Amsterdam Public Health

Amsterdam UMC

 Data Reuse
 Set-up & Conduct- Study Preparation

 VERSION
 1.0

Before you start your project, consider whether any existing source of data can be reused. The data, or a part of the data, you want to collect may already be available in existing databases or in the EHR (Electronic Health Record) system.

Why

Reusing data has many advantages: you can obtain reference data for your research, you can avoid doing new, unnecessary experiments, you can make your research more robust by aggregating results obtained from different methods or samples, and you can gain novel insights by connecting and meta-analysing data-sets.

How to find data to reuse?

In general, there are three types of data that you can reuse: care data from Amsterdam UMC EHRs (Epic, imaging, gene banks and others), other Amsterdam UMC data, or non-Amsterdam UMC data.

Reusing care data

Data from Epic can be made available for research either directly or via the Research Data Platform (RDP). The RDP (for <u>AMC</u> and <u>VUmc</u>) is a platform that retrieves data from Epic and other sources (e.g., laboratory, biobank, imaging) and can deliver datasets to researchers. The types of data that you can request using the RDPs are defined identically across both locations of Amsterdam UMC in the form of Detailed Clinical Models (DCMs), clusters of content-related data. Intake for any reuse of care data for research is performed via RDM support (<u>VUmc</u> and <u>AMC</u>).

The Standard Operating Procedure RDM002 (Reuse of care data for the purpose of research) contains a flowchart that can be used to choose the appropriate procedure in a given situation. Also consult: <u>SOP RDM001</u> 1.13, <u>SOP RDM002</u>

Reusing other data

Other Amsterdam UMC data

There is no central database for Amsterdam UMC research data yet. In order to find data to reuse, you can contact individual researchers (that you can find in <u>Who is Who</u> at location AMC or PURE at location <u>VUmc</u>) or research groups (e.g. via <u>Tulpconnect</u>).

Other Non-Amsterdam UMC data

To find existing datasets that may help answer your research question, you could search the re3data.org database to find suitable repositories for your research topic, as descriptions of content and characteristics are included. Commonly used general repositories you can also find there include a.o. <u>DANS</u> (EASY, DataverseNL, etc) the <u>Open Science Framework</u>, Zenodo, Figshare and <u>NIH</u> (e.g. GEO). These general repositories contain a list of sources you can consult to find research data to reuse for multiple research fields. Most scientific publications also include conditions for reuse, including a link to their data and/or contact info.

Conditions for reuse

Please note that you should sign a formal agreement with the owner of the data that includes the conditions for reuse, including the consent of the subjects, Intellectual Property and publication

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rights, unless the data can be reused without restriction. The department of <u>Legal Research Support</u> (at Amsterdam UMC) or <u>Innovation Exchange Amsterdam</u> (VU/UvA) can be consulted for setting up conditions for reuse of data.

Also consult: <u>SOP RDM001</u> for Amsterdam UMC policy regarding reusing data (Phase 1) and making data available for reuse yourself (Phase 5).

Reusing controlled access (genomic) data

Specific procedures apply for reusing controlled access (genomic) data. The <u>intranet of both</u> <u>location AMC</u> and <u>location VUmc</u> contain more information about this.

Research Data Management Helpdesk - AMC:

<u>https://intranet.amc.nl/web/organisatie/domeinen/research/research-life-cycle/rdm-helpdeks.htm</u> Research Data Management Contact - VUmc: <u>https://intranet.vumc.nl/afdelingen-themas-</u>

1/datamanagement/contact.htm

LINKS

	Link
Re3data.org	https://www.re3data.org/
RDP VUmc	https://rdm.elixir-europe.org/re-using#why-data-re-use-is-important
Amsterdam	https://www.amsterdamumc.org/research/support/about/research-data-management.htm
UMC	
research	
support RDM	
VUmC RDM	https://intranet.vumc.nl/afdelingen-themas-1/datamanagement/research-datamanagement-
	procedures-en-templates.htm
AMC RDM	https://intranet.amc.nl/web/organisatie/domeinen/research/research-life-cycle/rdm-helpdeks.htm
RDP DCM	http://sp-rs-bi11/BI/web/rdp_catalogus.asp
Catalogus	
AMC	http://rdpcatalogus.amc.nl/
RDPcatalogus	
SOP RDM001	http://kwadraet.amc.nl/iDocument/Viewers/Frameworks/ViewDocument.aspx?DocumentID=4d7ce52d-
	<u>8125-45ad-8fd1-c1fd4c21d561</u>
SOP	http://kwadraet.amc.nl/iDocument/Viewers/Frameworks/ViewDocument.aspx?DocumentID=8efa33b4-
RDM002	<u>9dfa-4575-a284-03b8fd8c7115</u>

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DOCUMENT APPROVAL

Role	Name	Date
Project Leader	Dr. Seta Jahfari	17MAY2021