

Simplifying privacy risk assessment (DPIA) to support research and data management

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A privacy risk assessment should

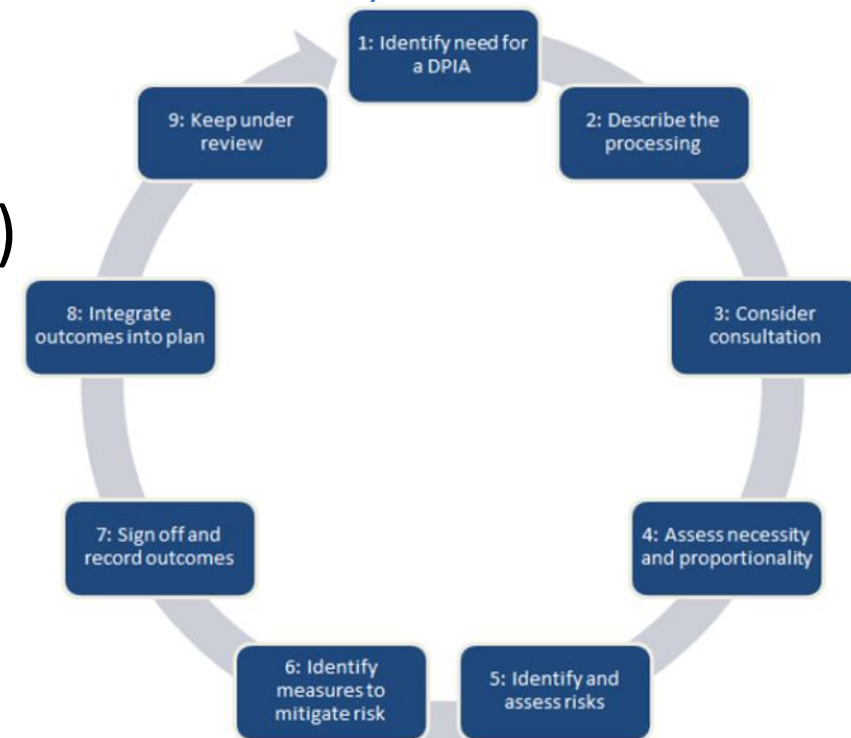
1. Describe the nature, scope, context and purposes of the processing
2. Assess necessity, proportionality and compliance measures
3. Identify and assess risks to individuals
4. Identify any additional measures to mitigate those risks

A privacy risk assessment should begin before processing and run alongside the research lifecycle

- Ethics application/self-assessment: ethical considerations about data protection are decided
- Information letter, informed consent, privacy statement: reassure individuals that their privacy interests are protected
- Agreements: the roles and responsibilities for the processing are documented
- Data management plan, data sharing, data publication: make use of data protection by design and default
- Data processing register, statement of compliance: demonstrate compliance with the accountability obligations under the GDPR

A privacy risk assessment should identify and minimise the data protection risks of a research project

- Fit in with institute's data protection policies and risk management procedures
- Carry out a DPIA for processing of personal data that is likely to result in a high risk to the rights and freedoms of individuals (article 35 GDPR)
- Know how to carry out a DPIA (e.g. see [ICO](#) and think about prior consultation article 36 GDPR etc)
- Know who to carry out a DPIA with (e.g. data controller, data processor, Data Protection Officer, privacy officer, security officer)



LCRDM Task Force on Privacy Risks per Research Scenario

Why?

The national Disciplineoverleg Sociale Wetenschappen (Consultative Body for Social Sciences) (DSW) requested the forming of a task group that will pave the way for the sharing of Data Protection Impact Assessments (DPIA's) at a national level for frequently used research scenarios in Social Sciences, to make it easier for researchers to comply and prevent a large number of DPIAs

Task

How can a DPIA be carried out and maintained, whereby for a large part of new research applications only the appropriate scenario needs to be selected?

Taskforce

Data managers, privacy officers, data protection officers, researchers: Erik van den Beld (Saxion), Magchiel Bijsterbosch (SURF), Marlon Domingus (EUR), Pam Dupont (TiU), Raymond van Erkel (LEI), Jasper de Groot (UU), Cristina Montagner (RUG), Fieke Schoots (LEI), Inge Slouwerhof (RU), Dick Vestdijk (HU), Raoul Winkens (UM)

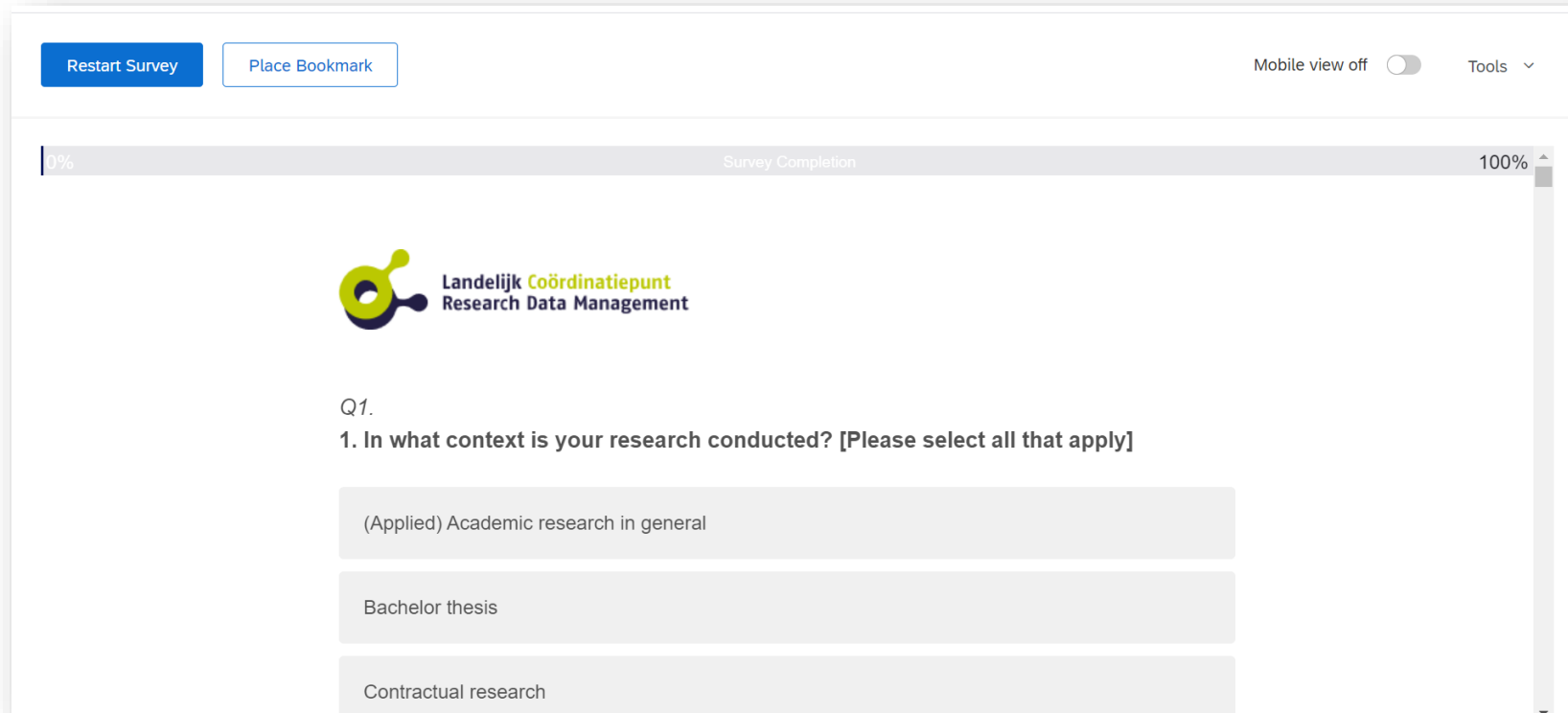
What to think about?

1. Research characteristics (research protocols, ethics assessments)
2. Indicators of likely high risk (European Data Protection Board)
 - Assessing people on the basis of personal characteristics (including profiling) (article 35 GDPR)
 - Automated decisions
 - Systematic and large-scale monitoring (article 35 GDPR)
 - Sensitive data (article 35 GDPR)
 - Large-scale data processing
 - Combining databases
 - Data concerning vulnerable data subjects
 - Use of new technologies
 - Blocking of a right, service, or contract
3. List of the types of processing that require a DPIA in the jurisdiction of the [Dutch data protection authority](#)
4. List of processing operations which do not require a DPIA

Privacy risk assessment questionnaire (available in Excel)

- Online example:

https://leidenuniv.eu.qualtrics.com/jfe/preview/SV_2if3fRPsKdG34ah?Q_CHL=preview



The screenshot shows a survey preview interface. At the top, there are buttons for 'Restart Survey' and 'Place Bookmark', along with a 'Mobile view off' toggle and a 'Tools' dropdown menu. A progress bar indicates '0%' completion. The survey title is 'Landelijk Coördinatiepunt Research Data Management'. The question is 'Q1. 1. In what context is your research conducted? [Please select all that apply]'. The response options are: '(Applied) Academic research in general', 'Bachelor thesis', and 'Contractual research'.

Measures

Organizational Measures

- Access control list
- Access restriction
- Contact privacy officer
- Information to data subjects or privacy statement
- Informed consent
- Policy for data retention
- Privacy training
- Publication results on aggregated level
- Storage limitation

Technical Measures

- Anonymisation
- Data minimisation
- Encryption of data storage
- Encryption of data transfer (e.g. SURFfilesender)
- Pixelating (video recording)
- Pseudonymisation (level 1,2 or 3)
- Voice alteration techniques (audio recording)

Agreements (Organizational Measures)

- Collaboration agreement (ext. party)
- Data sharing/use agreement (ext. party)
- Data processor agreement (ext. party)
- Joint controllers agreement (ext. party)
- Material transfer agreement (ext. party)
- Non disclosure agreement (ext. party)
- Non disclosure agreement (student)

Match measures with research characteristics (available in Excel)

Research characteristic (general)	Research characteristic (specific)	Access control list	Policy for data retention	Privacy training	Access restriction	Storage limitation
Study design	Data research from online platform (social media, online public databases, etc)	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
	Data research from third party	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
	Experimental/intervention research	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
	Interview research	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
	Longitudinal research	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
	Observation research by photo, audio or video recording (e.g. visual ethnography)	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
	Observation research by researcher in person	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
	(Online) survey research	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
	Research using focus groups and/or stakeholders workshops	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
	Other, please specify					
Innovative data processing methods	Privacy-invasive methods or technologies (e.g., covert observation, surveillance, tracking)	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
	Using camera systems to monitor behaviour or record sensitive information	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
	Data mining (including data collected from social media networks), web crawling or social network analysis	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
	Profiling individuals or groups (particularly behavioural or psychological profiling)	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
	Using artificial intelligence to analyse personal data	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
	Using automated decision-making that has a significant impact on the data subject(s)	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Data categories	Audio recordings	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
	Behavioral data (task data files, e.g. Eprime)	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
	DNA data	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
	Excel files	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
	Eye tracking data (Tobii)	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
	Hard-copies of documents (e.g., dossiers)	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
	Hand-written documents (e.g. field notes, diaries, observations)	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
	Hormone data	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
	Material objects	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
	MRI data (anatomical/functional., e.g. HDR, PAC, BIDS)	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>

Findings

- One basic, structured questionnaire for the risk assessment
- Research is difficult to put in scenarios due to a combination of (too) many research characteristics. Some universities have started working with basic research protocols for ethical assessments that include some privacy aspects (best practices: e.g. [Universiteit Utrecht](#) and [Tilburg University](#))
- Measures to be taken can be matched with research characteristics but are mostly the same on a higher level
- Risks to be classified by institute (risk management policies vary)
- Measures to be implemented by institute (various technical solutions and multiple templates for agreements)
- Support, advice, information to be organized by institute

Recommended next steps

- Discuss how to make use of the questionnaire in your institute's processes for ethical review, consent form, data management plan, data processing register, etc
- Try and integrate your institute's templates and tools for the researcher (best practice: e.g. Leiden University's Social Sciences)
- Advise the researcher on the outcome of the risk assessment and the measures to be taken, based on your institute's solutions and the matrix for research characteristics and measures
- In collaborations try and implement the questionnaire (e.g. declaration of local feasibility) and coordinate the risk management policies and the measures and templates
- Continue developing the questionnaire and the matrix (e.g. for research with MRI data, for research with online platforms, etc)



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