

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

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<http://playnpause.org/>

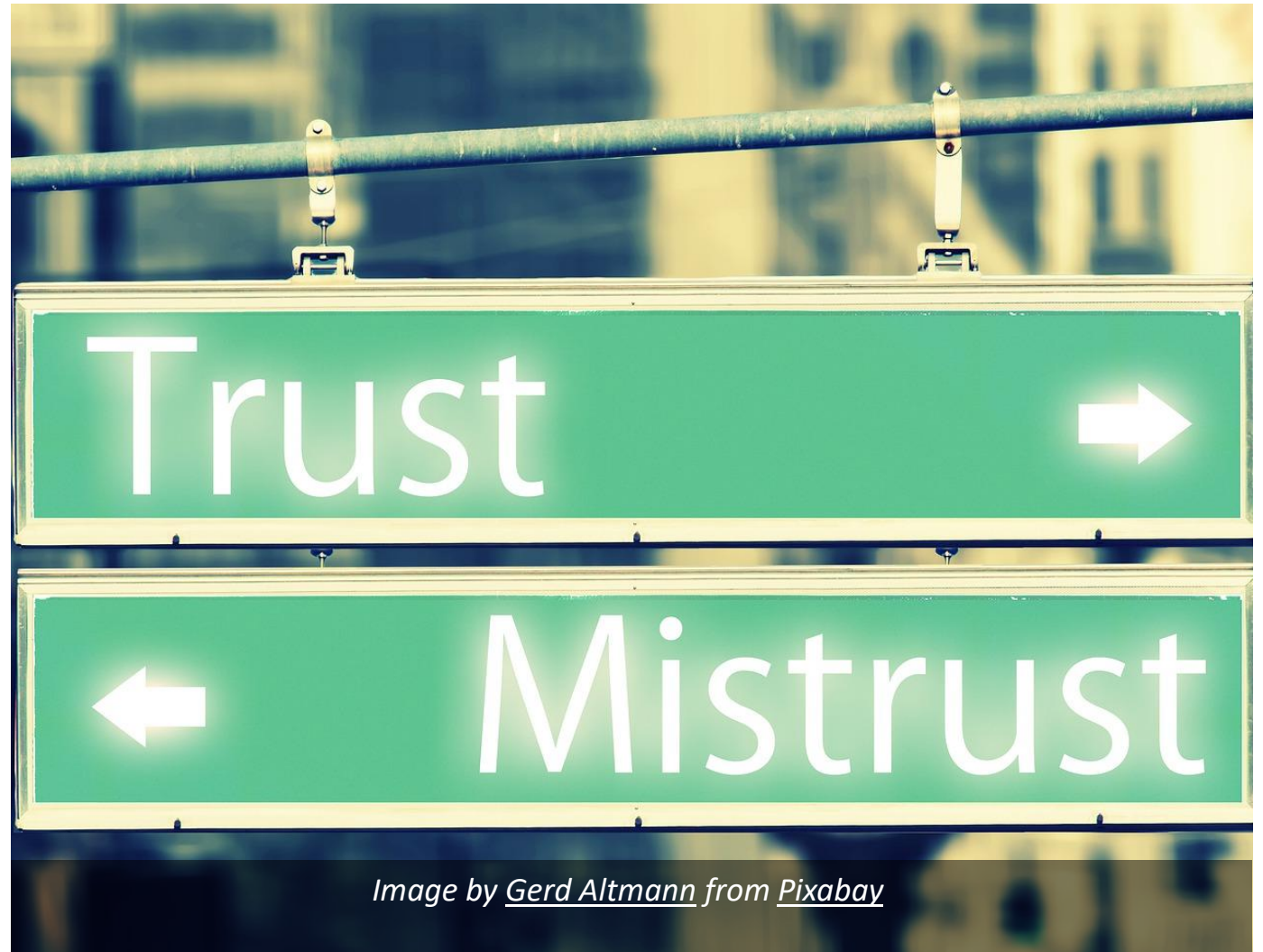


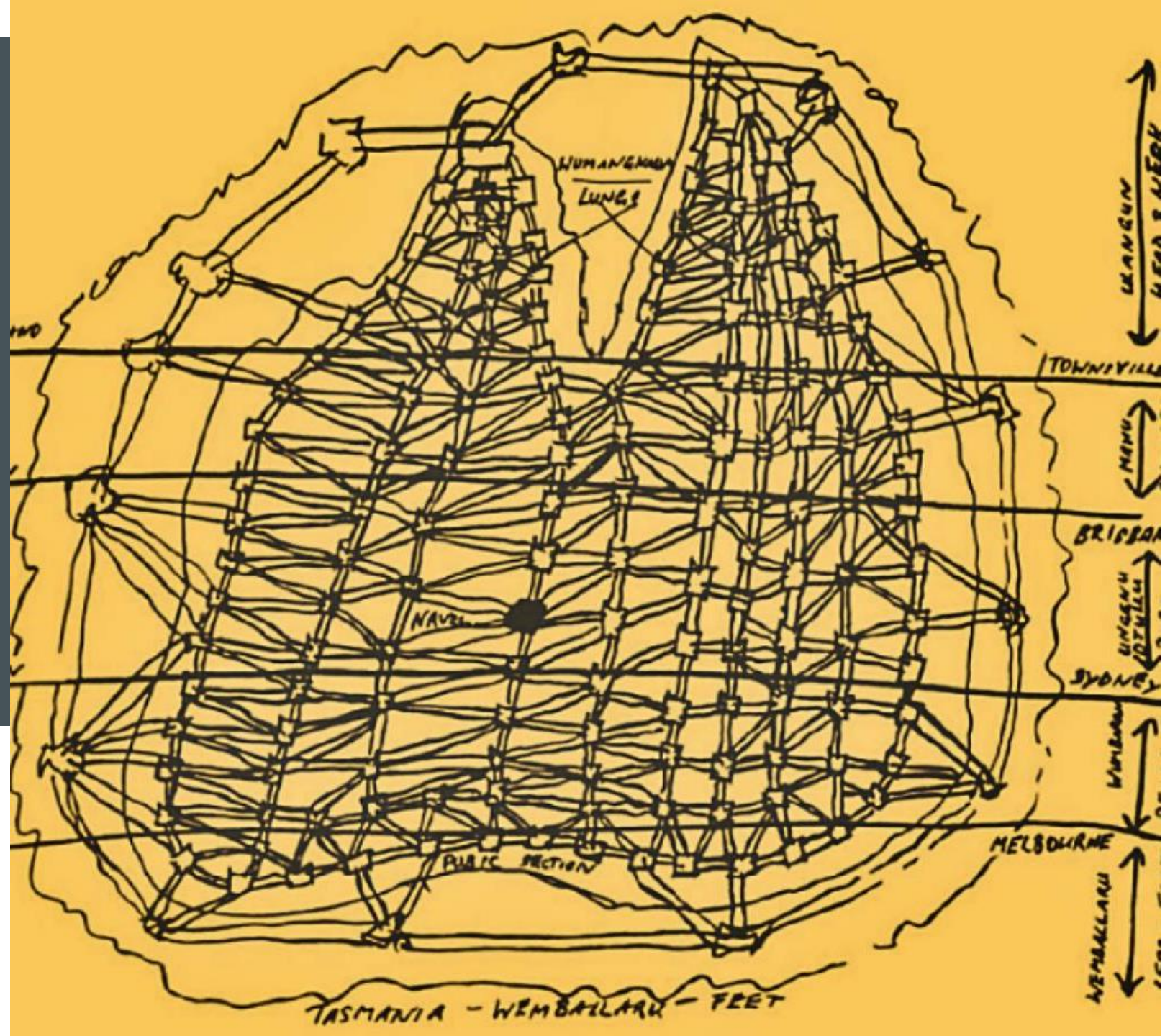
Image by [Gerd Altmann](#) from [Pixabay](#)

## 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 Mowaljariai (1992)***

*Dreaming song lines across Australia's  
lands and seas*





*Soft toys placed to entertain children during coronavirus lockdowns.  
Photograph: James D Morgan/Getty Images*

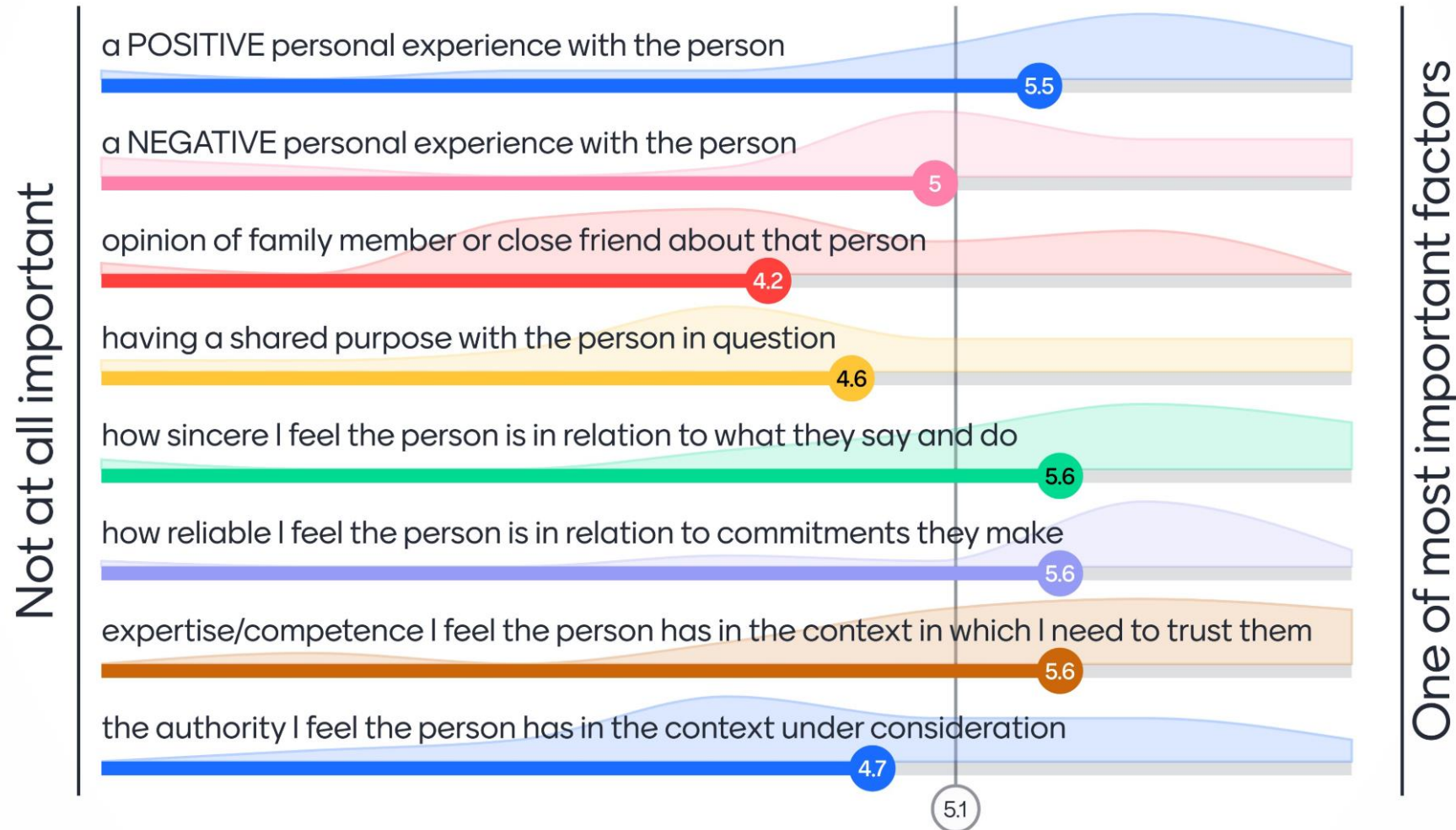
“it’s a matter of trust”

“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.”

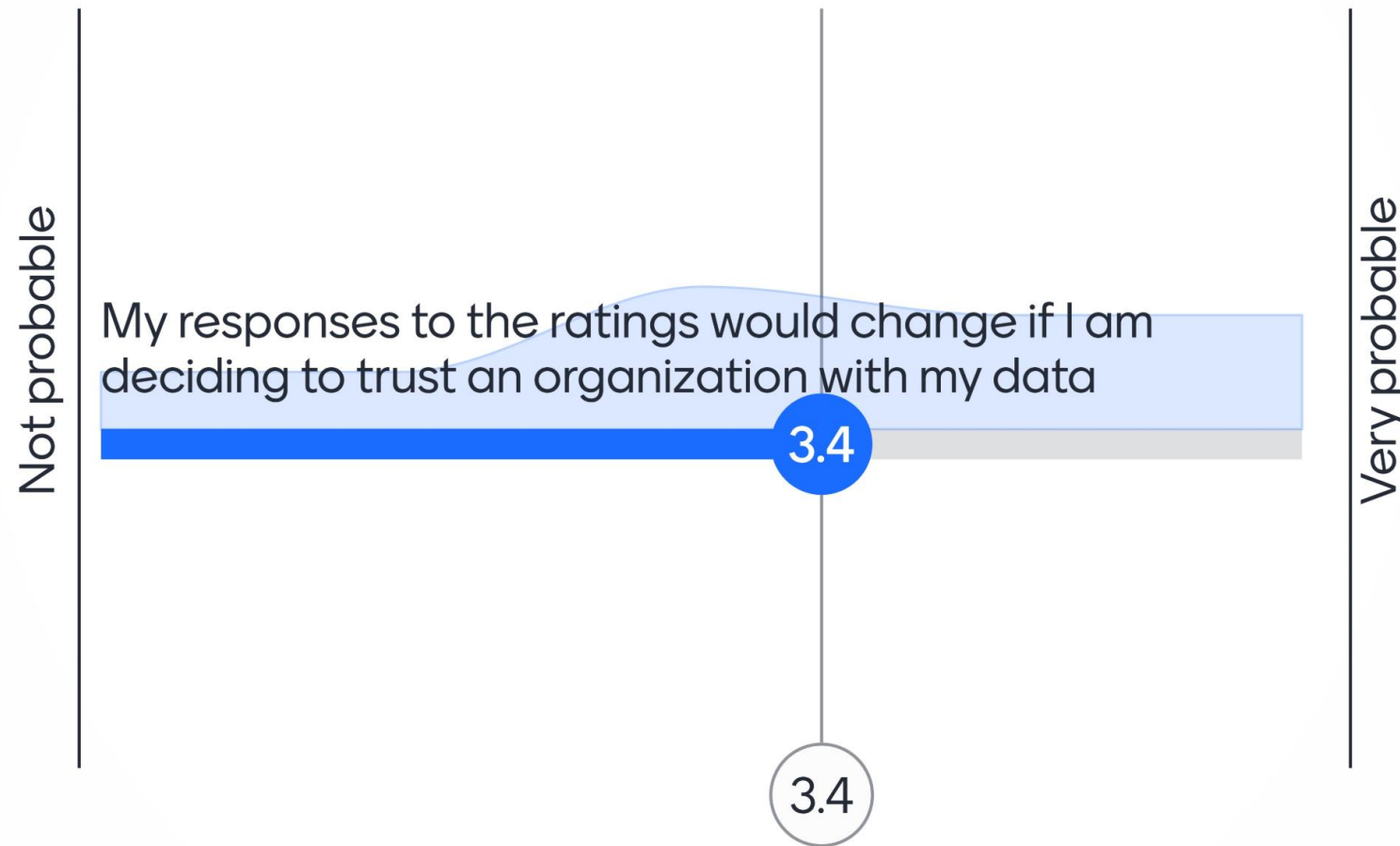
Edelman CEO Richard Edelman,  
*Edelman Trust Barometer*

**Share your views....**

Rate each of following criteria in terms of how important they are to you when deciding whether or not someone is trustworthy



# Do you agree or disagree with this statment?



# 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”

<https://www.adalovelaceinstitute.org/our-work/covid-19/covid-19-exit-through-the-app-store/>

## Rapid policy briefing

NUFFIELD  
COUNCIL ON  
BIOETHICS



Ethical considerations in responding to the COVID-19 pandemic

17 March 2020

The Government has indicated a number of further public health measures may be needed in order to manage the COVID-19 pandemic in the UK. The current situation (as of 17 March 2020) is summarised in the annex, including an overview of the Government's action plan of 'contain, delay, research and mitigate'.

The following review of ethical considerations draws on the findings of a number of in-depth inquiries conducted by the Nuffield Council on Bioethics, including those concerned with public health,<sup>1</sup> solidarity,<sup>2</sup> and research in global health emergencies.<sup>3</sup> For further commentary on the ethical considerations associated with research into COVID-19, see the Nuffield Council blog *The ethical imperative of preparedness*.<sup>4</sup>

## Summary

Public health measures need to take into account the following ethical principles:

- Interventions should be evidence-based and proportionate. The aim(s) of the interventions being implemented, and the science, values and judgments underpinning those interventions, should be clearly communicated to the public.
- Coercion and intrusion into people's lives should be the minimum possible consistent with achieving the aim sought.
- People should be treated as moral equals, worthy of respect. While individuals may be asked to make sacrifices for the public good, the respect due to individuals should never

# 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](#)

“recognize-explain-act”



Photo : Ignaz Semmelweis krepelt die Ärmel hoch ,  
By Immanuel Giel, CC BY 3.0, <https://commons.wikimedia.org/w/index.php?curid=55033889>

# Building Trust in four quadrants



## **Reassurance:**

communication, professionalism



## **Resilience:**

persistence, creativity



## **Relationships:**

Building & maintaining connections

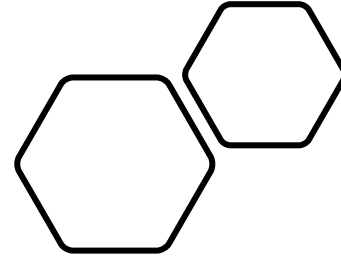


## **Reflection:**

time to think & test

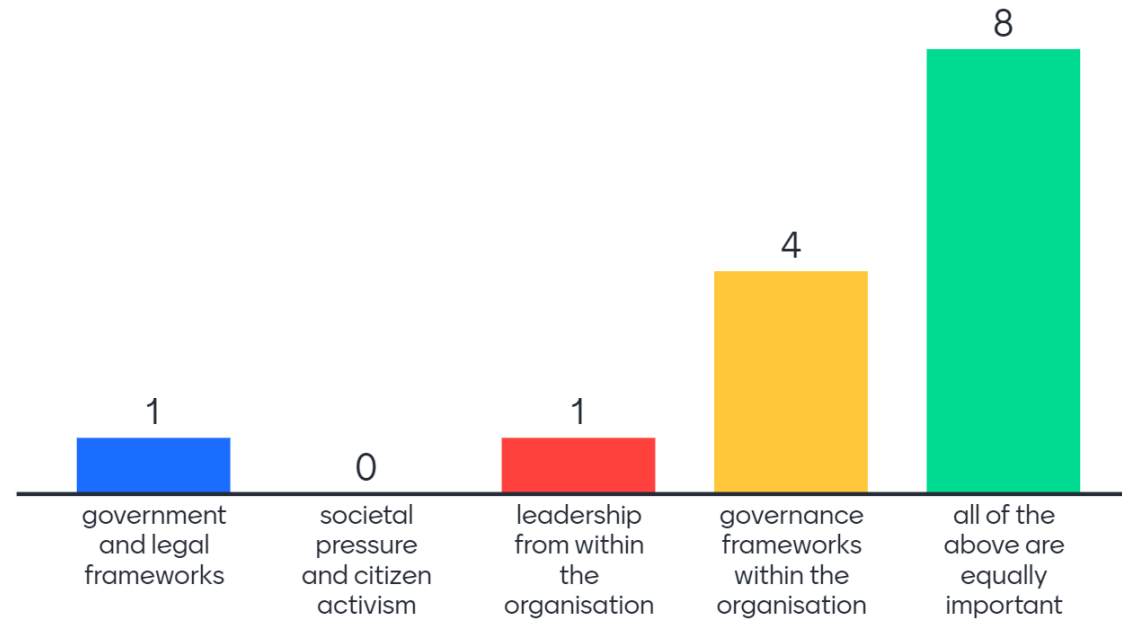
## Observation #1

Trust building  
is...



Personal  
Local  
Political

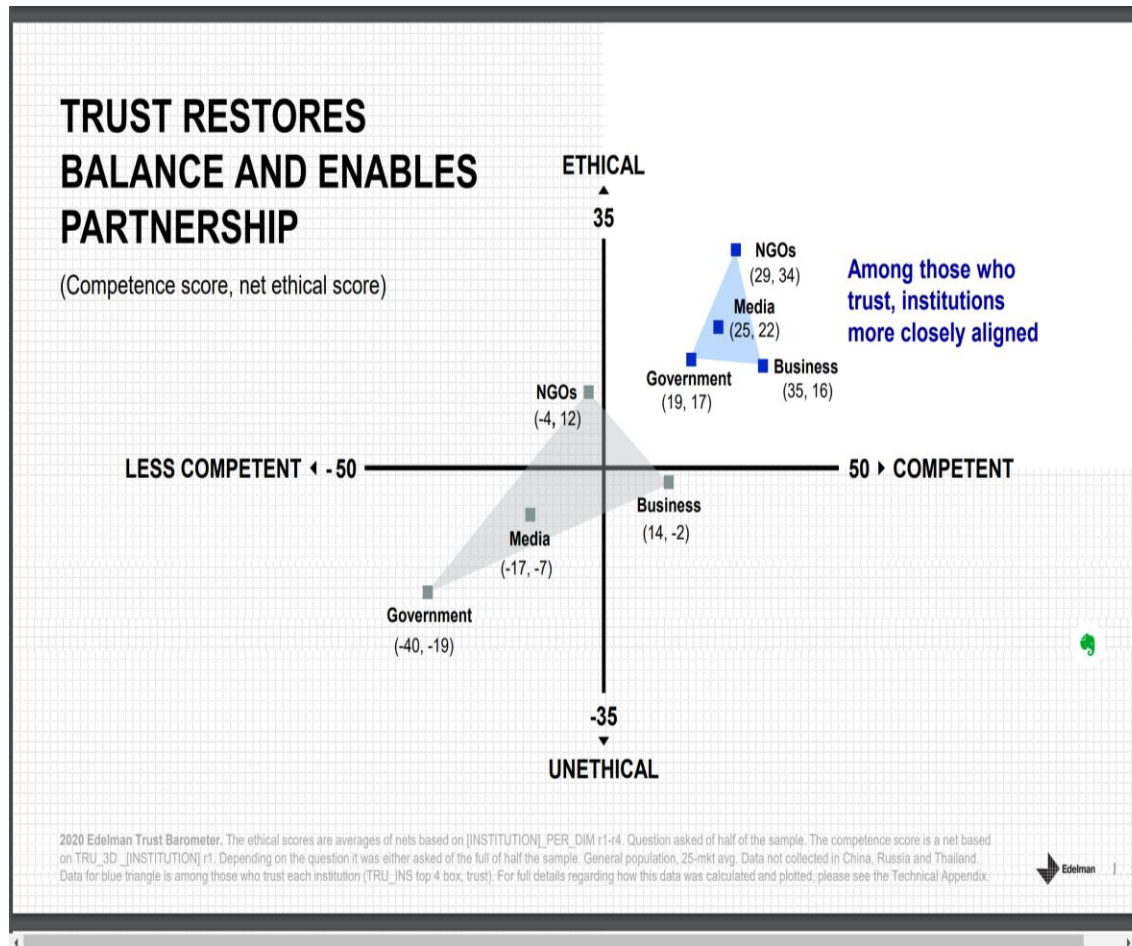
# The key to creating a trustworthy organisation is ...



# How would you rate these statements?



# 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>)



***“thriving in uncertainties”***

*Anderson, 2006*

(See <http://informationr.net/ir/15-4/colis721.html>)

## Observation #2

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

# 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

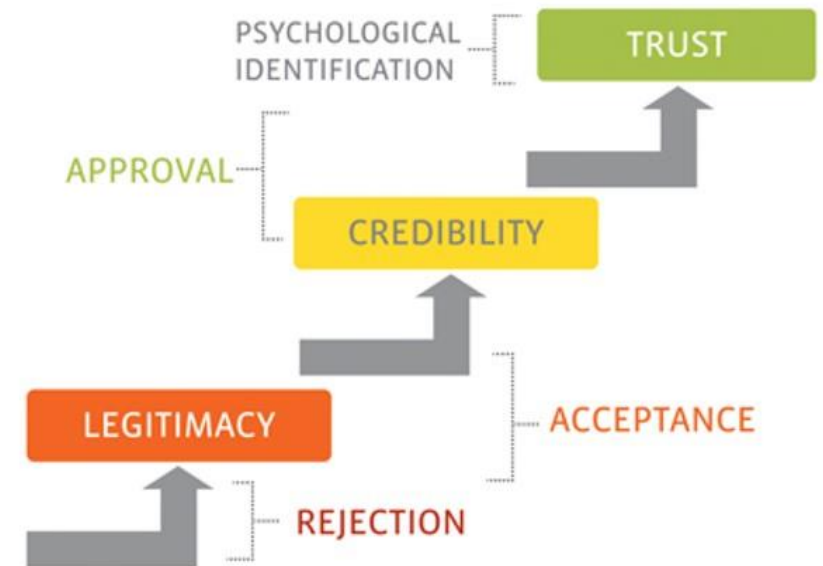


For more information  
**[StopTheSpread.sa.gov.au](https://stopthespread.sa.gov.au)**



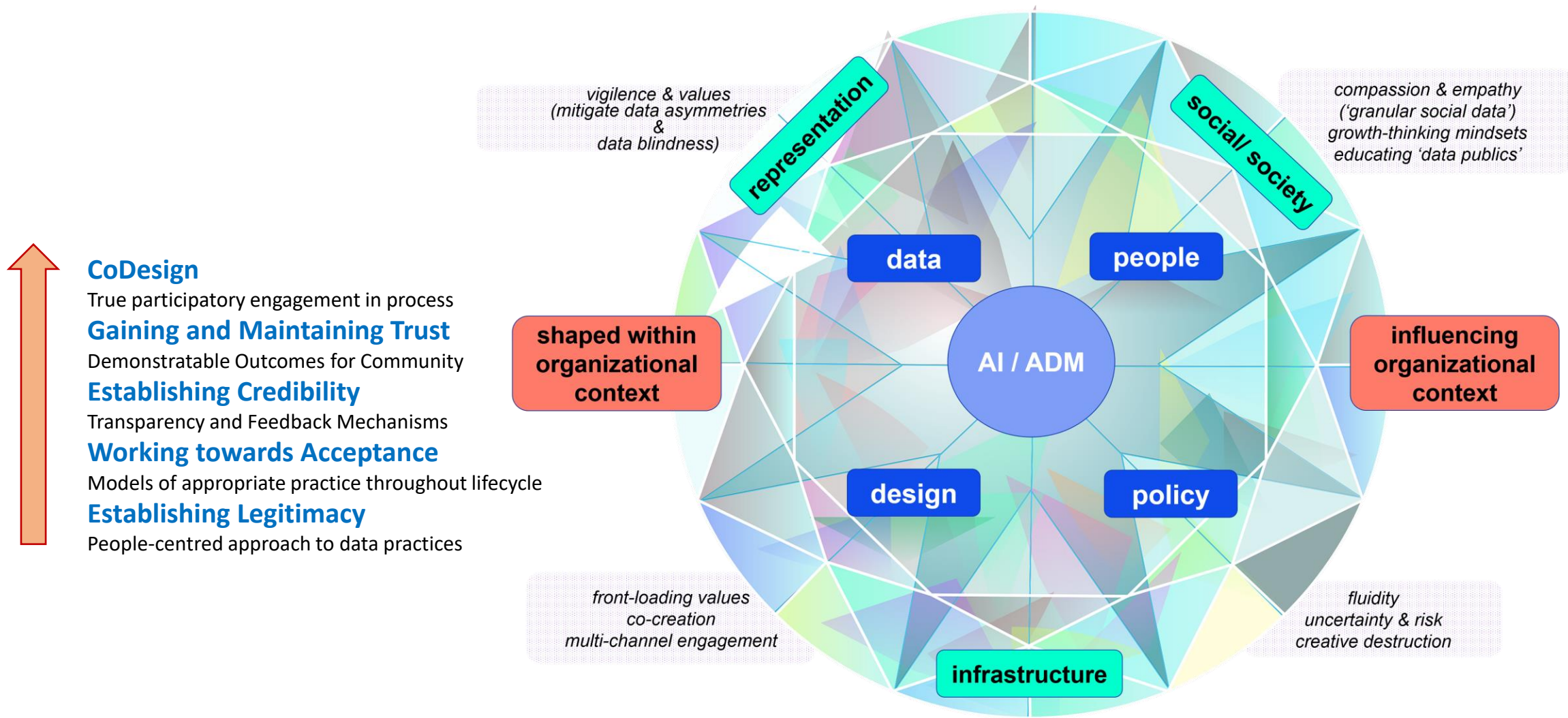
Government of South Australia  
SA Health

## Gaining the Social License



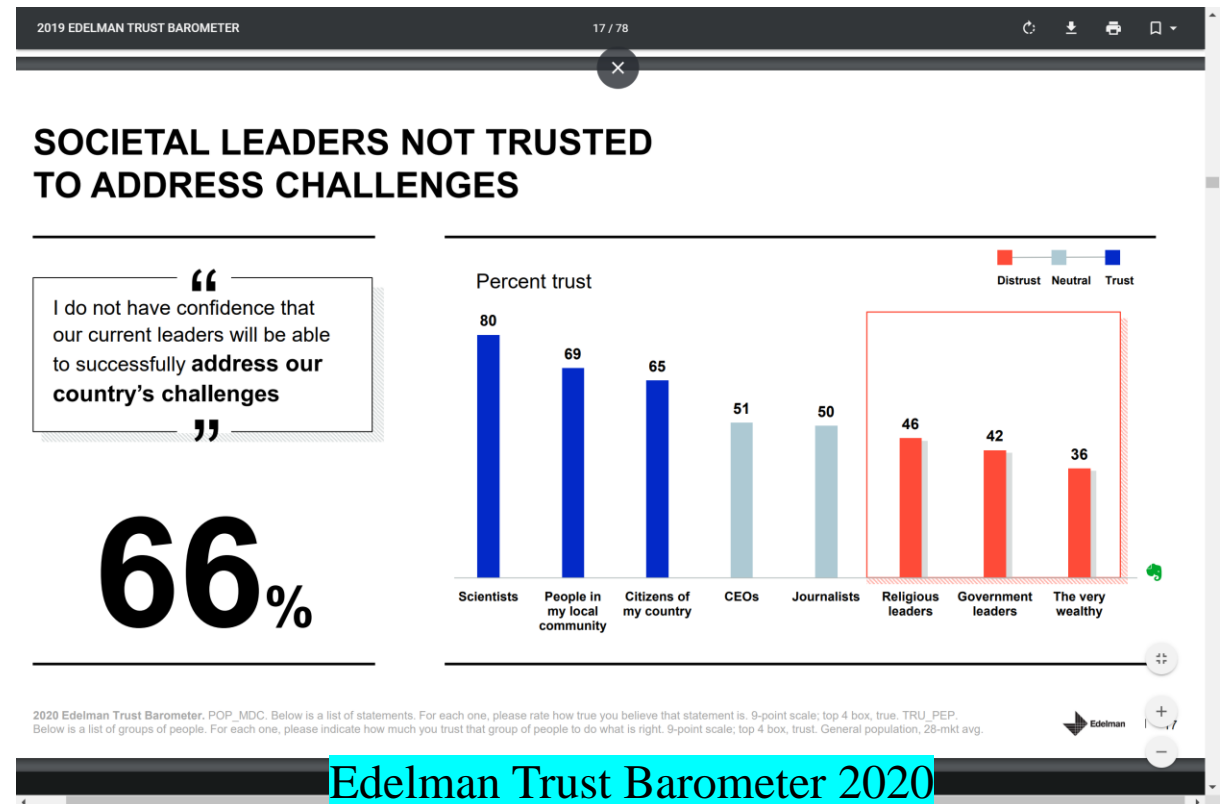
© On Common Ground Consultants Inc 2003

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



# Trust is not a universal or stable concept


## It's interpretation varies across locations and contexts of use




# 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.”*


  
Opinion

  
South China Morning Post


Andrew Sheng

## The world is running a trust deficit. Can governments regain trust in the time of coronavirus?

- Inequality and fake news are undermining trust worldwide. Notably, however, Chinese trust Beijing more than Americans trust Washington
- Out of the coronavirus crisis will come the winners – the institutions able to inspire trust



Andrew Sheng  
Published: 8:00pm, 28 Feb, 2020

 Why you can trust SCMP

<https://www.scmp.com/comment/opinion/article/3052828/world-running-trust-deficit-can-governments-regain-trust-time>



## Three reasons why Jacinda Ardern's coronavirus response has been a masterclass in crisis leadership

April 6, 2020 6.05am AEST

Jacinda Ardern/Facebook

Email

Twitter 877

Facebook 171.5k

LinkedIn

Print

Imagine, if you can, what it's like to make decisions on which the lives of tens of thousands of other people depend. If you get things wrong, or delay deciding, they die.

Your decisions affect the livelihoods of hundreds of thousands of people, resulting in huge economic disruption, mass layoffs and business closures. Imagine you must act quickly, without having complete certainty your decisions will achieve what you hope.

Author



**Suze Wilson**  
Senior Lecturer, Executive Development, Massey University

Disclosure statement

Suze Wilson does not work for, consult, own shares in or receive funding from any company or organisation that would benefit from this article, and has disclosed no relevant

## Characteristics of a trusted public figure?

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

- direction-giving
- meaning-making
- empathy



### Observation #3

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)

# Trust & Data Governance

Insight from  
Indigenous Data Sovereignty &  
Indigenous Data Governance



[Global Indigenous Data Alliance \(GIDA\) #BeFAIRandCARE](https://www.gida-global.org/care)  
<https://www.gida-global.org/care>

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

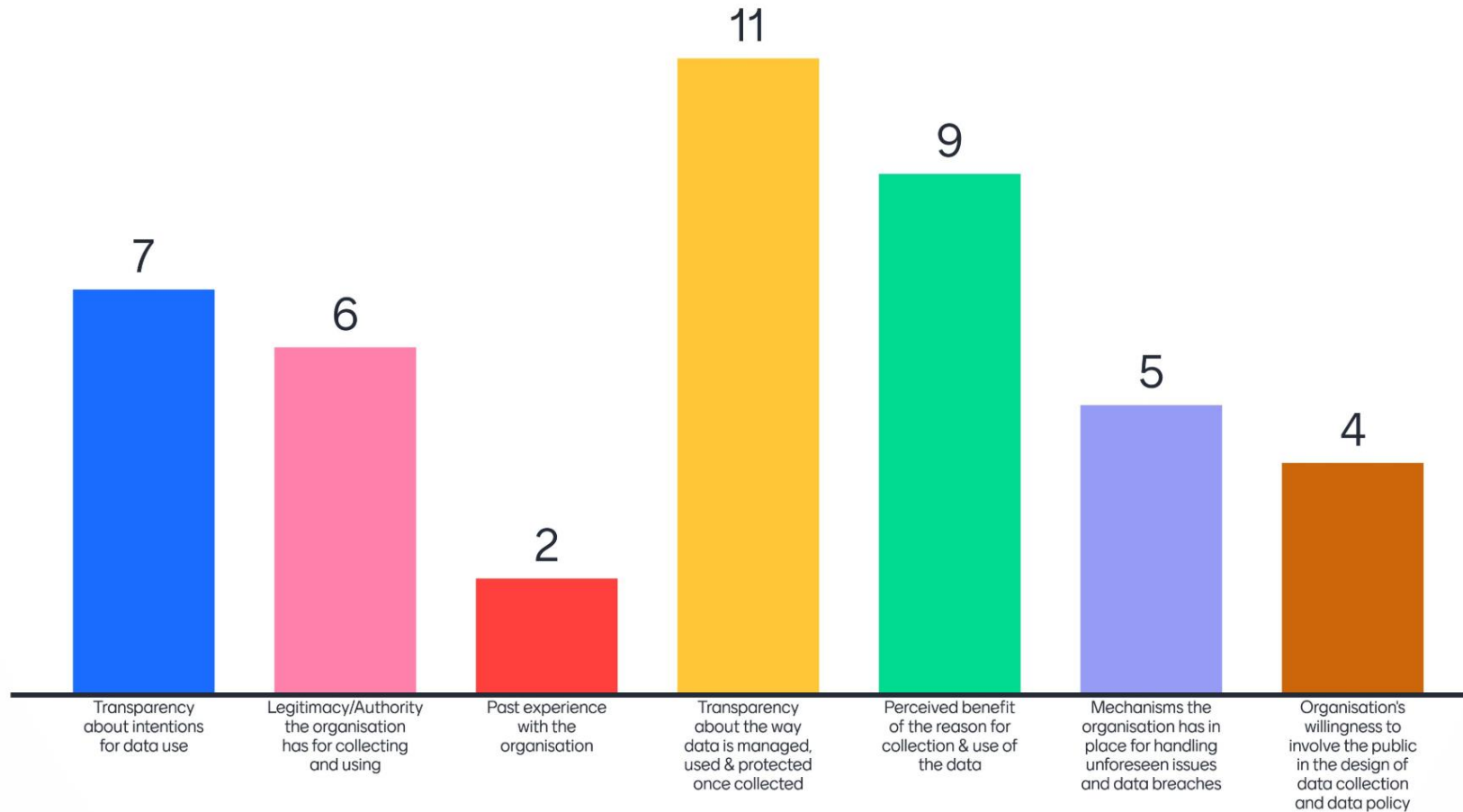
*Data for governance raises the question: what data do nations need to govern effectively?*

*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)

<https://datascience.codata.org/articles/10.5334/dsj-2019-031/>

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



# What is your most important consideration when deciding to share your personal data?

Credits

privacy

Purpose and added value to target audience

Privacy and confidentiality

motive of data usage

legitimacy of intent

Value to social science or public good

Trust Reliability and Transparency

Trust

Data Privacy, Privacy of Individuals

Reliability

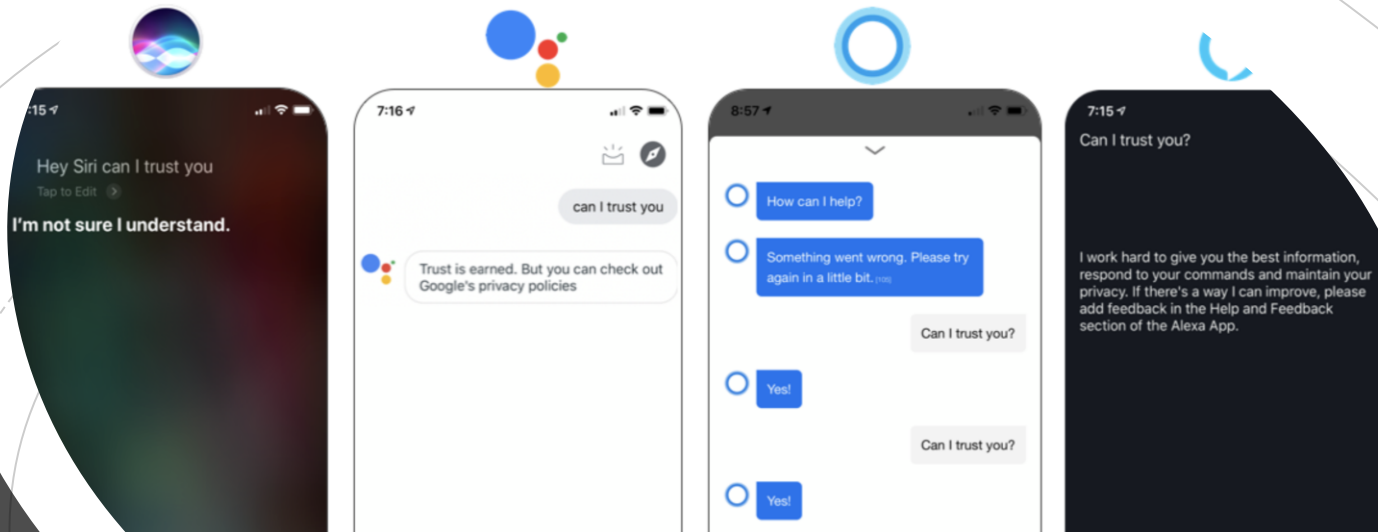
what is the purpose of the data how it helps to the user community, privacy and results, trustworthiness .



## Observation #4

"[AI\_Name], Can I Trust You?"

Technology  
can amplify  
concerns  
about trust

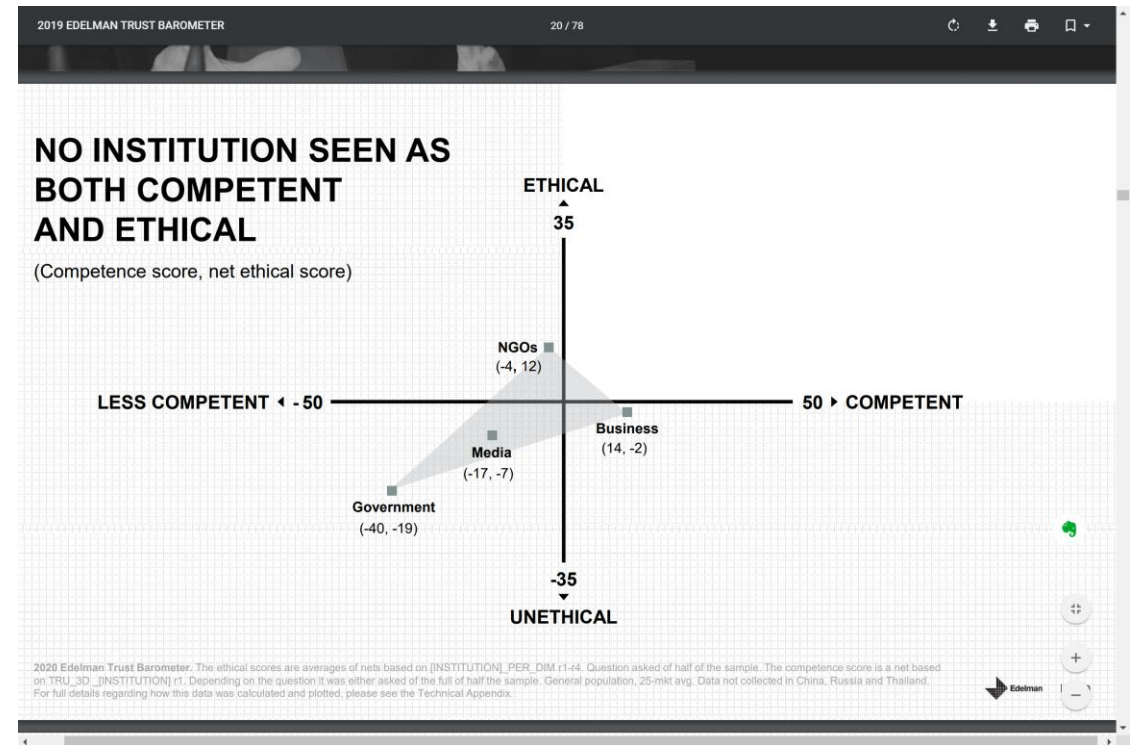
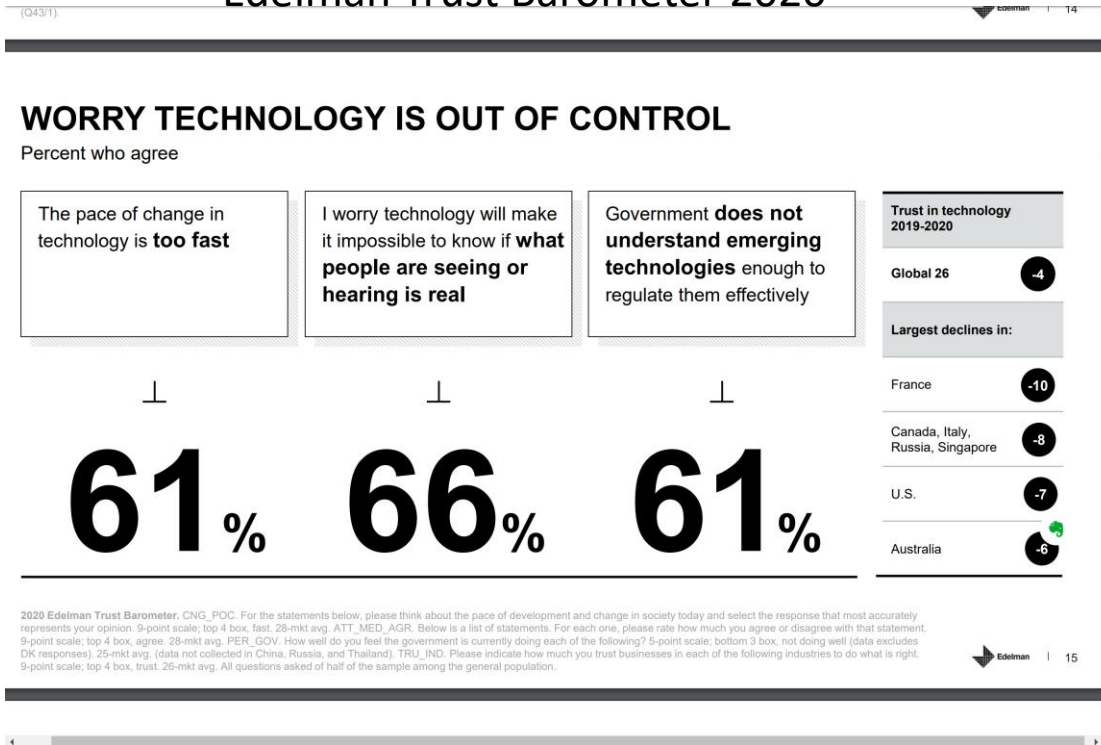


Data Privacy gets a lot of lip service these days. We have Apple declaring that they bake privacy into every product, Google deciding to delete millions of Google+ accounts (there were millions?) because of a coding error that potentially exposed private data, and even Zuckerberg's latest op-ed about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

Image: <https://towardsdatascience.com/hardcoding-trust-one-year-of-sad-privacy-responses-from-your-favorite-ai-e8dd6bb0cd21>

# Managing technology requires competence & ethics

## Edelman Trust Barometer 2020



Source: <https://www.edelman.com/trustbarometer>

# Creating Safe Contexts for Data Sharing, Use & Outcomes

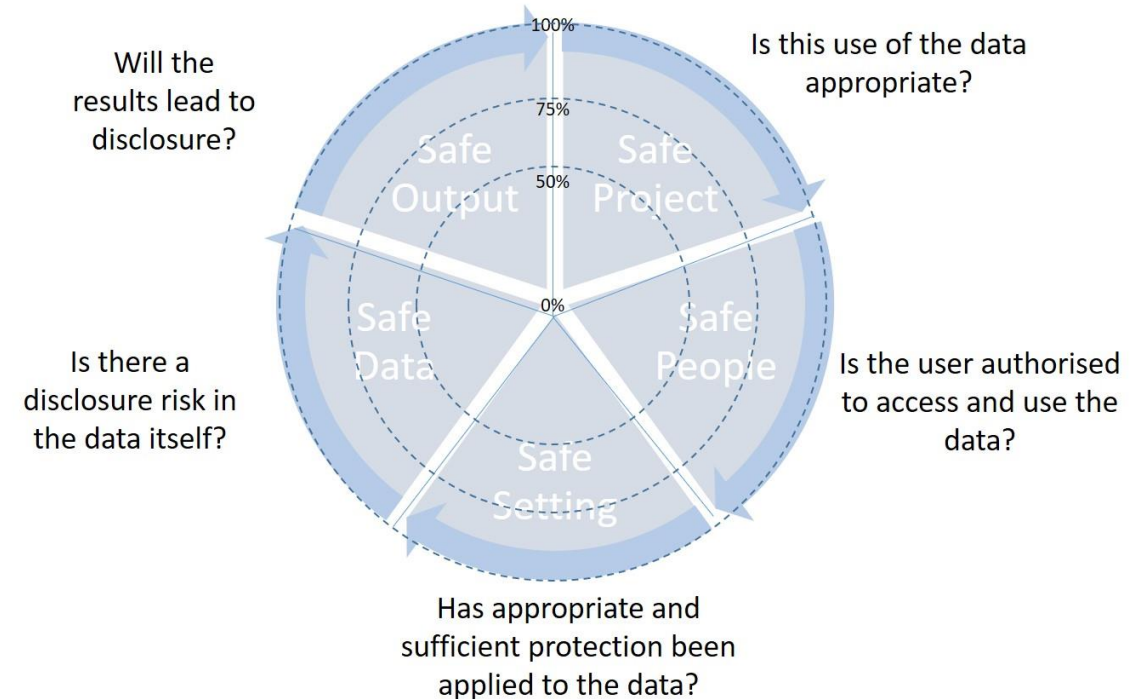


December 2019



## Privacy-Preserving Data Sharing Frameworks

People, Projects, Data  
and Output



<https://www.infogovanz.com/wp-content/uploads/2020/01/191202-ACS-Privacy-eReport.pdf>



# Trust Anchors in Data & Analytics

KPMG 2018  
report, [Guardians  
of trust](#),  
identified trust in  
data & analytics  
is founded on  
four key anchors:

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

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

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

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

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see example:

<https://home.kpmg/xx/en/home/insights/2018/06/building-trust-in-governments-use-of-data.html>

# Humanising Data Science

Embedding  
Data Humanism  
in the  
Training of Data Scientists

*From UTS MDSI Graduate Attributes  
(2014-2018)*

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

*Bowker, 2005*

## **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



Observation #4

# 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**

<https://www.aspistrategist.org.au/solving-global-problems-will-require-a-new-social-contract/>

## Solving global problems will require a new social contract

20 Feb 2020 | Minouche Shafik

SHARE



# 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”

OECD Report *Embracing Innovation in Government* (2017)

**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

raised privacy and data-protection concerns. In 2014, privacy concerns urged the GSM Association (an industry organization that represents the interests of mobile operators worldwide) to issue on the protection of privacy in mobile-phone data for response to Ebola outbreak<sup>6</sup>.

In the data-intensive world of ubiquitous data points and digital surveillance tools can easily exacerbate those concerns. China, the country most affected by COVID-19, is reportedly using ubiquitous sensor data and check apps to curb the disease<sup>7</sup>. According to a *New York Times* article,

and safeguards the rights and freedoms of the data subject.

As big data will be critical for managing

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.

Ienca, M., Vayena, E. On the responsible use of digital data to tackle the COVID-19 pandemic. *Nat Med* 26, 463–464 (2020). <https://doi.org/10.1038/s41591-020-0832-5>

Not everything  
you hear about  
**COVID-19** is true



# 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)

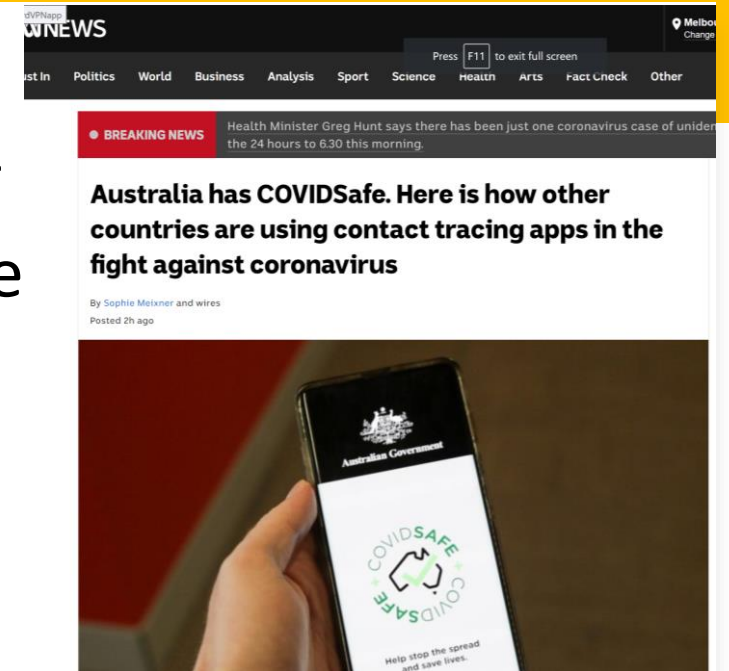
<https://www.who.int/news-room/feature-stories/detail/countering-misinformation-about-covid-19>

<https://www.crikey.com.au/2020/05/11/virus-watch-protests-conspiracy-theories/>

# 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



# Closing considerations: Sharing a foundational framing and experiential observations



Public trust is not lightly given -- it is earned over time and is an going process of engagement with the community that involves:

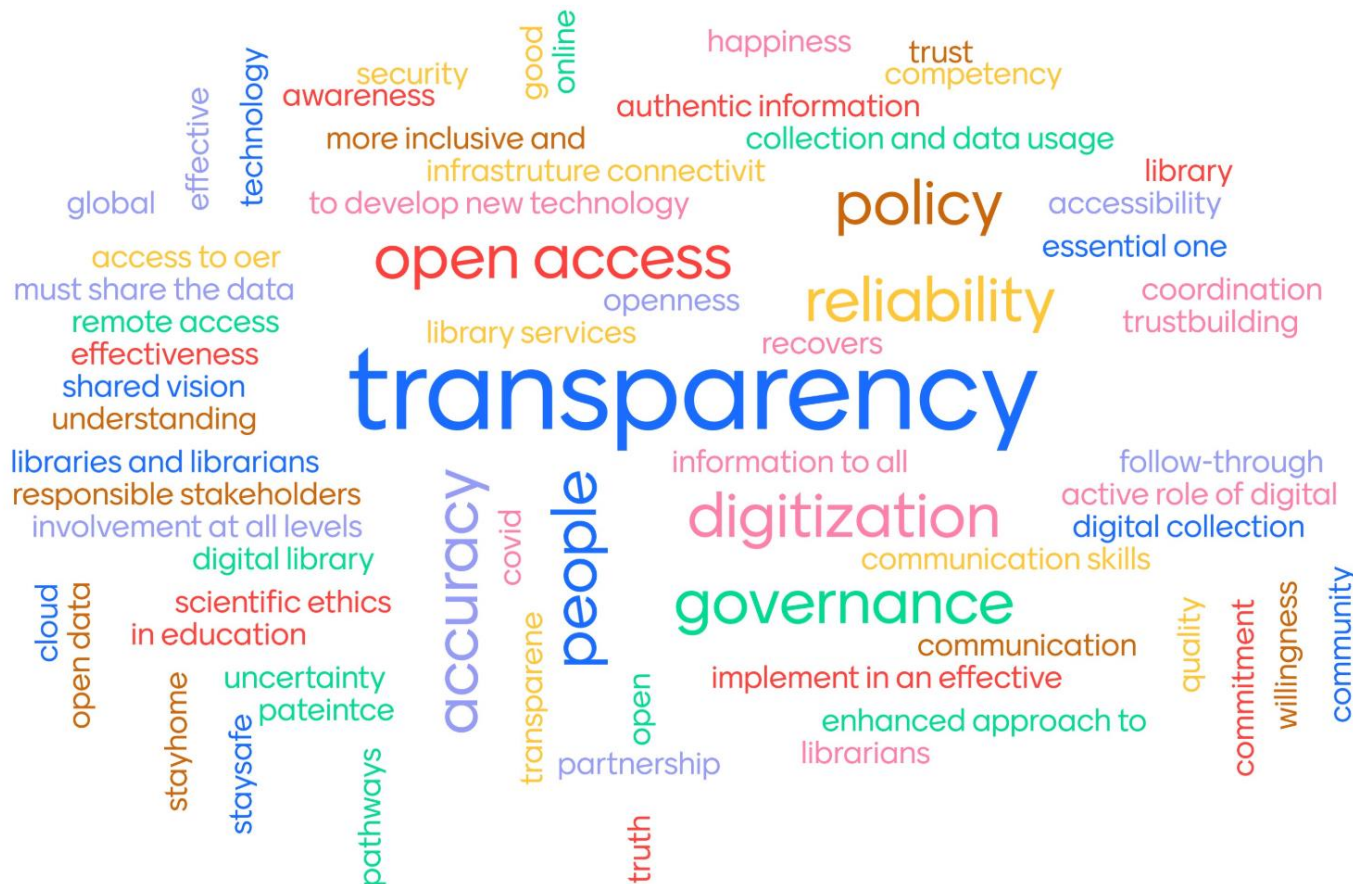
**Appreciating** the landscape of knowledge production in all its entangled human-machine complexity is vital first step for designing ethical evidence based decision-making frameworks

**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: trustbuilding 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?

Reliability, Trust and Safety assurance

data falsification or obfuscation under political / bureaucratic direction

destruction of existing collaboration structures

Too much focus on covid19 specific practices, lack of long term guidance on data reuse, and integration with existing working principles.

Misinterpretation of data

Large amount of data available worldwide during covid 19 its important to provide exact and relevant information to users is one of the biggest challenge. Other than that privacy of users' data is also challenge.

data literacy, data quality, metadata

Role of College Library in sharing information through online

Not real data provided by some countries and this could be more



*To view all the responses to this question please view the report*

\_\_\_\_\_

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\_\_\_\_\_

*develop new ways of living in a world without foundations*  
(Eisenberg, 2001)

*Thank you*

Check out: <https://utscic.edu.au/replay-humans-data-ai-ethics/>  
<https://www.youtube.com/watch?v=q37GTvnsgWc&t=2s>



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[linkedin.com/in/theresadanderson](https://www.linkedin.com/in/theresadanderson)

<http://playnpause.org/>

*Image by Theresa Anderson, 2009*