Project Number: grant agreement No 825046

Project Acronym: SAPHIRe

Project title: Securing Adoption of Personalised Health in Regions

INITIAL DATA MANAGEMENT PLAN

HISTORY OF CHANGES			
Version	**Date**	**Change**	
1.0	26.04.2019	Initial version	CdG VLAAMS GEWEST (VLO EWI)
1.1	23.05.2019	Processing of some remarks	CdG VLAAMS GEWEST (VLO EWI)

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1. Data Summary

What is the purpose of the data collection/generation and its relation to the objectives of the project?

What types and formats of data will the project generate/collect?

Will you re-use any existing data and how?

What is the origin of the data?

What is the expected size of the data?

To whom might it be useful ('data utility')?

This document is the initial DMP for SAPHIRe (consortium for Securing the Adoption of Personalised Health in Regions funded by European Union's Horizon 2020 research and innovation programme under grant agreement No 825046 that will run from 1st Dec 2018 till the end of 2021) and is designed as a 'living document', which can be completed and up-dated based on the progress of the project.

SAPHIRe is in a particular situation as it is not a classical research project with scientific peer reviewed publications or patent as result. Therefore no classical research data will be produced like in most research projects but observing/scouting & networking/connecting & supporting/activating will be the core of SAPHIRe. The project was not designed to produce classical research data, instead we will produce sets of recommendations, guidelines and summary documents that will enable networking, connections, supporting and activating the implementation of Personalised Medicine across regions in Europe. All these documents will be publicly available on www.saphire-eu.eu.

The major aims of SAPHIRe are to support regions in Europe to structure the implementation and adoption of Personalised Medicine in regional healthcare systems by identifying and addressing specific regional gaps and barriers. To realise these goals, SAPHIRe will create a network of regions and their ecosystems, including all stakeholders across the entire value chains. Regions are well placed to bring personal medicine and healthcare closer to the citizen. Pilot projects in and between regions could provide the much-needed evidence for the adoption of Personalised Medicine in regional as well as national health systems. Best practices on the implementation of Personalised Medicine from regions across Europe will allow to develop a modular roadmap. Region-specific recommendations on policy, funding and investments needs will be extracted to stimulate the development and deployment of interregional (cross-border) collaboration projects. SAPHIRe will run over the next three years and plans to engage with regional stakeholders, including policymakers, industrial and academic actors via a series of thematic workshops.

SAPHIRe will collect existing information on organisations, best practices, regional statistics, facilities, policies…in the field of Personalised Medicine and provide a roadmap at the end of the project to

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promote the implementation of Personalised Medicine at regional level. Different types of data including questionnaire data (e.g. face to face/paper-based/online questionnaires like EU Survey tool/internet search) will be gathered.

Publications (like reports, advice/discussion/white papers; presentations and roadmap,..) will be generated based on the data gathered and the organized workshops. All these generated documents will be publicly accessible on the project website www.saphire-eu.eu & most of the time also on own institution's websites and pushed via the social media. See also the SAPHIRe Communication and Dissemination Plan (Deliverable D5.1) .

The database is linked to the SAPHIRe website but will be hosted at a partner's institution so that it will not be lost afterwards at the end of the project.

The database with best practices is open to the public (only personal data is password protected); data export will be possible with CSV (use of non-proprietary formats CSV instead of Excel)

Data will be linked to other data to provide context thanks to data import (manually/via WS-exact way of import tb analysed) of EU regional stats (density, R&D,…). All data will be geographically linked on NUTS2 level in most cases; some exceptions are for small countries where NUTS0 will be used and for Belgium & UK where NUTS1 will be used.

2. FAIR data

2. 1. Making data findable, including provisions for metadata

No classical research data produced

2.2. Making data openly accessible

Which data produced and/or used in the project will be made openly available as the default? If certain datasets cannot be shared (or need to be shared under restrictions), explain why, clearly separating legal and contractual reasons from voluntary restrictions.

Note that in multi-beneficiary projects it is also possible for specific beneficiaries to keep their data closed if relevant provisions are made in the consortium agreement and are in line with the reasons for opting out.

How will the data be made accessible (e.g. by deposition in a repository)?

What methods or software tools are needed to access the data?

Is documentation about the software needed to access the data included?

Is it possible to include the relevant software (e.g. in open source code)?

Where will the data and associated metadata, documentation and code be deposited? Preference should be given to certified repositories which support open access where possible.

Have you explored appropriate arrangements with the identified repository?

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If there are restrictions on use, how will access be provided?

Is there a need for a data access committee?

Are there well described conditions for access (i.e. a machine readable license)?

How will the identity of the person accessing the data be ascertained?

No classical research data produced

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The database with best practices is open to the public (only personal data is password protected); data export will be possible with csv (use of non-proprietary formats CSV instead of Excel)

2.3. Making data interoperable

Are the data produced in the project interoperable, that is allowing data exchange and re-use between researchers, institutions, organisations, countries, etc. (i.e. adhering to standards for formats, as much as possible compliant with available (open) software applications, and in particular facilitating re-combinations with different datasets from different origins)?

What data and metadata vocabularies, standards or methodologies will you follow to make your data interoperable?

Will you be using standard vocabularies for all data types present in your data set, to allow inter-disciplinary interoperability?

In case it is unavoidable that you use uncommon or generate project specific ontologies or vocabularies, will you provide mappings to more commonly used ontologies?

No classical research data produced

2.4. Increase data re-use (through clarifying licences)

How will the data be licensed to permit the widest re-use possible?

When will the data be made available for re-use? If an embargo is sought to give time to publish or seek patents, specify why and how long this will apply, bearing in mind that research data should be made available as soon as possible.

Are the data produced and/or used in the project useable by third parties, in particular after the end of the project? If the re-use of some data is restricted, explain why.

How long is it intended that the data remains re-usable?

Are data quality assurance processes described?

No classical research data produced

3. Allocation of resources

What are the costs for making data FAIR in your project?

How will these be covered? Note that costs related to open access to research data are eligible as part of the Horizon 2020 grant (if compliant with the Grant Agreement conditions).

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Who will be responsible for data management in your project?

Are the resources for long term preservation discussed (costs and potential value, who decides and how what data will be kept and for how long)?

No classical research data produced

Other data will be managed by the Coordinator VLAAMS GEWEST (VLO EWI).

4. Data security

What provisions are in place for data security (including data recovery as well as secure storage and transfer of sensitive data)?

Is the data safely stored in certified repositories for long term preservation and curation?

Appropriate technical and organisational measures to protect the personal data will be taken but the exact measures have to be defined when the database will be implemented

5. Ethical aspects

According to GDPR, a privacy policy has been set up to process personal data in order to execute this project, SAPHIRe will process these data for the realisation of following purposes:

- name, professional contact details and job function so we can contact the person to join our workshops where we want to collect as much input as possible for the SAPHIRe project.

- name, professional contact details and job function so we can invite the person to future events, related to the SAPHIRe.

- name, professional contact details and job function so we can keep the person informed on the progress of the project.

- SAPHIRe will also store name, professional contact details and job function in the SAPHIRe database in order to contact the person for your expertise in the field

- pictures will be taken during workshops and other events and put on website with the consent of the person involved

Personal data will only be processed for the purposes mentioned above if the person consents to this. The person's consent will be asked for each purpose through a consent form. After giving consent the person will have the right to withdraw his consent at any time. However, this withdrawal of consent shall not affect the lawfulness of processing based on consent before its withdrawal. To withdrawal consent, see further under RIGHTS OF THE DATA SUBJECT and CONTACT. If the person doesn't give his consent to any of the processing activities, we will respect this decision and we will no longer contact him concerning this project and we won't process his data any longer for the purposes of this project.

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THE RETENTION PERIOD OF THE PERSONAL DATA

We take appropriate technical and organisational measures to protect the personal data and to make sure we keep these data only as long as necessary for the realisation to the purposes mentioned above. The retention period of the personal data therefore depends on the purpose for which they were collected. The person can contact us if he no longer wants us to keep his data or if he wishes to receive more information concerning the retention period of his personal data. More information on how to contact us, can be find under CONTACT in this policy.

RIGHTS OF THE DATA SUBJECT

With regards to his personal data, the person has several rights he can exercise.

The person has the right of access to his personal data; he also has the right to rectify personal data that is no longer accurate or complete.

Furthermore, he has the right to object to processing of his personal data, to request the restriction of processing of his personal data, he has the right to obtain the erasure of his personal data and he has the right to request the portability of his data.

Finally, for the processing of personal data for which the person gave his consent, he has the right to request the withdrawal of that consent at any time. However, this withdrawal of consent shall not affect the lawfulness of processing based on consent before its withdrawal.

6. Other issues

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