How do citizens view forced unconsented access to their own smartphone data during medical emergency situations?

Unconsented Data Transfusions:
Attitudes Towards Extracting Personal Device Data for Public Health Emergencies

1. At a glance

User attitudes were collected through a small-scale proof of concept focus group approach to reveal what citizens' opinions may be towards extraction of medical data from their smartphones in the event of a public health incident. The study found:

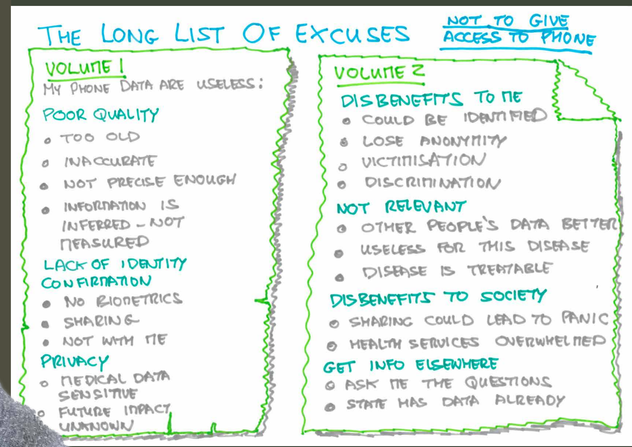
- Smartphones are viewed akin to organs or limbs, where forced access, without consent, is assault
- The benefits to society of unconsented access to medical and other personal data on mobile devices must be overwhelming before such acquisition is considered acceptable
- The analysis also points to the difficulty of gaining consent, a lack of knowledge about legal aspects, and a distrust about the state collecting data.

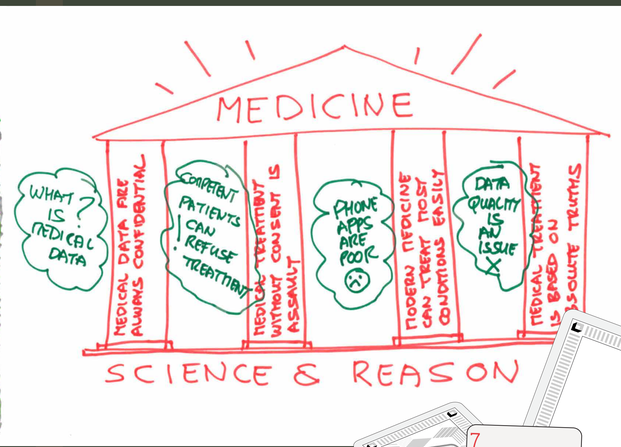
3. How do people perceive their smartphones?

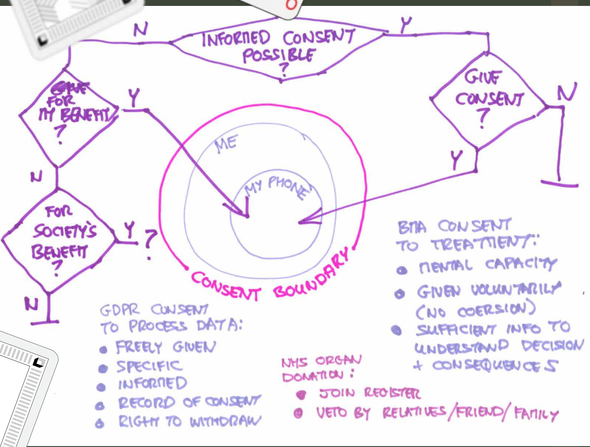
Smartphones can be perceived as tools forming extensions to human bodies, not merely in a McLuhanian metaphorical sense, but quite directly with innate emotional relevance to the people using the technology.

4. What is particularly interesting in the findings?

The findings highlight a high degree of reluctance by the participants to any form of unconsented access in the absence of overwhelming evidence of greater society-wide benefits.







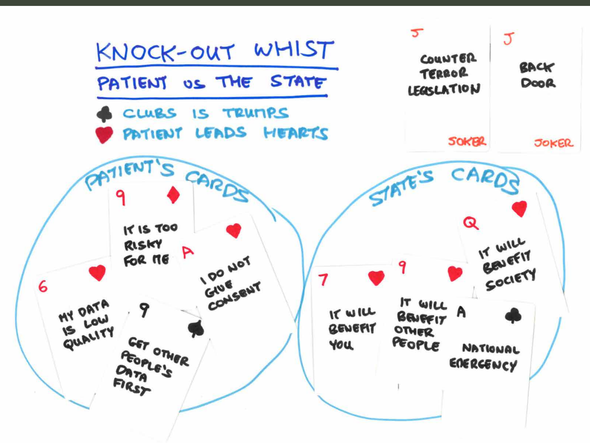


Figure A ▲
Illustrations of the four approaches to theme generation from the coded transcribed data

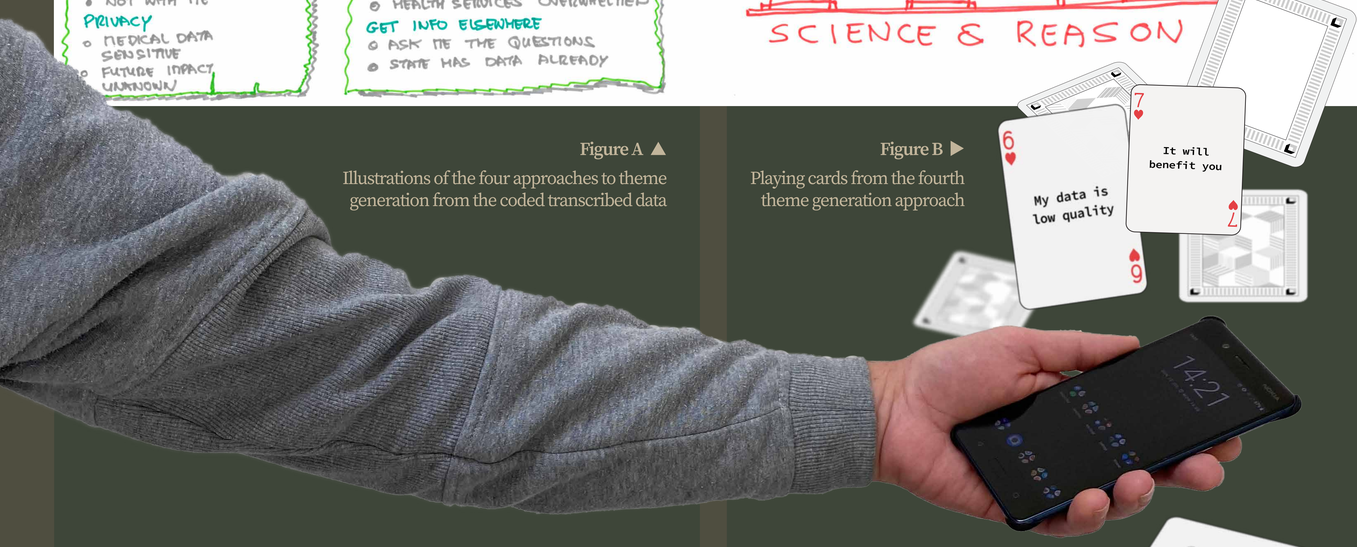


Figure B ▶
Playing cards from the fourth theme generation approach

2. Method

Convenient subjects were self-selecting digitally literate trainee researchers from non-vulnerable groups, aged 20-39 years old, living in England took part in semi-structured discussion groups:

- Single-participant pilot
- Three-participant pre-study.

The assisted discussion was framed to illicit a range of views, moving from a general medical data consent topic to more specific national emergency issues:

- Heart condition
- Tuberculosis
- Influenza pandemic.

Inductive thematic analysis on the verbatim transcribed audio recordings was performed using visually and textually supported creative mind-mapping to identify themes (Figure A).

5. What is happening now?

The discussions were executed before the coronavirus/ COVID-19 pandemic and the resulting grave international impact became apparent. In the light of this, lockdowns and deployments of digital technologies for data collection for public health purposes such as contact-tracing applications, we are currently augmenting this work with follow-up studies and also to investigate the quantitative differences between the presented scenarios.

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