

Health data drives innovation

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Clinical Research Value and Transparency*



How to maximise the value of patient engagement for improving research quality and transparency in a post-COVID-19 world



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Positive impressions

- The need to collect information from everybody to understand a new disease
- The importance of countries working together to share knowledge, and to learn from each other
- The balance between individual privacy versus data sharing for societal benefit
- The importance of clinical research to study a new disease and treatments
- The importance of industry to develop vital solutions (vaccines, treatments)
- The role of clinical trials and the value of participating in them
- The societal benefits when all of the above work together well

Negative impressions

- Sensationalised press reporting of emerging evidence
- The discord between emerging (sometimes confusing) evidence, the media statements by individual scientists, and the statements of politicians
- The lack of transparency behind decision-making
- The different strategies adopted by different countries, ignoring evidence and experience from other countries
- Confusing measures, sometimes seem completely illogical
- Persuading the public to install apps, reveal personal information, before (without ever?) explaining how the information will be used and protected
- The invisibility of patient and public stakeholders in research priorities and in decision making

My own uncertainties about public opinion

- Is science now held in higher, or lower esteem?
- Has the importance of data sharing and research been strengthened?
- Has the contribution of industry, especially pharma, become better recognised?
- Do people better understand what a clinical trial achieves?
- Has public trust in personal data use been gained, or lost?
- (Let us not discuss public trust in politicians!)

How can we now harness public interest in research and science?

- Valuing research and data use as a societal good
- Appreciating the actors who conduct research and use findings
- Being more willing to allow their EHR data to be used
- Being more willing to contribute personally collected data
- Becoming more engaged in the adoption of evidence and innovation into practice
- Becoming more engaged in articulating and championing research priorities