Conceptual Framework: Individual Concepts

CONCEPT	DESCRIPTION
Data Donor	
Sovereignty	The power to control our personal data. It encompasses excluding others from one's own personal space and allowing others to access it in specific ways. *Related concepts: control, agency, data stewardship, autonomy.*
Privacy	Contextually and selectively setting boundaries around the personal information that is disclosed. Supporting data donors in setting their own privacy preferences is fundamental and might incentivize their participation and foster or increase trust. *Related concepts: privacy, privacy tradeoff, data curation, local processing, choice, agency*
Digital Abilities	The ability to successfully transfer personal data to a data recipient. Data donation is a process that requires labor and effort, being aware of data regulations, and having digital skills to navigate various systems and platforms. *Related concepts: regulatory awareness, digital literacy, digital skills, donation effort, labor.*
Solidarity and Expectations	When contributing to a data donation project, data donors exert solidarity, recognizing sameness or similarity to a specific project or context that is relevant to them. In doing so, they have expectations; not of reciprocity but of recognition, empowerment, knowledge, or some type of benefit that derives from research. *Related concepts: relevance, needs, value-gain, expectations, benefits, empowerment.*
Data	
Sensitivity	Donated data are not in the public domain or public data. They are private data at the individual level and include potentially sensitive information about an individual, their social relationships, and interactions. They have unknown elements. *Related concepts: non-public data, intimacy, invasive data, obscure data, relational data.*
Structure and Richness	Donated data are personal, retrospective, and vast. They contain meaningful information not available otherwise. They are often presented in multiple formats, and well structured – the structure is determined by the data controllers. They can be duplicated and used in multiple instances. *Related concepts: structured rich data, data multiplicity, existing data, retrospective data, dynamic data, timestamped data, structured data, data form, data format.*
Transaction of Data	
Relationality	Data donations are relational by nature. They are complete once they have been received. Thus, they strengthen or change the donor's relationship to the person or entity that they donate something to, and vice versa. *Related concepts: participation, relational data, trust, expectations.*
Participation	Donors participate actively and directly in scientific research by donating their data. Their participation is mainly contributory, they contribute with the donated data and further contribute with other types of personal information and annotations.

	Related concepts: participation, data annotation, data contextualization.
Informed Consent	Voluntarily participating in research with sufficient understanding. Due to the opaque and sensitive nature of the data, it is one of the biggest challenges in data donation. Data donors need support in better understanding their data and what the implications are. *Related concepts: truly informed consent, consent, intent, understanding data, awareness, data curation.*
Data Recipients	
Research Project	
Participation Compliance	The willingness to participate in a study and to follow the requirements related to participation. In data donation, these normally include requesting a copy of the data from a data controller and uploading it. Compliance is low in data donation and might lead to sample bias. To increase compliance, some researchers use monetary incentives. *Related concepts: participation, willingness, sample bias, monetary incentives.*
Sensitive Datasets	The non-public individual data that results from data donation is of a more private or sensitive nature than public and open data. For this reason, they should be treated differently than FAIR and open datasets. They are often kept secure or deleted after the research concludes. *Related concepts: security, sensitivity*
Data Minimization	The personal data available through data donation is so rich that ought to be minimized, by only using what is necessary to answer a specific research question. This is not so easy with research contexts that are open-ended and exploratory. Related concepts: rich data, retrospective data, open-endedness, data multiplicity.
Data Misuse	Since data can be copied, duplicated, and used indefinitely it is important to set limits on the (future) use of a dataset and avoid using it for a purpose donors did not consented to. Related concepts: future use, open-endedness, data multiplicity.
Exchange of Information	
Transparency	To open and ethically communicate about the specific context of the data donation. Including the purposes for which the data is requested, how the data will be collected and handled, and the insights gained from the data that may be relevant to donors. It can foster or increase trust. *Related concepts: transparency, communication, accountability, ethics, return of information, understanding purpose, trust.*
Direct Communication	Data recipients are in direct contact with data donors as they communicate the research goal and directly receive data donations. *Related concepts: transparency, trust, communication, accountability, ethics.*