

Commercial use of health data in the dock – results of a public “trial”

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Introduction

Surveys suggest that there is a dichotomy in how citizens view research for public good and research for commercial gain. As a consequence, the idea that a research initiative, such as a learning health system, for both public and commercial benefit may be controversial and reduce public trust.

Objectives and Approach

This study aims to investigate what informed citizens considered to be appropriate uses of health data in a learning health system. Two paired four-day juries were run, with different jurors but the same purpose, expert witnesses and facilitators. Overall, 694 people applied to be jurors; 36 were selected to match criteria based on national demographics and their prior privacy views. Jurors considered whether and why eight exemplar data uses of depersonalised patient data were acceptable. The exemplars were data uses planned by the learning health system initiative to improve care pathways (planned uses), and possible unplanned data uses.

Results

All planned uses were considered appropriate by most, but not all, jurors, as they had the potential of benefitting the public through improving care. Positive health outcomes were more acceptable than improved efficiency of services, given jurors prior beliefs about how the NHS operates raising concerns about whether improving efficiency would lead to inequitable distribution or closure of services. The potential uses were considered appropriate where there were improvements in drugs, treatments, or lower NHS costs. Some jurors became more accepting of commercial uses as they understood them better. Commercial uses that prioritised generating profit and did not produce health benefits for the public were unacceptable, regardless of any safeguards for the data. Commercial gain that occurred secondary to achieving public benefit were generally accepted.

Conclusion/Implications

Juries elicit more informed and nuanced judgement from citizens than surveys. Jurors tended to be more accepting of data sharing to both private and public sector after the jury process. Many jurors accept commercial gain if public benefit is achieved. Some were suspicious of data sharing for efficiency gains.

