# SPHN Project Final Report

Reporting period: xx.xx.20xx – 31.12.2020

Report to be submitted to [info@sphn.ch](mailto:info@sphn.ch) until 31.03.2021

**Project details**

|  |  |
| --- | --- |
| Project number |  |
| Project title |  |
| Project start – end dates (incl. cost-neutral extension if applicable) |  |
| Project duration (months) |  |

**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);
* Revised lay summary of the work accomplished as part of the project (Word document);
* Copy of project outputs (e.g. policies, framework, variables, etc.).

*Please note that your 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

### **Main achievements and results presenting how these compare against the milestones set in the proposal (5 to max. 6 pages)**

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

*We kindly ask you to provide an overview of the activities undertaken during the entire project period. Please describe the progress made with respect to the overall approved project plan. Additionally, please provide in the milestone dashboard (table 1) an update on each project milestone compared to the information provided in your last annual activity report. Please indicate for each milestone any issue and/or obstacle encountered during the reporting period 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]. Please copy the data provided in your last annual activity report and update them by highlighting any progress and new information.*

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | **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** |
| ***Example***  *(2019)*  *(2020)* | *Collection of baseline data* |  |  | *X* | *X* |  | * *Included ~~329~~ 957 patients* * *Recorded demographic and laboratory data* * *Recorded treatment data* * *Baseline data set transferred to BioMedIT* | * *Consent form had to be adapted* * *Lab values needed coding in LOINC* * *Outpatient treatment data not standardized* |
| **Work package 1** |  |  |  |  |  |  |  |  |
| *Milestone 1.1* |  |  | X |  |  |  |  |  |
| *Milestone 1.2* |  | X |  |  |  |  |  |  |
| **Work package 2** |  |  |  |  |  |  |  |  |
| *Milestone 2.1* |  |  |  |  |  |  |  |  |
| *Milestone 2.2* |  |  |  |  |  |  |  |  |

1. **Data standards: Which specific clinical and non-clinical data standards (other than CHOP, ATC, ICD) and exchange formats are used in the project and why? How did or will your project help to integrate these standards into the SPHN Infrastructure (e.g. clinical data warehouse) in a sustainable way?**

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

1. **Infrastructures: Contribution towards reaching the overall aims of SPHN, including coordination with other SPHN activities/projects, BioMedIT and the DCC working groups (max. 1 page)**

*In this section, please describe to what extent the results of the project contribute to the overall aims of SPHN. The impact for the entire community should be put forward; associated infrastructures that could benefit from the project should also be listed. Please also include and describe activities that were performed with 1) other SPHN projects, 2) BioMedIT, and 3) DCC working groups.*

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

*In this section, please describe to what extent the project has resulted in usable research infrastructure components as follows:*

* *An ‘infrastructure component’ can be any process, service or product of the project that can be re-used for subsequent research projects or in a clinical context.*
* *List all re-usable infrastructure components that were created in the context of the project.*
* *Describe what each infrastructure component is achieving (max. 5 bullet points) and describe how it can benefit other researchers; please provide links to access them.*
* *Please assign each infrastructure component to one of the following 5 categories:*
  + ***P****atient or citizen oriented (Harmonisation of formats and semantics [clinical data, health data]; Hospital infrastructure, interoperability; Accessibility to encoded patient or citizen data; Databases [data warehouse, disease registers, healthy cohorts and biobanks])*
  + ***E****thics, legal domain, data protection, patient information (Consent support structures; Implementation of data protection and safety measures, data governance; Ethics support structure; Patient involvement)*
  + ***A****nalytical platforms, e.g. genomics, metabolomics, proteomics, etc (Harmonisation of formats and semantics [molecular –omics data and samples]; Platform infrastructure, interoperability [e.g. harmonising sample process workflows]; Accessibility to platform services; Databases, biobanking and data repository)*
  + ***B****ioinformatics, medical informatics, big data analytic platforms (Harmonisation of formats and semantics; Community contributions to open-access data standards, analysis tools and workflows; Platform infrastructure, interoperability; Accessibility to platform services [e.g. data analysis tools, knowledge platforms]; Databases and data repository)*
  + ***N****ational 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 and biobanking)*
* *Under “Score”, please indicate the level of implementation and general availability of the various newly built infrastructure components using the following implementation scale:*
  1. *Concept established;*
  2. *Infrastructure component built and tested;*
  3. *First scientific study successfully performed using the described infrastructure component;*
  4. *Infrastructure component tested with multiple studies within the project consortia;*
  5. *Validated infrastructure component available for projects outside the project consortium;*
  6. *Infrastructure component tested with multiple studies outside the project consortia.*
  7. *If applicable: Infrastructure component used for clinical diagnostic or therapeutic applications.*

**Table 2: Newly built re-usable infrastructure components**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Infrastructure component** | **Achievements (general)**  *(max. 5 bullet points)* | **Achievements (Re-usability)** | **Category***(P/E/A/B/N)* | **Score**  *(1-7)* |
| *Data Access Committee DAC (example)* | * *Establishment of a functional DAC for the cancer consortia* * *Data Access Policy and criteria published; Data access request form published* * *Roles and responsibilities of DAC defined* * *4 external researchers applied for, and 3 received access to our dataset (1 lacked ethics approval)* | * *All material documentation, etc finalized and published on the project website (link)* * *The Cardiology consortium used our blueprint for the setup of their DAC* | *E* | *5* |
|  |  |  |  |  |
|  |  |  |  |  |
|  |  |  |  |  |
|  |  |  |  |  |
|  |  |  |  |  |
|  |  |  |  |  |
|  |  |  |  |  |

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. This section is not meant as an assessment but is intended to help us identify whether a particular aspect of the framework has been more challenging to implement. Detailed feedback is very helpful for us to address bottlenecks that are affecting SPHN consortial projects.*

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **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 and non-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 per e-mail by the SPHN Management Office to compile your detailed financial report.*

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

**

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

****

*In addition, we kindly ask you to 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)**

***For Driver projects:*** *In this section, please provide an overview of the work that will be performed beyond the project duration. Please include a short assessment of the degree of progress of the project compared with the original, 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.*

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

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

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