## FWO DMP Template - Flemish Standard Data Management Plan

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		
Name Grant Holder & ORCID	Kato Ramaekers (https://orcid.org/0000-0003-0023-7940)	
Contributor name(s) (+ ORCID) & roles	Kathleen Freson (promotor)	
	Veerle Labarque (copromotor)	
Project number <sup>1</sup> & title	1126723N Improved disease modelling and genetics for inherited platelet disorders	
Funder(s) GrantID <sup>2</sup>	FWO 1126723N	
Affiliation(s)	■ KU Leuven	
	☐ Universiteit Antwerpen	
	☐ Universiteit Gent	
	☐ Universiteit Hasselt	
	□ Vrije Universiteit Brussel	
	□ Other:	
	Provide ROR <sup>3</sup> identifier when possible:	

<sup>&</sup>lt;sup>1</sup> "Project number" refers to the institutional project number. This question is optional since not every institution has an internal project number different from the GrantID. Applicants can only provide one project number.

<sup>&</sup>lt;sup>2</sup> 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.

<sup>&</sup>lt;sup>3</sup> Research Organization Registry Community. https://ror.org/

Please provide a short project description

Inherited platelet disorders (IPD) are highly heterogeneous with genetic defects in 63 genes and characterized by a high susceptibility to bleeding and often associated with syndromic features. Many genes have been discovered by whole exome/genome sequencing (WES/WGS) but their exact role in platelet formation and function remains unknown due to the lack of animal or efficient cell-based models. Today, high throughput-sequencing multi-gene panel tests comprising these genes can diagnose 48 to 26% of patients with platelet formation and function disorders, respectively. Many patients still remain undiagnosed and even with WGS data available, it remains extremely difficult to pinpoint the causative genetic defect because of the hundreds of rare coding variants present. This project therefore aims to deliver a rapid stem cell-based model to study known (but functionally undefined) and novel genes using CRISPR/Cas technology, quantitative in vivo imaging and genetic studies. Novel genes will be obtained from WGS data obtained for undiagnosed patients with very well-known platelet disorders, supplemented with platelet transcriptomes. This will allow WGS data analysis of differentially expressed genes. Validated novel candidate genes will be used to expand our existing diagnostic multi-gene panel test to increase detection of patients with the same IPD. This project will provide novel insights in platelet biology that is of use for therapeutic discoveries.

## 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<sup>4</sup>.

				ONLY FOR DIGITAL DATA	ONLY FOR DIGITAL DATA	ONLY FOR DIGITAL DATA	ONLY FOR PHYSICAL DATA
Dataset	Description	New or Reused	Digital or	Digital Data Type	Digital Data	Digital Data	Physical Volume
Name			Physical		Format	Volume (MB, GB,	
						TB)	
Whole	WGS data of	☐ Generate new	<b>☑</b> Digital	□ Observational	□ .por	□ < 100 MB	
genome	patients	data	□ Physical	□ Experimental	□ .xml	□ < 1 GB	
sequencing	mentioned in	■ Reuse existing		☐ Compiled/	⊠ .tab	□ < 100 GB	
	the project	data		aggregated data	⊠ .csv	<b>区</b> < 1 TB	
	application			□ Simulation	□ .pdf	□ < 5 TB	
				data	⊠ .txt	□ < 10 TB	
				☐ Software	□ .rtf	□ < 50 TB	
				⊠ Other	□ .dwg	□ > 50 TB	
				□ NA	⊠ .tab	□NA	
					□ .gml		
					☑ other: .bam		
					□ NA		
RNAseq	RNAseq data of	☑ Generate new	<b>☑</b> Digital	□ Observational	□ .por	□ < 100 MB	
	platelets,	data	□ Physical	□ Experimental	<b>⊠</b> .xml	□ < 1 GB	
	monocytes,	■ Reuse existing		☐ Compiled/	□ .tab	□ < 100 GB	
	neutrophils and	data		aggregated data	<b>⋉</b> .csv	<b>区</b> < 1 TB	
	T-cell for			□ Simulation	□ .pdf	□ < 5 TB	
	patients with an						

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	inherited platelet disorder and healthy controls			data □ Software ☑ Other □ NA		□ < 10 TB □ < 50 TB □ > 50 TB □ NA
Flow cytometry data	Flow Cytometry and FACS sort files (FlowJo and equipment specific files)	☑ Generate new data ☐ Reuse existing data	☑ Digital ☐ Physical	□ Observational  ☑ Experimental □ Compiled/ aggregated data □ Simulation data □ Software □ Other □ NA	□ .por □ .xml □ .tab □ .csv ☑ .pdf □ .txt □ .rtf □ .dwg □ .tab □ .gml ☑ other: .fcs .jpg .ti ff □ NA	□ < 100 MB  ▼ < 1 GB □ < 100 GB □ < 1 TB □ < 5 TB □ < 10 TB □ < 50 TB □ > 50 TB □ NA
Cytation5 imager	Imaging and quantification files from BioTek Cytation5 imager (KU	☑ Generate new data ☐ Reuse existing data	☑ Digital ☐ Physical	<ul><li>□ Observational</li><li>☑ Experimental</li><li>□ Compiled/</li><li>aggregated data</li><li>□ Simulation</li></ul>	□ .por  ☑ .xml □ .tab □ .csv □ .pdf	□ < 100 MB □ < 1 GB ☑ < 100 GB □ < 1 TB □ < 5 TB

	Leuven servers).			data	□ .txt	□ < 10 TB
				□ Software	□ .rtf	□ < 50 TB
				□ Other	□ .dwg	□ > 50 TB
				□ NA	□ .tab	□ NA
					□ .gml	
					<b>☑</b> other:	
					.jpg .tiff .mp4 .exp □ NA	
Confocal	Imaging files	☑ Generate new	<b>坚</b> Digital	☐ Observational	□ .por	□ < 100 MB
microscopy	from confocal	data	☐ Physical	■ Experimental	□ .xml	□ < 1 GB
	microscope	☐ Reuse existing		□ Compiled/	□ .tab	<b>坚</b> < 100 GB
		data		aggregated data	□ .csv	□ < 1 TB
				□ Simulation	□ .pdf	□ < 5 TB
				data	□ .txt	□ < 10 TB
				☐ Software	□ .rtf	□ < 50 TB
				□ Other	□ .dwg	□ > 50 TB
				□ NA	□ .tab	□NA
					□ .gml	
					☑ other: .jpg .tiff	
					□ NA	
Data analysis		☑ Generate new	☑ Digital	☐ Observational	□ .por	□ < 100 MB
and		data	☑ Physical	■ Experimental	<b>≭</b> .xml	□ < 1 GB
manuscript		☐ Reuse existing		⊠ Compiled/	□ .tab	区 < 100 GB
preparation		data		aggregated data	□ .csv	□ < 1 TB
				□ Simulation	☑ .pdf	□ < 5 TB
				data	⊠ .txt	□ < 10 TB
				□ Software	⊠ .rtf	□ < 50 TB
				□ Other	□ .dwg	□ > 50 TB

		□ NA	□ .tab □ .gml ☑ other: .docx .jpg .tiff □ NA	□NA	
SUIDANCE:  ATA CAN BE DIGITAL OR PHYSICAL (FOR EXAMPLE BIOBANK, BIOLOGICAL SAMPLES,). DATA TYPE: DATA ARE OFTEN GROUPED BY TYPE (OBSERVATIONAL, EXPERIMENTAL ETC.), FORMAT AND/OR COLLECTION/GENERATION INTERPOLATION INTERPOL					
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.	WGS data: This data is s Computing facility, Fres RNAseq: part of this dat Donck and is stored on	on K (promotor) ha ta (20 control platel	s access to this serve et samples) has beer	er.	

 $<sup>^{\</sup>rm 5}\,{\rm These}$  data are generated by combining multiple existing datasets.

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, please describe these issues further and refer to specific datasets or data types when appropriate.	<ul> <li>Yes, human subject data</li> <li>Yes, animal data</li> <li>Yes, dual use</li> <li>No</li> <li>If yes, please describe:</li> <li>Reference to ethical committee approval: S63666</li> </ul>
Will you process personal data? If so, briefly describe the kind of personal data you will use. Please refer to specific datasets or data types when appropriate. If available, add the reference to your file in your host institution's privacy register.	□ No
Does your work have potential for commercial valorization (e.g. tech transfer, for example spinoffs, commercial exploitation,)? If so, please comment per dataset or data type where appropriate.	<ul> <li>Yes</li> <li>□ No</li> <li>If yes, please comment:</li> <li>If data will be obtained of interest for valorization, IP restriction will be claimed. It is not clear from the start what novel genetic targets relevant for megakaryopoeisis and platelet formation/function can be identified.</li> </ul>

Do existing 3rd party agreements restrict	¥ Yes
exploitation or dissemination of the data you	□ No
(re)use (e.g. Material/Data transfer agreements,	If yes, please explain:
research collaboration agreements)?	The megakaryocyte model itself "imMKCL" cannot be protected by IP restrictions as this model was
If so, please explain to what data they relate and	developed by our collaborators and we have signed an MTA (with dr K Eto, Kyoto university). If this model
what restrictions are in place.	is needed for the overall IP restriction, a joined application is a possibility (as stated in the MTA). The flow
	chamber to enhance platelet production from imMKCL cells from the Bristol group (PI A. Poole) cannot be
	protected by IP restrictions as we have signed an MTA to use these slides in this project.
Are there any other legal issues, such as	□ Yes
intellectual property rights and ownership, to be	⊠ No
managed related to the data you (re)use?	If yes, please explain:
If so, please explain to what data they relate and	
which restrictions will be asserted.	

## 3. Documentation and Metadata

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).

Generated sequencing data will be uploaded to EGA in combination with related metadata (e.g. age, gender, case/control status, sequencing platform/library... etc.) to be accessible to the public.

Flow cytometry and sorting: information on gating strategy for cell identification and sorting will be saved in electronic files with details on antibody concentrations and protocols for cell preparation and staining will be described in detail in lab books.

Imaging (confocal and cytation5 imager): images and settings will be saved in electronic files. Details on staining techniques and antibody or dye concentrations and protocols for cell preparation will be described in detail in lab books.

Will a metadata standard be used to make it easier to <b>find and reuse the data</b> ?	¥ Yes □ No
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.	If yes, please specify (where appropriate per dataset or data type) which metadata standard will be used: The metadata standards of EGA will be used for submission of sequencing data, as can be consulted on https://ega-archive.org/submission/sequence/unaligned  If no, please specify (where appropriate per dataset or data type) which metadata will be created:
REPOSITORIES COULD ASK TO DELIVER METADATA IN A CERTAIN FORMAT, WITH SPECIFIED ONTOLOGIES AND VOCABULARIES, I.E. STANDARD LISTS WITH UNIQUE IDENTIFIERS.	

4. Data Storage & Back-up during the Research Project		
Where will the data be stored?	PC owned by the group	
How will the data be backed up?	Double backup on: KU Leuven OneDrive, external SSD drive	
What storage and backup procedures will be in place to prevent data loss? Describe the locations, storage media and procedures that will be used for storing and backing up digital and non-digital data during research. <sup>6</sup>		
REFER TO INSTITUTION-SPECIFIC POLICIES REGARDING BACKUP PROCEDURES WHEN APPROPRIATE.		

<sup>&</sup>lt;sup>6</sup> Source: Ghent University Generic DMP Evaluation Rubric: <a href="https://osf.io/2z5g3/">https://osf.io/2z5g3/</a>

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 ☐ No If yes, please specify concisely: external SSD capacity of 2 TB, KU Leuven OneDrive capacity of 2 TB (can be increased) If no, please specify:
How will you ensure that the data are securely stored and not accessed or modified by unauthorized persons?	The KU Leuven OneDrives are protected from unauthorized persons. External SSD will be stored in a locked cabinet.
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. 7	
What are the expected costs for data storage and backup during the research project? How will these costs be covered?	OneDrive is included for all employees of KU Leuven (no additional storage cost), J drive storage (add. Backup) costs 52 euro per year

5. Data Preservation after the end of the Research Project			
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).	Data that will no longer be used for analyses will be transfer from our active KULeuven servers to the archive KULeuven-servers after 10 years. No data will be disposed.		

Where will these data be archived (stored and	The data will be stored on the university's central archive servers (with automatic backup procedures) for
curated for the long-term)?	at least 10 years, conform the KU Leuven RDM policy.
What are the expected costs for data preservation during the expected retention	Permanent storage after the project for at least 10 years after the end of the project: (Archive storage K-drive) €5,69 per 100GB per year.
period? How will these costs be covered?	

6. Data Sharing and Reuse	
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.  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	<ul> <li>Yes, in an Open Access repository</li> <li>Yes, in a restricted access repository (after approval, institutional access only,)</li> <li>No (closed access)</li> <li>Other, please specify:</li> <li>DNA and RNA datasets will be shared on EGA servers after publication (open access repository). Other data can be obtained by researchers after request and approval by the PI (Kathleen Freson).</li> </ul>
If access is restricted, please specify who will be able to access the data and under what conditions.	Researchers can access that data after request.
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.	<ul> <li>Yes, privacy aspects</li> <li>Yes, intellectual property rights</li> <li>Yes, ethical aspects</li> <li>Yes, aspects of dual use</li> <li>Yes, other</li> <li>No</li> <li>If yes, please specify: DNA samples from patients can't be shared because of privacy reasons.</li> </ul>
Where will the data be made available? If already known, please provide a repository per dataset or data type.	The WGS and RNAseq data will be made available on the EGA, where access to data is granted based on applications to a data access committee that oversees the dataset.

When will the data be made available?	After publication of the research results in a peer-reviewed journal
THIS COULD BE A SPECIFIC DATE (DD/MM/YYYY) OR AN INDICATION SUCH AS 'UPON PUBLICATION OF RESEARCH RESULTS'.	
Which data usage licenses are you going to provide? If none, please explain why.	Genetic data can be reused after submission to EGA.
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.	
EXAMPLE ANSWER: E.G. "DATA FROM THE PROJECT THAT CAN BE SHARED WILL BE MADE AVAILABLE UNDER A CREATIVE COMMONS ATTRIBUTION LICENSE (CC-BY 4.0), SO THAT USERS HAVE TO GIVE CREDIT TO THE ORIGINAL DATA CREATORS." 7	
Do you intend to add a PID/DOI/accession	¥ Yes
number to your dataset(s)? If already available,	□ No
please provide it here.	If yes: EGA submission is accompanied by a specific accession number that will be mentioned in the publications
INDICATE WHETHER YOU INTEND TO ADD A PERSISTENT AND UNIQUE	
IDENTIFIER IN ORDER TO IDENTIFY AND RETRIEVE THE DATA.	
What are the expected costs for data sharing? How will these costs be covered?	Data will be released after publication of a manuscript and data sharing costs will be covered by the publication cost.

<sup>&</sup>lt;sup>7</sup> Source: Ghent University Generic DMP Evaluation Rubric: <a href="https://osf.io/2z5g3/">https://osf.io/2z5g3/</a>

7. Responsibilities		
Who will manage data documentation and metadata during the research project?	PI Kathleen Freson and PhD student Kato Ramaekers	
Who will manage data storage and backup during the research project?	Pls Kathleen Freson, Veerle Labarque PhD student Kato Ramaekers Technician Chantal Thys	
Who will manage data preservation and sharing?	PI Kathleen Freson	
Who will update and implement this DMP?	The PI bears the end responsibility of updating & implementing this DMP.	