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Public perspectives on the use of health data in research and innovation

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Contents

- 1 Executive summary 4**
 - Introduction and method.....4
 - Key findings4
- 2 Introduction and method..... 6**
 - Introduction.....6
 - Method.....6
- 3 General views on data sharing 8**
 - Use of health services and participation in health research.....8
 - Views on data sharing9
- 4 Public views on data access to support traditional and non-traditional research 11**
- 5 Suggested conditions on traditional and non-traditional researchers for access to health data..... 15**
 - Traditional researchers from Scottish universities 15
 - Non-traditional researchers (commercial organisations) 17
- 6 Future priorities for health researchers in Scotland 18**
- 7 Conclusions 19**

List of figures

- Figure 3.1: Have you personally taken part in health care research in the past three years, in any of the following ways?8**
- Figure 3.2: Overall, which of the following statements is closest to your view?9**
- Figure 4.1: Would you support or oppose each of the following types of organisations using health data about you for research and development purposes? 11**
- Figure 4.2: Would you support or oppose AI developers using health data about you for these purposes? 13**
- Figure 4.3: Thinking now about health research that is carried out by pharmaceutical companies, such as GlaxoSmithKline or Roche. As you may know, most pharmaceutical company research studies with NHS patients involve a partnership with the NHS. For example, research studies may take place in an NHS setting, such as a hospital, and be run locally by NHS staff. What difference, if any, does this make to how confident you feel about research funded by pharmaceutical companies?.....14**
- Figure 5.1: Which of the following conditions, if any, would you want to have in place before [researchers from Scottish universities / commercial organisations] could access health data about you for research purposes?..... 16**
- Figure 6.1: Which, if any, of the following do you think health researchers in Scotland should focus their efforts on in the future? 18**

1 Executive summary

Introduction and method

DataLoch¹, a partnership of the University of Edinburgh and NHS Lothian at the time of writing, commissioned Ipsos Scotland to carry out survey research to measure public perceptions of the use of potentially sensitive health data² for various uses linked to South East (SE) Scotland's Data-Driven Innovation Programme's priorities. The survey was administered through the Ipsos KnowledgePanel, an online survey panel recruited via a random probability unclustered address-based sampling method. Fieldwork took place between 17th and 23rd March 2022. All panellists eligible for the research (aged 16+ and living in SE Scotland, defined as the following local authority areas: Fife, Edinburgh, East Lothian, Midlothian, West Lothian and Scottish Borders) were invited to take part. A total of 915 were invited to participate, and a total of 595 respondents completed the survey, a response rate of 65%. Data were then weighted in line with population statistics for the region.

Key findings

The public in SE Scotland are broadly positive about the sharing of health data. A majority (72%) agreed more with the statement 'We should share all the health data we can because it benefits health services and me', than 'We should not share health data as the risks to people's privacy and security outweigh the benefits'. The over-55s and those living in the least deprived areas were more likely to hold this view.

More people are also supportive of access to health data for commercial organisations than are opposed to it. Among the public in SE Scotland, 60% agreed more with the statement 'I would want the research to be conducted by commercial organisations if there is a possibility of new treatments for diseases, medical devices being developed, or health services being made more efficient', than with the statement 'I would not want commercial organisations to have access to this health data, even if this means the research does not take place'.

Looking at access to health data by type of research organisation, traditional researchers (NHS and universities) received higher support than non-traditional researchers (commercial organisations, charitable organisations, private health care companies and pharmaceutical companies). However, access to health data for all types of researchers, whether traditional or non-traditional, was supported by over half of the public. Graduates and those living in the least deprived areas were more likely to support data sharing. Views on data sharing with AI developers were also broadly positive, with a majority (70%) in support of AI developers using health data about them for research and development purposes.

¹ DataLoch is a data service. It is currently a partnership between University of Edinburgh and NHS Lothian, but it is expected that other NHS Boards and councils in South East Scotland will join the partnership in future. DataLoch works to:

- Bring together health and social care data for the SE Scotland region
- Work with experts to understand and improve this data
- Provide safe access to data for researchers

² By health data, we mean any information gathered through health services. Data sources could include GP records, hospital records, information about prescriptions, or laboratory data.

Respondents were asked which conditions they would want to see in place before researchers were able to access health data about them for research purposes. For both traditional researchers (NHS and universities) and non-traditional researchers (commercial organisations, charitable organisations, private health care companies and pharmaceutical companies), the most popular conditions were the removal of personally identifying information, strict rules that data could not be passed on to any other organisation, contracts put in place so data could only be used for agreed purposes, and data only being accessible in a secure IT environment.

The most popular areas that the public in SE Scotland wanted health researchers in Scotland to focus on in future were making health services more efficient (40%), developing new medicines and treatments (39%), improving patient care to bring about better health outcomes (36%), preventing ill health (35%) and understanding the causes of ill health (26%).

2 Introduction and method

Introduction

DataLoch, a partnership of the University of Edinburgh and NHS Lothian at the time of writing, commissioned Ipsos Scotland to carry out survey research to measure public perceptions of the use of potentially sensitive health data for various uses linked to its Data-Driven Innovation Programme's priorities. Data-Driven Innovation (DDI) is central to the Edinburgh and South East Scotland City Region Deal, and the DDI programme aims to develop innovative and financially sustainable models of health and social care that improve lives. This research aims to provide a baseline understanding of how people in SE Scotland feel about traditional and non-traditional researchers using health data for research and development, what conditions should be in place before access to health data is granted, and whether these conditions differ between different types of organisations.

Method

The survey was administered through the Ipsos KnowledgePanel, an online survey panel recruited via a random probability unclustered address-based sampling method. This means that every household in the UK has a known chance of being selected to join the panel. Letters are sent to selected addresses in the UK (using the Postcode Address File) inviting them to become members of the panel. Invited members can sign up to the panel by completing a short online questionnaire or by returning a paper form. Members of the public who are digitally excluded are able to register to the KnowledgePanel either by post or by telephone, and are given a tablet, an email address, and basic internet access which allows them to complete surveys online.

Fieldwork took place between 17th and 23rd March 2022. All panellists eligible for the research (aged 16+ and living in SE Scotland, defined as the following local authority areas: Fife, Edinburgh, East Lothian, Midlothian, West Lothian and Scottish Borders) were invited to take part. A total of 915 were invited to participate, and 595 respondents completed the survey, meaning a response rate of 65%.

Data were weighted to ensure the results were as representative of the population of SE Scotland as possible. As up to two members per household are allowed to register on the KnowledgePanel, a design weight was employed to correct for unequal probabilities of selection of household members. Calibration weights were also applied using population statistics for the region. Two sets of calibration weights were applied:

- Calibration weighting was applied using the following variables: age, gender and region as separate variables. All three use National Records of Scotland 2020 mid-year population estimates as the weighting target.
- Demographic weights were then applied to correct for imbalances in the achieved sample. The data was weighted by education and Scottish Index of Multiple Deprivation (quintiles). Estimates from the National Records of Scotland 2020 mid-year population estimates were used as the weighting target.

Any differences between sub-groups referred to in this report are statistically significant at the 95% confidence level. Where differences by sub-group are not mentioned (for example, by ethnic background or religion), these differences are either not significant, or the sample is too small to reliably test for statistical significance. Where responses do not sum to 100%, this may be due to rounding, multiple responses or the exclusion of 'don't know' categories.

3 General views on data sharing

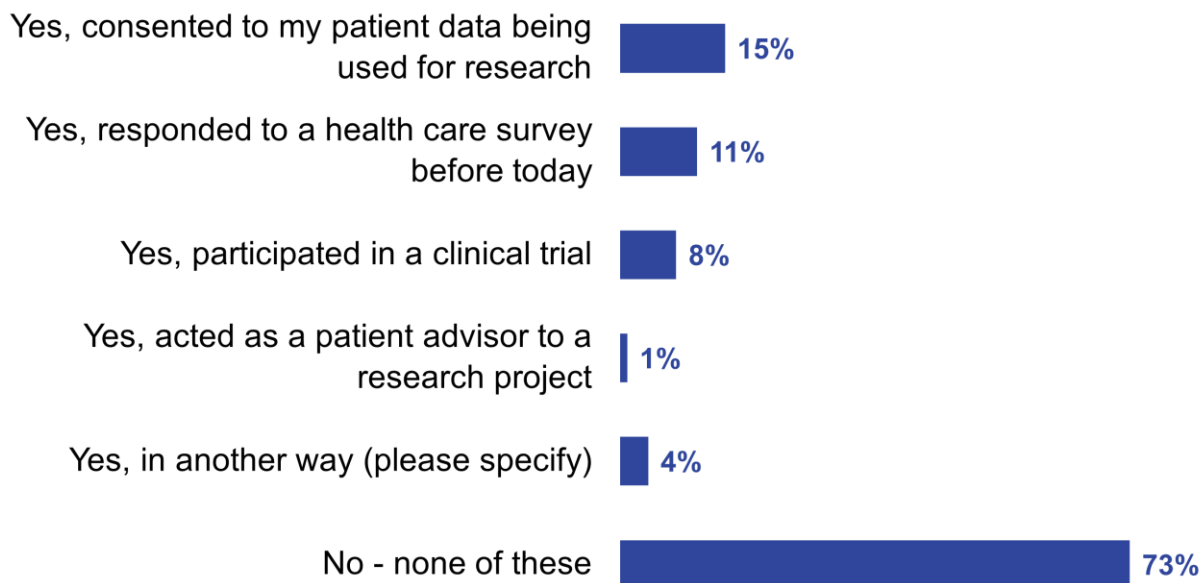
Use of health services and participation in health research

Almost all respondents (96%) reported using at least one health service over the past three years. The most used health services were a GP practice or GP out-of-hours service (used by 81% of respondents in the past three years), dentist (75%), and pharmacist (73%).

Women were more likely than men to have been to their GP practice or GP out-of-hours service (87%, compared to 73% of men) and to have used the NHS 111 telephone or online service (36%, compared to 20% of men). Those in the 55+ age group were more likely than average to have used a pharmacist service (82%, compared to 73% overall), and those in the youngest age group (16-34) were more likely than the 55+ age group to have accessed NHS 111 services (38%, compared to 19% of those aged 55+) and mental health services (23%, compared to 5% of those aged 55+).

Twenty-seven per cent of respondents reported that they had taken part in health care research in the past three years. This participation in health care research had most commonly taken the form of consenting for their patient data being used for research (15% of the sample), responding to a health care survey (11%) or participating in a clinical trial (8%) (Figure 3.1).

Figure 3.1: Have you personally taken part in health care research in the past three years, in any of the following ways?



Base: 595 KnowledgePanel respondents aged 16+, living in SE Scotland

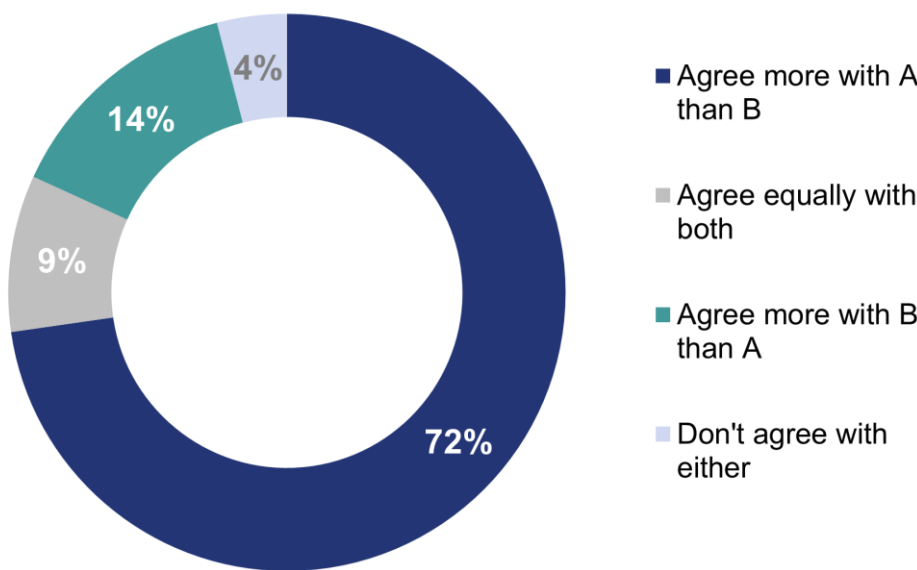
Those living in the least deprived areas (SIMD 4 and 5) were more likely to have consented to their data being used for research (20%, compared to 15% on average) and to have responded to a health care survey (16%, compared to 11% on average).

Views on data sharing

To gauge views on data sharing generally, respondents were presented with two statements and asked which one they agreed with more: ‘We should share all the health data we can because it benefits health services and me’, or ‘We should not share health data as the risks to people’s privacy and security outweigh the benefits’. The order of the statements was rotated for half the sample to avoid response bias. A majority (72%) stated that they agreed more with statement A than statement B, indicating that they were broadly positive about the sharing of health data. Fourteen per cent agreed more with B than A, indicating that they were broadly opposed to the sharing of health data.

Figure 3.2: Overall, which of the following statements is closest to your view?

- A. We should share all the health data we can because it benefits health services and me**
- B. We should not share health data as the risks to people’s privacy and security outweighs the benefits**



Base: 595 KnowledgePanel respondents aged 16+, living in SE Scotland

Differences by age group were evident, with those in the oldest age group (55+) more likely to feel positively about data sharing (82% agreed more with statement A than with statement B) than those in the youngest age group (59% of 16-34 year-olds agreed more with A than with B). Respondents living in the least deprived areas of Scotland were also more likely to hold this view: 80% of those in SIMD 4 and 5 areas agreed more with A than with B, compared to 62% of those in the most deprived areas (SIMD 1 and 2).

To explore general views on commercial organisations being able to access health data, respondents were then asked which of these two statements they agreed more with:

- A. ‘I would not want commercial organisations to have access to this health data, even if this means the research does not take place’
- B. ‘I would want the research to be conducted by commercial organisations if there is a possibility of new treatments for diseases, medical devices being developed, or health services being made more efficient’

Again, the order of the statements was rotated for half the sample to avoid response bias.

Three in five were broadly positive about commercial organisations being able to access health data; 60% agreed more with the statement which was more positive about data sharing (statement B) than with statement A. However, 29% felt that they would not want commercial organisations to access health data even if it meant that the research did not happen as a result. As this indicates, the public in South East Scotland are slightly more positive about health data sharing in general than they are about data being shared with commercial organisations specifically, although twice as many are broadly positive about commercial organisations having access to health data than are against it.

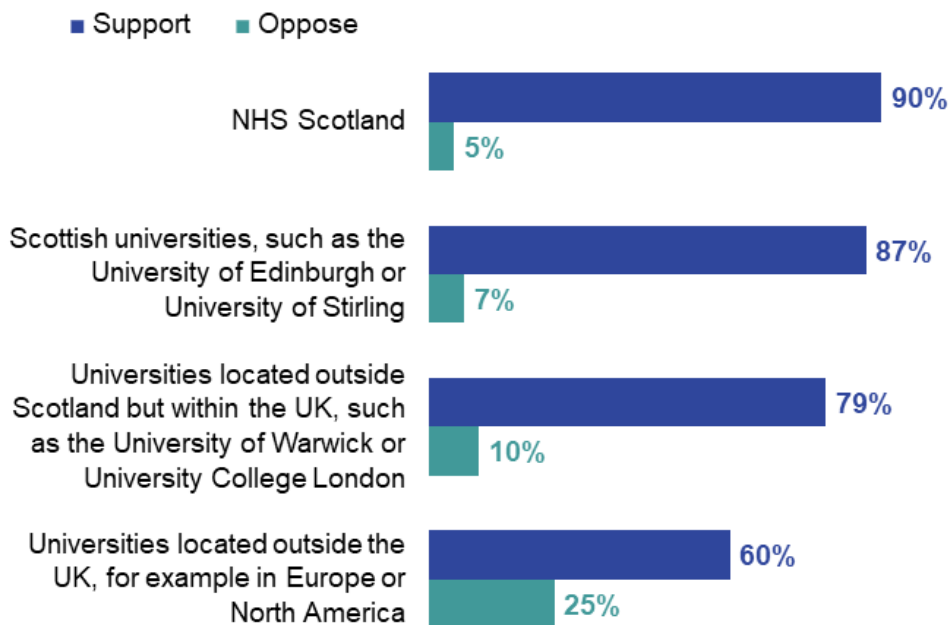
Those living in the least deprived areas were more likely to agree with data sharing for commercial organisations than those in the most deprived areas: 69% agreed more that they would want research to be conducted by commercial organisations if there is a possibility of new treatments for diseases, medical devices being developed, or health services being made more efficient, compared to 44% of those in the most deprived areas.

4 Public views on data access to support traditional and non-traditional research

On the whole, support for a range of different types of organisations using health data for research and development purposes is high. For all the types of organisations asked about, more than half of the public in the SE Scotland city region supported health data sharing for these purposes.

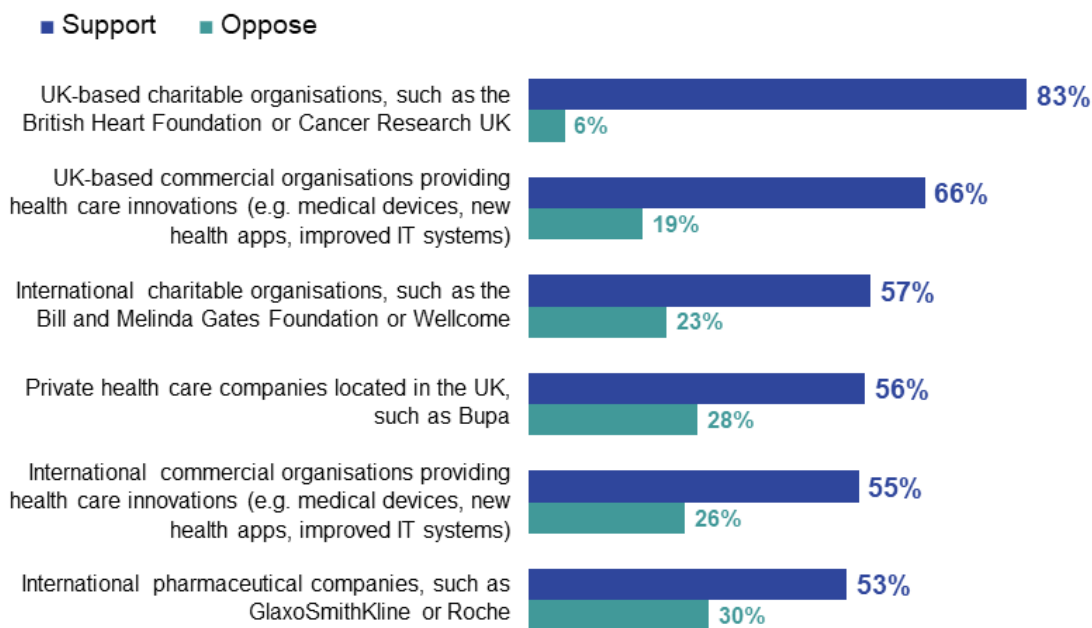
Figure 4.1: Would you support or oppose each of the following types of organisations using health data about you for research and development purposes?

Traditional research organisations



Base: 595 KnowledgePanel respondents aged 16+, living in SE Scotland

Non-traditional research organisations



Base: 595 KnowledgePanel respondents aged 16+, living in SE Scotland

The organisations with the highest public support for using health data are NHS Scotland (90% support), Scottish universities (87%), UK-based charitable organisations (83%), and UK universities located outside Scotland (79%). The types of organisations with the lowest levels of public support for health data sharing are international pharmaceutical companies (53%), international commercial organisations providing health care innovations (55%) and UK-based private health care companies (56%). However, more of the public still support these organisations using health data about them for research and development purposes than oppose it.

Strength of support also varied – for example, NHS Scotland and Scottish universities received similarly high levels of support (90% and 87% respectively), but the public were more likely to say they ‘strongly support’ NHS Scotland using health data about them (62% ‘strongly support’ and 29% ‘tend to support’) than they were to say the same of Scottish universities (47% ‘strongly support’ and 40% ‘tend to support’).

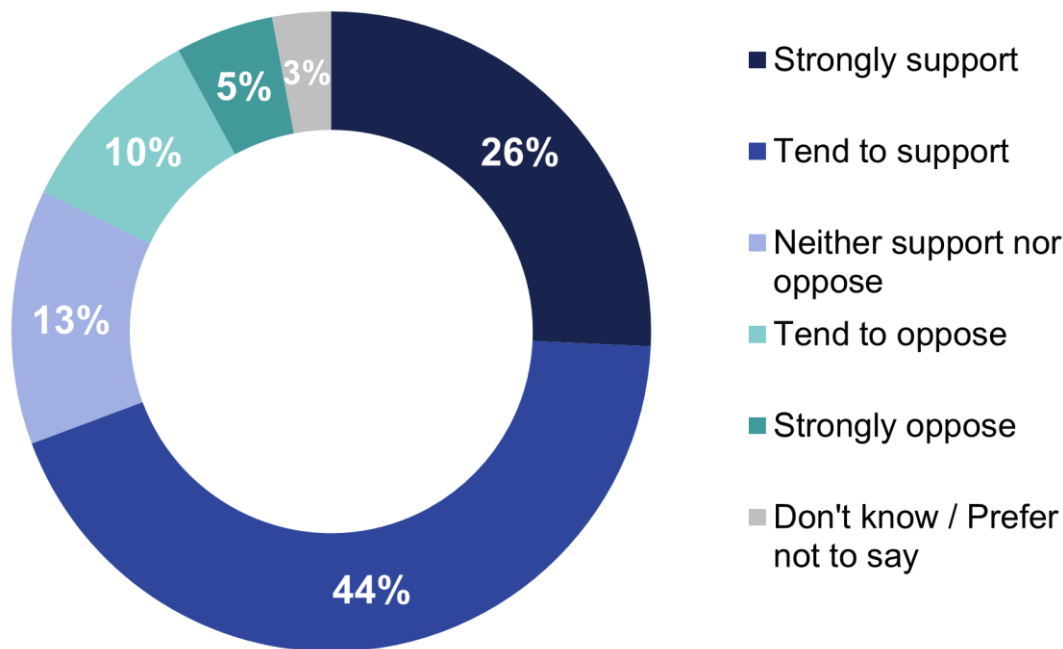
Women were more likely to support UK-based charities using health data (87%, compared to 78% of men) and UK-based commercial organisations providing health care innovations (72%, compared to 60% of men). Those aged 55+ were more likely to support international pharmaceutical companies (the type of organisation with the lowest support overall) accessing health data (61% compared to 53% on average).

Graduates were more likely than non-graduates to support health data access for Scottish universities (92%, compared to 84% of non-graduates), UK-based universities outside of Scotland (89%, compared to 74% of non-graduates), and universities located outside the UK (71%, compared to 54% of non-graduates). Those living in the least deprived areas of SE Scotland were more likely than average to support access to health data for all types of organisations asked about. In contrast, those living in the most deprived areas were less likely than average to support access to health data for Scottish universities, UK universities outside of Scotland, UK-based commercial organisations, international charitable organisations, international commercial organisations and international pharmaceutical companies.

Unsurprisingly, those who demonstrated a generally positive attitude to data sharing in earlier questions (agreeing more that 'We should share all the health data we can because it benefits health services and me') were more likely than the average to support access to health data for every type of organisation asked about.

Views of data sharing with AI developers were broadly positive, with a majority (70%) in support of AI developers using health data about them for research and development purposes. Support was higher among those in the least deprived areas (78% of those in SIMD 4 or 5) than among those in the most deprived areas (56% of those in SIMD 1 or 2).

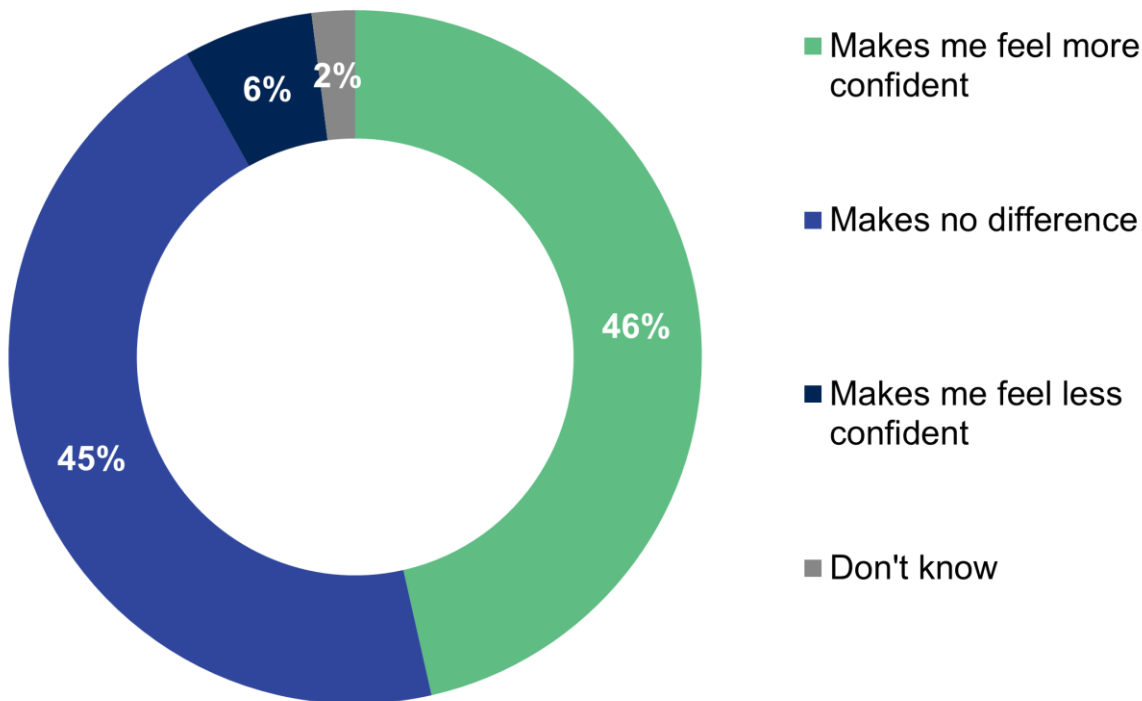
Figure 4.2: Would you support or oppose AI developers using health data about you for these purposes?



Base: 595 KnowledgePanel respondents aged 16+, living in SE Scotland

Respondents were informed that most pharmaceutical company research studies with NHS patients involve a partnership with the NHS and were asked whether that made them feel more confident about research funded by pharmaceutical companies, less confident, or made no difference. Over two in five (46%) said it made them feel more confident and 45% said it made no difference, while 6% said it made them feel less confident about these studies. Older respondents aged 55+ were more likely than average to say it made them feel more confident (51%).

Figure 4.3: Thinking now about health research that is carried out by pharmaceutical companies, such as GlaxoSmithKline or Roche. As you may know, most pharmaceutical company research studies with NHS patients involve a partnership with the NHS. For example, research studies may take place in an NHS setting, such as a hospital, and be run locally by NHS staff. What difference, if any, does this make to how confident you feel about research funded by pharmaceutical companies?



Base: 595 KnowledgePanel respondents aged 16+, living in SE Scotland

5 Suggested conditions on traditional and non-traditional researchers for access to health data

Traditional researchers from Scottish universities

Respondents were asked which conditions they would want in place before Scottish university researchers could access health data about them.

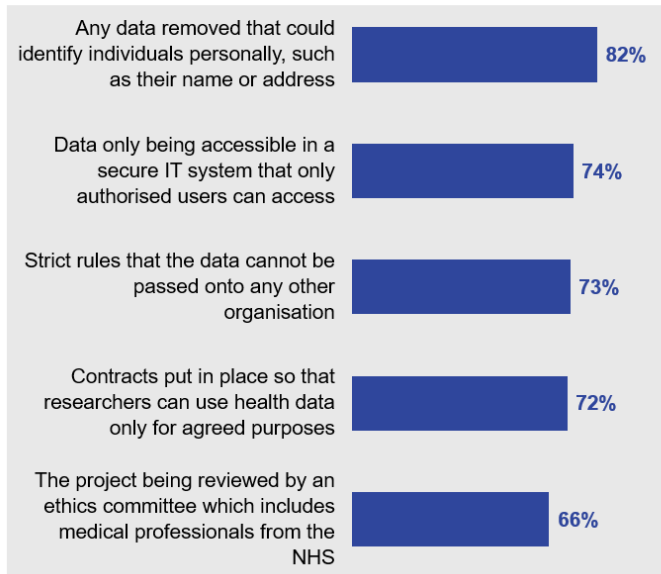
Respondents were given the following ten conditions to choose from:

1. Strict rules that the data cannot be passed onto any other organisation
2. Any data removed that could identify individuals personally, such as their name or address
3. Data only being accessible in a secure IT system that only authorised users can access
4. Access to data being allowed only after an assessment of the research project's benefits for patients
5. Contracts put in place so that researchers can use health data only for agreed purposes
6. The project being reviewed by an ethics committee which includes medical professionals from the NHS
7. The project being reviewed by an ethics committee which includes a member of the public
8. Having a member of NHS staff as part of the research team for every project
9. Researchers needing to have a formal accreditation (showing they have been trained on how to use health data securely and responsibly) before accessing the data
10. Another condition [PLEASE SPECIFY]

Respondents who wanted to see conditions selected an average of six options from the above list. Those who did not select any of the conditions either were content for university researchers to have access to health data without any of the conditions in place (4%), did not want university researchers to have access to health data at all (4%), said they didn't know (1%) or preferred not to say (1%).

Figure 5.1: Which of the following conditions, if any, would you want to have in place before [researchers from Scottish universities / commercial organisations] could access health data about you for research purposes?

Scottish university researchers priority conditions:



Commercial organisations priority conditions:



Base: 557 KnowledgePanel respondents aged 16+ who were content for Scottish university researchers to access health data, and 451 KnowledgePanel respondents aged 16+ who were content for commercial organisations to access health data

Women were more likely to want personally identifying data to be removed before Scottish university researchers could have access (86% of women who were content for Scottish university researchers to access health data, compared to 77% of men). University graduates were more likely than non-graduates to want to see the following conditions before Scottish university researchers could access data: removal of personally identifying data (87% of those graduates content for Scottish university researchers to have access compared to 79% of non-graduates), data only being accessible in a secure IT system (81% compared to 71%), contracts put in place so data can only be used for agreed purposes (78% compared to 69%), the project being reviewed by an ethics committee including an NHS professional (74% compared to 63%), and access to data only being allowed after an assessment of the research project’s benefit for patients (55% compared to 40%).

Those in the least deprived areas were more likely than those in the most deprived areas to want data to be accessible to Scottish university researchers only in a secure IT environment (77% of those in SIMD 4 or 5 areas who were content for Scottish university researchers to have access gave this response, compared to 68% of those in SIMD 1 or 2) and to want researchers to have accreditation before being able to access the data (67%, compared to 50% of those in SIMD 1 or 2 areas).

Those who had participated in health research during the past three years were more likely than average to want to see the following conditions in place before Scottish university researchers could access health data:

- Identifying data removed
- Data only accessible in a secure IT system
- Strict rules that data could not be passed on
- Contacts put in place so that researchers could only use data for agreed purposes
- Researchers needing formal accreditation before accessing the data.

Non-traditional researchers (commercial organisations)

Respondents were asked to choose which, if any, conditions they would want to see in place before they were comfortable with commercial organisations accessing health data. The list of conditions was the same as the options listed in the previous question about conditions for university researchers, with one additional condition included: 'The NHS receiving a percentage of the profits made from the products developed'. Respondents who wanted to see conditions selected an average of 7 options from the 11 conditions listed. Those who did not select any of the conditions were either content for commercial researchers to have access to health data without any of the conditions in place (6%), did not want commercial researchers to have access to health data at all (21%), said they didn't know (3%) or preferred not to say (1%).

When asked about the conditions they would want in place for commercial organisations to access health data, the top three conditions (for those who were content for commercial organisations to have access) were similar to those for traditional researchers: removal of personally identifying information (79%), strict rules that the data cannot be passed on (73%), and contracts put in place so that researchers can use health data only for agreed purposes (71%).

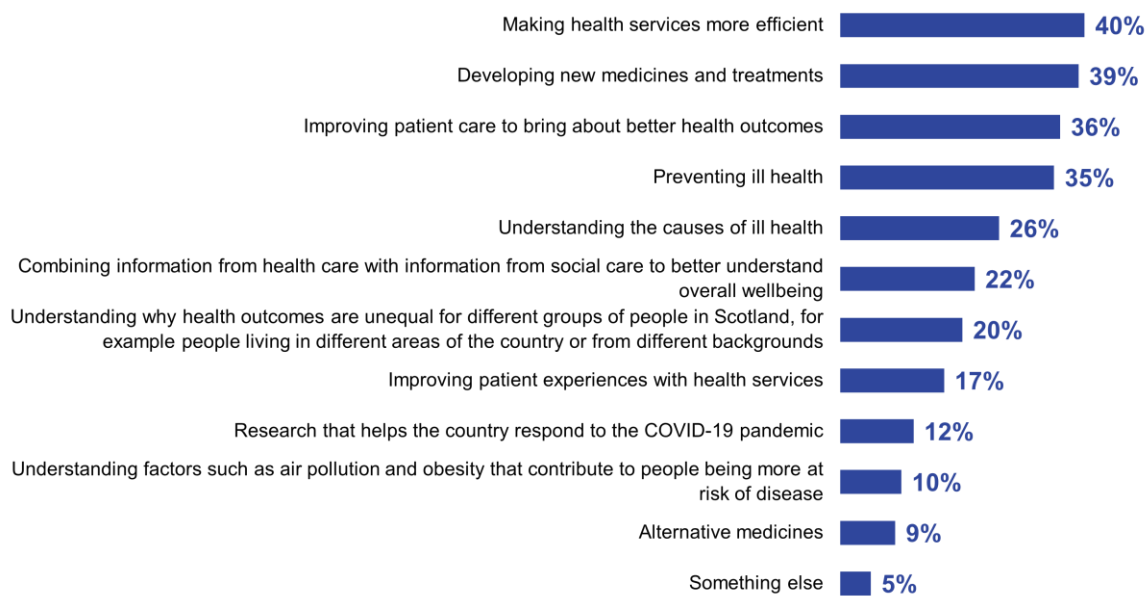
Women were more likely to want to see strict rules that data could not be passed on (81%, compared to 63% of men) and the NHS receiving a percentage of profits from products developed (72%, compared to 54% of men) before they were comfortable with commercial organisations accessing health data.

As was the case for traditional researchers, university graduates were more likely than non-graduates to want almost every condition to be in place before commercial organisations could access health data. Those in the least deprived areas also wanted to see more conditions than those in the most deprived areas before commercial organisations could access health data.

6 Future priorities for health researchers in Scotland

The most popular areas that the public in SE Scotland wanted health researchers in Scotland to focus on in future were making health services more efficient (40%), developing new medicines and treatments (39%), improving patient care to bring about better health outcomes (36%), preventing ill health (35%) and understanding the causes of ill health (26%).

Figure 6.1: Which, if any, of the following do you think health researchers in Scotland should focus their efforts on in the future? Please select up to three that feel most important to you.



Base: 595 KnowledgePanel respondents aged 16+, living in SE Scotland

Priorities varied across different demographic groups. For example, preventing ill health was a higher priority for men (44%) than for women (28%), as was understanding the causes of ill health (32% of men, compared to 21% of women). For women, the two most popular priorities were developing new medicines and treatments (41%, compared with 36% of men) and making health services more efficient (40%, a similar proportion to the 39% of men who said this). Making health services more efficient and preventing ill health were more popular priorities among those living in the least deprived areas of the city region, compared with the average.

Those who were positive towards health data sharing in general were more likely than those who were less positive about data sharing to want health researchers to prioritise combining information from health care with information from social care to better understand overall wellbeing (24% compared to 9%).

7 Conclusions

The results of this survey show that a majority of the public in the South East of Scotland hold generally positive views about data sharing in health care for research, development and innovation purposes. Over seven in 10 (72%) agreed more with the statement 'We should share all the health data we can because it benefits health services and me', than 'We should not share health data as the risks to people's privacy and security outweigh the benefits', indicating that they were broadly positive about sharing health data.

Respondents were asked about their support for health data access by different types of research organisations. The strongest support was found for traditional researchers (NHS and universities) but support for every type of non-traditional researchers accessing health data was also above 50%. Seventy per cent supported AI developers having access to health data for innovation purposes.

Support for data sharing was highest among respondents living in the least deprived areas of SE Scotland, and among those who had graduated from university.

The most popular conditions for access to health data (for both traditional and non-traditional researchers) included the removal of identifiable data, data only being accessible through a secure system, strict rules that data cannot be passed on, and contracts put in place so that data can only use for agreed purposes.

The most popular areas that respondents wanted future health care researchers in Scotland to prioritise were making health services more efficient, developing new medicines and treatments, improving patient care to bring about better health outcomes, and preventing ill health.

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.



Market Research Society (MRS) Company Partnership

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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