

## **Swiss Personalized Health Network: Mandate of the ELSI Advisory Group (ELSlag) (09.09.2016)**

The ELSIag is an advisory body to the entire SPHN as it is outlined in Article 15.1 of the Rules of Procedure. As such it is tasked to address key ethical, legal and societal challenges that are relevant to the SPHN's activities.

The ELSIag will therefore:

- Identify the most urgent ethical challenges to the various aspects initiative. Several key topics have already been identified as of primary urgency for the initiative. Three topics that the ELSIag should address immediately are:
  1. Data sharing policy. This refers to the duties and responsibilities of researchers and institutions to share (or not) with other researchers and institutions in Switzerland and in the context of projects funded by the SPHN.
  2. Relationships with the private sector. This refers to principles of engagement between the SPHN and related industries. More specifically it addresses access to resources, to data generated from SPHN activities, as well as intellectual property and patent issues.
  3. Informed consent procedures for the SPHN research projects. This refers to the principles for consent as well as documentation for sample/data collection and use within SPHN activities.
- Invite other bodies of the SPHN to submit ethics related questions for consideration;
- Develop principled recommendations as a response to each identified challenge;
- Propose the recommended policies for adoption by the NSB.

The ELSIag cannot enforce the recommendations and cannot monitor compliance with the recommended policies. The ELSIag recommendations operate at a principle level and do not constitute legally binding documents. Legal agreements cannot be authorized or reviewed for legitimacy, however the group can provide advice on agreements and their alignment with the recommended policies.

### **Working principles:**

- The ELSIag addresses the key ethical, legal and societal issues as they pertain to the SPHN activities.
- It considers relevant evidence when available, key arguments for different policy options and deliberates with the aim to provide recommendations for the most appropriate and ethically robust response to any particular challenge it examines.
- It delivers actionable recommendations to the organizational bodies and members of the SPHN in the form of action papers and policy briefs.
- Consults the organizational bodies of the SPHN for ensuring the identification of the most relevant issues to be addressed by the group and for input on the recommendations.
- Works in a timely and lean fashion.

**Procedures:**

The ELSlag members bring expertise in ethical and legal issues that are most closely relevant to the questions that should be considered. However, as most of these topics are controversial and highly debated in the literature, it is necessary that before the topic is put to the group for discussion a background document is prepared outlining the challenge, relevant arguments, existing policies, international responses to the challenge. This is important and substantive work without which it will be difficult for the ELSlag to advance its work in a meaningful and timely manner.

1. The background document will be approved by the Chair before it will be delivered to the members as background discussion document.
2. Members are then invited to discuss the document and on the basis of the discussion to draft recommendations. The minutes of the discussion in the form of recommendations will be circulated back to the members for final approval.
3. The report of the ELSlag will be sent to the Chair of the SPHN's Executive Board for comments. It is at the discretion of the EB's Chair whether the ELSlag reports are circulated to all members for comments or for information.
4. The ELSlag Chair will send the final version of each report to the NSB for approval. The ELSlag will report to the NSB and will work in close collaboration with the MO.

