

D U C H E N N E F A I R D A T A DECLARATION

1. Patient derived or provided data are not owned by those who collect them, and their reuse should be primarily controlled by the donors of these data. Researchers, charities, companies and health professionals are custodians.
2. To enable the optimal reuse of data, the data needs to be Findable, Accessible, Interoperable and Reusable (i.e. FAIR) by medical professionals, patients and in particular also by machines.
3. The optimal reuse of data should be supported at all levels, by professionals and custodians (allow federated learning on the data upon request, give the data to the donor in FAIR format when asked), care professionals (capture data at the source in FAIR format wherever possible), analytics environments (adapt to FAIR data) and regulators (demand FAIR data throughout and optimally use them in the regulatory process). There is a need to educate all stakeholders about the FAIR principles and their importance ('FAIR Aware')
4. Optimal care should be taken to restrict the need to reveal the actual identity of individuals associated with certain data, and to protect privacy with all possible means, but we realize privacy is subordinate in many cases to fast-tracking of better solutions for the diseases we suffer from.
5. Therefore, the right to allow identification of the individual associated with certain data should also be placed in the hands of that individual or a chosen trusted party.
6. Techniques and tools should be developed to enable optimal co-investigation by researchers, medical and health care professionals, charities, companies, patients and machines to form a 'social health machine' aimed at better solutions and care.
7. Regulators should optimally enable fast-tracking of key interventions and involve citizen and machine participation in that process to the largest possible extent.
8. The field should actively discourage publishing of health-related information exclusively in classical narrative journals. These are very difficult to access and understand by both informed lay people and by machines. Instead, data and information should be published in a way that makes it more readily reusable by others than a small inner circle.
9. Funding agencies should have good data stewardship following the FAIR principles included in their grant conditions.
10. The role of health insurance institutions/companies should also be made clear: they should publicly state that having full access to real world data, even when these are re-identifiable for them to 'their' clients, will not be abused, such as for example increase premiums based on genetic predisposition.
11. Health insurance institutions/companies and governments should join forces and support (also financially) the development of trusted environments where real world citizen data can be maximally reused for the betterment of health care and the massive saving of costs to keep optimal healthcare affordable for all.

