



GLOSSARY

**VERSION 1
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SWISS BIOBANKING PLATFORM

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BIOBANK

BIOBANK*

An organized entity responsible for the management and the custodianship of biological resources.

** It may also be referred to as Collection, Biorepository, Repository, Biological Resource Center or Biospecimen Resource.*

BIOBANK INFRASTRUCTURE

An organized facility that offers services to biobanks.

BIOBANK CUSTODIANSHIP

Management responsibility of biological resources in compliance with the legal requirements, ethical and professional standards.

BIOBANKING

Process of sampling, transport, receiving, processing, storing, retrieving and distributing biological resources.

BIOLOGICAL MATERIAL

Any material obtained or derived from a biological organism.

BIOLOGICAL RESOURCES

Biological material and associated data.

SPECIMEN*

A specific quantity of biological material such as tissue, blood or urine taken from a single subject or participant at a specific time.

** It may also be referred to as Biospecimen or Primary Sample.*

SAMPLE*

A single unit containing material (e.g. plasma, serum, DNA, RNA, cells, etc.) derived from one specimen.

** It may also be referred to as Biological Sample, Biosample or Derivative.*

ALIQUOT

Portion of a homogenous sample or specimen which has been divided into separate parts.

DATA

DATABASE

An organized collection of data.

ASSOCIATED DATA*

Personal and/or preanalytical data.

** It may also be referred to as Annotations or Related Data.*

PREANALYTICAL DATA*

Data related to the sampling, processing, storage and usage of biological material (e.g. sampling time, transport temperature, centrifuge speed, storing temperature, etc.).

** It may also be referred to as Annotations or Related data.*

PERSONAL DATA*

All information relating to an identified or identifiable person, including health-related data.

** It may also be referred to as Annotations, Related Data, Clinical Data or Identifying Information.*

HEALTH-RELATED DATA*

Data related to the health or disease of a participant, including genetic data (e.g. clinical, epidemiological, socio-economic data, etc.).

** It may also be referred to as Annotations, Related Data or Clinical Data.*

ANONYMIZATION

The irreversible removal of the link between the biological material and/or associated data and the participant, so that no specific participant can be reidentified.

CODING*

The reversible removal of the link between the biological material and/or associated data and the participant, so that a specific participant can only be reidentified through a key.

** It may also be referred to as Pseudonymization or Reversible Anonymization.*

KEY

The information which allows the coding to be undone, so that the biological material and/or associated data can be linked back to a specific participant.

SBP DATA SET

Set of documented information required to guarantee quality standards and enable optimal usage of biological resources.

CONSENT

PARTICIPANT

Living or deceased person who provides his/her biological material and/or associated data to the biobank.

INFORMED CONSENT

Voluntary and informed expression of the free will of a participant or his/her legal representative to allow the collection, storage, use and transfer of his/her biological material and/or associated data for research purposes.

GENERAL CONSENT*

A form of informed consent given by a participant to allow collection, storage, further use and transfer of his/her biological material and/or associated data collected for future not yet defined research projects.

** It may also be referred to as Broad Consent or Biobank Consent.*

SPECIFIC CONSENT

A form of informed consent given by a participant concerning the collection and storage of his/her biological material and/or associated data as well as their use and transfer for a defined/specific research project.

NON-OPPOSITION*

A consent mechanism where consent is implied unless an active choice is made to refuse a process after having been informed.

** It may also be referred to as Opt Out.*

WITHDRAWAL*

Withdrawal of previously given consent.

(Consequences of withdrawal are defined in consent form and should be disclosed with the concerned participant during the consent process.)

** It may also be referred to as Revocation.*

OTHER

DATA TRANSFER AGREEMENT

A legally binding agreement that governs the transfer of data between two parties, when the recipient intends to use them for research purpose. It defines the rights and obligations of the provider and recipient with respect to the use of the data and other related issues, such as confidentiality or intellectual property rights.

MATERIAL TRANSFER AGREEMENT

A legally binding agreement that governs the transfer of biological material and data between two parties, when the recipient intends to use them for research purpose. It defines the rights and obligations of the provider and recipient with respect to the use of the material and data and other related issues, such as confidentiality or intellectual property rights.