

Discussion Paper: An international example of Data Ethics Advisory

Purpose and scope

1. This paper has been prepared on behalf of the Government Chief Data Steward for the Data Ethics Advisory Group. It discusses the [National Statistician's Data Ethics Advisory Committee](#) (NSDEC) operating in the UK which is supported by the UK Statistics Authority (UKSA). This paper explores practices of the committee and the support team (particularly [triage and engagement](#)) which may be relevant to the function of the Group as it matures. This paper is not official New Zealand government policy.
2. This paper is intended to support the general discussion of 'best-practice' for data ethics advisory and the function of the Group. The issues canvassed should not be considered reflective of the position of any specific government agency (including Stats NZ).

Executive summary

3. The NSDEC was established to advise the National Statistician in areas of access, use and sharing of public data for research and statistical purposes. The committee aims to develop public trust in the ethical use of government data while enabling data benefits that serve the public good. This is similar to, but not necessarily the same as, the independent advisory function that the Group provides to the Government Chief Data Steward.
 - a. Projects and policies are self-assessed in their entirety based on [22 sub-principles](#), and in cases where potentially ethically contentious data is used or there are risks or harms which cannot be fully mitigated, it is recommended to go before the committee for a 'full independent ethical review'.
 - b. The NSDEC provides more technical advice specific for projects and policies. This is a different approach from some other advisory groups such as the Danish [Data Ethics Council](#) which addresses broader issues such as the implications of data linkage.
4. Development of processes has helped the NSDEC streamline its core functions over time. There has been a deliberate transition from a 'start-up' phase into a 'support' phase to address an increased level of engagement and to better advise for the developments that have occurred with 'big data' and the data science field.
 - a. The 'start-up' phase established guiding ethical principles and a narrative to encourage cultural change. The 'support' phase developed sub-principles, user-support processes, a [self-assessment tool](#) and project-based themes or '[precedents](#)' which could be applied to different projects with similar characteristics.
5. Over 150 projects have been engaged, either directly by the NSDEC or by its support processes since 2015. Approval has been granted for [44 projects](#) which have gone directly to the committee. 'Very few' projects are rejected by the Committee as prior support helps to mitigate ethical issues at early stages. Feedback can often involve recommended changes and researchers have been receptive and responsive to feedback. The findings and considerations of the advisory process are made public in meeting minutes for transparency purposes.
 - a. An auditing process has recently been developed and is carried out by a support team to ensure recommendations, such as major revisions, are acted on.
6. Currently, submissions primarily involve the linking of health data, research regarding children or some other aspect of qualitative research. Generally, these are government or academic led projects rather than projects involving private partners and government-held data, although these types of projects are also accepted.

The NSDEC operates in a *similar* way to the Data Ethics Advisory Group

8. Initially launched in 2015, the NSDEC is designed to advise the National Statistician on access, use and sharing of public data, for research and statistical purposes, and to ensure these activities are ethical and for the public good. The group was established with three aims:
 - a. *“provide ethical consideration of proposals to access, share and use data*
 - b. *advise on individual policies and projects against NSDEC’s ethical principles*
 - c. *develop a consistent ethical framework for relevant projects related to official statistics”*
9. Relative to other international advisory groups, there are more similarities between how the NSDEC and the Group operate. Other prominent and public facing advisory groups have been listed in **Table 1** with some characteristics on their membership, resourcing, governance, and encouragement for innovation as *perceived* from online accessible information.
10. While general information about the NSDEC, and some other advisory groups, can be found easily (aims and a brief history), more technical information, such as resourcing, internal processes and feedback on functions is not easily accessible for the public. It is noted that most groups do include some form of contact (e.g. an email address or contact form), so interested parties can get in touch. This has been an obstacle for this stream of work and limits the communication and uptake of ‘best-practice’ to groups and individuals with personal connections to work in this space.
 - a. In particular, it is more difficult to find details for newly established groups and limited information was freely accessible for the Smart Dubai’s [AI Ethics Advisory Board](#) and the Singapore [Advisory Council on the Ethical use of AI and Data](#).

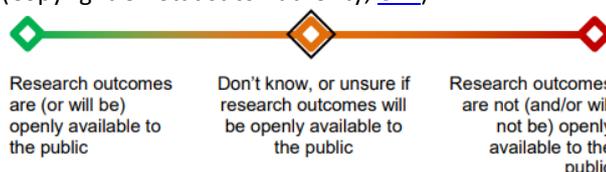
A ‘start-up’ phase helped the NSDEC to establish operating procedures

11. Early in development the UKSA formulated [six ethical principles](#) based on consultation with the NSDEC, established an [application process](#) and designed a narrative to express the need and benefit for ethical consideration when using government data. The ethical principles, which are subject to ‘periodic’ review (and external input), provide the underlying framework that is used by the committee to evaluate projects and include:
 - a. **Public good** – *“The use of data has clear benefits for users and serves the public good.”*
 - b. **Confidentiality and data security** – *“The data subject’s identity (whether person or organisation) is protected, information is kept confidential and secure.”*
 - c. **Methods and quality** – *“The risks and limits of new technologies are considered and there is sufficient human oversight so that methods employed are consistent with recognised standards of integrity and quality.”*
 - d. **Legal compliance** – *“Data used and methods employed are consistent with legal requirements such as the DPA, the Human Rights Act, the SRSA and the common law duty of confidence.”*
 - e. **Public views and engagement** – *“The views of the public are considered in light of the data used and the perceived benefits of the research.”*
 - f. **Transparency** – *“The access, use and sharing of data is transparent, and is communicated clearly and accessibly to the public.”*
12. The narrative that the NSDEC used set out to explain ‘why data ethics advisory is important’ and ‘what the benefits are for scrutiny of research projects’. This primarily targeted current users of government-held data through presentations at conferences and was expanded to other groups and audiences over time.
 - a. The *importance of data ethics* aspect was presented as a need to clearly communicate the ‘public good’ of research, in adherence with the [Research Code of Practice and Accreditation Criteria](#), and to assess the public acceptability through engagement.
 - b. The *benefit* aspect of NSDEC was presented as independent membership which gave impartial, credible and transparent perspectives to advise and challenge uses of data. The NSDEC promoted a consistency across the Government Statistical Service and provided independent justification for a given project over its development.

Transition to a 'support' phase helped the NSDEC to streamline processes

13. By the start of 2018, the NSDEC had engaged with and approved around 20 projects. To address an increased demand for advisory, the committee committed work to develop several workstreams:
 - a. Subprinciples to help expose nuance in ethical designs.
 - b. A self-assessment tool to encourage adherence from the outset of projects.
 - c. A support process for applications so that projects which needed NSDEC oversight were escalated.
 - d. A project-based 'precedent' approach to apply outcomes to different projects with similar characteristics.
 - e. An online learning component for users outside of government is under development and aims to be ready by the end of 2020.
14. Sub-principles were chosen to expand on the six-high level principles and there were 22 in total (shown in **Appendix 2** and **3**). For example, the 'confidentiality and data security' principle was broken in to 'direct identification' (individuals), 'indirect identification' (groups), 'data security', 'consent' and 'permitted use of data' sub-principles.
15. The [self-assessment tool](#) is a publicly accessible form which uses the sub-principles on either a five or three point Likert-type scale¹ with justifications for researcher selections. All sub-principles should be addressed or have a satisfactory justification for why it may be irrelevant for a given project. It is encouraged that researchers conduct self-assessment as early as possible to encourage an 'ethics by design' approach and repeat the process throughout the project lifecycle.
 - a. The self-assessment tool provides a consistent framework to enable NSDEC's principles to be applied to research. The UKSA provides specialist and interactive user support to support researchers whilst completing the tool, which serves as a start point of triage (general process tree is shown in **Appendix 3**).
 - b. The tool includes 'tolerance limits' which are used to avoid the averaging out of ethical issues in the overall score, and 'weights' for data types (e.g. when data includes information on health, children or vulnerable adults). When limits are reached it indicates to the researchers that they should consider actions to mitigate the ethical risks of a given sub-principle.
 - c. After completion, all assessments should be sent to the UK Statistics Authority's Data Ethics team to start processing.
16. The Data Ethics team supports the self-assessments with an open and friendly 'here to help' approach. This has been developed to foster interaction of researching groups with data ethics, to provide benefit to groups who undergo this process.
 - a. In cases where the received self-assessment has reached a tolerance limit this indicates an underlying ethical issue. In situations where mitigation is not possible or does not satisfactorily address the ethical issues, the project is recommended to be sent to the NSDEC for a 'full independent ethical review'.
 - b. In addition, if the data used is considered to be more ethically contentious (e.g. health data), a 'full independent ethical review' by the NSDEC would typically be recommended independent of the self-assessment results.

¹ A Likert scale is a rating scale which is often used in survey responses to a question or given parameter. E.g. for *public access to outcomes* (Copyright UK Statistics Authority, [URL](#)):



- c. In situations where risks and/or harms of ethical issues are perceived to be low, the Data Ethics team supports the application and can recommend other steps of self-guidance such as peer-review from other relevant units internal or external to the research institution.
 - d. This process is flexible and allows for changes during the development process and further guidance or review by the NSDEC can be carried out if and when required.
 - e. An auditing process is used to ensure that any recommendations which the support process or the NSDEC has prescribed, such as major revisions, are acted on, particularly when government-held data is involved.
17. Projects which the NSDEC has advised on has built up a library for particular research approaches and aims. The Data Ethics team has developed a project-based '[precedent](#)' approach where in cases where the outcomes for projects of similar characteristics can be reapplied and remodelled as required.

The NSDEC approach is unique from other data ethics advisory groups

18. The scope of the NSDEC is focused on providing technical advice for projects or policy rather than with a high-level technology or legislative focus like other groups (e.g. the Danish [Data Ethics Council](#)). This is similar to the approach that the Group which makes it a relevant model for best practice.
19. Managing workloads is an ongoing challenge as advisory groups develop and the level of engagement increases. The NSDEC 'support' approach is designed to streamline workloads and the key component of this is the self-assessment tool. Self-assessment tools have been implemented elsewhere, particularly for AI ethics guidelines², however it appears to be the only self-assessment that is directly associated and used as part of a publicly facing advisory group's processes.
- a. The total 'uptake' (e.g. how often the self-assessment tool is used but no further engagement with the Data Ethics team is taken) currently cannot be easily identified. There is an opportunity for self-assessment of this type to be implemented online in a way that can monitor the broader adoption of the self-assessment and in time be used to improve it (e.g. provide benchmarking or relative scoring). There is interest for the NSDEC to explore this in the future, however a deployment is reliant on available resources. The Smart Dubai [AI System Ethics Self-Assessment Tool](#) or Canadian Government [Algorithmic Impact Assessment](#) are examples of where an online implementation of self-assessment has been taken.
20. Transparency is a key principle for the NSDEC and all meeting papers and minutes are published on the UKSA [Website](#). For other groups which have broader scopes, transparency is reflected through public discourse, perhaps through public documentation (e.g. UK [Centre for Data Ethics and Innovation](#)), consultation (e.g. AU [National Data Ethics Committee](#)), public forums (e.g. NY [Automated Decision-Making Task Force](#)), or public lectures (e.g. the Danish [Data Ethics Council](#)).
- a. Advice delivery is carried out during meetings (typically four per year) and this is made publicly available in the meeting minutes alongside the full project application form. There are some case where time constraints require direct correspondence, rather than waiting for the next meeting. In addition, advice on revisions may be directly given. In these cases, correspondence is noted in the following meeting minutes for transparency.
21. Auditing is a relatively new function for the NSDEC. This workstream is carried out by the newly formed 'Data Protection Compliance Team' which has completed two data ethics compliance reports (one is included in minutes for [May 2019](#)). The Committee is currently developing

² For example, see the [Ethics & Algorithms Toolkit](#) and the [Algorithmic Impact Assessment](#)

auditing procedures, and this may include quarterly reviews of a sample of projects which have used the self-assessment tool.

- a. [Non-compliance](#) has not been a prominent issue for the NSDEC and processes have not yet been fully developed, as above.
- b. The Australian [National Data Ethics Committee](#) is formulating legislation for data sharing, and under this legislation there will be regulatory aspects which can be used for legal responses to non-compliance. However, the current project funding will not cover compliance aspects and submission for new funding will be required to enact this aspect.

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22. [Engagement](#) with the NSDEC has been encouraged primarily through efforts to develop strong narratives, for example: “it’s about making clear that the ethical processes are not there to serve as a blocker- the aim is quite the opposite”. This has involved internal communications approaches such as online training, actively engaging with the different business areas, and media such as blogs.

- a. This non-binding approach appears to be the primary way engagement is encouraged for advisory groups and it relies on a ‘moral obligation’ to seek advisory when needed. No mandated aspects were identified regarding advisory engagement during this work which indicates the current data ethics advisory processes are limited to parties who willingly engage.
- b. To improve this, advice delivery is aimed in a way that is enabling research rather than a judgement based on risks or harms, and groups which have engaged tended to be positive about the guidance and perceived benefits.
- c. The user support aspect was also noted as an important component to encourage engagement. This provided researchers a ‘place to go’ for advice rather than being left to navigate ethical considerations in isolation.

23. Notable aspects, like an ethical oath or an ethical seal (recommendations from the Danish [Expert Group on Data Ethics](#)), are not included in the NSDEC process.

The NSDEC process has similarities to data ethics groups and tools in Aotearoa New Zealand

24. Other groups conduct data ethics advisory functions relating to the public sector (e.g. ACC [Ethics Panel](#) or the Ministry for Social Development [Ethics Panel](#)) and some use assessment tools. Examples of assessment tools include the [Five Safes](#) which is used by the Integrated Data Infrastructure (IDI) for research projects and the [Privacy, Human Rights and Ethics](#) (PHRaE) framework used by the Ministry for Social Development (MSD) for internal projects.

- a. The process for these tools are generally similar (**Appendix 4**), however the NSDEC requires some of the formal assessment responsibility be taken up by project leads through [self-assessment](#). The self-assessment also gives applicants direct feedback and clarity on how a project may be assessed, which may be useful during early development phases to facilitate an ‘ethics-by-design’ approach.
- b. In all cases an application form queries project leads for explanation on several practical aspects and how the project meets ethical criteria (**Appendix 5**). It should be noted that the criteria that are used can vary, which may in part be due to different objectives and use cases for a given tool.
- c. After submission of the form, a support team assesses the project and establishes the risk or complexity of a given project. If a project is deemed higher risk or complex, it may be escalated to undergo review by an ethics panel.
- d. For the IDI and the NSDEC, when a new application is similar to a prior project, the outcomes of ethical review can be repurposed to maximise the efficiency of ethical review and reduce resource costs. This is called ‘president’ for NSDEC and ‘standard’ for the IDI.

Appendix 1

Table 1 Perceived characteristics of government-focused international data ethics advisory groups based on online available resources.

Group – NGOs noted in italics	Formed	Acronym	Detail	Innovation Focus	Support Resourcing	(#) Group Membership	Meetings Per Annum
UK Government, National Statistician’s Data Ethics Advisory Committee	2016	UK NSDEC	Specific	Med	Low (1.75 FTE)	(9) Mix	3-4
<i>Alan Turing Institute</i> and Data Ethics Group	2017	UK ATI	Broad	Low	High (£42m – NZ\$86m)	(13) Acade.	-
<i>Ada Lovelace Institute</i> and Board Members	2018	UK ALI	Broad	Low	High (£5m – NZ\$10m)	(10) Acade./Priv.	-
UK Government, Centre for Data Ethics and Innovation and Board	2018	UK CDEI	Broad	Med	High (£9m – NZ\$18m, 2.25 FTE)	(12) Gov.	>4
DataEthics.eu and Advisory Board	2018	EU DE	Broad	Low	Low (US\$25k – NZ\$40k)	(8) Mix	-
SG Government, Advisory Council on the Ethical use of AI and Data	2018	SG ACEAID	Broad private sector	High	High (US\$4.5m – NZ\$7m)	(11) Priv./Gov.	?
New York City, Automated Decision Systems Task Force	2018	US ADSTF	Broad	Med	?	(20) Gov./Acade.	~6
AU Government, National Data Advisory Council	2019	AU NDAC	Specific legislation	Med	High (18.5 FTE)	(9) Gov./Priv.	2-4
DK Government, Data Ethics Council	2019	DK DEC	Broad	Med	?	(13) Mix	4-5
CA Government, Advisory Council on Artificial Intelligent	2019	CA ACAI	Broad	Med	?	(15) Mix	?
UAE Government, Smart Dubai’s AI Ethics Advisory Board	2019	UAE AIEAB	?	High	?	(12) Gov./Priv	?
AU Government, Data Ethics Advisory Committee	N/a	AU DEAC	-	-	-	-	-

Appendix 2



Figure 1 A dendrimer diagram showing the subprinciples which make up the six primary principles – 1) public good, 2) confidentiality, 3) methods and quality, 4) legal compliance, 5) public views and engagement, 6) transparency. Copyright UK Statistics Authority, [URL](#).

Appendix 3

Self-Assessment Form

Version 2.1

Project Title

Project Timeline *Please provide some details about your project timeline (e.g. start data, end date, any key dates for dissemination activities)*

Project Summary *Please provide some details about your project (e.g. data sources, how data are collected, used, processed and shared)*

Public Benefit *Please describe the public benefit of undertaking this project*

	Weight level	Type 1 if applicable
Is this a data linkage project?	10%	
Does the project involve the use of sensitive personal data (under the DPA and GDPR)?	20%	
Does the project involve the use of patient level health data?	40%	
Does the project include data on children or vulnerable adults?	40%	
Data Sources	Social media	10%
	Rich media sources	15%
	Metadata or Paradata	5%
	Web scraped data	5%
	Big Data (inc. sensor and mobile data)	5%

Result	
-	Project requires an ethical review before proceeding

Figure 2 NSDEC self-assessment form (part 1). Copyright UK Statistics Authority, [URL](#)

Appendix 3 Cont.

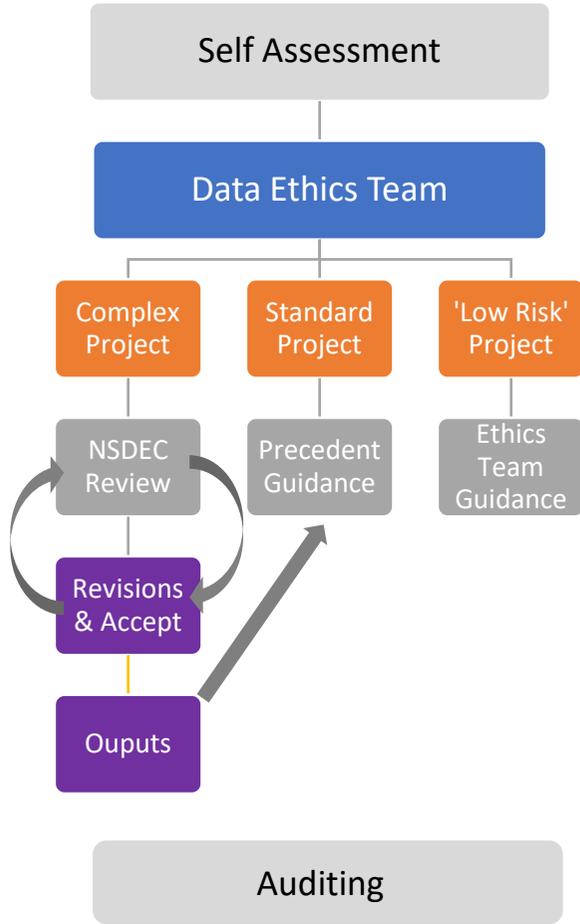
		Please type "1" in the appropriate box below to indicate your rating for each question. Please add a comment in the far right column to briefly justify your selection							Score per principle	Please use this section to give a short justification of your selected rating
Item	Principle 1	Score	1	2	3	4	5	N/A		Score Justification
1	Public benefit		1	2	3	4	5		-	
2	Population coverage		1	2	3	4	5			
3	Potential harm		1	2	3	4	5			
4	Biases		1	2	3	4	5			
	Principle 2	Score	1	2	3	4	5	N/A		Score Justification
5	Direct identification		1	2	3	4	5		-	
6	Indirect identification		1	2	3	4	5			
7	Data Security		1	2	3	4	5			
8	Consent		1	2	3	4	5			
9	Permitted use of data		1	2	3	4	5			
	Principle 3	Score	1	2	3	4	5	N/A		Score Justification
10	Validity		1	2	3	4	5		-	
11	Standards		1	2	3	4	5			
12	Training		1	2	3	4	5			
13	Human oversight		1	2	3	4	5			
14	New technologies		1	2	3	4	5			
15	Potential to realise benefits		1	2	3	4	5			
	Principle 4	Score	1	2	3	4	5	N/A		Score Justification
16	Established legal gateways		1	2	3	4	5		-	
17	Established legal frameworks		1	2	3	4	5			
	Principle 5	Score	1	2	3	4	5	N/A		Score Justification
18	Public views		1	2	3	4	5		-	
19	Public engagement		1	2	3	4	5			
	Principle 6	Score	1	2	3	4	5	N/A		Score Justification
20	Public access to outcomes		1	2	3	4	5		-	
21	Sharing of methods or tools		1	2	3	4	5			
22	Data curation and re-use		1	2	3	4	5			

Figure 3 NSDEC self-assessment form (part 2). Copyright UK Statistics Authority, [URL](#)

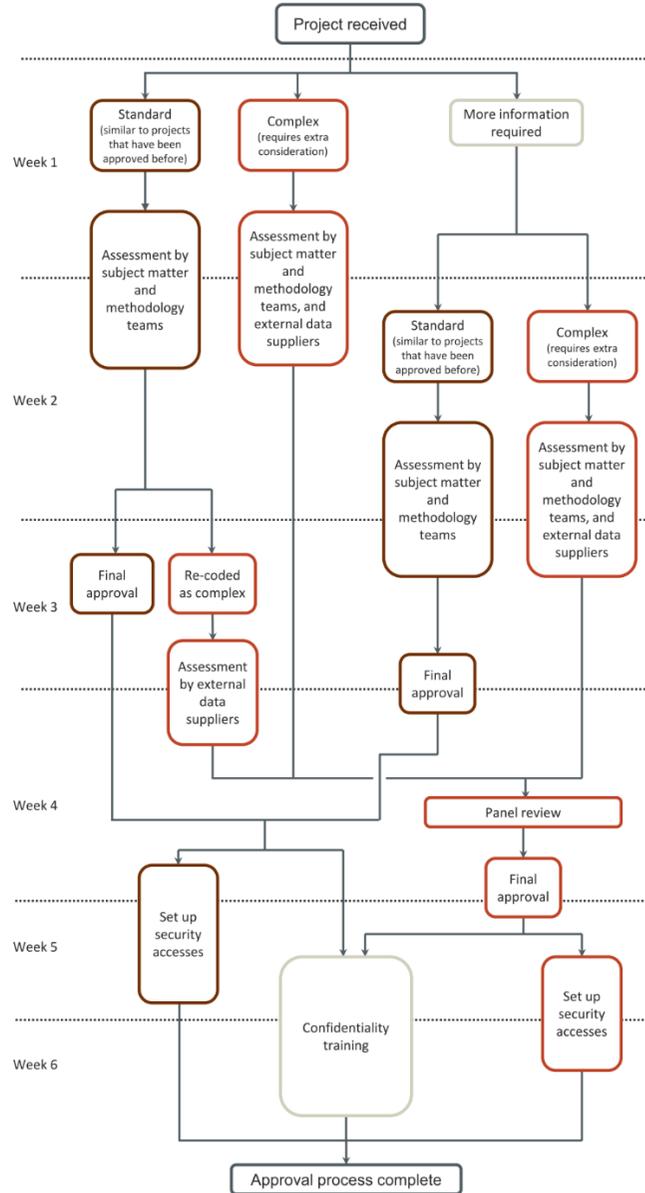
Appendix 4

Table 2 Flow diagrams for the assessment processes of the NSDEC, the IDI and the PHRaE. Images are copyright to StatsNZ and Ministry for Social Development, respectively.

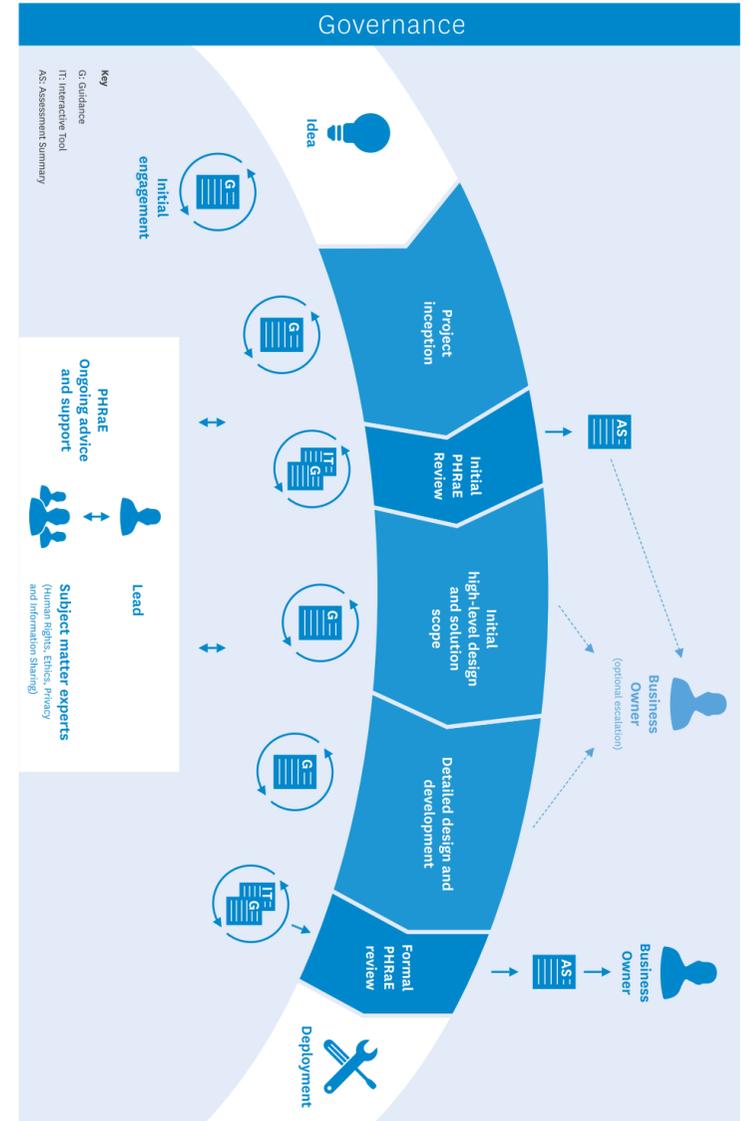
NSDEC flow diagram



IDI flow diagram (self-published)



PHRaE flow diagram (self-published)



Appendix 5

Table 3 General criteria of applications for the example groups and frameworks.

NSDEC - Self-Assessment	IDI – Application Form	IDI – Five Safes Audit	PHRaE Framework – Online Prototype
<u>Public good</u> – public good, population coverage, potential harm, bias	<u>About you</u> – researchers involved, researcher credentials, background check	<u>Safe people</u> * – research supervision, induction and training, corrective actions (if needed)	<u>Aims</u> - objective, solution rational, alternatives, current services/process, target data, external involvement, alignment with Ministry/Public sector,
<u>Confidentiality</u> – direct identification, indirect identification, data security, consent, permitted use of data	<u>About your organisation</u> - organisation involved, research location	<u>Safe projects</u> * – public interest, statistical purpose, non-identifiable data, project supervision, capacity/capability for multiple projects	<u>Consequences</u> – benefit for individuals and groups, involved person benefits, harms to minorities, individual or group harms, public concern over use, harm to the Ministry, harm mitigation
<u>Methods and quality</u> – validity, standards, training, human oversight, new technology, potential for benefits	<u>Project</u> – research questions, anticipated outcomes, research objectives, public value	<u>Safe settings</u> * - lab audits, output checking, computer requirements, physical security, IT security, supervision of lab settings	<u>Openness</u> - informed use, consent, understanding of consent (e.g. children) data access, data correction, timeframe of data storage
<u>Legal compliance</u> – established legal gateways/agreements, established legal frameworks	<u>Research methodology</u> – research methodology, research design, data of interest, population size	<u>Safe data</u> * (mostly internal) - compliance of integrated datasets, data integration guidance, de-identification, fit-for-purpose data, data access, data security	<u>Culture</u> – impact on Māori, consultation with Māori
<u>Public views and engagement</u> – public views, public engagement	<u>Treaty responsiveness and human rights</u> – benefits and risks for specific populations, specific population support, consultation and advice with specific populations, research experience with specific populations, ongoing consultation	<u>Safe outputs</u> – output checking standards, output checking independence, output confidentiality, output checking training, output disclaimers	<u>Personal data</u> – identifiable data, identifiable data minimisation, unique identifiers, de-identification, target data
<u>Transparency</u> – public accessibility to outcomes, sharing of methods and tools, data curation and re-use	<u>Anticipated outputs</u> – expected intermediate and final outputs, granularity of results, output rules, confidentiality	* for all components the audit will explore if policies/procedures are in place and compliance to these	<u>Held data</u> – Ministry held data, third-party held data, specific data elements, collection purpose, legal authority for collection, privacy legislation, communication of third-party data use, agreement with third-party
	<u>Alternatives</u>		<u>New data</u> – data collection methods, specific data elements, collection purpose, authority to collect data, privacy legislation, public concern over collection
	<u>Dissemination methods</u> – output formats, public accessibility for outputs, public accessibility for source code		<u>Safety</u> – data safety certification and accreditation, safeguards for data loss, safeguards for inappropriate access, safeguards for unauthorised use/disclosure/modification
	<u>Practical aspects</u> - timeframes, dataset requirements, rational for dataset access, prior ethical approval		<u>Accuracy</u> – steps to ensure data is accurate/up-to-date/complete/relevant and not misleading, bias in data, methods to mitigate bias, use of predictive modelling, accuracy of model, accuracy of model over time, output accuracy, justification of model predictors, automation of decision making, review of decision making
	<u>Considerations</u> – public value, treaty and human rights, confidentiality, research ability, alternatives, data availability, agreement with StatsNZ, public dissemination		<u>Discrimination</u> – target audience, delineation of groups, outcomes of delineated groups, delineation on prohibited grounds, benefits and disadvantages for delineated groups, alternatives to delineation, corrective delineation
			<u>Data sharing</u> – specific data elements, data recipients, data sharing purpose, method of data sharing, de-identification, authority for data sharing, data sharing agreement, privacy legislation, informed sharing