Data sharing and open access - access to research data for researchers

ITM recognises the importance and societal obligation of making its research data accessible for secondary research with as few restrictions as possible and in a timely manner.

ITM adheres to the European FAIR principles (Findable – Accessible – Interoperable – Reusable) and recognises that data should be “As open as possible and as closed as necessary”.

Since much of ITMs research data is personal data, health-related or otherwise sensitive, legal as well as ethical obligations and restrictions apply. Data sharing must assure anonymity of research participants and confidentiality and comply with the European General Data Protection Regulation 2016/679, and also legislation of the country where data is generated. Secondly, research participants must be sufficiently informed about, or have consented that their anonymised or pseudonymised data might be used for further research. Lastly, the risks of stigmatisation of researched populations or communities must be avoided wherever possible.

Consequently, the approach for sharing specific datasets will depend greatly on the sensitivity of the data. Restrictions for data access will be proportionate to the sensitivity of data.

Access requests for ITM research data can be made to ITM’s central point for research data access by means of submitting the completed Data Access Request Form. These requests will be reviewed for approval by ITMs Data Access Committee.

If approved, a Data Sharing Agreement (DSA) must be written and signed by the applicant and ITM prior to any data transfer. Such DSA will describe what data will be shared, what it can be used for, as well as legal requirements, restrictions and other contractual clauses.

ITM will always attempt to include sufficient context and metadata to the requested data (including e.g. the research protocol, variables descriptions/code books, laboratory protocols, coding standards used, etc.). As much as possible, data will be made available in open data formats, be machine-readable and interoperable, depending on the technicalities and standard practices for the specific research.

Within reasonable time after conclusion of the DSA, data will be transferred by means of a secure file transfer method.

In case you have any other questions related to ITMs data sharing policy, please contact the central point for research data access.