

The future of health research in the UK

**An online dialogue project for the
Academy of Medical Sciences**

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Contents

Executive Summary	4
Health research means different things to people, but it is seen as incredibly important	4
Low awareness of how health research is funded, with an assumption it is charity-funded	4
A sense that government should be funding more research	4
The importance of retaining and boosting a diverse workforce	4
Future priorities included greater transparency, regulation, and ring-fenced government funding for research	4
1 Initial awareness and views on health research	5
What ‘health research’ meant to participants	5
Associations of health research with COVID-19	5
Where participants received information about health research	6
2 Informed views on health research	7
Familiarity with the information provided	7
Early expectations around who should fund health research	7
The importance of volunteers for clinical trials	8
The importance of health research	8
3 Long-term goals and challenges for health research: funding options and financial choices	10
Views about where funding should come from	10
Government	10
Industry	11
Charity sector	11
Participants’ views changed as they learned more throughout the session	12
4 Sustainability of the workforce	13
Retaining and valuing existing staff	13
New ways into the field	13
Showcasing existing staff to attract new talent	13
Diversifying where research happens	14
5 Top priorities for the future	15
6 Methodological Annex	16
Methodology	16
Limitations of this methodology	17

Executive Summary

This report details the findings from three online workshops carried out with members of the public from across the UK, by Ipsos between 30 May and 1 June 2020 on behalf of the Academy of Medical Sciences. The workshops explored public views of health research in the UK and ways of ensuring sustainability of the sector for the future. A dialogue approach was taken, where participants received information about health research to help them engage in the issues, ask questions of experts to better their understanding, and arrive at more informed views. The findings are qualitative; rather than presenting a representative picture of public attitudes, they indicate the variety of perspectives that exist.

Health research means different things to people, but it is seen as incredibly important

Initial discussions about health research were informed by participants' personal experience with health research, or the experience of close friends or family members, and what people had read or heard in the media. Participants consistently spoke positively about health research, using words like 'progressive', 'ground-breaking' and 'the way forward'. There was a strong sense that health research is incredibly important to all, as it has the potential to apply to everyone at some stage in their lifetime.

Low awareness of how health research is funded, with an assumption it is charity-funded

While there were varying levels of existing awareness with information provided around how health research is funded, participants were most surprised to learn about the involvement of different sectors. A common misperception was that health research is funded predominantly by charities. On hearing more, participants voiced expectations around government plugging the research funding gap, especially since money coming into charities from public donations is likely to be compromised with the rising cost of living. Participants expressed multiple reasons as to why health research is important, including the ability to save lives, provide people with quality of life, prevent and tackle disease, ensure safe and effective treatments, while boosting the economy and innovating, and moving the UK forward.

A sense that government should be funding more research

As participants discussed funding from government, industry, and charities in more detail, they initially expressed that industry (given the high profits made from research) should be funding more research. However, as conversations progressed, the role of the government in funding became more crucial, despite an awareness that government funding would need to come from taxes.

The importance of retaining and boosting a diverse workforce

Participants discussed the importance of valuing and retaining the people who work in health research, based on a perception that poor working conditions could lead to poor outcomes for research. Participants also expressed the importance of career development and training, as well as supporting parents returning to work. Participants valued expanding the routes into research, through (for example) apprenticeships rather than only via university degrees. It was especially important to participants that the workforce becomes more diverse, so that those carrying out research are more representative of the wider population. Similarly, there was appetite for expanding where research happens.

Future priorities included greater transparency, regulation, and ring-fenced government funding for research

Participants discussed key priorities for the Academy of Medical Sciences in its work. These included greater transparency about industry contributions and profits, more ring-fenced government funding for research and tighter regulation of charities and work. As well as expanding where research takes place around the country, and education in schools and colleges around careers in research.

Overwhelmingly, in these early uninformed discussions, **participants spoke positively about health research**, using words like ‘progressive’, ‘technological innovation’, ‘the way forward’ and ‘ground-breaking’ to caveat their contributions. Additionally, while there was a feeling that research is relied upon by people who already have certain diseases, there was also a sense that health research is **incredibly important to all** as it has the potential to apply to everyone at some stage in their lifetime.

Where participants received information about health research

While there were participants who claimed they knew very little about health research or how to get involved in it, occasionally referring to this as “mysterious”, there were also participants who were **more familiar due to personal experience** (for example, several reported being part of clinical studies) or **because of close friends’ or family members’ experiences**.

[Speaking about a sibling who had been recently diagnosed with cancer] ***“She’s part of a new research group trying out new treatments, so that’s a really positive thing really.”***
(Female, Workshop 2)

There was also a sense that **participants accessed information about health research through the media**. For example, there were frequent mentions of advertisements for clinical trials on television and radio.

“I’ve heard of something called the Medical Evaluation Unit, which looks for volunteers. Some people who have got certain things wrong with them, say migraines, and want to do a trial. And then you see adverts for people who are perfectly healthy, and they want them to do trials for certain things.” (Female, Workshop 3)

Even in these early discussions, **questions arose around funding** (*where does the money come from?*), with mentions of government-funded research, private companies funding research, and charities.

“It’s usually the bigger illnesses that get more funding from the government. There’s a lot of lifestyle related illnesses that they should be putting more funding into. I think it depends on how high a profile it is to how much funding it gets.” (Female, Workshop 1)

In this vein, there was some discussion around **who benefits from health research** (*is it for the public, or is it to drive profits?*).

2 Informed views on health research

Participants were presented with some information about health research: what it is; what is involved; and some examples to date, including the discovery of penicillin, the development of MRI, and the first COVID-19 vaccination. Participants also watched a video² introducing who is involved in health research.

Familiarity with the information provided

There were varying levels of familiarity with this information among participants, but participants consistently described feeling “uplifted” and “positive” in response to the potential of health research to advance healthcare and cure disease.

“It just goes to show that without these three sectors, we wouldn’t be able to provide people with what they need. Without one of them, they would be lost.”
(Female, Workshop 1)

The realisation that all three sectors (government, industry, and charities) are involved, as well as the roles they each play and the importance of their collaboration, was new to some participants in each of the groups. Previous assumptions were that funding predominantly comes from charities (i.e., Cancer Research).

“I didn’t know the government funded medical trials, unless it was something like the pandemic. I thought the money was going towards the NHS. That was a new thing for me, I thought it was charities and maybe a demand in the industry that was then funded within itself as an investment.” (Male, Workshop 3)

Early expectations around who should fund health research

Suggestions that industry should put more funds into health research were voiced, given the huge profits that commercial organisations make from it. This came with an expectation, from some, that such organisations should be donating money to research that they were not necessarily involved with going forward.

“Businesses that make massive profit, they should have to do it. That’s my personal opinion.” (Female, Workshop 1)

This view was challenged by others, who questioned the reality of commercial organisations investing in health research that would not benefit them financially.

On learning that it was not *just* charities that were funding health research, as noted above, participants spontaneously cautioned the source of funding from charities given the cost of living crisis. There was a sense that this will impact the amount of money going into health research from charities, given that donations from the public will likely be compromised.

“I just wonder at the moment, with the state of the economy, what impact it has on the charity part of this. If people don’t have their own funds, is that going to impact on what they’re giving to charity at the moment?” (Female, Workshop 2)

² Association of Medical Research Charities video: <https://www.youtube.com/watch?v=pgZLBaORBeM>

Participants suggested that the government should make up the shortfall.

“It probably would have been better if the government invested more, instead of letting it [go] on charities. Especially now with people finding it hard to live. I think the government should be doing a bit more with the researching side of things.”

(Male, Workshop 1)

The importance of volunteers for clinical trials

There were participants who reported personally putting themselves forward for clinical trials (a migraine sufferer, someone who previously had a double brain haemorrhage), and others reflected on the importance of involving the public in health research.

“How important the public are to testing and making it a success. You need volunteers to take a risk.” (Male, Workshop 1)

However, caution was raised by some concerning a lack of trust in health research within some communities. The COVID-19 vaccination was highlighted as an example of this, with participants frequently mentioning the importance of transparency and education to counter this.

The importance of health research

Reiterating what people had said in the initial uninformed discussion, participants returned to the importance of health research at this point, providing multiple reasons as to why this is (Figure 2.1).

There were participants who were clearly moved by receiving information about health research, and who had previously been ambivalent.

“Before this conversation I would’ve said it’s not important at all. However, I think it’s important [and it would be good] if there were more groups like this. It’s informed discussions, there’s no shouting over each other. It’s good to have these discussions where we can discuss, learn, be heard.” (Male, Workshop 2)

Figure 2.1: Summary of participants’ reasons for why health research is so important in the UK.



Participants had questions at this stage, including:

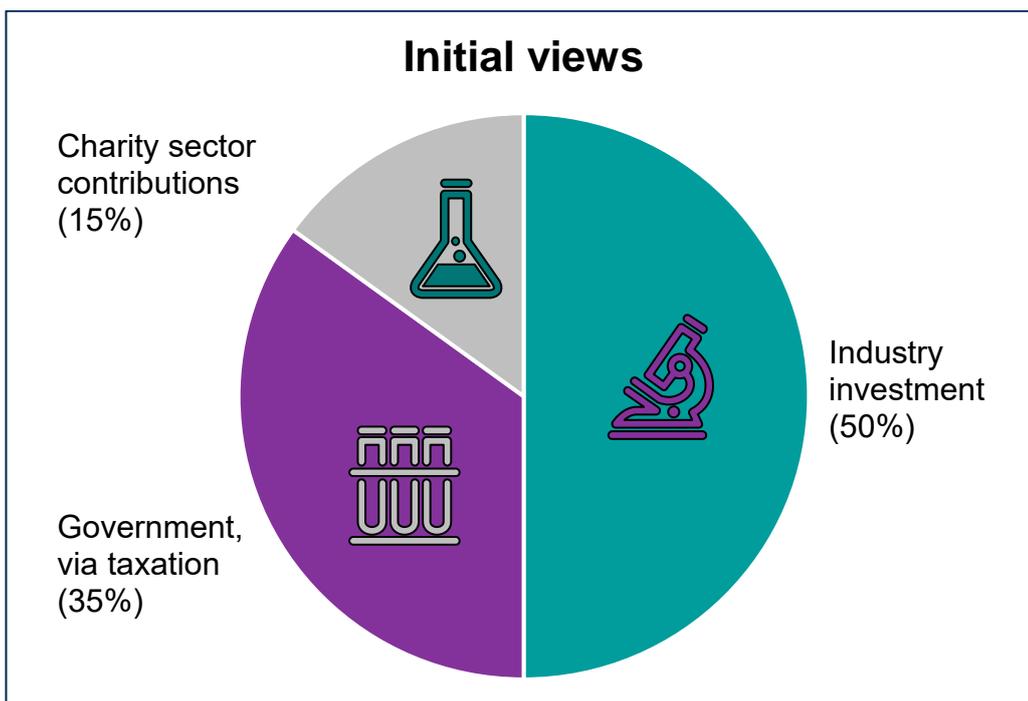
- Whether medicines need to be continuously re-tested (to ensure that they continue to be safe and effective)
- Whether there is a regulatory body for health research
- Where research takes place in the UK
- How the public can find out about research if people are interested in getting involved
- How much money is spent on health research each year in the UK
- How much of the total research spend is funded by government
- Who decides which research is funded and where the money is spent? *With some suggestion that the cost of producing medicines and treatments drives this.*
- What percentage of charitable donations go towards medical research.

3 Long-term goals and challenges for health research: funding options and financial choices

Participants next heard a presentation about the long-term ambitions for health research in the UK, including the UK government's goal to be a 'science superpower'. The presentation also covered some challenges currently facing the sector, such as the lack of funding; difficulties in the workforce; and the complexities of creating a more joined-up system. These discussions are covered in this and the following chapter.

Participants discussed how best to apportion responsibility for health research funding, and there were mixed views across the groups about this. These conversations covered different funding sources such as government support via taxation, industry investment, and charity sector contributions. Initial suggestions were that a greater proportion of funding should come from industry, with the remaining split between government (more so) and charities – as shown in Figure 3.1.

Figure 3.1: Theoretical weighting that participants gave to organisations involved in funding health research, at the outset of the workshop.



Views about where funding should come from

Government

Participants tended to feel positive about government investment in health research, suggesting that those providing health services in the NHS should be involved in the development of new technologies. A popular suggestion was that there should be independent oversight of, and accountability for, the way government funding is used. Participants felt that at least some public involvement should be required for this – 'taking it out of the political sphere'.

“I’ve got no problem paying taxes and funding the NHS or research. The problem is the government is not putting enough money into it. They’re privatising parts of the NHS, which is worrying.” (Female, Workshop 1)

Participants were also generally in favour of ring-fencing government spending for health research.

“A certain amount should be allocated and the public should be made aware.” (Male, Workshop 2)

“If the government wants it to be a science super house, they need to step up and invest more money themselves because it’s going to cost money. They need to step up and pay for it.” (Female, Workshop 2)

Industry

The key finding in relation to industry was that participants thought industry as a whole, and pharmaceutical companies in particular, should contribute a greater proportion of health research funding than they do at present. This was due to the perception that these companies are making huge profits from selling drugs and devices back to the NHS, and therefore they should be paying for research. Alongside these caveats, there was a general acceptance (and some support) for industry being involved in the health research sector.

“For the government and charities in the country to contribute, it doesn’t seem fair that these big multinationals don’t contribute as much as they could, given the profitability for them.” (Female, Workshop 3)

“It does make sense that industry should pay a bit more for research. Because they are making the bulk of the profit.” (Male, Workshop 1)

Charity sector

Participants generally felt that there is a place for charity funding in health research, but that this should be a smaller proportion than government and industry contributions. People argued that the public already contributes to health research through taxes, and that charities should not have to be responsible for propping up essential services.

As previously noted, there were some concerns about the sustainability of relying on charity sector funding for health research, given the current cost of living crisis and its impact on people’s ability to donate to charity.

“The people who give to charity are the ones who can afford to give to charity. Now with the way things are going for everyone with the cost of living, how much money am I now able to give to charity?” (Female, Workshop 2)

Another point emphasised across the workshops was that charity funding should go to research, including paying for researchers’ salaries, and not to the salaries of top executives within the funding organisations. This was especially the case in relation to charity, but also government funding.

“Ensure that the charity funds are going to research rather than going into salaries.” (Male, Workshop 3)

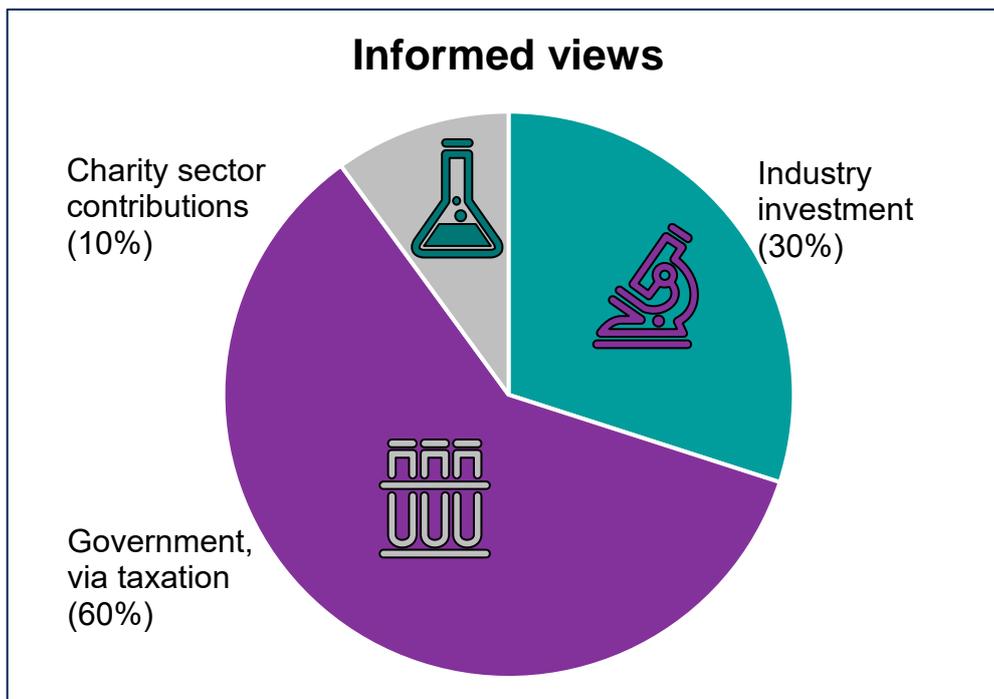
“My problem still remains with the charity organisations that so little of the money goes to the research. There’s a general feeling that the directors get paid such a high percentage that the money goes to pay their wages.” (Female, Workshop 3)

Participants' views changed as they learned more throughout the session

Across the three evenings, as participants learned more about the topic and discussed it with others in their group, views around the responsibility for funding health research shifted – as shown in Figure 3.2. Although not universal, this shift was witnessed in relation to industry and government funding. Where participants had initially stated that industry should be responsible for funding the majority of health research (for reasons previously outlined around profiting), as time went on there was a sense that government should be funding more health research. Participants maintained this view in the face of reminders that government funding comes from taxes.

A small number of participants commented that they would not mind paying more tax, if they knew the money would be invested in something as important as health research. Caution should be taken from these assertions given the well-recognised 'say-do gap' – the 'dilemma of reported concern or intentions not being followed up in action'.³ This does, however, emphasise the importance participants attributed to health research, and has implications for decision-making in future.

Figure 3.2: Theoretical weighting that participants gave to organisations involved in funding health research, towards the end of the workshop.



³ <https://www.ipsos.com/en/true-understanding/say-do-gap>

4 Sustainability of the workforce

Following a question-and-answer session with a specialist representing the Academy, participants returned to their break-out rooms to discuss issues facing the health research workforce.

Participants were, by and large, unaware of the difficulties experienced by people working in the field of health research. Having already discussed the importance of health research itself, the conversation moved on to emphasise the value of the staff carrying out that research. Participants were concerned that a poor working environment for researchers could lead to poorer outcomes of their research, which would have implications for the rest of the population reliant on the medicines and interventions they develop.

Retaining and valuing existing staff

Participants emphasised the value in retaining staff, as opposed to allowing circumstances that lead high turnover and, as a result, having to train new staff.

“I can tell you, as a retired businessperson, that it is far more expensive to recruit and train than it is to invest in your existing staff. I know that for a fact. Therefore, I often wonder why more companies don’t invest in their existing staff.” (Male, Workshop 3)

There were also mentions of helping parents to return to jobs, and providing support for career development and training.

New ways into the field

Participants were also in favour of challenging the narrow and traditional routes into research, adjusting from a mentality in which researchers are required to hold a university degree, and encouraging apprenticeship and 'earn as you learn' type models.

“You were taught your trade... Whereas now, you’ve got to go to university, you’ve got to get all your degrees. At one time, they would train you onsite over 3 years. All that’s gone.” (Female, Workshop 3)

Showcasing existing staff to attract new talent

Participants felt it was important for the sector to showcase its staff; particularly role models from a variety of backgrounds and communities. This was seen as important for creating the building blocks for a diverse future workforce, as well as helping the public to appreciate the extent of the work that goes into developing drugs and treatments.

“Pull medical researchers from behind a curtain. Show that these people do exist, you don’t get a medicine which is just there.” (Female, Workshop 3)

“The transparency between the researchers, the research, and the public, has to be improved. Whether that involves an educator or ambassador from the research or big pharma organisations. Podcasts, talk shows... they should be on TikTok, Instagram.” (Male, Workshop 3)

Encouraging greater diversity in the sector

Participants saw the value in making health research a viable career path for people from a wide variety of backgrounds, and in making the field more representative of the wider population. It was felt that achieving this would mean a greater diversity of views.

“We can encourage people from minority backgrounds by sharing that there’s a space for them... You need representation to go from top to bottom. That gives people accountability and ideas. No one person’s idea will be the answer; everyone will bring something to the table. It needs to be top to bottom, it can’t just be an entry point.”
(Male, Workshop 1)

“Having diversity is good but it would be difficult to have the same level of representation as the wider public. There’s issues around access to higher education.” (Male, Workshop 1)

A key theme that came out of conversations was the need to encourage women to join the health research workforce. One participant mentioned having seen an advertisement for science jobs, featuring a female scientist, which they thought was particularly effective.

“It’s quite a catchy picture that they’ve put, and it’s saying, ‘Come and join our rapidly expanding research facility’. It’s a female, she’s got her loop earrings in, she’s probably got her false nails on under her gloves, and she’s a scientist. People probably think of a scientist as a boffin, don’t they, with a big forehead. So, it is really catchy.” (Female, Workshop 3)

Diversifying where research happens

There was enthusiasm for the idea of a range of workplaces and locations being made available in which to do this work – including academics at universities, people working for the NHS, and people working for private companies.

When participants discussed the ‘Golden Triangle’ in which much UK-based health research currently takes place, there were some strong views that this trend should not continue. Participants pointed out that universities and businesses in all four nations could benefit from being involved in this work, and that laboratories and hospitals already exist throughout the country that could be utilised for this important work.

“The industry needs wider area operation in terms of offices, clinical trials, and recruiting people from different parts of the country.” (Male, Workshop 3)

The role of patients and the wider public

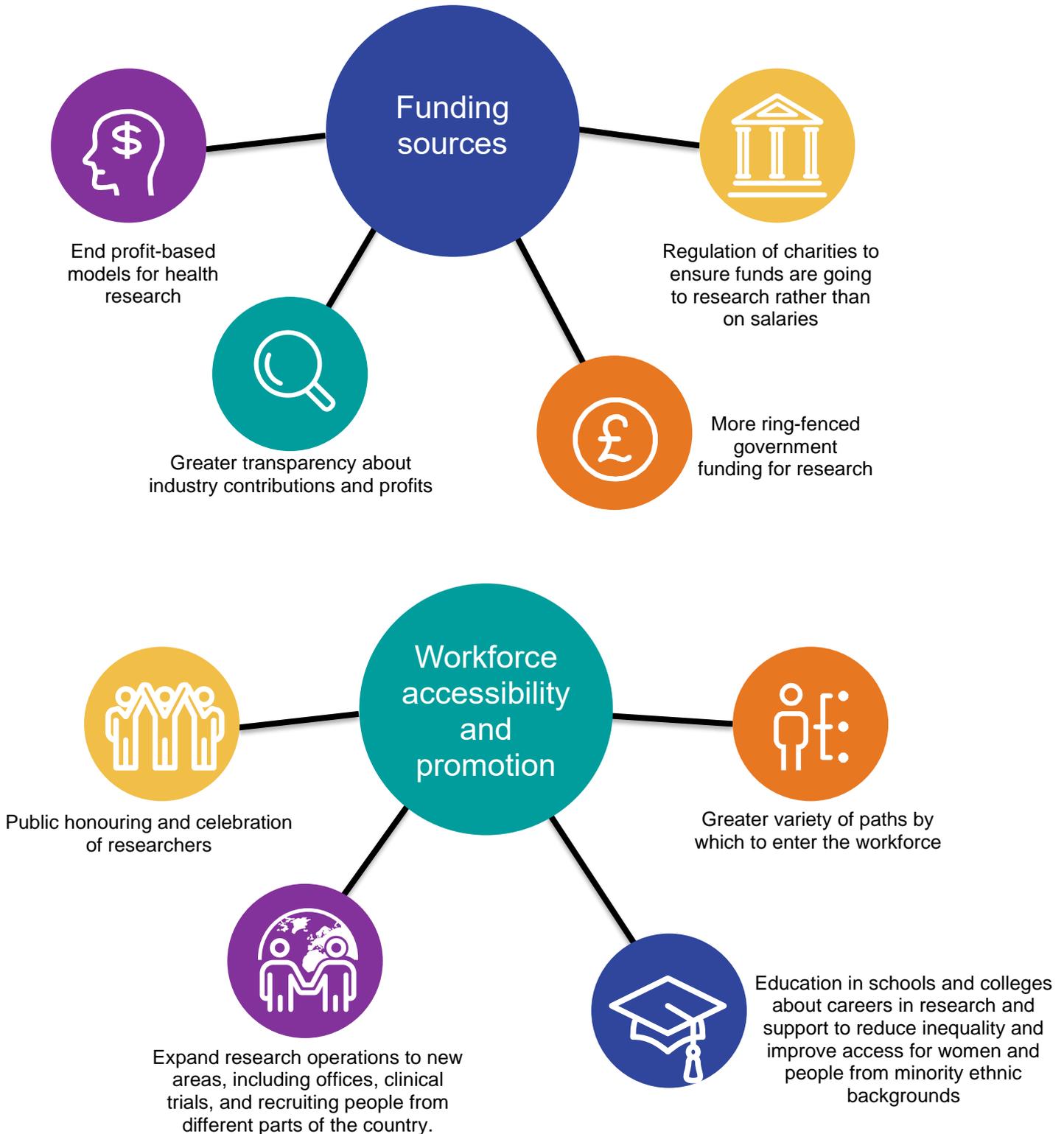
Participants generally felt that the public has an important role to play in health research, and that it would be helpful for this need to be publicised more widely to encourage greater engagement.

“I hadn’t realised] how important that public are to testing and making it a success. You need volunteers to take a risk. It struck me on the slide that we have a really engaged public, so on paper it could work, but the funding isn’t there.” (Male, Workshop 1)

5 Top priorities for the future

As the workshop drew to a close, participants were asked to list their top priorities for the Academy of Medical Sciences to take forward with regards to the issues that they had been discussing, summarised in Figure 5.1. A cross-cutting theme was the importance of educating the public and raising awareness.

Figure 5.1: Participant’s top priorities for the Academy of Medical Science.



6 Methodological Annex

This report summarises the key findings from three three-hour online workshops conducted with members of the public, to understand their views about and priorities for health research in the UK.

The workshops involved group discussion and stimulus in the form of videos, a presentation of information, and a question-and-answer session with specialists representing the Academy of Medical Sciences. The workshops were held to bring the public's voice into strategic planning for the long-term sustainability of health research in the UK. This report feeds into wider work carried out by the Academy of Medical Sciences exploring this topic, which aims to show how public investment in health research can be effectively and sustainably utilised, together with funding from charities and from industry, for the benefit of all.

It is important to note that the scope of this research was limited to views about how research should be carried out in the future – e.g. where it should take place; what people and organisations should be involved; and how it should be funded. The research did not cover views about *what* research should be done.

As with any qualitative research the findings are descriptive and illustrative and are not statistically or nationally representative – they cannot be said to be the views of a wider population. Instead, its key strength is that it gathers a wide range of spontaneous and considered attitudes and allows moderators to ask open-ended questions and develop lines of enquiry as they emerge during the discussion. In including people from a wide range of backgrounds and with a variety of demographic characteristics, the widest possible set of perspectives are sought, and these are reflected in the analysis and reporting.

Methodology

Three three-hour workshops were held online with 13-16 members of the public (a total of 44), on the evenings of 30 May, 31 May, and 1 June 2022. Recruitment was balanced across the groups: participants were recruited from across England, Scotland, Wales, and Northern Ireland, with quotas to ensure a balance of genders, age group, social grade, and ethnic background. An additional quota was used to represent a variety of views about the importance of health research. The quotas achieved are shown in the table 6.1 below.

Table 6.1: Summary of participant characteristics

Characteristics	Quota achieved
Age	14x 18-30
	17x 31-54
	13x 55+
Sex	19x Males
	25x Females
Area of the UK	23x England (spread across North, South & Midlands)
	8x Wales
	10x Scotland
	3x Northern Ireland
Views about health research	28x Very important
	11x Fairly important
	5x Neither important nor unimportant

Ethnicity	18x from a minority ethnic background
	2x Asian or Asian British – Chinese
	5x Asian or Asian British – Indian
	4x Asian or Asian British – Pakistani
	2x Black or Black British – African
	2x Black or Black British – Caribbean
	3x Mixed ethnicity
Social grade ⁴	25x social grade ABC1
	19x social grade C2DE

Limitations of this methodology

- As part of the recruitment process, participants were screened on their views about the importance of health research. All of the members of the public approached for this project viewed health research as either 'neither important nor unimportant', 'somewhat important', or 'very important'. None of those approached said that they had negative views about health research. This is in line with previous national surveys⁵ and is perhaps unsurprising given the context of the ongoing COVID-19 pandemic.
- Information was presented at the workshop by a clinical academic researcher, who was also on hand to answer questions alongside staff from the AMS. Participants did not hear from other types of researchers (for example those involved in discovery/basic research), hence there is a chance that their views may have been biased towards clinical research. Throughout the stimulus, there were however references to discovery/basic research as well as translational and clinical research.

⁴ Market Research Society, Definitions employed in social grading, <https://www.mrs.org.uk/pdf/Definitions%20used%20in%20Social%20Grading%20based%20on%20OG7.pdf>

⁵ https://research.hscni.net/sites/default/files/HRA_NIHR_general_public_omnibus_survey_2017_FINAL.pdf

Our standards and accreditations

Ipsos' standards and accreditations provide our clients with the peace of mind that they can always depend on us to deliver reliable, sustainable findings. Our focus on quality and continuous improvement means we have embedded a "right first time" approach throughout our organisation.



ISO 20252

This is the international market research specific standard that supersedes BS 7911/MRQSA and incorporates IQCS (Interviewer Quality Control Scheme). It covers the five stages of a Market Research project. Ipsos was the first company in the world to gain this accreditation.



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By being an MRS Company Partner, Ipsos endorses and supports the core MRS brand values of professionalism, research excellence and business effectiveness, and commits to comply with the MRS Code of Conduct throughout the organisation. We were the first company to sign up to the requirements and self-regulation of the MRS Code. More than 350 companies have followed our lead.



ISO 9001

This is the international general company standard with a focus on continual improvement through quality management systems. In 1994, we became one of the early adopters of the ISO 9001 business standard.



ISO 27001

This is the international standard for information security, designed to ensure the selection of adequate and proportionate security controls. Ipsos was the first research company in the UK to be awarded this in August 2008.



The UK General Data Protection Regulation (GDPR) and the UK Data Protection Act (DPA) 2018

Ipsos is required to comply with the UK GDPR and the UK DPA. It covers the processing of personal data and the protection of privacy.



HMG Cyber Essentials

This is a government-backed scheme and a key deliverable of the UK's National Cyber Security Programme. Ipsos was assessment-validated for Cyber Essentials certification in 2016. Cyber Essentials defines a set of controls which, when properly implemented, provide organisations with basic protection from the most prevalent forms of threat coming from the internet.



Fair Data

Ipsos is signed up as a "Fair Data" company, agreeing to adhere to 10 core principles. The principles support and complement other standards such as ISOs, and the requirements of Data Protection legislation.

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