# SPHN Project

## Annual Report - Year 2019 (Version: 20.02.2020)

**Project details**

|  |  |
| --- | --- |
| Project number |  |
| Project title |  |

**Contact details of the Main Applicant**

|  |  |
| --- | --- |
| Last name |  |
| First name |  |
| Position |  |
| Institution |  |
| Address |  |
| Postcode |  |
| City |  |
| E-mail address |  |
| Telephone |  |

**Attachments:**

* Detailed financial information (Excel document).

*Please note that this feedback will not only be used to evaluate the progress of your project, it will also contribute to the mapping of existing research infrastructures of the SPHN. Infrastructure mapping will be published on the SPHN homepage and should help principle investigators of future research projects optimising their studies, finding collaborations and using existing infrastructures.*

Place, Date \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ Signature \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Name, Position

### **Summary (2-3 pages max.)**

*Please provide an overview of the endeavours undertaken during the reporting period.*

***Driver Project:*** *Please describe in a short summary (max. 250 words) the main outcomes of the research part of your driver project.*

1. **Main achievements and results, detailing how these achievements and results compare against the milestones set in the proposal.**

*In this section, please describe the progress made during the reporting period with respect to the overall project plan. Additionally please provide a progress report (Table 1) on each project milestones. Please indicate for each milestone any issue and/or obstacle encountered during the reporting and explain how they were/will be addressed (Gap analysis).*

**Table 1: Milestone dashboard**

*In the milestone dashboard, please list all the milestones described in the proposal and indicate the level of completion with an [X].*

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | **Deliverable/**  **Outcome** | **Level of completion** | | | | **Estimated completion time (month/**  **year)** | **Progress made**  **(max. 5 bullet points)** | **Issues/obstacles (gap analysis)**  **(max. 5 bullet points)** |
| **Not started** | **Started** | **Partially completed** | **Completed** |
| **Work package 1** |  |  |  |  |  |  |  |  |
| *Milestone 1.1* |  |  | X |  |  |  |  |  |
| *Milestone 1.2* |  | X |  |  |  |  |  |  |
| **Work package 2** |  |  |  |  |  |  |  |  |
| *Milestone 2.1* |  |  |  |  |  |  |  |  |
| *Milestone 2.2* |  |  |  |  |  |  |  |  |

1. **Infrastructures: To what extent are your infrastructure sustainable after the SPHN funding period. What is the benefit and reusability of your infrastructure component for the community.**
2. **Data standards: Which specific clinical and non-clinical data standards are used in the project and why (other than CHOP, ATC, ICD).**

*Please provide a list of standards with a short description and their use case within your project.*

1. **Infrastructures: Newly built infrastructures and degree of implementation and usability**

*In this section, please describe in what extent the results of the project have resulted in usable research infrastructures as follows:*

*Please* **categorise** *your project by selecting 3 domains from Table 2 with an X;*

1. *For the 3 selected domain, please describe your achievements using max. 5 bullet points;*
2. *Under “Score”, please indicate the degree of implementation and general availability of the various newly built infrastructures using the following implementation scale:*
   1. *Concept established;*
   2. *Infrastructure built and tested;*
   3. *First scientific study successfully performed on the described infrastructure;*
   4. *Infrastructure tested with multiple studies;*
   5. *Infrastructure available for projects outside the project consortium;*
   6. *Infrastructure used for clinical diagnostic or therapeutic applications.*

**Table 2: Newly built infrastructures**

|  |  |  |  |
| --- | --- | --- | --- |
|  | **Domain**  *(select 3 and mark with an X)* | **Achievements**  *(max. 5 bullet points)* | **Score**  *(1-6)* |
|  | ***Patient or citizen oriented***  *(Harmonisation of semantics [clinical data]; Hospital infrastructure, interoperability; Accessibility to encoded patient data; Databases [data warehouse, disease registers, biobanks])* |  |  |
| **X** | ***Ethics, legal domain, data protection, patient information***  *(Consent support structures; Implementation of data protection and safety measures, data governance; Ethics support structure; Patient involvement)* | * *E-consent app (example)* | *2* |
|  | ***Analytical platforms (e.g. genomics, metabolomics, proteomics, etc)***  *(Harmonisation of semantics [molecular –omics data and samples]; Platform infrastructure, interoperability [e.g. harmonising sample process workflows]; Accessibility to platform services; Databases, biobanking, data repository)* |  |  |
|  | ***Bioinformatics, medical informatics, big data analytic***  ***platforms***  *(Harmonisation of formats and semantics; Community contributions to data analysis tools and workflows; Platform infrastructure, interoperability; Accessibility to platform services [e.g. data analysis tools]; Databases, data repository)* |  |  |
|  | ***National registries, technology, and analytical networks (e.g. imaging, telemedicine platforms, etc)***  *(Harmonisation of formats and semantics; Platform infrastructure, interoperability; Accessibility to platform services; Data repository, databases, biobanking)* |  |  |

1. **Progress made towards the implementation of the Ethical Framework for Responsible Data Processing within SPHN**

*In this section, please provide details regarding the implementation of the guidance outlined in the Ethical Framework for Responsible Data Processing within SPHN. The purpose of this section is not meant as an assessment, however, it is intended to help us identify whether a particular aspect of the framework has been more challenging to implement.*

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **I. Respect for persons** | **Yes** | **No** | **n/a** | **Comments** |
| 1. Further research use of personally identifiable data (genetic and non-genetic):    * + Have all research participants provided informed consent for the specific further research use of their personally identifying genetic data? |  |  |  |  |
| 1. Further research use of coded or anonymized data and biological samples:    * + Have all research participants, whose data are coded, provided at least general consent for the possible use of their data in further research projects?      + Have all research participants, whose data and/or biological samples will be used in anonymized form, been informed about the possible use of their data further research projects?      + Will you exclude research participants who dissented to further research use of their coded or anonymized genetic data been excluded from use in further research projects? |  |  |  |  |
| 1. Further research use of health-related personal data in the absence of informed consent (with the exclusion of personally identifiable 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 a system in place where research participants can request information about their health-related data and human biological material, including information related to their collection, storage, use and sharing? |  |  |  |  |
| 1. Do you have policies and mechanisms in place for the communication of clinically relevant actionable information to research participants that may request such information to be disclosed? |  |  |  |  |
| 1. Do you have a system in place that allows you to act swiftly in case of an individual revoking consent, including processes to remove or destroy the data and human biological material if wished by the research participant? |  |  |  |  |
| **II. Privacy** | **Yes** | **No** | **N/A** | **Comments** |
| 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? |  |  |  |  |
| 1. Is the research personnel that handles health-related personal data and human biological material at your institution trained on the technical, legal and ethical requirements of data protection in the handling of such research data? |  |  |  |  |
| **III. Data Fairness** | **Yes** | **No** | **N/A** | **Comments** |
| 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? |  |  |  |  |
| 1. Did you grant any exclusive data access rights to third parties outside the SPHN or do you intend to do so? |  |  |  |  |
| 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** | **Comments** |
| 1. Are your governance structure and your policies for processing of health-related personal data and human biological material, including authorization of data access requests, publicly available? |  |  |  |  |
| 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 responsible for the processing of health-related personal research data and human biological material?    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 health-related personal research data and human biological material at your institution? |  |  |  |  |

1. **Financial report (max. 2 pages)**

*In this section, please provide an overview and comment i) the use of SPHN funds, ii) own contributions ‘in cash’ and ‘in kind’ provided by the involved partners (“Matching Funds“).*

*Please copy-paste the Tables of the “Overview tab” and of the “Summary tab” from the Financial report Excel file provided by the SPHN Management Office to compile your detailed financial report. A blank template of this file is available on the SPHN website (*[*www.sphn.ch/en/funding/documents-forms.html*](http://www.sphn.ch/en/funding/documents-forms.html)*).*

*Replace this table with the table of the “Summary tab” of the Financial Report Excel file*

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*Replace this table with the table of the “Summary tab” of the Financial Report Excel file*

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*In addition, please answer the following questions:*

1. *Please list any ongoing dispute with third parties or within the institutions participating to the project that could result in financial impacts not listed in the annual financial reporting?*
2. *How much money was provided to each University Hospital for data providing and IT services?*
3. *How much money was reallocated in the budget?*
4. **Next steps (max. 1 page).**

***Driver projects:*** *In this section, please provide an overview of the work that will be performed in the following reporting period. Please include a short assessment of the degree of progress of the project compared with the overall project plan. Additionally please outline how you will contribute to the SPHN infrastructure in the future e.g. contributing to the DCC working groups.*

***Infrastructure development projects:*** *Summary on how the achievements/results of your project can be implemented into the SPHN-wide infrastructure. Provide a gap analysis and next steps towards this integration.*

1. **Output data: Information on published articles, talks at scientific conferences**

*In this section, please list any outputs that resulted from this project (e.g. articles, presentations, patents, …).*