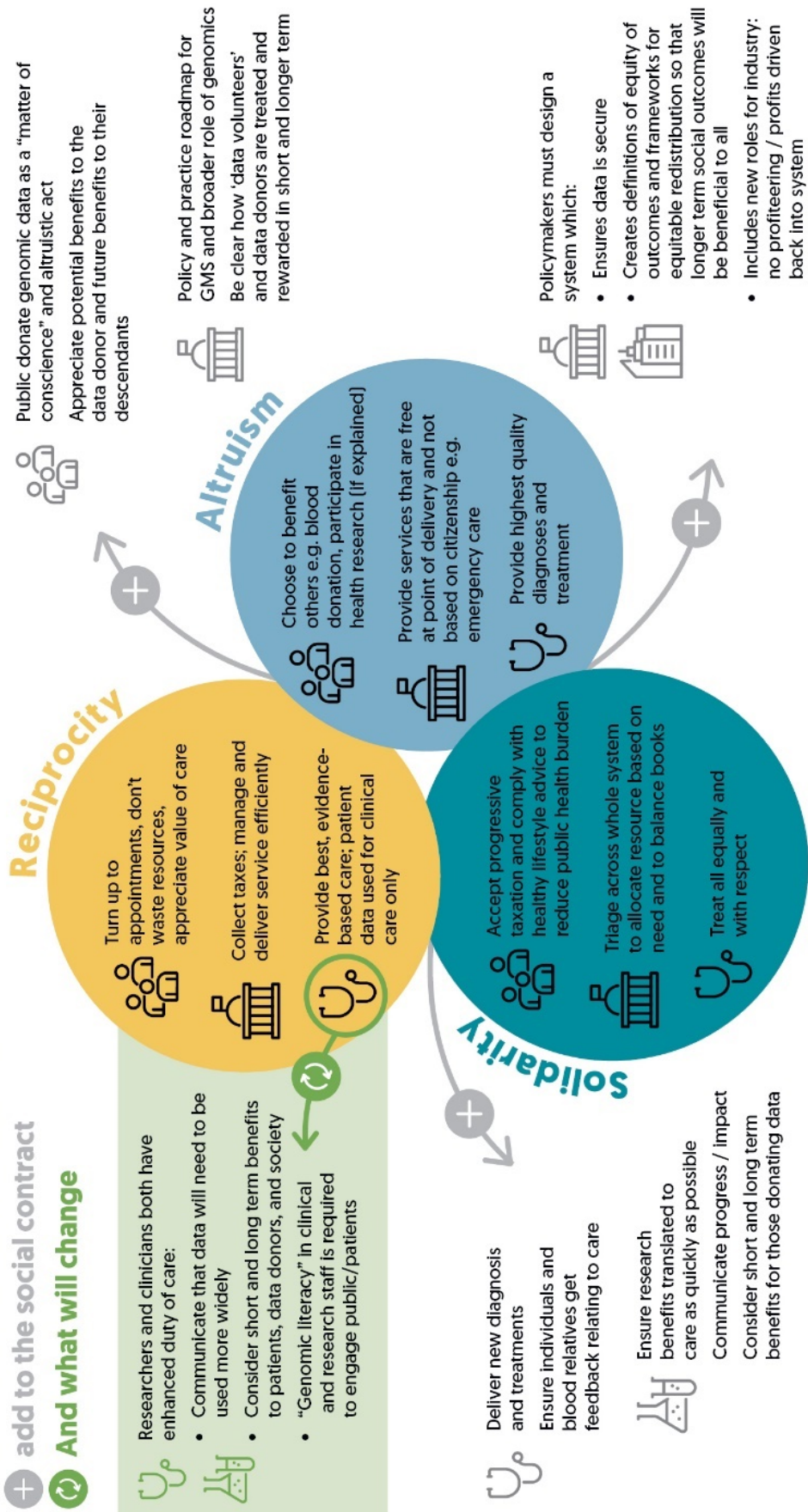
Public views of what genomics will

+ add to the social contract

🔄 And what will change

Researchers and clinicians both have enhanced duty of care:

- Communicate that data will need to be used more widely
- Consider short and long term benefits to patients, data donors, and society
- "Genomic literacy" in clinical and research staff is required to engage public/patients



5. Red lines: unacceptable uses of genomic data

Participants had some clear limits for how far they thought genomic data, and information derived from genomic analysis, should be used.

- **Genetic engineering:** Participants saw huge ethical issues around editing the human genome, especially to enhance human capabilities. They wanted to prevent this happening, at least without much more public engagement around the uses of genomic data.
- **Surveillance society:** many participants had a sense of fatalism that the day would come when genomic data would be used, either by corporate interests (e.g. insurance) or by the state (e.g. crime and justice and taxation) to stratify society in order to identify and penalise individuals with acute healthcare needs, and unfairly monitor groups in society; they wanted to prevent this.
- **Administrative and political uses:** there was a general feeling that more data is being collected all the time which has the potential to be used in ways which reduce access to state funded services such as welfare, and create a general sense of control in society; participants wanted to prevent this.
- **Predictive insurance tests:** participants were not supportive at all of using genomic information to set personal insurance premiums
- **Targeted marketing:** participants were very clear that data should not be used for marketing, or other areas of product development which might enable profiteering, especially by international corporates.

Participants wanted assurances from policy makers, the government, as well as independent stakeholders (e.g. data privacy campaign groups) that there is a robust governance framework in place which ensures their red lines don't happen in practice, which incorporates a consent process that makes it clear what researchers intend to do with genomic data.

Public views of what genomics will

change + **...and red lines**

Reciprocity

Altruism

Solidarity

Researchers and clinicians both have enhanced duty of care:

- Communicate that data will need to be used more widely
- Consider short and long term benefits to patients, data donors, and society
- "Genomic literacy" in clinical and research staff is required to engage public/patients

Turn up to appointments, don't waste resources, appreciate value of care

Collect taxes; manage and deliver service efficiently

Provide best, evidence-based care; patient data used for clinical care only

Choose to benefit others e.g. blood donation, participate in health research (if explained)

Provide services that are free at point of delivery and not based on citizenship e.g. emergency care

Provide highest quality diagnoses and treatment

Accept progressive taxation and comply with healthy lifestyle advice to reduce public health burden

Triage across whole system to allocate resource based on need and to balance books

Treat all equally and with respect

Deliver new diagnosis and treatments

Ensure individuals and blood relatives get feedback relating to care

Ensure research benefits translated to care as quickly as possible

Communicate progress / impact

Consider short and long term benefits for those donating data

Public donate genomic data as a "matter of conscience" and altruistic act

Appreciate potential benefits to the data donor and future benefits to their descendants

Policy and practice roadmap for GMS and broader role of genomics

Be clear how "data volunteers" and data donors are treated and rewarded in short and longer term

Data should not be used for marketing or other uses which enable profiteering (especially by international corporates)

Genomic information should not be used to set personal insurance premiums unless substantiated that the applicant has inherited the defective gene

Policy and practice roadmap for GMS and broader role of genomics

Be clear how "data volunteers" and data donors are treated and rewarded in short and longer term

Data should not be used for marketing or other uses which enable profiteering (especially by international corporates)

Genomic information should not be used to set personal insurance premiums unless substantiated that the applicant has inherited the defective gene

Policy and practice roadmap for GMS and broader role of genomics

Be clear how "data volunteers" and data donors are treated and rewarded in short and longer term

Data should not be used for marketing or other uses which enable profiteering (especially by international corporates)

Genomic information should not be used to set personal insurance premiums unless substantiated that the applicant has inherited the defective gene

Policy and practice roadmap for GMS and broader role of genomics

Be clear how "data volunteers" and data donors are treated and rewarded in short and longer term

Data should not be used for marketing or other uses which enable profiteering (especially by international corporates)

Genomic information should not be used to set personal insurance premiums unless substantiated that the applicant has inherited the defective gene

Policy and practice roadmap for GMS and broader role of genomics

Be clear how "data volunteers" and data donors are treated and rewarded in short and longer term

Data should not be used for marketing or other uses which enable profiteering (especially by international corporates)

Genomic information should not be used to set personal insurance premiums unless substantiated that the applicant has inherited the defective gene

Design governance frameworks to prevent the development of a surveillance society – either from corporate interests (e.g. insurance) or by the state (e.g. crime & justice, immigration, taxation)

6. Communicating genomics as a collective endeavour in healthcare

This dialogue suggests that the public are likely to be open and welcome to the idea of using genomics more widely in healthcare.

- Initially, participants had a **limited understanding of genomics**; almost nobody had heard of a 'genome' or 'genomics'. When introduced to the ideas, however, almost all responded positively and many developed high **expectations of genomics**, envisaging a near-term future with new treatments and personalisation of care, and significant cost savings for the NHS. Others were initially worried about who would be using their genomic data and for what purposes even though they could recognise the benefits of their genomic data being used in health research.
- **Almost all were relaxed about their health and genomic data being used in health research.** This support is, however, conditional on consent being obtained first; the use of de-identified data only and red lines being respected; robust risk assessment and safeguards being implemented and maintained by policy makers, researchers and clinicians; and genomics seen to be having real clinical impact.

Realising the potential of genomics in the longer term will require a **critical mass of UK citizens supporting it to the extent they are willing to participate**. While this is a longer-term aim, creating and implementing a genomics narrative should be an immediate priority as the dialogue participants were clear that policy makers and the NHS have a responsibility to do more to inform people about genomics.

The narrative on genomics will need careful framing, because, if the benefits of genomics are over-hyped, or the uncertainties or limitations downplayed, there is a **risk of fracturing the public's trust in genomics**, and in health research more generally. Communications should convey the idea that genomics is an **ambitious, potentially ground-breaking programme of activities** that aims to:

- redefine what best care is: for example genomics is moving away from "one size fits all" treatments to patient care tailored to their unique genetic make-up
- deliver new medical discoveries
- but also change healthcare in ways which cannot be predicted with certainty.

It should not be confused with a service like blood or organ donation; a key misunderstanding in discussions. Instead, communicating the idea of a **"national moonshot"** or shared endeavour may work to link genomics to a wider UK programme of innovation in which we are all involved.

In the longer-term as genomic medicine is scaled-up, genomics will need a call to action - if a social contract around genomics is going to work the public need to know what genomics is and be motivated to take part, so there is a need for a mission statement that conveys the idea that success needs solidarity, altruism and reciprocity. We can infer from the participants' discussions that the following statement might work as a call to action, as well as communicate the essence of the social contract in an intelligible way.

"People powered genomics".

As genomics evolves, further public and stakeholder engagement may be needed to ensure the social contract remains relevant and useful.

Conclusions

The insight from the genomics literature review, plus the input from experts, as well as contributions from members of the public and patients have enabled us to offer conclusions and advice for what to do next in the NHS Genomic Medicine Service.

Governance framework for genomics

- **Policy makers and the UK government will need to provide reassurance on the use of patients' data.** Specifically, they will need to inform the public that they will remain responsible for patient data and ensure the system conforms to the highest standards of data security and governance across sectors and national jurisdictions, and be accountable (individually and organisationally) if things go wrong.
- **Access to data by insurance companies, or other private sector organisations, needs to be carefully reviewed,** as the new ABI code approach was seen as too 'voluntary', leaving too much to the discretion of private companies.

New definitions for equity of outcomes and access

- In the short-term, the dialogue participants recognised that genomics is in its early stages and **could accept that the benefits of genomics won't be equally distributed across the UK population.**
- But, in the longer-term, the **public want to be reassured that their altruistic act will not be wasted,** and that the budget for genomic medicine allows all sections of society to benefit fairly. The long-term roll-out should be **nationally balanced both in terms of equity of access and outcomes.**
- Policy makers and the NHS will need to tell the wider public **what are the expected timescales for adding other conditions and diseases to the genomic test directory⁶,** so as to manage expectations, while maintaining support for investing in genomics.
- Participants thought that **policy makers should implement a mechanism** which delivers treatments for rare/ultra-rare diseases, a fair price for new treatments, and re-investment in clinical care and research, in recognition of the fact that genomics creates new financial opportunities for pharmaceutical companies.

Inscribing the genomics social contract in the NHS constitution

Actors in the genomics system should not use the term social contract; it is not widely understood and is not likely to resonate with the public. However, participants in this dialogue concluded that the **elements of the social contract do need to be written down,** and then communicated to everyone who has a role to play in genomics.

⁶ <https://www.england.nhs.uk/publication/national-genomic-test-directories/>

The key elements which need to be communicated are the **new expectations of behaviours of all actors in the system**, which we have noted in the main report.

“There have to be guidelines in the world of genomics. Everyone has to understand where the responsibilities fall.” Leeds event 2

Finally, given the profound effect that genomics is likely to have on healthcare in the UK, **we recommend inscribing in the NHS constitution**: the ways in which genomics adds to, and changes, the social contract.

Sarah Castell
Quality Director
Sarah.Castell@ipsos.com

Graham Bukowski
Project Director
Graham.Bukowski@ipsos.com

Sam Yetman
Project Executive
Samuel.Yetman@ipsos.com



For more information

3 Thomas More Square
London
E1W 1YW

t: +44 (0)20 3059 5000

www.ipsos-mori.com
<http://twitter.com/IpsosMORI>