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# Public Perception of the Collection and Use of Critical Care Patient Data Beyond Treatment: a Pilot Study

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## Background

Technology has transformed critical care medicine and increasingly leads to the development of large databases of patient information. There is public interest in use of this data; it is a valuable source which can drive clinical research and lead to improved patient treatment, but concerns are voiced about the security and privacy of this data. We describe a survey which asked the general public at a science festival about this topic.

## Methods

We asked the following: if participants were aware of the potential of medical data for research purposes; previous involvement in clinical research; their use of social media; whether data should be used for research purposes and how likely would they be to share their own personal data for research; if they trust clinicians with their data; and their opinions on the role of private companies in supporting and/or carrying out research on their medical data.

## Results

39 out of 41 adults responded to the survey. 32 (82.1%) were aware that medical data could be used for research. 31 (79.5%) regularly use social media, of these only 1 (2.56%) shared health information on it. 34 (87.2%) strongly agreed/agreed that medical data should be used for research whilst 4 (10.3%) were undecided. 32 (82.1%) strongly agreed/agreed they were happy to share their medical data, 4 (10.3%) were undecided and 2 (5.1%) disagreed/strongly disagreed. 27 (69.2%) strongly agreed/agreed that they trusted clinicians with their medical data, 7 (17%) were undecided and 3 (7.7%) disagreed/strongly disagreed. Whereas, 8 (20.5%) strongly agreed/agreed that they trusted private companies to use medical data for research purposes, 20 (51.28%) were undecided and 9 (23.1%) disagreed/strongly disagreed.

## Conclusions

Response to the use of medical data for research purposes is positive; a majority supported and trusted clinicians. This was not as strongly observed when private companies were involved; this has implications for healthcare providers, policy makers and researchers. This study will be followed up with a more extensive survey.