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D1.4 Data Management Plan

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Abstract:

The Data Management Plan (DMP) is WideHealth's core document that facilitates the generation, maintenance and utilization of high-quality data. Hence, the DPM ensures the quality of the project related data, with respect to principles and normatives, such as FAIRification of data, as well as GDPR compliance. This document also facilitates the path towards Open Science maintaining high quality of data during the entire project lifecycle for its exploitation afterwards.

Keyword list: Data Management, GDPR, FAIR DATA

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Abbreviations

Data Management Plan (DMP)

Findability, Accessibility, Interoperability, and Reusability (FAIR)

General Data Protection Regulation (GDPR)

Google Shared Drive (GDrive)

Open Research Data Pilot (ORDP)

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1 Introduction

The Data Management Plan (DMP) is WideHealth's focal document that fosters the generation, maintenance and utilization of high quality data with a lawful compliant approach. In this manner the DPM is created to ensure the quality of the project related data, with respect to well established principles and normatives, such as FAIRification of data, as well as GDPR compliance. Moreover, WideHealth adopts the strategy for Open Research Data Pilot (ORDP). As such, the project aims at improving and maximising the access and reuse of the data generated while complying with ethical and legal issues. Hence, this document also facilitates the path towards Open Science maintaining high quality of data during the entire project lifecycle for its exploitation afterwards. The core part of this deliverable focuses on the Data Summary, FAIR Data concept and WideHealth's GDPR compliance.

2 Data Summary

This section describes the main aspects related to data utilized in the WideHealth project that have been defined in the first four months of the project and have been approved by partners before the submission of this document to the European Commission.

2.1 Data purpose and objectives

The data used in WideHealth is primarily related to dissemination and communication purposes. As the overarching goal of the project is to enable a new generation of researchers in the Widening Countries to develop and adapt novel eHealth technologies exploitable in the longer run in their different healthcare contexts, the project will establish a sustainable network of knowledge research and dissemination across Europe in the Pervasive Health topic. In this manner, the project will process data for dissemination and communication purposes. Moreover, the knowledge of requirements and available technologies for eHealth will be shared and become complementary between early-stage researchers in the community. As such, the project will disseminate the research knowledge via workshops and summer/winter schools, resulting gathered participants' data that will be managed and handled by the project.

2.2 Data types and formats

The WideHealth project will generate several types of data, where some of them are within the material scope of the General Data Protection Regulation EU 2016/679 (i.e. personal data) elaborated in section 4. WideHealth is primarily focused on networking and knowledge dissemination between the partners. Hence, the project does not manipulate any health-related data such as health records, health sensors data, genomic, or biometric data. In this manner, the research related personal data, used in the projects of early stage researchers is covered by corresponding DMPs of relevant scientific projects and all measures with regards to ethics, privacy and data protection are regulated by separate permits and agreements which are not part of the current project.

The complete list of WideHealth generated and collected data can be found in section 2.4. Because WideHealth does not generate novel clinical/research data, the main bulk of data is related to dissemination and communication activities, such as advertisement, newsletter, workshops, schools etc. Specifically, the project has identified to main categories of data:

- **Dissemination and communication related data.** This data includes all information related to maximising project visibility.
- **WideHealth knowledge activities data.** This data includes the database of the participants' personal data that are the target of the WideHealth activities in WP4.
- **Joint WideHealth Outputs.** This data focuses on the concrete outcomes from the training activities in the project, such as joint paper peer-reviewed publications and EU project proposals.

As most of the data discussed above is related to the dissemination and communication activities, which is still in early stage it is difficult to precisely estimate the size and the chosen format of the dataset. However, the WideHealth consortium will give preference to open formats (e.g. csv, txt) or at least formats that are widely accessible without significant difficulties accessing them. With respect to the data size, it can be estimated that the complete volume for both the dissemination and communication as well as knowledge activities data, would not exceed several hundreds of MB, as most of the data is related to brochures, papers, and textual databases of contact information.

2.3 Data storage

The WideHealth data is stored and managed by FBK on a private Google Drive repository. FBK uses a trusted third-party service provider (G-Suite – Business version), which is compliant with the GDPR requirements¹. Moreover, part of the data related to the scientific publications will be stored on well-known and widely used open-source repositories, such as ResearchGate.

2.4 Data sets

This section describes the foreseen datasets within the WideHealth project. The information related to the different data types is defined in Table 1.

¹ <https://cloud.google.com/security/gdpr/resource-center>

Table 1. WideHealth Data sets.

Data set	WP origin	Type	Data utility	GDPR compliance	Storage location
Dissemination, Materials and Networking	WP1	Multimedia data (Dissemination materials – e.g. flyers, newsletters) (Networking – e.g. schools, conferences, workshops)	Data utilised for maximising project visibility	No	FBK administered GDrive during project and then moved to an Open Repository (e.g. Zenodo [2]). Also available on the WideHealth website.
Dissemination, Project visibility	WP1	Multimedia data (e.g. press releases, presentations)	Data utilised for maximising project visibility	No	FBK administered GDrive during project and then moved to an Open Repository (e.g. Zenodo [2]). Also available on the WideHealth website.
Participant details	WP4	Numeric /text data (e.g. Name, surname, email, Affiliation, position, etc.)	Data used for: 1) Knowledge widening 2) communication and dissemination activities	Yes (personal data)	FBK administered GDrive
Peer-reviewed publications	WP1/ WP5	Scientific Articles	Researchers, Healthcare professionals	No	FBK administered GDrive and Open Repositories (e.g. ResearchGate, Zenodo [2])
Portfolio for EU funding possibilities and submitted proposals	WP5	Numeric /text data	Data used for the internal purposes of the project. Achieving the envisioned KPIs, with respect to joint project proposal submissions.	No	FBK administered GDrive

2.5 Data Lifecycle

Each of the data sets, described in Table 1, follow the generic data lifecycle:

1. Data collection / generation
2. Data storage
3. Data process / analysis
4. Publish / share / re-use

The specific lifecycle of the data sets of interest are presented in the WideHealth data set lifecycle matrix, Table 2. It must be noted that some of the lifecycle information is preliminary, as the project is still in its early stages.

Table 2 WideHealth Data set lifecycle matrix

<i>Data set</i>	Data collection/generation	Data Storage	Data processing/analysis	Publish / share / re-use
<i>Dissemination, Materials and Networking</i>	Data generated within the WP1 related activities for project communication and dissemination.	Stored as textual/multi media format (e.g. PDF) on the project cloud repo.	Data utilised for maximising project visibility. Disseminated through official WideHealth's channels, such as webpage, social media, e-mail feeds.	The data is publicly available for everybody and will be maintained as such over the duration of the project and after its completion. After the project completion, the data will be available on the project website.
<i>Dissemination, Project visibility</i>	Data generated within the WP1 related activities for project communication and dissemination.	Stored as textual/multi media format (e.g. PDF, video format) on the project cloud repo.	Data utilised for maximising project visibility. Disseminated through official WideHealth's channels, such as webpage, social media, e-mail feeds.	The data is publicly available for everybody and will be maintained as such over the duration of the project and after its completion. After the project completion, the data will be available on the project website as well as Open Repository such as Zenodo [2].

<i>Participant details</i>	Data gathered during project activities related and WP4, and events such as workshops and/or schools.	Envisioned to be stored as textual tabular data, such as excel.	Data used for knowledge widening and communication and dissemination activities.	This data is not publicly available and will be erased after the project completion.
<i>Peer-reviewed publications</i>	Data generated by joint collaboration between the partners in the project as part of the activities in WP5.	Stored as textual/multi media format (e.g. PDF) on the project cloud repo as well as open repositories.	Data used to strengthen the project visibility, between Researchers, Healthcare professionals.	The data is publicly available and will be maintained on open cloud repositories, such as ResearchGate, Zenodo, Publisher's website (Open Access availability)
<i>Portfolio for EU funding possibilities and submitted proposals</i>	Data generated by joint collaboration between the partners in the project as part of the activities in WP5.	Envisioned to be stored as textual and tabular data, such as word and excel.	Data used for the internal purposes of the project. Achieving the envisioned KPIs, with respect to joint project proposal submissions.	This data is not publicly available and will be erased after the project completion.

3 FAIR data

The WideHealth data management policy adopted has been developed in order to be compliant with the FAIR principles following guidelines of the European Commission for the Horizon 2020 Programme. This chapter details how the WideHealth Consortium will make the data gathered / generated Findable, Accessible, Interoperable, and Reusable.

3.1 Making data and metadata findable

In order to make data and findable, the WideHealth will adopt the following naming convention that provides a clear version numbers followed by the document title:

>> DATA_DELIVERABLE_NUMBER - NAME.FORMAT <<

>> e.g. D1.4 - Data Management Plan.docx <<

In order to make metadata and findable, the project will adopt the same naming convention that as for project data:

>> METADATA_NAME_ROLE_DATE.FORMAT <<

>> e.g. Readme_privacy_policy_1.1.2021.docx <<

Scientific publications and articles will be discoverable, identifiable and locatable by means of a standard identification mechanism (e.g. persistent and unique identifiers such as Digital Object Identifiers).

3.2 Making data openly accessible

In order to foster this requirement, the project has identified several means of making the data openly accessible. Namely, dissemination and communication related material will be shared with the ecosystem by conventional dissemination channels such as, e-mail notifications, social media posts, etc. More information can be found in deliverable D1.3. Moreover, data with respect to the project's publications and presentations will be made publicly available, on specific open repositories, such as Zenodo, ResearchGate. Additionally, journal publications will be published under the open access clause, and will be available on the publisher's portals, free of charge.

3.3 Making data interoperable

Because WideHealth does not collect research data, it does not generate any tangible data outputs that have to follow strict interoperability rules. All WideHealth accessible data does not require specific data formatting for interoperability.

3.4 Increase data re-use

The findings and results will be available in all published scientific articles under the WideHealth project open access strategy. As such, the findings and results will be always available under open access privileges and can be easily reused for further researching.

4 GDPR compliance

The sections above have defined what activities will include the processing of personal data, i.e. the events organised in WP4 and the communication and dissemination activities foreseen in WP1. All these activities will comply with the General Data Protection Regulation. The sections below define the GDPR roles within the WideHealth Consortium and how the project will comply with principles related to the processing of personal data (art. 5 GDPR) and what is the legal basis used for processing personal data (art. 6 GDPR).

4.1 GDPR Roles

Each WideHealth partner must respect the policies set out in this Data Management Plan. Datasets must be created, managed and stored appropriately and in line with applicable legislation.

In the WideHealth project, UKIM and FC.ID are Joint Controllers as they are the partners responsible for determining the objectives and the means of processing, while FBK is a Data Processor as it provides the storage for the personal data.

Considering the small amount and the nature of personal data processed within the project and the type of processing, the respective responsibilities of each Joint Controller are determined in a transparent manner pursuant to art. 26 of GDPR including the Joint Controllership Agreement within this Data Management Plan and considering it formalised within section 4.1.1 and 4.1.2. For the same reason, pursuant to art. 28 of GDPR the Data Processor is considered appointed within section 4.1.2 of this Data Management Plan.

The project coordinator, UKIM, is based in North Macedonia, a Country that is not included in the adequacy list of the European Commission², meaning those Countries that are not part of the European Union but ensure the necessary conditions for data processing. However, that Country has approved on 16.02.2020 a law that is specifically related to Data Protection and has a Data Protection Authority³ but does not yet guarantee an adequate standard for data processing in compliance with GDPR. Being aware of the actual scenario, in order to be compliant with all GDPR requirements, the WideHealth project is adopting the necessary organisational and security measures for the correct and compliant data management by, for example, storing all the personal data collected in a repository managed by the Bruno Kessler Foundation (FBK) which is based in Italy.

4.1.1 Joint Controllership Agreement (JCA)

UKIM and FC.ID, the “Joint Controllers”, agree that the personal data will be processed in order to reach the objectives defined in Annex I of the Grant Agreement of the WideHealth and mentioned in section 2 of the present document. The means of the processing of personal data has been determined within this document and will be updated, if needed, during the project lifetime. The personal data will be collected for events participation and/or newsletter subscription. Personal data (name, surname, affiliation, email, carrier profile) will be gathered through a google form and stored in a dedicated folder on a Google Shared Drive with restricted access: if possible, encryption will be applied as an additional security measure. The data will be used to send events reminders, details for access, materials shown and / or to send newsletters. At the end of the project, all personal data will be

² https://ec.europa.eu/info/law/law-topic/data-protection/international-dimension-data-protection/adequacy-decisions_en

³ <https://dzlp.mk/en>

deleted and only aggregated and anonymised data (e.g. number of people attending the events divided per gender, profile) will be kept to be included in the final project reporting to the European Commission.

UKIM and FC.ID agree that, for the purposes of this Agreement and in particular the processing of personal data carried out in the context of the activities described above, they act as Joint Controllers, under Art. 26 GDPR. The parties' responsibilities can be defined as follows:

- UKIM, as project coordinator, defines the objectives for all the personal data gathered within the project. As leader of the dissemination and communication, it is responsible for defining the means for the data gathered for the related activities (e.g. newsletters).
- FC.ID, as leader of Work Package 4, defines the means according to which data are gathered for the WP4 activities.

The Joint Controllers agree that they will bear the following responsibilities for compliance with their obligations, each one for the respective role and activities carried out in the framework of the project, under GDPR:

- i) to provide adequate information notices to Data Subjects, under Arts. 12, 13, 14 and 26 GDPR;
- ii) to engage any Processors which may be involved in the Processing of Personal Data carried out in the context of the Relationship by means of written personal data processing agreements, under Art. 28 GDPR (and to ensure the lawfulness of any transfers of Personal Data to any Non-EU Entities engaged). The Joint Controllers have identified FBK as Data Processor as the entity will provide storage for the personal data on behalf of them and therefore they agree to appoint FBK in section 4.1.2 of this Data Management Plan;
- iii) to provide any necessary cooperation with, and act as main point of contact to data subjects and Supervisory Authorities, under Art. 31 GDPR;
- iv) to ensure that adequate technical and organisational security measures are in place, under Art. 32 GDPR;
- v) to comply with and Process all Shared Personal Data in accordance with the GDPR;
- vi) to promptly notify other Parties about any circumstance where it is unable to comply with the GDPR or any actual or potential changes to the data protection legislation, which affect its ability to comply with its obligations under this Agreement.

4.1.1.1 Joint Controllers and Data Processor contact points for Data Subjects

Any communication related to the data processing of the Project and consequent to the Joint Controllership Agreement and to any Data Processors appointment shall be sent to the following contacts in Table 3:

Table 3. Data controller and Processor Contacts.

	UKIM	FC.ID
For communications related to the JCA	Risto Chavdarov (Internal Data Processor) christo@feit.ukim.edu.mk	André Rodrigues (Internal Data Processor) afrodrigues@fc.ul.pt

	----- Hristijan Gjoreski (Project Manager) hristijang@feit.ukim.edu.mk	----- Tiago Guerreiro (Project Manager) tjvg@di.fc.ul.pt
In case of Data Subjects' requests	Nada Velkova nada.karamanova@feit.ukim.edu.mk	Tiago Guerreiro tjvg@di.fc.ul.pt
For Data Breaches and for future amendments to the JCA	Nada Velkova (Data Protection Officer) nada.karamanova@feit.ukim.edu.mk	David Pedrosa (Data Protection Officer) dmpedrosa@fciencias-id.pt

4.1.2 Data Processor

Data processors involved in the project must comply with the rules outlined in this Data Management Plan. FBK will act as WideHealth Data Processor as it provides the storage for the personal data on behalf of the Joint Controllers, and manages the personal data for the dissemination and communication activities. FBK provides sufficient guarantees to implement appropriate technical and organisational measures in such a manner that processing will meet the requirements of GDPR and ensure the protection of the rights of data subjects. A dedicated folder on Google Shared Drive will be created: this will have restricted access to those persons identified by the Joint Controllers and encryption will be considered as an additional security measure. FBK ensures that persons authorised to process personal data have committed themselves to confidentiality or are under an appropriate statutory obligation of confidentiality.

Any communication related to the data processing of the Project and consequent to the Data Processors appointment shall be sent to the following contacts:

Internal Data Processor: Oscar Mayora +39.0461.312.475 omayora@fbk.eu

Project Manager: Sara Testa +39.0461.312.451 stesta@fbk.eu

Data Protection Officer: Anna Benedetti +39.0461.314.370 privacy@fbk.eu

4.2 Data protection and security

Data protection and security provisions (including data recovery as well as secure storage and transfer of sensitive data) as well as privacy and security issues related to data storage has been taken into consideration. The WideHealth project uses a trusted third-party service provider in order to securely store and transfer data in the course of the project, in particular for installing and maintaining the

WideHealth Cloud platform. The terms and conditions of the third-party service provider (G-Suite – Business version) have been reviewed to ensure that storage and transfer comply with the security standards required for the protection of personal information. Google Cloud and its services Google Shared Drive is certified ISO 27001 [1], which is an international standard on the management of information security.

The data sets are collected and processed in order to reach the project objectives, as discussed in Section 2, and will not further be processed in ways that are incompatible with those objectives. Therefore, Consortium members will only collect the data that are adequate, relevant and limited to what is necessary for reaching the scope for which they are gathered.

Security will be the guiding principle for all activities related to the management of personal data. Data sets will be stored in repositories that will be managed by FBK's GDrive services. Its access will be limited to those Consortium members who will need the data to perform WideHealth project activities as elaborated in previous sections.

In the WideHealth project, Joint Controllers (UKIM and FC.ID) will be responsible for, and be able to demonstrate, compliance with GDPR. In particular, UKIM's DPO - in coordination with FBK for the management of personal data - will monitor compliance with GDPR having due regard to the risk associated with processing operations, taking into account the nature, scope, context and purposes of processing.

The above principles apply to personal data (including any sensitive data that might be processed at the behest of Data Subjects), as well as any other information that shall be kept confidential.

Pursuant to art. 13 of GDPR, Joint Controllers will provide the Data Subjects with a specific and detailed privacy policy (also called informed consent) in order to receive their consent to data processing and allow them to participate to the project events and to subscribe to the newsletter.

5 Conclusion

This document, D1.4 Data Management Plan defines the strategy that the WideHealth Consortium will implement in relation to data management in relation to the whole data management during the project duration. The deliverable provides a summary of the data that will be generated / collected during the project activities and the list of datasets. Moreover, it details the approach towards FAIR data. The document also elaborates the project's alignments with respect to the GDPR requirements.

It must be also noted that any updates regarding the data management plan will be provided to the EC, during the first-year project review, if deemed necessary.

References

- [1] Google LLC, ISO/IEC 27001. Found at: <https://cloud.google.com/security/compliance/iso-27001>, [Accessed: April 2021.]
- [2] Zenodo: <https://zenodo.org> [Accessed: April 2021.]