Category	Barrier		Definition
TECHNICAL These barriers for the most part are well understood as part of resilient challenges in health information system capacity and continue to form a major obstacle to the availability and use of public health data. Solutions to these barriers have been identified but sustainable implementation and political/financial commitment have been limited.	B-1	Data not collected	As long as severe limitations persist in public health data collection, data sharing will not be considered a priority. The WHO Health Metrics Network, the CDC/USAID Data for Decision Making project (DDM) and other agencies have found significant gaps in public health data systems, in particular in low- and middle income countries. Disease surveillance systems in many countries cannot meet standards set by the 2005 International Health Regulations. Civil registration systems in many countries are lacking as well.
	B-2	Data not preserved	public health data are often collected for short-term purposes such as outbreak detection. Data preservation or archiving is often not prioritized, especially in situations of limited capacity and resources
	B-3	Data not found	Even if data have been preserved, data retrieval systems may be lacking. This is amplified by relocation of offices, staff turnover, physical damage to paper or electronic files, computer viruses, computer theft, etc.
	B-4	Language barrier	Routinely collected public health data are often recorded in local languages, limiting the possibility to integrate and use such data together with other data sets, particularly in an international context.
	B-5	Restrictive data format	Despite major advances in computational resources in public health, a large volume of public health data such as disease surveillance data and administrative data continue to be collected and preserved in hardcopy paper format or in electronic format that may be antiquated or incompatible with modern software systems.
	B-6	Technical solutions not available	Technical software solutions to collect, harmonize (transformation and recoding to enhance inter-operability), integrate (combining harmonized datasets), and share complex and heterogeneous data have been developed in the private or research sector, but have not become widely available to public health agencies.
	B-7	Lack of metadata standards	Oftentimes, metadata that describe data content, origin, methods, etc. are lacking for public health data and standards for data format, variables, and metadata are insufficiently used, limiting secondary data use and interoperability. Some advances have been made through the development of the International Classification of Diseases (ICD), the Data Documentation Initiative (DDI) and the Standard Data and Metadata eXchange (SDMX). These standards are not always used efficiently however. For example, between 1950 and 2010, up to 20% of deaths in certain countries were attributed to ill-defined ICD codes.
MOTIVATIONAL These include barriers based on personal or institutional motivations and beliefs that limit data sharing. Solutions for this group of barriers lie in building trust or develop- ing transparent legal agreements.	B-8	No incentives	Data sharing requires time and resources that are chronically lacking in public health settings. Personal and institutional incentives are often required to prioritize data sharing over other pressing duties, particularly if the benefit of data sharing is delayed and uncertain (e.g. possibly more efficient disease control programs) instead of immediately relevant to data providers (e.g. scientific credit or training).
	B-9	Opportunity cost	Public health officers who have invested time and effort in data collection could anticipate that scientific credit or other opportunities may be lost if data recipients with greater capacity for analysis could gain the majority of credit. This is a particular challenge in low resource settings.
	B-10	Possible criticism	Data providers could be discredited by errors found during secondary use of their data and disease control efforts may be criticized if data would reveal continued disease occurrence. In the worst case, data sharing could reveal data fabrication or manipulation. For example, studies have shown over-reporting of vaccine coverage by country statistics compared to independent surveys after introduction of GAVI incentive funding for vaccination programs.
	B-11	Disagreement on data use	Disagreement on data use. Data providers may disagree with the intended secondary use of their data or may consider their data inappropriate for a certain use.
ECONOMIC These barriers concern the potential and real cost of data sharing and solutions depend on the recognition of data value and on sustainable financing mechanisms.	B-12	Possible economic damage	Data sharing in public health is challenged by the economic damage that this may cause to data providers. Public sharing of disease outbreak data, for example, can result in economic damage due to reduced tourism and trade. The global SARS outbreak led to estimated economic losses of 50 billion USD between 1998 and 2004 and Foot & Mouth Disease in the UK resulted in losses of 30 billion USD between 1998 and 2003. The possibility of such significant economic implications due to (over) reactive market forces could cause great reluctance among health agencies to rapidly release disease data.
	B-13	Lack of resources	The process of data sharing requires human and technical resources for data preparation, annotation, communication with recipients, computer equipment, internet connectivity, etc. These resources are frequently lacking in public sector agencies under economic pressure or in low income settings.
POLITICAL These are fundamental structural barriers embedded in the public health governance system that are grounded in a political or socio-cultural context. Solutions for these barriers are not clear-cut and will require global and national processes to build consensus and political will.	B-14	Lack of trust	Trust between a data provider and user greatly enables data sharing. In the absence of trust, providers could anticipate potential misinterpretation, misuse or intentional abuse of the data. For example the Indonesian government refused to share H5N1 influenza samples with the international community during the 2007 pandemic due to lack of trust on the potential use of these samples for financial gain. Legal arrangements were required in the absence of a trust relationship which led to the development of the Pandemic Influenza Preparedness Framework.
	B-15	Restrictive policies	Agencies may have developed official policy guidelines that restrict data sharing, resulting from various possible underlying factors such as a general sense of distrust, negative prior experiences, or other factors.
	B-16	Lack of guidelines	Frequently, official guidelines on data sharing simply do not exist, are unclear or inconsistent. The balance between making data accessible, safeguarding privacy, and protecting intellectual, time and financial investments by public health staff is often not well regulated or standardized, resulting in protective policies on sharing of public health data in general.
LEGAL These barriers are legal instruments used to restrict data sharing, resulting from the underlying willingness (or not) to share data. Solutions to this group of barriers include legal instruments to facilitate data sharing and are highly dependent on solutions to underlying political barriers.	B-17	Ownership and copyright	Ownership and copyright. Agencies that collect public health data are often responsible for the protection of individual and community privacy and may feel that a guardianship or ownership role is bestowed on them by the public. This could result in a default of restricting access to most data. Copyright can be used to restrict rather than expand access to data. In practice, it is often not well documented or known who owns public health data, resulting in inconsistent ad-hoc guidelines. For example a project in Canada to integrate National Population Health Survey data with provincial data required a different approval process in each province.
	B-18	Protection of privacy	Protection of privacy. Public health agencies have the mandate and authority to collect private data from the population governed by the Health Insurance Portability and Accountability Act (HIPAA) in the US or similar legislation in other countries. A clear distinction between data containing personal identifiers and fully anonymous data may not always be possible, leading to restrictive policies on all types of data due to privacy concerns. Aggregated data without personal identifiers may not be sufficiently detailed for certain applications. Existing tools and standards for the de-identification of personal identifiers such as statistical data masking may not be known or available in many contexts.
ETHICAL These are normative barriers involving conflicts between moral principles and values. Solutions for these barriers will involve a global dialogue among all stakeholders on the ethical principles that should govern data sharing.	B-19	Lack of proportionality	Lack of proportionality. The issue of proportionality, the careful deliberation in assessing the risks and benefits that derive from the amount and type of data requested compared to the potential impact of its secondary use, has been identified as a guiding ethical principle for public health data sharing. Public health agencies may disagree with data requestors about the proportional risks and benefits of the secondary use of data and its impact on public health.
	B-20	Lack of recoprocity	Lack of reciprocity. Data sharing practices have not always been fair, and data producers have often felt exploited in transactions where they receive little credit or benefit from their work, while data users that can rapidly analyze data and publish results benefit from academic credit and career advancement as has happened in the past.

Adapted from: van Panhuis WG, Paul P, Emerson C, et al., A systematic review of barriers to data sharing in public health. BMC Public Health. 2014;14(1):1-9.

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