# FWO DMP Template - Flemish Standard Data Management Plan

## Version KU Leuven

Project supervisors (from application round 2018 onwards) and fellows (from application round 2020 onwards) will, upon being awarded their project or fellowship, be invited to develop their answers to the data management related questions into a DMP. The FWO expects a **completed DMP no later than 6 months after the official start date** of the project or fellowship. The DMP should not be submitted to FWO but to the research co-ordination office of the host institute; FWO may request the DMP in a random check.

At the end of the project, the **final version of the DMP** has to be added to the final report of the project; this should be submitted to FWO by the supervisor-spokesperson through FWO's e-portal. This DMP may of course have been updated since its first version. The DMP is an element in the final evaluation of the project by the relevant expert panel. Both the DMP submitted within the first 6 months after the start date and the final DMP may use this template.

The DMP template used by the Research Foundation Flanders (FWO) corresponds with the Flemish Standard Data Management Plan. This Flemish Standard DMP was developed by the Flemish Research Data Network (FRDN) Task Force DMP which comprises representatives of all Flemish funders and research institutions. This is a standardized DMP template based on the previous FWO template that contains the core requirements for data management planning. To increase understanding and facilitate completion of the DMP, a standardized **glossary** of definitions and abbreviations is available via the following link.

| 1. General Project Information | |
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| Name Grant Holder & ORCID | **Tim Debroyer - 0000-0003-2556-8674** |
| Contributor name(s) (+ ORCID) & roles | **Kaat Wils – 0000-0002-9828-3760 – Full professor at KU Leuven, Faculty of Arts**<br>**Joris Vandendriessche - 0000-0002-6304-8437- Tenure-track assistant professor, KU Leuven, Faculty of Arts** |
| Project number [1] & title | **3H230624 - Beyond self-help: Patient organisations, health activism and representations of disease in Belgium since 1940** |
| Funder(s) GrantID [2] | **11P8C24N** |
| Affiliation(s) | **X** KU Leuven<br>☐ Universiteit Antwerpen<br>☐ Universiteit Gent<br>☐ Universiteit Hasselt<br>☐ Vrije Universiteit Brussel<br>☐ Other:<br>ROR identifier KU Leuven: 05f950310 |

[1] "Project number" refers to the institutional project number. This question is optional. Applicants can only provide one project number.

[2] Funder(s) GrantID refers to the number of the DMP at the funder(s), here one can specify multiple GrantIDs if multiple funding sources were used.

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| Please provide a short project description | Coinciding with the development of the welfare state, patients increasingly united in patient organisations to cope collectively with their disease. These new organisations assumed more extensive medical and social roles beyond self-help within communities of patients than is often acknowledged. This project enlarges the scope by taking into account the broader functions such organisations fulfilled in acting against healthcare and government, but also in influencing wider society. As such, it questions if patient organisations could be considered 'forgotten architects' of the modern welfare state. Belgium thereby constitutes a promising case due to the historically close collaboration between patients and physicians, but also due to the striking difference in the evolution of patient organisations in the two parts of the country. The project scrutinises patient organisations for the first time by using a combination of oral history and a qualitative analysis of archival and published sources. It thereby looks into the history of Belgian organisations for diabetes, multiple sclerosis, breast cancer, Crohn's disease and AIDS from the onset of the welfare state in the 1940s. As such, the project contributes to the historiography of medicine and health, but also offers a historical perspective on the current topic of patient organisation and participation. |

## 2. Research Data Summary

List and describe all datasets or research materials that you plan to generate/collect or reuse during your research project. For each dataset or data type (observational, experimental etc.), provide a short name & description (sufficient for yourself to know what data it is about), indicate whether the data are newly generated/collected or reused, digital or physical, also indicate the type of the data (the kind of content), its technical format (file extension), and an estimate of the upper limit of the volume of the data [3].

| | | | | *ONLY FOR DIGITAL DATA* | *ONLY FOR DIGITAL DATA* | *ONLY FOR DIGITAL DATA* | *ONLY FOR PHYSICAL DATA* |
|---|---|---|---|---|---|---|---|
| Dataset Name | Description | New or Reused | Digital or Physical | Digital Data Type | Digital Data Format | Digital Data Volume (MB, GB, TB) | Physical Volume |
| | | ☐ Generate new data<br>☐ Reuse existing data | ☐ Digital<br>☐ Physical | ☐ Audiovisual<br>☐ Images<br>☐ Sound<br>☐ Numerical<br>☐ Textual<br>☐ Model<br>☐ Software<br>☐ Other: | | ☐ < 1 GB<br>☐ < 100 GB<br>☐ < 1 TB<br>☐ < 5 TB<br>☐ > 5 TB<br>☐ NA | |
| Literature: Bibliographic information | Database of literature references | Generate new data | Digital | Database | Zotero database | < 1 GB | / |
| Public database of sources for the history of Belgian patient organisations | References to sources collected during prospective research but to be extended during this project | Generate new data + Reuse existing data | Digital | Database | Zotero database | < 1 GB | / |
| Sources: Archives, periodicals, | Digital reproductions (photographs) | Generate new data | Digital | Images and textual data | .jpg initially, then .pdf | < 1 TB | / |

[3] Add rows for each dataset you want to describe.

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| newspapers, publications | and notes of sources from patient organisations, physicians, newspapers and governments | | | | | | |
| Sources: Interviews with patients, members of patient organisations and physicians | Audio-files, transcriptions and informed consents of interviews | Generate new data | Digital | Audiovisual and textual data | .WAV/.mp3 for audio files; .docx initially, then .pdf for transcriptions; .pdf for informed consents | < 100 GB | / |
| Notes: Annotations about literature and sources | Digital notes on literature and sources | Generate new data | Digital | Textual data | OneNote notes | < 100 GB | / |

*GUIDANCE:*
*The data description forms the basis of your entire DMP, so make sure it is detailed and complete. It includes digital and physical data and encompasses the whole spectrum ranging from raw data to processed and analysed data including analysis scripts and code. Physical data are all materials that need proper management because they are valuable, difficult to replace and/or ethical issues are associated. Materials that are not considered data in an RDM context include your own manuscripts, theses and presentations; documentation is an integral part of your datasets and should described under documentation/metadata.*
*RDM Guidance on data*

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| If you reuse existing data, please specify the source, preferably by using a persistent identifier (e.g. DOI, Handle, URL etc.) per dataset or data type. | Public database of sources for the history of Belgian patient organisations: Tim Debroyer, "Database of Sources for the History of Belgian Self-Help Groups and Patient Organisations 1950-2000" (KU Leuven RDR, 2023), https://doi.org/10.48804/PIJPCY. |
| Are there any ethical issues concerning the creation and/or use of the data (e.g. experiments on humans or animals, dual use)? If so, refer to specific datasets or data types when appropriate and provide the relevant ethical approval number. | ☒ Yes, human subject data; provide SMEC or EC approval number:<br>☐ Yes, animal data; provide ECD reference number:<br>☐ Yes, dual use; provide approval number:<br>☐ No<br>Additional information:<br>Specific datasets for ethical approval:<br>- Sources: Archives, periodicals, newspapers, publications<br>- Sources: Interviews with patients, members of patient organisations and physicians<br>➔ In the process of obtaining ethical approval from SMEC: G-2023-7203-R4(MAR) |
| Will you process personal data[4]? If so, please refer to specific datasets or data types when appropriate and provide the KU Leuven or UZ Leuven privacy register number (G or S number). | ☒ Yes (provide PRET G-number or EC S-number below)<br>☐ No<br>Additional information:<br>Specific datasets for privacy approval:<br>- Sources: Archives, periodicals, newspapers, publications<br>- Sources: Interviews with patients, members of patient organisations and physicians<br>➔ In the process of obtaining privacy approval from SMEC: G-2023-7203-R4(MAR) |
| Does your work have potential for commercial valorization (e.g. tech transfer, for example spin-offs, commercial exploitation, …)?<br>If so, please comment per dataset or data type where appropriate. | ☐ Yes<br>☒ No<br>If yes, please comment: |

[4] See Glossary Flemish Standard Data Management Plan

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| Do existing 3rd party agreements restrict exploitation or dissemination of the data you (re)use (e.g. Material/Data transfer agreements, research collaboration agreements)?<br>If so, please explain to what data they relate and what restrictions are in place. | ☐ Yes<br>☒ No<br>If yes, please explain: |
| Are there any other legal issues, such as intellectual property rights and ownership, to be managed related to the data you (re)use?<br>If so, please explain to what data they relate and which restrictions will be asserted. | ☒ Yes<br>☐ No<br>If yes, please explain:<br>Sources: Archives, periodicals, newspapers, publications: Some materials like periodicals, newspapers and publications are probably under copyright; when I'm photographing, I'll be very careful to note down all available copyright information I can find to decide on future reuse options. |

| 3. Documentation and Metadata | |
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| Clearly describe what approach will be followed to capture the accompanying information necessary to keep **data understandable and usable**, for yourself and others, now and in the future (e.g. in terms of documentation levels and types required, procedures used, Electronic Lab Notebooks, README.txt files, Codebook.tsv etc. where this information is recorded).<br><br>*RDM guidance on documentation and metadata*. | - **Literature: Bibliographic information:** References are organised in Zotero folders per disease/theme. Information in the Zotero database should provide enough information for future use but the content and structure of the dataset will be explained in a README file.<br>- **Public database of sources for the history of Belgian patient organisations:** References are organised in Zotero folders per disease and per organisation by using tags. Information in the Zotero database should provide enough information for future use but the content and structure of the dataset will be explained in a README file.<br>- **Sources: Archives, periodicals, newspapers, publications**: Archival information is sorted per theme/disease and if applicable per organisation on a lower level. Information on the collecting and processing of these materials will be gathered. Still to be determined which materials can be shared for future research and how these could be provided with documentation. The content and structure of these sources will be explained in a README file.<br>- **Sources: Interviews with patients, members of patient organisations and physicians**: Interviews are sorted per organisation and witness on a lower level. If interviewees consent, future researchers will be able to consult interviews at KADOC. All metadata on the person interviewed, the interview and informed consent will be gathered in a report together with the transcription. The content and structure of these sources will be explained in a README file.<br>- **Notes: Annotations about literature and sources**: Sorted per theme/disease and on a lower level chronologically. The content and structure of these notes will be explained in a README file. |
| Will a metadata standard be used to make it easier to **find and reuse the data**?<br><br>If so, please specify which metadata standard will be used. If not, please specify which metadata will be created to make the data easier to find and reuse.<br><br>*Repositories could ask to deliver metadata in a certain format, with specified ontologies and vocabularies, i.e. standard lists with unique identifiers.* | ☐ Yes<br>☒ No<br>If yes, please specify (where appropriate per dataset or data type) which metadata standard will be used:<br><br>If no, please specify (where appropriate per dataset or data type) which metadata will be created:<br>➔ See previous question |

| 4. Data Storage & Back-up during the Research Project | |
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| Where will the data be stored?<br><br>*Consult the interactive KU Leuven storage guide to find the most suitable storage solution for your data.* | ☐ Shared network drive (J-drive)<br>☐ Personal network drive (I-drive)<br>☒ OneDrive (KU Leuven)<br>☐ Sharepoint online<br>☐ Sharepoint on-premis<br>☐ Large Volume Storage<br>☐ Digital Vault<br>☐ Other: |
| How will the data be backed up?<br><br>*WHAT STORAGE AND BACKUP PROCEDURES WILL BE IN PLACE TO PREVENT DATA LOSS?* | ☒ Standard back-up provided by KU Leuven ICTS for my storage solution<br>☐ Personal back-ups I make (specify)<br>☐ Other (specify) |
| Is there currently sufficient storage & backup capacity during the project? If yes, specify concisely. If no or insufficient storage or backup capacities are available, then explain how this will be taken care of. | ☒ Yes According to the current prognosis, the current 2TB limit on my KU Leuven Faculty of Arts OneDrive will be sufficient. If that is not the case, I will request a free extension to 5TB in time.<br>☐ No<br><br>If no, please specify: |

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| How will you ensure that the data are securely stored and not accessed or modified by unauthorized persons?<br><br>*CLEARLY DESCRIBE THE MEASURES (IN TERMS OF PHYSICAL SECURITY, NETWORK SECURITY, AND SECURITY OF COMPUTER SYSTEMS AND FILES) THAT WILL BE TAKEN TO ENSURE THAT STORED AND TRANSFERRED DATA ARE SAFE.*<br>*Guidance on security for research data* | Data will only be accessed via my KU Leuven laptop which is secured via Bitlocker. All data will be backed-up by using the secured KU Leuven OneDrive. |
| What are the expected costs for data storage and backup during the research project? How will these costs be covered? | Apart from the purchase of a laptop secured by the ICT service of the Faculty of Arts, the data storage and back-up facilities of the Faculty of Arts are free of charge. |

| **5. Data Preservation after the end of the Research Project** | |
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| Which data will be retained for at least five years (or longer, in agreement with other retention policies that are applicable) after the end of the project? In case some data cannot be preserved, clearly state the reasons for this (e.g. legal or contractual restrictions, storage/budget issues, institutional policies...).<br><br>*Guidance on data preservation* | ☒ All data will be preserved for 10 years according to KU Leuven RDM policy<br>☐ All data will be preserved for 25 years according to CTC recommendations for clinical trials with medicinal products for human use and for clinical experiments on humans<br>☐ Certain data cannot be kept for 10 years (explain) |

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| Where will these data be archived (stored and curated for the long-term)?<br><br>*Dedicated data repositories are often the best place to preserve your data. Data not suitable for preservation in a repository can be stored using a KU Leuven storage solution, consult the interactive KU Leuven storage guide.* | ☐ KU Leuven RDR<br>☒ Large Volume Storage (longterm for large volumes)<br>☐ Shared network drive (J-drive)<br>☐ Other (specifiy): |
| What are the expected costs for data preservation during the expected retention period? How will these costs be covered? | Over the course of the project, I will explore the possibilities of different large-volume storage options like a SharePoint online-site and a Teams site which are free of charge, or a SharePoint on premise-site (with a considerable cost). I will thereby look for a storage option which offers sufficient capacity, access options, but also confidentiality guarantees. |

## 6. Data Sharing and Reuse

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| Will the data (or part of the data) be made available for reuse after/during the project? Please explain per dataset or data type which data will be made available.<br><br>*Note that 'available' does not necessarily mean that the data set becomes openly available, conditions for access and use may apply. Availability in this question thus entails both open & restricted access. For more information: https://wiki.surfnet.nl/display/standards/info-eu-repo/#infoeurepo-AccessRights* | ☒ Yes, as open data<br>☐ Yes, as embargoed data (temporary restriction)<br>☒ Yes, as restricted data (upon approval, or institutional access only)<br>☐ No (closed access)<br>☒ Other, please specify:<br><br>- **Literature: Bibliographic information:** References in Zotero database will be made publicly available.<br>- **Public database of sources for the history of Belgian patient organisations:** References in Zotero database will be made publicly available.<br>- **Sources: Archives, periodicals, newspapers, publications**: Pictures of archives, periodicals, newspapers and publications will be made available if privacy and intellectual property rights allow the sharing of data. Possibility of looking into the options of restricted access.<br>- **Sources: Interviews with patients, members of patient organisations and physicians**: Audio-files, transcriptions and informed consents will be preserved at KADOC if interviewees consent. If they accept this, future researchers will be able to consult the interviews there. KADOC will thereby only share these interviews after researchers have motivated the goal of their research and when they accept the terms in the informed consent of the interview like, for example, anonymity.<br>- **Notes: Annotations about literature and sources**: Notes via OneNote. Possibility of looking into the options of restricted access. |
| If access is restricted, please specify who will be able to access the data and under what conditions. | I will look into the possibilities of offering restricted access to researchers who have an ethical clearance issued by an internationally recognized research institute. |

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| Are there any factors that restrict or prevent the sharing of (some of) the data (e.g. as defined in an agreement with a 3rd party, legal restrictions)? Please explain per dataset or data type where appropriate. | ☒ Yes, privacy aspects<br>☒ Yes, intellectual property rights<br>☒ Yes, ethical aspects<br>☐ Yes, aspects of dual use<br>☐ Yes, other<br>☐ No<br><br>If yes, please specify:<br>- **Sources: Archives, periodicals, newspapers, publications**: The sharing of pictures of archives, periodicals, newspapers and publications could be restricted by privacy and intellectual property rights.<br>- **Sources: Interviews with patients, members of patient organisations and physicians**: The sharing of audio-files, transcriptions and informed consents could be restricted by privacy aspects. |
| Where will the data be made available?<br>If already known, please provide a repository per dataset or data type. | ☒ KU Leuven RDR<br>☐ Other data repository (specify)<br>☐ Other (specify) |
| When will the data be made available? | ☒ Upon publication of research results<br>☐ Specific date (specify)<br>☐ Other (specify) |

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| Which data usage licenses are you going to provide? If none, please explain why.<br><br>*A DATA USAGE LICENSE INDICATES WHETHER THE DATA CAN BE REUSED OR NOT AND UNDER WHAT CONDITIONS. IF NO LICENCE IS GRANTED, THE DATA ARE IN A GREY ZONE AND CANNOT BE LEGALLY REUSED. DO NOTE THAT YOU MAY ONLY RELEASE DATA UNDER A LICENCE CHOSEN BY YOURSELF IF IT DOES NOT ALREADY FALL UNDER ANOTHER LICENCE THAT MIGHT PROHIBIT THAT.*<br>*Check the RDR guidance on licences for data and software sources code or consult the License selector tool to help you choose.* | ☒ CC-BY 4.0 (data)<br>☒ Data Transfer Agreement (restricted data)<br>☐ MIT licence (code)<br>☐ GNU GPL-3.0 (code)<br>☐ Other (specify) |
| Do you intend to add a PID/DOI/accession number to your dataset(s)? If already available, please provide it here.<br><br>*INDICATE WHETHER YOU INTEND TO ADD A PERSISTENT AND UNIQUE IDENTIFIER IN ORDER TO IDENTIFY AND RETRIEVE THE DATA.* | ☒ Yes, a PID will be added upon deposit in a data repository<br>☐ My dataset already has a PID<br>☐ No |
| What are the expected costs for data sharing? How will these costs be covered? | The use of KU Leuven RDR is free of charge. |

| **7. Responsibilities** | |
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| Who will manage data documentation and metadata during the research project? | I will manage data documentation and metadata during the research project. |
| Who will manage data storage and backup during the research project? | I will manage data storage and backup during the research project. |
| Who will manage data preservation and sharing? | I will manage data preservation and sharing during the project, afterwards my supervisor Prof. Joris Vandendriessche will manage data preservation and sharing. |
| Who will update and implement this DMP? | I will update and implement this DMP. |