Deliverable 7.1 – POPD – Requirement 2
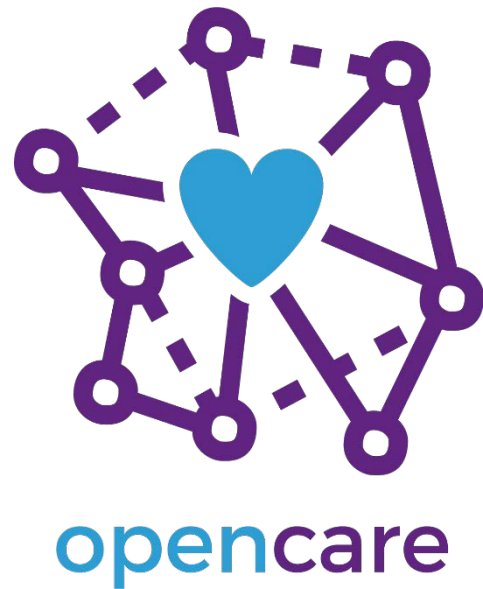
opencare

Project Acronym	OPENCARE
Title	Open Participatory Engagement in Collective Awareness for REdesign of Care services
Project Number	688670
Work package	**WP7 – Ethics requirements**
Lead Beneficiary	Université de Bordeaux, FR

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STOCKHOLM SCHOOL OF ECONOMICS

EHFF INSTITUTE FOR ECONOMIC AND BUSINESS HISTORY RESEARCH

université de BORDEAUX

POPD – Requirement 1

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Ethics requirements - Protection of personal data

Detailed information must be provided on the procedures that will be implemented for data collection, storage, protection, retention and destruction and confirmation that they comply with national and EU legislation.

Procedures for data collection, storage, protection are described in opencare's description of action

-> see section 2.2 Measures to maximise impact, paragraph c) Data and knowledge management strategies, p. 31.

By volunteering to the Open Data Research Pilot, the opencare consortium updated and enhanced its Data Management Plan by June 2016, in accordance with the European Commission's requirements for data management.

Data collection, storage, protection, retention

Opencare's platform being a fundamental component of the Opencare project, the Consortium has to appropriately inform the contributors about its data handling policies.

Information is classified as *personal* whenever it relates to an identified or identifiable natural person, independently of the private, professional, or the circumstances under which it is disclosed.

It is clear that the level of traceability and accountability which is desired by the EU regulators and which will soon be formulated as an absolute requirement would be incompatible by design with the choice to maintain conversations on the platform in clear to occasional visitors.

However, Opencare can be interpreted as a co-creative micropublishing service (or co-creative blog), which is the social contract we recommend to propose to its contributors.

The contributors will retain their right to amend/remove their personal information, but will be otherwise informed that what they post is shared under a CC-BY license, and is as such accessible and usable by anyone.

Data collection, storage, protection, retention

In fact, it is understood that the users will share via secured and encrypted means access to research data, marked up for ethnographical study, after pseudononymization. Samples of these data in the form under which they are handled during transfer should periodically undergo remapping testing and to restrict profiles by sensitive properties (e.g.: health, sexual lifestyle, ethnicity, political opinion, religious or philosophical conviction,...), to offer an experimental estimation of the solidity of procedures, and to update the information and guidelines shared with the website users.

Even though anonymized data are generally considered no longer sensitive, and even though the sensitive data still included in the research dataset would be covered by an informed consent from the users, each partner will be responsible of data security when data are transmitted and stored under their premises. This includes the obligation to store them under encryption, to prevent unwarranted disclosure of the keys to third parties even within the same organization, and lastly to report to the consortium about data loss and breaching, to maintain the highest reasonable standard of protection and accountability. Each consortium partner planning to handle data from the platform will have to identify a primary responsible for these operations, in charge of coordinating with Edgeryders's data responsible.

Data collection, storage, protection, retention

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opencare's data strategy
(Description of Action, Annex 1 GA)

Table 2.2a – Data strategy

Type of data generated	Standard and license	Stewardship and access
Primary: online conversation	As HTML-rich text in a SQL database, licensed as Creative Commons 4.0 Unported	Preserved in the edgeryders.eu database with daily backups. Accessible through Drupal APIs after pseudonymization.
Secondary: ethnographic coding	As RDFa in a SQL database, licensed as Creative Commons 4.0 Unported	Preserved in the edgeryders.eu database with daily backups. Accessible through Drupal APIs after pseudonymization.
Secondary: conversation social network.	As GEXF or other standard format for graphs, licensed as Creative Commons 4.0 Unported	Regenerated daily via Edgesense. Accessible through a download button from the Edgesense dashboard.
Tertiary: conversation semantic social network	As GEXF or other standard format for graphs, licensed as Creative Commons 4.0 Unported	Minimally, as a data dump downloadable from edgeryders.eu. Hopefully better.

Additional information
within opencare's Data Management Plan
(as of June 2016)

We collect and store data accordingly with the standards set within the Frictionless Data project.

> **Frictionless data** is a side-project of Open Knowledge International, a worldwide non-profit network of people passionate about openness, using advocacy, technology and training to unlock information and enable people to work with it to create and share knowledge.

We use World Wide Web Consortium (W3C)'s Guidelines for best practice.

Data collection, storage, protection, retention

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Additional information
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Sharing (2016-2017): through APIs (Views JSON Drupal module) that return a JSON file containing fresh data.

Metadata: via API documentation on Mashape, also redundant on edgeryders.eu as a wiki.

Sharing and conservation (from late 2017): at the end of the project, the latest version of the JSON files are dumped onto the Zenodo repository.

The metadata of the data dump is documented using the Data Package standard.

Data Packages are a coherent collection of data and other assets which provide the basis for convenient delivery, installation and management of datasets. This practice is commonly used for open-source software.

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Additional information
within opencare's Data Management Plan
(as of June 2016)

The complete graph is maintained in a **Neo4j graph database on the Edgeryders server**. Periodic calls to the edgeryders.eu APIs add new posts, comments and codes to the graph database.

Tertiary data will be shared in the late stages of the project, in the form of **a Neo4j data dump** hosted on [Zenodo](#).

Metadata is made available in the [Data Package standard](#), and more specifically its [extension to graph data](#) developed in the course of an FP7 project called CATALYST.

This solution also takes care of long term preservation.

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opencare's knowledge management strategy
(Description of Action, Annex 1 GA)

Table 2.2b – Knowledge management strategy

Project output	License	Stewardship and access
Reports	Creative Commons 4.0 Unported	Self-archived and downloadable from the project's website. This is developed as an area of the Edgeryders platform, so that it lives on as long as Edgeryders itself.
Research papers	Compliant with the Berlin Declaration on Open Access to Knowledge in the Sciences and Humanities	Minimally, self-archived and downloadable as above. Hopefully published.
Software code	GNU Lesser General Public License version 3 (Tulip plugins); Gnu General Public License version 2 or compatible (Drupal Plugins)	As contributions to open source projects, our software components are accessible in the appropriate repositories (example: a Drupal plugin is downloadable from drupal.org).
Hardware design files and other digital documentation of physical prototypes	Depending on project: • Creative Commons Attribution, Share-Alike (BY-SA) • GNU General Public License (GPL) V3 • CERN OHL V1.2	We follow the best practices defined by Open Source Hardware Association and Open Design Group regarding the progressive release of: source files, auxiliary design files, bills of materials and suppliers, software and firmware, multimedia (Photos and videos), instructions and explanation. All files will be published on online source-code repositories to make it easy to publish changes and track bugs or future enhancements.

Additional information
within opencare's Data Management Plan
(as of June 2016)

Publications available through CERN-managed Zenodo repository, following official recommendations from the EC

Software code available through open source repositories such as GitHub

Available through open source repositories such as GitHub

Data destruction

The person responsible for the information contributed by users to Opencare is Ms. Noemi Salantiu, Edgeryders' community manager. This is clearly indicated, together with relevant contact details (contact@edgeryders.eu), and clear instructions are offered to the users of the platform about how to obtain copies of their data, or how to have them removed. It is this person's duty to inform all the consortium partners of the eventual changes to the previously shared datasets, and to coordinate the process of erasure of the affected data when necessary.

Compliance with national and EU legislation

National legislation

- Bundesdatenschutzgesetz

- Loi n° 78-17 du 6 janvier 1978 relative à l'informatique, aux fichiers et aux libertés

Both laws are of utmost importance for the opencare project, as the Edgeryders platform is archived on servers located in Germany and data is being processed and analysed by the University of Bordeaux.

EU legislation

References:

- **Directive 95/46/EC on the protection of individuals with regard to the processing of personal data and on the free movement of such data** (Data Protection Directive), OJ 1995 L 281

- **Handbook on European data protection law - 2nd edition**, European Union Agency for Fundamental Rights, Council of Europe, April 2014

The opencare consortium has reached to its respective National Authorities for Data protection for advice and assessment of its compliance with the European Directive on Data Protection and respective national laws.