

Ethically conscious use of data and apps for pandemic response

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23 June 2020, Location

Challenges for Using Personal Data in Response to Pandemics

naturemedicine

Comment | Published: 27 March 2020

On the responsible use of digital data to tackle the COVID-19 pandemic

Marcello Ienca  & Effy Vayena

Nature Medicine (2020) | [Cite this article](#)

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Large-scale collection of data could help curb the COVID-19 pandemic, but it should not neglect privacy and public trust. Best practices should be identified to maintain responsible data-collection and data-processing standards at a global scale.

- Compared with previous outbreaks, the COVID-19 pandemic is occurring in a much more digitized and connected world.
- “It is therefore imperative to leverage big data and intelligent analytics and put them to good use for public health.”

Ethical uses of Personal Data in Response to Pandemics

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- In the collection of data from affected people, the **principle of proportionality** should apply:
- the data collection must be
 - (i) proportional to the seriousness of the public-health threat,
 - (ii) limited to what is necessary to achieve a specific public-health objective, and
 - (iii) scientifically justified.

Ethical uses of Personal Data in Response to Pandemics (cont...)

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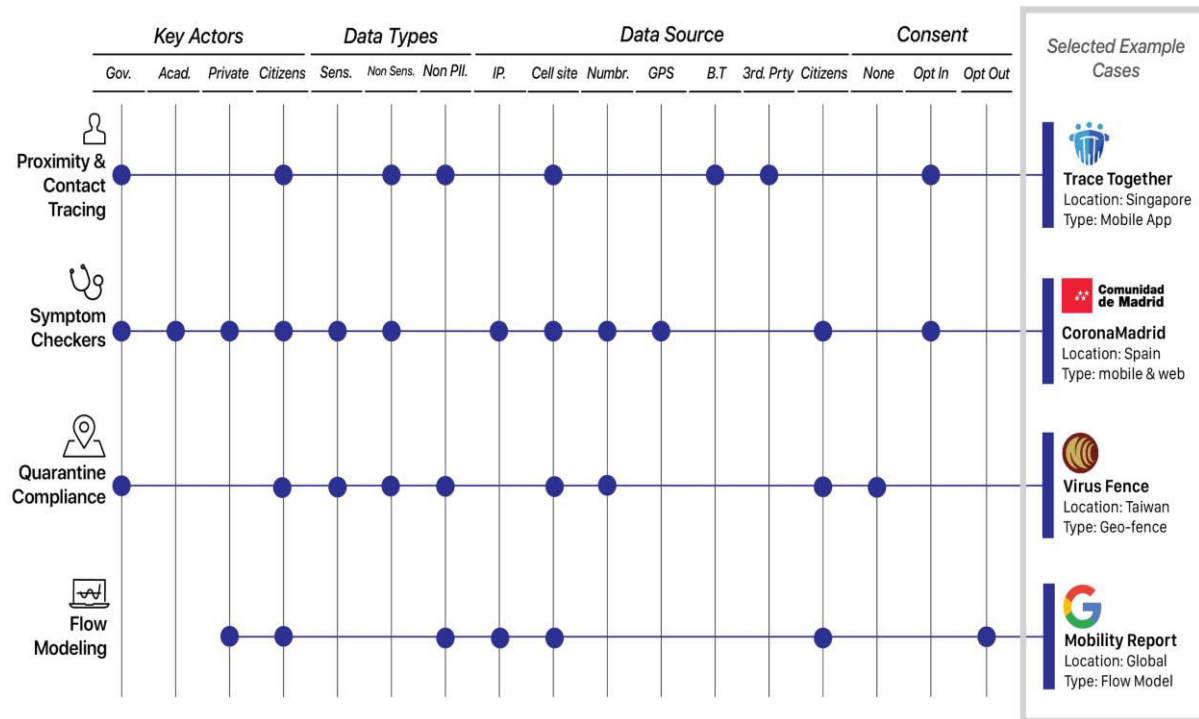
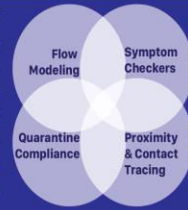
Large-scale collection of data could help curb the COVID-19 pandemic, but it should not neglect privacy and public trust. Best practices should be identified to maintain responsible data-collection and data-processing standards at a global scale.

- At the data-processing level, **data quality** and **security** controls are needed.
- Data-integrity weaknesses, which are common when data from personal digital devices are used, can introduce small errors in one or multiple factors, which in turn can have an outsized effect on large-scale predictive models. **Data breaches**, insufficient or ineffective de-identification and biases in datasets can become major causes of **distrust** in public-health services.

Ethical Uses of Public Health Technologies in Response to Pandemics

Typology of Digital Public Health Technologies against COVID-19

This typology is based upon an analysis of primary cases of COVID-19 digital public health technologies. Note, there may be variations due to the rapid proliferation & evolution of national, international & private actor initiatives in this domain. Further, some technologies may combine purposes or have overlaps in approaches.

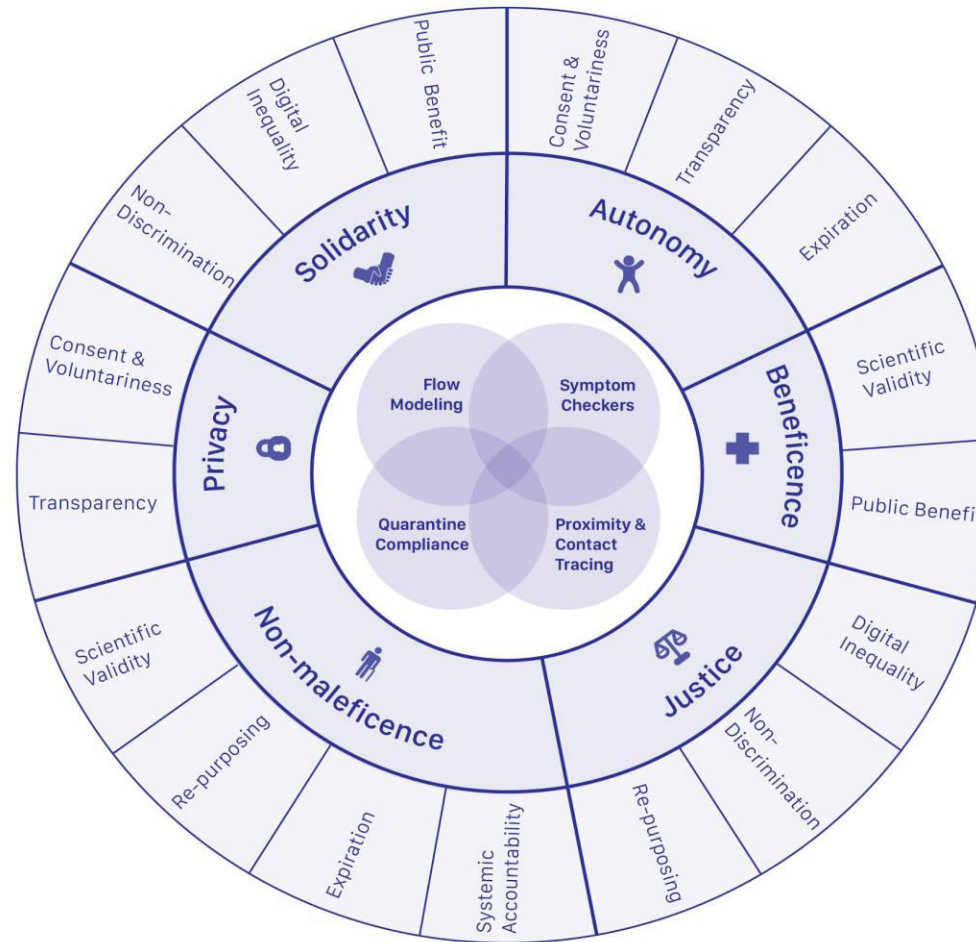


- Personal data and public health technologies have been utilised at an unprecedented level in the response to the COVID-19 pandemic
- However, many of these uses have raised questions about whether they are *ethical* (GSMA, 2014)
- How do data processors and controllers (health departments, governments, researchers) ensure ethical uses of data and public health technologies?
- Do these ethical concerns change with different uses?

Potential Ethical and Legal Challenges

Issues raised by applying Ethical Principles to COVID-19 Digital Public Health Technologies

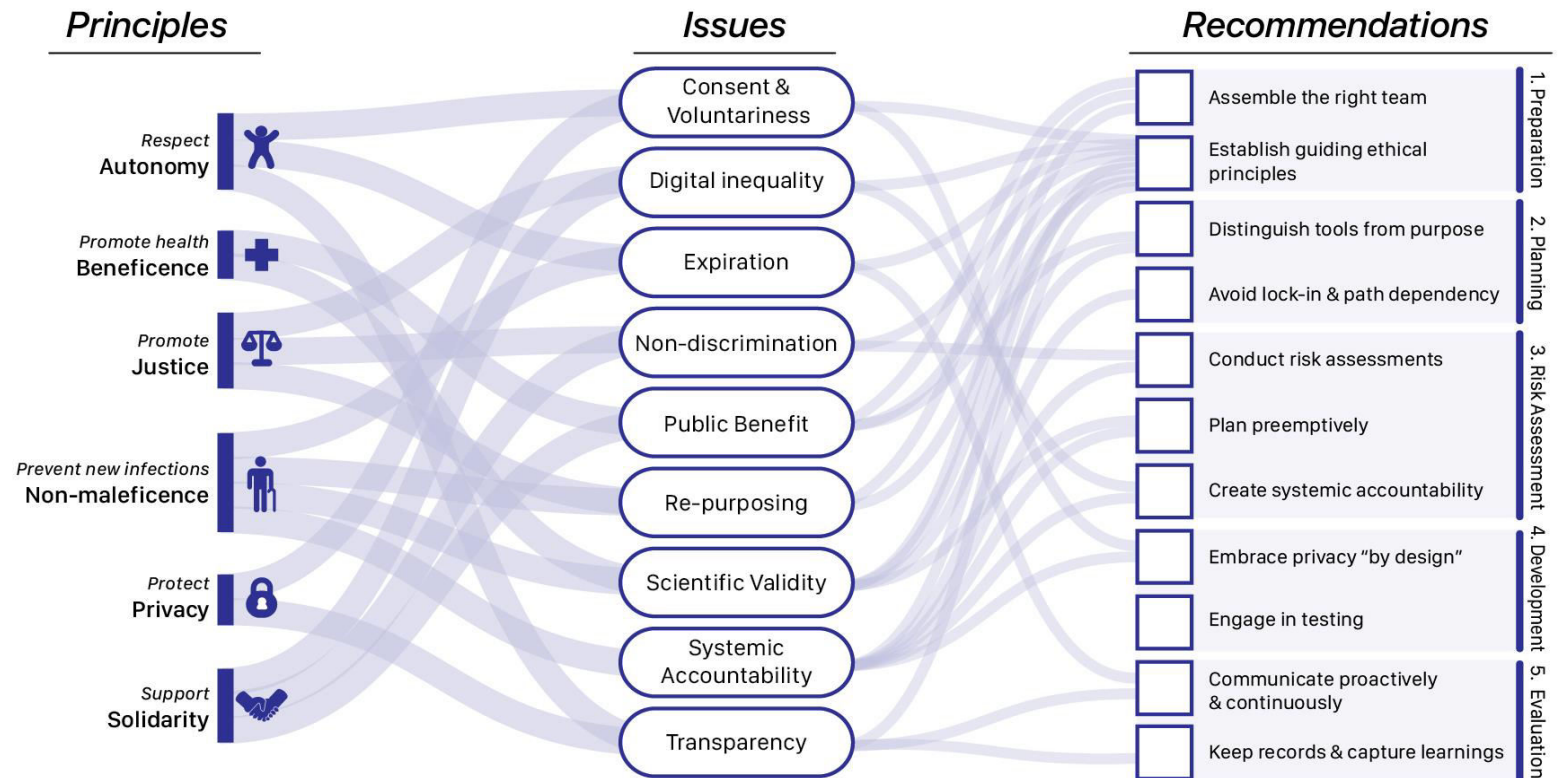
This sunburst diagram presents how the six ethical principles raise ethical and legal issues when considered in relation to digital public health technologies against COVID-19. As shown by the intersecting circles at the center, these principles apply equally to symptom checkers, proximity & contact tracing, quarantine compliance and flow modeling.



Ethical and Legal Recommendations for App Development

Ethical Principles + Ethical & Legal Issues + Recommendations

This alluvial diagram represents the relationships between the ethical principles, issues and recommendations discussed in this paper. These principles and recommendations apply equally to the four Covid-19 digital public health technologies.



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Acknowledgements:

Professor Effy Vayena (effy.vayena@hest.ethz.ch), ideas for and drafting of the paper

Dr Urs Gasser (ugasser@cyber.harvard.edu) idea for and work of the paper

Joanna Sleigh (joanna.sleigh@hest.ethz.ch) images on slides 5, 6, and 7.

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