

# M7.1: Draft Guideline for data users on how to use data in a secure processing environment – public consultation questions

## 1 Part A questions for generic feedback

These questions will be asked in each public consultation to provide an understanding of the recipients' demographics, the quality of the document and to gather generic feedback. Questions marked with an asterisk are mandatory.

### 1.1 Demography

#### Country\*

Sweden

#### Type of the responder\*

Academic or research institution

#### Sector\*

Education and academia

#### Organisation size\*

Large enterprise (250+ employees)

#### Professional role/function

### 1.1.1 Quality

#### From your perspective, how ready is the document to meet the expected needs?\*

Minor additions/changes needed

#### What is the level of quality of the document?\*

3

#### Is the document easy to understand?\*

3

#### How well does the document address the key issues and challenges related to its subject matter?\*

3

**How feasible and implementable do you find the guidelines or technical specifications presented in the document?\***

2

## 1.2 Generic feedback

**Do you have any suggestions for improving the document? Are there any additional topics or areas that should be covered?** (Please provide feedback and ideas for enhancing the document) [Open text field (Max. 750 characters.)]

*Page 13*

It is stated “Strong password should only be changed ...”. It is generally recommended to change passwords regularly, and it should be similar here, since we deal with sensitive data.

*Page 14*

It is stated that results from the SPE should be securely handled. At the same time, no sensitive data could be exported from the SPE. Thus, the phrasing seems a bit illogical.

*Page 17*

It is described that a data permit could be issued for at most 10 years and extended once at most 10 years. This will most likely be sufficient for most projects, but there might be some that have a life time well over 20 years, and would benefit from longer timelines; alternatively they have to reapply every 20 years, which also is a way to solve this.

## 2 Part B questions for specific feedback

**What are you representing?** [Single selection: Health Data Access Body (HDAB), Data holder, Data User, Trusted third party (TTP), Data protection authority, Secure Processing Environment (SPE) provider, Other (please specify)]

**How experienced are you with handling data (i.e., data analysis or data curation) in a secure processing environment?** [Rate 1 (no experience; not at all) – 2 (limited experience; 1– 2 times per year) – 3 (infrequent experience; on a monthly basis) – 4 (frequent experience; on a daily basis)]

**What type(s) of data do you plan to make accessible or use in a secure processing environment?** [Select multiple: Not applicable, Tables, Relational databases, Imaging data, Genomic data, Bio-sample data, Unstructured data, Other (please specify)]

**Do you think that the guidelines support data users before submitting a data access application and/or after receiving a granted permit?** (Please elaborate and consider all chapters.) [Open text field (Max. 750 characters.)]

**Are there inconsistencies or specific topics missing regarding why and when data users need a specific secure processing environment?** (Please elaborate.) [Open text field (Max. 750 characters.)]

**Are there inconsistencies or specific topics missing when considering how to choose an appropriate secure processing environment?** (Please elaborate.) [Open text field (Max. 750 characters.)]

**Are there inconsistencies or specific topics missing about the fees linked to secure processing environment usage?** (Please elaborate.) [Open text field (Max. 750 characters.)]

**Are there inconsistencies or specific topics missing when communicating with the secure processing environment provider?** (Please elaborate.) [Open text field (Max. 750 characters.)]

**Are there inconsistencies or specific topics missing on how to get access to the secure processing environment?** (Please elaborate.) [Open text field (Max. 750 characters.)]

**Do the descriptions in the guideline comply with your access procedures? Would they be implementable and what steps would need to be taken?** (Please elaborate.) [Open text field (Max. 750 characters.)]

**Are there inconsistencies or specific topics missing on how to analyse data within the secure processing environment?** (Please elaborate.) [Open text field (Max. 750 characters.)]

**Do the descriptions in the guideline comply with your analysis procedures for data in the secure processing environment? Would they be implementable and what steps would need to be taken?** (Please elaborate.) [Open text field (Max. 750 characters.)]

**Are there inconsistencies or specific topics missing regarding controllership of data in a secure processing environment?** (Please elaborate.) [Open text field (Max. 750 characters.)]

**Are there inconsistencies or specific topics missing about what happens in case of rule violation?** (Please elaborate.) [Open text field (Max. 750 characters.)]

**Are there inconsistencies or specific topics missing regarding what happens after finishing the analysis and/or archiving?** (Please elaborate.) [Open text field (Max. 750 characters.)]

**What are differences between the steps proposed in the guideline and your current secure processing environment infrastructure?** (Please elaborate.) [Open text field (Max. 750 characters.)]

**What would be the impact on you to implement what is recommended here?** (Please indicate if this is applicable to you and if yes, please elaborate.) (Max. 750 characters.)

**-Voluntary provision of personal contact information if interested in possible future workshops related to the topic of this document.-**