

**Submission for The Future of Privacy Forum in collaboration with the National Science Foundation, Duke Sanford School of Public Policy, and Intel Corporation presents Privacy & Pandemics: Responsible Uses of Technology and Health Data During Times of Crisis -- An International Tech and Data Conference**

Perspective: Areas where access to data was limited

## **Responsible uses of technology and health data during times of crisis**

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For many reasons, the evolution of healthcare documentation and its subsequent digitisation takes significant time. Not only does new knowledge need to be discovered, but it also needs to be evaluated and approved before a process of updating clinical documentation occurs. To work around these limitations, users often update static paper systems by incorporating annotations. Annotations are hand-written notes inserted into pre-printed documents by users. They are used to personalise standardised care-plans or add new knowledge that has emerged in between version updates. Potential annotations can be shared between users, and these could then be used appropriately in future paper documents. Annotations can refer to anything the user might find relevant to patient care. For instance, a patient assessment question, such as ‘do you use home oxygen?’; essentially knowledge that is now known to be relevant to care but was not known when the initial document was developed. Data can also become redundant.

Once records are digitised, similar issues can occur. That is, new knowledge emerges in-between version updates. However, rather than annotate a paper page, users sometimes add additional information as free text (if the option is available). What this could mean is the system (either paper or electronic) potentially may not contain the most up-to-date data set. This has implications for new users who, separated by time or geography, may not have been aware of the additional data required. This is particularly relevant during a pandemic where knowledge is changing and evolving at a rapid pace.

This study, set in a single contact tracing centre, identified and described the underlying mechanisms that facilitated emerging knowledge to be quickly incorporated into updated versions of the digital

platform. The platform was developed and used during the COVID19 pandemic in a contact tracing centre. The nature of the pandemic – ongoing emergence of information, improving understanding of the disease, changing needs of stakeholders, including patients – provided a setting where access to the most up to date knowledge was vital by all users. In the setting, documentation and ICT tools for COVID 19 contact tracing and support were developed and updated in real-time.

The study was carried out to identify what mechanisms allowed CTC to operate and what changes could be made should a similar situation arise in the future. One of the findings from the study was that knowledge flowed between patients, volunteers and management, facilitated by the role of the superuser, allowed for speedy evolution of required documentation and ICT tool development. Superusers is used in this context to the role of a clinical expert with experience in relevant processes and technology. Their main function is to provide support, identify user issues and problem solve and report any issues to relevant stakeholder. In addition to their clinical and technical abilities, super users would have training in infection prevention measures.

A further finding was that relevant knowledge was rapidly incorporated into the system so that it could be shared beyond time and geography. This quick turnaround allowed the processes, documentation and ICT tools used to be continuously updated. Underlying mechanisms that supported these knowledge pathways included the role of leadership, the role of superusers, a sense of purpose, available support, expectation of changes and communication.