UK Research and Innovation

sciencewise

How should society shape the future of life?

Insights from a decade of Sciencewise public dialogues

The UKRI Sciencewise public dialogue programme connects the public to decision making about science and technology, leading to better research, better policy and better outcomes.

Reports published on over 60 Sciencewise public dialogues, carried out with UK Government, the Research Councils and third sector organisations, have had major impact on UK science and innovation policy and research.[1]

These reports represent a significant body of evidence about public views and preferences on socially important scientific and technological questions.

About this report

This report draws together findings from multiple Sciencewise dialogues conducted over the last decade in relation to the life sciences and biotechnology

It is one of a series exploring what Sciencewise-supported projects reveal about public values and attitudes to contemporary scientific and technological issues, organised by Sciencewise's four key themes.

The report series is intended to be a resource to support policy makers and research funders considering their own dialogues or for those looking for societal insights.

Also published is an Executive Summary, synthesising key themes from across the series.

Sciencewise dialogues reviewed for this report

This report focuses on life sciences and biotechnology which is important across a range of sectors including human and animal health, food production, and medical research. A number of Sciencewise dialogues have explored the application of these technologies in agriculture, research using animals, and synthetic biology, as well as the use of genomic science. In those dialogues which have explored technologies being developed or applied to human health, there is a strong focus on the implications of the data which is collected, used and shared.

Genomic Medicine	Global Food Security	Human Tissue and Health Data Research	John Innes Centre Science Strategy
Mitochondrial Replacement	National Food Strategy	Whole Genome Sequencing for Newborn Screening	Openness in Animal Research
Rothamsted's Work With Industry	Stratified Medicines	Synthetic Biology	Whole Genome Sequencing for CF Newborn Screening

1 See forthcoming Sciencewise report: 'How can public dialogue deliver better outcomes? Key impacts from UKRI's Sciencewise programme'.

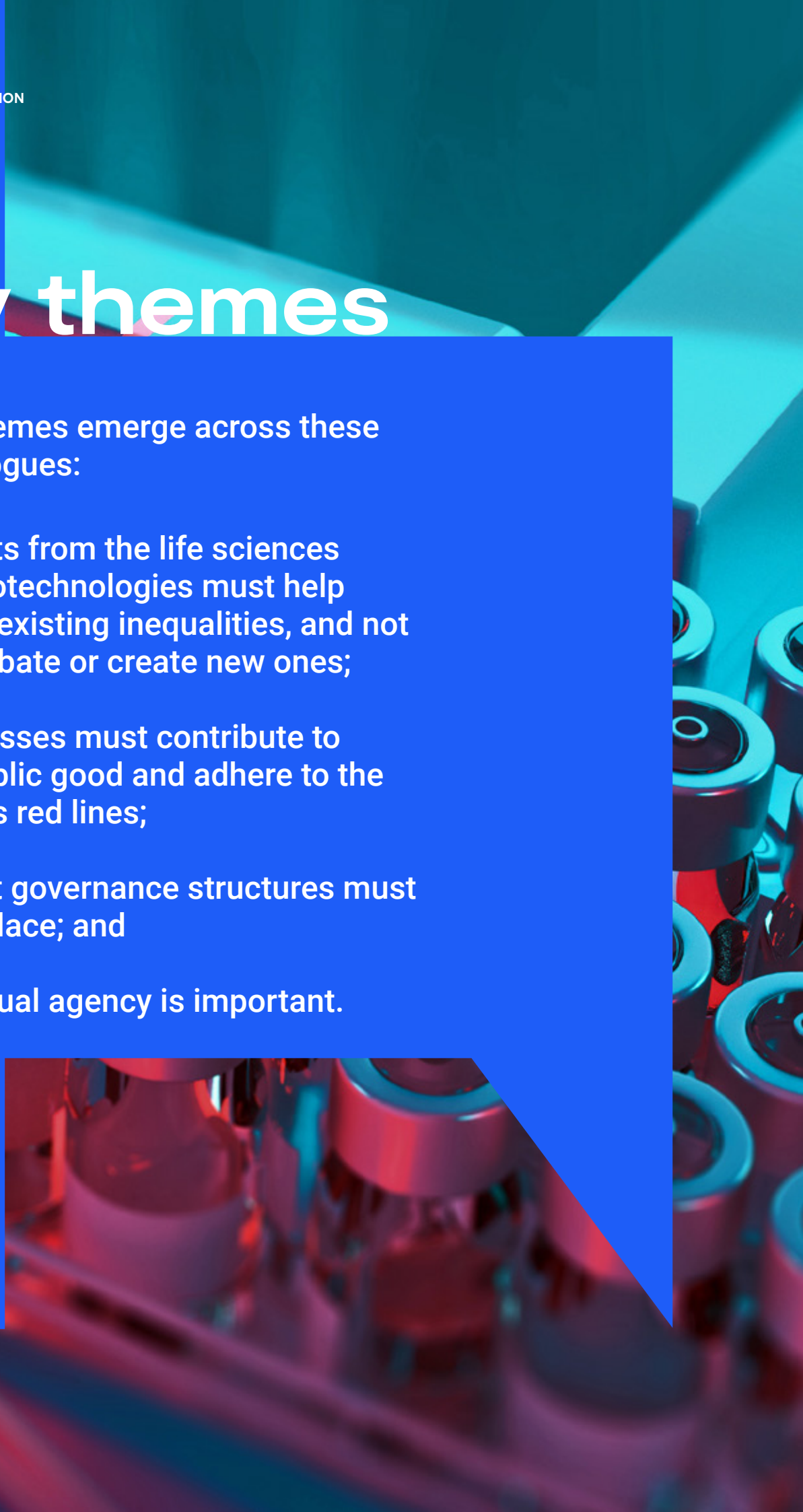
2 The four reports in this series each focus on one of the Sciencewise priority themes. The four themes are:

- Climate and Environment: How can society live sustainably?
- Data, AI and Robotics: How should society shape the digital world?
- Health, Ageing and Wellbeing: How should society live healthy lives?
- Life Sciences and Biotechnology: How should society shape the future of life?

Key themes

Five key themes emerge across these public dialogues:

1. Benefits from the life sciences and biotechnologies must help tackle existing inequalities, and not exacerbate or create new ones;
2. Businesses must contribute to the public good and adhere to the public's red lines;
3. Robust governance structures must be in place; and
4. Individual agency is important.



Benefits from the life sciences and biotechnologies must help tackle existing inequalities, and not exacerbate existing or create new ones

The public want to see life sciences and biotechnologies developed and used in ways which deliver public good. Minimising negative impacts from resultant products and applications is also a key priority.

The public want life sciences and biotech research to help tackle social inequalities[3]. For example ensuring that datasets used in research are inclusive of minority groups in order to support effective personalised medicine for all. They also want to see equal access to the benefits from novel products and applications such as human augmentation.[4]

The public also see a risk of the profit motive contributing to unequal outcomes and access[5]. Therefore, the public are keen to ensure treatments and procedures derived from breakthroughs in life sciences and biotechnology are available for free at the point of delivery[6].

> **"I think I'm getting worried that the screening will be tailored towards White people. And we saw earlier with sickle cell that people from other backgrounds are more prone to different things and if we're tailoring people's medicine, people from different backgrounds will need different things.**
>
> **Dialogue participant, Black, Asian & Minority Ethnic Group, Whole Genome Sequencing for Newborn Screening, 2021**

This fear of precipitating unequal and unfair outcomes is also seen when dialogues explore the role of biotechnology and life sciences in agriculture. Here, participants expressed concerns about the types of food people can afford based on their wealth and how that might impact on their health.

Participants identified a trade-off faced by people on lower incomes who have to choose between more nutritious and more affordable food.[7]

3 Wider genomic sequencing for cystic fibrosis newborn screening, 2021. Developing stratified medicine, 2013-14.

4 Human tissue and health data research, 2017. Synthetic Biology, 2009-2011. Developing stratified medicine, 2013-14.

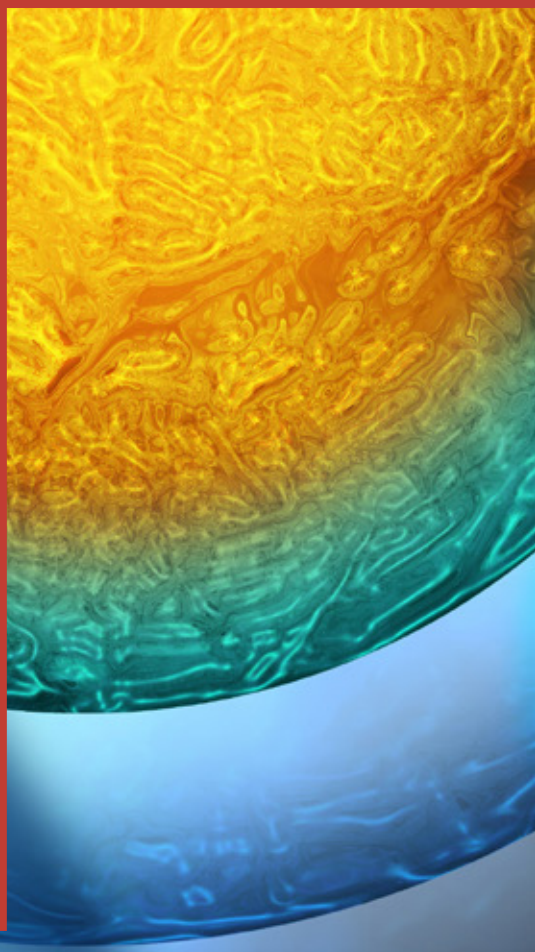
5 Developing stratified medicine, 2013-14.

6 Mitochondrial Replacement Therapy, 2012-13. Implications of whole genome sequencing for newborn screening, 2021. Wider genomic sequencing for cystic fibrosis newborn screening, 2021.

7 National Food Strategy, 2019-20.

Businesses must contribute to the public good and adhere to red lines

The public see an important role for businesses in research and development, but want to see excessive profiteering prevented and certain red lines respected to ensure private interests do not negatively impact benefits to the wider public good.



Generally, participants in public dialogues were comfortable with private businesses having a role in researching and developing life sciences and biotechnologies. They recognised that there is public benefit to be gained from private sector involvement in research which can result in benefits to large numbers of people or those who are vulnerable to specific diseases[8]. An example of this is the sharing of genomic data for research that can provide tangible benefits for people requiring care[9].

The public can struggle to specifically define what "public good" always is, but they tended to recognise it as positively impacting people's lives. In some cases, the public are more able to define what working for the public good would necessarily prevent rather than achieve, such as preventing dystopian futures created by misuse of genomic science[10].

In addition, they were not comfortable with excessive profits in this field and wanted to see clear roles set out for businesses which prioritise public benefit. They also set out clear red lines which businesses should not cross[11].

A common red line for business involvement in this field is that human data from life sciences and biotechnology work should not be sold to companies such as insurance or marketing companies[12]. This was because the public anticipate that doing that could discriminate against individuals with underlying health conditions by insurance companies[13].

There was concern that areas of life sciences and biotechnology might not be prioritised because a viable product could not be commercialised. In such cases, the public see a positive value in public institutions working towards the public good in order to ensure that treatments are developed even if it is not commercially viable to do so[14].

> **"Developments of technology happen and then, there's some harm caused and then, there's a scramble to, or people advocate for new policies and regulations to be put in place. But I feel like, for this, we should try and do that beforehand.**
>
> **Dialogue participant, Black, Asian & Minority Ethnic Group, Whole Genome Sequencing for Newborn Screening, 2021**

8 Genomic Medicine, 2018-19; John Innes Centre Science Strategy, 2015.

9 Genomic Medicine, 2018-19.

10 Genomic Medicine, 2018-19.

11 Developing stratified medicine, 2013-14.

12 Human tissue and health data research, 2017; Genomic Medicine, 2018-19.

13 Implications of whole genome sequencing for newborn screening, 2021.

14 John Innes Centre Science Strategy, 2015.

The public sees governance as key to ensuring that equitable outcomes are achieved and that private business involvement contributes to the public good.

The public want to see a range of potential public benefits from life science and biotechnologies. And to realise this, they want to see robust and effective regulation[15].

Policymakers and regulators are seen to have an essential role in doing the long-term thinking about how different sciences and technologies could benefit society generally. This includes how to prevent minority groups being discriminated against by the development and use of these sciences and how the private sector can help to achieve those public goods.

The public want to see long-term planning that links up the science of research and development with the social reality of people's lives through public engagement so that the former can be informed by and benefit the latter[16].

Individual agency is important

The public believe it is vital that individuals are able to make informed decisions about their own treatment and health when considering therapies developed through life science and biotechnology innovation.

In public dialogues, the public are sometimes asked about specific therapies, treatments and screening procedures which are already very well developed. Here, the public think it is crucial that individuals have the agency, or are given support, to make informed decisions about their own health. For example, while dialogue participants saw the enabling of mitochondrial replacement therapy as a positive development, they also thought that individuals should be able to choose whether to use the technology or not.[17]

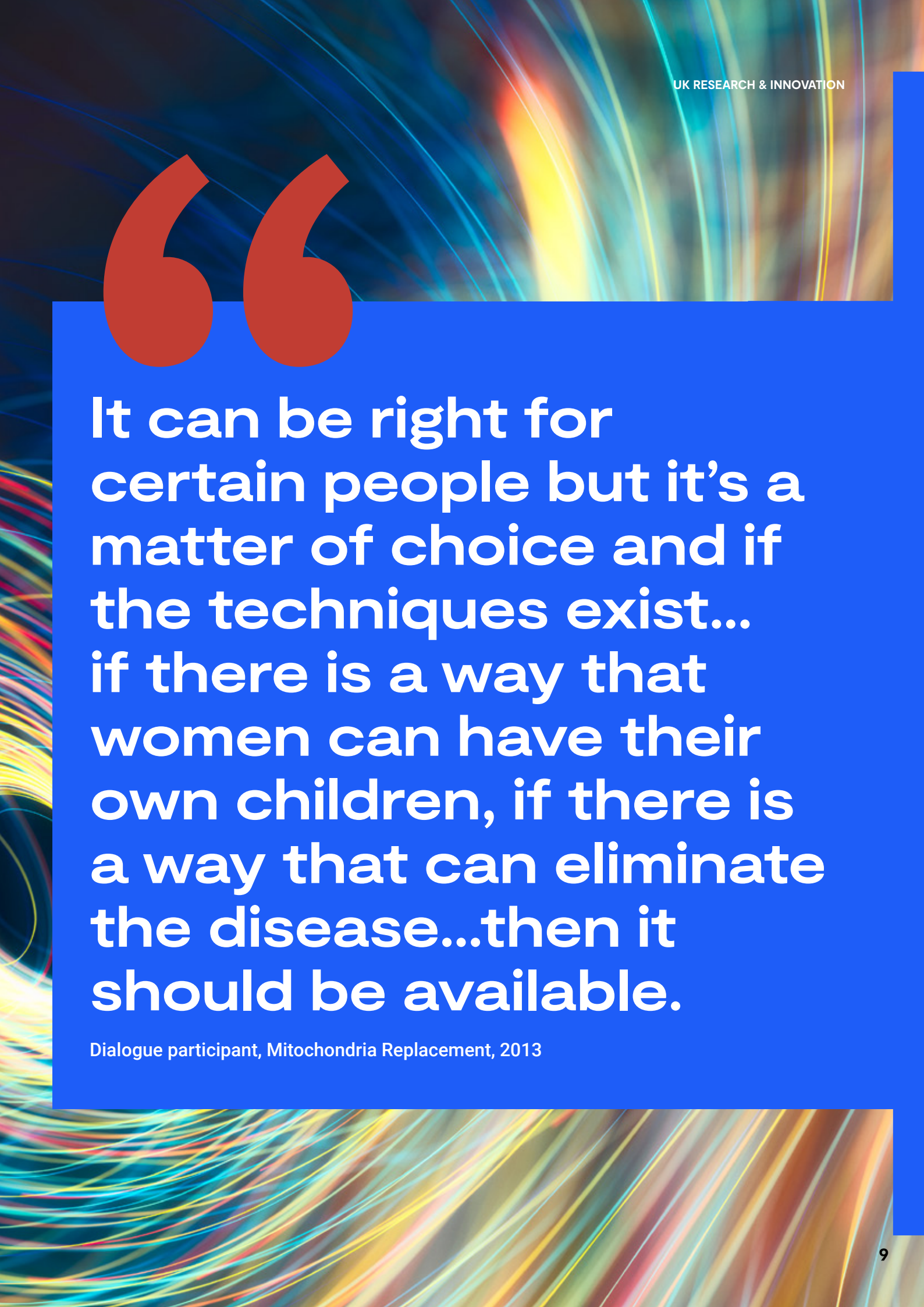
Additionally, when considering approaches which create new cells or redesign existing cells to carry out new tasks[18], dialogue participants thought that whether or not any emerging applications were used in treatment should still be firmly based on individual consent, rather than a broad decision made for all of society.

15 Mitochondrial Replacement Therapy, 2012-13; National Food Strategy, 2019-20; Implications of whole genome sequencing for newborn screening, 2021; Wider genomic sequencing for cystic fibrosis newborn screening, 2021.

16 Openness in Animal Research, 2013-14. Rothamstead Research, 2013-14.

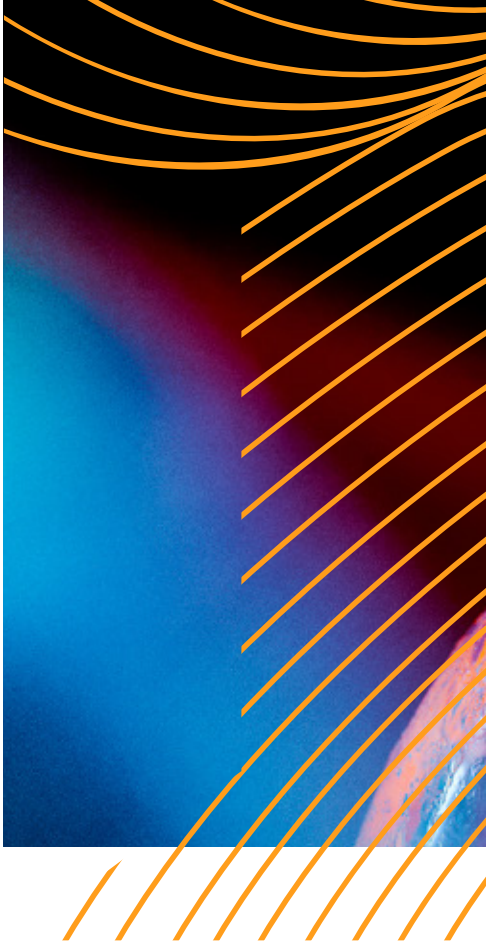
17 Mitochondrial Replacement Therapy, 2012-13

18 Synthetic Biology, 2009 - 2011



> It can be right for certain people but it's a matter of choice and if the techniques exist... if there is a way that women can have their own children, if there is a way that can eliminate the disease...then it should be available.

Dialogue participant, Mitochondria Replacement, 2013



Conclusions

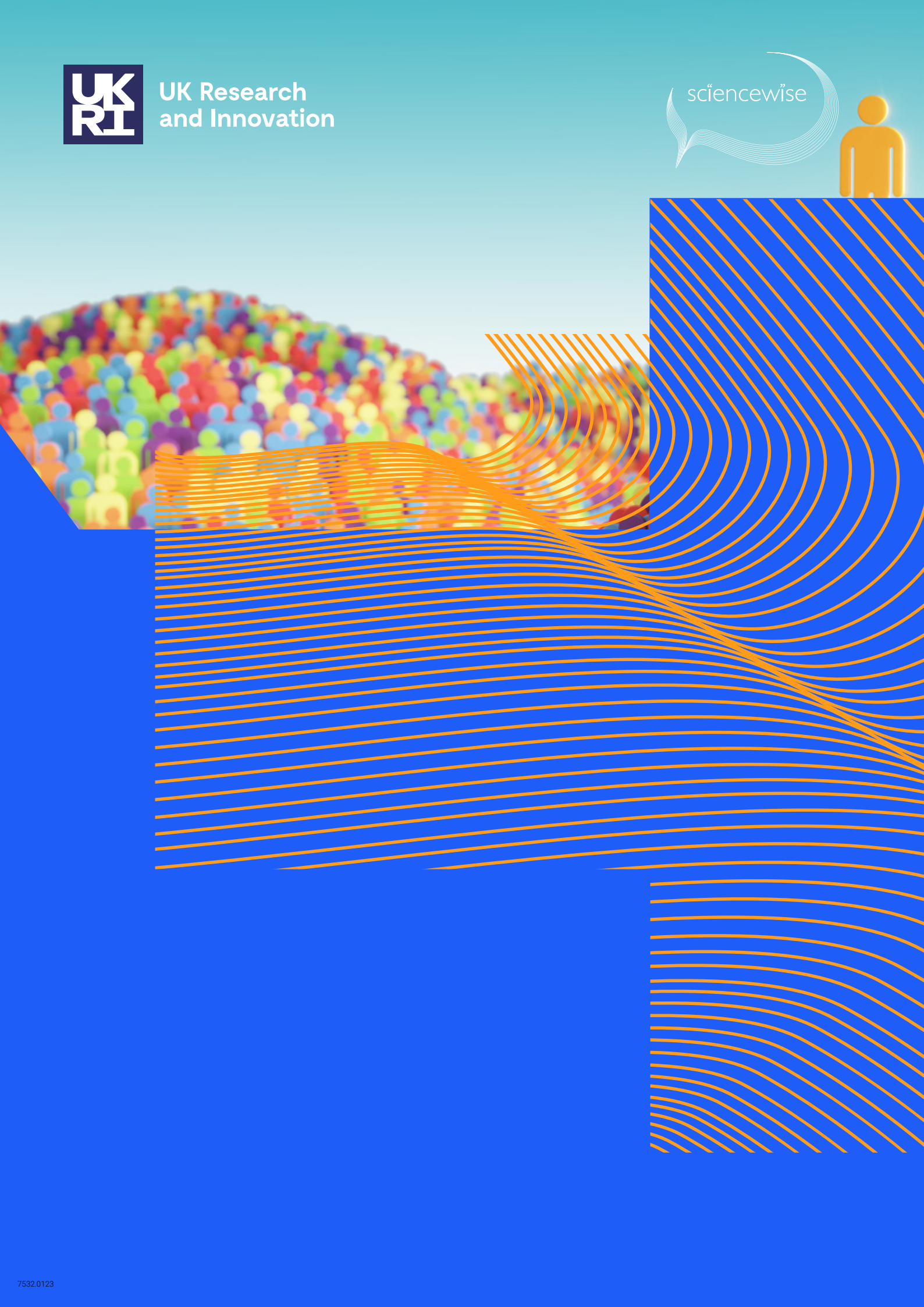
The research, development and rollout of any life science and biotechnology is viewed by the public as both carrying significant potential benefits and specific risks. Dialogue participants are most often concerned that existing inequalities could be increased, and new inequalities created, if proper care is not taken.

Another commonly expressed concern is that private interests, such as the desire to pursue the greatest profit, might negatively shape how life sciences and biotechnologies are developed, including who they are designed to benefit and who has access to them. However, the public sees an important role for the private sector in developing the science and technology in this area.

In terms of safeguards, the public wants to see robust regulations which both help ensure that societal benefits are secured and that the public's concerns are mitigated against. This governance should serve to meaningfully connect science and technology with the social reality of people's lives.

About UKRI Sciencewise

- The report is commissioned by Sciencewise, a UKRI funded public dialogue programme that supports government departments and other public bodies to listen to and act on diverse voices, to shape science and technology innovation policy and priorities. Important benefits of the programme include:
- Helping decision makers to formulate policy with a deeper understanding of public views, concerns and aspirations;
- Supporting high quality, best practice public dialogue; and
- Bringing credibility and independence to public sector-led public dialogue projects.
- Further information on the Sciencewise programme including impact case studies can be found at the following link: https://sciencewise.org.uk/
- To get in touch please contact: simonburall@sciencewise.org.uk and graham.bukowski@ukri.org



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