ADOPT BBMRI-ERIC
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REPORT ON EDUCATIONAL AND TRAINING EVENTS AND TOOLS

Executive Summary

This report provides an overview on how the educational and training events and tools in relation to ethical, legal and societal issues (ELSI) were identified, planned and executed through the BBMRI-ERIC Common Service ELSI, which is a well-established key asset of the research infrastructure. Educational training events and tools were based on identified user needs and implemented in collaboration with BBMRI-ERIC ELSI experts (task forces) and (where appropriate) in collaboration with other initiatives and projects.

Designing these events and tools in the context of the ADOPT BBMRI-ERIC project also guaranteed funding for public activities (e.g., conference participations, Ethics Cafés) as well as internal educational and training workshops (e.g., webinars or the workshop on *Ethical Review for Biobank-Based Research Projects: Towards a Risk-Based Ethical Reviews*). Additionally, new guidance documents and tools (e.g., the GDPR Code of Conduct for Health Research) relevant for the BBMRI as well as for the ESFRI BMS communities were accomplished.

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This report accounts for the key activities in relation to the educational and training events and tools. Ultimately, the events and tools were designed to be integrated in the work plan of BBMRI-ERIC (e.g., Knowledge Base, Ethics Café). This guarantees their sustainable maintenance and further development, with the overall objective being to facilitate regulatory compliance and best practice, by not only raising awareness of key ethical and regulatory issues but also by being on hand as a support service to provide necessary ELSI assistance. Operating on the basis of the BBMRI-ERIC federated model, a network of ethical and legal institutions and experts from academia and practice across Europe, which are located in BBMRI-ERIC Member and Observer Countries, are utilised in order to obtain and share relevant expertise and continue the activities as described in this report.

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Document log

Issue	Date (yyyy-mm-dd)	Comment	Author/partner
D5.5	2019-03-26	Report M36	Michaela Th. Mayrhofer Jasjote Grewal
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Background

The overall objective of the CS ELSI is to provide information, guidance, tools and best practices in order to ensure the appropriate awareness and ability of biobankers to address the ethical, legal and societal challenges. For this, BBMRI-ERIC operates on a federated model, with a network of ethical and legal institutions and experts from academia and practice across Europe, which are located in BBMRI-ERIC Member and Observer Countries. The network is utilised in order to obtain and share relevant expertise and has been established in 2014.

The objective in the context of ADOPT BBMRI-ERIC was to establish key educational and training events and tools (public and internal) that the CS ELSI organised or participated in.

Strategically, the CS ELSI invested in activities that could (after the end of ADOPT) be maintained or improved by BBMRI-ERIC or their National Nodes, therewith ensuring sustainability. This report highlights the key educational and training events and tools (public and internal) that the BBMRI-ERIC Common Service ELSI organise or participate in thanks to ADOPT funding, as well the strategies that have been developed to further promote education and training.

Approaches (Methods)

The aims of this deliverable were (a) to identify key topics, (b) to identify formats of appropriate tools and events, and (c) to ensure maximum outreach in a sustainable manner. Key topics for consideration were taken from requests submitted to the ELSI Helpdesk, as well as input provided by ELSI experts. The topics were further discussed in the respective task forces of BBMRI-ERIC CS ELSI and implemented via the Knowledge Base, FAQs, webinars, etc. Where appropriate, the implementation was done in collaboration with other initiatives (e.g. CHIP-me for the survey).

Enquiries received through the ELSI Helpdesk were tracked and monitored both for the purpose of conducting internal assessment of service quality, as well as to identify the nature of incoming requests. Furthermore, an internal survey was developed and issued to all Common Service ELSI experts in order to identify key ELSI questions that are encountered within the context of research projects (see Appendix 1). Therefore, engagement with both users and ELSI experts enabled identification of key topics and tools needed.

Key Topics

Requests submitted to the ELSI Helpdesk showed a lack of knowledge about the GDPR and its compliance requirements, about how to complete the Ethics Self-Assessment for EU projects and about how to ensure societal engagement and the need to share best-practices thereof. These topics were given priority based on input received by Common Service ELSI experts through regular meetings, and also feedback received by users, whether by way of face-to-face engagement or via the ELSI Helpdesk. The relatively recent implementation of the GDPR also

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indicated a significant increase in discussions and ambiguities on the topic within the biobanking and BMS community, as could be seen at networking events, as well as on social media channels.

Key Educational and Training Events and Tools

Knowledge Base

http://www.bbmri-eric.eu/BBMRI-ERIC/elsi-knowledge-base/

Based on the experiences and assessments of previous ELSI guidance tools, which are excellent in their own right but limited in their usage, we proposed a reconceptualization that defines a clear user group and established the ELSI Knowledge Base (Mayrhofer, Schlünder 2018), where we develop and share practical guidelines for researchers in our open access resource platform. In order to identify key ELSI topics, as well as particular issues that should be addressed in the Knowledge Base, Common Service ELSI experts were asked to provide input both in relation to key ELSI topics and also key documentation that should be included within the Knowledge Base (see Appendix 1). In short, the ELSI Knowledge Base now contains further accessible information on relevant ELSI matters in biobanking and continues to grow.

FAQs and How-To Guides

Frequently Asked Questions (FAQs) and How-to Guides have been identified as low-key tools for spreading knowledge. The "How-To Guides" are 2-pagers that aim to help biobankers and researchers ask the right questions for developing internal policies or employing best practices on a specific topic, such as participant engagement or informed consent.

In the context of ADOPT, FAQs on the GDPR have been developed to inform what is expected to apply to biobanks.[1] Furthermore, National Nodes also have the opportunity to publicise the FAQs on the own national websites. Indeed the FAQs are currently promoted, for instance, on the BBMRI-NL website, thereby maximising outreach and impact (https://www.bbmri.nl/newsroom/biobanks-collections-human-samples-and-associated-health-data-%E2%80%93-how-apply-eu-gdpr) or translated into other languages (e.g., FR, GR, PL). Ultimately, the FAQs do not constitute legal advice and may be subject to change, as a result of further analysis or when provisions of the GDPR are being implemented. Nonetheless, the download rate and feedback received identify FAQs as an excellent tool.

Survey

In collaboration with several projects and organisations[2], a survey on informed consent practices[3] portrays the experiences and opinions of 272 biobankers from 32 countries. The results were first presented at Europe Biobank Week 2018, highlighting the differences of

[1] http://www.bbmri-eric.eu/BBMRI-ERIC/elsi-knowledge-base/

[2] These include COST Action IS1303 CHIPME (http://www.cost.eu/COST_Actions/isch/IS1303), FP7 project RD-connect (https://rd-connect.eu), H2020 project ADOPT BBMRI-ERIC (http://www.bbmri-eric.eu/scientific-collaboration/adopt-bbmri-eric/), the IMI project DO-IT (https://www.imi.europa.eu/projects-results/project-factsheets/do-it) and Biobank Norway (https://bbmri.no).

[3] http://www.bbmri-eric.eu/news-events/survey-on-elsi-challenges-in-biobank-based-research/

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informed consent as a legal basis under the GDPR for data processing and informed consent as an ethical and legal requirement to ask participants for their approval to partake in a study. A publication has been accepted in PLOS One (Goisauf et al. 2019), arguing that consent practices are an important part of a biobank's governance, but are not exclusive. Ultimately, the key findings informed the development of the "How-to Guide: Governance".[4]

Webinars

Webinars have been identified as a key online learning tool. Originally, BBMRI-ERIC contributed with three webinars to the CORBEL webinar series that aims to address challenges and share best practices among biological and medical research infrastructures. After piloting two webinars specific to biobanks and the GDPR in April and June 2018 respectively[5], BBMRI-ERIC decided to host its own regular webinar series, focusing on practical topics for biobankers on ELSI, quality and IT and the interrelationship between these three. The strategy for the webinar series was an outcome of ADOPT BBMRI-ERIC, with a set of internal and external checklists being developed when organising webinars (see Appendix 2).

Blog

http://www.bbmri-eric.eu/bbmri-eric-blog/

The BBMRI-ERIC blog was set up in spring 2018, with the aim of both sharing information and educating audiences about biobanking and BBMRI-ERIC. Blog articles are set to cover all aspects of biobanking and BBMRI-ERIC's scope of activities, including IT, Quality Management and ELSI amongst others, and have been written in a manner that is both accessible and comprehensive. Furthermore, individual stories highlighting the benefit of biobanking are also included within the blog in order to promote awareness about the positive impact and important role that biobanks have in society. These 'Impact Stories' have been collected after a call for stories was launched within the European biobanking community. This call was executed in the context of ADOPT BBMRI-ERIC by the TF Societal Issues. These stories are and will continue to be published on a regular basis on the Blog.

[4] https://doi.org/10.5281/zenodo.3516948
[5] The webinars are hosted on the ELSI Knowledge Base library: http://www.bbmri-eric.eu/elsi-library/

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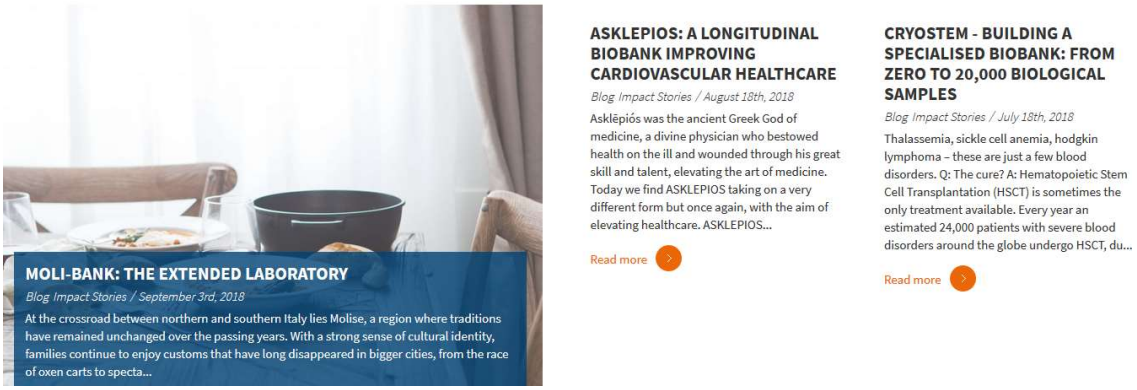

Image 1: Screen Shot of BBMRI-ERIC Blog

Events

Ethics Cafés

The format of an Ethics Café provides an opportunity to share views on specific topics in an informal setting. A debate is kick-started by a provocative opening statement or an engaging talk. The audience is invited to participate, ask questions, provide new insights for an ultimately thought-provoking dialogue. The Ethics Cafés were co-organized as sessions in the context of the Global Biobank Week 2017, Europe Biobank Week 2016 and Europe Biobank Week 2018.[6] Collaborations with other initiatives or units, depending on the topic of the Ethics Café, were considered where appropriate (e.g. Ethics Café 2018, collaboration with ESBB and Ethics Unit DG RTD).

Art & Science Workshops

Art and biobanking have come together thanks to ADOPT BBMRI-ERIC in a year-long collaboration between BBMRI-ERIC and the Art & Science faculty, at the University of Applied Arts Vienna in Austria[7], which investigates the relationships between different artistic and scientific cultures. Commencing in October 2018, the initiative saw BBMRI-ERIC and art students from the master's programme engaging in a dialogue, whereby students were exposed to the multi-faceted world of biobanking. Through workshops and guided visits to biobanks, an overview of biobanking was given, which included developments in science and technology, as well as quality management, European policy, patient advocacy, and arising ethical, legal and social issues (ELSI) from experts. With this input, a foundation was laid for students to produce and exhibit artistic works. With a final exhibition of artistic works by Art & Science students in May/June 2019[8], a new space for fresh ideas and perspectives with regards

[6] https://www.bbmri-eric.eu/wp-content/uploads/EBW-2018-Ethics-Cafe-Summaryv3.pdf
[7] http://artscience.uni-ak.ac.at/
[8] http://artscience.uni-ak.ac.at/people?personen_id=1539853114225

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to biobanking activities was created, thereby engaging and educating not only the existing biobanking community, but also new audiences in novel and imaginative ways.

Ethical Review for Biobank Based Research Projects: Towards a Risk-Based Ethical Review
20 February 2018, Paris
Co-funded by EURORDIS, RD-CONNECT, BBMRI-ERIC, ADOPT-BBMRI-ERIC (internal report available)
The meeting started with presentations on risk-based ethics reviews in Europe and the US, discussed the Code of Conduct initiative and ultimately split participants into two groups to discuss 3 secondary research scenarios. In the final discussion, it was agreed that RECs tend to be overburdened with their work, particularly in developing countries. The same role could also be taken by internal committees, such as Data Access Committees. There were diverging views as to what constitutes high risk and low risk. Operating without RECs as a safeguard was contested between participants, particularly given that risk will always be context specific.

Code of Conduct
http://code-of-conduct-for-health-research.eu
The EU General Data Protection Regulation entered into force on 25 May 2018, with direct effect in Member States. Given that legal texts are not always easily accessible, BBMRI-ERIC, together with other stakeholders, considers the code of conduct as described in Art 40, 41 of the GDPR as a key tool to develop a guide for researchers and administrative staff (especially data controllers and processors) to reduce unnecessary fear relating to compliance and to enhance data sharing for the purpose of stimulating research. Several meetings that contributed to the development of the GDPR Code of Conduct for Health Research have benefited from ADOPT funding (travel/accommodation, see Annex 3).

ELSI Helpdesk Meeting
http://www.bbmri-eric.eu/BBMRI-ERIC/elsi-helpdesk/
The ELSI Helpdesk is a personalised support service assisting researchers and research infrastructures who have ethical, legal and societal questions. By sharing expertise, the ELSI Helpdesk provides initial orientation and knowledge concerning relevant ELSI issues. A significant aspect of activities relating to the ELSI Helpdesk has concerned assessing and identifying national ELSI support across Member Countries, whether as part of National Node activities or otherwise. Having conducted a mapping of the provision of national ELSI support across the BBMRI network, a BBMRI ELSI Helpdesk / Support Service meeting will take place on 29-30 April 2019 in Vienna, in collaboration with CORBEL. This meeting will bring together national ELSI service providers located in Member Countries, as well as other European Health Research Infrastructures. The aim of the meeting will be to exchange knowledge about the provision of ELSI support, as well as to discuss next steps concerning ELSI education and assistance.

CDPD Conference 2019
https://www.youtube.com/watch?v=-qrMjaY0tvo

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co-organised by: BBMRI-ERIC, ADOPT-BBMRI-ERIC, INSERM, biobanques, Turun Yliopisto, FINBB, NHS Health Authority, Academy of Athens/BRFAA, Hospital District of Southwest Finland, University of Sheffield

On 1 February 2019, a session called "The impact of the GDPR on health research practices" was held. It highlighted that the EU General Data Protection Regulation may have significant implications for data protection practices of researchers and donor involvement. Especially so as the regulation provides space for national and EU-level derogations and specifications in areas such as scientific research. This panel aimed to assess the practical consequences of the GDPR for data sharing within the EU with regards to biomedical research, especially biobanking.

Other

Several events ensured expert participation and consequently appropriate outreach of expertise. These events were, however not organised by ADOPT (see Annex 1, specification: participant).

Outreach

Blog posts, events and tools have been promoted publicly via the BBMRI e-newsflash, website, Twitter and LinkedIn, and internally via the Common Service ELSI mailing list as well as to GA4GH (Global Alliance), P3G and ELSI 2.0 partners.

Image 2: Screen Shot Twitter

Resources

IN-KIND BBMRI-ERIC: Common Service ELSI – experts

Operating on the basis of the BBMRI-ERIC federated model, we work in partnership with a network of ethical and legal experts from academia and practice across Europe, coming from our Member and Observer Countries and funded by the BBMRI-ERIC core budget. Our ELSI experts are at the core of any service we provide and any activities we undertake.

ADOPT BBMRI-ERIC: ELSI Helpdesk Coordinator and additional expertise

ADOPT funding allowed the creation of the role of the ELSI Helpdesk Coordinator (50% employment). The ELSI Helpdesk Coordinator is responsible for coordinating requests to the ELSI Helpdesk, replying to requests for an Ethics Check and updating the Knowledge Base and

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events and webinars. Proven a key role, the ELSI Helpdesk Coordinator is, as of spring 2019, an integral part of the BBMRI-ERIC Common Service ELSI as ELSI Services Officer (accounting for the fact that the Services go beyond the helpdesk). This post is funded by the BBMRI-ERIC core budget. Additionally, thanks to ADOPT funding, several ELSI experts (Jasjote Grewal, Irene Schlünder, Anne-Cambon Thomsen, Michaela Th. Mayrhofer, Mats Hansson, Melanie Goisauf) could contribute additional time to specific tasks that would have otherwise not been feasible.

ADOPT BBMRI-ERIC: Other costs (meetings & travel)
ADOPT funded Common Service ELSI resources for hosting and participating in meetings, workshops, seminars, and conferences specific to and relevant for raising awareness and spreading knowledge on ethical, legal and societal issues relevant for biobanking.

Results

Without the additional funding of ADOPT BBMRI-ERIC, the Common Service ELSI could not have advanced as it did. The achievements reached over the duration of the project are solidly integrated in the Common Service ELSI, and sustainability as well as accuracy of formats and tools (e.g. FAQs, How-To Guides, webinars, knowledge exchange) is guaranteed:

The educational and training events and tools presented in this report have been conceptualized and enabled ('kick-started') thanks to the funding by ADOPT BBMRI-ERIC. In order to ensure longevity and sustainability, they were designed as reoccurring events as much as possible. They have become an integral part of the Common Service ELSI of BBMRI-ERIC, complementary to either the Ethics Check or policy work or collaborations with others. All activities are interdependent, inform each other and lead to clearer description of roles. Consider for instance the ELSI Helpdesk Coordinator. Originally, the task was to respond to helpdesk questions and coordinate the network of experts. In the course of ADOPT BBMRI-ERIC, it further developed into the role of ELSI Services Officer, whose responsibilities include developing and implementing all ELSI services including online ELSI training, communication aspects, bridging art and science, and promoting events and tools. Ultimately, BBMRI-ERIC commits to continue the activities started and enabled by ADOPT BBMRI-ERIC, maintaining and improving the educational tools and events described in this report, especially the webinars, thematic workshops and Ethics Café. Steps to improve awareness about the events and services as well as the promotion of their success have already been taken. It has been most successful on Twitter. The restructuration of the website and cross-links/outreach to other initiatives is still ongoing and needs to be included in an overall dissemination strategy of BBMRI-ERIC.

References

Jan-Eric Litton, We must urgently clarify data-sharing rules, Nature 541, 437 (26 January 2017), doi:10.1038/541437a

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Michaela Th Mayrhofer, Irene Schlünder (2018), Mind the Gap: From Tool to Knowledge Base, Biopreservation and Biobanking 16(6), DOI:10.1089/bio.2018.0018.

Melanie Goisauf et al (2019), Data in Question: A survey of European biobank professionals on ethical, legal and societal challenges of biobank research. Plos One https://doi.org/10.1371/journal.pone.0221496

Deborah Mascalzoni, et al (2019) Are Requirements to Deposit Data in Research Repositories Compatible With the European Union's General Data Protection Regulation? Ann Intern Med. 2019;170(5):332-334.

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Appendices

Appendix 1: Input provided by CS ELSI Experts for the ELSI Knowledge Base

Country	Research Scenarios considered most important by CS ELSI expert
Estonia	a. Use of pre-existing samples (e.g. NBS collection of individuals who by now are adults)
	b. Return of research findings, practical guidelines, how to deal with clinically significant research findings, where is the line between rights/duties of researchers vs clinicians, rights of relatives to know information of a deceased individual
	c. Collaboration with companies
Greece	a. Setting a study with data and samples already collected within the context of medical practice (retrospective research)
	b. The lack of bioethics committees in hospitals – their duties are covered by scientific boards
	c. "Informed consent letters" that are too vague, usually "for every scientific purpose". These are given by the doctors they cooperate with, yet the researchers themselves are not in the position to draft an informed consent
	d. Difficulties when cooperating within several different frameworks with third countries. Lack of knowledge of their legislation mainly regarding data process/privacy issues
IARC	a. Studies where ethnicity represents a potential issue for inclusion and participation
	b. Studies on previously collected samples lacking the consent for the use of residual samples

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Italy	a. Studies on archived historical tissues (FFPE pathology samples)
	b. Studies on previously collected samples lacking the consent for the use of residual samples
	c. Collection of samples in the frame of a clinical trial: will the samples remain to be a collection or can they be deposited in a biobank considering a long follow up period
	d. Collection of samples from minors
	e. Re-use of collected samples
	f. Matrix for informed consent
Malta	a. Research using archived pathological samples including tissues. ISSUE: Acquiring informed consent in the absence of consent for research at the time of clinical sample collection. Do we go back to the patient? Do we need consent from clinical consultant who originally ordered the test?
	b. Studies using archived material forensic histo-pathological tissues from medico-legal autopsies ISSUE 1: as above, as no consent was obtained from victims or relatives at time of sample collection, whose consent is necessary? ISSUE 2: if the research findings are of direct benefit to immediate family, can they be communicated to the family? (who are unaware that research is being undertaken)
	c. Dealing with incidental findings when it was not dealt with in setting up the research protocol.
	d. Maintaining confidentiality within research studies in rare diseases in a very small population is impossible. However, the patient support groups and patients themselves are keen to have the public exposure because of the positive impact it might have on participation and obtaining research funding
	e. Currently research ethics committees often demand that the samples are only stored for a finite timeframe ISSUE: it would be unethical to dispose of potentially useful samples
Poland	a. Research project design
	b. Funding applications
	c. Research Ethics Committee (REC) or Bioethics Committee opinions

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	d. Collaboration with other entities and samples transfer (esp. collaboration with foreign and private entities and companies)
	e. Audit and controls.
Sweden	a. Setting up a prospective study with collection of new samples and data in country X
	b. Setting up a prospective study with collection of new samples and data in countries X-Z
	c. Setting up a study reusing already collected samples and data in country X
	d. Setting up a study reusing already collected samples and data in country X-Z
	e. Designing an information and consent procedure for biobank related research
	f. Setting up a governance structure for sharing and access to samples and data
	g. Collecting samples and data for minors
	h. Seeking ethics approval in national projects
	i. Seeking ethics approval in trans-national projects
	j. Reporting of results
UK	a. One of the issues the Human Tissue Authority and Health Research Authority are working on in the UK concerns consent to linking tissue with patient data. Especially where consent is sought for future linking where the participant may not be clear what will be in their medical record in the future.

Country	**ELSI Questions encountered in the context of Projects by CS ELSI Expert**
Estonia	a. Consent procedures, including re-contacting and the need for re-consent despite or because of initial broad consent
	b. MTA & DTA
	c. Return of research results procedure
Greece	a. Their questions are mostly around retrospective research, namely how they can reuse samples/data; should they require consent de Nuovo, for data considered to be anonymised.

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	b. There is a certain confusion also regarding terminological issues regarding anonymity of data. They tend to misunderstand the fact that even though they only have access to a code and not to the personal data per se, the data still remain personal and therefore they must seek informed consent
	c. In view of the –omics development there are a lot of ongoing questions regarding incidental findings and how they should include them in the information procedure/ informed consent
IARC	a. Ethnicity issues: Are subgroups of the population treated fairly?
	b. Lack of original "broad" consent: Are the rights of individual research participants protected? Based on legal authorization from the local Institutions and on the CIOMS regulating the use of historical material, one option may be to waive the requirement of the individual informed consent for the use of residual samples
Poland	a. Transfer of samples and data abroad
	b. Collaboration with private companies
Sweden	a. Information and consent procedures (broad consent, need of re-consent, consent/assent of minors, how to deal with that when they get older, specific content of IC)
	b. Sharing and access of data/samples
	c. Data protection, balancing of privacy and scientific efficiency, public and patient acceptance/engagement, what is sensitive information (e.g. genetic information), anonymization, pseudonymization/coding
UK	a. Data linkage
	b. Incidental findings

Country	**Documents that should be included in the Knowledge Base according to CS ELSI expert**
Greece	a. MTA/DTA templates
	b. Informed consent templates
	c. General info – e.g. FAQs on privacy and biomedical research related issues
	d. MTA/DTA templates

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IARC	a. The IARC Ethics Committee (IEC) has developed a standard ICF (for adult participants) based on WHO example (available here)
	b. http://ethics.iarc.fr/Documents/IBC_consent.pdf
	c. https://cioms.ch/shop/product/international-ethical-guidelines-for-health-related-research-involving-humans/
Italy	a. The IARC Ethics Committee (IEC) has developed a standard ICF (for adult participants) based on WHO example (available here)
	b. http://ethics.iarc.fr/Documents/IBC_consent.pdf
	c. The IARC Ethics Committee (IEC) has developed a standard ICF (for adult participants) based on WHO example (available here)
Malta	a. Guidelines by research ethics committees for approving projects from local and international institutions
	b. Template as guideline for issues to be included in informed consent
	c. Database of researchers in national nodes with areas of expertise for potential collaborative projects
	d. Contacts of key stakeholders;
	e. Links to legislation relevant to research practice, clinical trials, biobanking and data protection in each national node
Poland	a. National node links
	b. Contact to national experts,
	c. National Data Protection Authorities
	f. Collaboration with other entities and samples transfer (esp. collaboration with foreign and private entities and companies)
Sweden	a. Access policy
	b. MTA and DTA templates
	c. International Charter of principles,
	d. RD-Connect Code of Practice
	e. IMI-Code of Conduct,
	f. Templates for informed consent
	g. Guidance documents for the selection of appropriate information and consent procedures (carefully selected publications)
	h. Introduction documents to GDPR

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Appendix 2: BBMRI-ERIC Webinars

Internal Checklist

A. Format of the Webinar

BBMRI-ERIC webinars run for approximately 45 minutes and include a live Q&A session for a further 15 minutes. The moderator of the webinar briefly introduces the webinar topic and the webinar speakers. The moderator also leads the Q&A session. Webinars are recorded and uploaded to the BBMRI-ERIC website.

B. Webinar Platform

The current webinar platform is Go-To Webinar.

- Template for webinar series

C. Organising the Webinar

The following material is needed to organise and advertise the webinar:

- Proposed date for the webinar
  - Date should be at least 1 month after initial publication
  - Suggested time slot: Tuesday/Wednesday/Thursday 13:00-14:00 or 14:00-15:00 CEST
- Title of the talk
- Abstract (including who the target audience is)
- Under which theme does the webinar fall (BBMRI-ERIC - IT – Quality - ELSI services - Other)?
- Speaker biography

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- Speaker Twitter handle if applicable (or other relevant Twitter account)
- Registration link from the webinar platform

D. Tasks and Timeline

ONE MONTH BEFORE THE WEBINAR

———————————————————

Setup Webinar (to be completed)

Website Webinar Page (http://www.bbmri-eric.eu/)

- Create Webinar page based on information sent by the organiser
- Test the link provided

Dissemination of the webinar announcement

Once the webinar details are published on the BBMRI-ERIC website (i.e. one month before the seminar, as described above), the promotion of the webinar begins:

- Email the BBMRI-ERIC communications officer with all the necessary details
- Add webinar
- Email the National Node communication officers, they shall inform their partners and disseminate the announcements via their communication channels
- Tweet announcing the webinar, directing the users to the website; tweets will be placed in regular intervals until the seminar takes place
- Add webinar announcement to the regular BBMRI-ERIC newsletter (if applicable).

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ONE WEEK BEFORE THE SEMINAR

- Send reminder to the RI communication officers
- Tweet daily promoting the webinar, encouraging people to register

TWO DAYS BEFORE THE WEBINAR

- Collect slides from the presenters
- Run a test seminar with the presenters **a few days in advance**. Explain how the questions will be selected and offered
- Moderator and other speakers identify a couple of questions for the webinar
- Ask speakers to connect **30min** earlier on the day of the event

WEBINAR DAY

- Connect at least **30 min**. before the scheduled webinar time
- Send a private message to presenters to communicate only with messages; depending on the platform the broadcast is started immediately
- **Prepare slides**
- Use a "clean desktop" - close all applications that are not in use
- Go in full screen mode
- Select what to "**Show**" and click on the triangle
- Click on "**Record**" (do this as early as possible, webinar will be edited anyway!)
- Explain in detail how the listeners can ask questions and remind them the webinar is being recorded

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AFTER THE WEBINAR IS FINISHED (youtube.com + slideshare.com + website)

———————————————————————

- Edit the webinar in a movie editor
- Upload the movie to BBMRI-ERIC website
- Upload slides to **SlideShare** + add a **link to the webinar's webpage**
- A week later, save as **PDF all responses** from the feedback form and **upload to One Drive**

Suggested text for follow-up email to attendees

———————————————————————————————

We hope you enjoyed our webinar! We'd very much like to make future editions as valuable as possible to participants. Please, let us know about your experience and expectations. That will help us make future webinars more useful for you. The survey has just a few, very short questions:

https://goo.gl/XXXXXXXX - **USE THE CORRECT URL**

If you want to see the webinar again (or share it with your colleagues), you can find a recording on our website [insert link]. There we keep an archive of previous events that we hope you will find useful in your day-to-day activities.

Looking forward to seeing you soon!

Suggested text for follow-up to absentees

———————————————————————————

We're sorry you weren't able to attend our webinar.

If you want to see the webinar (or share it with your colleagues), you can find a recording at our website [insert link]. There we also keep an archive of previous events that we hope you will find useful in your day-to-day activities.

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Follow-up actions

- Email the BBMRI-ERIC HQ to inform the recorded webinar is online
- Email the National Node communication officers; they shall inform their partners and disseminate via their communication channels that the recorded webinar is online
- Tweet that the recorded webinar is online

E. Tips & Tricks

- Having more that 1 speaker can help with the dynamic of the webinar if you would like to encourage discussion.
- Have a few questions prepared in advance, the host can start with that question while the attendees add their questions to the chat panel.
- Speaker handovers are the most likely fail points, avoid these if possible. Test in advance if the speaker slides display the presenter mode automatically. This needs to be turned off as the screen share will display the presenter mode.
- Turn on recording as early as possible to avoid forgetting it; any additional time can be edited afterwards.

F. Future Considerations

- In order to expand our outreach, BBMRI-ERIC should consider organizing invited webinars from outside speakers/projects

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SPEAKER INSTRUCTIONS: GO-TO WEBINAR

We are delighted that you will be presenting a BBMRI-ERIC webinar. Below you will find instructions to assist you with Go-To Webinar:

Getting Ready for the Webinar

You will already have had your test-run webinar with the moderator.

Please don't forget to send your PowerPoint presentation, or a pdf copy, to the moderator prior to the day you will be presenting.

On the Day: Joining the Webinar

Please ensure that your laptop is charged and you have a headset with a microphone. We would also advise you to connect to the same internet server as in the test-run.

The moderator, or if necessary back-up moderator, of the webinar will open the Go-To Webinar line before you are able to enter the webinar. Please join the webinar 30 minutes before the start time of the advertised webinar.

Note: You will already have received an email informing you that you are a panellist for your webinar (from customercare@gotowebinar.com) – please use the link in the email to join the webinar. These links are personalised.

If using Go-To Webinar for the first time you will need to download a small plugin – it will do this automatically when you click on the link.

Once you have Joined the Webinar

You will then get a dashboard on one side of your desktop

You will also get a notice about connecting your audio – click to use your computer audio.

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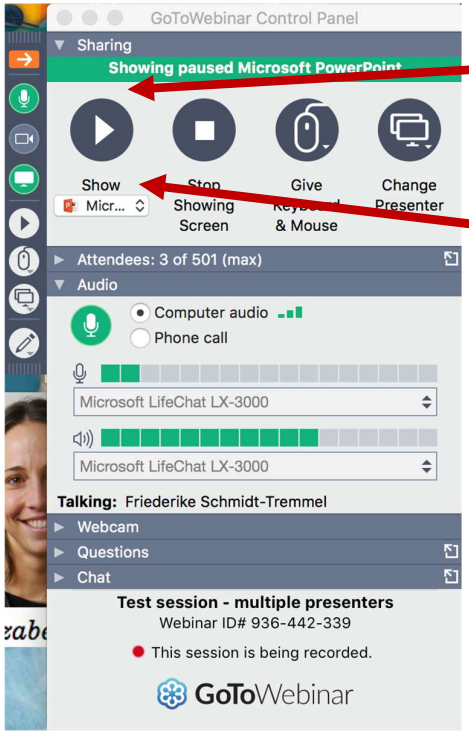
You can speak to the moderator and other presenter (=speakers) before the webinar is made live to the attendees.



Green microphone shows your audio is on, if red you are muted

Green screen shows you are sharing your screen (either main or app only). If you want to stop sharing click the stop button, to start sharing click on the play button.

Before the moderator starts the webinar, all speakers should mute themselves. The moderator and Go-To Webinar will remind you when the webinar is about to start.

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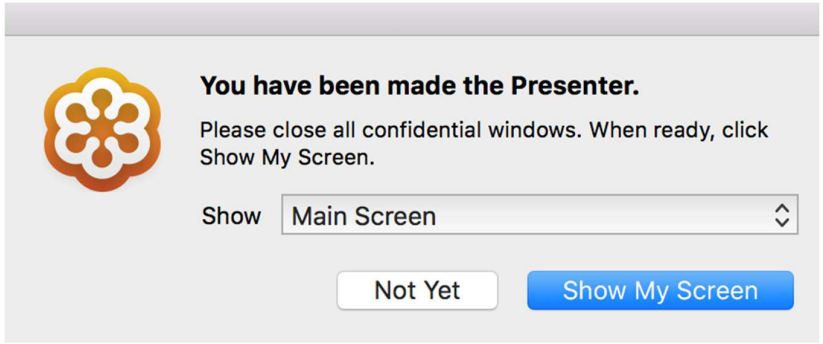
Loading Your Webinar Presentation

The moderator will indicate verbally when they will pass presenter rights to the first speaker.

If presenter rights have been passed to you, you will be notified:



You will need to select *Show My Screen*, you can either share your main screen or select an application only (e.g. PowerPoint on the drop down).

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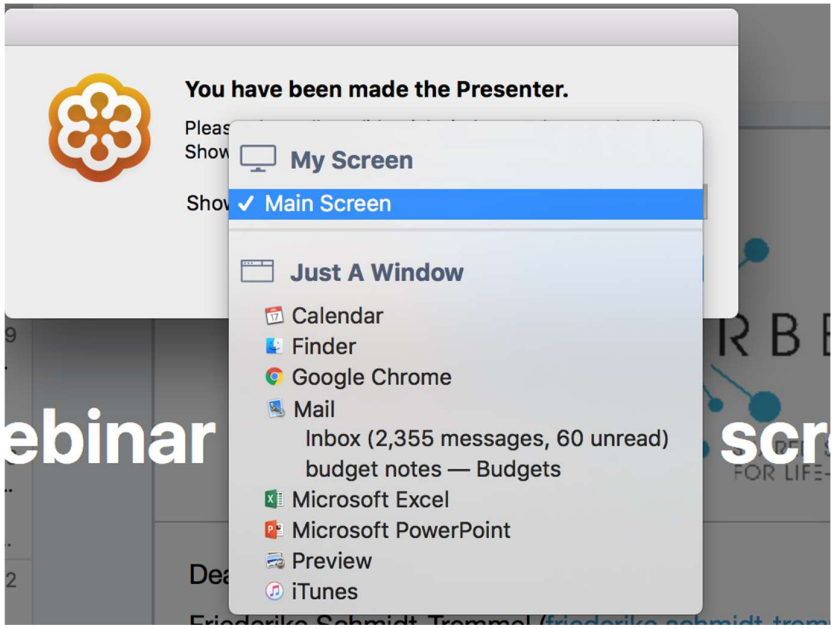

Please note that if you are using a MAC you may need to reselect PowerPoint even after having selected it initially in order to show your slides in full screen mode.

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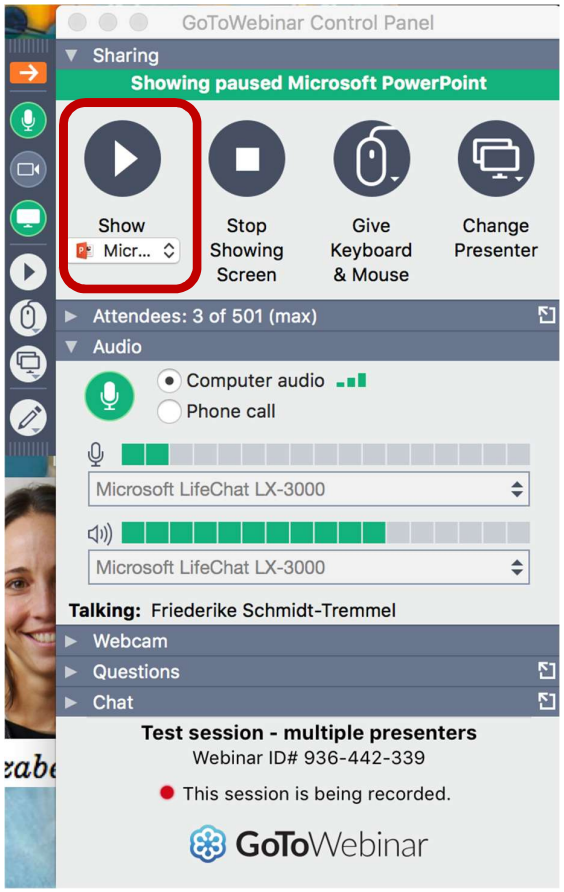

If the screen sharing notification does not appear, under *sharing*, select *Show Screen* as in the above picture.

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Start Presenting!

Remember to unmute yourself!

Please check verbally with the host whether your slides are visible and if we can hear you. The host will confirm.

If there is more than one presenter and you are ready to hand over to the next presenter, please say "I am going to hand over to XX" so that the host can pass the presenter controls.

Remember to mute yourself if you are no longer the speaker.

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ADOPT BBMRI-ERIC gateway for health

Appendix 3: List of Events (co-)funded by ADOPT

Type of Activity	Specification (if applicable)	Main leader	Title	Date	Place
Meeting	Organizer	BBMRI-ERIC	Stakeholder Forum	18.04.-19.04.2016	Brussels, Belgium
Meeting	Participant	BBMRI-ERIC	European Medicines Agency conference	22.04.2016	London, UK
Meeting	Participant	BBMRI-ERIC	Stakeholder Forum & Personalized Medicine	31.05.-02.06.2016	Brussels, Belgium
Meeting	Participant	BBMRI-ERIC	Stakeholder Forum	25.07.-26.07.2016	Brussels, Belgium
Meeting	Participant		International Consortium Precision Medicine Challenge Groups meeting	01.09.2016	Brussels, Belgium
Meeting	Participant	BBMRI-ERIC	CS ELSI Task Force f2f meeting	13.11.2016	Vienna, Austria
Meeting	Participant	BBMRI-ERIC	CS ELSI ADOPT	27.11.2016	Toulouse, France
Meeting	Organizer	BBMRI-ERIC	Berlin WP5 f2f meeting	05.12.2016	Berlin, Germany
Congress	Participant	BBMRI-ERIC	Europe Biobank Week, Biobanking for Health Innovation	13.09.-16.09.2016	Vienna, Austria
Meeting	Organizer	BBMRI-ERIC	Code of Conduct writing group meeting: structure	26.07-27.07.2017	Brussels, Belgium
Meeting	Participant		Seminar on the GDPR Code for Conduct for Health Research and Implications for FP9	06.11.2017	Brussels, Belgium
Meeting	Organizer	BBMRI-ERIC	Code of Conduct meeting and Code of Conduct Workshop on Anonymisation	22.11-24.11.2017	Paris, France
Meeting	Organizer	BBMRI-ERIC	Stakeholders Forum	24.01.-26.01.2018	Brussels, Belgium
Meeting	Organizer	BBMRI-ERIC, CORBEL, DO-IT, RD-Connect	CoC Drafting Group Face to Face Meeting	22.01.-23.01.2018	Brussels, Belgium
Meeting	Organizer	BBMRI-ERIC	CS ELSI Helpdesk working meeting	31.01.2018	Vienna, Austria
Meeting	Organizer	BBMRI-ERIC, DO-IT, CORBEL, RD-Connect	Code of Conduct meeting: glossary	21.02-22.02.2018	Vienna, Austria
Meeting	Organizer	BBMRI-ERIC	Adopt WP5 GDPR Glossary Meeting (definitions)	08.06.18	Vienna, Austria
Meeting	Organizer	BBMRI-ERIC	WP5 Writing Meeting ELSI Survey Consent	06.07.2018	Milan, Italy
Meeting	Participant	EFPIA	EFPIA GDPR Working Group	22.01.-23.01.2018	Brussels, Belgium
Conference	Organizer	BBMRI-ERIC	CDPD 2018 - session on the code of conduct initiative	25.01.2018	Brussels, Belgium
Conference	Participant	ESOF, BBMRI-ERIC	ESOF 2018: Session: Biobank as springboard for open science and engagement	12.09.2018	Toulouse, France

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Workshop and Visit	Organizer	BBMRI-ERIC	Art & Science Collaboration: Guided Visit of the MedUni Wien Biobank, Introductory Workshop on BBMRI-ERIC & Quality Management	09.10.2018	Vienna, Austria
Conference	Organizer	BBMRI-ERIC, BRFAA, TURUN YLIoPISTO, INSERM, HOSPITAL DISTRICT OF FINLAND, FINBB, Univ. Sheffield	CDPD 2019 - session on health research	01.02.19	Brussels, Belgium
Meeting	Organizer	BBMRI-ERIC	ADOPT WP5 Consent Working Group	22.02.19	Bolzano, Italy
Teleconference	Organizer	BBMRI-ERIC	WP5 - TF Societal Issues	Monthly, since June 2016	www
Meeting	Organizer	BBMRI-ERIC, RD-Connect, Do-It, CORBEL, EUREC	Code of Conduct drafting group	2018 11 04-05	Rome, Italy
Workshop	Organizer	BBMRI-ERIC	Art & Science Collaboration: Workshop on Biobanking, ELSI and European Policy	09.10.2018	Vienna, Austria
Workshop and Visit	Organizer	BBMRI-ERIC	Art & Science Collaboration: Guided Visit of the Graz Biobank, Workshop on BBMRI-ERIC and Art	09.10.2018	Graz, Austria
Conference	Organizer	BBMRI-ERIC	Ethics Café Session during EBW	07.11.18	Antwerp, Belgium
Conference	Organizer	BBMRI-ERIC	Ethics Café Session during GBW	15.11.17	Stockholm, Sweden
Conference	Organizer	BBMRI-ERIC	Ethics Café Session during EBW	14.11.16	Vienna, Austria
Teleconference	Organizer	BBMRI-ERIC	WP5 - TF International Organisations	Quarterly, since January 2017	www
Teleconference	Organizer	BBMRI-ERIC	WP5 - TF Success Stories	Every second month since December 2017	www
Meeting	Organizer	BBMRI-ERIC, RD-Connect, EURORDIS	Ethical Review for Biobank Based Research Projects: Towards a Risk Based Ethical Reviews	20.02.18	Paris, France
Meeting	Organizer	BBMRI-ERIC	WP5 - Working Meeting CS ELSI	2017 01 25	Berlin, Germany
Meeting	Organizer	BBMRI-ERIC	CS ELSI/IT Meeting	2017 02 27	Berlin, Germany
Meeting	Organizer	BBMRI-ERIC	Biobanking Workshop: ethical and legal issues	2017 06 19-20	Athens, Greece
Meeting	Organizer	BBMRI-ERIC	WP5 - Engagement Workshop	2017 09 12	Stockholm, Sweden
Meeting	Participant	BBMRI-ERIC, ISC	ISC, GDPR Seminar	2017 11 06	Brussels, Belgium
Meeting	Organizer	BBMRI-ERIC	WP5 - TF IO - Meeting UNESCO	2018 03 15	Paris, France
Meeting	Organizer	BBMRI-ERIC, RD-Connect, CORBEL	Code of Conduct drafting group - consent	2018 07 26	Berlin, Germany
Meeting	Organizer	BBMRI-ERIC, RD-Connect, CORBEL, DO-IT	Code of Conduct drafting group - structure	2018 07 30-31	Brussels, Belgium

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