Trust building for effective data sharing as the global community recovers from COVID-19

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Acknowledgement of Country

I acknowledge and pay my respects to the traditional owners and custodians on whose lands we walk, work and live. I pay respect to the Elders past, present and emerging, descendent of those traditional custodians and extend that respect to any Indigenous people listening to this webinar.

Bandaiyan: The Body of Australia, by the late Ngarinyin Elder David Mowaljarlai (1992) 
Dreaming song lines across Australia’s lands and seas
“it’s a matter of trust”

“Trust today is granted on two distinct attributes: competence, delivering on promises, and ethical behaviour, doing the right thing and working to improve society. It is no longer only a matter of what you do – it’s also how you do it.”

Edelman CEO Richard Edelman, *Edelman Trust Barometer*

Soft toys placed to entertain children during coronavirus lockdowns. Photograph: James D Morgan/Getty Images
Rate each of the following criteria in terms of how important they are to you when deciding whether or not someone is trustworthy:

- A positive personal experience with the person: 5.5
- A negative personal experience with the person: 5
- Opinion of a family member or close friend about that person: 4.2
- Having a shared purpose with the person in question: 4.6
- How sincere I feel the person is in relation to what they say and do: 5.6
- How reliable I feel the person is in relation to commitments they make: 5.6
- Expertise/competence I feel the person has in the context in which I need to trust them: 5.6
- The authority I feel the person has in the context under consideration: 5.1
Do you agree or disagree with this statement?

My responses to the ratings would change if I am deciding to trust an organization with my data

3.4
Exit through the App Store?

A rapid evidence review on the technical considerations and societal implications of using technology to transition from the COVID-19 crisis

Key findings

There is an absence of evidence to support the immediate national deployment of symptom tracking applications, digital contact tracing applications and digital immunity certificates. While the Government is right to explore non-clinical measures for transition, for national policy to rely on these apps, they would need to be able to:

1. Represent accurate information about infection or immunity
2. Demonstrate technical capabilities to support required functions
3. Address various practical issues for use, including meeting legal tests
4. Mitigate social risks and protect against exacerbating inequalities and vulnerabilities

At present the evidence does not demonstrate that tools are able to address these four components adequately. We offer detailed evidence, and recommendations for each application in the report summary.

“Effective deployment of technology to support the transition from the crisis will be contingent on public trust and confidence, which can be strengthened through the establishment of two accountability mechanisms”

What is trust?

“Reputation is an essential but backward-looking concept, an outcome of the past. Trust implies a projection; it involves a judgement that mobilizes both rational and emotional components, direct and indirect experiences. That’s why Trust is such a powerful KPI. Trust is forward-looking and predictive in nature; it also implies a relationship between an organization and its stakeholders and an element of risk. The more trust there is, the more the risk is accepted, leading to a stronger, more fluid relationship, conducive to business resilience and performance.”

Source: https://www.edelman.com/expertise/edelman-trust-management
Sociohistorical snapshot of trust & crisis: evolving understandings of infection

Dr. Ignaz Semmelweis
father of infection control & hand hygiene

“Semmelweis experienced great difficulties in convincing his colleagues and administrators of the benefits of this procedure. In the light of the principles of social marketing today, his major error was that he imposed a system change (the use of the chlorinated lime solution) without consulting the opinion of his collaborators. Despite these drawbacks, many lessons have been learnt from the Semmelweis intervention; the “recognize-explain-act” approach has driven many investigators and practitioners since then and has also been replicated in different fields and settings.”

WHO Guidelines on Hand Hygiene in Health Care: Chapter 4 Historical perspective on hand hygiene in health care
Building Trust in four quadrants

Reassurance: communication, professionalism

Resilience: persistence, creativity

Relationships: Building & maintaining connections

Reflection: time to think & test
Observation #1

Trust building is...

Personal
Local
Political
The key to creating a trustworthy organisation is ...

- Government and legal frameworks: 1
- Societal pressure and citizen activism: 0
- Leadership from within the organisation: 1
- Governance frameworks within the organisation: 4
- All of the above are equally important: 8
How would you rate these statements?

- Governments have a moral obligation to explain how and why they collect and use data gathered from the public: 6.1
- Organisations collecting data from the public have a responsibility to be transparent about the way they intend to use that data: 6.3
- Aligning existing national and organizational policies with an international standard for ethical data sharing can contribute to building public trust: 5.7
- We all have a responsibility to keep governments and organisations accountable for their actions: 6.2
Edelman Trust Barometer 2020: Urgency of Trust Partnerships

“People today grant their trust based on two distinct attributes: competence (delivering on promises) and ethical behavior (doing the right thing and working to improve society).”

- No institution seen as both competent and ethical
- Government and media are perceived as both incompetent and unethical

PARTNERSHIP: AN OPPORTUNITY TO BUILD TRUST

“This year, we asked Edelman Trust Barometer respondents to tell us how well each institution is doing on a long list of issues that are challenging society. The most consistently low score for NGOs, business and government is on partnership, with each institution not seen as a good partner to the others.”

(Source: https://www.edelman.com/trustbarometer)
Observation #2

To be worthy of trust takes more than authority, especially in times of crisis

"thriving in uncertainties"

Anderson, 2006

(See http://informationr.net/ir/15-4/colis721.html)
Building Trust from inside » out

Involves working within community and for it
Accepting risk, responsibility, accountability

LET’S NOT UNDO ALL THE GOOD.

Keep playing your part to help Stop the Spread

- Keep practising good hygiene
- Stay 1.5 metres apart
- Download the COVIDSafe app

For more information
StopTheSpread.sa.gov.au

Gaining the Social License

- Approval
- Credibility
- Legitimacy
- Acceptance
- Trust
- Rejection

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Developing and Demonstrating Competence: Trustbuilding and ethical data/AI practices

CoDesign
True participatory engagement in process

Gaining and Maintaining Trust
Demonstratable Outcomes for Community

Establishing Credibility
Transparency and Feedback Mechanisms

Working towards Acceptance
Models of appropriate practice throughout lifecycle

Establishing Legitimacy
People-centred approach to data practices

Locating trustbuilding and ethical data practice in a sociotechnical framework (Dr. Theresa Anderson, v2, November 2019)
Trust is not a universal or stable concept
It’s interpretation varies across locations and contexts of use

I do not have confidence that our current leaders will be able to successfully address our country’s challenges

66%
To be worthy of trust takes more than authority

Good governance in unusual times requires better listening

“Those who are able to inspire trust – whether they are individuals, corporations or states – will be the big winners when the dust settles. The world has too many leaders and not enough statesmen. In this age of confusion, those who can rise above individual or factional interests will be the real winners.”

https://www.scmp.com/comment/opinion/article/3052828/world-running-trust-deficit-can-governments-regain-trust-time
Characteristics of a trusted public figure?

three key things leaders must address to motivate followers to give their best

• direction-giving
• meaning-making
• empathy

Pursuing a shared understanding of “well-being” can drive our ethics & contribute to building public trust
Ways forward: Building Public Trust with well-being as our driver

**Reassurance**: Repairing trust deficit from inside-out as well as outside-in (competence, communication, consultation, Bildung)

**Resilience**: Nurturing capacity for insight and innovation in face of challenges (diversity; curiosity; flourishing)

**Relationships**: Partnering to build trust essential to tackle ‘wickedness’ of challenges (putting expertise into context; using co-design & stewarding principles)

**Reflection**: Making time to think and learn from success and failure (education, empathy)
If “wellbeing” determines ethics of a system, governance is in the service of a community’s “foundational capacity” to make and implement strategic decisions about their affairs.

Data for governance raises the question: what data do nations need to govern effectively?

Data Governance in service of a community should enable the collection and use of accurate, relevant, and timely data for policy and decision-making, where terms, conditions and relevancy are collectively and dynamically determined.

(Carroll et al, 2019)

Which of these options are most important to you for determining whether or not to share data with an organisation? (choose 3)

- Transparency about intentions for data use: 7
- Legitimacy/Authority the organisation has for collecting and using: 6
- Past experience with the organisation: 2
- Transparency about the way data is managed, used & protected once collected: 11
- Perceived benefit of the reason for collection & use of the data: 9
- Mechanisms the organisation has in place for handling unforeseen issues and data breaches: 5
- Organisation's willingness to involve the public in the design of data collection and data policy: 4
What is your most important consideration when deciding to share your personal data?

- Credits
- Privacy and confidentiality
- Value to social science or public good
- Data Privacy, Privacy of Individuals
- privacy
- motive of data usage
- Trust Reliability and Transparency
- Reliability
- Purpose and added value to target audience
- legitimacy of intent
- Trust
- what is the purpose of the data how it helps to the user community, privacy and results, trustworthiness.
Technology can amplify concerns about trust.

Observation #4

"[AI_Name], Can I Trust You?"

Data Privacy gets a lot of lip service these days. We have Apple declaring that they bake privacy into every product, Google deciding to delete millions of Google+ accounts (there were millions?) because of a coding error that potentially exposed private data, and even Zuckerberg’s latest op-ed for the entire internet, which we dissected piece by piece in our previous discussions.

Managing technology requires competence & ethics

Source: https://www.edelman.com/trustbarometer
Creating Safe Contexts for Data Sharing, Use & Outcomes

Privacy-Preserving Data Sharing Frameworks
People, Projects, Data and Output

Will the results lead to disclosure?
Is there a disclosure risk in the data itself?
Has appropriate and sufficient protection been applied to the data?

Is this use of the data appropriate?
Is the user authorised to access and use the data?

KPMG 2018 report, *Guardians of trust*, identified trust in data & analytics is founded on four key anchors:

**Quality.** Are D & A models good enough?

**Effectiveness.** Do the analytics deliver the desired results?

**Integrity.** Is use of D&A ethical - and legal?

**Resilience.** How well are governance, security and accuracy of data managed for the long term?

“Raw data is both an oxymoron and a bad idea; to the contrary, data should be cooked with care”

Bowker, 2005

Humanising Data Science

Embedding Data Humanism in the Training of Data Scientists

From UTS MDSI Graduate Attributes (2014-2018)

Making the invisible visible:
- recognize, uncover & address the missing, underrepresented, or misrepresented

Embracing ethical responsibilities:
- Interrogate and justify ethical responsibilities to create a framework for practice

Leading data science:
- Take a leadership role in promoting positive change in data science contexts
Why trust matters in crisis

Trust underpins social order

“...trust underpins or makes possible social action and makes possible expectations of consistent future social action rendering a social order possible and meaningful” (Neyland, 2006 p161).

We understand and enact ‘trust’ through breaches, expectations and repairs of (social) world/order
Trust & social contracts

“In crises, the state plays an essential and expanded role, protecting people and organizing the response. This power shift transforms long-held expectations about the roles of individuals and institutions.”

McKinsey COVID-19: Briefing note, April 13, 2020

Governments need to be “transparent about the data they collect, and clearly demonstrate the resulting value of the resulting products”


Do governments and leaders have a moral/social obligation to reassure the public about their management of data & analytics using controls, processes and standards and to provide greater transparency about the way data is used?
On the responsible use of digital data to tackle the COVID-19 pandemic

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.

Marcello Ienca and Effy Vayena

On 30 January 2020, the World Health Organization (WHO) director-general declared the coronavirus disease 2019 (COVID-19) outbreak a public-health emergency of international concern (PHEIC). Six weeks later, the outbreak was categorized as a pandemic. COVID-19 has already caused 24 times more cases (as of 18 March 2020) than the previous coronavirus-induced PHEIC—the 2002–2003 severe acute respiratory syndrome (SARS) outbreak—and the COVID-19 numbers are expected to grow. Compared with the 2002–2003 outbreak, however, the COVID-19 emergency is occurring in a much more digitized and accelerated context.

This risk of mistrust is even greater in countries in which citizens place a much lower level of trust in their government, such as Italy, France and the USA. Therefore, whenever access to these data sources is required and is deemed proportional, the public should be adequately informed. Secrecy about data access and use should be avoided. Transparent public communication about data processing for the common good should be pursued. Data-processing agreements, for example, should disclose which data are transmitted to third parties and for which purpose.
Trust deficit fallout?

Disinformation and the Disenfranchised

- Conspiracy theories
- Filter bubbles & echo chambers
- Information poverty


PROTESTERS OUTSIDE PARLIAMENT HOUSE IN MELBOURNE
(IMAGE: AAP/SCOTT BARBOUR)
How might we ‘turn data around’

design systems taking into account the well-being of people from whom the data is taken in the first place

create ‘real, functioning data publics’ (Thorp, 2016) by bringing data into public, shared spaces
Possible way forward for Public Engagement

Pursuing “interactive accounting” of values of data sharing and privacy to determine

1. **where** to draw the line (“category judgements” for privacy limits, acceptable data use, etc.)
2. **how** to establish “accountability relations”

Identifying vulnerable populations underrepresented or overrepresented in (e.g.: vulnerability & uncertainty scale)

Making decision-makers aware of the value of building public trust through ongoing citizen engagement **and** building education into campaigns
Public trust is not lightly given -- it is earned over time and is an ongoing process of engagement with the community that involves:

**Appreciating** the landscape of knowledge production in all its entangled human-machine complexity is vital first step for designing ethical evidence based decision-making frameworks

**Shaping** multi-perspective foundations for ethical expertise and data practice must be intertwined and **demonstrated**

**Making** space for public reflection of the lessons learnt from past practices (successful AND not).

**Working** from inside-out AND the outside-in to keep building and refreshing our practices and creating better education ‘data publics’
Finish this sentence: trust building for effective data sharing pathways in and after COVID-19 crisis involves...
### What is your greatest data concern as the global community responds to the COVID19 pandemic?

<table>
<thead>
<tr>
<th>Concern</th>
<th>Details</th>
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<tbody>
<tr>
<td>Reliability, Trust and Safety assurance</td>
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<tr>
<td>Too much focus on covid19 specific practices, lack of long term</td>
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<td>guidance on data reuse, and integration with existing working</td>
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<td>principles.</td>
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<td>Role of College Library in sharing information through online</td>
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<td>data falsification or obfuscation under political / bureaucratic</td>
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<td>direction</td>
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<td>Misinterpretation of data</td>
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<tr>
<td>data literacy, data quality, metadata</td>
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<tr>
<td>Not real data provided by some questionnaire and this can be seen.</td>
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<tr>
<td>Large amount of data available worldwide during covid 19 its</td>
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<td>important to provide exact and relevant information to users is one of</td>
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<td>the biggest challenge. Other than that privacy of users' data is also</td>
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<td>challenge.</td>
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*To view all the responses to this question please view the report*
Appreciate complexity one connection at a time

Making the invisible visible takes time. Through collective creation we make the best possible world for us and our communities. We must resist the temptation to not pause and make more deliberate time for thinking before acting.

develop new ways of living in a world without foundations

(Eisenberg, 2001)

Thank you

https://www.youtube.com/watch?v=q37GTvnsGwC&t=2s

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Image by Theresa Anderson, 2009