

# Good Data: Sharing Data and Fostering Public Trust and Willingness

WHITE PAPER

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# Executive summary

The key to “good data” lies in how data is handled.

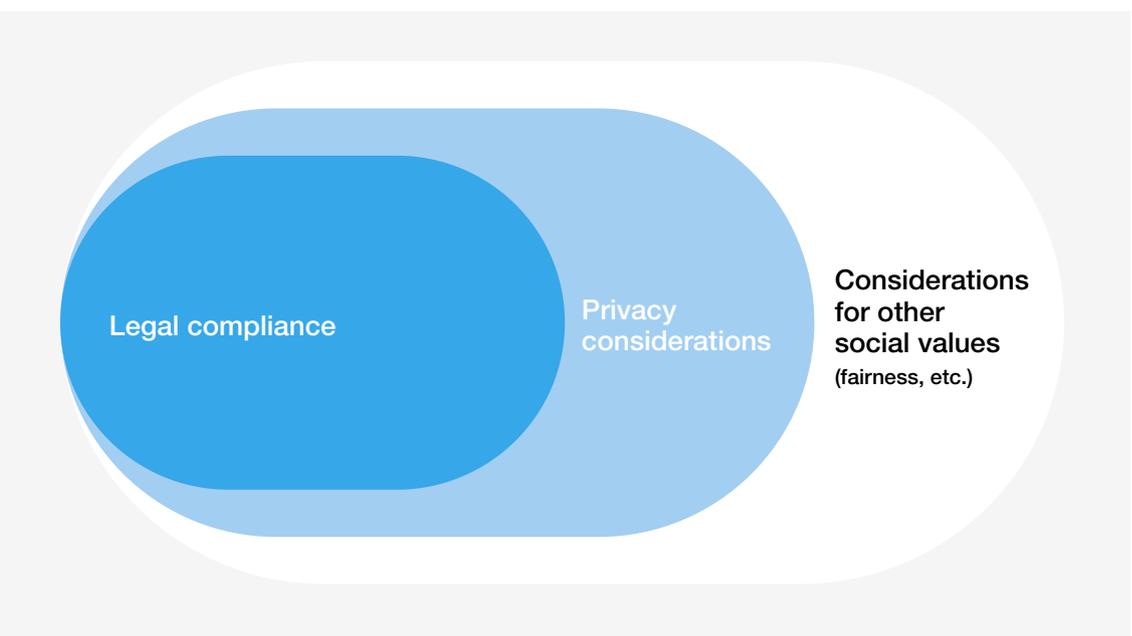
COVID-19 has revealed social disparities and delays in digitalization in many countries, highlighting the large gap that exists between the current reality and the optimal Fourth Industrial Revolution society that is seamless and inclusive of the socially vulnerable. The World Economic Forum Annual Meeting 2021 and its theme, the “Great Reset”,<sup>1</sup> advocated building the foundations of economic and social systems for a future that is just, sustainable and resilient. What is needed instead of a choice between public health and the economy, for instance, is a new social contract that ensures sustainability while protecting human life, dignity and social justice.

Data can be a powerful tool in this effort. Data is not only a “primary” asset, with value to the organizations that collect and use it for specific

purposes, but also a “secondary” asset, in which additional worth is created through broader circulation. How to safely promote this secondary use of data is now a major topic of discussion around the world.

Various challenges related to the secondary use of data exist, however. Some involve data governance systems and how they address aspects of data handling, such as ethical, legal and social implications and responsible research and innovation. These issues show that the key to “good data” lies in how data is handled: with consideration for privacy, fairness, social justice and ethics, not to mention legal compliance (Figure 1). By handling data properly, data users can gain the trust of the public, as individuals and as data subjects, and increase people’s willingness to provide data.

FIGURE 1 Scope of considerations needed in data utilization



Source: World Economic Forum

Global regulations on these issues have been introduced, such as the Organization for Economic Co-operation and Development (OECD) Privacy Guidelines,<sup>2</sup> the Asilomar Artificial Intelligence (AI) Principles,<sup>3</sup> the OECD’s Recommendation of the Council on Artificial Intelligence<sup>4</sup> and the European Commission’s Ethics Guidelines for Trustworthy Artificial Intelligence.<sup>5</sup> When considering how data is handled in real-world settings, however, these principles and guidelines may not function

sufficiently as they do not indicate specific interpretations and methods for practical application.

To gain trust in data utilization and strengthen people’s willingness to provide data, the data governance model known as “notice and consent”, in which each individual data subject is notified and asked for consent each time his or her data is collected, must be revisited.<sup>6</sup> In reality, few users read privacy policies carefully, a situation that is

“ One challenge raised in the pilot project in Japan has been how data users can gain public trust and secure the willingness of individuals to provide data on dementia.

likely to be exacerbated by the development of the internet of things (IoT).<sup>7</sup> In addition, it can be difficult to apply the notice and consent model to people whose cognitive functions have declined, such as certain seniors, because their ability to understand their situation and to reason – the prerequisite of notification and consent – may be compromised. Thus, a new scheme for data handling that can be trusted by all, including cognitively impaired people, may need to be developed.

In this context, this White Paper presents two frameworks as tools for accelerating innovation while building trust. It describes attitudes and processes that various data users can adopt to protect social values.<sup>8</sup>

- **The Trust and Willingness Framework – A framework for building public trust**
- **The Good Data Framework – An ethically sound framework for data handling**

These frameworks are an embodiment of the Trust and Governance Framework proposed in the World Economic Forum White Paper “Rebuilding Trust and Governance: Towards Data Free Flow with Trust (DFFT)”,<sup>9</sup> which focuses on cases in which data holders act as governance entities. Based on the four governance methods outlined in that document (social norms; markets; rules; and the “by-design” approach), this White Paper describes the importance of these means of governance, which has conventionally influenced business entities. It seeks to encourage the engagement and proactive efforts of business entities as data holders in the search for new ways to build trust through multistakeholder collaboration.

This White Paper is intended principally for:

- Stakeholders who aim to promote data utilization while gaining trust from the public, going beyond simple legal compliance
- Entities connected to the policy-making process regarding data utilization.

Chapter 1 summarizes the value of secondary data use and data sharing. Chapter 2 presents the Trust and Willingness Framework, a process for building public trust in the secondary use of data. It examines the importance of trust in data distribution in the era of the Fourth Industrial Revolution, mechanisms by which trust is lost and approaches to building trust. Chapter 3 describes the Good Data Framework and its checkpoints for ethical considerations in data utilization.

The frameworks presented in Chapters 2 and 3 are intertwined in terms of accountability. By implementing the initiatives for ethical considerations in data handling presented in Chapter 3 and sharing and communicating these initiatives with stakeholders using the framework outlined in Chapter 2, data holders can fulfil their duty of accountability, which will lead to trust building.

Chapter 4 illustrates the potential for solving issues pertaining to the notice and consent regime, which is the legal basis for data utilization in many countries, by data users using the framework presented in Chapters 2 and 3.

BOX 1

**A pilot project in Japan: Infrastructure development for value creation by circulating data on elderly people, including those with dementia**

In 2019, the Japanese government published a national strategy related to dementia called the “Framework for Promoting Dementia Care”.<sup>10</sup> Various policies are being carried out under the framework, based on the twin themes of preventing dementia and supporting the quality of life of people living with the condition. One of the strategy’s themes is data utilization, and an

industry–academia–government–public initiative for infrastructure development to circulate data on the elderly, including those with dementia, is under consideration. One challenge raised has been how data users can gain public trust and secure the willingness of individuals to provide data on dementia. That issue led to this White Paper.

The World Economic Forum invites discussion on data use and sharing and looks forward to exploring opportunities for future pilot projects with those who show interest in this White Paper. The hope is that

this paper will contribute to building the foundation for accelerating innovation through data utilization while protecting social values.

1

# Secondary data use and data sharing

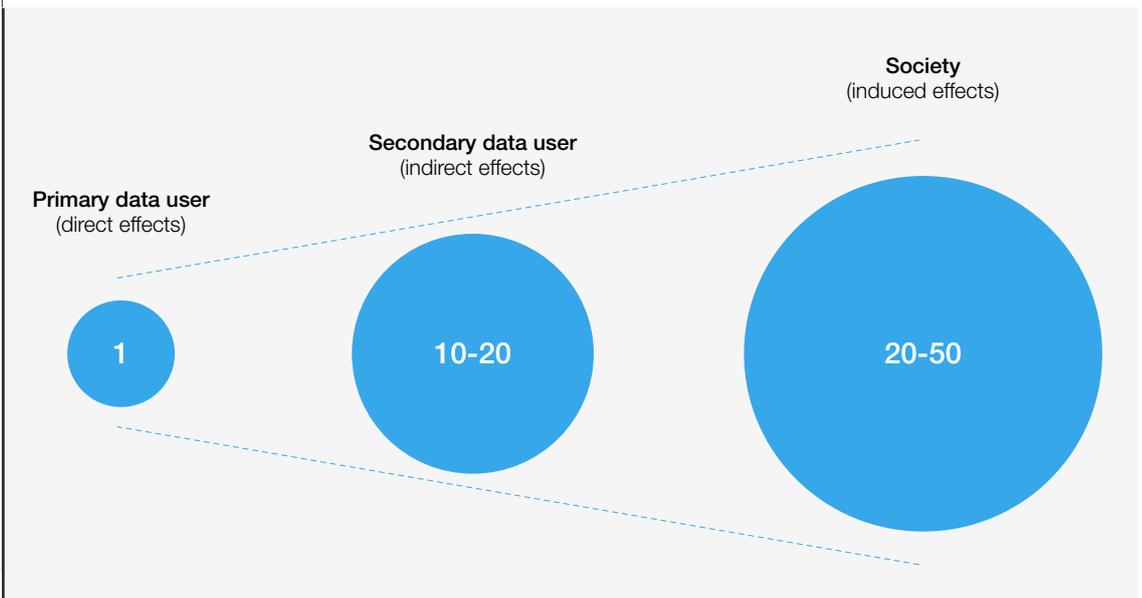
To accelerate healthcare innovation while protecting social values, the establishment of a practical corporate data ethics framework is needed.

## 1.1 The growing expectations for secondary data use

Data utilization is moving from the primary-use phase, in which each organization or group collects and uses data for a specific purpose, to the secondary-use phase, in which value is created by circulating data in society. According to the

OECD, data from data holders is 10-20 times more valuable when shared and used by other data users, and 20-50 times more valuable to the economy as a whole (Figure 2).<sup>11</sup>

FIGURE 2 The value of data



Source: World Economic Forum

## 1.2 Current initiatives to promote data sharing

In Finland, the Act on the Secondary Use of Health and Social Data<sup>12</sup> came into force in May 2019. This act makes it possible to use anonymized healthcare data for corporate research and development, as well as for innovation activities in addition to academic research and statistical purposes. The Finnish Government, in collaboration with the National Institute of Health and Welfare, established Findata, the Health and Social Data Permit

Authority, which is responsible for reviewing the secondary use of data and data provision services. This Finnish initiative is a leading example of implementing a mechanism to promote secondary data use together with a governance system, based on the organized and integrated national database.

In another example, in Japan, the provision of anonymized information on health insurance claims

and specific health check-up and prescription data, etc., for public interest purposes, including for use by private companies, began in October 2020.

Nevertheless, according to the OECD, although as many as 205 government initiatives promoting data sharing in 37 countries have been identified,

65% of these initiatives have limited scope and only deal with the sharing of data held by the public sector. As is often cited as a challenge, only 15% are related to the facilitation of data sharing in the private sector. Furthermore, initiatives involving personal data account for less than half of the data-sharing initiatives in the private sector.<sup>13</sup>

## BOX 2

### Bill Gates: “We must share data to fight Alzheimer’s.”<sup>14</sup>

As of 2018, the number of elderly people with dementia worldwide reached approximately 50 million. This number is expected to triple to over 150 million by 2050.<sup>15</sup> The percentage of people with dementia living in low- and middle-income countries already accounts for 60% of the total, and this percentage continues to increase.<sup>16</sup> Leaving this issue unaddressed will lead to the further widening of social disparities.

In November 2020, the Alzheimer’s Disease Data Initiative (ADDI) was launched.<sup>17</sup> This initiative’s three objectives are to: 1) ensure interoperability among existing databases so that data can be transferred smoothly; 2) promote data sharing between academia and the private sector; and 3) support identifying, combining and analysing data

in dementia research. This effort strongly believes in the potential for innovation through data sharing.

In addition, the World Wide FINGERS organization shares findings, knowledge and protocols of dementia prevention research conducted in various countries, such as from the Finnish randomized controlled study on dementia prevention, the FINGER Study.<sup>18</sup> The organization also aims to enable the future data combination and analysis of dementia prevention research in numerous countries to improve the quality of each study. In Japan, discussions on developing a research protocol that allows the sharing and secondary use of data obtained from dementia prevention research are under way.<sup>19</sup>

## 1.3 The public response to innovative data use

“ Information leakage and illegality are not the only concerns. Issues related to privacy, discrimination and unimaginable uses of data are also problematic.

One of the challenges of data sharing is “difficulty in managing risks such as privacy violations”. Between the enforcement of the EU General Data Protection Regulation (GDPR) in May 2018 and November 2020, 435 sanctions were imposed. After the California Consumer Privacy Act came into force in January 2020, by October 2020, 23 lawsuits had been filed.<sup>20</sup> Concerns and unexpected reactions regarding the negative effects of greater data sharing have been raised around the world by the public against companies and governments that have engaged in innovative data use (Table 1). Information leakage and illegality are not the only concerns. Issues related to privacy, discrimination and unimaginable uses of data are also problematic. The intentions of the data users are not the main issue here; rather, the focus is on public reaction. The factors that contribute to public responses against data utilization include the following, which have been grouped into five categories:

1. Lack of understanding and empathy from data subjects and the public regarding the purpose

of data use and the business model, due to insufficient communication, explanation, etc. (lack of accountability)

2. Doubts about obtaining appropriate consent (inadequate consent process)
3. Lack of technology and understanding to ensure data processing and handling in a fair and conscious manner (lack of considerations of fairness)
4. Risk of invasion of privacy due to excessive collection of data during the data collection phase or extensive use of data after its collection
5. Inappropriate data utilization that fails to take into account social values other than 3 and 4.

This list shows that public demands on data users are not limited to compliance with laws and regulations but also include considerations of privacy and social values such as fairness and democracy.

TABLE 1 | Cases of public concern regarding data utilization

Event	Case	Overview	Factor
1. Social movement	Installation of cameras in stations	An initiative examined the possibility of creating human flow statistics to contribute to safety measures in the event of a disaster by taking pictures of people passing through stations. The initiative was halted because of privacy concerns.	1 2 3 4 5
2. Law enforcement	Employment support service	A website that provides employment support services collected data such as the browsing history of students hunting for jobs and analysed it by AI to calculate the possibility of declining job offers. The data was sold to multiple companies.	1 2 3 4 5
3. Law enforcement	Collection of employees' fingerprints	An employee sued a company for allegedly violating the Biometric Information Privacy Act (BIPA) by collecting employees' fingerprints for attendance management purposes without prior consent. The court rejected the suit.	1 2 3 4 5
4. Law enforcement	Advertising auction bidding	A class action lawsuit was filed against a company for real-time bidding (auction bidding for advertisements), claiming that the company was processing data without obtaining appropriate consent from users.	1 2 3 4 5
5. Social movement	Corporate recruitment algorithms	A human rights NGO demanded that the government investigate an AI-based corporate recruiting tool, claiming it constituted an "unfair and deceptive" practice. It was concerned that the algorithms, based on biased learning, "promote discrimination" by making it more likely to select applicants who are white or male.	1 2 3 4 5
6. Media report	Misrecognition of a photo app	A photo application identified a black woman in a photo as "a gorilla".	1 2 3 4 5
7. Media report	Shoplifter detection system	Privacy concerns were raised over a report that retailers would use face scans to detect shoplifters and alert security guards when they enter the store.	1 2 3 4 5
8. Social movement	Humanitarian use of biometrics	An NGO published a report stating that due to concerns about reliability, reusability, security, reputation and social impact, the use of biometrics for humanitarian purposes should be reconsidered because risks often outweigh benefits.	1 2 3 4 5
9. Social movement	COVID-19 digital surveillance	More than 100 human rights NGOs issued a joint statement expressing concern over human rights violations in response to the widespread use of digital surveillance technology as a measure against COVID-19 in various countries.	1 2 3 4 5
10. Media report	Cross-border transfer of social networking service data	It was reported that data held by a social networking service had been transferred overseas and that it could have been unintentionally viewed by third parties.	1 2 3 4 5
11. Social movement	Approaches based on AI and human rights	An NGO that promotes sustainability in business released a report highlighting the importance of taking human rights-based approaches in the development and implementation of AI.	1 2 3 4 5
12. Media report	Surveillance technology of citizens in a different country	It was reported that facial recognition technology developed by a start-up company that was a business associate of the concerned private company was used to monitor citizens of a different country.	1 2 3 4 5
13. Law enforcement	Impact on democratic decision-making	A case occurred where personal information collected by social networking services was provided to third parties and used for promotion related to elections and voting.	1 2 3 4 5

Source: World Economic Forum

## 1.4 The various players in healthcare innovation



Software has eaten the world...and healthcare is next.<sup>21</sup>

Innovators in the healthcare field are a very diverse group. The Big Five US tech companies (Alphabet, Amazon, Apple, Facebook and Microsoft) and the major tech companies in China known as BATs understand that their strengths in data, resources and ecosystems can create significant value when combined with real-world healthcare data, and they are investing in and acquiring companies in the healthcare field.<sup>22</sup> In addition to these tech companies, businesses in a variety of other industries, including energy, insurance, real estate and telecoms, are entering the healthcare market. Furthermore, 2019 saw the birth of a digital health unicorn company with the total value of more than \$90 billion,<sup>23</sup> and a number of other start-ups are also contributing to the expansion of the market.

In the field of medical research, a governance system has been established to balance ethical

considerations and innovation (medical progress), which can be seen in ethical principles such as the Declaration of Helsinki.<sup>24</sup> However, today's innovators in the healthcare field are not necessarily well versed in this area. Also, some healthcare services can be developed through non-invasive approaches, such as exercise and dietary guidance, or through data use without intervention. Thus, since assumed risks and benefits for data subjects differ from one case to another, it is essential to discuss each case.

To accelerate healthcare innovation while protecting social values, the establishment of a practical corporate data ethics framework is needed that business entities can refer to in their capacity as data holders, so they can deal in advance with reactions from the public, as indicated in the previous section.

## 1.5 Issues

The following issues on the secondary use of data and data sharing can be identified:

1. Lack of initiatives to establish a governance structure in the private sector for the appropriate secondary use of data and data sharing
2. Rising public concern about data utilization
3. Concerns regarding the data ethics literacy of business entities as healthcare data users.

In this context, this White Paper presents two frameworks as tools for accelerating innovation while building trust. It describes attitudes and processes that various data users can adopt to protect social values.

- **The Trust and Willingness Framework – A framework for building public trust**
- **The Good Data Framework – An ethically sound framework for data handling**

2

# The Trust and Willingness Framework: A framework for building public trust

Social uncertainty exists between data users and data subjects due to information asymmetry and the characteristics of data.

## 2.1 The importance of trust in data circulation

“Trust is strongly recognized when it is being broken and lost.”<sup>25</sup>

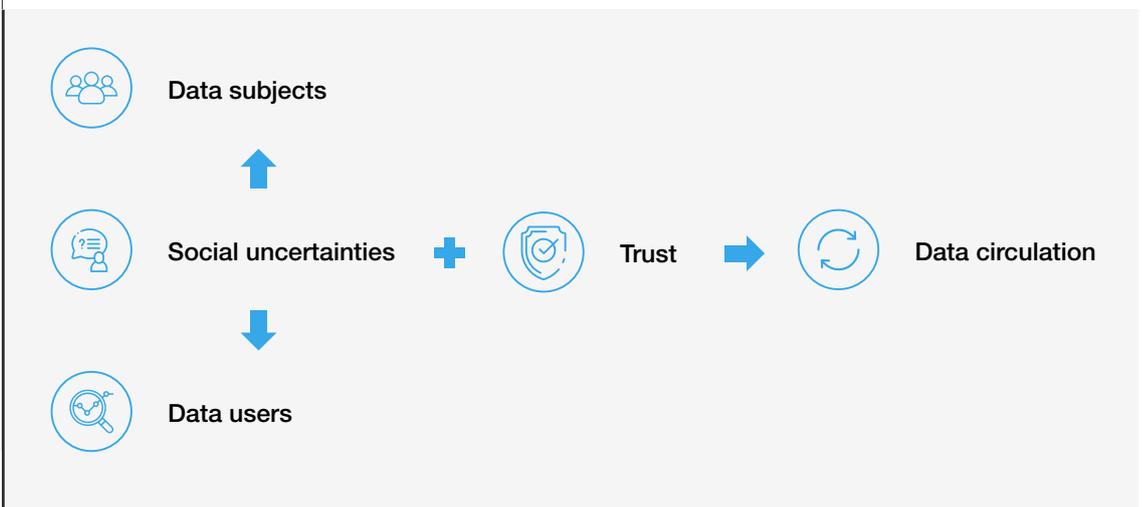
Social uncertainty exists between data users and data subjects due to information asymmetry and the characteristics of data (intangible, easiness of reproduction and transfer, etc.). In this context, social uncertainty refers to the situation in which it is difficult for individual data subjects to accurately understand how data users manage or use their data. As individuals must give consent to the use of their data despite social uncertainty, what is important here is trust.

Trust is a polysemous word. It is a broad topic that has been studied not only in psychology and sociology, but also in the social sciences, science and engineering, although the discussions across these disciplines are not necessarily based on the same definition and concepts. This White Paper

focuses the discussion on social uncertainty and trust (Figure 3).

Trust, in all of its aspects, plays an important role in people’s lives and functions as a lubricant for economic activity. Sociologist Niklas Luhmann views trust as something that “reduces social complexity by exceeding available information and generalizing expectations of behavior in that it replaces missing information with an internally guaranteed security”.<sup>26</sup> If individuals or organizations were to become unable to trust other people or organizations, they would have to be constantly vigilant to protect themselves. The cost of this mistrust would be extremely high and would have a significant negative impact on the efficiency of society and the economy as a whole.

FIGURE 3 Importance of trust in data circulation



Source: World Economic Forum

People are not always very conscious of trust in their daily lives, however. For instance, trust lies behind the behaviour of numerous people who agree to the terms of privacy policies without reading them. Many people expect companies to engage in good data governance or implicitly believe that governance can be improved through litigation or social criticism. Trust is also social capital as it reduces the cost of transactions and cooperation. When transactions and cooperation

become part of a daily routine, a virtuous circle is created based on the general belief that other people are trusting also.

Therefore, trust exists even when people are not aware of having trust; it is only when a discrepancy arises that causes it to break down that data users and the public become keenly aware of it, as seen in the cases of public concern over data utilization listed in Table 1.

## 2.2 Why and how trust is broken and lost

“ The antonym of consent is not dissent, but surprise.

A Telecom company

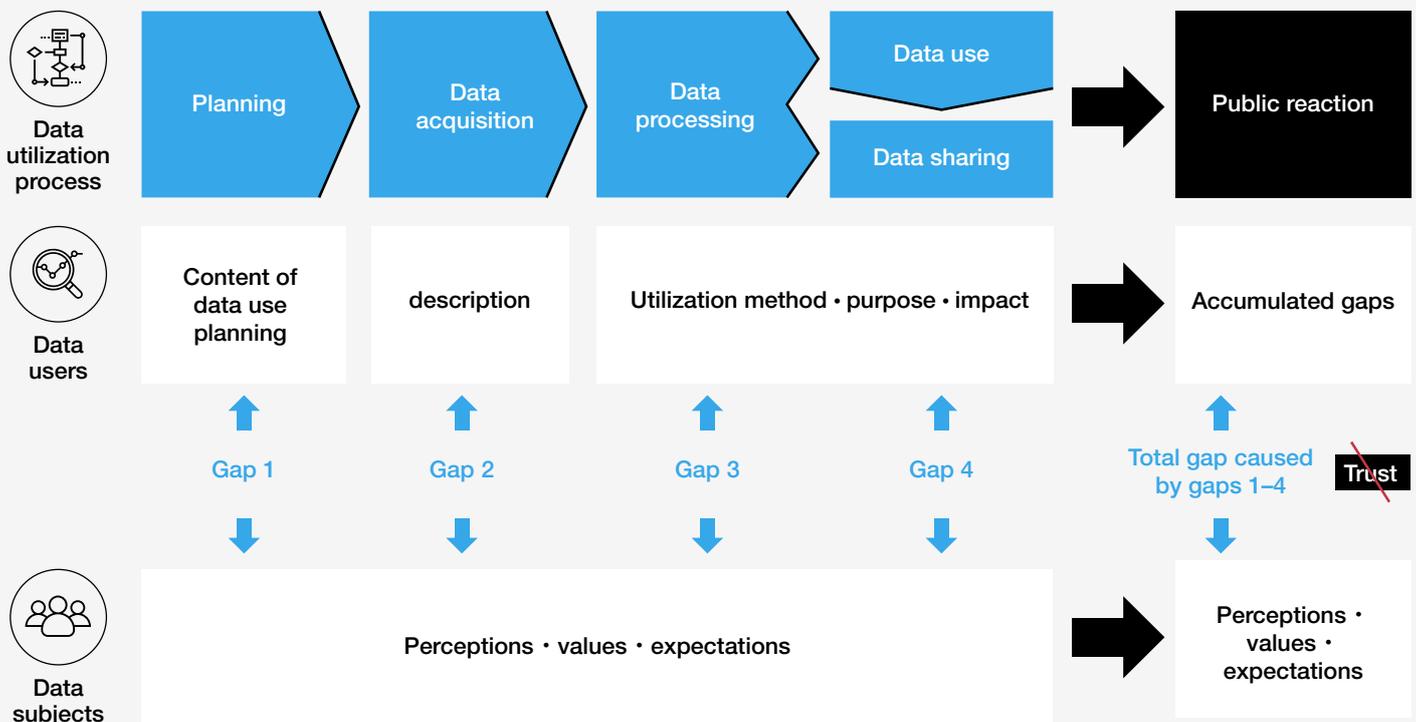
Why and how is trust broken and lost?

Certain research has categorized trust into “trust in competence” and “trust in motive”.<sup>27</sup> Matching the perceptions, values and expectations of data subjects and the public with the purposes and motives of data users fosters data subjects’ willingness to provide data. However, gaps can occur between the methods and effects of data utilization and the perceptions, values and expectations of individuals and the public at the

data utilization phase. This gap can cause negative surprises to individuals and the public, resulting in broken and lost trust.

Figure 4 outlines the kinds of gaps that arise between the perceptions, values and expectations of individuals as data subjects and the actual data utilization by data users, the reasons the gaps appear and their effects, along each phase of the data utilization process.

FIGURE 4 Gaps in data utilization



Source: World Economic Forum

“ Within the governance relying on legal sanctions, the motivation for innovation and development may be stifled or inhibited, and only unduly mild sanctions may be applied.

Gaps 1 to 4 in Figure 4 that occur in each phase of data utilization are described as follows:

**Gap 1: Gap arising from uncertainty about the methods used to deal with data in an ethically appropriate manner at the planning phase**

In this planning phase, ethical consideration based on the perceptions, values and expectations of individuals and the public should be given. There is no clarity, though, regarding the right way to deal with them. The size of the gap resulting from this uncertainty depends on the extent to which the planning entity strives to understand this gap.

**Gap 2: Gap arising from the way explainers communicate with data subjects and the data subjects’ literacy at the data acquisition phase**

The research showed that consent givers did not fully understand the content of the consent document when it was provided only via a website.<sup>28</sup> Different understandings may arise if a detailed explanation is given along with the opportunity to ask questions, even if the content of the explanation is identical to that in the consent document. In addition, the contents of consent forms and terms of service are becoming increasingly complex. This indicates that, even if appropriate methods and purposes of data utilization are designed, data subjects may not understand them properly, and thus the involved parties may underestimate or overestimate the original gap.

**Gap 3: Gap arising from differences from the planning stage or unforeseen effects during the implementation stage, including data processing, use and sharing**

At times, data processors use data in ways that were not clearly envisioned at the planning phase or when explained to data subjects. These uses are often different from those that the public and data subjects expect. This leads to data subjects’ perception that their data has been used in an unintended manner, creating and widening the gap.

**Gap 4: Gap arising from biased reporting and information, excessive simplification and distortion by the media and social networking services (SNS), etc.**

The state of data use can be overly simplified, or exceptional events can be diffused expansively even if data utilization is detailed and well designed, due to bias in reporting and information or an effort to convey information in an easy-to-understand manner. As a result, the facts may be distorted and then conveyed, which can widen the gap.

In light of these gaps, data users can consider the following ways to gain the trust of the public regarding data utilization:

<1> Efforts to build public trust by identifying and communicating with stakeholders, while recognizing that social uncertainty cannot be completely eliminated

<2> Sustainable approaches to reduce the gaps that lead to losses and breaks in public trust in data utilization.

These two approaches are closely related to each other in terms of accountability. <1> Sharing and communicating with stakeholders about the efforts to build public trust and <2> working to reduce the gaps will lead to accountability and fostering trust and willingness.

Figure 5 presents the Trust and Willingness Framework and its process for building public trust in the secondary use of data. This Framework is an expression of the Trust and Governance Framework proposed in the Forum White Paper “[Rebuilding Trust and Governance: Towards Data Free Flow with Trust \(DFFT\)](#)”. It shows efforts mentioned in <1> to identify and communicate with stakeholders to build trust in the face of social uncertainty. A framework that can be leveraged for the approaches mentioned in <2> is introduced in Chapter 3.

## 2.3 A framework for building public trust in the face of social uncertainty

The Trust and Willingness Framework outlines how, from whom, to whom and about what trust should be built, given the assumption that social uncertainty exists.

**Object of trust (In what do you trust?)**

Sociologist Bernard Barber distinguished between two types of trust objects:<sup>29</sup>

1. Competence to fulfil the role
2. Fulfilment of entrusted duties and responsibilities

These can be summarized as **1** trust in competence and **2** trust in motive.

**Trustee (Whom do you trust?)**

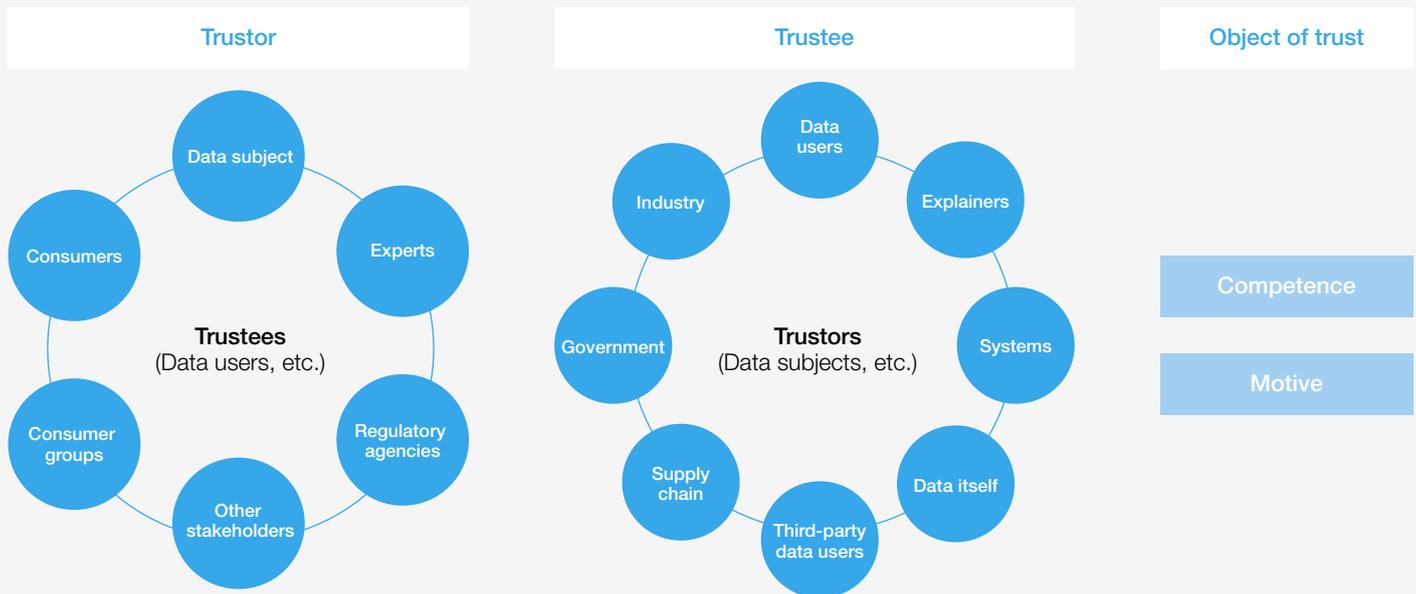
When the data user is a legal entity, the trustee is not limited to that entity. The industry to which the data user belongs and the country or system in which the entity operates can also be trustees. In addition, in a case where an employee of the entity explains to and obtains consent from data subjects, the employee also becomes a trustee.

### Trustor (From whom does an entity gain trust?)

For data users, the trustors are not only the data subjects. The various stakeholders involved in

the data utilization, such as consumers, experts, consumer groups, regulatory agencies and media, are also trustors.

FIGURE 5 The Trust and Willingness Framework: A framework for building public trust



Source: World Economic Forum

### How to build trust

“ Trust begins where prediction ends.<sup>30</sup>”

Thinking about ways to build trust requires an understanding of trust and trustworthiness.

Trust may be generated by such actions as imposing a heavy punishment or complying with certification from an internationally recognized standard-setting body (e.g. the International Organization for Standardization). These are ways that help data users build trust as they objectively demonstrate their motives, actions and competencies – that is, they demonstrate trustworthiness.

For instance, attempting to rationally control the behaviour of a trustee through the threat or imposition of severe punishment is a traditional governance method to reduce uncertainty by increasing trustworthiness. In the context of data utilization, data governance under the GDPR in Europe is an approach that builds trustworthiness, and its effectiveness has already been mentioned.

Yet when it comes to governance that relies on legal sanctions, the following issues may arise:

- In an era of rapid technological progress, governance based on laws and regulations alone cannot appropriately keep pace with change and thus fails to truly protect social values.
- The motivation for innovation and development may be stifled or inhibited, and only unduly mild sanctions may be applied.

In summary, trust is not a mere reflection of trustworthiness. As trust has its own significance, which cannot be reduced to trustworthiness, an approach based on trustworthiness alone is not sufficient to build trust. The framework proposed in this paper aims not only to demonstrate trustworthiness as the necessary condition to objectively trust, but also to achieve data utilization that data subjects can subjectively trust.

## 2.4 Application of the Trust and Willingness Framework

The Trust and Willingness Framework can be used as a tool for accelerating innovation while building trust. As an example, Table 2 lists actions that can

help build trust in the use of data to address the medical and social dimensions of dementia.

TABLE 2 Application of the Trust and Willingness Framework to the case of dementia

Trustee	Truster	Object of trust		Specific action	Issues addressed	Trustworthiness
		Competence	Motive			
Industry/ supply chain/ business entity	General public		●	Guidelines by public institutions	1 2 3 4	Trustworthiness
		●		Certification system for business companies by industry groups	1 2 3 4	Trustworthiness
			●	Industry self-regulation guidelines	1 2 3 4	Trustworthiness
		●		Guidelines for anonymized processing of nursing care data	1 2 3 4	Trustworthiness
			●	Initiatives on data ethics through the involvement of academia	1 2 3 4	Trustworthiness
			●	Agreement among industry, academia, government and the private sector on the social vision to be pursued	1 2 3 4	Trustworthiness
		●	●	Initiatives on voluntary governance by business entities	1 2 3 4	
	Supervisory authorities		●	Initiatives on ethical, legal and social implications (ELSI) through industry-academia-government collaboration	1 2 3 4	
			●	Involvement in the service development process	1 2 3 4	
	Consumer groups and concerned parties			Consensus building on ELSI for each use case	1 2 3 4	
			●	Initiatives on ELSI through industry-academia-government collaboration	1 2 3 4	
	Experts			Detailed information disclosure and communication on technology and security	1 2 3 4	
	Literate consumers	●		Implementation of media communications	1 2 3 4	
Media	●	●	Dissemination of information on the above measures	1 2 3 4		
	●	●	Continuation of multistakeholder communication	1 2 3 4		
General consumers		●				
		●				

TABLE 2 | Application of the Trust and Willingness Framework to the case of dementia (continued)

Trustee	Trustor	Object of trust		Specific action	Issues addressed	Trustworthiness	
		Competence	Motive				
Business entities	General public	●	●	Third-party review of data use purposes and processes	1 2 3 4	Trustworthiness	
			●	Assurance of transparency through external communication	1 2 3 4	Trustworthiness	
			●	Establishment of an internal governance system	1 2 3 4	Trustworthiness	
		●		Improvement of employees' literacy	1 2 3 4	Trustworthiness	
			●	Creation of internal policies and guidelines	1 2 3 4	Trustworthiness	
	Nursing home users and their families			●	Feedback to data subjects and their families on data utilization	1 2 3 4	
				●	Involvement in the service development process	1 2 3 4	
			●	Consensus building on ELSI for each use case	1 2 3 4		
Employees	Nursing home users and their families		●	Relationship building	1 2 3 4		
		●	●	Easy-to-understand explanations and tools through face-to-face communication	1 2 3 4		

Source: World Economic Forum

**Gap 1:** Gap arising from uncertainty about the methods used to deal with data in an ethically appropriate manner at the planning phase

**Gap 2:** Gap arising from the way explainers communicate with data subjects and the data subjects' literacy at the data acquisition phase

**Gap 3:** Gap arising from differences from the planning stage or unforeseen effects during the implementation stage, including data processing, use and sharing

**Gap 4:** Gap arising from biased reporting and information, excessive simplification and distortion by the media and social networking services, etc.

3

# The Good Data Framework: An ethically sound framework for data handling

Applying these approaches can reduce the gaps that lead to losses and breaks in public trust in data utilization.

This White Paper underscores data users' lack of practical frameworks to avoid the loss of trust. In response, this paper offers:

1. An ethically sound framework for data handling: the Good Data Framework
2. Methods to categorize data utilization use cases to consider when using this framework
3. Recommendations for conducting impact assessments using this framework.

The Good Data Framework was developed through the following process:

- Examination of negative public reactions to data utilization from case studies

- Interviews on data utilization
- Examination of best practices for ethical data utilization
- Discussions with experts.

The framework for data handling was based on previous research on profiling.<sup>31</sup> It was developed for data users willing to go beyond legal compliance and to take into account ethical and social issues.

It is important to note that the framework should be revised as necessary according to future changes in information legislation, public opinion and technological progress.

## 3.1 An ethically sound framework for data handling

The data-handling process can be divided into five phases: planning (including communication and explanations to data subjects), data acquisition, data processing, data utilization (implementation) and data sharing (circulation). Table 3 presents the Good Data Framework with recommendations for data users in each phase. The framework includes a

comprehensive summary of checkpoints for ethical considerations in data utilization. Applying these approaches can reduce the gaps that lead to losses and breaks in public trust in data utilization. (The briefing paper issued by the World Economic Forum offers more detailed information on each point.<sup>32</sup>)

TABLE 3 | The Good Data Framework – An ethically sound framework for data handling

<b>Planning</b>	1-1	Appropriateness of data use	In the planning phase, the values and benefits to be realized by data utilization should be clearly determined.
	1-2	Purpose of data use	The type of data involved and the purpose for which it is to be used should be clarified.
	1-3	Use of the Ethics by Design approach in organizations using data	A design to reduce legal, ethical and social risks should be considered.
	1-4	Whether it is possible to obtain understanding and support from data subjects and the public regarding the purpose of data use and the business model	Taking into consideration public perspectives and backgrounds, examination and confirmation are needed regarding whether it is possible to gain understanding and support for the purpose of data use and the business model without causing anxiety, concern or discomfort.
<b>Data acquisition</b>	2-1	Appropriate means of acquiring data and obtaining consent	Data should be acquired through appropriate means. And when acquiring personal information, consent should be obtained through appropriate methods.
	2-2	Effective user interfaces and other components for data acquisition	Methods to effectively support the decision-making of data subjects should be devised.
	2-3	Avoidance of bias in data sets	Bias in data sets should be examined.
<b>Data processing</b>	3-1	Privacy infringement risks in data analysis and evaluation	The risk of privacy infringement in data analysis and evaluation should be considered.
	3-2	Risks to stakeholders other than data subjects resulting from data processing, analysis and evaluation	The risks to and effects on stakeholders other than data subjects in data analysis and evaluation should be considered.
	3-3	Introduction of fair data analysis and learning technologies	Consideration should be given to introducing technological measures that take into account social justice and anti-discrimination in light of the product's purpose.
	3-4	Introduction of models that address accountability	Consideration should be given to accountability, explainability, interpretability, transparency, etc., and the data used should be specified. Also, the introduction of interpretable models should be thought out.
	3-5	Other social values	Consideration should be given to social values other than fairness, accountability and transparency.
<b>Data utilization</b>	4-1	Principle of human involvement in the use of profiling and AI	Human involvement in the evaluation process using profiling and AI should be considered.
	4-2	Accountability	When data utilization has an impact on individuals and stakeholders, consideration should be given to explaining the process behind that outcome in non-technical terms.
	4-3	Implementation of safety control measures	In light of the potential impact of data-processing results on individuals, careful attention should be paid to safety management.
	4-4	Accuracy of data content	The accuracy and authenticity of data content should be guaranteed.
	4-5	Establishment and handling of procedures for disclosure, correction, suspension of use, withdrawal of consent, etc., of data analysis results and constructed health scores	Procedures for handling complaints from data subjects and evaluatees should be developed.
	4-6	Data handling in case of death	The handling of data in the event of the data subject's death or after service suspension should be clearly stated when obtaining consent.
	4-7	Improvement of literacy in data use, analysis and evaluation	Training should be provided to those who use data (such as business units and company Human Resource departments) to ensure they properly handle and evaluate the results of data processing and analysis.
	4-8	Responses of data subjects, service providers, etc.	Designers should consider potential influences on the behaviours and preferences of data subjects, those who use services, etc.
	4-9	Auditability	Auditability should be ensured.

TABLE 3 | The Good Data Framework – An ethically sound framework for data handling (continued)

<b>Data sharing</b>	5-1	Provision of data to third parties and its governance with consideration to the impact on data subjects, etc.	Governance system should be agreed upon through contracts on data provision, etc., regarding the purpose of data use by those to whom the data is provided, restrictions on rolling distribution, prohibition of re-identification, etc.
	5-2	Procedures to provide data analysis results and constructed health scores to third parties	Considerations should be given when providing data analysis results to third parties.
	5-3	Government access	Policies on how to respond to inquiries from the police and other national agencies should be established.

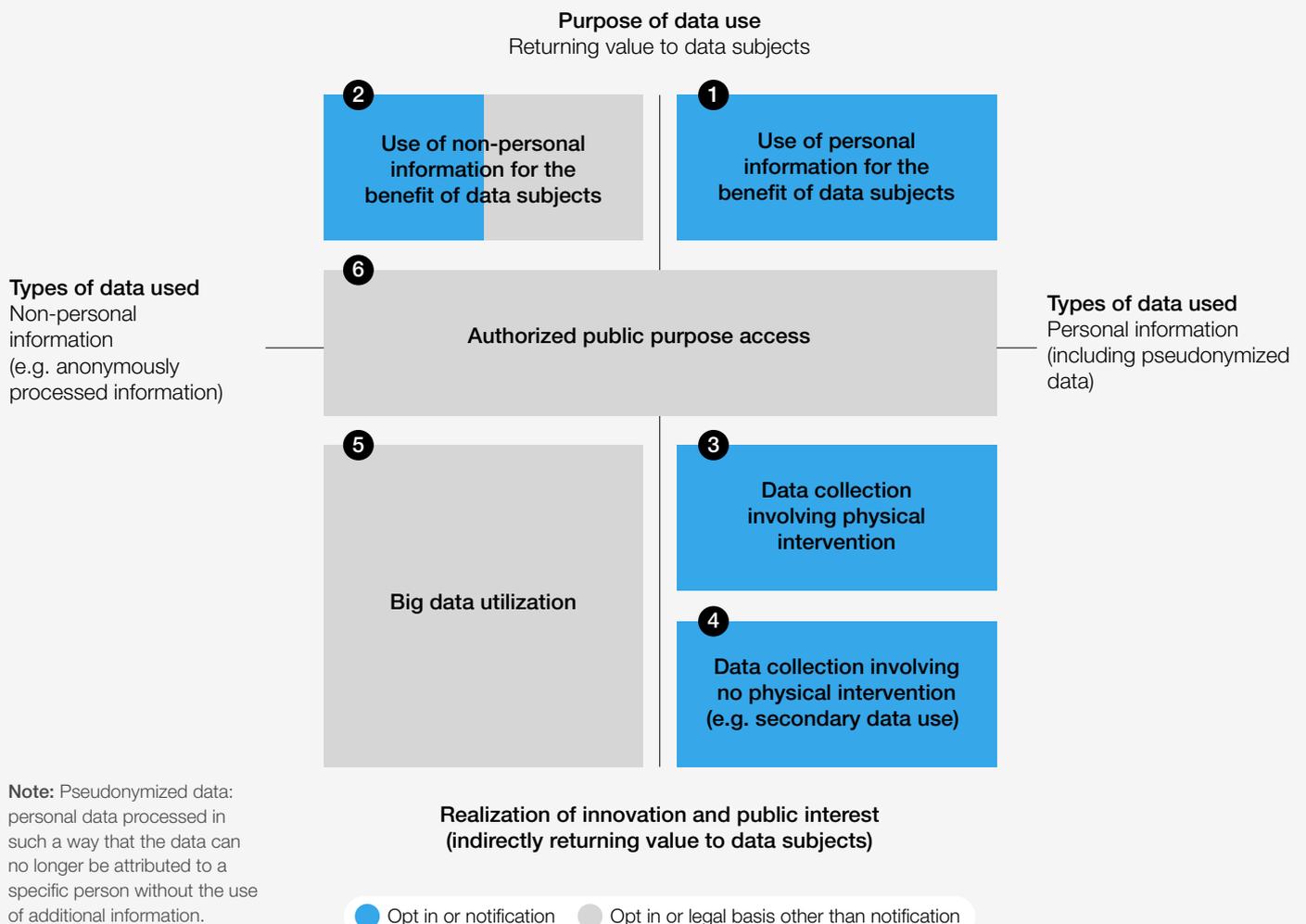
Source: World Economic Forum

### 3.2 | The classification of data utilization

Table 3 provides a comprehensive summary of checkpoints in data utilization but the points to be taken into consideration vary depending on the kind of data used and the purpose of use. Data utilization can be separated into four quadrants, based on whether the information is personal or non-personal and whether the purpose of use returns value to

data subjects (Figure 6). It is then organized into six patterns of use cases. The examples offer solutions for challenges in a super-ageing society comprising people with dementia and in nursing care. Further discussion is necessary, however, on the key points of each use case.

FIGURE 6 | The classification of data utilization



**Note:** Pseudonymized data: personal data processed in such a way that the data can no longer be attributed to a specific person without the use of additional information.

Source: World Economic Forum

“ The impact on society becomes larger, and the degree of due care, or social responsibility, increases functionally.

#### 1. Use of personal information for the benefit of data subjects

This includes data use to improve the quality of a company’s service and user experience. It also applies to cases where an algorithm or model is used and implemented in society to provide value to data subjects.

- Example: The development of personalized care plans using an AI care plan system, and the improvement of medical and nursing care services by sharing data with other professionals who provide care in collaboration

#### 2. Use of non-personal information for the benefit of data subjects

As in 1, this applies to cases where the data is used to improve the quality of a company’s services and user experience, or where the algorithms and models are implemented in society to provide value to data subjects. However, the data used is non-personal information.

- Example: A service that detects potential fraud based on changes in bank account balances

#### 3. Data collection involving physical intervention (promotion of innovation and the public interest through the use of personal information)

This includes product service development and effectiveness verification by using data acquired through physical intervention, such as exercise and dietary guidance.

- Example: Verification of the effectiveness of exercise and dietary guidance in dementia prevention

#### 4. Data collection involving no physical intervention, e.g. secondary use of data (promotion of innovation and the public interest through the use of personal information)

This applies to cases of developing a product or service by secondary use of data collected in a core

business without anonymization within the scope of obtained consent, the use of data collected by sensors, or combining data with data in other databases.

- Example: The use of personal data without anonymization (similar to the purpose in 5), the use of data collected by sensors, the use of data after combining it with data in other databases by name sorting

#### 5. Big data utilization (promotion of innovation and the public interest through the use of non-personal information)

This applies to cases where data collected in core business operations is used secondarily for service development, such as algorithm and model building, after removing personal information through data anonymization, etc.

- Example: The development of an algorithm for an AI care plan, the formalization of explicit knowledge on dementia care by using AI, the development of a nursing care consulting model, the development of a health condition prediction model

#### 6. Authorized public purpose access<sup>33</sup> (data utilization without explicit consent)

This applies to data sharing among medical professionals to provide treatment to data subjects in the event of a disaster, and data collection for disease registries that need to ensure comprehensive coverage.

- Example: According to the Basic Act on Disaster Management in Japan (Act No. 223 of 15 November 1961), the sharing of a registration list and relevant information of persons requiring support from residents’ associations and other organizations in order to provide adequate assistance in the event of a disaster, or the use of a disease registry for medical research and policy-making

### 3.3 Governance in the emerging era of data utilization

The World Economic Forum Centre for the Fourth Industrial Revolution Japan is examining opportunities to conduct a pilot project that uses the **Trust and Willingness Framework** and the **Good Data Framework** presented in this White Paper in collaboration with stakeholders interested in building trust in the use of nursing care data, including data on people with cognitive decline.

Expectations are rising for the secondary use of data and data sharing to contribute to addressing the social issue of dementia, and the value that can be created from data utilization is now being explored. Thus, it could be said that this field is in its infancy. Even in the early days of the industry,

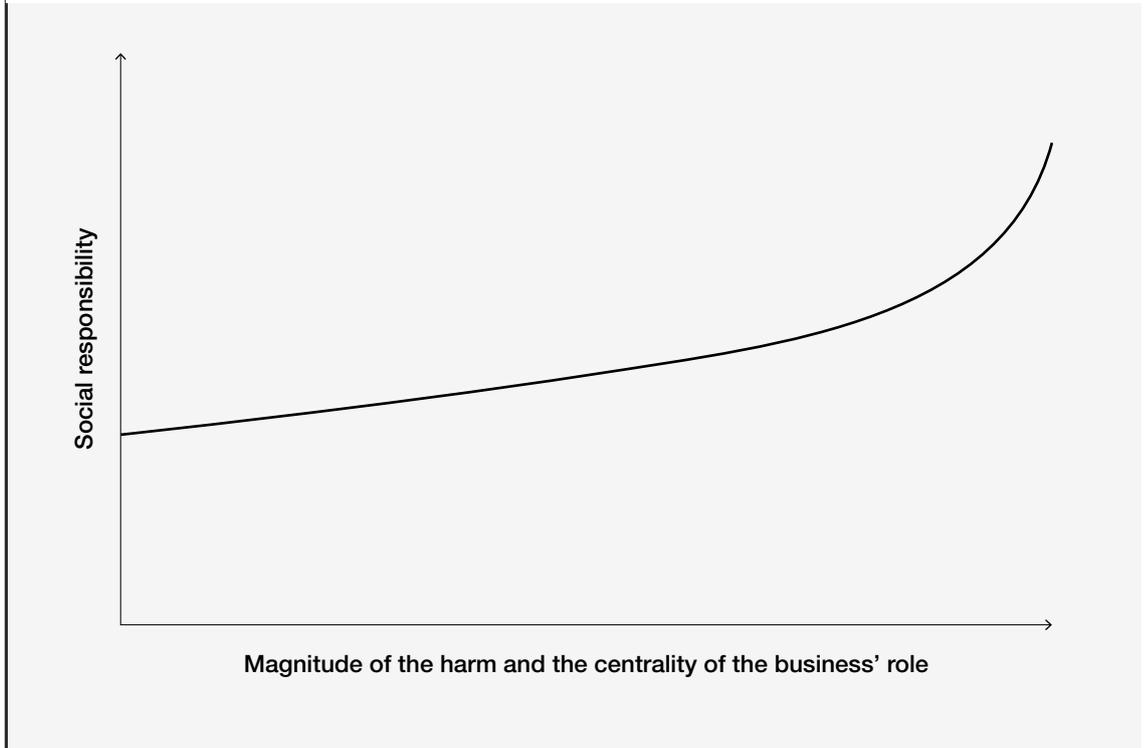
the importance of ethically sound data use is undeniable, although a balance is also needed.

Alpern et al. propose that the degree of “due care” that should be taken in engineering ethics should be understood as a “function of the magnitude of the harm threatened and of the centrality of one’s role in the production of that harm”.<sup>34</sup> In terms of data utilization, for example, there is currently much debate about the need to consider various social values when major tech companies such as Google make use of data, but at the time of its founding in 1998, no one would have expected Google to be as socially responsible as it is today. In the context of the business, the “function of the magnitude of the harm

threatened and of the centrality of one's role in the production of that harm" may be similar to the scale of the business. Although the number of customers as well as the impact on society may be small when a company is founded, as the business grows and the number of customers rises, the impact on society becomes larger, and the degree of due care, or

social responsibility, increases functionally. Alpern et al. call this principle the "corollary of proportionate care" (Figure 7) and formulate it as follows: "When one is in a position to contribute to greater harm or when one is in a position to play a more critical part in producing harm than is another person, one must exercise greater care to avoid so doing."<sup>35</sup>

FIGURE 7 Corollary of proportionate care



Source: World Economic Forum

Abstract discussions on data use and privacy tend to be conservative and are not constructive in emerging industries. Therefore, what is now needed to build public trust in data utilization to address social issues such as dementia are communication and an exchange of opinions among industry, academia, government and the public on the

issues and challenges likely to arise when each party carries out its role. Through such dialogue, gaps caused by various biases and differences in information literacy can be reduced. It is important for all the relevant parties to understand correctly what the data users hope to achieve.



**Japan's nursing care is the world's future.**

Hiroaki Miyata, Professor and Chair, Department of Health Policy Management, Faculty of Medicine, Keio University, Japan

As the world's population continues to age, Japan – the country that is ahead of the rest of the world in terms of ageing – should demonstrate how to use data appropriately to address social issues related to a super-ageing society, such as nursing care and dementia. By doing so, the country can provide important lessons for other nations that will face similar issues in the near future. The purposes of the pilot project in Japan can be summarized as follows:

- To reach a consensus among industry, academia, government and the public on the ideal vision of society to be achieved through data utilization, and the roles that each party should play
- To ensure that all the stakeholders involved correctly understand the value that data users hope to achieve and the issues they wish to solve

- To bridge gaps caused by various biases and differences in information literacy by exchanging opinions among industry, academia, government and the public on the issues and challenges that are likely to arise when each stakeholder carries out its role.

In light of the Good Data Framework, the ethically sound framework for data handling presented in this chapter, it is important for the pilot project in Japan to confirm especially point 1-4 presented in the framework: whether it is possible to obtain understanding and support from data subjects and the public regarding the purpose of data use and the business model during the planning phase.

### 3.4 | Proposal for a human impact assessment that uses the checkpoints

The data users are recommended to use the checkpoints for ethical considerations outlined in Table 3 to conduct an impact assessment of the data-use methods that the data users intend to implement. Under the GDPR, the European Commission requires that a data protection impact assessment be conducted when data processing “is likely to result in a high risk to the rights and freedoms of natural persons”.<sup>36</sup> While the focus of this impact assessment is on privacy, it also casts light on other fundamental rights, such as freedom of speech, thought and movement, the prohibition of discrimination, and the right to liberty, conscience and religion, which are also the values upheld in this White Paper. The Good Data Framework will be helpful to data users to assess risks and devise countermeasures.

This White Paper also recommends that a human impact assessment be conducted to focus on and clarify the benefits of data utilization. This suggestion

is made because the questions about the benefits data utilization provides and to whom (including but not limited to data subjects) are extremely important for both data subjects and the public when they consider their stance on data use, and it is also essential for data users to gain public trust.

The human impact assessment is not a supervisory tool that the government or other regulatory agencies oblige data users to employ. Rather, it is intended to help data users identify the problems they want to solve, the value they want to provide, and to whom they want to provide it, thereby helping the data users communicate appropriately with stakeholders. This will ultimately increase data subjects' and the public's trust in data users and promote innovation through data utilization.

# From notice and consent to trust and willingness

The two frameworks presented do not assume that notification and consent allows data users to dodge their responsibilities.

The data utilization described in this White Paper is based on the premise that the data user notifies the data subject of the purpose of data use, and that the data subject consents to that use. The notice and consent regime is currently the legal basis for many cases of data utilization. Therefore, many data users attempt to build public trust based on the premise of notice and consent. Yet issues in data utilization related to the notice and consent

model exist (discussed in the Forum White Paper “Redesigning Data Privacy: Reimagining Notice & Consent for human-technology interaction”).<sup>37</sup> This chapter examines the background, current state and issues of the notice and consent model. The prospect of data utilization that does not rely on notice and consent is then illustrated as a model for fostering public trust and willingness to provide data.

## Background and state of the notice and consent model

A key concept in many guidelines, from the OECD Privacy Guidelines to the GDPR, is the notice and consent model to ensure the individual's right to the self-determination of information.<sup>38</sup> Many countries outside of the EU also use notice and consent as a legal basis for collecting and using personal information, and for providing it to third parties.

In the case of data utilization based on opt-in consent, data use that is not readily apparent from the content of the notification (consent form) can

lead to negative surprises for data subjects. As discussed in Chapter 2, reducing these surprises by minimizing gaps will lead to greater trust.

One of the ethical considerations regarding consent that is not limited to data handling is the discussion of “informed consent” for patients and research participants in the field of medical research and advanced medical care. Informed consent is required based on the principle of respect for autonomy in medical ethics.

## Challenges of the notice and consent model

The notice and consent model assumes that data subjects read privacy policies carefully when giving consent. In reality, however, very few people do so. In addition, when data subjects read privacy policies very carefully, consent fatigue can occur. This situation may become more serious with the development of IoT.<sup>39</sup> This White Paper articulates the importance of obtaining appropriate consent and the need to devise ways to reduce gaps between individuals' perceptions and expectations towards data utilization and the actual data use. However, if the number of devices and services continues to increase, at some point they will exceed the cognitive ability of humans. In other words, the approach consisting in reducing all the aforementioned gaps in data utilization by sending appropriate notification and obtaining consent may cease to work.

For data like genomic data, where a single piece of data involves multiple parties, another issue is the high cost of notifying and obtaining consent from all the data subjects involved. In addition, because of difficulties in confirming the will of elderly people with dementia, limits exist on the extent of relying on the autonomy of an individual expressed at a certain point in time. While medical care is an act that directly benefits the individual, such as protecting their life and health, the use of data may not directly benefit the data subject. In cases with no direct benefit to data subjects, the difficulty is even greater to determine what to do in the face of the importance of respecting the autonomy of the data subject and the reality of the limitations of autonomy.

## A model that does not rely on notice and consent

As for the notice and consent model, issues related to the limits of human cognitive ability and the cost of notifying and obtaining consent from a large number of data subjects have been identified, posing challenges to creating value through trusted data use.

The two frameworks presented in this paper postulate the process of notification and consent but do not assume that notification and consent

allows data users to dodge their responsibilities. The frameworks were designed in the hope that the gaps between the expectation of data use and the actual data use are reduced beforehand, and that the willingness of data subjects to provide data is enhanced through ethically sound data utilization and communication with the public. Therefore, they are tools for fostering public trust and willingness, without treating notice and consent mechanisms as blank checks to use data.

## Communication with the public and citizens as trustees (utilization of science communication)

Public consensus building based on multistakeholder discussions is important in implementing any model that does not employ notice and consent as a legal basis. However, comparative studies of risk perceptions between experts and the public indicate that the one-way dissemination of information and risk assessments discussed only between experts are less acceptable to the public. Also, the one-way dissemination of information alone causes a gap between the judgement of experts and the understanding of citizens. These issues arise in the context of data utilization as well, and they are important perspectives in promoting consensus building by many stakeholders. Therefore, combining multiple approaches from science communication is recommended.

The term “science communication” has a broad scope. It includes the promotion of communication between experts and society/citizens, such as communicating science and technology to the public in an easy-to-understand manner or providing feedback to experts on the public’s awareness of problems. The consensus conferences organized by the Danish Board of Technology in Denmark and Science Cafés in the United Kingdom are examples.

In the process of implementing science and technology in society, creating new value and transforming society, it is important to determine how the public starts to accept the particular science or technology. But experts and citizens view risk from different perspectives.<sup>40</sup> As the transformation of society through science and technology has both bright and dark sides, it is becoming increasingly important for each member of society to share their understanding of those positive and negative sides and to communicate and collaborate on the kind of society that is desirable.

One way to facilitate communication between experts and citizens is to develop communication tools (information provision materials). Useful approaches to increasing trust in data use and

other technology include clarifying the concerns of citizens related to science (for example, big data) through workshops, and developing and improving communication tools for experts such as engineers and business operators so they consider the desirable state of technology and society together with citizens.

**“I feel left behind.”**

[A comment by a person with dementia](#)

While this White Paper articulates the importance of a mutual, interactive process with the public (the science communication approach), the significance of a multistakeholder process is worth reiterating.

While it is important and effective to involve data subjects such as consumers and consumer groups in the process of considering and implementing data-related policies as well as initiatives, in an increasing number of cases such involvement has, perhaps unconsciously, become a mere formality.

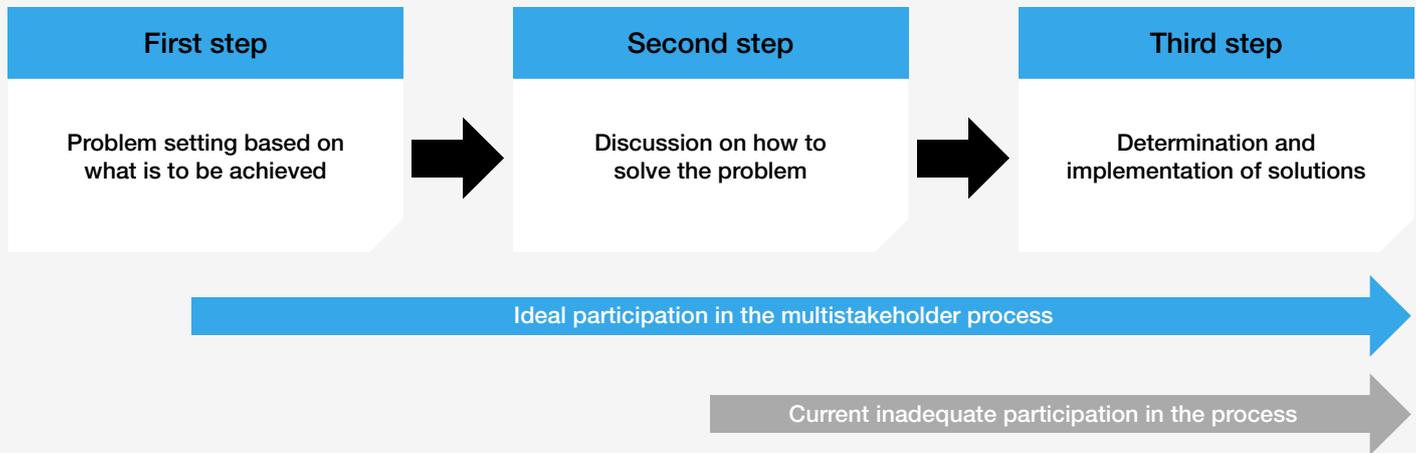
Differences in background knowledge are inevitable when multiple stakeholders with various positions and experiences come together. In order for everyone to discuss issues from a level standpoint, various rational considerations need to be kept in mind. These considerations, which should be discussed in advance, include how to conduct meetings, with thought given to the speed at which the participants speak, the language they use, the eye contact they make, and so on.

The first step in these discussions is usually to define the problem and what the data users hope to achieve. The next step is to discuss the solutions, followed by decisions and information on the implementation of solutions. But in some cases, people are involved only after the initial discussion of the problem and potential outcomes. Thus their opinions may not be considered or fully reflected, such that their participation in the discussion is little more than a formality. Now that the usefulness of the multistakeholder approach is more widely

acknowledged and its application in society is becoming more common, a more appropriate and feasible multistakeholder process is needed to

ensure that appropriate rational consideration is being given (Figure 8).

FIGURE 8 Multistakeholder process with rational consideration



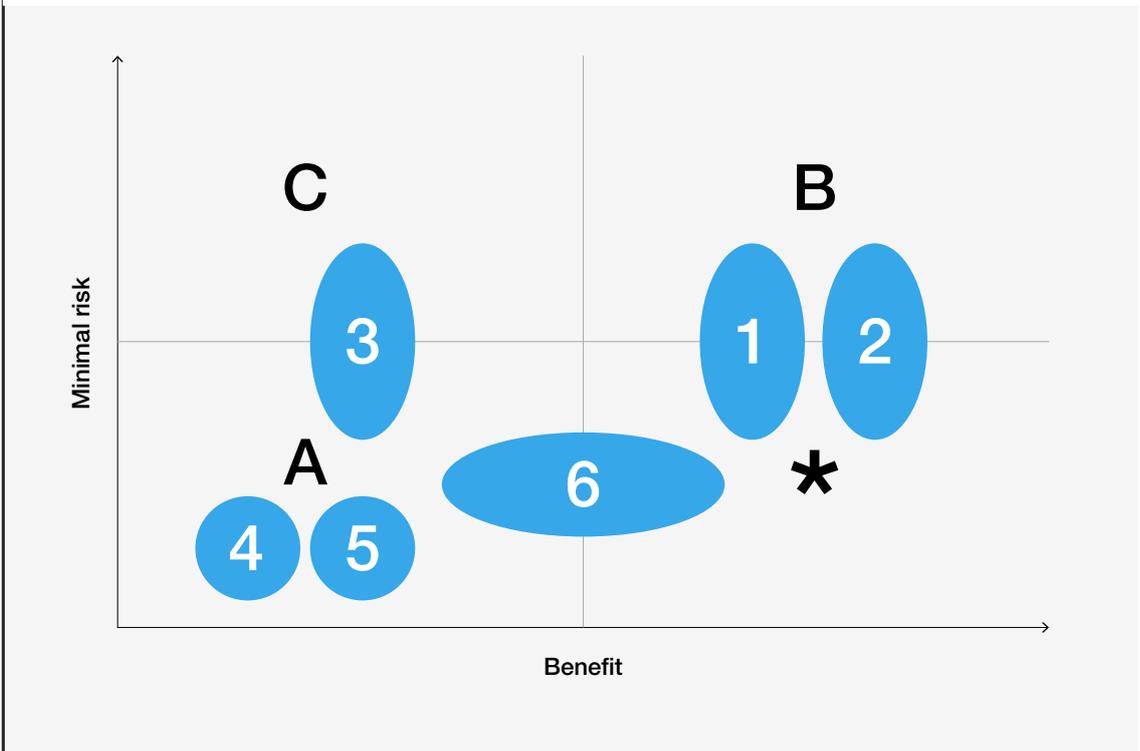
Source: World Economic Forum

### Case study: a model that does not rely on notice and consent (research participation and decision-making support for people with dementia)

What consideration should be given elderly people with dementia who are clearly limited in their use of the notice and consent model? The guideline proposed by the American Alzheimer's Association is useful here.<sup>41</sup> This guideline stipulates the process for recruiting people with dementia as subjects in research that may not directly benefit them. This case is a good reference as it is similar to the case of secondary use of data in that it addresses the situation of no direct benefit to data subjects.

Figure 9 shows four quadrants proposed by the American Alzheimer's Association to depict the level of risk and benefit to the data subject. The Association's guideline suggests ways of treating proxy consent in three quadrants (excluding the quadrant representing minimal risk with benefit for the data subject) where there are conflicting opinions about the appropriate balance between "autonomy" and "no harm".

FIGURE 9 Participation in research of people with dementia: level of risk and benefit



**Note:** The assumption is made that the risks to privacy or occurring during data processing are controlled appropriately; thus the risks of damaging social values (e.g. fairness) are not taken into consideration in the appraisal of minimal risk.

**Source:** American Alzheimer's Association, "Protection of Participants in Research Studies", 2015, <https://www.alz.org/media/Documents/protection-of-participants-in-research-statement.pdf> (accessed 19 April 2021).

The US National Institute of Mental Health defines "minimal risk" as: "the probability and magnitude of harm or discomfort anticipated in the research are not greater than those ordinarily encountered in daily life or during the performance of routine physical and psychological examinations or tests and that confidentiality is adequately protected."<sup>42</sup>

Benefits comprise not only direct benefits but also potential benefits. However, the debate continues about potential benefits and whether they include benefits not only to the data subjects but also to the group to which the person belongs. Further discussion is also needed on whether indirect benefits, such as satisfaction gained through social contribution, should be regarded as benefits for the patients in the context of decision-making support.

The Alzheimer's Association's guideline considers the following cases:

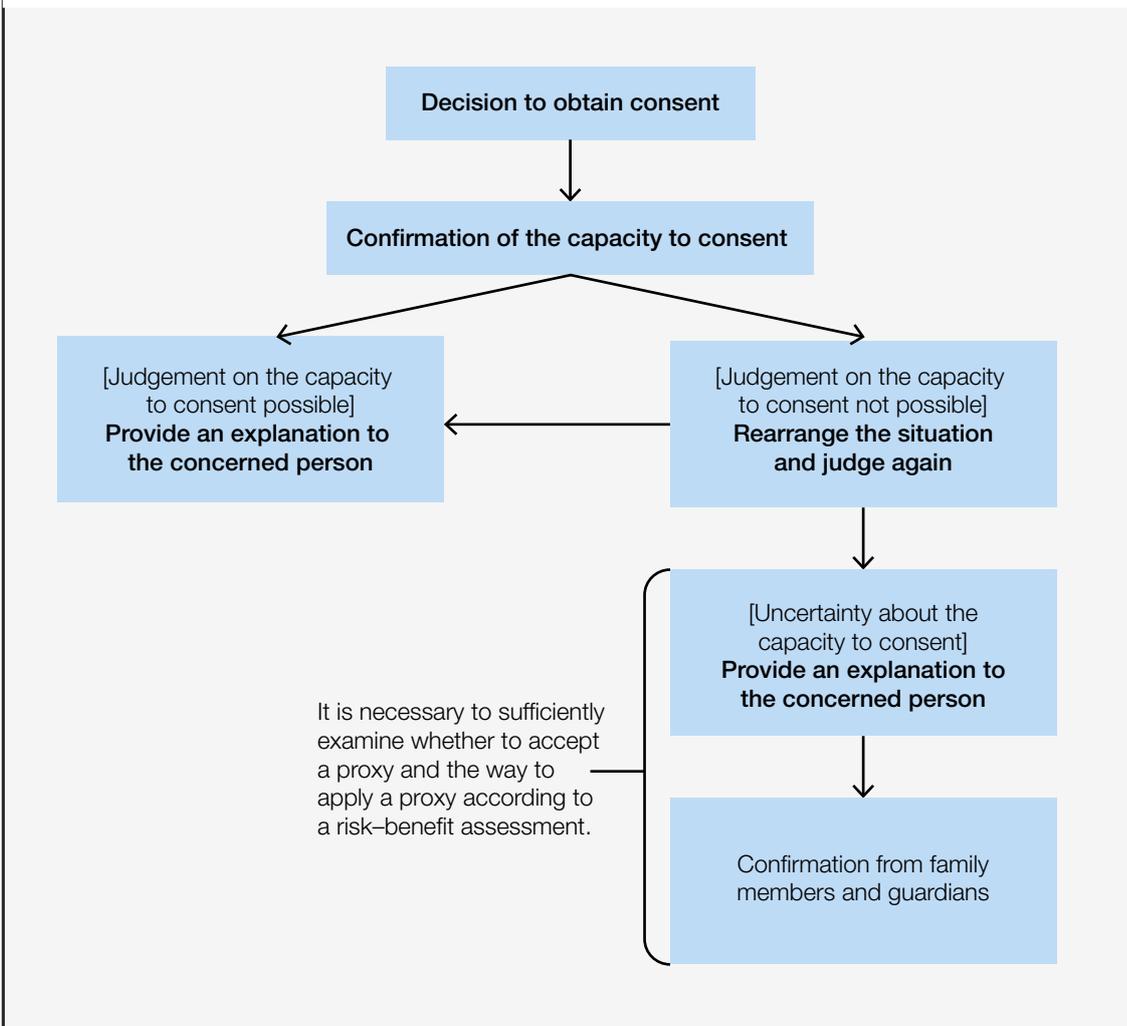
- **Quadrant A: Minimal risk but no benefit:** A family member, etc., can act as a proxy without an advance directive (a document that stipulates what actions should be taken for the data subject's health if they are no longer able to make decisions for themselves).

- **Quadrant B: Greater than minimal risk but with benefit:** Proxy consent is acceptable. Proxy consent needs to be based on the data subject's advance directive or the best-interest standard.
- **Quadrant C: Greater than minimal risk and no benefit:** The data subject can participate in research when that person can give consent directly, or when an advance directive exists regarding participation in the research. In both cases, the proxy will carefully monitor the process.

The six patterns of use cases (numbers 1-6 in Figure 9) correspond to those outlined in Figure 6 above (the classification of data utilization).

The guideline of the Alzheimer's Association also indicates the need to shift from a competency-based approach, in which only those with decision-making capacity can give consent, to a relationship-based approach, in which consent is based on relationships with the people around the concerned person. Shared decision-making and assent/dissent, which are already being implemented in the field of medicine, fall under the latter approach. Figure 10 shows the process flow for obtaining consent for data utilization.

FIGURE 10 Consent support flow



Source: World Economic Forum

### Potential for application to data utilization

When applying the concept proposed in the guideline of the Alzheimer’s Association to data utilization, it is necessary to address any intervention beyond the minimum risk in the acquisition of data. In the case of secondary use of data generated and obtained from the core business operations of a private business entity (for example data generated and obtained through nursing staff’s care services to data subjects), as the data has already been acquired, there is no further intervention towards data subjects in terms of data collection. Thus, from this perspective, it can be viewed as being of minimal risk under the

proposed concept. If the purpose of the secondary use of data is for innovation, such as service development, there is no direct benefit to data subjects. This case falls into the above category of “minimal risk but no benefit”, and data utilization in this case can be considered permissible based on proxy consent by family members, etc., without an advance directive. Also, it should be noted that the appropriate processing and utilization of the data need to be verified so its use does not exceed the minimum risk, in order to preserve social values such as individual privacy and fairness.

# Conclusion

Most important is to communicate with the public by demonstrating through will, intention and attitude the value that data users wish to create.

One of the aims of this paper is to help advance the understanding of the ambiguous term “trust” and convey specific approaches to building trust.

Critical to understand is that trust is something that is usually difficult to recognize and is often acutely felt only when it is lost. It is therefore a topic that is difficult to address proactively, especially in business. This difficulty has already been experienced in the field of security. Industry has perceived security as a cost centre; as laws and guidelines have been established in response to various problems, industry has taken the passive attitude that, since ensuring security is a legal requirement, it will respond to it within the scope of the law. The same mistakes in data ethics should not be repeated. It is possible to learn from the past.

The private sector’s collective efforts to gain public trust in data utilization in emerging technologies

and industries will not be easy. Yet these efforts will improve the sustainability of individual companies, the industries they belong to, and eventually the private sector as a whole. Most important is to communicate with the public by demonstrating through will, intention and attitude the value that data users wish to create by using data. By doing so, companies can renew their business models and service designs and gain the public’s trust. In addition, the public sector is expected to support the construction of frameworks on trust, based on the discussions.

The World Economic Forum continues its work to promote the importance of building public trust in data utilization and hopes leading companies and industries will communicate cases and share the benefits to society.

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