

EULAR: Points to consider when using 'big data'

1. April 2020, Kilchberg, Switzerland – The European League Against Rheumatism, EULAR, showcases its points to consider when using big data and computer-aided research methods in rheumatic and musculoskeletal diseases.

The points were first shared online in 2019, and have now been published in the *Annals of Rheumatic Diseases*. The points are intended to provide a framework for rheumatologists, health professionals, patients and other stakeholders about how best to use big data and artificial intelligence to help answer important research questions.

'Big data' is an emerging concept that refers to the sheer size and complexity of modern data sets – and as a result the need to analyse them with computer-based methods or models, rather than by hand. Big data may come from a variety of sources – including electronic health records, insurance databases, molecular research, or online data networks and repositories. The use of big data in medical research has enormous potential, but so far there have been no academic consensus guidelines on how it should be used.

One of EULAR's key strategic objectives is to advance high-quality research and improve care for people living with rheumatic and musculoskeletal diseases. As such, the society has taken a great interest in big data, and has developed a set of points to consider when collecting, analysing and using these kinds of datasets. Based on a systematic literature review and expert opinion, an international, multidisciplinary task force comprising healthcare professionals, data scientists and patients was set up by EULAR. This task force has formulated three overarching principles and 10 points to consider. They also propose a definition of terms and a research agenda to help move the field forward.

Definitions:

- 'Big data' refers to extremely large datasets which may be complex, multidimensional, unstructured and from heterogeneous sources, and which accumulate rapidly.
- Big data may arise from multiple data sources including clinical, biological, social and environmental data sources.
- Computational technologies, including artificial intelligence (eg, machine learning), are often applied to big data.

The three overarching principles are:

1. For all big data use, ethical issues related to privacy, confidentiality, identity and transparency are key principles to consider.
2. Big data provides unprecedented opportunities to deliver transformative discoveries in research and practice.
3. The ultimate goal of using big data is to improve the health, lives and care of people including health promotion and assessment, prevention, diagnosis, treatment and monitoring of disease.

The 10 points to consider cover various aspects of data collection and analysis, as well as highlighting considerations around data privacy and the need for careful interpretation and implementation.

(Note: Indications of strength for each point follow the Oxford Levels of Evidence. Strength A indicates the highest levels of evidence from trials; Strength B indicates somewhat lower levels of evidence from trials with higher risk of bias; Strength D indicates points based primarily on expert opinion.)

1. The use of global, harmonised and comprehensive standards should be promoted to facilitate interoperability of big data. (C)
2. Big data should be Findable, Accessible, Interoperable and Reusable (FAIR principle). (D)
3. Open data platforms should be preferred for big data related to rheumatic and musculoskeletal diseases. (D)

4. Privacy by design must be applied to the collection, processing, storage, analysis and interpretation of big data. (C)
5. The collection, processing, storage, analysis and interpretation of big data should be underpinned by interdisciplinary collaboration, including biomedical/health/life scientists, computational and/or data scientists, relevant clinicians/health professionals and patients. (C)
6. The methods used to analyse big data must be reported explicitly and transparently in scientific publications. (C)
7. Benchmarking of computational methods for big data used in RMD research should be encouraged. (D)
8. Before implementation, conclusions and/or models drawn from big data should be independently validated. (C)
9. Researchers using big data should proactively consider the implementation of findings in clinical practice. (D)
10. Interdisciplinary training on big data methods in RMDs for clinicians/health professionals/health and life scientists and data scientists must be encouraged. (D)

These new EULAR points to consider discuss important ethical considerations and terminology, and provide a framework for the use of big data in real-life clinical scenarios. Based on the low level of evidence available, it was not possible to develop full recommendations, and the work has been presented instead as 'points to consider'. It is expected that this new field will continue to grow rapidly in the coming years, and an update to full recommendations will be possible in the future.

Sources

Gossec L, et al. *Ann Rheum Dis* 2020;**79**:69–76.

About EULAR

The European League against Rheumatism (EULAR) is the European umbrella organisation representing scientific societies, health professional associations and organisations for people with rheumatic and musculoskeletal diseases (RMDs). EULAR aims to reduce the burden of RMDs on individuals and society and to improve the treatment, prevention and rehabilitation of RMDs. To this end, EULAR fosters excellence in education and research in the field of rheumatology. It promotes the translation of research advances into daily care and fights for the recognition of the needs of people with RMDs by the EU institutions through advocacy action.

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Notes to Editors

EULAR Recommendations: https://www.eular.org/recommendations_home.cfm

EULAR Strategy: https://www.eular.org/eular_strategy_2018.cfm

EULAR School: <https://esor.eular.org/>

EULAR Campaign: https://www.eular.org/eular_campaign.cfm

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