

Proceeding Paper

Informing Antibiotic Guardianship to Combat Antimicrobial Resistance: The Liverpool Citizens' Jury on AMR [†]

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Abstract: The Liverpool Citizens' Jury was a public consultation on the use of health data to tackle the significant problem of Antimicrobial Resistance (AMR) and is the first step in creating a local AMR network with national and international relevance. The 18 jurors were tasked with learning about AMR as it relates to research and considered how organisations might collect, share and utilise pseudo-anonymised patient data. The overarching aim is to produce a new model supporting societal change focused on Antibiotic Guardianship and to combat the public health challenge of AMR. The model will be implemented in the UK and provided to an international network enabling global knowledge transfer.

Keywords: citizen jury; public engagement; deliberative democracy; AMR; antimicrobial resistance; data; health data; pharmaceuticals; Liverpool; Liverpool City Region



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1. Project Overview

This study was conducted as a collaboration between the University of Liverpool, the Center for New Democratic Processes and Pfizer Inc. The University of Liverpool and Pfizer Inc. were the study sponsors.

This Citizens' Jury project was a public engagement event that formed the basis of the consultation stage of phase 1 of a multi-year programme of work to develop a better information and data sharing model for Antibiotic Guardianship. The first consultation was delivered using the deliberative method of a Citizen Jury. The jury (wherein people are recruited to broadly reflect the demographics of a particular catchment area) were asked to hear and weigh the evidence, discuss together, and use their values to assess trade-offs and make judgements regarding their remit.

The evidence came from a range of expert witnesses who had been briefed to create presentations that provide the jury with a fair balance of relevant information. Over two weeks, jurors encountered and engaged with a series of frameworks to assess the challenge(s) at hand, learnt from presenters, and worked collaboratively to assess the benefits and trade-offs of proposed solutions. They made informed recommendations regarding the legal, ethical, and regulatory aspects of the proposal.

The jurors considered patients in hospital with confirmed urinary tract infections (UTI) who were prescribed different antimicrobial regimens by their healthcare practitioners. They were then asked questions based on the scenario to provide an understanding of the public perceptions of information and data access that required for optimal use of newly approved drugs and treatments.

Jurors were generally supportive of the sharing of health data for AMR research, although support varied depending upon the activity and the parties involved. When considering hospital staff use of data, jurors indicated 95% support for data use to identify trends in AMR manifesting in serious illness. When asked the same question about researcher and pharmaceutical companies using health data to investigate trends in AMR, jurors indicated 84% and 89% support, respectively. However, only 56% of jurors supported government researchers using data to analyse trends in AMR [1].

The jurors identified five areas for future consideration as the project progresses. These were: access to data, acquiring consent for data use, quality of data use, security of data and use of data [2] (pp. 25–26).

Jurors generally indicated that they found the jury a positive experience, with 100% answering that they found the jury process ‘very interesting’ when polled in the final jury session [2] (p. 30). Jurors were quoted as saying,

“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 [1] (p. 3)”.

“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 [1] (p. 33)”.

The whole process was facilitated by a third party, the Center for New Democratic Processes, and was overseen by an independent panel whose purpose was to ensure fairness in the information provided to the jury. They worked with the jury to provide a safe space to express opinions and concerns. The jury produced a final report complete with recommendations for the next stages of the project and this was presented back to the project team, which was accepted in its entirety.

2. Outcomes and Impact

2.1. Citizen AMR Champions and AMR Awareness

Delivery of the event stimulated conversations on social media (Twitter, LinkedIn) about AMR, raising the profile locally and nationally. Follower counts on social channels increased considerably, and impression counts were in the top quartile of similar posts. Additionally, the event raised the importance of meaningful public involvement in research across the research and development community.

The 18 members of the jury received significant education on a broad range of topics related to AMR, drug development and legal and ethical considerations of data usage. Consequentially, they are extremely enthusiastic to champion Guardianship more broadly, with one juror explaining how this experience “has changed my life for the better”.

2.2. Knowledge Exchange

All materials, slides and presentations for the event were produced by leading experts in their field, were assessed by an oversight panel to address any perceived bias and written for a lay audience. Distillation of the results was published in a series of reports and all raw data are available. A dedicated webpage is hosted by the University of Liverpool to hold all assets, which are freely accessible.

2.3. Understanding Public Perception

The key outputs were gaining insight into what the public thought about:

- The visibility of AMR and AMR research;
- What information the public would like to see about AMR;
- Which sources of information are trusted by the public;
- Public and private sector organisations accessing data;
- Public and private partnerships working together;
- What legal, ethical and regulatory considerations they most value.

These insights will be incorporated into the ongoing work and will enable the co-development of a framework that will support a community to become Antibiotic Guardians.

3. Future Development

The Citizens' Jury project forms the basis of the consultation stage of phase 1 of a multi-year programme of work to develop a better information and data sharing model for Antibiotic Guardianship. The learnings from public perceptions are currently being incorporated into the initial programme design. Changes have already been made in terms of the ways of working, the level and types of outreach work and an emphasis on explaining process as well as outcomes. The Jury told us that clear communication on data use was something that helped with the building of trust and displaying of trustworthiness. The public involvement section of the programme will be significantly expanded to enable repeated involvement of the public in further iterations of the design and implementation processes.

Nationally and internationally, we have been developing an expansive network to ensure that the knowledge gained from this exercise is reused and starts to form the foundations of a better way of involving the public at the heart of system design. However, some of the recommendations of the jury have already been implemented and guided similar projects in Liverpool that use connected health data.

Supplementary Materials: The following supporting information can be downloaded at: <https://www.mdpi.com/article/10.3390/msf2022015009/s1>, Conference Poster: A new model to inform Antibiotic Guardianship and combat Antimicrobial Resistance: The Liverpool Citizens' Jury.

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Institutional Review Board Statement: Ethical review and approval were waived for this study as it was deemed by the University of Liverpool as public engagement and not research.

Informed Consent Statement: Informed consent was obtained from all subjects involved in the public engagement event.

Data Availability Statement: The data presented in this study are available in https://www.liverpool.ac.uk/media/livacuk/iib/AMR_Full_Report_Final,V1.4.pdf.

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Conflicts of Interest: The authors declare no conflict of interest. Funders were not involved in the study design or management of the Citizens' Jury process.

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