

PANDORA & ALERRT Data Sharing Principles – Final version, approved 19MAR19

PANDORA and ALERRT are discrete, synergistic, global research partnerships addressing priority research questions for emerging infectious diseases in sub-Saharan Africa. The partners that comprise these consortia generate evidence to better characterise, treat and respond to infectious diseases with epidemic potential within sub-Saharan Africa.

PANDORA and ALERRT recognise that sharing research data has the potential to advance scientific and public health aims. To this end, and given that similar challenges may be encountered by both networks, the consortia have developed the principles below to guide data-sharing practice that optimises the positive impact on health and research in sub-Saharan Africa.

While there is no internationally accepted policy framework to govern data sharing, discussions and reflection by ALERRT partners, PANDORA partners and the EDCTP Networks of Excellence during the ICREID meeting in Addis Ababa (March 2018) and the EDCTP Forum in Lisbon (September 2018), have produced a draft set of data sharing principles. These draft principles were developed to align with other recognised data sharing principles such as FAIR(1), FREE FAIRER(2), and those developed by GloPID-R(3), the Expert Advisory Group on Data Access(4) and the ICSU World Data Systems(5). The draft principles were circulated amongst ALERRT and PANDORA governing bodies for feedback in Q4 2018 and Q1 2019. Feedback from this circulation has been incorporated in the revision below for the consideration of each consortium.

The draft principles are as follows:

1. **Fairness** – Data access policies should recognize and protect the interests of those who generate the data and promote their collaboration in the use of available data.
2. **Ethical** - Data should be shared in a manner that protects the rights and privacy of individuals, communities and countries where the data originates. Data access mechanisms should have appropriate clearance from all responsible research ethics bodies.
3. **Equity** – Data should be accessed for research relevant to the regions of data origin, either by addressing priority knowledge gaps or by contributing to research capacity.
4. **Quality** – The highest possible level of data accuracy, consistency and completeness should be ensured in advance of making data accessible. Where quality assurance limits exist, for example in the rapid sharing of outbreak data, as much information as possible regarding data quality should be made transparent and data should be used accordingly.
5. **Usability** – Data and associated meta-data should be shared in a format that enables discoverability, interoperability and reuse. Limitations on data access should be imposed only with appropriate justification (e.g. ‘sensitive’ or ‘restricted’ data), and should in any event be made available for use on the least restrictive basis possible.
6. **Transparency** – Data access and data use should be transparent with respect to governance, terms of access, decisions on requests for access, and reporting of secondary research outputs.
7. **Timely** – Data should be made available upon publication of manuscripts which report on their analysis. In the context of an active public health emergency, data should be

made available as soon as possible, but without jeopardizing the scientific integrity and therefore the social value of the research, in compliance with the other principles, and according to the terms of relevant stakeholder policies.

PANDORA and ALERRT have agreed to abide by these principles in the formulation of their policies and in their practices.

References:

1. The FAIR Guiding Principles for scientific data management and stewardship | Scientific Data [Internet]. [cited 2018 Dec 21]. Available from: <https://www.nature.com/articles/sdata201618>
2. Data sharing in public health emergencies: A study of current policies, practices and infrastructure supporting the sharing of data to prevent and respond to epidemic and pandemic threats [Internet]. [cited 2018 Dec 21]. Available from: https://wellcome.figshare.com/articles/Data_sharing_in_public_health_emergencies_A_study_of_current_policies_practices_and_infrastructure_supporting_the_sharing_of_data_to_prevent_and_respond_to_epidemic_and_pandemic_threats/5897608
3. Data Sharing – GloPID-R [Internet]. [cited 2018 Dec 21]. Available from: <https://www.glopid-r.org/our-work/data-sharing/>
4. Expert Advisory Group on Data Access | Wellcome [Internet]. [cited 2018 Dec 21]. Available from: <https://wellcome.ac.uk/what-we-do/our-work/expert-advisory-group-data-access>
5. Data Sharing Principles — World Data System: Trusted Data Services for Global Science [Internet]. [cited 2019 Jan 14]. Available from: <https://www.icsu-wds.org/services/data-sharing-principles>