**Adherence to Ethical Framework: checklist for preparing**

**your application to the SPHN Call for Proposals 2017**

*This checklist accompanying the Ethical Framework should serve as a guide for proposal preparation and help applicants to adhere to this Framework. The checklist does not have to be submitted as part of the proposal. Answering “no” to one or several questions shall not preclude for proposal submission and evaluation. However, it should raise awareness on issues that should be addressed.*

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| **I. Respect for persons** | **Yes** | **No** | **n/a** |
| 1. Further research use of non-anonymized data:
* Have all research participants provided at least general consent for the further research use of their encoded or non-encoded non-genetic health-related data?
* Have all research participants provided informed consent for the further research use of their personally identifying genetic data?
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| 1. Further research use of anonymized genetic data:
* Have all research participants been informed about the possible use of their anonymized genetic data for further research purposes?
* Have the research participants who dissented to further research use of their anonymized genetic data been excluded from your research project?
 |  |  |  |
| 1. Further research use of health-related personal data in the absence of informed consent (with the exclusion of personally identifying genetic data):

Do you have an authorization from the competent cantonal ethics review committee to use such data and to share them with other SPHN partners? |  |  |  |
| 1. Do you have policies and mechanisms in place for the communication of clinically actionable information to research participants?
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| 1. Do you have policies and mechanisms in place for the communication of clinically relevant information to research participants that may request such information to be disclosed?
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| 1. Do you have a system in place that allows you to act swiftly in case of an individual revoking consent?
 |  |  |  |
| **II. Privacy** | **Yes** | **No** | **N/A** |
| 1. Do you have regular auditing of your privacy protection and confidentiality procedures?
 |  |  |  |
| 1. Do you have a procedure for the re-identification of coded data in case research participants need to be recontacted?
 |  |  |  |
| **III. Data Fairness** | **Yes** | **No** | **N/A** |
| 1. Are you able to make your scientifically-relevant data available to the network partners in a timely manner?
 |  |  |  |
| 1. Do you intend to charge a data access fee or to require any form of in kind compensation for data access?
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| 1. Did you grant any exclusive data access rights to third parties outside the SPHN or do you intend to do so?
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| 1. Do you have policies regarding IP protection and attribution with respect to the use of data collected by or stored at your institution?
 |  |  |  |
| 1. Have you included dissemination plans of your research results to the wider public?
 |  |  |  |
| **IV. Accountability** | **Yes** | **No** | **N/A** |
| 1. Are your governance structure and your policies for processing of personal data, including authorization of data access requests, publicly available?
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| 1. Do you conduct regular audits of your data processing mechanisms?
 |  |  |  |
| 1. Is anyone (body or individual) at your institution designated as the point of reference accountable for the processing of personal research data?
	1. Is this person/body also responsible for legal compliance with human research and data protection laws?
	2. If not: who is responsible for legal compliance?
 |  |  |  |
| 1. Do you have a policy for assessing data access requests by third parties?
 |  |  |  |
| 1. Do you have mechanisms/procedures for monitoring, assessing and auditing the security of personal research data at your institution?
 |  |  |  |
| 1. Is the research personnel that handles personal data at your institution trained on the technical, legal and ethical requirements of data protection in the handling of personal research data?
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