

Data Sharing Guidelines

The data sharing guidelines aim to help you to decide on how to share your research data. Funders require that data is made 'As open as possible, as closed as necessary' and UMC Utrecht also follows this as a guiding principle in data sharing.

“Not all data can or should be preserved in the long term. In some cases, the sheer size of raw data may mean that only derived data products can be archived. In such cases, the corresponding metadata should remain FAIR and reference the decision not to retain the data. The criteria for prioritisation, appraisal and selection of the data to be retained should be detailed in the Data Management Plan.

Likewise, not all data can be made fully open. Where data raise privacy or security concerns, controls and limits on data access will be required. In some cases, it will be appropriate for researchers to delay or limit access to data in order to secure intellectual property protection.

There may also be other reasons to keep data closed. Any restrictions on access should be explicit and justified in the Data Management Plan, and such data should still be managed in line with the FAIR principles. For researchers, the move to FAIR data means that they have to think about what data their research will produce, how these data will be described, and how they can be made available in such a way as to benefit science and society in general. This means that they have to draw up a Data Management Plan and find suitable data repositories.”

Quotation from *Open Research Data and Data Management Plans*, ERC Scientific Council, Version 4.0 11 August 2021.

Different levels of [data sharing](#)

Research data may have different sources and may be sensitive in nature. The UMC Utrecht guidelines for data sharing provide three levels of sharing: Open, Conditional and Restricted.

DATA SHARING LEVEL	LICENSE/AGREEMENT	DATA RIGHTS	LINK
1. OPEN DATA	CREATIVE COMMON LICENSE: CC BY/CC 00.	Free sharing of data by recipient to third parties	CC Licenses - Creative Commons
2. CONDITIONAL DATA	UMC UTRECHT LICENSE	Use of data by recipient under general conditions	-link naar corporate website-
3. RESTRICTED DATA	DATA SHARING AGREEMENT	Use of data by recipient under project-specific conditions	Contact person legal affairs

OPEN (1) means that data and the metadata describing the data are findable and accessible under a [creative common license](#): choose between CC-BY or CC-0. The data is shared with little restrictions, as long as UMC Utrecht is credited. This level is not suitable for personal data, valuable data, nor for data derived from third parties. Examples for which this data sharing level is useful are non-valuable cell line data and summary statistics. Computer systems are able to recognize this data as 'open'.

CONDITIONAL (2) means suitable for data and meta data which is generated by UMC Utrecht and which does not contain personal data. Data is made available under standard terms and conditions as prescribed by UMC Utrecht, which are non-negotiable. Recipient may use for its own research, not

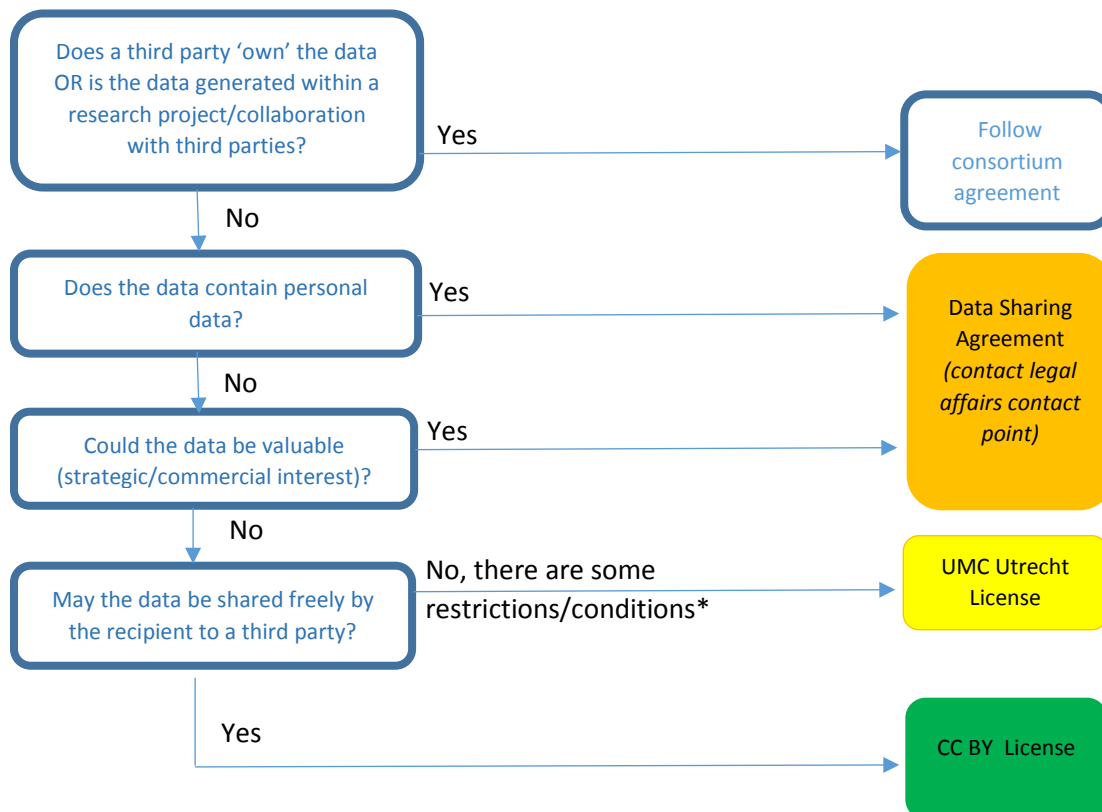
to share with other (commercial) parties. Use this data sharing level when UMC Utrecht needs to be cited. An example for which this data sharing level is useful is a multipurpose anonymized dataset.

RESTRICTED (3) means that the data cannot be freely shared and is subject to restrictions. This concerns personal data, valuable data and/or data received from third parties. Metadata can most of the time be made findable and accessible. In some cases (for example when metadata unavoidably include personal data) metadata is also restricted. Sharing this data is only allowed after approval of legal affairs (Juridische Zaken) UMC Utrecht. An example for which this data sharing level is useful is a pseudonimized dataset.

NOTE: Creative commons licenses were not created for research data; UMC Utrecht has decided to opt for an UMC Utrecht license and a UMC Utrecht data transfer agreement because legally it offers our research(ers) better protection.

How to decide on how to share

This flowchart guides you with a couple of questions to the level of 'openness' in sharing data.



*see above: Conditional (2)

Is the data provided by third parties or generated within a research project?

Agreements which are concluded for receiving this data or before the data is generated are decisive. Please contact your contact person legal affairs to determine if this data can be shared.

What about “ownership” of data?

Data cannot be owned in a legal (property) sense. However, a person/party can control data and contractually agree which rights it grants other with regards to such data. If an UMC Utrecht employee generates data, UMC Utrecht controls this data and determines what the data may be used for.

Suggested additions

Give the researchers a series of tips so that not every study/publication needs to go through the Department of Legal Affairs (Juridische Zaken).

Is there a PIF that contains text concerning re-usage or sharing of data?

Does the IC allow re-usage or sharing of data?

Check the agreement with other parties involved in the research: can the data be re-used or shared? There should be a paragraph "Publication" in the agreement.

Who controls the data?

Is it allowed to place the data on a platform of a third party, even after proper pseudonymization? Why would you do this if not strictly necessary to achieve the goals of the study?

Is there a DPIA and if so, is this included in the "verwerkingsregister"?

If you want to share data outside the EER: is this allowed by the PIF, and ensure that a SCC or other suitable privacy measure is taken.

Contact the ISO of the division: apart from asking for privacy advice the researcher should also ask the ISO to register the publication of the dataset in the "verwerkingsregister"? Note: is this necessary before publication of a dataset, or before granting an access request for a published dataset?