BBMRI-ERIC ELSI KNOWLEDGE BASE

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INTRODUCTION

The BBMRI-ERIC ELSI Knowledge Base is an open-access resource platform containing information on ethical, legal, and societal issues relevant to the life sciences, most notably biobanking.

AIMS

The aims of the BBMRI-ERIC ELSI Knowledge Base are:

- To **close the knowledge gap** by providing practical hands-on guidance and promoting practical know-how for researchers.

- To provide users with **a first orientation on the subject matter**, as well as allowing them to explore more detailed information if desired in a self-service manner.

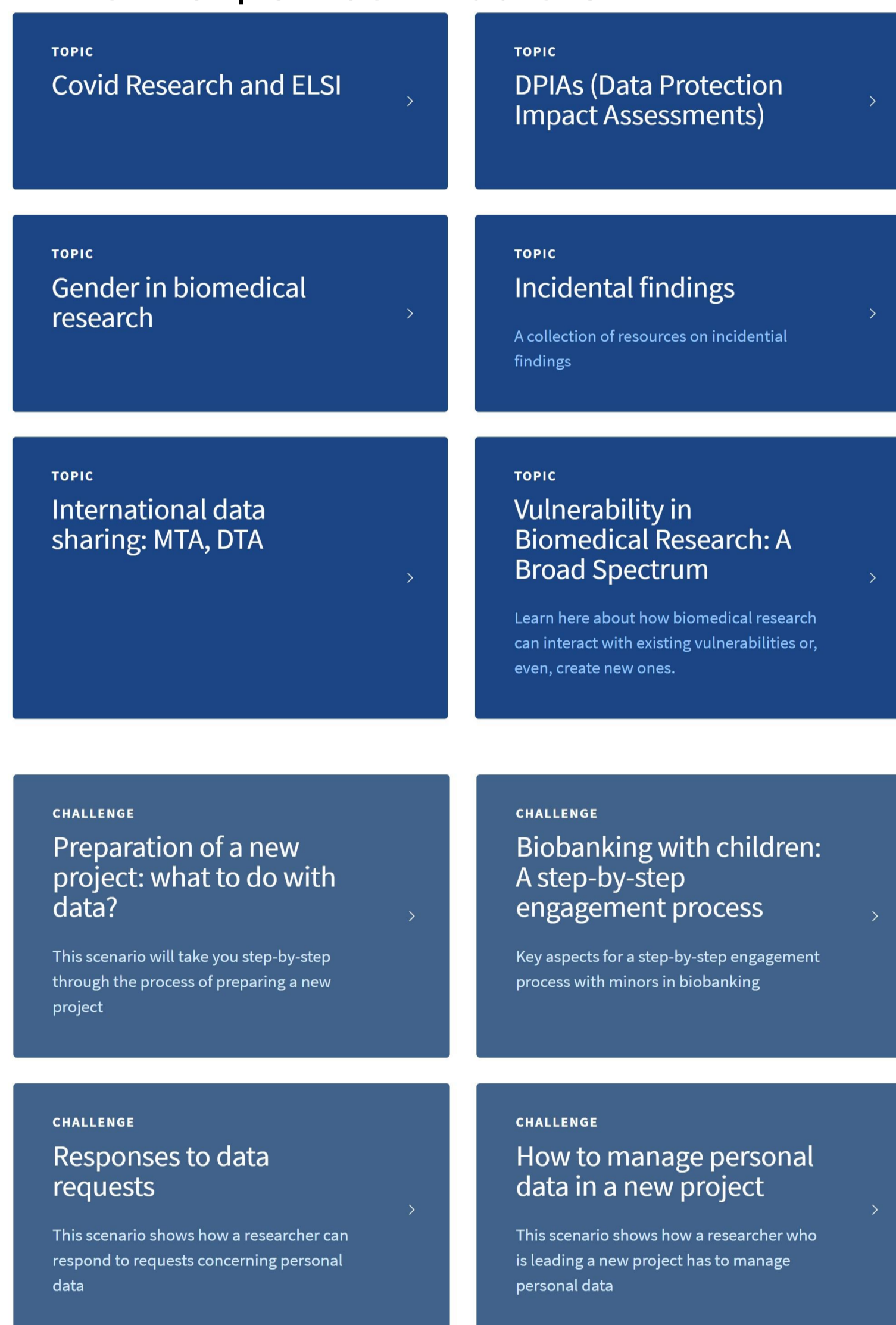- To provide information to the user on **a self-serve basis.**

DISCLAIMER

BBMRI-ERIC will not provide with all the information exhaustively relevant to a topic.

Based on our combined expertise, however, BBMRI-ERIC ELSI team can provide practical guidance on specific ethical, legal, and societal issues related to biobanking and biomedical research via the ELSI Helpdesk Network.

CHARACTERISTICS

The information gathered in the Knowledge Base to provide hands-on guidance and promote practical know-how for the main actors of biobanking comes from multiple sources, usually from expert contributors.

TOPIC	TOPIC
Covid Research and ELSI	DPIAs (Data Protection Impact Assessments)

TOPIC	TOPIC
Gender in biomedical research	Incidental findings — A collection of resources on incidental findings

TOPIC	TOPIC
International data sharing: MTA, DTA	Vulnerability in Biomedical Research: A Broad Spectrum — Learn here about how biomedical research can interact with existing vulnerabilities or, even, create new ones.

CHALLENGE	CHALLENGE
Preparation of a new project: what to do with data? — This scenario will take you step-by-step through the process of preparing a new project	Biobanking with children: A step-by-step engagement process — Key aspects for a step-by-step engagement process with minors in biobanking

CHALLENGE	CHALLENGE
Responses to data requests — This scenario shows how a researcher can respond to requests concerning personal data	How to manage personal data in a new project — This scenario shows how a researcher who is leading a new project has to manage personal data

The resources are organized in three sections:

1) "**Topics**:" topics for which the ELSI Services and Research Unit has found a special interest or need in the life sciences community;

2) "**Challenges and solutions**:" scenario-based guidance; and

3) "**Guidelines for good research**:" a compilation of important documents that include the legal framework and ethical landscape of biobanking research.

GUIDELINES, RECOMMENDATIONS, AND ETHICAL STANDARDS

Research Integrity	+
Research involving minors	+

LEGAL FRAMEWORK

The resources that you can find on our Knowledge Base follow the logic of the European Hierarchy of Norms.

Research involving minors	+
Human rights	+
Data sharing and data protection	+
Biobanking and biomedical research	+

The BBMRI-ERIC ELSI Knowledge Base intends to be user-friendly, practical, and accurate.

Concerning user-friendliness and practicality, the KB avoids long lists of links, a confusing structure, and legalistic language.

Regarding its accuracy, the long-term sustainability (including technical maintenance) and correctness of the content are among our key concerns, so the contents are highly curated and frequently reviewed.

By combining a scenario-based and topic-based approach, the BBMRI-ERIC ELSI Knowledge Base provides guidance and empowers our community to gain knowledge independently on relevant topics.

CONCLUSIONS

ELSI KNOWLEDGE BASE

The ELSI Knowledge Base is our open-access resource platform containing information on ELSI-related matters relevant in biobanking. Here you will find practical guidance on specific ELSI topics.

In need of ethical legal, or societal guidance? Browse our library below!

https://www.bbmri-eric.eu/elsi-knowledge-base/

ACKNOWLEDGEMENTS

REFERENCES

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CONTACT INFORMATION

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