Communicating genetic risk in the family: potential solutions to ethical challenges

A Data Management Plan created using DMPonline.be

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Research Data Summary

List and describe all datasets or research materials that you plan to generate/collect or reuse during your research project. For each dataset or data type (observational, experimental etc.), provide a short name & description (sufficient for yourself to know what data it is about), indicate whether the data are newly generated/collected or reused, digital or physical, also indicate the type of the data (the kind of content), its technical format (file extension), and an estimate of the upper limit of the volume of the data.

Dataset name / ID	Description	New or reuse	Digital or Physical data	Data Type	File format	Data volume	Physical volume
		*Indicate: **N**(ew data) or **E**(xisting data)*	Indicate: **D**(igital) or **P**(hysical)	Indicate: **A**udiovisual **I**mages **S**ound **N**umerical **T**extual **M**odel **SO**ftware Other (specify)		Indicate: <1GB <100GB <1TB <5TB >5TB NA	
Research notes	Notes from a workshop organized by the research team prior to the start of this research project will be used to finalize a journal article based on the workshop discussions.	E	D	T	.docx .pdf	<1GB	None
Journal articles	Literature, including empirical studies, reviews, and normative documents, will be used in order to analyze how the concept of actionability is understood by different stakeholders.	E	D	T	.pdf	<1GB	None

If you reuse existing data, please specify the source, preferably by using a persistent identifier (e.g. DOI, Handle, URL etc.) per dataset or data type:

We will use existing data in the form of meeting notes from a workshop we organized just before the start of this research project. These meeting notes have not been shared elsewhere and are only accessible by the research team.
We will also use the data already generated by other researchers in the form of published journal articles and normative documents, all of which are publicly accessible.

Are there any ethical issues concerning the creation and/or use of the data (e.g. experiments on humans or animals, dual use)? If so, refer to specific datasets or data types when appropriate and provide the relevant ethical approval number.

- No

Will you process personal data? If so, please refer to specific datasets or data types when appropriate and provide the KU Leuven or UZ Leuven privacy register number (G or S number).

- No

Does your work have potential for commercial valorization (e.g. tech transfer, for example spin-offs, commercial exploitation, …)? If so, please comment per dataset or data type where appropriate.

- No

Do existing 3rd party agreements restrict exploitation or dissemination of the data you (re)use (e.g. Material or Data transfer agreements, Research collaboration agreements)? If so, please explain in the comment section to what data they relate and what restrictions are in place.

- No

Are there any other legal issues, such as intellectual property rights and ownership, to be managed related to the data you (re)use? If so, please explain in the comment section to what data they relate and which restrictions will be asserted.

- No

Documentation and Metadata

Clearly describe what approach will be followed to capture the accompanying information necessary to keep data understandable and usable, for yourself and others, now and in the future (e.g. in terms of documentation levels and types required, procedures used, Electronic Lab Notebooks, README.txt files, codebook.tsv etc. where this information is recorded).

The workshop meeting notes are already organized according to the structure of the workshop whereby there were guided discussions on various topics.
The article resulting from a synthesis of the existing literature will include a section outlining the methods used regarding how all literature used was found, filtered, and analyzed. All sources used in this article will be properly cited in the article's references.

Will a metadata standard be used to make it easier to find and reuse the data?
If so, please specify which metadata standard will be used.

If not, please specify which metadata will be created to make the data easier to find and reuse.

- No

Data Storage & Back-up during the Research Project

Where will the data be stored?

- OneDrive (KU Leuven)
- Shared network drive (J-drive)

How will the data be backed up?

- Standard back-up provided by KU Leuven ICTS for my storage solution

Is there currently sufficient storage & backup capacity during the project?

If no or insufficient storage or backup capacities are available, explain how this will be taken care of.

- Yes

How will you ensure that the data are securely stored and not accessed or modified by unauthorized persons?

The data used in this project is not sensitive. Most of what will be used are already published journal articles or normative documents (such as guidelines) which are all publicly accessible.

What are the expected costs for data storage and backup during the research project? How will these costs be covered?

There are no expected costs for data storage and backup foreseen in this research project at present.

Data Preservation after the end of the Research Project

Which data will be retained for 10 years (or longer, in agreement with other retention policies that are applicable) after the end of the project?

In case some data cannot be preserved, clearly state the reasons for this (e.g. legal or contractual restrictions, storage/budget issues, institutional policies...).

- All data will be preserved for 10 years according to KU Leuven RDM policy

Where will these data be archived (stored and curated for the long-term)?

- Shared network drive (J-drive)

What are the expected costs for data preservation during the expected retention period? How will these costs be covered?

There are no costs foreseen for the data preservation.

Data Sharing and Reuse

Will the data (or part of the data) be made available for reuse after/during the project?
Please explain per dataset or data type which data will be made available.

- Other (specify below)

The meeting notes used to report on the workshop will not be directly shared although their content will be reflected through the resulting manuscript.

The journal articles and normative documents used will already be publicly accessible. A list of sources as well as our methods for finding, filtering, and analyzing the sources will be shared.

If access is restricted, please specify who will be able to access the data and under what conditions.

The access will not be restricted.

Are there any factors that restrict or prevent the sharing of (some of) the data (e.g. as defined in an agreement with a 3rd party, legal restrictions)?

Please explain per dataset or data type where appropriate.

- No

Where will the data be made available?

If already known, please provide a repository per dataset or data type.

- KU Leuven RDR (Research Data Repository)

When will the data be made available?

- Upon publication of research results

Which data usage licenses are you going to provide?

If none, please explain why.

- Other (specify below)

This question is not applicable to this research project.

Do you intend to add a persistent identifier (PID) to your dataset(s), e.g. a DOI or accession number? If already available, please provide it here.

- No

What are the expected costs for data sharing? How will these costs be covered?

There are no expected costs for data sharing.

Responsibilities

Who will manage data documentation and metadata during the research project?

The data documentation process will be managed by Amicia Phillips and overseen by Professor Pascal Borry.

Who will manage data storage and backup during the research project?

Data storage will be managed by Amicia Phillips and overseen by Professor Pascal Borry.

Who will manage data preservation and sharing?

Data preservation and sharing will be primarily managed by Amicia Phillips and overseen by Professor Pascal Borry.

Who will update and implement this DMP?

This DMP will be implemented by Amicia Phillips and overseen by Professor Pascal Borry.