Big Data 4 Better Hearts - Sofia ref.: 116074

Reporting

Project Information

BigData Heart

Grant agreement ID: 116074

[Project website ↗]

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10.3030/116074 ↗

[Project closed]

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28 February 2023

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SOCIETAL CHALLENGES - Health, demographic change and well-being

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EU contribution
€ 9 664 970,00

Coordinated by
UNIVERSITAIR MEDISCH CENTRUM UTRECHT
🇳🇱 Netherlands

Periodic Reporting for period 6 - BigData Heart (Big Data 4 Better Hearts - Sofia ref.: 116074)

Reporting period: 2022-03-01 to 2023-02-28

Summary of the context and overall objectives of the project ⌄

Launched in March 2017, BigData@Heart was a six-year project involving patient networks, learned societies, SMEs, pharmaceutical companies, and academia. The project aimed to tackle the evolving healthcare landscape in Europe, which faces challenges to the sustainability and quality of healthcare provision. The combination of demographic change and rapid innovation has led to inconsistent

medical care across the continent.

Despite significant advancements in managing prevalent cardiovascular diseases (CVDs) such as acute coronary syndrome (ACS), atrial fibrillation (AF), and heart failure (HF), their burden remains substantial. These conditions are complex, with unclear molecular definitions and the added challenge of co-existing morbidities. Consequently, interindividual therapeutic responses vary greatly, prognoses are heterogeneous, and treatment guidelines rely on conventional risk factors and clinical markers of organ damage. These barriers hinder the development and delivery of targeted CVD treatments.

BigData@Heart aimed to leverage big data approaches to improve patient outcomes in ACS, AF, and HF. By bringing together key stakeholders in the CVD field, the project strives to overcome the aforementioned challenges.

Work performed from the beginning of the project to the end of the period covered by the report and main results achieved so far ⌄

The BigData@Heart consortium has achieved significant milestones. This text outlines the accomplishments made by the consortium in various areas of research.

Standardized Disease Definitions and Outcome Sets for AF:
The consortium successfully established a globally agreed AF Standard Set of Outcomes, accompanied by electronic health record codes for all variables. This groundbreaking development enables consistent measurement and comparison of critical outcomes across countries. To facilitate the implementation of this set, a framework for designing and reporting studies using coded EHR data has been thoughtfully developed and published with the input of key stakeholders from industry, journal editors, regulators, HTA, and patients. (https://doi.org/10.1136/bmj-2021-069048 ⬈)

Expanded Data Sources and Phenotype Discoveries:
In addition to standardized disease definitions (https://doi.org/10.1093/eurheartj/ehz871 ⬈ and https://www.jacc.org/doi/10.1016/j.jchf.2019.09.007 ⬈) they have made remarkable new phenotype discoveries, as evident in the following publications:
https://doi.org/10.1016/S0140-6736(21)01638-X ⬈
https://doi.org/10.1002/ejhf.2169 ⬈
https://doi.org/10.1101/2022.06.27.22276961 ⬈

Mapping and Curating Data Sources:
The consortium conducted comprehensive mapping workshops with data owners, successfully mapping the CALIBER and ABUCASIS datasets to the OMOP data model. The EMIF catalogue at emif-catalogue.eu has been enriched with real-world data sources for HF, ACS, and AF, ensuring researchers have access to a diverse range of relevant information. The curated EHR phenotypes available in the open-access CALIBER Portal have been extensively utilized by 40 international research groups in 61 publications. (Link: doi.org/10.1093/jamia/ocz105)

Omics Enrichment:

The consortium established a dedicated HF phenotype group to develop validated definitions of disease outcomes and relevant covariates for HF. An enrichment project in collaboration with industry partner SomaLogic and the third party Erasmus University of Rotterdam was conducted, resulting in a published paper with several others submitted.

Exploration of Wearable Data:

The consortium delved into the promising area of wearable data, exploring new possibilities for cardiovascular research and disease monitoring. Their findings are documented in the following publications:

https://doi.org/10.1093/eurheartj/ehab098 ↗

https://doi.org/10.1001/jama.2020.23138 ↗

Communication of Results and Guidance Documents:

The consortium actively engaged in conferences, published external newsletters, and maintained a vibrant social media presence. Interviews with key scientific leads were shared, and webinars were organized to communicate results. The consortium's work resulted in over 103 peer-reviewed articles being published.

Ethics, Legal, and Data Privacy:

The consortium demonstrated their dedication to improving patient engagement and public trust by actively working on ethical and legal aspects. Their efforts are reflected in the following publications:

https://doi.org/10.1186/s12910-019-0359-9 ↗

https://doi.org/10.1136/medethics-2019-105651 ↗

https://doi.org/10.1186/s12910-021-00677-5 ↗

Progress beyond the state of the art and expected potential impact (including the socio-economic impact and the wider societal implications of the project so far) ⌄

The BigData@Heart consortium has made significant strides in advancing Real-World Evidence (RWE) research by proposing a comprehensive new research guideline. This guideline has been co-published in three reputable journals and has been added as a reporting standard to the prestigious EQUATOR network, providing a solid foundation for future study designs and publications. (Link: https://doi.org/10.1136/bmj-2021-069048 ↗)

One of the major accomplishments of the consortium is the establishment of standardized disease definitions for heart failure (HF) and atrial fibrillation (AF). This critical development ensures consistency and accuracy in data interpretation across various studies.

Furthermore, the consortium successfully converted large databases into a common data model known as OMOP, which facilitates data harmonization and comparability. Additionally, they explored

innovative methods like federated data analysis, resulting in novel approaches for cardiovascular research. Researchers conducting future studies can now leverage these standardized datasets and methodologies, promoting collaboration and accelerating research progress.

Next to improved access to RWE databases the consortium has contributed to the discovery of new phenotypes, enriching the understanding of various health conditions. Moreover, the consortium has made considerable strides in exploring the utilization of wearable data, paving the way for innovative research opportunities.

Importantly, the consortium has also emphasized the need for enhanced patient engagement and public trust. Their published work in this area serves as a crucial step in fostering stronger connections between researchers, patients, and the wider public, ultimately leading to more meaningful and impactful research outcomes.

In conclusion, the BigData@Heart consortium's pioneering efforts in disease understanding, outcomes definition, developing research guidelines, implementing novel data analysis methods, and improving patient engagement have contributed to the advancements of cardiovascular research. Their achievements will shape the future of RWE studies, benefiting both researchers and patients alike.

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