

ADOPT BBMRI-ERIC Grant Agreement no. 676550

DELIVERABLE REPORT

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Implementation of new ELSI tools

Executive Summary

The implementation of new ELSI tools, notably procedures to enhance public debate are related with the efforts of various Task Forces as launched by the BBMRI-ERIC Common Service ELSI to address the various ethical, legal and societal aspects (exemplarily public engagement, access procedures or dataprotection). It required an assessment of existing tools and actual user needs (e.g., patient/industry/member state/citizen/researcher) and is closely linked with making the tools known and user-friendly, consequently used.



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BBMRI-ERIC provides tools and expertise, as well as knowledge and experience sharing on ethical, legal and societal issues for the biobanking community through its Common Service ELSI. The service offers support on ethical, legal and societal issues related to biobanking activities. It is primarily intended for users located in Member Countries of BBMRI-ERIC.	3
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Background

BBMRI-ERIC provides tools and expertise, as well as knowledge and experience sharing on ethical, legal and societal issues for the biobanking community through its Common Service ELSI. The service offers support on ethical, legal and societal issues related to biobanking activities. It is primarily intended for users located in Member Countries of BBMRI-ERIC.

By making an assessment of existing ELSI tools, BBMRI-ERIC focused on identifying the actual user and stakeholder needs. Stakeholders include patient organisations, the industry, biobankers and researchers as well as the general public. Ultimately, developing tools requires an ongoing engagement with especially the National Nodes, the Common Service IT and the Stakeholder Forum of BBMRI-ERIC.

Description of work and efforts

The goal was to identify new ELSI tools and, wherever feasible, build on existing ELSI tools to promote knowledge and expertise on ethical, legal and societal issues (ELSI). It became apparent that the Common Service ELSI has to be promoted in places where stakeholders/users are meeting.

Conference Participations – Introducing the Common Service ELSI (selection)

03 March 2016: European Congress of Radiology, Vienna/Austria

31 May 2016: Stakeholder Forum (patient organisations), Brussels/Belgium

25-29 July 2016: 1st Conference on Social Impact of Science (SIS2016), Barcelona/Spain

16 September 2016: BBMRI-LPC Forum, Vienna/Austria

Europe Biobank Week

Between 13-16 September 2016, eight sessions addressed specifically ethical, legal and societal issues within the theme “putting patients into the centre of the health innovation process” in the context of the Europe Biobank Week conference. Namely, (1) Participation of patients and public in biobanking, (2) ELSI issues-practical, (3) Patient engagement: how to bridge between science and healthcare?, (4) From Donors to biobanking – from biobanks to patients, (5) New concepts and tools for public engagement, (6) Biobanks engaging society, (8) What will change under the upcoming GDPR? (FAQ format) and (9) Sharing results with donors? (ethics café format) It attracted 682 participants, thereof 17 patient organisations.

Additionally, the following internal workshops and meetings took place:

- Board of Directors Meeting (afternoon session)
- ELSI Team Meeting (lunch session)
- Task Force GDPR Meeting (morning session)
- 13 September 2016: Task Force Chairs’ Meeting (lunch session)



- 15 September 2016: Task Force Societal Meeting (morning session)
- 14 September 2016: Task Force Help Desk Meeting (lunch session)
- 15 September 2016: Code of Conduct Meeting (evening session)

As regards to the promotion of knowledge and expertise, the Common Service ELSI also relies on the following BBMRI-ERIC communication tools: monthly e-newsflash/5,000 subscribers; public website/www.bbmri-eric.eu, intranet, periodic magazine “Biobanks Europe” and mailinglists.

In assessing the existing tools, it became apparent to engage with the users (especially during conferences) and to provide them tools and services in a manner appropriate to their needs (e.g., FAQs, best-practice examples). In collaboration with the CORBEL project, BBMRI-ERIC assessed in an online questionnaire the user needs on ELSI tools, which determined that such tools should have biobankers/researchers as primary audience.

Conclusions, what a useful ELSI tool should be/provide:

- checklists, procedures, FAQs and templates
- concrete answers with (best-practice) examples (no legalistic language)
- interdisciplinary discussion platform
- simple, accessible and user-friendly (not list of links)
- contact person

Schedule

Deliverable on time.

Results/Outcome

The implementation of new ELSI tools required an assessment/reconceptualization of existing tools, which provide knowledge, guidance as well as general information in a user friendly and accessible manner.

Existing tools revised:

- **Website:** restructured and launched in a new structure/design allowing to direct the user to his/her information as researcher/member state/citizen/patient/industry (see Image 1: Screenshot Website) - regular updates.
- **Monthly e-Newsflash:** containing specific section on ELSI (see Image 4: e-newsflash) - a thematic e-newsflash has been conceptualised and will be launched in Q1/2017 (other topics: IT, quality).
- **“Biobanks Europe” Magazine: #4** (September 2016) informed on the ELSI services – a special issue on ELSI is planned for 2Q 2017.



- **WIKI legal, LAT (BioMedBridges tool), hSERN:** promoted/hosted by BBMRI-ERIC (sustainability) – integration into one online tool ongoing, envisioned 4Q/2016.

New ELSI tools identified and means to reach them:

- **Flyer:** restructured and launched in a new structure/design allowing to direct the user to his/her information as researcher/member state/citizen/patient/industry (see Image 1: Screenshot Website) - regular updates.
- **Sessions/booths at conferences:** e.g., Global Biobank Week (September 2017, Stockholm/Sweden) introducing/promoting the services and tools
- **Best-practice models:** The Task Force Societal has met on 15 September 2016 in Vienna/Austria. BBMRI.it, BBMRI.mt, BBMRI.at and BBMRI-NL presented their national activities on public/research participant and patient/donor engagement respectively. – regular updates

Next Steps

Building on the existing engagement activities and the experience in the National Nodes, best practice models and practical conclusions relevant for European biobankers will be drafted and shared to the community (online and promoted during conferences, workshops and disseminated via the communication tools described above).

In particular, the Task Force Societal will address biobanking as a social concern and make best-practice models for how biobanks can engage with these concerns available on the BBMRI-ERIC website (sections Help Desk as well as Common Service ELSI).

References

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Appendix I

Image 1: Screenshot Website

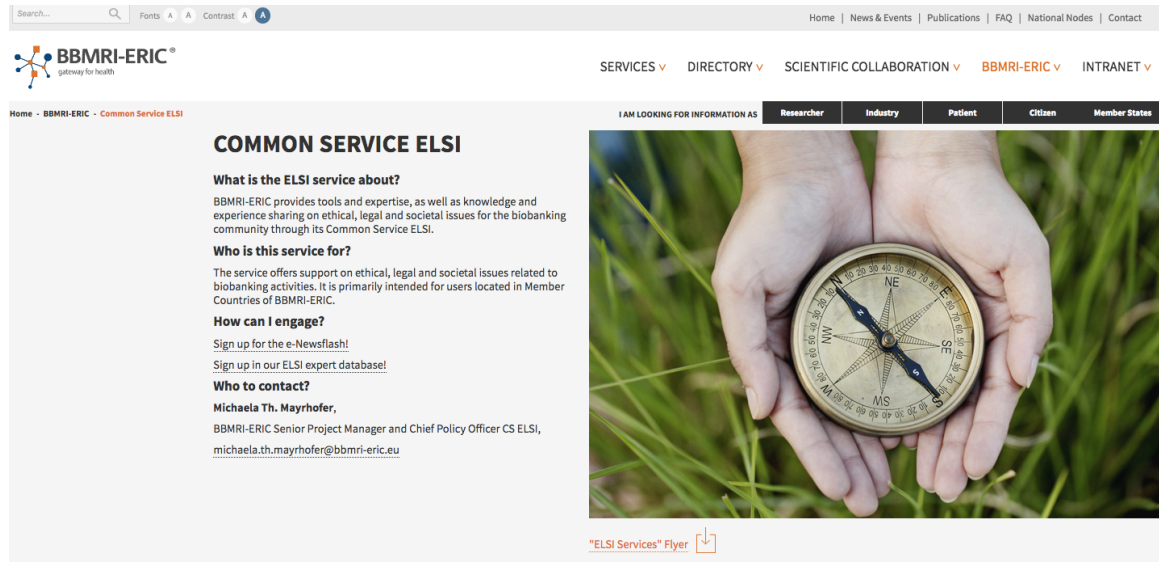


Image 2: Screenshot ELSI Services Flyer



Horizon 2020

ADOPT BBMRI-ERIC is funded by the European Union (EU) Horizon 2020 under Grant number 676550.

Image 3: Europe Biobank Week Conference



Final Programme

To download EBW programme, [click here](#)


To download BBMRI-LPC forum programme, [click here](#).

To download the abstracts book, [click here](#)

P – Plenary session – keynote lectures	A – Innovation sessions	B – Patient and ELSI sessions
C – Data sessions	D – Biomarker sessions	E – Quality management
F – BBMRI-LPC forum	G – Biobanking for environmental and biodiversity	Social events

Image 4: e-newsflash

BBMRI-ERIC e-Newsflash no 26 (29 September 2016) [View this email in your browser](#)



Circulating our twenty-sixth monthly BBMRI-ERIC e-Newsflash!

JAN-ERIC LITTON ABOUT THE EUROPE BIOBANK WEEK 2016
The recent Europe Biobank Week in Vienna "Biobanking for Health Innovation" conference concluded as a big success for the biobanking community bringing together [...read more](#)

CORBEL 1ST OPEN CALL FOR RESEARCH PROJECTS
CORBEL (www.corbel-project.eu) seeks to harmonise access to European research infrastructures joining their various expertise across the range of life science dis [...read more](#)

BIOBANK PERSPECTIVES NEWSLETTER
If you did not get your fill during the biobank week in Vienna, the Centre for Research Ethics & Bioethics (CRB) gives you more biobank related news. In this [...read more](#)



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