Liverpool Antimicrobial Resistance (AMR) Citizens' Jury

Liverpool AMR Citizens' Jury Full Report

19-21 January + 24-26 January 2022

Commissioned by:

Designed and delivered by:

This project was funded by the University of Liverpool and Pfizer Inc. The findings and results in this report do not necessarily reflect those of the commissioning bodies, funders, or project team.

This initiative was codeveloped between Pfizer Inc, the University of Liverpool and the Center for New Democratic Processes. Pfizer Inc. provided funding and support to the project. Pfizer Inc. collaborated with this project as it aligned closely with Pfizer's commitment to understanding the public perception of antimicrobial stewardship and related issues.

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“Hopefully the work we have done will go towards a very positive and important project of finding an answer to AMR. This project is the brainchild of people in our Merseyside region and it’s good to see that we could be having such an input into the future health of the country and the world as a whole.”

Quote from Jury member

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Liverpool Antimicrobial Resistance

(AMR) Citizens' Jury

Foreword:

University of Liverpool Programme Directors

Antimicrobial resistance is one of the top 10 global health threats that we all face. Tackling such big and complex problems requires a large team effort enabling us to understand the best way to support communities to implement the changes they need to protect their health and wellbeing.

It is our belief that the best way to combat such large global threats is through a system approach that is codesigned with the community that will be most impacted. To design the right system, we need to ensure that all voices are heard, and actions are taken to implement the best solutions on their behalf. For our team in Liverpool that means working with the local community to understand their opinions and then to use those insights to start to build the foundation of our future research and development activities. It is for this reason we commissioned the Citizen Jury to be undertaken by the Centre for Democratic Processes on our behalf.

We were delighted with the insights that the people of Liverpool City Region so generously shared with us during this Citizen Jury. There was strong understating of the urgency to act. A strong understanding of the need for multiple organisations to work together for the greater good. There was also a lot of detail for us to consider, particularly in our future planning around the use and access of data.

Our commitment is to take forward these insights and start to build them into our plans as they develop. We will work alongside the people of Liverpool City Region to implement a system that works with them, provides benefit for them and the global community as we work together to combat antimicrobial resistance.

Dr Amanda Lamb, on behalf of the University of Liverpool Programme Directors

Thank You from:

University of Liverpool Team

The University of Liverpool team would like to thank everyone involved in creation, delivery and reporting of the Liverpool City Region Antimicrobial Resistance Citizens' Jury. With gratitude we acknowledge the following people whose involvement has been crucial to the success of the project.

Thank you to our jurors, selected from across the Liverpool City Region for their time, openness to the jury process and their insightful perspectives.

Thank you to the Oversight Panel for supporting the process, ensuring the minimisation of bias and for acknowledging the uniqueness of engaging with the public at such an early stage of project planning.

Thank you to the Center for New Democratic Processes and Citizens' Jury CIC for your independent facilitation, for creating a safe space for our jurors to discuss the topic of AMR and for your unending professionalism.

Thank you to our funders.

Thank You:

Center For New Democratic Processes

The Center for New Democratic Processes (CNDP) would like to thank our partners and colleagues from the University of Liverpool and Pfizer Inc. for their investments in and dedication to this project.

We also wish to thank our colleagues at Citizens' Juries CIC for recruiting a fantastic panel of Liverpool residents to serve on this Jury. We are grateful to the Oversight Panel for their contributions and insights, which were invaluable for ensuring the integrity of this process. We also must thank the Expert Witnesses for volunteering their time and energy to develop presentation slides and for interacting so graciously with the jurors during their presentations and Q&A sessions. Finally, we must thank the jurors themselves for their positivity, generosity, seemingly boundless energy, and their tireless efforts to collaboratively learn about and tackle the complex and important task in front of them.

Project Background

A Citizens' Jury was commissioned by the University of Liverpool and Pfizer Inc. to explore attitudes and perspectives about relationships among public and private entities collaborating to monitor and develop responses to antimicrobial resistance in the Liverpool City Region.

The jury has been commissioned by the University of Liverpool as part of its strategic commitment to involving local citizens in the codesign of research and development. It will provide insights for two University of Liverpool programmes. The first is the Centre of Excellence in Infectious Disease Research (CEIDR) from grant funding provided by Pfizer Inc. CEIDR recognises the urgent need to develop antimicrobials to tackle emerging resistance in 'superbugs' and plans to develop a programme in the Liverpool City Region that tackles the treatment of AMR. The second is the Civic Data Cooperative (CDC) which has been established with funding from the Liverpool City Region Combined Authority. The CDC works with organisations that want to use data about citizens to better inform decisions, policies, and new ideas, helping to improve health, well-being, and wealth across the region. CDC projects must involve the public to demonstrate transparent and trustworthy use of data.

University of Liverpool project activities were managed by an experienced team in an initiative called Health Innovation Liverpool (known as the HILL). The HILL supports better translation of research into positive public impact by working with the public to understand their perspectives before research is designed and developed.

In addition to funding, Pfizer Inc. supported this collaboration with question design and scenario development. Pfizer Inc. had no input with identification, enrolment or management of the jurors. Pfizer Inc. collaborated with this project as it aligned closely with Pfizer's commitment to understanding the public perception of antimicrobial stewardship and related issues.

Project sponsors commissioned the Center for New Democratic Processes, creators of the Citizens' Jury process and global leaders in deliberative public participation and civic engagement, to design and facilitate this event in partnership with Citizens' Juries CIC, a Manchester (UK) based social enterprise.

The jury has been funded by contributions from Pfizer Inc., the CDC, and the University of Liverpool.

This six-day, online Citizens' Jury was conducted digitally on Wednesday 19 January through Friday 21 January 2022 and from Monday 24 January through Wednesday 26 January 2022. Jury participants were selected from within the Liverpool City Region to include a broadly representative mix of people in terms of age, gender, ethnic group, educational attainment, employment status and geographical spread.

Project sponsors will use the results of the Jury to shape the development of a multi-party project to investigate and tackle issues of antimicrobial resistance (AMR). Jurors assessed scenarios covering multiple patient pathways in order to provide recommendations for information sharing and the structure of relationships among public and private actors whose goal is to monitor and respond to antimicrobial resistance (AMR) in the Liverpool City Region.

“This is a complex issue and we as a society need to look at the implications of AMR and its surrounding issues. The public needs to be made aware that we have only been able to discuss the issues with limited knowledge of the proposed collaboration as there has been no set plan brought to us, so a lot of the issues can be seen as speculative. Going forward we need to be more open about what we plan to do as a society in tackling this issue but also address the issues around personal medical data sharing.”

Quote from Jury member

Why a Citizens’ Jury?

One proven method for bringing complex challenges to the public is a citizens’ jury. A jury – wherein people are recruited to broadly reflect the demographics of a particular catchment area – can be asked to hear and weigh the evidence, deliberate together, and use their values to assess trade-offs and make judgements regarding their remit. The evidence comes from expert witnesses who are briefed to make presentations that provide the jury with a fair balance of relevant information. As a multi-day event, jurors encounter and engage a series of frameworks to assess the challenge(s) at hand, learn from presenters, and work collaboratively with one another to weigh the benefits and trade-offs of proposed solutions.

A cornerstone of Citizens’ Juries is that they are independent processes, which utilise a series of safeguards to ensure that the jury is designed and implemented without undue influence from project sponsors and those with vested interests in the outcomes. Steps are taken to shield the work of the jurors from external influence and minimise the unintentional introduction of bias from project sponsors and convenors. Project materials (including the Jury Questions and expert presentations) are reviewed by a project Oversight Panel whose role is to monitor for potential bias in the development and implementation of the Jury. Citizens’ juries are independently designed and facilitated so that project sponsors and commissioners gain valuable insights into the public’s assessment of the topic under consideration while ensuring that these insights are representative of the participants’ views.

Why a Citizens’ Jury on AMR?

Antimicrobial Resistance (AMR), which occurs when bacteria and other pathogens evolve in response to medicines, can cause medicines such as antibiotics to stop working effectively.[1]

The World Health Organisation has labelled AMR as one of the top 10 global public health threats facing humanity. AMR is considered a significant global health and development threat.

Healthcare providers, researchers, and drug developers need to be able to interface with one another and analyse large data sets to develop immediate and long-term mitigation and treatment strategies. Yet addressing AMR presents a series of complex challenges. Often, AMR outbreaks are regional, but healthcare professionals and hospital systems are unable to quickly communicate with one another in order to understand and purposefully monitor situations as they evolve. Researchers also often lack timely access to data in order to better understand AMR, how it is treated and transmitted, and how to best slow the spread of existing AMR while forecasting the emergence of new AMR strains. Finally, the development of new drugs to treat AMR is a slow and expensive process for pharmaceutical companies, particularly as the spread of AMR continues to outpace drug companies’ ability to develop new, targeted treatments.

The complexity of these challenges requires the input not only of healthcare professionals, researchers, and drug developers, but members of the public, as well. It is, after all, the public whose data will be shared in these systems. In this case, the University of Liverpool and Pfizer commissioned a Citizens’ Jury to invite a diverse microcosm of Liverpool residents to learn about AMR and the proposed AMR monitoring network, to deliberate about the potential benefits and risks of such a system, and to make informed recommendations regarding the legal, ethical, and regulatory aspects of this undertaking.

1 Wellcome (2020). “The Global Response to AMR: Momentum, success, and critical gaps” (pg. iii).

AMR Citizens' Jury Remit

The Citizens' Jury participants (jurors) were tasked with learning about AMR as it relates to research and development of antimicrobial pathologies, prescribing patterns, treatment plans, and drug development. More specifically, jurors learned about a proposed collaboration between the University of Liverpool and a network of (yet-to-be-determined) public and private partners collaborating to develop a system with the goal of more effectively tracking, researching, treating, and mitigating AMR.

This collaboration would rely upon pseudo-anonymised patient data such as comprehensive care histories, prescribing, and treatment patterns. Access to this information would allow parties in the system to anticipate and mitigate AMR, understand and improve treatments, and better understand and develop treatments to address AMR. It is therefore essential for healthcare professionals, researchers, governmental agencies, pharmaceutical companies, and other interested parties to gain a more comprehensive understanding of the public's attitudes and opinions about the use of healthcare records for these purposes.

Jurors were charged with evaluating patient healthcare data for AMR treatment and mitigation from multiple perspectives and for multiple ends. Participants assessed scenarios covering four patient pathways while in hospital and registered their level of comfort with sharing pseudo-anonymised data about their medical history, response to AMR-related treatment, and other healthcare information with the proposed AMR system. Jurors also provided recommendations for information sharing and the structure of relationships among public and private actors whose goal is to monitor and respond to AMR in the Liverpool City Region. The jury considered how organisations might collect, share, and utilise pseudo-anonymised patient data for purposes including:

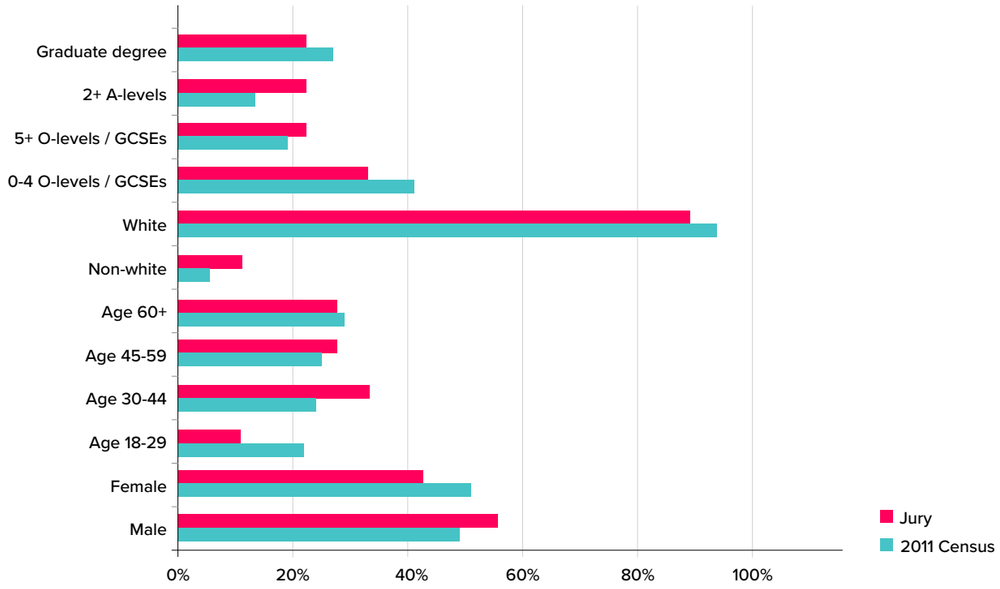
- Guiding individual treatment and informing hospital utilisation
- Identifying trends in antimicrobial resistance to current medications (microbiological surveillance)
- Identifying areas of unmet clinical need for future research into the development of new medicines
- Shaping public policy and determining the public benefit of AMR treatments (including public investment in research and development)

Juror Recruitment and Demographics

Jury applicants were recruited from within the Liverpool City Region. Jury applicants entered their personal details, including relevant demographic information, into an online survey. Applicants were then pseudo-anonymised and a Sortition Foundation algorithm was used to select a stratified sample to closely map onto the population of the Liverpool City Region. Selected jurors were stratified to broadly represent a mix of Liverpool residents in terms of age, gender, ethnic group, educational attainment, employment status, and geographical spread within the Liverpool City Region. Citizens' Juries CIC led participant recruitment and selection activities.

Participants were compensated for their participation in the project upon completion of the event. Laptops and other equipment and/or materials were provided to participants to ensure ability to participate virtually. Juror onboarding and orientation procedures included inquiries into what (if any) necessary accommodations for juror participation were to be provided by and/or addressed by organisers.

Demographic breakdown of jury participants compared to 2011 census data for England



Expert Witness Presentations

Jurors heard from and asked questions of a range of expert witnesses. Presentation topics included an introduction to AMR, an overview of the ethical and regulatory environment for pharmaceuticals, commercial pharmaceutical research and development processes, academic and clinical research on AMR, the hospital care journey and patient pathway, an overview of the proposed collaborative network, and various scenarios and care pathways for antimicrobial resistance in hospital settings.

What is AMR?

Presented by:

Professor Esmita Charani
(Imperial College London; University of Cape Town; Amrita University)

Followed by Questions & Answers

Introduction to AMR Research Environment and Relationships

Presented by:

Professor William Hope
(Director, Centre of Excellence in Infectious Diseases Research (CEIDR), University of Liverpool)

Followed by Questions & Answers

Regulatory and Ethical Environment Overview

Presented by:

Dr. Sumati Nambiar
Child Health Innovation and Leadership Department, Johnson and Johnson; former U.S. Food and Drug Administration)

Followed by Questions & Answers

Antimicrobial Resistance (AMR) and the Role of the Pharmaceutical Industry

Presented by:

Seema Patel
(Pfizer Hospital Medical Lead - Northern Cluster)

Followed by Questions & Answers

Hospital Care Journey and Patient Pathway Overview

Presented by:

Dr. Stacy Todd
(Infectious Disease Consultant, Liverpool University Hospitals)

Followed by Questions & Answers

Introduction to Data Sharing and Information Governance

Presented by:

Gary Leeming
(Director, Liverpool Civic Data Cooperative)
Helen Duckworth
(Deputy Director of Planning, Performance and Delivery, Liverpool CCG)

Followed by Questions & Answers

CEIDR Proposed Collaborative Network and Project Overview

Presented by:

Professor William Hope
(CEIDR)
Andy Townsend
(Pfizer Hospital External Medical Engagement Director)

Followed by Questions & Answers

AMR Scenario Explanations and Discussion

Presented by:

Dr. Alex Howard
(Consultant Microbiologist, Liverpool University Hospitals)

Followed by Questions & Answers

Commissioned by: University of Liverpool & Pfizer Inc.

Liverpool AMR Citizens' Jury Project Team

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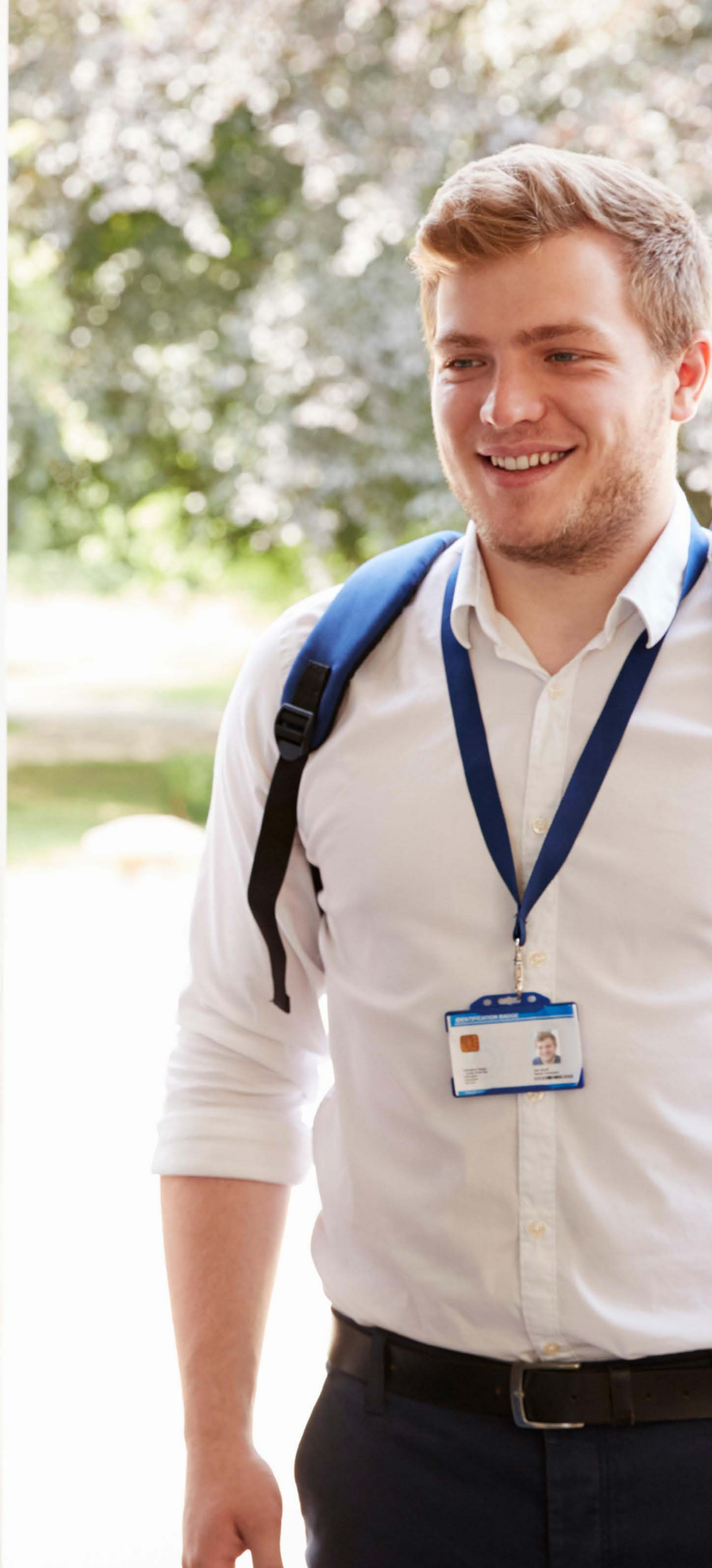
- **Professor Martin Llewelyn**
  University Hospitals Sussex NHS Trust / University of Sussex
- **Candace Plouffe**
  Free-lance Consultant, Gloucestershire Closing the Digital Divides

Project Funding

Funding for the AMR Citizens' Jury was provided by (in alphabetical order) the Civic Data Cooperative, Pfizer Inc., and the University of Liverpool.



Jury Results & Findings

Jury Scenarios

Jurors were asked to evaluate four discrete scenarios pertaining to a patient in hospital who has been diagnosed with a urinary tract infection. Jurors subsequently explored and reflected upon this patient's data use for the following purposes by a range of actors.

Scenario A

1. Patient A is in hospital recovering from a routine medical procedure when they begin to notice symptoms of a urinary tract infection.
2. The Consultant runs a series of tests, including a test for a urinary tract infection, which they have had in the past.
3. The test confirms a urinary tract infection.
4. The Consultant prescribes STANDARD DRUG.
5. Within one week, the patient reports that symptoms have subsided.

Scenario B

1. Patient B is in hospital recovering from a routine medical procedure when they begin to notice symptoms of a urinary tract infection.
2. The Consultant runs a series of tests, including a test for a urinary tract infection, which they have had in the past.
3. The test confirms a urinary tract infection.
4. The Consultant prescribes STANDARD DRUG and within one week, the patient reports symptoms have not subsided.
5. The Consultant prescribes NEWLY APPROVED DRUG.
6. After a total of three weeks from the initial test, the patient reports symptoms have subsided.

Scenario C

1. Patient C is in hospital recovering from a routine medical procedure when they begin to notice symptoms of a urinary tract infection.
2. The Consultant runs a series of tests, including a test for a urinary tract infection, which they have had in the past.
3. The test confirms a urinary tract infection.
4. The Consultant prescribes STANDARD DRUG and within one week, the patient reports symptoms have not subsided and have become worse.
5. A follow-up test confirms that the patient now has developed a persistent urinary tract infection.
6. The Consultant prescribes NEWLY APPROVED DRUG.
7. After a total of three weeks from the initial test, the patient reports symptoms have subsided.

Scenario D

1. Patient D is in hospital recovering from a routine medical procedure when they begin to notice symptoms of a urinary tract infection.
2. The Consultant runs a series of tests, including a test for a urinary tract infection, which they have had in the past.
3. The test confirms a urinary tract infection.
4. The Consultant prescribes NEWLY APPROVED DRUG.
5. Within one week, the patient reports symptoms have subsided.

The Project Commissioners identified a series of key questions and four corresponding patient pathway Scenarios for the jurors to consider during the Liverpool AMR Citizens' Jury. Jurors deliberated about and responded to these Jury Questions during their time together.

Jury Questions

The jurors were asked to rate these questions on a scale and were then asked to explain the rationale for their rating.

1. If you were patient A/B/C (see Scenarios below) how comfortable would you be with your data about the STANDARD drug's efficacy, sensitivity patterns, etc., taken from your medical records and made into pseudo-anonymised data and incorporated into a larger dataset about that drug via this newly proposed (University of Liverpool) system?

- Very Uncomfortable - Somewhat Uncomfortable - Neither Uncomfortable nor Comfortable - Somewhat Comfortable - Very Comfortable

2. If you were patient B/C/D (see Scenarios below) how comfortable would you be with your data about the NEWLY APPROVED drug's efficacy, sensitivity patterns, etc., taken from your medical records and made into pseudo-anonymised data and incorporated into a larger dataset about that drug via this newly proposed (University of Liverpool) system?

- Very Uncomfortable - Somewhat Uncomfortable - Neither Uncomfortable nor Comfortable - Somewhat Comfortable

3. How supportive are you of:

1. Hospital staff (including Consultants) / GPs / Healthcare Providers (direct care)
2. Healthcare Systems (CCGs and other NHS bodies)
3. Pharmaceutical Companies
4. Researchers (academics and other NGOs)
5. Government

a. ...having access to a pool of pseudo-anonymised data about prescribing patterns and the drug's efficacy in order to guide individual treatment and inform hospital utilisation?

a. Somewhat Unsupportive - Neither Unsupportive nor Supportive - Somewhat Supportive - Very Supportive

b. ...having access to a pool of pseudo-anonymised data about prescribing patterns and the drug's efficacy in order to identify trends in antimicrobial resistance manifesting as serious infections?

a. Somewhat Unsupportive - Neither Unsupportive nor Supportive - Somewhat Supportive - Very Supportive

c. ...having access to a pool of pseudo-anonymised data about prescribing patterns and the drug's efficacy in order to identify areas of unmet clinical need and to shape the research and development of new medicines (eg assessing prescribing patterns, trend maps and/or other research with the ultimate goal of developing commercial products in the form of new treatments or drugs to address AMR)?

a. Somewhat Unsupportive - Neither Unsupportive nor Supportive - Somewhat Supportive - Very Supportive

QUESTION 1 - SCENARIOS A, B, C

If you were patient A/B/C (see Scenarios) how comfortable would you be with your data about the STANDARD drug's efficacy, sensitivity patterns, etc., taken from your medical records and made into pseudo-anonymised data and incorporated into a larger dataset about that drug via this newly proposed (University of Liverpool) system?

Juror Responses for Question 1 in Percentages (%)

Answer choices	Scenario A	Scenario B	Scenario C	Total
Very Uncomfortable	0%	0%	0%	0%
Somewhat Uncomfortable	6%	6%	11%	7%
Neither Uncomfortable nor Comfortable	11%	17%	17%	15%
Somewhat Comfortable	78%	61%	50%	63%
Very Comfortable	6%	17%	22%	15%
TOTAL	**100%**	**100%**	**100%**	**100%**

(Response totals may not add up to 100% due to rounding)

Overall jurors were generally comfortable with their pseudo-anonymised data about Standard Drug efficacy, sensitivity, and other related health information being incorporated into a larger dataset about that drug regardless of the patient pathway Scenario (A/B/C) under consideration in Question 1.

In aggregate, 78% of jurors responded either "Somewhat Comfortable" (63%) or "Very Comfortable" (15%) across the three scenarios. A total of 7% of jurors were "Somewhat Uncomfortable," while no jurors expressed being "Very Uncomfortable" across Scenarios A, B, and C. The remainder of responses were "Neither Uncomfortable nor Comfortable (15%).

Rationale*

Some reasons jurors identified to be comfortable incorporating pseudo-anonymised data about Standard Drug usage into a larger dataset for the proposed collaborative network included:

- A reason to be comfortable with this data use is because it aids in the retrieval of information about drug efficacy and sensitivity of the antimicrobial for research purposes. Hence, this is beneficial for the public both for the present and future utilisation of such drugs and future manufacturing and improvement on production of that antimicrobial. (Scenario A)
- A reason to be comfortable is that the data is protected to an extent by the GDPR, Data Protection Act 2018, and the patient confidentiality common law. (Scenario A)
- A reason to be comfortable is that the urinary tract infection has been resolved and valuable data is being incorporated into a larger dataset, which will improve the outcome of patients' care. (Scenario B)
- A reason to be comfortable is that there are data protection procedures in place. (Scenario B)
- A reason to be comfortable with this data use is that the information is pseudo-anonymised and that data protection legislation would protect patient details from being accessed by those who did not have direct responsibility for their care. (Scenario C)
- A reason to be comfortable with this data use is the knowledge that the information given ensures the next patient gets a drug more tailored to their needs. (Scenario C)

Some reasons jurors identified to be uncomfortable incorporating pseudo-anonymised data about Standard Drug usage into a larger dataset for the proposed collaborative network included:

- A reason to be uncomfortable with this data use is the risk of identification and level of exposure of personal information associated with an individual's medical records in which the person is not willing to share or make public. (Scenario A)
- A reason to be uncomfortable with this data use is an uncertainty on security as hacks or data leaks could prove to be detrimental. (Scenario A)
- A reason to be uncomfortable is the involvement of Pfizer or other pharmaceutical companies in the process and how that data may be used in the future and, for example, whether or not it could be used for other purposes. (Scenario B)
- A reason to be uncomfortable is that there is not enough information to ensure that the patient understands what they are consenting to. (Scenario B)
- A reason to be uncomfortable with this data use is that more information might be added to the system about a patient who requires a new drug. This could mean that the patient is more easily identified. Also, if someone is shown to be resistant to standard drugs, what if their status could mean that they are a potential 'spreader' of a resistant bug? (Scenario C)
- A reason to be uncomfortable with this data use is that it is implied consent. If you cannot opt-out for any reason, your information can still be used. (Scenario C)

** Sections headers demarcated with an asterisk were produced by jurors themselves so these sections may contain colloquial language or other idiosyncrasies.*

QUESTION 2 - SCENARIOS B, C, D

If you were patient B/C/D (see Scenarios above) how comfortable would you be with your data about the NEWLY APPROVED drug's efficacy, sensitivity patterns, etc., taken from your medical records and made into pseudo-anonymised data and incorporated into a larger dataset about that drug via this newly proposed (University of Liverpool) system?

Juror Responses for Question 2 in Percentages (%)

Answer choices	Scenario B	Scenario C	Scenario D	TOTAL
Very Uncomfortable	6%	6%	6%	6%
Somewhat Uncomfortable	11%	11%	22%	15%
Neither Uncomfortable nor Comfortable	11%	11%	17%	13%
Somewhat Comfortable	44%	39%	33%	39%
Very Comfortable	28%	33%	22%	28%
TOTAL	**100%**	**100%**	**100%**	**100%**

(Response totals may not add up to 100% due to rounding)

Overall jurors were fairly comfortable having pseudo-anonymised data about Newly Approved Drug usage incorporated into a larger dataset for the proposed collaborative across the patient pathway Scenarios for Question 2.

In aggregate, 67% of juror responses were either "Somewhat Comfortable" (39%) or "Very Comfortable" (28%). Conversely, 21% of juror responses were either "Very Uncomfortable" (6%) or "Somewhat Uncomfortable" (15%) with 13% of juror responses being "Neither Uncomfortable nor Comfortable".

Rationale*

Some reasons jurors identified to be comfortable incorporating pseudo-anonymised data about Newly Approved Drug usage into a larger dataset for the proposed collaborative network included:

- A reason to be comfortable with this data use is that it is important in research in terms of providing proof of efficacy and sensitivity of the newly approved drug to the antimicrobial agent (which is beneficial to the public). (Scenario B)
- A reason to be comfortable with the data use is upon hearing from the experts that Liverpool has (or is one of) the highest areas for having antibiotics prescribed would help the region to lower those statistics and help to reduce AMR in future. (Scenario B)
- A reason to be comfortable with this data use is it will disseminate information about AMR resistance, the effectiveness of alternative treatments, as well as inform new drug development, providing wider public health benefits in the long-term. (Scenario C)
- A reason to be comfortable with this data use is that in the larger scale of things, this could help other patients in need. (Scenario C)
- A reason to be comfortable with this data use is because it helps having live feedback on how that new drug is working, its side effects can be monitored, and it would show where there are peaks of AMR. (Scenario D)
- One reason to be comfortable with the data use is that previously collected information can be used to provide treatment to other patients, rather than unnecessarily prescribing the new drug which could lead to the acceleration of AMR. (Scenario D)

Some reasons jurors identified to be uncomfortable incorporating pseudo-anonymised data about Newly Approved Drug usage into a larger dataset for the proposed collaborative network included:

- A reason to be uncomfortable with this data use is the level of access to personal/identifiable data that would be given to the individuals involved in this process, such as the researchers and pharmaceutical companies. (Scenario B)
- A reason to be uncomfortable is uncertainty about the data being shared would be who has access to my data, whether the appropriate safeguards are in place, and making sure there can be no data breach. (Scenario B)
- A reason to be uncomfortable with this data use is that that data set's utility depends on the quality of the data inputted by the doctor, etc. (Scenario C)
- A reason to be uncomfortable with this data use is lack of clarity around how the patient information would or would not be specific to the new drug and/or the infection that was being treated at the time. (Scenario C)
- A reason to be uncomfortable with this data use is that for a newly approved drug, in particular, data could be inaccurate as it is inputted by humans. (Scenario D)
- A reason to be uncomfortable with this data use is that the patient should have been previously identified as resistant to standard antibiotics. It is unclear if this patient would then appear in a second data set, which may need to contain a higher level of personal information which could make them more easily identifiable. (Scenario D)

QUESTION 3.1 - HOSPITAL STAFF

How supportive are you of:

1. Hospital staff (including Consultants) / GPs / Healthcare Providers (direct care)

a. ...having access to a pool of pseudo-anonymised data about prescribing patterns and the drug's efficacy in order to guide individual treatment and inform hospital utilisation?

b. ...having access to a pool of pseudo-anonymised data about prescribing patterns and the drug's efficacy in order to identify trends in antimicrobial resistance manifesting as serious infections?

c. ...having access to a pool of pseudo-anonymised data about prescribing patterns and the drug's efficacy in order to identify areas of unmet clinical need and to shape the research and development of new medicines (eg assessing prescribing patterns, trend maps and/or other research with the ultimate goal of developing commercial products in the form of new treatments or drugs to address AMR)?

Juror Responses for Question 3.1 - Hospital Staff - in Percentages (%)

Answer choices	Treatment (%)	Trends (%)	Clinical Need (%)	Total (%)
Very Unsupportive	0%	0%	0%	0%
Somewhat Unsupportive	0%	0%	0%	0%
Neither Unsupportive nor Supportive	0%	6%	0%	2%
Somewhat Supportive	39%	39%	44%	41%
Very Supportive	61%	56%	56%	57%
TOTAL	**100%**	**100%**	**100%**	**100%**

(Response totals may not add up to 100% due to rounding)

Overall, jurors were generally supportive of healthcare staff having access to pseudo-anonymised data about prescribing patterns and the drug's efficacy regardless of the data usage under consideration. In aggregate, 98% of jurors' responses were "Very Supportive" (57%) or "Somewhat Supportive" (41%) of hospital staff having access to this data.

Jurors indicated unanimous support for sharing data with hospital staff to guide individual treatment (61% "Very Supportive and 39% "Somewhat Supportive).

Jurors indicated 95% support for sharing data with hospital staff to identify trends (59% "Very Supportive" and 39% "Somewhat Supportive") while 6% of jurors' responses were "Neither Unsupportive nor Supportive" for this use.

Jurors indicated unanimous support (100%) for sharing data with hospital staff to identify areas of unmet clinical need (56% "Very Supportive" and 44% "Somewhat Supportive").

Rationale*

Some reasons jurors identified to be supportive of hospital staff having access to a pool of pseudo-anonymised data about prescribing patterns and the drug's efficacy in order to guide individual treatment and inform hospital utilisation, identify trends in antimicrobial resistance manifesting as serious infections, and to identify areas of unmet clinical need and to shape the research and development of new medicines included:

- A reason to be supportive of this data use is that the Hospital will have the right information to help and support the patient. (Treatment)
- A reason to be supportive of this data use is that it will help tailor the patient's treatment, meaning they'll get better more quickly and the risk of AMR will be greatly reduced. (Treatment)
- A reason to be supportive of this data use would be the financial savings that could be had and those resources could be better used elsewhere. i.e with diagnosis, medication spends, less resources spent on the patient. (Treatment)
- A reason to be supportive of this data use is that it would enable the hospital staff to see trends in AMR and could administer an antibiotic more suitable to the patients needs therefore reducing recovery time. (Trends)
- A reason to be supportive of this data use is it would improve the efficiency of the hospital staff and support them in identifying trends in antimicrobial resistance manifesting as serious infection, thereby reducing treatment failures and AMR in the long run. (Trends)
- A reason to be supportive of this data use is that hospital staff having access to pseudo anonymised data to look for trends is that new outbreaks of AMR's in a particular setting could be more easily identified and responded to. (Trends)
- A reason to be supportive of this data use is that by giving these medical practitioners this kind of data, they are only going to be using it for the wellbeing of their patient, but possibly protect other people from AMR. (Clinical Need)
- A reason to be supportive of this data use is that since hospital staff have genuine care for their patients and that they want them to become well as soon as possible, it would assist them in providing that care. (Clinical Need)
- A reason to be supportive of this data use is it will help identify and create treatment options for others in the future, whilst safeguarding patients' details. (Clinical Need)

Some reasons jurors identified to be unsupportive of hospital staff having access to a pool of pseudo-anonymised data about prescribing patterns and the drug's efficacy in order to guide individual treatment and inform hospital utilisation, identify trends in antimicrobial resistance manifesting as serious infections, and to identify areas of unmet clinical need and to shape the research and development of new medicines included:

- A reason to be unsupportive of this data use is the data may be leaked onto people who are not meant to have access to it. (Treatment)
- A reason to be unsupportive of this data use is that data protection policies may need updating. For Hospitals and GP Practices, it is unclear if the data stored is 100% safe and unclear if data may be sent to outsourced private companies. (Treatment)
- A reason to be unsupportive of this data use is that implementing the database would increase the financial burden on the NHS by having to employ more staff to input and analyse the data, the I.T. department, staff training, etc. (Treatment)
- A reason to be unsupportive of this data use is that management for Doctors, etc. needs to be considered. Currently our system is "overwhelmed" as it stands. Does this add pressure to a system that's already overly pressured? The system is only as efficient as the information that is put into it. (Trends)
- A reason to be unsupportive of this data use relates to whether the small or large amount of patient information was gathered is sufficient. (Trends)
- A reason to be unsupportive of this data use is that doctors may end up relying too much on the database, making decisions solely on this dataset. (Trends)
- A reason to be unsupportive of this data use is that there could be many ways to access the data, thus increasing the risk of a data breach. (Clinical Need)
- A reason to be unsupportive of this data use is that medical practitioners are busy enough working with patients and do not have time and resources to be filling in more forms about possible outcomes/trends that might have little to do with their current patient. (Clinical Need)
- A reason to be unsupportive of this data use is that potential due to time and service pressures data input may be of poor or inadequate quality, rendering the process ineffective. (Clinical Need)

"Having listened to a number of presentations from esteemed professionals, we have collaborated as a 'Jury' to express our views on proposals to use and share personal data for the purposes of addressing this important area of public health. Put simply, it is to try and find solutions to the fact that antibiotics are becoming less effective and we need to research, fund and find new treatments and drugs for the benefit of us all. Our findings will help shape policy to address these issues."

Quote from Jury member

QUESTION 3.2 - HEALTHCARE SYSTEMS

How supportive are you of:

2. Healthcare Systems (CCGs and other NHS bodies)

a. ...having access to a pool of pseudo-anonymised data about prescribing patterns and the drug's efficacy in order to guide individual treatment and inform hospital utilisation?

b. ...having access to a pool of pseudo-anonymised data about prescribing patterns and the drug's efficacy in order to identify trends in antimicrobial resistance manifesting as serious infections?

c. ...having access to a pool of pseudo-anonymised data about prescribing patterns and the drug's efficacy in order to identify areas of unmet clinical need and to shape the research and development of new medicines (eg assessing prescribing patterns, trend maps and/or other research with the ultimate goal of developing commercial products in the form of new treatments or drugs to address AMR)?

Juror Responses for Question 3.2 - Healthcare Systems - in Percentages (%)

Answer choices	Treatment (%)	Trends (%)	Clinical Need (%)	Total (%)
Very Unsupportive	0%	0%	6%	2%
Somewhat Unsupportive	0%	0%	0%	0%
Neither Unsupportive nor Supportive	6%	6%	6%	6%
Somewhat Supportive	44%	39%	56%	46%
Very Supportive	50%	56%	33%	46%
TOTAL	**100%**	**100%**	**100%**	**100%**

(Response totals may not add up to 100% due to rounding)

Overall, jurors indicated a high degree of support for healthcare systems having access to pseudo-anonymised data about prescribing patterns and the drug's efficacy regardless of the data usage under consideration. In aggregate, 92% of jurors' responses were "Very Supportive" (46%) or "Somewhat Supportive" (46%) of healthcare systems having access to this data.

Jurors indicated high levels of support for sharing data with healthcare systems to guide individual treatment (50% "Very Supportive and 44% "Somewhat Supportive).

Jurors indicated 95% support for sharing data with healthcare systems to identify trends (56% "Very Supportive" and 39% "Somewhat Supportive") while 6% of jurors' responses were "Neither Unsupportive nor Supportive" for this use.

Jurors indicated high levels of support for sharing data with healthcare systems to identify areas of unmet clinical need (33% "Very Supportive" and 56% "Somewhat Supportive") with 6% of jurors' responses as "Neither Unsupportive nor Supportive").

Rationale*

Some reasons jurors identified to be supportive of healthcare systems having access to a pool of pseudo-anonymised data about prescribing patterns and the drug's efficacy in order to guide individual treatment and inform hospital utilisation, identify trends in antimicrobial resistance manifesting as serious infections, and to identify areas of unmet clinical need and to shape the research and development of new medicines included:

- A reason to be supportive of this data use is that the healthcare system will have the required information on the database and this will make their life easier, instead of having to ask patients thousands of questions. (Treatment)
- A reason to be supportive of this data use would be because it could allow the sharing of info more easily across sites when a patient is transferred to another hospital or health care setting. (Treatment)
- A reason to be supportive of this data use would be the financial savings that could be had and those resources could be better used elsewhere. i.e with diagnosis, medication spends, and avoiding duplication of resources and waste of resources (e.g might be able to stock less antibiotics in certain hospitals). (Treatment)
- A reason to be supportive of this data use by healthcare systems is that without all the information, treatments to tackle AMR could be less effective. (Trends)
- A reason to be supportive of this data use is because at this level, more data and information could support more accurate diagnoses across the health system. (Trends)
- A reason to be supportive of this data use is that the database would highlight trends in overprescribing antibiotics. (Trends)
- A reason to be supportive of this data use by healthcare systems means that they can deliver a more efficient and tailored approach in the future through the use of research and data collection. (Clinical Need)
- A reason to be supportive of this data use is that data already exists within the healthcare system setting without being breached and this data could therefore be incorporated with data related to AMR in order to address it. (Clinical Need)
- One reason to be supportive of this data use is that each department could share the information regarding the patient, so that the patient does not have to remember what their illnesses are, and forget to say something that could be important relating to their medical history/care. (Clinical Need)

Some reasons jurors identified to be unsupportive of healthcare systems having access to a pool of pseudo-anonymised data about prescribing patterns and the drug's efficacy in order to guide individual treatment and inform hospital utilisation, identify trends in antimicrobial resistance manifesting as serious infections, and to identify areas of unmet clinical need and to shape the research and development of new medicines included:

- A reason to be unsupportive of this data use is that healthcare providers and healthcare systems, which may be private companies, will have access to this data. (Treatment)
- A reason to be unsupportive of this data use is that the information on the database is inputted by humans and this could lead to health professionals and healthcare systems giving the wrong information to the patients and other health professionals. (Treatment)
- A reason to be unsupportive of this data use is that implementing the database would increase the financial burden on the NHS by having to employ more staff to input and analyse the data, the I.T. department, staff training, etc. (Treatment)
- A reason to be unsupportive is this data use is the risk of breach in confidentiality and exposure of patients' information to unauthorised third parties. (Trends)
- A reason to be unsupportive of this data use would be because the type of data (trends and statistics) collection at this level would be better suited to be collected and sorted automatically with software. (Trends)
- A reason to be unsupportive of healthcare systems having access to look for trends is that the available data: a) needs to be adequately input onto the system and b) properly analysed. Would all hospital consultants/healthcare system staff etc be made aware of these identified trends and how would these be communicated to all relevant staff so that a consistent approach could be developed? Just knowing a trend is developing is useful, but how will it be responded to? (Trends)
- A reason to be unsupportive of this data use is that the data could be breached. (Clinical Need)
- A reason to be unsupportive of this data use is that sometimes human error occurs and patient data could potentially be exposed which would not have any influence on addressing AMR. (Clinical Need)
- A reason to be unsupportive is that it would be unclear how consent/opt out would work with a patient who has limited capability or objection to research. (Clinical Need)

QUESTION 3.3 - PHARMACEUTICAL COMPANIES

How supportive are you of:

3. Pharmaceutical Companies

a. ...having access to a pool of pseudo-anonymised data about prescribing patterns and the drug's efficacy in order to guide individual treatment and inform hospital utilisation?

b. ...having access to a pool of pseudo-anonymised data about prescribing patterns and the drug's efficacy in order to identify trends in antimicrobial resistance manifesting as serious infections?

c. ...having access to a pool of pseudo-anonymised data about prescribing patterns and the drug's efficacy in order to identify areas of unmet clinical need and to shape the research and development of new medicines (eg assessing prescribing patterns, trend maps and/or other research with the ultimate goal of developing commercial products in the form of new treatments or drugs to address AMR)?

Juror Responses for Question 3.3 - Pharmaceutical Companies - in Percentages (%)

Answer choices	Treatment (%)	Trends (%)	Clinical Need (%)	Total (%)
Very Unsupportive	6%	0%	0%	2%
Somewhat Unsupportive	6%	0%	6%	4%
Neither Unsupportive nor Supportive	17%	11%	22%	17%
Somewhat Supportive	44%	56%	56%	52%
Very Supportive	28%	33%	17%	26%
TOTAL	**100%**	**100%**	**100%**	**100%**

(Response totals may not add up to 100% due to rounding)

Overall jurors indicated moderate levels of support for pharmaceutical companies having access to a pool of pseudo-anonymised data about prescribing patterns and the drug's efficacy across use cases. In aggregate, 78% of jurors' responses were "Very Supportive" (26%) or "Somewhat Supportive" (52%) for pharmaceutical companies having access to this data while 17% of jurors' responses were "Neither Unsupportive nor Supportive". A total of 6% of jurors' responses were either "Very Unsupportive" (2%) or "Somewhat Unsupportive" (4%) of these uses.

Jurors indicated moderate levels of support for sharing data with pharmaceutical companies to guide individual treatment (28% "Very Supportive and 44% "Somewhat Supportive).

Jurors indicated 89% support for sharing data with pharmaceutical companies to identify trends (33% "Very Supportive" and 56% "Somewhat Supportive") while 11% of jurors' responses were "Neither Unsupportive nor Supportive" for this use.

Jurors indicated moderate levels of support for sharing data with pharmaceutical companies to identify areas of unmet clinical need (17% "Very Supportive" and 56% "Somewhat Supportive") with 22% of jurors' responses as "Neither Unsupportive nor Supportive") and 6% of jurors' responses as "Somewhat Unsupportive".

Rationale*

Some reasons jurors identified to be supportive of pharmaceutical companies having access to a pool of pseudo-anonymised data about prescribing patterns and the drug's efficacy in order to guide individual treatment and inform hospital utilisation, identify trends in antimicrobial resistance manifesting as serious infections, and to identify areas of unmet clinical need and to shape the research and development of new medicines included:

- A reason to be supportive of this is that pharmaceutical companies can use this data to monitor and observe the sensitivity, efficacy, resistance and side effects of any antimicrobial they manufacture. Hence it provides room for improvements on the drugs produced, or targeted treatments for microbes. (Treatment)
- A reason to be supportive is that data can be used to develop antibiotics better and drugs more efficiently and at a faster pace. (Treatment)
- A reason to be supportive of this is so that a wider range of treatments can be developed through the use of data about prescribing patterns and the drug's efficacy to help minimise the threat of AMR. (Treatment)
- One reason to be supportive is that the pharmaceutical people will know how the trends of this drug are affecting people based on this database. (Trends)
- A reason to be supportive is that without adequate research there may not be enough or sufficient progress made to tackle AMR. (Trends)
- One reason to be supportive is that pharmaceutical companies would be able to respond more quickly to emerging trends by focussing more specifically on producing relevant medications to address the problems raised by such trends. (Trends)
- One reason to be supportive is they can work in collaboration to provide access to new drugs. They can report back to researchers letting them know when there is need for improvement. (Clinical Need)
- One reason to be supportive of this is that it may potentially speed up the research process for new drugs, which could ensure faster results when combating AMR. (Clinical Need)
- A reason to be supportive is that ultimately pharmaceutical companies will have the responsibility of developing new antibiotics so it is vital they have access to the data. (Clinical Need)

Some reasons jurors identified to be unsupportive of pharmaceutical companies having access to a pool of pseudo-anonymised data about prescribing patterns and the drug's efficacy in order to guide individual treatment and inform hospital utilisation, identify trends in antimicrobial resistance manifesting as serious infections, and to identify areas of unmet clinical need and to shape the research and development of new medicines included:

- The process is an opt out process meaning that patient consent is assumed. This could be problematic if not explained well or if the patient is unable to withdraw consent due to illness, etc. (Treatment)
- A reason to be unsupportive is if the data used was misused and sold to third parties and not used for medical professions, therefore putting patients' health at risk. (Treatment)
- The general consensus regarding pharmaceutical companies is that they are only in it for the money. Whether or not this is true or not remains a matter of opinion, however, that stigma is still there in peoples' minds. So for that reason, this might cause people to feel uneasy about allowing their data to be shared. (Treatment)
- A reason to be unsupportive of the pharma companies having this information is the uncertainty of their own security levels when dealing with personal information and whether they would use it for other financial projects that may well be off-piste and only beneficial to themselves. (Trends)
- One reason to be unsupportive is that pharmaceutical companies may not use the information we give them to just tackle the issue at hand. They are profit driven and could use our data in several ways. (Trends)
- One reason to be unsupportive is that pharmaceutical companies would be in competition to gain access to this information, which could lead to data trends becoming a valuable financial commodity. Would this reduce the security of data held on the AMR database? Would implied consent of 'opt in' mean that control over data be less clearcut? (Trends)
- One reason to be unsupportive of this is that, due to opt-out, many people may be unaware of the pharmaceutical company obtaining their data. (Clinical Need)
- One reason to be unsupportive is because the data provided should be limited; they have worked for many years without this data and should have access to only the data that's absolutely necessary to complete the task. (Clinical Need)
- One reason to be unsupportive is that these are now large multinational companies with immense power and I worry how they may use or seek to benefit from the data in other ways unrelated to this matter and perhaps gain competitive advantage. (Clinical Need)

"It's important for those involved in the AMR collaborative to understand the jury's concerns regarding data breaches & the issue of consent. It's important for the public to understand, as we the jury now do, the very real threat that AMR poses to world health."

Quote from Jury member

QUESTION 3.4 - RESEARCHERS

How supportive are you of:

4. Researchers (academics and other NGOs)

A. ...having access to a pool of pseudo-anonymised data about prescribing patterns and the drug's efficacy in order to guide individual treatment and inform hospital utilisation?

B. ...having access to a pool of pseudo-anonymised data about prescribing patterns and the drug's efficacy in order to identify trends in antimicrobial resistance manifesting as serious infections?

C. ...having access to a pool of pseudo-anonymised data about prescribing patterns and the drug's efficacy in order to identify areas of unmet clinical need and to shape the research and development of new medicines (eg assessing prescribing patterns, trend maps and/or other research with the ultimate goal of developing commercial products in the form of new treatments or drugs to address AMR)?

Juror Responses for Question 3.4 - Researchers - in Percentages (%)

Answer choices	Treatment (%)	Trends (%)	Clinical Need (%)	Total (%)
Very Unsupportive	0%	0%	0%	0%
Somewhat Unsupportive	6%	6%	6%	6%
Neither Unsupportive nor Supportive	28%	11%	22%	20%
Somewhat Supportive	56%	67%	50%	57%
Very Supportive	11%	17%	22%	17%
TOTAL	**100%**	**100%**	**100%**	**100%**

(Response totals may not add up to 100% due to rounding)

Overall jurors indicated moderate levels of support for researchers having access to a pool of pseudo-anonymised data about prescribing patterns and the drug's efficacy across use cases. In aggregate, 74% of juror responses were "Very Supportive" (17%) or "Somewhat Supportive" (57%) for researchers having access to this data while 20% of jurors' responses were "Neither Unsupportive nor Supportive". A total of 6% of jurors' responses were "Somewhat Unsupportive" of these uses.

Jurors indicated moderate levels of support (67%) for sharing data with researchers to guide individual treatment (11% "Very Supportive and 56% "Somewhat Supportive).

Jurors indicated higher levels of support (84%) for sharing data with researchers to identify trends (17% "Very Supportive" and 67% "Somewhat Supportive") while 11% of jurors' responses were "Neither Unsupportive nor Supportive" for this use and 6% of responses as "Somewhat Unsupportive" for this use.

Jurors indicated moderate levels of support (72%) for sharing data with researchers to identify areas of unmet clinical need (22% "Very Supportive" and 50% "Somewhat Supportive") with 22% of jurors' responses as "Neither Unsupportive nor Supportive" and 6% of jurors' responses as "Somewhat Unsupportive" for this use.

Rationale*

Some reasons jurors identified to be supportive of researchers having access to a pool of pseudo-anonymised data about prescribing patterns and the drug's efficacy in order to guide individual treatment and inform hospital utilisation, identify trends in antimicrobial resistance manifesting as serious infections, and to identify areas of unmet clinical need and to shape the research and development of new medicines included:

- A reason to be supportive of this is that it supports findings made by hospital staff and healthcare systems, can relieve pressure on particular teams, and assist in the tailored treatment of patients. (Treatment)
- One reason to be supportive is that it is vital to the research of new drugs and how AMR is responding to current treatments. We need research for treatment options in the future. This will help improve patient treatments and prevent serious infections. (Treatment)
- A reason to be supportive is that their broader knowledge and expertise is important to the collaborative process. (Treatment)
- A reason to be supportive would be knowing who the researchers were, what information they would require, how it would be used, and how much data they would require. (Trends)
- A reason to be supportive would be that researchers will be able to use the data better than others when looking at new developments and analysing trends to combat AMR manifesting as serious infections in the future. (Trends)
- A reason to be supportive is that research is of vital importance to address AMR and I would feel supportive of these types of people/ organisations if I could be sure they would only use patient data for this purpose alone. (Trends)
- A reason to be supportive is that the requirements for accessing data by different groups are determined on a case-by-case basis and only those who have a qualified purpose can access the information. (Clinical Need)

- A reason to be supportive is that some of the best scientific work has come from collaborations with NGOs (ex. Covid vaccines). (Clinical Need)
- A reason to be supportive is that researchers need data in order to investigate new areas of interest or of emerging health issues. The data on the AMR database would be vital in perhaps doing comparative research with other regions/ countries etc to share findings and proposals for further research. This research is more robust with valid data sets to inform findings. (Clinical Need)

Some reasons jurors identified to be unsupportive of researchers having access to a pool of pseudo-anonymised data about prescribing patterns and the drug's efficacy in order to guide individual treatment and inform hospital utilisation, identify trends in antimicrobial resistance manifesting as serious infections, and to identify areas of unmet clinical need and to shape the research and development of new medicines included:

- One reason to be unsupportive of this is that there is potential for another avenue in which data can be leaked. With so many different people involved, there is the chance for human error alongside malicious intent e.g. hackers. (Treatment)
- A reason to be unsupportive is that smaller NGOs and individual researchers may not have very secure systems. (Treatment)
- A reason to be unsupportive is there are hundreds of groups who would be interested in this data. Where do you draw the line and say "No, you can't have access?" The people who have access should be strictly limited. (Treatment)
- A reason to be unsupportive of this relates to questions about who the researchers are and whether they use the data in a constructive and beneficial way. (Trends)
- A reason to be unsupportive is that there is a lack of clarity on who makes the decisions of which researchers and NGOs are involved and who monitors and audits them. (Trends)
- A reason to be unsupportive is if the data retrieved was used or shared with other parties not involved with AMR or the welfare of the health services. (Trends)
- A reason to be unsupportive is that access to the data needs to be controlled and the rationale for each use would need to be clearly defined and communicated with the public. (Clinical Need)
- A reason to be unsupportive is that we don't know how many companies will be involved and what guidelines are going to be for the end result of our data being used. (Clinical Need)
- A reason to be unsupportive is that there is not enough clarity about who has access to the data and if this access applies to all areas of that data. (Clinical Need)

QUESTION 3.5 - GOVERNMENT

How supportive are you of:

5. Researchers (academics and other NGOs)

A. ...having access to a pool of pseudo-anonymised data about prescribing patterns and the drug's efficacy in order to guide individual treatment and inform hospital utilisation?

B. ...having access to a pool of pseudo-anonymised data about prescribing patterns and the drug's efficacy in order to identify trends in antimicrobial resistance manifesting as serious infections?

C. ...having access to a pool of pseudo-anonymised data about prescribing patterns and the drug's efficacy in order to identify areas of unmet clinical need and to shape the research and development of new medicines (eg assessing prescribing patterns, trend maps and/or other research with the ultimate goal of developing commercial products in the form of new treatments or drugs to address AMR)?

Juror Responses for Question 3.5 - Government - in Percentages (%)

Answer choices	Treatment (%)	Trends (%)	Clinical Need (%)	Total (%)
Very Unsupportive	11%	17%	22%	17%
Somewhat Unsupportive	22%	17%	28%	22%
Neither Unsupportive nor Supportive	28%	11%	0%	13%
Somewhat Supportive	39%	56%	39%	44%
Very Supportive	0%	0%	11%	4%
TOTAL	**100%**	**100%**	**100%**	**100%**

(Response totals may not add up to 100% due to rounding)

Overall jurors indicated lower levels of support for government having access to a pool of pseudo-anonymised data about prescribing patterns and the drug's efficacy across use cases. In aggregate, 48% of jurors' responses were "Very Supportive" (4%) or "Somewhat Supportive" (44%) for researchers having access to this data while 13% of jurors' responses were "Neither Unsupportive nor Supportive". A total of 39% of jurors' responses were either "Somewhat Unsupportive" (22%) or "Very Unsupportive" (17%) of these uses.

Jurors indicated relatively low levels of support (39%) for sharing data with government to guide individual treatment (0% "Very Supportive and 39% "Somewhat Supportive) with 28% of responses as "Neither Unsupportive nor Supportive", and a total of 39% of responses as either "Somewhat Unsupportive" (22%) or "Very Unsupportive" (11%) for this use.

Jurors indicated relatively low levels of support (56%) for sharing data with government to identify trends (56% "Somewhat Supportive") while 11% of jurors' responses were "Neither Unsupportive nor Supportive" for this use and a total of 34% of responses as either "Somewhat Unsupportive" (17%) or "Very Unsupportive" (17%) for this use.

Jurors indicated equal level of support (50%) for sharing data with government to identify areas of unmet clinical need (11% "Very Supportive" and 39% "Somewhat Supportive") and 50% of jurors' responses as either "Somewhat Unsupportive" (28%) or "Very Unsupportive" (22%) for this use.

Rationale*

Some reasons jurors identified to be supportive of government having access to a pool of pseudo-anonymised data about prescribing patterns and the drug's efficacy in order to guide individual treatment and inform hospital utilisation, identify trends in antimicrobial resistance manifesting as serious infections, and to identify areas of unmet clinical need and to shape the research and development of new medicines included:

- One reason to be supportive is that the government may fund some research and development as it is in the government interest to help find solutions to AMR. (Treatment)
- One reason to be supportive is that the government (e.g., Dept of Health) would be aware of where funding needs to be directed for the use of specific drug treatments in hospitals. (Treatment)
- A reason to be supportive is that we pay into a system that government and elected leaders manage and areas such as AMR and over prescribing need to be tackled by our representatives. (Treatment)
- One reason to be supportive is that ministers can direct funding into AMR research since they will have the data on AMR trends to look at. (Trends)
- A reason to be supportive is that AMR is a worldwide issue so it is necessary to collate relevant data on a national level to inform policies to tackle AMR resistance. (Trends)
- A reason to be supportive is that in the future it could be information shared internationally to fight the battle of AMR. (Trends)

- One of the reasons to be supportive of this is that the government may need to financially support the research and development of new medicines, hence they would need data to support their investment to the public (for instance the production of vaccines for Covid-19). (Clinical Need)
- One reason to be supportive of this is that the government can highlight whether awareness needs to be spread on a national scale and establish campaigns for this. (Clinical Need)
- One reason to be supportive for the government to have access is that this could allow them to see the bigger picture and invest more money. (Clinical Need)

Some reasons jurors identified to be unsupportive of government having access to a pool of pseudo-anonymised data about prescribing patterns and the drug's efficacy in order to guide individual treatment and inform hospital utilisation, identify trends in antimicrobial resistance manifesting as serious infections, and to identify areas of unmet clinical need and to shape the research and development of new medicines included:

- One reason to be unsupportive is that the government and its inspection processes could use such data to penalise, rather than support, hospitals who wish to procure new drugs which may be expensive, etc. (Treatment)
- One reason to be unsupportive is the lack of clarity as to which departments will be involved and how they will communicate outcomes. (Treatment)
- One reason to be unsupportive is whether or not you have faith in your political system having data around your medical issues and whether that be anonymous or not. (Treatment)
- One reason to be unsupportive of this is because our data may not solely be used for the intended purposes, if another directive becomes popular or necessary enough within the government. Due to opt-out, many people may not even know that this is taking place. (Trends)
- One reason to be unsupportive is there is mistrust in the government and how they use data. (Trends)
- One reason to be unsupportive is because reassurance would be necessary to ensure that the government would not use trends in overprescribing of antibiotics to potentially reduce funding to some clinical settings. (Trends)
- One reason to be unsupportive of this is in regards to security, i.e, a data breach on this scale could be detrimental amongst other issues regarding the public's relationship with the government. (Clinical Need)
- One reason to be unsupportive is that the government might use the data for other purposes beyond the research into new remedies. (Clinical Need)
- One reason to be unsupportive is the potential that the government will sell data to different organisations. (Clinical Need)

“As a jury we have collaborated to find the best ways of both protecting public data and providing information to the relevant bodies in the continued effort to research and resolve AMR. The work has been challenging and multifaceted, with many different perspectives which all raised unique points.”

Quote from Jury member

QUESTION 3a - TREATMENT

The following table represents juror levels of support for various actors/ organisations having access to a pool of pseudo-anonymised data (Questions 3.1-3.5) in order to guide individual treatment and inform hospital utilisation ("Treatment").

Responses to Questions 3.1-3.5 for "Treatment" in Percentages (%)

Answer choices	Hospital Staff (%)	Healthcare Systems (%)	Pharmaceutical Companies (%)	Researchers (%)	Government (%)	Total (%)
Very Unsupportive	0%	0%	6%	0%	11%	3%
Somewhat Unsupportive	0%	0%	6%	6%	22%	7%
Neither Unsupportive nor Supportive	0%	6%	17%	28%	28%	16%
Somewhat Supportive	39%	44%	44%	56%	39%	44%
Very Supportive	61%	50%	28%	11%	0%	30%
TOTAL	**100%**	**100%**	**100%**	**100%**	**100%**	**100%**

(Response totals may not add up to 100% due to rounding)

QUESTION 3b - TRENDS

The following table represents juror levels of support for various actors/ organisations having access to a pool of pseudo-anonymised data (Questions 3.1-3.5) in order to identify trends in antimicrobial resistance manifesting as serious infections ("Trends").

Responses to Questions 3.1-3.5 for "Trends" in Percentages (%)

Answer choices	Hospital Staff (%)	Healthcare Systems (%)	Pharmaceutical Companies (%)	Researchers (%)	Government (%)	Total (%)
Very Unsupportive	0%	0%	0%	0%	17%	3%
Somewhat Unsupportive	0%	0%	0%	6%	17%	4%
Neither Unsupportive nor Supportive	0%	6%	11%	11%	11%	8%
Somewhat Supportive	39%	39%	56%	67%	56%	51%
Very Supportive	61%	56%	33%	17%	0%	33%
TOTAL	**100%**	**100%**	**100%**	**100%**	**100%**	**100%**

(Response totals may not add up to 100% due to rounding)

QUESTION 3c - CLINICAL NEED

The following table represents juror levels of support for various actors/ organisations having access to a pool of pseudo-anonymised data (Questions 3.1-3.5) in order to identify areas of unmet clinical need and to shape the research and development of new medicines ("Clinical Need").

Responses to Questions 3.1-3.5 for "Clinical Need" in Percentages (%)

Answer choices	Hospital Staff (%)	Healthcare Systems (%)	Pharmaceutical Companies (%)	Researchers (%)	Government (%)	Total (%)
Very Unsupportive	0%	6%	0%	0%	22%	6%
Somewhat Unsupportive	0%	0%	6%	6%	28%	8%
Neither Unsupportive nor Supportive	0%	6%	22%	22%	0%	10%
Somewhat Supportive	39%	56%	56%	50%	39%	48%
Very Supportive	61%	33%	17%	22%	11%	29%
TOTAL	**100%**	**100%**	**100%**	**100%**	**100%**	**100%**

(Response totals may not add up to 100% due to rounding)

Areas for Future Consideration

A number of themes and recurring questions arose throughout the process, including during Jurors' deliberations, Q&A sessions with witnesses, and as captured through jurors' individual responses to Jury Questions. These themes and questions are important to consider and address as project partners continue the development of this proposed collaborative network.[2]

Access to Data

- Who might be future members in this collaborative and what process will be in place for their involvement?
- What mechanisms will be in place for partners applying for access to the data? Who will have access to the data within each user group and how is this managed, particularly for partners and collaborators who are based outside the UK?

Acquiring Consent for Data Use

- Jurors expressed a desire for more information about patient consent, particularly transparency about implied consent and a person's ability to opt-out of the initiative.
- If a patient or patient representative chooses to opt-out of the initiative, what occurs to their data?
- What pseudo-anonymised patient information would be shared with the initiative (eg., an individual's entire health record or a portion of the health record, how much?)?

Quality of Data

- Participants indicated concern over whether or not NHS staff will have the capacity to gather and enter data correctly (i.e. How will staff be trained to input this data correctly?).
- How might requirements for NHS staff having a new system or additional fields to build out this dataset increase the burden on staff who are already overextended?
- Jurors were interested to know how effectiveness of the data/network will be measured and what benchmarks will be utilised for assessing the data's efficacy for addressing AMR. For example: Could the data highlight trends in overprescribing antibiotics? How might we tell if the data is resulting in better patient outcomes?

2 This section ("Areas for Future Consideration") was drafted by report authors.

Security of Data

- What initial and ongoing steps will be taken to ensure that the data is secure?
- Would there be different levels of data use auditing depending on the user / organisation accessing data and if so, how would these be determined?
- What occurs if there is a data breach? Who will be responsible for a data breach or improper use/ access, and how will the public and/or individuals be notified if this occurs?

Use of Data

- How long will data be held and used (or will it be held and used indefinitely)?
- Would it be possible for this data to be used for other purposes beyond the proposed Liverpool collaborative network (eg., Would the data eventually be used for AMR research on a national or even global scale?)?
- Could this data be used for commercial or treatment purposes other than those related to AMR?
- Would any of the collaborative partners be able to monetize this data?

Important Information from Presentations

Jurors identified several key takeaways from each presentation. A small sample of these key findings and jurors takeaways are listed following each expert witness section below.

Day 1.1 - Dr. Esmita Charani: Introduction to Antimicrobial Resistance (AMR)*

- It is important to know that AMR is here to stay and will be a form of a pandemic.
- It is important to know that everyone is involved in the fight against AMR. From the healthcare professionals, to the patients, the carers and family members are all involved. Hence, everyone needs to take responsibility for their actions. Cultural beliefs and backgrounds also affect the acceptance and use of antibiotics.
- It is important to know that a big issue relating to AMR is patient compliance in various ways such as few antibiotics recycling antibiotics, not being able to take certain forms, taking other peoples' drugs, or stopping treatments early, all of which contribute to AMR across all different countries/cultures. Wider education could help this, even in more highly developed countries like the UK.
- It is important to know about the scale of the AMR challenge and lack of awareness the general public has on AMR because this relates to a public health and public protection issue on a global scale.
- It is important to know that so are being researched and they are not as profitable as other drugs.

Day 2.1 - Prof. William Hope: AMR Collaboration and Research Environment Overview*

- It is important to know that the cost to develop new antibiotics is costly and not overly profitable to big pharmaceutical companies.
- It is important to know how to resolve the key problems in the drug discovery and development phases. This would help in providing solutions for AMR.
- It is important to know patients' safety is paramount and considered of the highest importance.
- It is important to know what data would be required to get a clearer picture of AMR issues, as well as how difficult this is where there is no joined up strategy.
- It is important to understand the huge cost and time needed for development of new drugs.

Day 2.2 - Dr. Sumati Nambiar: Regulatory and Ethical Environment Overview*

- It is important to know about the process required for the clinical trials.
- It is important to know that patient safety is at the heart of clinical trials and that there are mechanisms to stop them if needed etc.
- It is important to know, but not a surprise, that drug discovery is time consuming and expensive but that there are ethical considerations and constraints in place.
- It is important to know that regulatory authorities across the globe broadly operate in a similar way.
- It is important to know that strict regulatory procedures during control trials are required for new, effective and safe therapies to address the challenge of AMR.

Day 2.3 - Seema Patel: AMR and the Role of the Pharmaceutical Industry*

- It is important to know how many different phases and stages the drug goes through during research and development, before it's licensed for use, as it makes you aware of how much has gone into it.
- It is important to know that developers can do research for a new drug, to prevent deaths, and to see what effects this has on patients.
- It is important to know about the huge expense needed for development of new drugs and often they fall down at the first stage and no profits are ever made from them.
- It is important to know that there have been no new classes of antibiotics since 1980.
- It is important to know the timeline for normal medical research and how this was greatly reduced during the pandemic.

Day 3.1 - Dr. Stacy Todd: Hospital Care Journey and Patient Pathway*

- It is important to know that there could be some improvement in the hospital data sharing which may improve the journey/ patient pathway and possibly reduce treatment times.
- It is important to know about the challenges some of the staff face in treating patients (ex. broad spectrum antibiotics used in the first instance while awaiting further test results).
- It is important to know that the medical data for patients in the hospital care pathway are not linked in various hospitals and therefore there is a gap in information sharing between healthcare practitioners, and continuity of care.
- It is important to know that between 20% and 50% of patients do not have infections, but are given antibiotics.
- It is important to know about the care pathway to help me to understand how difficult it can be to make sure that antibiotics (and other care) isn't being repeated.

Day 3.2 - Helen Duckworth & Gary Leeming: Introduction to Data Sharing and Information Governance*

- It is important to understand how data is anonymized so that it gives the reassurance that it cannot be traced back to me as an individual.
- It is important to know that restrictions can be loosened with a COPI notice for something like Covid-19.
- It is important to know that there are laws to bypass the strict sharing of information when it is of national importance.
- It is important to know that the common law duty of confidentiality applies to health data, as well as GDPR and how this makes access to data so difficult for research purposes as AMR is clearly not yet seen to be a priority to allow greater access e.g. to infectious disease data.
- It is important to know about the different types of protected data e.g. pseudo-anonymised data, so that the patient is aware of what they are consenting to regarding the risk of re-identification.

Day 3.3 - Prof. William Hope & Andy Townsend: CEIDR Proposed Collaborative Network and Project Overview*

- It is important to know that this is a city-wide process and not focused on specific groups/people who are ill - and that everyone has an option to opt out, if they do not consent to sharing personal or sensitive information.
- It is important to know about any proposed trial in Liverpool and accompanying reasons for its formation (ex. Why Liverpool has been chosen over London, reasons for opt-out vs. opt-in consent).
- It is important to know about the benefits this proposed network has, i.e. rapid corrective action that would benefit society.
- It is important to know who is going to have potential access to our information and why.
- It is important to know that more thought will be put into the issue surrounding patient consent for their data to be included within the proposed collaborative when the patient is unable to give their consent.

“This jury was a collaboration of free minds with the public’s interest at heart.”

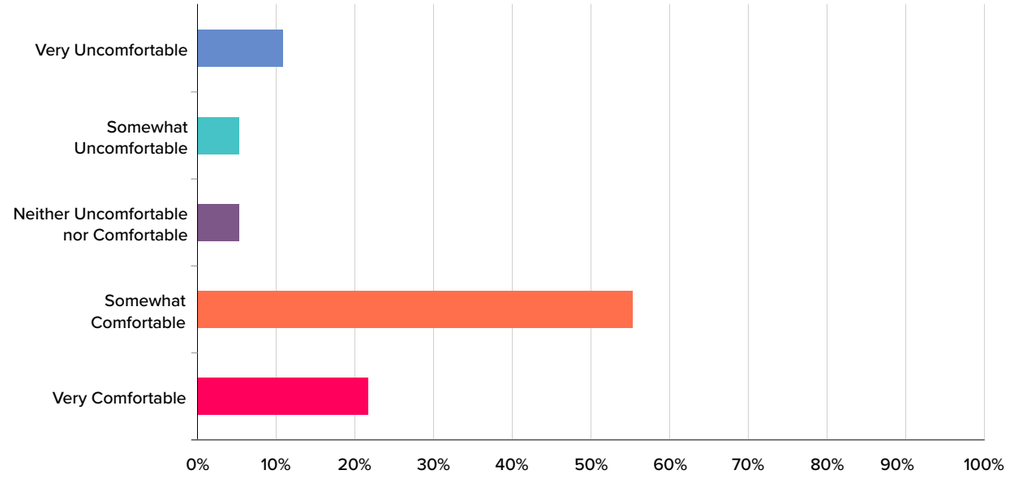
Quote from Jury member

Post-Jury Questionnaire Results

Upon conclusion of the AMR Citizens' Jury, participants completed a post-event questionnaire to provide feedback about their experience. Results from this survey are below.

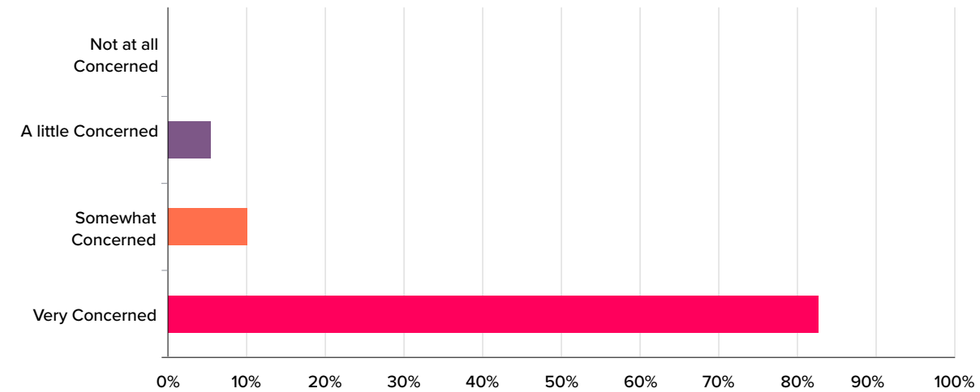
Thinking about your patient health records, in general how comfortable are you with sharing pseudo-anonymised data to monitor and respond to antimicrobial resistance (AMR) in Liverpool?

Answered: 18 Skipped: 0



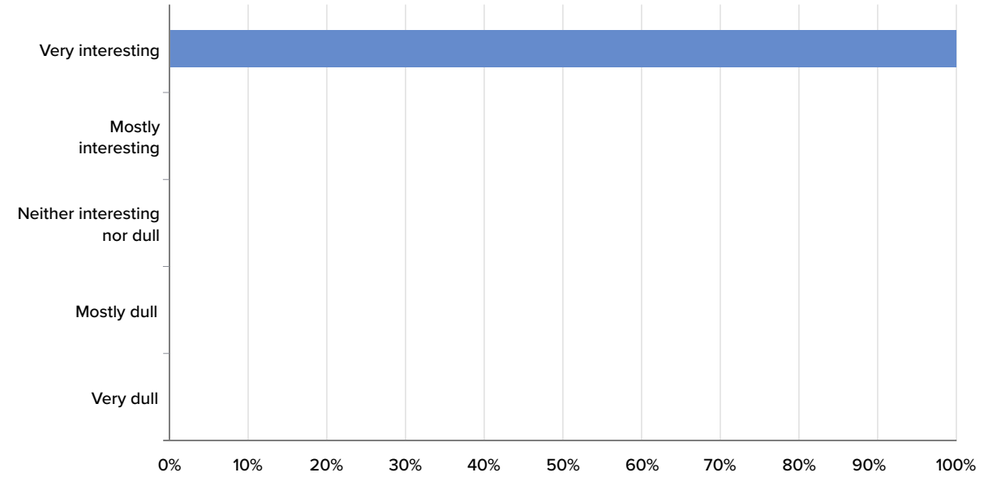
How concerned are you about the threats and challenges posed by antimicrobial resistance (AMR)?

Answered: 18 Skipped: 0



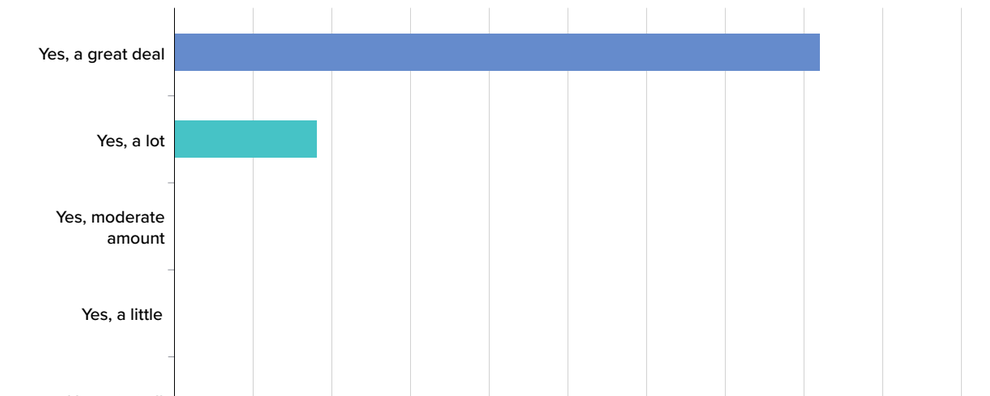
How interesting did you find the jury process?

Answered: 18 Skipped: 0



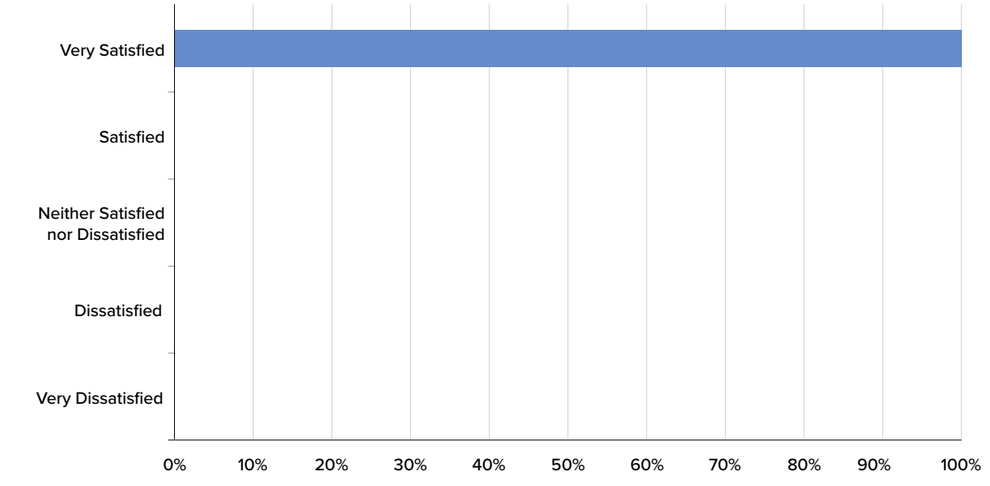
Did you feel you were encouraged to participate in the process?

Answered: 18 Skipped: 0



One of our aims is to have the facilitators manage the process in a neutral way. How satisfied are you in this regard?

Answered: 18 Skipped: 0



“This was a great experience, and it was a vital decision to include the public in this research. Finally, I truly hope I represented them (the public) well, and I hope the decisions I took on this jury would only affect their lives positively.”

Quote from Jury member

Oversight Panel Results

The Oversight Panel members were asked to complete a questionnaire as part of their role of monitoring and minimising potential bias in the Liverpool AMR Citizens' Jury. The results of this questionnaire, and Oversight Panel member comments, are included below.

1. Having reviewed the jury design documentation, how satisfied are you that the citizens' jury run in January of 2022 has been designed *with the aim* of minimising bias?

Answer choices	Responses	Percentage
Not Satisfied	0	0%
Partially Satisfied	0	0%
Mostly Satisfied	0	0%
Fully Satisfied	2	100%

2. How satisfied are you that this citizens' jury was *successfully* designed to minimise bias?

Answer choices	Responses	Percentage
Not Satisfied	0	0%
Partially Satisfied	0	0%
Mostly Satisfied	1	33%
Fully Satisfied	1	67%

Comments and qualifications to your answers above:

- "The expert witness slides, in particular the ones from Pfizer and Johnson & Johnson, were overly complex and in some regards tangential to the core issues. Not so much actively 'biased' as running the risk of 'drowning out' legitimate concerns and/or questions by overloading the jurors with detail."
- A comprehensive information pack was shared in advance to the oversight panel meetings giving sufficient time for a detailed review. The information included the aim/purpose of the Citizen's Jury, along with the set of slides the presenters were intended to use.
- Ample time was allocated for the pre-jury oversight panel meetings to go through each presentation in detail, allowing panel members to highlight questions and concerns to minimise bias.
- Kyle and Sarah were open to all feedback given, without dismissing any concerns raised. They were clear on how this will be shared with the presenters so that changes could be made.
- The oversight panel members were invited to observe the jury, which did mean that as a panel member I could see how comments made were taken into consideration and that bias was minimised.