



Basic guidance for obtaining informed consent for the Delta Framework indicators data collection



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www.deltaframework.org

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1. Framing

The Delta Framework provides a set of 15 impact and outcome indicators to measure sustainability improvements within and across the cotton and the coffee sectors. In order to promote a globally harmonised approach for reporting sustainability results, the Delta Framework has a strong alignment with the Sustainable Development Goals (SDGs).

The Delta Framework comprises a set of guiding documents to integrate the indicators into existing monitoring systems, to collect and analyse data, and to properly communicate sustainability improvements.

These guidelines are available on the [Delta Project website](#) and include:

- 1. Delta Framework Sustainability Indicators.** This document presents the set of 15 indicators, the rationale for their selection, definitions, methodological notes, and main references for each indicator. It also includes the learnings from pilot testing the indicators in different countries and settings.
- 2. Integrating new performance indicators into sustainability systems: practical considerations.** This document includes considerations and a set of guiding questions designed to support the inclusion of the indicators in the Monitoring, Evaluation and Learning (MEL) systems of Voluntary Sustainability Standards (VSS) and other organisations;
- 3. Basic guidance for obtaining informed consent for the Delta Framework indicators data collection.** This document guides the incorporation of informed consent for the Delta Framework indicators data collection into existing organisational data strategy and policies;
- 4. Description of a common data model for the Delta Framework indicators.** This document supports the implementation of common data models to facilitate future data aggregation and collective reporting;
- 5. Principles to define and communicate sustainability performance in the agricultural commodity sector.** This document directs public and private sector stakeholders on deriving sustainability information and messages on the production of agricultural commodities from the data.
- 6. Guidance and tool to aggregate producer-level sustainability data and report progress at national level.** This methodology aims to support national commodity associations and other relevant public bodies to aggregate producer-level data using the Delta indicators to assess the sustainability performance of the commodity's production at country level.

The present document is for people interested in incorporating informed consent for Delta Framework indicator data collection into their existing organisational data strategy and policies. This guidance assumes you have identified and described the various use cases for the indicator data. Along with the use cases, an organisation's existing data strategy and policies ultimately informs how to obtain, document, and manage consent for the collected data. Informed consent is predicated on understanding how data will be managed and used throughout the entire data life cycle, including collection use, sharing, disposing, and archival of the data.

Delta Framework Sustainability Indicators

- Indicators description
- Definitions
- Methodologies
- References
- Learnings from pilot testing the indicators

Integrating new performance indicators into sustainability systems: practical considerations

- Strategic framing for indicator integration process
- Data value chain
- Generation: data capture, acquisition, and obtaining informed consent
- Data transmission and validation
- Analytics: data processing and analysis
- Exchange: packaging and communicating insights, publishing, and sharing data

Basic guidance for obtaining Informed consent for Delta Framework indicator data collection

- Data protection and the categorisation of personal and sensitive data
- Recommendations for how to obtain informed consent

Description of a common data model for the Delta Framework indicators

- Overview of the information and data ecosystem
- Applying a common data model
- Mandatory data
- Application of existing data standards
- Ethical and data protection considerations
- Recommendations for how to apply the common reference data tables

Principles to define and communicate sustainability performance in the agricultural commodity sector

- Monitoring versus impact indicators
- Framework application principles
- Indicators-specific principles
- Data collection principles

Guidance and tool to aggregate producer-level sustainability data and report progress at national level

- Aggregate producer-level data
- Report sustainability progress at national level

2. Glossary of terms

Consent: any freely given, specific, informed, and unambiguous indication of the data subject's wishes by which he or she, by a statement or by a clear affirmative action, signifies agreement to the processing, use, and storage of data relating to data collected for the calculation of Delta Framework indicators.

Data controller: is the natural or legal person, public authority, agency, or other body which, alone or jointly with others, determines the purposes and means of the processing of data; where the purposes and means of such processing are determined by the Union or Member State law, the controller or the specific criteria for its nomination may be provided for by Union or Member State law.

Data processor: a natural or legal person, public authority, agency, or other body which processes data on behalf of the controller.

Data subject: a natural person whose data is processed by a data controller or processor.

Data collector: a person who, for any purpose, whether by automated collection or otherwise, handles, collects, disseminates, or otherwise deals with data and information from data subjects.

Data collection: is the systematic approach to gathering and measuring information from a variety of sources to get a complete and accurate picture of an area of interest. Data collection enables a person or organisation to answer relevant questions, evaluate outcomes, and make predictions about future probabilities and trends.

Non-personal data: any data or information relating to data subjects that is not personal data. It is data that does not contain any information that can be used to identify an individual. Thus, it can be either data that has no personal information to start (e.g., data from anonymous sensors, weather data, or market prices), data that has been pseudo-anonymised (e.g., identifiable strings substituted with random strings), or anonymised (irreversible removal of all personal identifiers).

Personal data¹: what precisely constitutes personal data is sometimes interpreted differently across jurisdictions. The individual that the information identifies is often referred to as the data subject. In general, personal data is information through which an individual can be either directly, or indirectly, identified. Whether a data subject can be identified from information is a matter of fact and degree. Some personal data is more obvious, such as name, date of birth, or a fingerprint. Others are less obvious, such as cookies or IP addresses.

¹ As related to the European Union General Data Protection Regulation, see also: <https://ico.org.uk/for-organisations/guide-to-data-protection/guide-to-the-general-data-protection-regulation-gdpr/key-definitions/what-is-personal-data/#1>

3. Introduction

The Delta Framework indicators require the collection and use of data about farming practices and sustainability performance results of individual farmers or data subjects. Data is a very powerful tool in telling a narrative about the results of sustainable practices, and how various agricultural commodities are produced. It is important to understand how these narratives may impact people's lives and be responsible in how data is used and presented. Ideally, the consent process is fully aligned with an organisation's overall data management policy and procedures for collecting, sharing, using, disposing, and/or archiving their data.

Informed consent refers to the process by which a data subject agrees to provide information for research or other data collection purposes. This process includes disclosure about how the data will be used, potential risks, benefits, and options for participation in the data collection process. The focus of any consent process should be on informing and protecting the privacy and rights of data subjects, through disclosure and discussion of relevant information, meaningful efforts to promote participants' understanding of how the data will be used, and by ensuring that decisions to participate, or to continue participating, are always made voluntarily. The consent model is designed to give individuals a degree of control over their personal information and in the case of the Delta Framework indicators, recognise individual's interests in information about their farming practices and sustainability performance results.

Consent can be a highly technical and context-specific matter with many legal and regulatory implications. This is a high-level primer about consent for data collection, use, and sharing in the context of performance monitoring using the Delta Framework indicators. However, it provides general recommendations that are broadly applicable to other data collection initiatives. **These basic guidelines are not a substitute for legal advice. To comply with context-relevant legal requirements, seek legal expertise.**

Data protection and the categorisation of personal and sensitive data

Any discussion about data needs to acknowledge the emergent legislation and regulation of data protection (see Resources section for articles specific to the agricultural context). The European Union General Data Protection Regulation is of particular importance for EU-based sustainability systems and institutes specific legal requirements for personal and sensitive data.

While personal data can categorically be considered sensitive², determining the potential sensitivity for non-personal data collected for the Delta Framework indicators requires additional contemplation. For example, sharing the location of high land conversion areas might attract illegal poaching, or the location of certified areas might be combined with other data to identify individuals. Even though this data is not personal data, in a particular context it may be considered sensitive (for further basic discussion on data categorisation see Annex 1).

² See ISEAL Data Governance Resource 4: Structuring data sharing agreements for personal and sensitive data. https://live-iseal-os.pantheonsite.io/sites/default/files/April_2020_Resource_4_Data_Sharing_Agreements_Personal_Data.pdf.

4. Recommendations for how to obtain informed consent

There is no authoritative description of consent practices for performance monitoring data collection or civil society. Obtaining fully informed consent may seem time-consuming or tedious, but it is incredibly important. It shows respect for people and their choices, and it helps ensure that your data collection processes are fair, well-considered, and non-exploitative.

To give informed consent, however, subjects must be given the information that a reasonable person would want to have to make an informed decision about whether to participate in data collection for the Delta Framework indicators, and an opportunity to discuss that information. While no one approach fits all contexts, best practice and ethical standards support that the consent process should include (but not be limited to) four key components or steps:

1. Disclosure provides data subjects information about the data collection objectives and associated risks and benefits of participating.
2. Data subjects understand the implications of participating.
3. Data subjects have the requisite capacity to make the decision to participate.
4. Data subjects voluntarily agree to participate, and consent is recorded.

4.1 What to include in the disclosure

Participants must be given all relevant information. This includes what it will take to be a participant, the risks and benefits of participating, how the data will be used and protected, etc. Fully informed consent likely requires that the following information is disclosed to data subjects:

- The nature and objectives of the data collection initiative. This may include programme structure, partners, and funders, as well as the specific objectives of the initiative and how those might change over time. This section should also include:
 - Name and identity of the data controller organisation and what the organisation does. Name of the data collector and affiliation with the data controller organisation.
 - Contact information for where people can go with additional questions. This can be as simple as an email address. However, the more information you provide, the more secure data subjects will feel. Providing a phone number and address as well can make an unknown organisation feel more reputable and trustworthy.
 - Description of how participants are chosen. Outline why this individual is being asked to participate, how many people are participating in total, etc.

- How the data will be collected. Explain what someone should expect if they participate. For example, what will the survey cover? What will participants be asked to do? How long will it take (or how many questions does it include)? What will happen after completing the survey (if anything)? This description should include information about what types of data (e.g., personal identifiers, photos, soil samples, income, etc.) are being collected. It should also include data collection frequency and timing.
- The purpose for which the data is being collected. It should describe a clearly identifiable purpose rather than a vague, open-ended description. It is useful to think about what question(s) will be answered with the data being collected.
- How the data will be used. This includes how the data will be used internally and publicly and should also include how the data will and will not be shared, and any limits to use or the time for which data can be stored and used in the future (e.g., whether and how the data will be archived).
 - It is important to explain how data will be handled once the data collection is completed including how and what data will be kept anonymous, confidential, and private.
 - Be clear about whom the data will be shared with, what types of data, how the data will be shared, and for what purposes. If, for example, digital applications are used to collect data, it is important to recognise that personal data can be collected via cookies. Similarly, data collection applications may also collect user behaviour data. For both instances explicit consent for use of personal data must be collected as well.
 - This description should also include how the results will be published and where they can be accessed. For example, will it be anonymised? Will it be aggregated or kept at an individual level? Will participants be able to see the results?
 - If you plan to use quotes or photos in public results, be sure to explain that (and explain if and how they'll be anonymised or credited).
 - If you are using any recording devices (video or audio), it is important to explain what will happen to the recordings.
 - Explain what opportunities data subjects will have to review and influence the data and its use over time, including opportunities to revoke consent. One way to do this is through setting up data subject access/delete request forms.
- A reasonable description of the foreseeable benefits to the data subject and/or their community for providing this information and participating in the data collection initiative.
- A description of what risks the data, and its use, might pose. What types of potential harm to the individuals or their community might occur and what steps are being taken to mitigate those risks. This description depends on the outcomes of risk assessment at the time of data collection and can never be exhaustive or authoritative. Harms can be physical, reputational, economic, or other, and may occur unintentionally. Disclosure will need to strike a balance between providing data subjects with the information they need to make a reasonably informed decision about consent, and overloading data subjects with information that will have a negative effect on their engagement and may itself present risks.

- A description of what happens if data collection contexts or data use objectives change, and what implications that has for the consent provided.

4.2 Making sure the information is communicated well

It's not enough to just be given information; participants must adequately understand the information. This means that a key part of informed consent is making sure that the information is communicated well, and people understand it. Due to the widely varying contexts in which sustainability systems work, this is not always a straightforward task.

It is important that the language used is understandable to all parties. This includes the language in which the consent disclosure content is communicated³, as well as any specific technical or legal terms used⁴. For people to be meaningfully informed, disclosure needs to be communicated in a way that is culturally, technically, and socially appropriate. This has implications for the types of information included in the disclosure, as well as the mechanisms for communicating them (e.g., whether this takes place in-person, or through another medium). Try to think about the following questions to help guide yourself through these issues:

- Are the methods of disclosing information about the data collection initiative to the data subject appropriate in terms of language, medium used and social contexts? Have you thought about how accessible the methods of disclosure are for the data subject (medium/literacy/etc.)?
- Are people seeking the consent adequately trained to do so? For example, can the staff manage issues of consent and power within interpersonal relationships, and can they answer common questions that participants might have?
- When the processes of providing consent or disclosing information are mediated by technology, it is important to note the ways in which specific platforms and media influence the experiences of individuals. Has this been factored in?
- If applicable, how can the consent received reflect on the data collection initiative? What might resistance to granting consent suggest about the meaningfulness of the initiative to the data subjects, the sensitivity of the information collected, or program relationships with the data subjects? Has sufficient care been taken to communicate about these topics in a way that the data subject understands?

Some general recommendations for setting up informed consent so that it is understood and not just explained include:

- Keep it short. Use a concise script or text that an individual can go through in a one or two minutes and, where possible, avoid long explanations. Depending on context, it can be broken down into more of a conversation style where there are pauses to allow for questions and a back and forth to facilitate comprehension.

³ Note that it is important to recognize the local dialects and spoken language of many rural contexts.

⁴ See ICPSR, [Recommended informed consent language for data sharing](#).

- Keep it simple. Information should be given in non-technical terms so that “anyone” can understand it.
- Use more than words. Incorporating pictures, charts and graphs can sometimes make things easier to understand.
- Speak in second person. The use of “you” (e.g., “You will be asked 10 questions”) can make certain statements clearer for the listener and personalise it for them. (Note that for the actual consent form/recording you will want to use first person (e.g., “I voluntarily agree to...”)).

4.3 Ensure data subjects have decision-making capacity for providing consent

Informed consent requires that participants can weigh the risks and benefits and come to their own decision about whether they want to participate. It’s important to remember that some groups, such as children and people with mental disabilities that may impede their decision-making capacity, cannot provide consent. The participant must be competent to provide consent and given the decision-making option.

Thus, practitioners will want to pay explicit attention to the socio-cultural and other contexts that can impact how consent is sought, including who gives consent, who obtains consent, and how it is obtained. For example, when interviewing one gender about their practices or preferences under informed consent, if you ask questions about their spouse’s practices or preferences, you should also obtain consent from the spouse, or interview the spouse directly.

4.4 Safeguard voluntariness of recorded consent

Participants must genuinely volunteer to participate, not be coerced, manipulated, or persuaded in any way. Data subjects may be compensated for providing data. Payment for participation is common in medical research for example. Compensation is not considered coercion or manipulation. It can, however, persuade or motivate participation. There are studies that suggest that compensation can sway the results based on who participates, but there is limited data. There is also literature examining if payment obscures risk perception. Generally:

- If risks are judged acceptable – is this a misplaced worry?
- Will subjects be asked to accept the same risks without financial incentive?
- Understanding of risks can be evaluated during the process of informed consent
- Limited data suggest payment does not obscure risk perception.

If payment is considered, subjects should be paid for inconvenience and time spent, and should be reimbursed for expenses incurred, in connection with their participation. The payments should not be so large as to induce prospective subjects to consent to participate against their better judgment.

It is important to explain that their participation is entirely voluntary, that participants have the option not to respond to any questions or data collection procedures, and that they can withdraw at any time without giving a reason.

The consent process includes a record of voluntary agreement. In many cases this is obtained in writing, often by checking a yes/no box following review and discussion of the disclosure information. When written consent may not be appropriate and oral consent is required, audio recording or signatures can be obtained.

Recognising that participants may change their mind about consent at various times, due to changing context or circumstances, there always needs to be a way to individually revoke their consent. In the disclosure content and process, it is important to ensure that you provide and explain how data subjects can revoke their participation in an easy and accessible manner so that the method of revocation does not in itself prove a barrier to exit. Some options (but not limited to these) include sending an email, making a phone call, or even stating this decision to the data collector during the data collection process.

It is important that the consent obtained is not structured as an opt-out; meaning that you automatically agree to share your data unless you state otherwise. Informed consent should always be structured as an opt-in decision. This means that the data subject has explicitly given their permission to be included or provide the requested data. Any individual that refuses to consent or does not respond should be excluded from the data collection initiative.

Obviously, there are implications when data subjects revoke consent, particularly in terms of calculating results. Depending on the time frame for revoking participation, calculated results may need to be adjusted, but it really depends on how the indicator data is used (is it periodic for example calculated annually and published). Generally, if a data subject consented in previous time periods and the results have been published, they can remain as calculated. However, if a subject declines in a current time period, any results under calculation would need to be adjusted for their consent revocation. Ultimately though, it depends on how the option to revoke consent is outlined in the consent form, meaning if it clearly states that once published, there is no option for retracting previously published results. It is important to note however, that for personal data other protections apply. For example under GDPR, there is the [right to be forgotten](#). For this guidance, we are not focused on personal data, so constructing options to revoke consent might be contingent on each new data collection time period. The important point is that this option to revoke consent needs to be thought through relative to how the data will be used and published and captured in the processes for obtaining consent.

4.4.1 Contractual agreements for certification as an exception

If there is any type of relationship between the data subject and data collector, it is advantageous to explain how participation or non-participation will affect that relationship (e.g., not participating in monitoring and evaluation activities will not preclude individuals from receiving program benefits). For certification systems that incorporate data collection for the Delta Framework indicators as part of their certification contractual agreements, the approach for obtaining consent diverges from typical research or project M&E initiatives.

When the data collection is embedded in a contractual relationship such as certification (which is entered into voluntarily by the data subject), there are potential repercussions and negative consequences for not participating in the data collection initiative. The benefits of being certified may be withheld, as well as any unique benefits associated with the data collection initiative itself, such as individualised data feedback opportunities. This withholding of benefits associated with voluntary certification changes the power dynamics associated with the data collection.

It is still important to obtain consent for data rights associated with the data collection initiative, but the various uses, risks and benefits now become part of the contractual agreement. While entering a contract for certification is a voluntary decision, it does include important and highly relevant power asymmetries. If the data collection is associated with certification contracts, a formal consent and data sharing license agreement is warranted. (See [ISEAL guidance on data sharing and licensing agreements](#)).

4.4.2 Relevance of informed consent for sustainability systems collection of non-personal data under certification contractual agreements⁵

The legal contexts in which sustainability systems collect, manage, and use data is in flux and what constitutes personal data is likely to change. To get ahead of this challenge and to address the potential power differential between the certified entity and certifying organisation, sustainability systems can allow individuals the rights to decide how non-personal data associated with their certified activities are being used by extending the consent model to this data.

Consent is a useful option for processing non-personal data related to certification if you want to offer individuals a real choice and control over how you use Delta Framework indicator performance data associated with their production activities. Consent is rooted in ethical standards regarding the respect and recognition that individuals are autonomous agents who can make informed and considered choices and to determine if those choices are consistent with their interests.

⁵ This section is slightly modified content from 2020 ISEAL Guidance (reproduced with permission): [Structuring data sharing and licensing agreements](#).

By basing the sustainability systems' processing of non-personal data on consent you are practicing the principles of transparency, fairness, and accountability by giving individuals an option and ongoing control over how data about their sustainability practices are used. This places the certified entity at the base of the data value chain. This ethic and practice can help to develop confidence and trust in your organisation, which can further enhance your reputation, improve levels of engagement, and inspire development of new services and products.

Ethically, data belongs to the individual that the data describes, as they should have the right to withhold consent and to remove their data from the process. However, given the different objectives and potential uses of the Delta Framework performance monitoring data, it is important to evaluate some basic questions regarding data rights:

- Does the individual have control over how their data is used?
- Do they have the power to stop their data from being used in a certain way?
- Are they aware of how the data will be used and is there a way to communicate changes in data use?
- How is your organisation accountable to the people reflected in the data?
- How is this accountability enforced?
- There are also important issues to address regarding the power dynamics that emerge during the use of and collection of data.

Transparency is an important principle for sustainability systems to uphold. It calls for disclosure and keeping an open and easily accessible account of methodology, intent of data use, who will use it and for how long, as well as how the data, the analyses, and the learnings will be shared, and with whom. It is important to think of transparency in terms of how the data is being released and whether all necessary steps to protect individuals have been considered. Ultimately, the responsibility of making these choices lies with the data controller.

5. Resources

This section includes a compilation of websites and publications that can serve as additional guidance and learning resources related to developing strong organisational policies and procedures for incorporating informed consent into ethical data collection practices for the Delta Framework indicators. All hyperlinks were last accessed on 20 January 2022.

- [Causeit](#) focuses on supporting organisations in digital transformation. Their guidebook on [data ethics](#) includes lots of relevant content and considerations related to informed consent.
- [EU Code of conduct on agricultural data sharing](#). Guidelines developed by nine (9) initially agro-associations for processing and sharing agricultural data. The Code is focusing on the contractual relations and provides guidance on the use of agricultural data, particularly the rights to access and use of data. Its scope is to create trust between the partners, set transparency principles, and define responsibilities.
- [DLA Piper](#) is a global law firm with lawyers located in more than 40 countries. The site maintains a [clickable map framing data protection laws across the globe](#) and includes a [downloadable handbook of data protection laws across the globe](#).
- The [humans of data](#) site provides a variety of articles and guides for data science and governance. This site includes an article entitled [Everything you need to know about informed consent](#).
- The United Kingdom Information Commissioner's Office ([ICO](#)) is an independent authority within the UK set up to uphold information rights in the public interest. They promote openness by public bodies and data privacy for individuals. ICO has produced a comprehensive guidance⁶ for consent as the lawful basis for processing of personal data under the General Data Protection Regulation. It is comprehensive and includes checklists, examples, links to other guidance, and further reading that are helpful for understanding consent that can be applicable beyond compliance with the General Data Protection Regulation. The ICO site includes a thorough framing of [informed consent](#) related to the EU General Data Protection Regulation and includes guidance for [anonymisation and managing data protection risk](#).
- [ICT Works](#) is a community for international development professionals utilising new and emerging technologies to support social and economic development. The article [How to add informed consent to your responsible data practices](#) explores basic principles and some implications of obtaining consent digitally.
- [ILIR Clippings](#) includes a story about [using images to help obtain informed consent](#) that may be useful in some contexts.
- Jouanjean, M., et al. (2020), "Issues around data governance in the digital transformation of agriculture: The farmers' perspective", OECD Food, Agriculture and Fisheries Papers, No. 146, OECD Publishing, Paris, <https://doi.org/10.1787/53ecf2ab-en>. This report focuses on farmers' concerns around access, sharing, and use of agricultural data and explores whether and how existing policy frameworks and other sectoral initiatives can help to foster greater trust.

⁶ United Kingdom ICO, [Consent](#).

- Myer, M. (2018), "Practical tips for ethical data sharing", *Advances in Methods and Practices in Psychological Science*, Vol. 1(1) 131-144, <https://doi.org/10.1177/2515245917747656>. This report is written as a tutorial, directed at incorporating data sharing plans in research initiatives. It includes discussion of what to say and not say in consent forms, tools for data de-identification and how to think about the risks of re-identification, and what to consider when selecting a data repository. The author also discusses the ethical and regulatory issues raised by sharing data when the consent form was either silent about data sharing or explicitly promised participants that the data would not be shared.
- [UK Data Service](#) provides a comprehensive [learning hub](#) and guidance for obtaining [consent for data sharing](#). The consent for data sharing page includes a general overview and links to further information including FAQs on GDPR, special considerations when gaining consent, a model consent form (see link below under templates), an example information sheet, and a survey information letter.
- Inter-University Consortium for Political and Social Research ([ICPSR](#)) is an international consortium of more than 750 academic institutions and research organisations. It maintains a data archive for research in social and behavioural sciences, and produces publications that address issues related to [data stewardship](#). The site also includes [recommended informed consent language for data sharing](#).
- Technical Centre for Agricultural and Rural Cooperation ACP-EU (CTA). [Review of codes of conduct, voluntary guidelines and principles relevant for farm data sharing](#). Reflections on the relevant codes in Agriculture (except the recent Australian Farm Data Code). Commonalities and differences between farm data codes, key challenges and recommendations for a farmer centred code of conduct on farm data.
- Wisemana, L. et al. (2019), "Farmers and their data: An examination of farmers' reluctance to share their data through the lens of the laws impacting smart farming", *NJAS - Wageningen Journal of Life Sciences*, Volume 90-91, <https://doi.org/10.1016/j.njas.2019.04.007>. Discusses challenges such as farm data ownership, privacy, cybersecurity and the equitable sharing of the benefits of digitization and data collection.
- World Bank Blog. (2021), "[How can policy allay farmers' concerns around agricultural data access, sharing, and use?](#)"

6. Templates

There are a variety of template examples of informed consent available online, particularly through internal review board pages of research institutions and universities. A selection of examples is compiled for consideration to inform development of organisation-specific approaches related to Delta Framework indicator data collection processes. These example templates should only be considered as starting points and it is strongly advised that you modify your specific data collection initiative and adhere to organisational data governance policies and procedures.

- [Open Brain Consent](#) includes a list of sample consent forms and their version of the [ultimate consent form](#).
- Oxford's research support page includes a [guidance and a variety of templates](#) for informed consent.
- Smithsonian Institution provides a very [basic template](#).
- UK Data Service 2018 [template](#) for data collection and research.
- University of Michigan [Research and Ethics Compliance](#) site includes a variety of downloadable templates and content regarding informed consent.

Annex 1: Considerations for categorising personal and sensitive data

Personal and sensitive Data⁷

The differentiation between personal and non-personal data forms part of the development of an organisation's data inventory⁸ and should be a step that is planned under the organisation's data governance policies⁹.

An organisation that is collecting and using personal data must have a legal basis for doing so, and it is subject to a variety of constraints. Personal data is information through which an individual can be either directly or indirectly identified. Personal data is a fundamental in the field of data protection law. Sensitive data is a special category of personal data that is considered especially sensitive and data protection laws restrict the use of this type of information. However, what precisely constitutes personal and sensitive data is sometimes interpreted differently across jurisdictions, so it is important to seek legal advice to ensure organisations are processing such data in accordance with the law. The most common list of categories for sensitive data include information relating to a person's health, race, genetics, political or religious beliefs, sexual orientation, trade union membership, criminal record, and biometric data. For an overview of the issues to consider when sharing personal and sensitive data, refer to ISEAL Data Governance Resource 4, "[Structuring data sharing agreements for personal or sensitive data](#)".

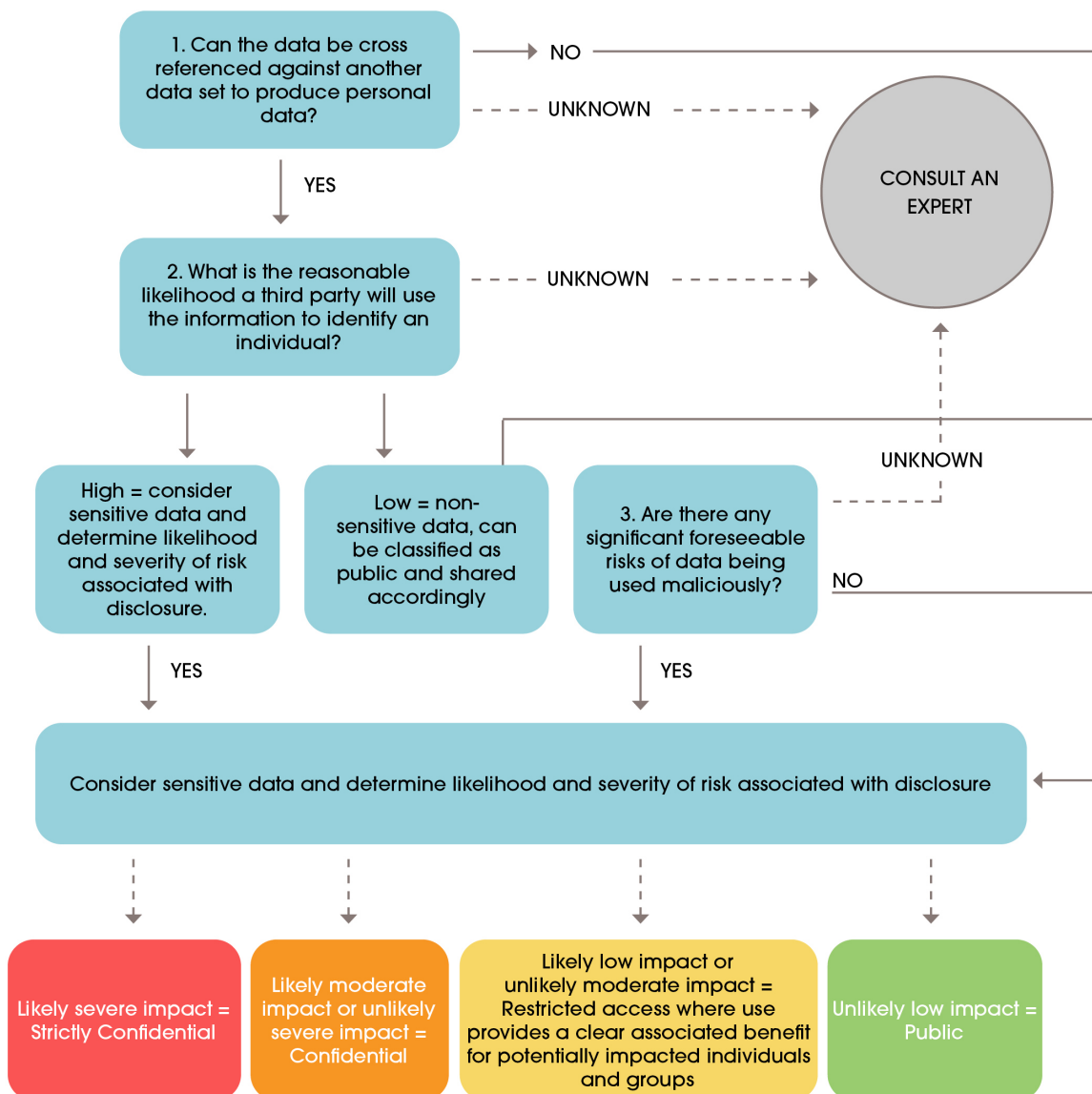
It is important to also bear in mind that data that does not appear to be within these special categories may become sensitive data when placed in a particular context or inadvertently become sensitive data, even where an organisation has not intended to hold sensitive data. An example might be where a group, community, or individual can be identified using location data and that group, community, or individual becomes a target for persecution or acts of violence. In this instance the location data would then become legally classified as sensitive data.

Organisations can use the following decision tree to support choices in categorising their data.

⁷ This annex is slightly modified content from [2020 ISEAL Guidance](#) (reproduced with permission): Structuring data sharing and licensing agreements.

⁸ See ISEAL Data Governance Resource 2: Developing a data inventory.

⁹ See ISEAL Data Governance Resource 3: Developing your data governance policy.



Use of the above decision tree must be context specific. This means that there will always be a degree of flexibility in applying this classification mechanism, and the decision maker will need to navigate based on their own experience and expertise. Where lack of experience and expertise is an obstacle to decision making, we recommend seeking advice from experts or colleagues with complementary knowledge.

Think about what data gets shared, and the implications of sharing (taking into account the context and point of view of those to whom the data relates), as you define licensing terms and conditions that can reduce the risk of harm while still permitting beneficial outcomes.

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