## Appendix D: Examples of requirements in participants’ own words

*“Identifiable health data is shared with the person’s circle of care… to support integrated, team-based care and the best diagnosis and treatment possible based on comprehensive data; to avoid harms to the patient from not sharing.”*

*“It is important for health data to be stored by a conscious entity with a clear mandate. Individuals with a role in collecting, capturing, coding and analyzing the data need to ensure confidentiality and be accountable both during their appointment and after they have left their post. Each person collaborating needs to understand their role and be conscious when accessing the data.”*

*“The public (patients, and patient advocates) should be consulted and included in discussion about privacy and security concerns related to the collection and use of health data. Trust for safeguarding the privacy and security of our health data is low… we need to be reassured that data gathering is really in the best interest of us all.”*

*“That data security be a priority. Participants must be convinced that every effort is made to ensure the confidentiality and security of their data… for a number of years, we have been confronted with fraudulent attacks of all kinds. This situation limits our desire to share our personal and sensitive information.”*

*“No sharing of data without the consent of the person in question: this is essential so that data are used for research purposes, the understanding of certain phenomena and in the best interest of the people who shared their data and not for commercial purposes or without their consent.”*

*“[There is] no possibility of connecting to the individual. Only an individual can manage their health record. If data are used, they must be free of personal information.”*

*“Nowadays, everyone is very aware of the importance of shared data being safe, and the adoption/authorization to share our data is usually dependent on the perception of security. It’s also essential because health data by definition are very personal.”*

*“No personal data must be provided, except where access is provided to a previously accredited care provider or services for the purpose of providing care and services expressly authorized by the patient.”*

*“Personal health data must be held in the strictest confidence, through measures such as access conditions, use conditions, and transparency of access policies and procedures, and ethics agreements. Data control to protect confidential info should have a legal basis.”*

*“Sharing anonymized data… is the only way for patients to be sure that their name cannot be linked to their personal data. It will also be necessary to demonstrate/prove that the data are truly anonymized. Social acceptability always starts with the individual, with the patient… the rest is the ‘sale’ of benefits.”*

*“The use, sharing and reuse of health data results in benefits for communities […] – from a common sense perspective, to improve the efficiency of the services offered by the health network.”*

*“Due to the nature of health data, the information could contain personal or easily identifiable information. For an entity to gain a social licence to use these data, a robust secure holding centre or data bank should be one of the top priorities.”*

*“It is easy to make assumptions that can cause harm based on data, for example Indigenous people have a higher instance of diabetes, without taking into account the effects of racism and colonialism.”*

*“People need to trust the data is being collected properly, secured, and used appropriately. Not industry/university/or government but an independent body accountable to patients/professionals and those bodies.”*

*“We have a diverse population but it [is] not represented. Reach out to low income, marginalized, other cultures. Go where they are, by connecting to a community leader and starting the partnership there.”*

*“Access on a consistent basis to federal Indigenous data e.g., Non-Insured Health Benefits, Indigenous Services Canada… this data would be useful for both reserve and off-reserve health centres so it could [be] analyzed according to their needs.”*

*“Access logging – to build confidence that only the right professionals have access to our health data.”*

*“Benefits for patients and society… data can help improve existing treatments and develop new ones, as well as improve health system management.”*

*“My first point of view is that the project must be very well defined at the outset with the aims and objectives and to which clientele the data collection is intended and for what purpose. This is essential in order to define the primary intent and to ensure that the elements related to it are circumscribed.”*

*“Healthcare team members have a fiduciary duty to patients. To instill trust, open and transparency of all derived health data from the patient is required to be provided to patients in machine readable format.”*