A new model to inform Antibiotic Guardianship and combat Antimicrobial Resistance: The Liverpool Citizens' Jury

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CATEGORY: PATIENT ENGAGEMENT

Aim

The overarching aim is to produce a new model supporting societal change focussed on Antibiotic Guardianship and to combat increasing rates of AMR. The model will be implemented in the UK and provided to an international network enabling global knowledge transfer.

Citizen Jury

The programme will be delivered in phases over multiple years, with many public and private sector partners. A key feature of the CONSULT stage is extensive, meaningful involvement of local citizens to provide insights and influence system design.

PHASE 1 → CONCEPT → CONSULT → DRAFT PLANNING → **ITERATE**

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, deliberate 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 were briefed to make 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, learn from presenters, and worked collaboratively with one another to weigh the benefits and trade-offs of proposed solutions. They made informed recommendations regarding the legal, ethical, and regulatory aspects of the proposed undertaking.

In this project the jury considered patients in hospital with confirmed Urinary Tract Infections (UTI) who were prescribed different drug regimens by their healthcare practitioners.

PATIENT A	PATIENT B	PATIENT C	PATIENT D
Standard drug	**Standard drug** Followed by **Newly approved drug** after symptoms do not clear.	**Standard drug** Followed by **Newly approved drug** after symptoms worsen.	**Newly approved drug**
Recovery: 1 week	**Recovery:** 1 week	**Recovery:** 3 weeks	**Recovery:** 1 week

Results

The Jury were asked three main questions relating to the patient scenarios.

Q1: 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.
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%).

Q2: 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 pathways
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".

Q3: Overall, jurors were generally supportive of **healthcare staff (98%)** and **healthcare systems (92%)** having access to pseudo-anonymised data about prescribing patterns and the drug's efficacy regardless of the data usage under consideration. They were moderately supportive of **researchers (74%)** and **pharmaceutical companies (78%)** having access to the same information. However there were lower levels of support for **governments (48%),** local or national, being able to see the same information.

Outputs

The major outputs from this exercise can be classified into three groups:

Citizen AMR Champions & AMR Awareness
Delivery of the event stimulated conversations on social media about AMR and raised the profile of the topic locally. It also raised the importance of meaningful Public Involvement in Research across the research and development community.
The 18 members of the jury received significant education in a broad range of topics related to AMR and drug development. Consequentially they are extremely enthusiastic to champion Guardianship more broadly.

Knowledge Exchange
All materials and slides for the Jury event were produced by experts in their field, were assessed by an oversight panel to remove any bias, and written for a lay audience. All the presentations of the material are freely available online through a dedicated webpage. Several reports have been produced summarising the results, available on the same site.

Understanding Public Perception
The key output was gaining insights 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 value most.

It is these insights which will be built into the ongoing work and will enable the co-development of a framework that will support a community to become Antibiotic Guardians.

Future Plans

The programme duration is expected to be implemented iteratively over the next decade. This Citizen Jury is one part of the CONSULT stage of Phase 1.

The learnings from public perceptions are currently being worked into the initial programme design. Changes have already been made in terms of the ways of working, the level of outreach work, and the emphasis on explaining process as well as outcomes. The Jury told us that this latter point was something that helped with the building of trust and displaying trustworthiness.

General system design recommendations were put forward by the jury and these are either under consideration or have already been confirmed in the design.

Areas to consider	Our Commitment
Access to data	Users must prove trustworthiness and that their use of data will benefit society
Use of data	Data will be used for the purposes described in data access requests, which will be approved ahead of use
Security of data	Multiple layers of security will be used. Access will be monitored and recorded for audit
Quality of data	We will not place additional burden on the NHS systems and will appropriately resource projects
Consent for data use	Access will be by consensual processes unless under emergency measures due to PH crisis

As the new model is co-developed with our citizen groups, the partnership will be sharing learning with other local networks, and with National and International colleagues. Blueprints and design principles will be shared. Recommendations will be made available including any red lines highlighted by future public involvement work.

ACKNOWLEDGMENTS

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What the Jury thought…

"Hopefully the work we have done will go towards a **very positive and important project in 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."

"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."

"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 jury now do, the very real threat that AMR poses** to world health."

"The **experience has been rewarding in helping shape the research and assistance surrounding AMR**, and the jury has the general public's best interests at heart in regards to their health care, support and the use of data."

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