

# An Ethics Framework for the Data and Intelligence Network



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# An Ethics Framework for the Data and Intelligence Network

The aim of the Data and Intelligence Network is:

*to provide a safe, expedient and ethical access to use data and intelligence from across public services in Scotland to effectively manage our response to the public health emergency caused by Covid-*

*19*

## Introduction

This Ethics Framework draws on the work of a number of similar frameworks that have been created in recent years at home and internationally. Most notably building on the [Caldicott Principles](#) and on the UK Governments [Data Ethics Workbook](#). It does so to ensure consistency of standards, but is framed specifically to meet the immediate needs of the Data and Intelligence Network working in the extraordinary environment of this public health emergency.

## What is the Data an Intelligence Network?

The Data and Intelligence Network [DIN] is a cross sectoral network, brought together by Scottish Government. It brings together partners from central and local government, across health and social care, along with skilled data scientists and academics. The DIN includes data holders, data users, data analysts, researchers and those managing the pandemic at national and local levels. It was set up in this way, to recognise that managing the pandemic required clear leadership and collaboration from across public services. It aims to help remove barriers to operating collaboratively; this requires people across public services to pool expertise, resources and to align regulation, guidance, systems and processes in the public interest in order to:

- Make accessible data from health and social care, the wider public and private sector and research projects to help inform effective pandemic response at national, local, and sectoral levels and to help evaluate the impact that COVID-19 has on health, care and societal harms.

- Mobilising a network of data and intelligence expertise across local authorities, health boards, Departments of Public Health, Health and Social Care Partnerships, Public Health Scotland, other public bodies, Scottish Government and academia.
- Working with local and regional delivery teams to co-produce rapid, actionable insights, integrating activity across Local resilience partnerships (charged with managing local responses) and the underpinning agencies to ensure sustainability...
- Inform policy making in Scottish Government and across public services to help protect vulnerable populations and minimise the spread of COVID-19 in Scotland by quickly identifying COVID resurgence, clusters, outbreaks and detecting co-circulation with winter respiratory viruses.

The DIN brought in expertise on ethics, governance, engagement and open government from across disciplines to ensure that the people using the intelligence and data and are making decision are equipped to do so responsibly and with processes, skills and systems of governance in place to support this.

## **Why do we need an Ethics Framework for the Data and Intelligence Network?**

Managing the Covid-19 pandemic effectively means understanding the impact of the virus at national, local and individual level. Scottish Government has published and updated the [Coronavirus \(COVID-19\): framework for decision making](#) along with a range of sector-specific guidance to provide transparent information on the plans to move out of lockdown safely. The routemap in this document shows that the pandemic is more than just a health crisis, it is also a social crisis and an economic crisis that is causing harm on an unprecedented scale. This requires difficult decisions to be made to reconcile these various inter-related harms in order to minimise overall harm. It also recognises that while the virus can affect everyone, the harms caused do not impact everyone equally. This means that using and linking data to understand all of the impacts is vital if we are to protect human rights overall and those most at risk in particular by the effective use of the information. The Data and Intelligence Network was established to provide up to date and accurate information to support decisions as we move through the phases of the routemap. This Ethics Framework is designed to provide a means to address the moral dilemmas that are presented in reconciling the privacy, rights and freedoms of people in Scotland with rapid and proactive, responsible use of information to manage the pandemic.

A public health emergency requires both speed and accuracy of response. In addition, it is the responsibility of public services to share data in ways that mean we can all better understand the whole picture. This is a time when **Caldicott principle 7; the duty to share information can be as important as the duty to protect patient confidentiality** is entirely relevant. Had it been possible in March and April 2020 to quickly bring together anonymised Covid-19 virus test data, hospital discharge data and care home admissions along with information on staffing, the impacts of the virus on the care home population may have been spotted earlier.

It is also important that making decisions quickly does not **diminish the standards for the use of data or intelligence** in any way – indeed they become more important as the management of the emergency requires a clear understanding of how people are infected, affected and how the virus is spread. The response must be proportionate to the urgency and threat posed. Which may mean increased surveillance **of the population to monitor the virus and the impacts of the pandemic in ways that may be unacceptable at other times**. The potential impact of this on public trust cannot be underestimated. **It is vital that we can provide reassurance to people about the use of the information they share** so we all understand the risks and feel a shared responsibility to act and accept the **limitations on our rights and freedoms that may be necessary if we are to keep people safe from the virus**. The information needed to manage the Test and Protect system is a particularly sensitive example of this and one that has, in other countries, been the subject of significant public concern. It is therefore important that the way the data is used is **both trustworthy and trusted** and is seen to be. This requires careful framing of the decision making processes and systems to ensure they embed transparency. It also requires data users to understand the benefit of engaging the public in ways that inform these decisions and so that they can review them; to ensure we have better informed decision making. The importance of engaging the population is highlighted by the World Health Organisation, which has clearly stated that our communities should have a voice, be informed, engaged and participate in managing the pandemic.

## Ways of Working

The DIN is dynamic and changing to adapt to the needs of the emergency. The aim is to provide cross-sectoral leadership and governance that will set out its operating model including provisions for governance and information governance; setting out where responsibilities lie for decisions and the implications of those decisions. It will require secure use of technology, transparent and effective information governance and, perhaps most important,

will identify and secure people with the range of skills required to undertake the work effectively and at pace. This includes the skills to address the **moral or ethical dilemmas** that will face us, particularly if we operate at pace and do so while protecting people's human rights and personal freedoms and recognising the unequal impact of Covid-19 .

Inevitably developing a more collaborative way of working is iterative; with this Framework as one piece of the governance framework that will be developed by the DIN. It will be important that those people with the skills and understanding of using data for public benefit are actively involved at all levels of the DIN's governance. For those people who are providing ethical input and are operating at speed the processes need to be in place to provide sufficient and clear information on which to base ethical advice, sufficiently early in the process to be able to properly influence the design of the project, problem or bid. That means considering ethics **at the inception of a project** and having access to advice in the 'engine room' both of the problem owner and of the DIN, in order for that advice to be able to influence the framing of the problem and solution.

As the DIN is operationalised a workbook will be developed to provide step-by-step guidance for the use of the Ethics Framework within that wider operating model. But it is important to stress that this is not a tick-box exercise. The ethics advisers involved need to have experience, confidence and competence along with a clear authority to offer effective, timely and transparent ethical advice. So, while ethics is and should be closely linked to information governance there will be times when the ethical and moral questions will determine the scale or scope of project work or whether or not the relationship between the public and private interest is being properly taken into account. They therefore need to be sufficiently independent to provide clear advice. During the initial phases of the DIN set up this advice is being provided by members of the DIN with knowledge in this area. As the DIN moves into effective operation there needs to be dedicated ethical advice available to the DIN centrally and to the project teams. The DIN is made up of people in a range of organisations, it is also worth noting that these are also likely to be the organisations who will be owners of the problems or delivery agents. Which means that the identification of roles and responsibilities in both the governance of the DIN itself and in each of the projects or programmes delivered by the DIN is vital, including having access to ethical expertise. The existing compliance structures like the Public Benefit and Privacy Panel have been revised to take account of the pandemic and will continue to operate, overseeing the granting of permission for the use of data and

intelligence. Transparency of these arrangements will be important for public trust as will clear external monitoring and scrutiny.

The DIN will identify priority projects requiring the use of combined data, identify the analytical capacity and secure location for the work to be carried out and ensure the safe use of the outputs. It will maintain a dynamic catalogue of data sources.

### Why does Security Matter in an Ethics Framework?

Managing the public health emergency effectively requires the bringing together of sensitive information, which, because of the way it is collected, has not necessarily been subject to specific consent from individuals. **Safety of use, to ensure it is de-identified and always secure, is therefore absolutely paramount.** Additionally, the research and data analytics undertaken by the DIN will be managed in specified, secure environments with monitored perimeters that are subject to testing to ensure malicious actors cannot penetrate the data. The DIN will put in place systems of governance and information governance that are transparent and rigorous.

The DIN will, of course, utilise and build on the existing information governance systems. It will also try to align the processes and practises to ensure rapid responses to applications during the public health emergency **while continuing to maintain the information governance standards and meet the requirements of the individual data controllers and their organisations, who will remain responsible for the use of the data or information.** This is to provide increasing consistency and the work on DIN governance and information governance will be dynamic and will be refined as the DIN becomes established. They will also be informed by the Ethics Framework and will, through the systems and processes, ensure that ethics are at the heart of the DIN's decision-making. The DIN and information governance processes will be developed and published separately from this Framework.

Having a secure system of workspaces to bring data and information together for analysis is a vital component of being able to reassure the public that their information is being used safely. In recent years a number of national and regional 'Safe Havens' and 'safe linking and working spaces' have been established to use health, statistical and other public service data securely. These are designed to provide secure environments supported by trained staff and

agreed processes whereby data can be processed and linked, making it available in a de-identified form for analysis. They are designed to safeguard confidential information. Researchers and data analysts applying for access to use the data must adhere to their principles and their bids are subject to approvals via one of the four approvals boards- Public Benefit and Privacy Panels or their equivalent- that will continue to be at the core of the DIN delivery model.

A Charter setting out the requirements for the Safe Havens provides principles and standards for the routine operation of these, where data from electronic records can be used to support research when it is not practicable to obtain individual patient consent while protecting patient identity and privacy. Information on the Safe Havens Charter can be found at Charter here [Safe Havens Scotland](#) and [Safe Havens- NHS Research Scotland](#) .

Pressures on the current system and its complexity, along with the need to improve response times during the pandemic, have highlighted the requirement for the DIN to build collaborations, partnerships and to set out clear and aligned ways of working that build on what is good in the current system. There is a clear imperative to align guidance, systems and processes if the work of the DIN is to be successful. There is also a need for investment in the skills and resources that are needed to expedite data analysis or research without losing any of the ethical rigour.

The benefit that the DIN brings is that it feeds ethics and information governance issues into projects from their inception; as issues are identified, a problem statement is developed and then prioritised, thus helping to bring time savings as they then go through the existing permissions processes. This will create a clear ethics assessment for the project, set out in a way that it will satisfy the needs of the user, data holder and the permission authority or public benefit and privacy panels.

## **Transparency, Monitoring and Scrutiny**

This speed of response to the pandemic makes the scrutiny and monitoring of the work of the DIN, and the transparency of the processes, absolutely vital. There should be a culture of proactive publication, both about the DIN itself and the work it is delivering. Public engagement and participation should be seen as a matter of routine, particularly where the use of data is contentious.



Publications should be in language that can be understood by the public and easily accessible. Where possible to do so securely, the DIN should also publish the methodology, metadata about the analytical or research model, and/or the model itself.

Eventually the DIN may benefit from having a distinctive web platform, but initially it may have to make use of a number of existing sites of the partner organisations involved in the DIN.

Having effective systems to identify who is responsible for applying the Ethics Framework at each decision point will ensure the operating model has advice at the right points. However, it does not provide independent scrutiny. In the medium term, given the exceptional circumstances and the practical difficulties in providing high quality and effective public engagement when projects are being delivered at speed, consideration should must, therefore, be given to providing external scrutiny to monitor and oversee the operation and to assess whether the outputs of the DIN have delivered public benefit set out in their Ethics Assessment at the beginning of the project.

In the short term this could be provided by an advisory board of experts appointed by Scottish Government (to take over from short-term task and finish groups created to establish the DIN). In the longer term a more effective means of securing independent advice would be the appointment of a Data Ethics Guardian or Commissioner for Scotland.

In addition, there is an opportunity for Scotland to innovate by having the Guardian or the Data and Intelligence DIN appoint a panel of randomly selected members of the public, informed by wider and deeper public engagement as appropriate, thus effectively creating 'citizen auditors' to monitor the work of the DIN. They would be supported by a small number of expert advisers.

## **Communications, Engagement and Participation**

The ethical dilemmas that are presented in reconciling the need for privacy while ensuring public benefit of managing the Covid-19 pandemic are exceptional, and are such that the World Health Organisation has clearly stated that the public should have a voice, be informed, engaged and be able to participate. In order to maintain trust in Scotland's response to the COVID-19 pandemic, it is therefore critical that the public, and people in the DIN or who use the products,

understand the activity of the DIN and are able to see that a trustworthy and trusted system is being created.

Therefore, there is a need to **proactively communicate and engage people in the work of the DIN**. This will be in order to inform a range of key audiences, including users, researchers, and the public, to share information on research bids at every stage and, where possible, to test the results with both groups who are affected by it and with the general public.

Both a communications and engagement plans will be developed to identify the audiences to whom the work of the DIN needs to be communicated and the ways that the public might become more involved. This is work that needs to be collaborative: the public-service partner organisations will each have a part to play, as will those undertaking the data analysis or research. It is not for the DIN to deliver engagement on the research project from the centre, but there may be a valuable role for DIN partner organisations to develop advice and guidance to help projects to develop effective engagement plans of their own.

Activity needs to promote the work of the DIN alongside an engagement approach that ensures insights from the public are fed back into the work of the DIN. An ongoing feedback loop needs to be established to ensure that stakeholders have clear channels that allow them to provide input that is subsequently fed back into activity. It is not the role of the DIN to undertake all of the engagement on Covid-19, or even on the role that data and information plays in that management. It is also important for an engagement plan to recognise and align this work with other activities already underway in Scotland. These include Scottish Government's work to develop a refreshed Data and Digital Strategy, the work to set out what being an Ethical Digital Nation means, and the development of a long-term strategy for the future of health and social care, all of which will be informed by the impact of Covid-19. In addition, public engagement is important in both local authorities and across the health and social care systems. Nonetheless, the work of the DIN is an important illustration of how information and data can help us to manage and understand the pandemic. The plan therefore needs to identify key audiences, set standards, identify who will be responsible both for engaging the public and sharing learning within the DIN; and perhaps most importantly identify the kinds of project where engagement will be a high priority, because of their nature or they types of data to be use are contentious or likely to be of concern to the public

## How to use the Ethics Framework

The Framework consists of a set of values and principles that can be used by the DIN either to apply to strategic decisions or to help frame problems or solutions for which members of the DIN are seeking to use data or digital technology. These are questions and prompts that will be found in much of the existing information governance systems in Scotland, but the processes and speed with which the DIN will apply them are specifically designed for the circumstances of the Covid-19 pandemic. Both the Framework and how it is applied will need to be reviewed regularly. A full review will be required should the work of the DIN extend beyond the public health emergency.

At the outset of projects being proposed the teams making the proposal will complete an initial template which includes a problem statement as well as initial information on both information governance and ethics. At this stage the team will be asked to complete an Ethics Assessment. This is to ensure the solutions to the problem can be designed in an ethical way – asking not whether something can be done, but whether it should be done. Then continuing to refer to the Ethics Assessment throughout the project to highlight and address potential issues during the project lifecycle. The development of an ethics assessment should be done by the ‘problem owner’ and their team, it will be a core element of design. We would encourage the use of the prompts and questions to help explain both the public benefit and potential harms of the work candidly. These should help identify the work necessary to manage the pandemic and highlight where what is proposed goes beyond this purpose, into research or analysis which may be of academic interest or be an innovative approach as well as having public benefit. Making transparent these additional elements will help to properly assess potential public interest.

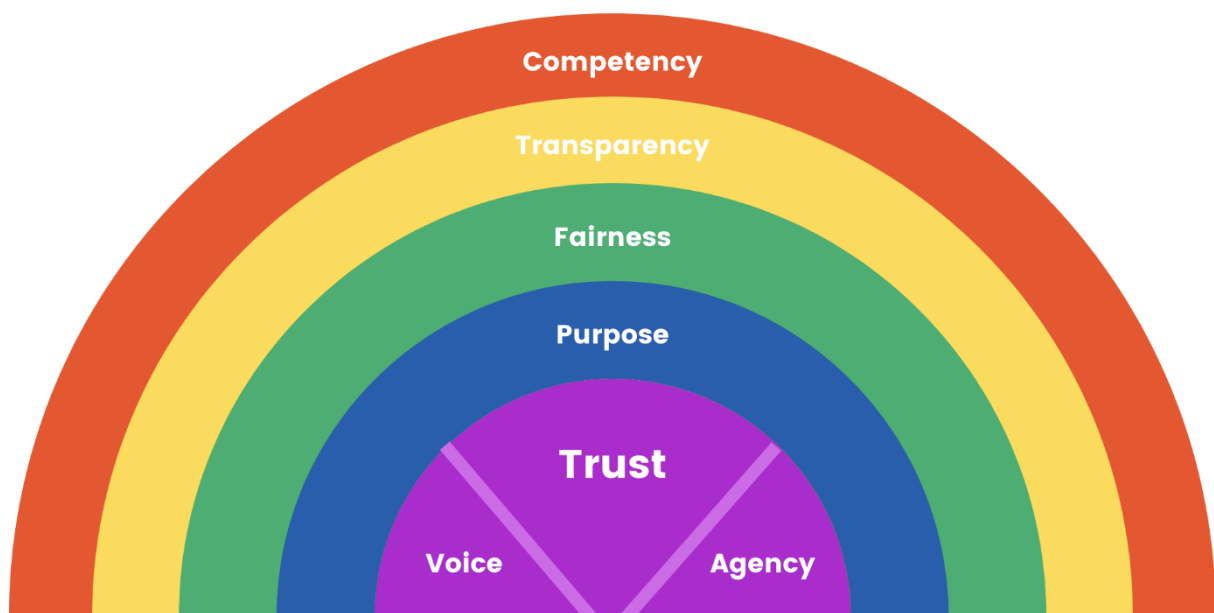
We also recognise that the scale and scope of projects undertaken by the DIN vary widely: some are limited in scope and can expect to be completed in hours or days, while others will have a profound and potentially long term impact on end-users. The Framework is designed to help the owner of the problem to identify the scale of work as well as the risks and benefits early in the process so that ethics, transparency and public involvement can properly be taken into account and be proportionate. The thinking it requires and the information it helps to distil should aid the project or programmes to complete the permissions required by the Public Benefits and Privacy Panels and the other required compliance documentation.

Think of Ethics Assessment as a map with key questions to help you think about your project design and its impact. The ethics assessment should be a dynamic document that is used to review and evaluate **the work** at the end of the project. This will help your team and others to understand the impact of your project from an ethical perspective.

The Ethics Framework should be used:

- To inform decisions on the governance of the DIN emergency
- To guide the development of projects and programmes to manage the health emergency
- form the scale, scope and public benefit of the work of the DIN during the health emergency

## Ethics Rainbow – Values and Principles



### Values

**Purpose** – responding to public health needs while balancing the rights of the citizen

**Fairness** – consistent treatment of citizens, empowering citizens’ voices

**Transparency** – a systematic approach to communication, arming citizens with meaningful information

**Competency**– adherence to the rule of law

**Voice and Agency**– the public are both listened to and heard

*These all lead to the building of trust in the activity of the DIN. Trust is earned through the consistent demonstration of adherence to these values.*

## **Principles**

**RESPONSIBLE:** Recognise the need to behave in a **trustworthy** way in the use of data and digital technology across systems and processes

**ACCOUNTABLE:** Be **accountable** and transparent to independent scrutiny and oversight, use **reliable practices** and work within your skillset

**INSIGHTFUL:** identify the limitations of the data and digital technology being used and recognise unintended bias, identify and apply mitigation

**NECESSARY:** Identify **reasonable** and **proportionate** requirements to meet that need

**BENEFICIAL:** Start with a clear articulation of need, **public benefit** and risks during the public health emergency

**OBSERVANT:** Implement all **relevant legislation and codes of practice**, including any relevant emergency legislation for the Pandemic

**WIDELY PARTICIPATORY:** Embed **public participation** through the development, implementation and monitoring of the work of the DIN

# Appendix

## *The Ethics Workbook*

The Ethics Assessment Process will be set out in a workbook to help guide project teams through the life of the project. Each of the stages will have prompt questions to aid that journey and to help this to be an integral part of the process and not a one off exercise. The stages it covers are: The Project; The Data or technology; The Public; Project Close.

### **1. The Project**

1.1 State the purpose and scope of your project.

**NECESSARY:** *What is the particular need for your project? How have you shown that your project is proportionate to the intended aims?*

1.2 State the intended impact of your project on the pandemic.

**BENEFICIAL:** *How have you justified the need for your project in the context of the public health emergency?*

1.3 What is the public benefit of your project...?

- At an individual level?
- At an aggregated level?
- At an institutional level?
- At a societal level?

**BENEFICIAL:** *How have you considered public benefit across a variety of groups, communities and categories?*

1.4 What are the potential risks of your project...?

- To the individual?
- At an aggregated level?
- At an institutional level?
- At a societal level?

**INSIGHTFUL:** *What steps have you taken to identify limitations of the project with regard to both the data and the intended impacts?*

1.5 How do you plan to mitigate these risks?

**RESPONSIBLE:** How will you ensure you use the data responsibly?

**OBSERVANT:** What relevant legislation and codes of practice will you reference to support your answers?

1.6 What other methods have you considered to deliver this project? Why have you selected this method?

**INSIGHTFUL:** How have you shown that data is the only way you could achieve the intended outcomes?

**NECESSARY:** What makes this method proportionate to the project aims?

1.7 Which other stakeholders or institutions might benefit (directly or indirectly) from the use of this data and/or methodology?

**RESPONSIBLE:** How have you identified potential positive and negative applications of your project? What are the implications?

## **2. The Data and Digital Technology**

2.1 What data sources are required for this project?

**NECESSARY:** How have you identified and chosen these sources?

2.2. How will these data sources be used, for what purpose, for how long and what will happen to it at the end of the project?

**ACCOUNTABLE:**

2.3 Have you completed the necessary Information Governance / Data Management /Data Protection Impact Assessment protocols for a COVID19 D&I Network project?

**OBSERVANT:** Reference the relevant legislation and codes of practice appropriate to your project. Evidence clearly additional legislation as a result of the Pandemic.

2.4 What steps have you taken to ensure that the minimum data required, or synthetic data, is used in your project?

- **RESPONSIBLE:** What data variables have you chosen to include and why?
- How are you balancing public benefit and privacy against project accuracy?

2.5 If bringing together data sets, what are the risks of this data linkage exercise...?

- At an individual level?
- At an aggregated level?
- At an institutional level?
- At a societal level?

**INSIGHTFUL:** What steps have you taken to mitigate any risks associated with data linkage?

2.6 What steps have you taken to ensure the limitations of the data and the digital technology being used are fully understood, including metadata?

- ◆ **INSIGHTFUL:** *Have you considered limitations such as bias, representation, data gaps, data variables, accuracy, excessiveness etc.? How have you communicated any limitations to the project team?*

2.7 How are you identifying and how do you intend to deal with errors and biases in the data?

- ACCOUNTABLE:** *What strategies have you used? How have you ensured that these will be reviewed and assessed appropriately?*

2.8 How will you embed privacy by design in any insights or outputs of the project?

2.9 Have you designed the approach with the public, the service user, policy team or a subject matter expert; including providing sufficient time and information for this to be effective?

- WIDELY PARTICIPATORY:** *How have you engaged with the public on your project so far, and how has this impacted your project's design?*

2.10 How will you communicate any assumptions throughout the project?

- ACCOUNTABLE:** *How have you justified any assumptions made?*

- BENEFICIAL:** *How have you ensured that assumptions made are still for public benefit?*

- WIDELY PARTICIPATORY:** *How have you ensured that this information is widely accessible?*

2.11 How will you communicate the accuracy, credibility and reliability of any insights and outputs?

- INSIGHTFUL:** *How have you documented the accuracy of your project?*

- WIDELY PARTICIPATORY:** *What steps have you taken to ensure this information is widely accessible?*

2.12 How will you ensure replicability? Could another analyst repeat your procedure based on your documentation?

- ACCOUNTABLE:** *How have you documented your work, and who can access this information?*

2.13 Where can you publish your methodology and outputs?

- OBSERVANT:** *What guidance, legislation and requirements have you considered when decided where to publish your work?*

- WIDELY PARTICIPATORY:** *How, if appropriate, have you planned to make this work widely accessible?*

2.14 How much of the work can you and your team speak about openly while protecting privacy?



**BENEFICIAL:** *What steps have you taken to ensure the whole project team is aware of their responsibilities?*

2.15 How do you intend to explain the methodology and output of the project to a variety of audiences?

**ACCOUNTABLE:** *What communications channels have you considered to ensure that your project methodology and results are easily accessible and transparent?*

**WIDELY PARTICIPATORY:** *What format/language/style would allow your methods to be widely accessible? If not appropriate to publish your findings publicly, explain why.*

### **3. The Public**

3.1 Have you clearly explained why you need to use this data in ways that members of the public could understand?

3.2 Do the public identify the same benefits and risks? Do the public balance them in the same way?

3.3 Does this use of data or technology interfere with or risk the rights or freedoms of individuals?

- If the answer is yes, is there a less intrusive way of achieving the objective?
- have you set out a mitigation strategy to reduce the risks?

3.4 How will you reconcile the rights of the individual with the interests of the community or society?

- Have you engaged the public to ensure the risk/ benefit analysis is viewed by them in the same way?
- By using data irresponsibly that the public has freely volunteered, would your project jeopardise people providing this again in the future?
- If yes, what is your mitigation strategy?

3.5 How has your proposal taken account of the views of the public and the groups adversely affected?

3.6 Have you thought through how you will engage the public in using the outcomes in the next phase of the work?

3.7 Have you completed an engagement plan which segments audiences, identify existing opportunities for engagement and plans for public participation for the design, delivery and scrutiny of your work; particularly where issues are contentious. Have you got senior sign-off for this plan, including the resources needed and the implications for the timeframe for decision-making and implementation?

3.8 How will you ensure that the whole team working on the project are aware of the DINs ethics values and principles?

3.9 How have you communicated an appropriate reporting framework for any ethical issues that arise during project delivery and after implementation?

## **4. Project Close Out**

4.1 How confident are you that the outputs are valid and reliable, and that any limitations and assumptions have been accounted for?

4.2 What is the quality of the project outputs, and how does this stack up against the project objectives?

4.3 If necessary, how can you (or external scrutiny) check that the combined data or algorithm is achieving the right output decision when new data is added?

4.4. What technology, if any, will be required for your project outputs to be used successfully? What are the implications of using this technology? (E.g. mobile apps)

4.5 Who has access to insights or outputs of the project, and how are they being given the appropriate support and training to use these outputs responsibly?

4.6. To which audiences will you communicate your findings/share project outputs, and why?

4.7 What structures are in place to ensure that your project outputs are used *only* for their original purpose and in the context of the pandemic? Are these boundaries clearly stated?

**For further information, contact**  
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