



## WP4 | PROJECT MANAGEMENT


### D4.2 (D13) – Data Management Plan (DMP)

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## History of changes

Version	Date	Created/modified by:	Comments
1.0	23/05/24	We CARE	1 <sup>st</sup> draft shared with AMC and CatSalut for review
2.0	28/05/24	We CARE	2 <sup>nd</sup> draft reviewed and approved by consortium and partners

## Executive Summary

This deliverable – prepared as part of WP4 “Project management” - presents the plan detailing what data the RESIL-Card project will generate, whether and how it will be exploited, or made accessible for verification and re-use, and how it will be curated and preserved.

During the course of the project, data will be generated by some of the WP activities. As the project is at an early stage, it is important that **timely dissemination of these findings** (data, survey results, publications) are open for scrutiny by the cardiovascular community, other researchers, and future potential partners.

The purpose of the Data Management Plan (DMP) is to **provide the main elements of the data management**. To this end, it describes types and formats of data to be generated or collected and the standards to be applied, the data-reservation methods, the data sharing policies for re-use.

The present document is the **first version** of the RESIL-Card DMP containing an initial overview of the foreseen RESIL-Card datasets. The DMP is a living document that will be modified and refined during the project period.

## Introduction

Data Management Plans (DMPs) are a **key element of good data management**. A DMP describes the **data management lifecycle** for the data to be collected, processed and or generate by a project. As part of making data findable, accessible, interoperable, and re-usable, a DMP should include information on:

- The handling of data during and after the end of the project
- What data will be collected, processed and/or generated
- Which methodology and standard will be applied
- Whether data will be shared, made open access and
- How data will be curated and preserved (including after the end of the project)

### Purpose and scope

This deliverable focuses on the **management of the data** in RESIL-Card. In the project, there will be 2 different data: the first strand relates to the **publications generated** as part of the project activities, and the second strand relates to **data collected from publications and stakeholders** that will be aggregated into data sets - some will comprise statistical and anonymous data – and used as part of the implementation of the project objectives and key results.

### Approach for WP and relation to other WPs and deliverables

This deliverable of the RESIL-Card project is prepared under WP4 and more specifically the task 4.5. In this task, we initiate the discussion of the data management processes and or generated by RESIL-Card in order to make the **data findable, accessible, interoperable, and reusable**. This DMP is a living document that will be edited and updated during the project period.

### Methodology and structure of the deliverable

Although RESIL-Card is not a Horizon 2020 project, the document follows the structure of the H2020 template for a Data Management Plan (DMP) and is comprised of the following chapters:

- **Section 1** presents a summary of what the purpose of the data collection and generation is in the case of RESIL-Card
- **Section 2** explains how the data and metadata will be made accessible, findable, and reusable
- **Section 3** covers the allocation of resources required for the management of the data
- **Section 4** focuses on the protection of data and long-term preservation
- **Section 5** addresses ethics about data sharing

## 1. Data Summary

RESIL-Card aims to enhance the preparedness and resilience of the European cardiovascular care pathways by developing and implementing a ground-breaking resilience assessment toolkit to be used by cardiovascular care stakeholders to assess and address identified gaps and challenges.

Out of the 4 WPs of the RESIL-Card project, **only WP1 and WP2 are relevant** for data collection and generation.

### 1.1. WP1

As the project follows a bottom-up approach, it is crucial in the first year to understand from the cardiovascular field how previous crises, such as the COVID-19 pandemic, have disrupted cardiovascular care and forced stakeholders to adapt and implement innovative solutions to ensure care continuity. The purpose of the data collected and generated in WP1 will aim to inform the development of the tool to support the EU healthcare systems in strengthening the continuity of care delivery.

Multiple sources of data will be used, with 3 main datasets: one for the literature review (task 1.1), one related to the survey (task 1.2), and the scripts from 3-6 focus groups (task 1.3).

The exact data size is not yet known, but will be made clearer in future iterations of the DMP.

The data will be useful to the RESIL-Card consortium partners to complete the subsequent tasks of the project. It may also be of interest to other researchers assessing the health system resilience from the healthcare professionals' perspective.

#### - **Scoping literature review**

A scoping literature review will be conducted to map and compare existing cardiovascular care pathways, assess disruptions from the Covid pandemic and innovative tools and practices implemented during that period to ensure care continuity for patients.

Data will be collected from scientific articles in published peer-reviewed papers, national and international reports available in the public domain - such as government websites, reports, documents, and media sources - and other grey literature.

A scoping review methodology will be used to retrieve articles and extract data with a software such as Rayyan, or similar, to select articles. Collected data will be compiled in an excel spreadsheet.

Processed data will result in a spreadsheet with qualitative data. Analysed data will be the results of qualitative analyses displayed in graphs or tables.

All project documents will be handled in an online folder in Amsterdam UMC's Sharepoint which only the research group have access to. This folder is protected under the privacy regulation of Amsterdam UMC.

The datasets generated and analysed during the study will be made available in online repositories such as the Zenodo.org (with a unique "doi"). To make data findable, we will crosslink any online sources where applicable (e.g., ORCIDs of researchers, PIDs of related publications or repository references within the project, trial registry numbers, project website, etc).

Results will be published in an Open Access journal that provides a PID (e.g., a DOI or URN).

- **Survey to healthcare professionals on experiences during COVID-19 pandemic**

The survey will collect, through a questionnaire, the insights and experience of healthcare professionals managing patients with cardiac diseases during the COVID-19 pandemic.

Data collected from the survey will be primary data, i.e. raw survey data from healthcare professionals, namely cardiologists and other physicians, nurses and allied professionals.

The tool used to send the online questionnaire will have a processing agreement regarding privacy with the Consortium members.

The acquired data will be stored as qualitative data in a read-only file, and a new file will be created for further processing and statistical analysis.

Information regarding transcribing and coding will be provided for the data processing phase. Analysed data will be presented as graphs or tables after qualitative and statistical analysis although the exact format is not yet known.

All project documents will be handled in an online folder in Amsterdam UMC's Sharepoint which only the research group have access to. This folder is protected under the privacy regulation of Amsterdam UMC. Data will be kept for 10 years after the study is published and the data will not be shared with external partners.

Results will be published in an Open Access journal that provides a PID (e.g., a DOI or URN).

Considering the need to guarantee the source anonymity, only the datasets generated and analysed during the study will be made available in online repositories such as the Zenodo.org (with a unique "doi"). To make data findable, we will crosslink any online sources where applicable (e.g., ORCIDs of researchers, PIDs of related publications or repository references within the project, trial registry numbers, project website, etc).

- **Focus groups**

The objective of the multistakeholder focus groups will be to build, validate and refine the findings resulting from the scoping literature review and HCP survey on resilience experience to describe the cardiovascular care pathways in specific settings. The outcome will contribute to the development of the resilience assessment tool that will support new policy approaches to ensure continuity of care for CVD patients in the future.

Raw qualitative data will be collected from 3-6 focus groups conducted as part of the WP - involving various stakeholders of the CV care pathways, such as hospital managers, patient advocates, and policy makers.

The focus groups, conducted online, will be recorded and transcribed via Microsoft Teams within the Amsterdam UMC work environment. In case some focus groups are organised in-person, professional equipment will be used for the sound recording and we will ensure data is encrypted. We will liaise with the ICT department of Amsterdam UMC to ensure secure sound recordings and secure ways to transfer recordings to the Amsterdam UMC Sharepoint are used. We do not anticipate the need to outsource the focus groups. Yet, in case there is the need to outsource the transcription of the focus groups, a processing agreement will be concluded with the party involved regarding privacy protection.

Data generated will be audio files (verbatim record) and/or field notes drawn from focus groups. The exact format for the processed data is not yet known; analysed data will be the results of qualitative analyses and displayed in graphs or tables.

All project documents will be handled in an online folder in Amsterdam UMC's Sharepoint which only the research group have access to. This folder is protected under the privacy regulation of



Amsterdam UMC. Researchers' notes on the focus groups will be kept for 10 years after the study is published, the recordings will be erased immediately after the publication of the study, and the data will not be shared with external partners.

Considering the need to guarantee the source anonymity, only the datasets generated and analysed during the study will be made available in online repositories such as the Zenodo.org (with a unique "doi"). To make data findable, we will crosslink any online sources where applicable (e.g., ORCID's of researchers, PIDs of related publications or repository references within the project, trial registry numbers, project website, etc).

Results will be published in an Open Access journal that provides a PID (e.g., a DOI or URN).

## 1.2. WP2

Once the resilience assessment toolkit is developed at the end of WP1, the next step will be to pilot-test it with selected cardiac care institutions and stakeholders from Spain (Catalonia) and Italy to check its comprehensiveness, applicability and usability.

The purpose of the data collected and generated will therefore aim to provide information about the use and perception of the tool by the participating healthcare professionals.

We expect to have 3 main datasets: one for the literature review used for the definition of the performance indicators (task 2.1), one for the list compiling the candidates willing to participate in the in-depth pilot test (task 2.2), and the scripts from the pilot test itself (task 2.3). The exact data size is not yet known, but will be made clearer in future iterations of the DMP.

The data will be useful to the RESIL-Card consortium partners to complete subsequent tasks of the project. It may also be of interest to other researchers assessing health system resilience from the healthcare professionals' perspective, although some aggregation and anonymisation will be required to guarantee the freedom of speech during the pilot test.

### - **Pilot test candidate selection**

Using selection criteria defined in coordination with WP1, this task will aim to identify a pool of candidates willing to participate in the pilot testing of the resilience assessment tool.

Collected data will consist primarily in professional contact information of healthcare professionals willing to participate in the in-depth review and testing of the tool, and will only be used to contact participants who will finally join the pilot test.

From a collection methodology standpoint, following a public call, data will be directly submitted - via mail or a website - by candidates willing to join the pilot testing.

Generated data will be an encrypted spreadsheet, containing sensitive information, in which collected data can be organised and classified according to the inclusion criteria to participate in the pilot test. No new data will be generated and dissemination will be restricted to the consortium members.

In the event of a publication, a specific consent will be sought from the candidate participants before the issue of any professional contact information.

Data will be preserved in an encrypted document in a private folder hosted by CatSalut, protected under the privacy regulation of the Catalan Health Service. The document will be erased after the distribution of the pilot test report.

- **In-depth pilot test**

The pilot testing phase will aim at collecting descriptive data from the enrolled centres/assessed systems in Spain (Catalonia) and Italy, as well as detailed feedback about the usefulness, comprehensiveness, and applicability of the resilience assessment tool from the users.

Collected data will be raw qualitative data from the pilot group that will be compiled using the performance indicator set.

The pilot group meetings, conducted online, will be recorded and transcribed via Microsoft Teams within the CatSalut work environment. Field notes will also be taken. In case in-person meetings are organised, data will be collected as field notes.

Generated data - audiovisual recordings and/or field notes drawn from the virtual meetings with professionals participating in the pilot test - will be compiled as an extended report detailing the methodology, sources and results. This report will be driven by the indicator set.

Results and their analysis will be published in an Open Access journal that provides a PID (e.g., a DOI or URN). Recordings will remain private and only shared, if required, within the Consortium members.

Data will be preserved in a private folder hosted by CatSalut and protected under the privacy regulation of the Catalan Health Service. Documents will be kept for as long as the Consortium Agreement is established.

Considering the need to guarantee the source anonymity, only the datasets generated and analysed during the study will be made available in online repositories such as the Zenodo.org (with a unique "doi"). To make data findable, we will crosslink any online sources where applicable (e.g., ORCIDs of researchers, PIDs of related publications or repository references within the project, trial registry numbers, project website, etc.).

- **Survey on users' experience (TBD)**

The user survey – collecting feedback online through the unmoderated use of the tool - would consist in a second stage pilot test at the time the final version of the resilience assessment tool – resulting from the feedback of the 1<sup>st</sup>-stage pilot test - is released and widely disseminated by WP3.

Data on surveillance assessment of the tool access, use and satisfaction will be compiled although the final form and scope will need to be defined.

Data collection will depend on the final form of the resilience tool and will follow one of the 3 approaches below:

1. A one-time, specific survey addressed to professionals who have received information about the resilience assessment tool and tested it;
2. A specific user's experience survey included at the end of the resilience assessment tool and to be completed each time anyone uses it;
3. A passive collection and analysis of the statistics related to webpage access, navigation, and use.

Generated data will depend on the selected data collection approach. Processed quantitative and qualitative data will be compiled in spreadsheets. Analysis results will be compiled as a report including graphs and tables, if required.

Results, in the form of aggregated data, will be open and published in an Open Access journal that provides a PID (e.g., a DOI or URN). Individual data, if any (options 1 and 2), will remain private and be shared, if required, within the Consortium members only.

Data will be preserved in a private folder hosted by CatSalut, protected under the privacy regulation of the Catalan Health Service. Documents will be kept for as long as the Consortium Agreement is established.

Considering the need to maintain the source anonymity, only the datasets generated and analysed during the study will be made available in online repositories such as the Zenodo.org (with a unique "doi"). To make data findable, we will crosslink any online sources where applicable (e.g., ORCIDs of researchers, PIDs of related publications or repository references within the project, trial registry numbers, project website, etc.).

## 2. FAIR data

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

WP1 results will be published in Open Access journals that provide a PID (e.g., a DOI or URN).

To make data findable, we will crosslink any online sources where applicable (e.g., ORCIDs of researchers, PIDs of related publications or repository references within the project, trial registry numbers, project website, etc).

For WP2, results and analyses of in-depth pilot test and user's survey (in an aggregated form) will be published in Open Access journals that provide a PID (e.g., a DOI or URN). Individual data, if any, as well as recordings will remain private and only be shared, if required, within the Consortium members.

For both WP, clear version numbers will be provided.

### 2.2. Making data openly accessible

For both WPs, only the datasets which will have been generated and analysed during the relevant tasks – scoping literature review, HCP resilience survey, focus groups, pilot-test and user experience survey – will be made openly available.

Datasets resulting from the collection of sensitive information will not be shared due to anonymity preservation.

Openly accessible datasets will be available in online repositories such as the Zenodo.org (with a unique "doi"). To make data findable, we will crosslink any online sources where applicable (e.g., ORCIDs of researchers, PIDs of related publications or repository references within the project, trial registry numbers, project website, etc).

### 2.3. Making data interoperable

For both WPs, we will ensure the data interoperability as far as possible. This will be discussed throughout the consortium's work and will be further detailed in future iterations of the Data Management Plan.

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

Datasets will be accessible once the final work is made available to the public and will remain in digital repositories for as long as these platforms allow. Data preparation and processing will be described in the deliverables and in the scientific papers whenever that is considered relevant.

## 3. Allocation of resources

No specific additional allocation of resources, beyond the ones already planned in the project, is expected.

## 4. Data security

For WP1, project documents will be handled in an online folder in Amsterdam UMC's Sharepoint, only accessible by the research group, and password protected with a dual-factor authentication under the privacy regulation of Amsterdam UMC.

For WP2, data will be preserved in a private folder hosted by CatSalut. This folder is protected under the privacy regulation of the Catalan Health Service. Documents will be kept for as long as the Consortium Agreement is established.

## 5. Ethical aspects

For the survey conducted in WP1, details about the management of confidentiality and collected data will be provided in the dissemination email. Informed consent for data sharing and long-term preservation will be included in the survey.

For WP2, contacting healthcare professionals will take place after confirmation of their interest and willingness to participate in the pilot test of the resilience assessment tool.

Information collected during the pilot test will follow specific confidentiality rules both ensuring the protection of the participants and enabling to carry out the needed analyses. These rules will be discussed throughout the consortium's work and further detailed in future iterations of the Data Management Plan.

## 6. Other issues

No other specific issues are foreseen at the time of preparation of this DMP version.

## Conclusion

This deliverable presents an **initial version of the plan for data management** in the RESIL-Card project. In this action, different types of data are envisioned to be collected - data from stakeholders of the cardiovascular care systems, from publications, open-source data - and generated - publications and deliverables.

The data used will either be anonymous, and from open data repositories, or sought to be anonymised as much as possible. Whenever personal data is collected, explicit consent will be required, and data will thereafter be anonymised.

The RESIL-Card Data Management Plan relies on methodologies and technical standards like Digital Object Identifiers, the Zendo research data repository, etc. This will ensure the results of the RESIL-Card project are preserved and stay accessible and usable after the end of the project.

Data will be stored in the WP leaders' premises fulfilling the relevant legislations. Data from publications will be stored in indexed repositories. Other publications such as deliverables will be stored on the project website.

This deliverable will be **updated as needed in subsequent releases**, at the project midterm (M12, M24) and for the final (M36) reviews. Aspects that are not fully clear at this stage, such as the exact form for all data and metadata, will be clarified as work progresses in all the relevant work packages.

## Appendix – Summary table

WPs / Tasks	Type of data		Dissemination	Methodology and standards			
	Collected	Generated		Data collection	Data generation	Data preservation	Data dissemination
<b>WP1 - Scoping literature review</b>	Scientific articles, National and International reports available in the public domain	Spreadsheet with qualitative data	Results published in an Open Access journal that provides a PID (e.g., a DOI or URN)	Scoping review methodology to retrieve articles and data extraction with a software such as Rayyan, or similar, to select articles; Data collection to an excel spreadsheet	Processed data: spreadsheet with qualitative data Analysed data: results of qualitative analysis in graphs or tables.	All project documents will be handled in an online folder in Amsterdam UMC's Sharepoint which only the research group have access to. This folder is protected under the privacy regulation of Amsterdam UMC.	Datasets generated and analysed during the study will be available in online repositories such as the Zenodo.org (with unique "doi"). To make data findable, we will crosslink any online sources where applicable (e.g., ORCIDs of researchers, PIDs of related publications or repository references within the project, trial registry numbers, project website, etc).
<b>WP1 - HCP survey on resilience experience</b>	Raw survey data	Spreadsheet with qualitative data	Results published in an Open Access journal that provides a PID (e.g., a DOI or URN)	Tool to send online questionnaire will have a processing agreement regarding privacy with the Consortium members.	The acquired data will be stored as a read-only file and a new file will be created for further processing and statistical analyses. Data processing: information regarding transcribing and coding will be provided. Analysed	All project documents will be handled in an online folder in Amsterdam UMC's Sharepoint which only the research group have access to. This folder is protected under	Considering the need to maintain the anonymity of the sources, only the datasets generated and analysed during the study will be available in online repositories such as the Zenodo.org (with unique "doi").

					data will be presented as graphs or tables after qualitative and statistical analysis - exact format is not yet known.	the privacy regulation of Amsterdam UMC. Data will be kept for 10 years after the study is published and the data will not be shared with external partners.	To make data findable, we will crosslink any online sources where applicable (e.g., ORCIDs of researchers, PIDs of related publications or repository references within the project, trial registry numbers, project website, etc).
<b>WP1 - Focus groups</b>	Raw qualitative data from focus groups	Audio files (verbatim record) and/or field notes drawn from focus groups with stakeholders involved in care to patients with CV diseases	Results published in an Open Access journal that provides a PID (e.g., a DOI or URN)	The focus groups conducted online will be recorded and transcribed via Microsoft Teams within the Amsterdam UMC work environment. In case some focus groups are organised in-person, professional equipment will be used for the sound recording and we will ensure data is encrypted. We will liaise with the ICT department of Amsterdam UMC to ensure secure	Processed data: exact format is not yet known Analysed data: results of qualitative analysis displayed in graphs or tables.	All project documents will be handled in an online folder in Amsterdam UMC's Sharepoint which only the research group have access to. This folder is protected under the privacy regulation of Amsterdam UMC. Researchers' notes on the focus groups will be kept for 10 years after the study is published, the recordings will be erased immediately after the publication of the study, and the data will not be shared	Considering the need to maintain the anonymity of the sources, only datasets generated and analysed during the study will be available in online repositories such as the Zenodo.org (with a unique "doi"). To make data findable, we will crosslink any online sources where applicable (e.g., ORCIDs of researchers, PIDs of related publications or repository references within the project, trial registry numbers, project website, etc).

				<p>sound recordings and secure ways to transfer recordings to Amsterdam UMC's Sharepoint are used. We do not anticipate the need of outsourcing the focus groups. Yet, in case there is the need to outsource the transcription of focus groups, a processing agreement will be concluded with the party involved regarding privacy protection.</p>		<p>with external partners.</p>	
<p><b>WP2 – Candidate pool for pilot test</b></p>	<p>Professional and contact information from candidate participants willing to join the pilot test</p>	<p>Encrypted spreadsheet with sensible information</p>	<p>Private within the Consortium members</p>	<p>Data will be directly submitted by the candidate participants willing to join the pilot test, via mail or website (TBD) after a public call.</p>	<p>No new data will be generated, data will just be organised and classified according to the inclusion criteria for participation in the pilot test.</p>	<p>Collected data will only be used to contact participants who will finally join the pilot test. Data will be preserved in an encrypted document in a private folder hosted by CatSalut. This folder is protected under the privacy regulation</p>	<p>Data will not be shared with external partners. The list will not be disseminated. Specific consent will be required from the candidate participants before the publication of any part of the information included in the professional and contact, in case any</p>



						of the Catalan Health Service. The document will be erased after the launch of the report of the pilot test.	publication is needed.
<b>WP2 – In-depth pilot test</b>	Raw qualitative data from the pilot group, compiled following the performance indicator set.	Audiovisual recording and/or field notes drawn from the virtual meetings with professionals participating in the pilot test.	Results and their analysis will be published in an Open Access journal that provides a PID (e.g., a DOI or URN). Recordings will remain private and only shared, if required, within the Consortium members.	The pilot group meetings, conducted online, will be recorded and transcribed via Microsoft Teams within the CatSalut work environment. Field notes will also be taken. In case any meeting is organised in-person, data will be collected as field notes.	Data will be compiled as an extended report detailing the methodology, sources and results. This report will be driven by the indicator set.	Data will be preserved in a private folder hosted by CatSalut. This folder is protected under the privacy regulation of the Catalan Health Service. Documents will be kept for as long as the Consortium agreement is established.	Considering the need to maintain the anonymity of sources, only datasets generated and analysed during the study will be available in online repositories such as the Zenodo.org (with a unique "doi"). To make data findable, we will crosslink any online sources where applicable (e.g., ORCIDs of researchers, PIDs of related publications or repository references within the project, trial registry numbers, project website, etc).
<b>WP2 – Survey on user's experience</b>	Data on surveillance assessment of the tool access, use and satisfaction should be compiled. Its final	Data generated will depend on the final form of the tool: 1) a one-time, specific survey addressed to	Results, in the form of aggregated data, will be open and published in an Open Access journal that provides a	Data could be directly recorded by the resilience assessment tool users through the completion of a	Processed quantitative and qualitative data will be compiled in spreadsheets. Analysis re-	Data will be preserved in a private folder hosted by CatSalut. This folder is protected under the privacy	Considering the need to maintain the anonymity of sources, only datasets generated and analysed during the study will

	<p>form and scope will need to be defined.</p>	<p>those professionals who have received information about the resilience assessment tool; 2) a specific survey on user's experience included at the end of the resilience assessment tool, to be answered each time anyone uses it; 3) a passive collection and analysis of the webpage access, navigation and use.</p>	<p>PID (e.g., a DOI or URN). Individual data, if any (options 1 and 2), will remain private and only be shared, if required, within the Consortium members.</p>	<p>survey form (options 1 and 2) or by the web analytical systems (option 3).</p>	<p>sults will be compiled as a report including graphs and tables, if required.</p>	<p>regulation of the Catalan Health Service. Documents will be kept for as long as the Consortium agreement is established.</p>	<p>be available in online repositories such as the Zenodo.org (with unique "doi"). To make data findable, we will crosslink any online sources where applicable (e.g., ORCIDs of researchers, PIDs of related publications or repository references within the project, trial registry numbers, project website, etc).</p>
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