

Italian Common Service ELSI as a Broadband Hard-core Infrastructural Service

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A hardcore service with all the actors involved

Facing biobanking as an infrastructure of knowledge, a direct and conscious involvement of all the actors is cornerstone not only for a good practice of biobanking, but above all for the very possibility of its development. Consequently the main ELSI purpose becomes to build a real frame of continuous in-formation, public information and scientific citizenship.

Consequently the Italian Common Service ELSI has been building as a hard-core service, as a broadband infrastructural service, a service systematizing and promoting biobanking through an interactive involvement of all the actors involved.

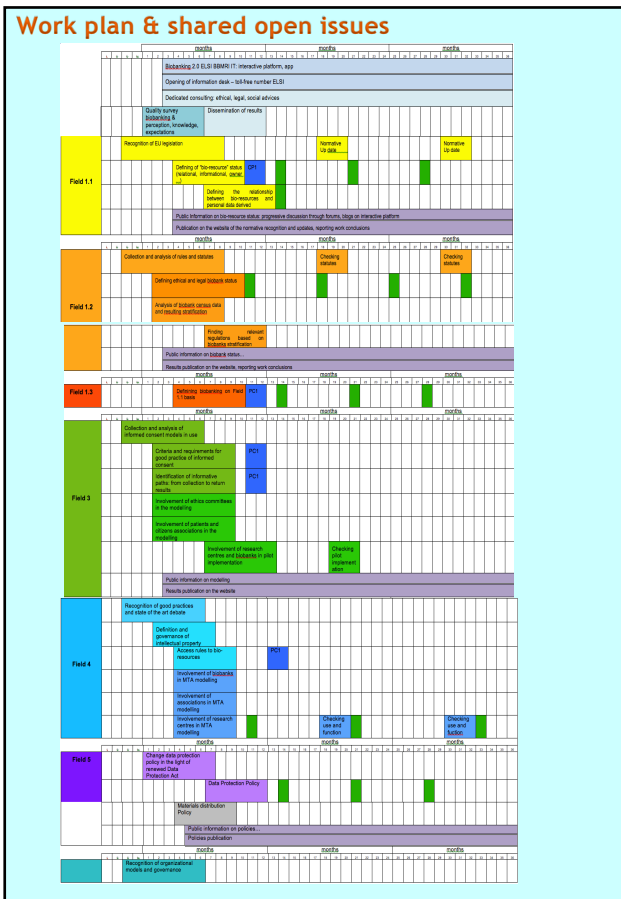
Over time this leads to a very more shared and assumed regeneration of the ethical and regulatory scenario for the development of advanced research and scientific knowledge.

The point

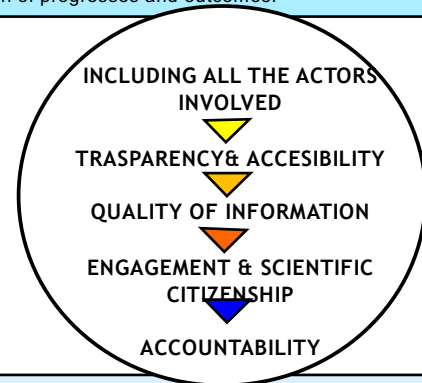
In-formation and the inclusion of all actors (patients, citizens, biobankers, researchers, health professionals, institutions and industries) in the joints of knowledge and decision-processes of biobanking, from the policies to the audit of processes.

CS ELSI BBMRI IT features as an institutional service dealing with these principal areas: Transparency & Accessibility of processes, Quality of information, Engagement & Scientific Citizenship, Accountability.

In particular Public Information has been designed to empower people to understand processes of analysis, co-production of knowledge, defining and fleshing out best practices, policy models; at the same time it is a condition of possibility for knowledge and scientific citizenship. Some specific interactive tools have been foreseen, in particular an innovative collaborative digital platform, public consultations, systematic participatory dissemination of progresses and outcomes.



1.1. Status of biosources	Defining the status of bio-resources from relational, informational and owner dimensions
1.2. Status of biobank	Biobank civil function with respect to decision-making processes, information and warranty.
1.3. Status of biobanking	Interrelationship between the status of bio-resources and infrastructure model of research and production of scientific knowledge
2. Public consultation	The citizen-patient as: - carrier of biobanking advanced research scenario - a decisional subject to be involved and engaged in the construction of the policies/governance
3. Modeling of informed consent as a process.	From a broad consensus to a participatory consensus
4. Access to bio-resources	Rules of access to biosources as scarce / limited. Definition and management of intellectual property (patentability, public domain, "benefit sharing")
5. Good practices of biobanking	Hard law/soft law? - Policy of data protection - Policy of materials distribution - Data sharing
7. Ethical Committees Network	Interaction and training of ethics committees in view of shared parameters of evaluation of protocols with human biological materials
8. Permanent Education	- education & training programmes dedicated to different actors - empowerment workshops - e-learning



Training together, building good practice

The ELSI service of BBMRI Italy provides specific service activities:

Public Information Training Orientation and Advice

Thus ELSI BBMRI IT acts as a broadband service of advanced training and of modelling good practice of biobanking

- ❖ promoting different level of training from basic to advanced, paying special attention to permanent education with programs dedicated to associations, researchers and biobankers,
- ❖ developing ethical-legal counselling and an open hard-core of knowledge best practices & policies (i.e. agreed policies on the use of historic unconsented samples, policies on the upgrade of archive tissues to biobanks),
- ❖ validating and auditing good ELSI practices.

On going tasks

- ❖ an interactive ELSI program of support for biobanks undertaking the path of BBMRI IT membership,
- ❖ a systematic cooperation with Patient Organizations intending to build an agreement of biobanking,
- ❖ with the Research Ethics Committees National Network, the co-production of a good practice for the evaluation of protocols dealing with human biological materials newborn screening as a great opportunity of systematic biobanking.

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