

sciencewise

How should society live healthy lives?

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 health, ageing and wellbeing.

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.²

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 health, ageing and wellbeing and explores the role of science and technology supporting us to live healthy lives. Many of the Sciencewise dialogues explored public views around health and health research, and the use of health data for these purposes. Other ones explored routes to health and wellbeing generally, or specifically through healthy food, good housing, or by using wellbeing as a frame to support effective policymaking.

The theme also includes healthy ageing, an issue of significant interest to both Sciencewise and policy-makers. To date, however, it has arisen tangentially in many dialogues but has never been addressed directly. For instance, our dialogues show that new technologies could be particularly



1 (Facing page) 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

- Private sector involvement must have the right checks and balances;
- Commercial access to health data must pass four key tests;
- **3.** Informed consent is vital; and
- New technology is welcomed if overseen by medical professionals.

valuable for older people (for example, autonomous vehicles) but they also show that take-up might be faster among younger people who are more open to change.



Private sector involvement in healthcare must have the right checks and balances

Initially people are anxious about the role of the private sector in healthcare. However, once they learn more about the value it can bring, most people will tolerate it, subject to checks and balances.

The public generally see healthcare as the domain of the NHS and do not immediately see the value that the private sector can bring. Almost all are instinctively nervous of the role of the private sector in health³.

After spending time exploring this topic, most conclude that private sector involvement in healthcare can be acceptable, as long as there are checks and balances in place. They want to see that companies are not able to make 'excessive profits' from people's ill-health, or from NHS health data⁴.

They also wanted assurances that access to healthcare is available to all and free at the point of delivery⁵.People do not endorse the involvement of the private sector if it could lead to a two-tier system of health where people who have greater have access to better care. The average person has a lot more trust in the NHS than pharmaceutical companies [All participants in this group note their agreement]. ... The pharmaceutical companies are in business to make money.

Dialogue participant, Bristol, Patient and Public Engagement Project, 2013



Commercial access to health data must pass four key tests

If health data is used outside the NHS, people expect four tests to be met: why (public benefit is vital); who (can they be trusted?); what (can data be linked back to me?); how (are there safeguards in place?).

People are typically comfortable for their health data to be used by the NHS for their own care and most are also comfortable with it being used for planning purposes. However, if data is being used by other organisations, then people's acceptance is predicated on four key tests⁶:

- 3 Human tissue and health data research, 2017; Health research: identifying and recruiting participants, 2014-2015; Health Research Authority patient and public engagement, 2013; Synthetic biology, 2009-2011; Genomic medicine, 2018-2019; National Data Guardian - Putting good into practice, 2020-2021; Stratified medicine, 2013-2014.
- 4 <u>Human tissue and health data research</u>, 2017; <u>Health</u> <u>Research Authority patient and public engagement</u>, 2013; <u>Stratified medicine</u>, 2013-2014.
- 5 <u>Human tissue and health data research</u>, 2017; <u>Stratified</u> medicine, 2013-2014.
- 6 <u>Genomic medicine</u>, 2018-2019.

- Why: It is vital that the research can be shown to be in the public interest and that there will be a social benefit⁷. Assurances are needed about the affordability and accessibility of any solutions developed utilising people's NHS data: it is important to ensure the patients who contributed to research, or other people with similar conditions in future, will be able to benefit, whether solutions are developed by the public or private sector.
- Who: It is vital that people feel they can trust the researchers using their data⁸. Typically, increased trust comes with increased seniority (e.g. a doctor or nurse is more trusted than a receptionist and a senior academic more trusted than a student). People are least likely to trust private sector employees, but are potentially more open to their involvement when they are assured there are checks and balances in place to ensure data is only used for the agreed purpose. People describe this in terms of what the person has to lose if they misuse the data.
- What: People typically assume that the data will be anonymous or that it will be accessed in such a way that it is impossible for the research team to re-identify individuals in the data⁹. It is most important that contact details are removed, but often people suggest that researchers should be limited so they can only access the data they need and not the whole data set available for individuals, thus minimising the risk of re-identification and data mining.
- How: It is imperative that data is stored securely and cannot be lost or hacked¹⁰. Systems that limit researcher access in secure settings are preferred, particularly if they incorporate checks and balances to ensure that the researchers are only accessing the data as agreed when access to the data was approved.

In line with current NHS practice, people believe their health data should never be shared with insurance or marketing companies under any circumstances¹¹. The motivations of these companies are not thought to pass the public interest test outlined above. While people can see how the companies could benefit, they fail to see anything but disbenefits to patients and the public. Even when the potential for lower premiums for those who pose a lower health risk is explained, people are not enthusiastic as they do not trust the companies to pass on these savings, while they anticipate people whose data suggests they are higher risk will definitely pay more.



Informed consent is vital

People want individual agency in decisionmaking about their healthcare and their data. Informed consent requires consent processes to be clear and simple, both for data sharing and for involvement in trials. It should not be possible for government to over-ride people's decisions at a later date.

People expect clear and simple consent processes that enable people to know what they are agreeing to, but which also do not place unnecessary restrictions on researchers once consent is given¹². This applies to participation in trials where the public emphasise the importance of ensuring patients are given unbiased information from which to make an informed decision, and where they would not necessarily trust their GP to support them to make it¹³.

- 7 National Data Guardian Putting good into practice, 2020-2021; Synthetic biology, 2009-2011.
- 8 Human tissue and health data research, 2017 Health research: identifying and recruiting participants, 2014-2015; National Data Guardian - Putting good into practice, 2020-2021.
- 9 <u>Human tissue and health data research</u>, 2017; <u>Whole</u> genome sequencing for newborn screening, 2021; <u>Health</u> research: identifying and recruiting participants, 2014-2015.
- 10 Human tissue and health data research, 2017.

- 11 Health research: identifying and recruiting participants, 2014-2015; <u>Stratified medicine</u>, 2013-2014; <u>Whole genome</u> sequencing for newborn screening, 2021; <u>Human tissue and</u> health data research, 2017.
- 12 Genomic medicine, 2018-2019; Human tissue and health data research, 2017; Health research: identifying and recruiting participants, 2014-2015; Health Research Authority patient and public engagement, 2013; Stratified medicine, 2013-2014.



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Dialogue participant, London, Genomic Medicine, 2019



It is vital that consent is sought at an appropriate time, when patients are not particularly vulnerable and people must be given time and space to make an informed decision¹⁴. People felt strongly that most trials should be run on an opt-in basis – the only potential exception is low- or norisk trials where nothing enters the body of the patient¹⁵.

Similarly, people want a consent-based approach to data-sharing, although most believe providing an opt-out (rather than opt-in) is acceptable as long as people are aware of it¹⁶. People also initially suggested a dynamic consent model for access data could be desirable, however, exploring this in more depth they often conclude it would be complex to manage and would also not be a priority from the patient perspective¹⁷. People noted that to ensure trust, it is vital that future governments or regulators cannot override any limits people choose to place on their consent¹⁸

People expect questions about consent to become increasingly complex, as technology such as genetic screening will have implications for a whole family and not just the individual who originally provides consent¹⁹. This is a topic that will need further investigation as the technology develops and draft ethical frameworks become available for debate.



New technology is welcomed if overseen by medical professionals

People will accept technology enabled healthcare if it delivers better (faster, more accurate) results, as long as there is human interaction when problems are identified.

When they can see clear benefits and limited risks, people are open to innovative solutions. Given that such innovative treatments or services have the potential to treat or prevent potentially serious illnesses²⁰, compared with other sectors, our dialogues show people are more open to new developments. Specifically, people are happy to support innovations likely to lead to benefits including improvements to the speed and accuracy of diagnosis or better treatments and cures. Examples of such technologies include genomic screening and stratified medicine.

However, they expressed more caution when a diagnostic might identify a disease with no known treatment . People were also concerned that they could receive a diagnosis or result from a piece of technology without human support to interpret the output and agree what happens next. They therefore

- Health Research Authority patient and public engagement, 2013; <u>Stratified medicine</u>, 2013-2014.
- Health Research Authority patient and public engagement, 2013.
- 15 <u>Health research: identifying and recruiting participants</u>, 2014-2015.
- 16 <u>Health research: identifying and recruiting participants</u>, 2014-2015.
- 17 Human tissue and health data research, 2017.

- 18 <u>Human tissue and health data research</u>, 2017; <u>Health</u> research: identifying and recruiting participants, 2014-2015; Whole genome sequencing for newborn screening, 2021.
- 19 Genomic medicine, 2018-2019.
- 20 Human tissue and health data research, 2017; Health. research: identifying and recruiting participants, Health. Research Authority patient and public engagement, 2013; Stratified medicine, 2013-2014; Synthetic biology, 2009-2011; Whole genome sequencing for newborn screening, 2021.
- 21 Stratified medicine, 2013-2014.

If you were to let people opt in and out on every use of data and sample people won't be bothered unless it's something big.

Dialogue participant, Sheffield, Consent to use human tissue and linked health data in health research, 2017

wanted a system that provides well-qualified practitioners to support them throughout the journey, especially if the conclusion is that there is no effective treatment for themselves²².

Another common concern is that technology might open the door to 'designer babies' or a 'eugenics society', with associated unintended consequences for society in general and disability rights in particular²³. Similarly, people emphasise the importance of not creating a postcode lottery, or two-tier health system (as discussed above) as a result of new technologies.

Recent findings suggest that COVID-19 and vaccines have impacted on people's views. Specifically, there was concern that vaccine hesitancy might also apply to the take-up of other new technologies in health and care leading to further divides in society. Transparent and complete information about new technologies, such as genomic screening, were therefore considered essential²⁵.



Key findings: Wellbeing and healthy lives

Public attitudes towards the role of science and technology in wellbeing and healthy lives are less clear cut. Sciencewise dialogues have covered different topics related to wellbeing and healthier lives. These dialogues are diverse, but the following themes emerge:

- Importance of autonomy for citizens
- Compelling businesses to do more to tackle key societal challenges

People are typically willing to accept the development of new science and technology solutions to improve wellbeing and address societal issues that will affect our ability to live long, healthy lives. However, they are not necessarily ready to welcome it into their own lives and want to retain control over what technology they decide to adopt personally.

It should be a government role] to ensure that stratified medicine is available to all equally and minimize discrepancies between rich and poor.

Dialogue participant, Glasgow, Stratified Medicine, 2013

22 <u>Genomic medicine</u>, 2018-2019; <u>Stratified medicine</u>, 2013-2014; <u>Whole genome sequencing for newborn screening</u>, 2021.

- 23 Human tissue and health data research, 2017.
- 25 Whole genome sequencing for newborn screening, 2021.

²⁴ National Data Guardian - Putting good into practice, 2020-2021; Stratified medicine, 2013-2014. Whole genome sequencing for newborn screening, 2021.

I don't mind making a contribution but this spins both ways, the government want us to go green urgently, there are all of the agreements out there, but how will it happen unless they support people in taking advantage of it?

Dialogue participant, Good Homes Dialogue, 2020



Importance of autonomy for citizens

People often insist that while they are keen to be better informed, they do not want to be compelled to make changes to their lifestyle, diet or home. Rather, they expect to be given a choice and supported to make the right one.

In line with the findings on consent and individual agency in healthcare decisions, people emphasise the importance of individual responsibility and choice²⁶. Even where they recognise the need to make changes, they want to do so on their own terms, and do not feel they should be compelled to change anything they do not want to. For example, they recognised it would be desirable to reduce carbon emissions, and that installing more insulation in every home would help, but did not want to be required to install it in their own homes unless they chose to do so.

Generally, information is considered necessary but not sufficient to bring about individual behaviour change, as a lot of information on wellbeing and healthier lives is already available²⁷. In some cases, people suggested that society, rather than individuals, will accrue most benefit from a change in behaviours or lifestyle (e.g. to ensure food security or achieve net zero). In these instances, they proposed that government should provide support and encouragement for people to do the right thing. As we saw above, in healthcare the benefit of trying a new treatment or intervention is clear: there is a possibility it will result in a better outcome. The benefits to individuals of adopting new technologies in other aspects of their lives (e.g. housing, food) are less clear cut and many perceive the use of new technologies to be expensive and not necessarily a priority. Consequently, they want active information, signposting and encouragement or inducement to do what they perceive to be the right thing , whether that be buying food from more sustainable sources or making sustainable improvements to their home.



Compelling businesses to do more to tackle key societal challenges

In contrast, people expect government to compel businesses to do more to tackle key societal challenges.

From food producers to private landlords, in a similar way to overseeing medical technologies and pharmaceuticals, people consistently want to see independent regulators taking a strong approach to ensure that businesses are operating in the interests of society²⁹. They can see the potential for science and technology to solve many of the challenges to wellbeing but only if private sector energies are directed appropriately³⁰, and not focused solely on making profits.

- 26 Food system challenges, 2014-2015; Good home inquiry, 2021; National Food Strategy, 2021; Ways to Wellbeing, 2011.
- 27 Good home inquiry, 2021; National Food Strategy, 2021.
- 28 Good home inquiry, 2021; National Food Strategy, 2021.
- 29 Food system challenges, 2014-2015; Good home inquiry,

2021; <u>National Food Strategy</u>, 2021; <u>Synthetic biology</u>, 2009-2011.

30 Food system challenges, 2014-2015; Synthetic biology, 2009-2011.



They also believe businesses have a role in supporting people to become 'informed consumers', for example, by providing clear digestible information which can support people to make better decisions³¹. They do not think businesses will do this without regulations requiring them to do so.

People are not squeamish about interventions which could cost the private sector money, due to the perceived profits that are made. While over the course of discussions people become more comfortable with the involvement of the private sector in their health and wellbeing, they maintain an expectation that regulators will watch closely to ensure businesses live up to their commitments, do not make 'excessive profits' and are working towards societal good³².



- 31 Food system challenges, 2014-2015; Good home inquiry, 2021; National Food Strategy, 2021; What Works Centre for Wellbeing: three themes, 2015.
- 32 Food system challenges, 2014-2015; Synthetic biology, 2009-2011.



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We're only doing this [cloning cows] so the top cats can make lots of money. Ethically it's completely wrong. Who'll be paying for the cloning, those companies that are going to make a fortune out of it later?

Dialogue participant, Cardiff, Food Systems Challenges, 2015



Conclusions

The insights derived from Sciencewise public dialogues demonstrate that science and technology is valued in health and care. Overall people are often supportive of new innovations as long as there are appropriate safeguards in place.

Our dialogues clearly show that health, ageing and wellbeing are very personal – we see that it is not only 'my body', 'my choice', but also 'my food', 'my house', 'my well-being'. While people believe the common good is often served by encouraging and supporting scientific and technological development, this does not necessarily mean they are willing to commit to being early adopters of such developments when they become widely available.

While people can see the benefit of science and technology, they are not welcoming it with open arms, due to concerns about personal risk, cost or a lack of incentive to change. Rather, they are cautiously optimistic and believe strongly that it should be an individual choice whether or not to embrace new technologies on a case-by-case basis.

In some of the dialogues, we have explicitly set out to recruit people with particular interests (e.g. people living in sub-standard homes, people with particular health conditions) to develop greater insight. During these dialogues there is a significant emphasis on the impact on our personal lives and the level of behaviour change that might be required.



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: <u>https://sciencewise.org.uk/</u>
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