



Decentralizing oncology research in the fields of Human and Social Sciences (SHS) and Quality Of Life (QOL): the WeShare program

Sibille Everhard¹, Maria Alice Franzi², Florence Joly³, Roman Rouzier³, François Garnier³, Sylvain Besle⁴, Véronique Christophe⁴, Etienne Minvielle⁵, Guillemette Jacob⁶, Marie Préau^{6,7}, Sandrine Dabakuyo⁸, Francis Guillemin⁸, Gwenn Menvielle², Cyrille Delpierre⁹, Olivier Aromatario¹⁰, Stephane Chaillou², Aloïs Trochard³, Hugo Crochet⁴, Benoit Couvois¹, Mathilde Bouvier¹, Guillaume Gary-Bobo¹, Pauline Crepel¹, Mathieu Robain¹, Anne-Laure Martin¹, Ines Vaz Luis²

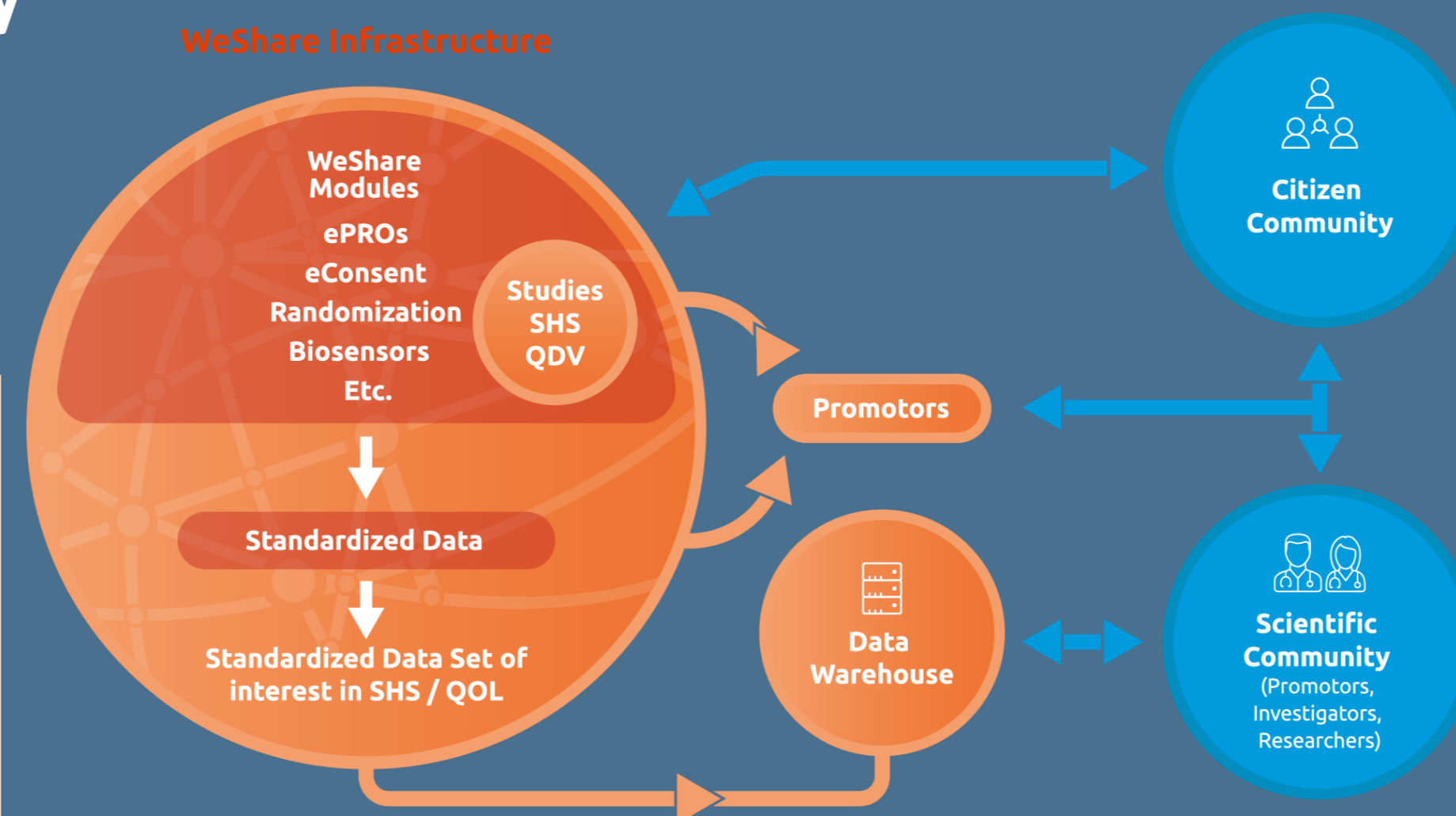
1 Unicancer, 2 Gustave Roussy, 3 Centre François Baclesse, 4 Centre Léon Bérard, 5 Ecole Polytechnique, 6 Associations Seintinelles, 7 Université Lyon 2, 8 Plateforme Nationale Qualité de Vie et Cancer, 9 CERPOP, UMR1295 Inserm, Université Toulouse III, 10 Université de Bordeaux, INSERM, BPH, U1219, Mérisp/PHARES

Introduction

Oncology research faces many challenges including elevated costs, burden, lack of diversity and inclusion, lack of focus on patient-centered research questions and co-design. WeShare "Web-based Exploitation of Social and Human sciences to Advance cancer Research" is a digital infrastructure program for decentralized oncology research with a focus on accelerating Human and Social Sciences (SHS) and Quality of Life (QOL) research.

Methodology

The WeShare program aims to: 1) facilitate the implementation of research in oncology through making available digital tools for decentralized research (e.g. e-consent, randomization, ePROs, wearables, automated collection of clinical data), 2) create a health data warehouse for secondary research purposes, 3) create and empower online patient and researcher communities for research co-design in the field of SHS and QOL.



Coordination: Unicancer, Project PI: Dr Ines Vaz Luis, Gustave Roussy (Villejuif)

Partners: Gustave Roussy (Villejuif), Centre François Baclesse (Caen), Centre Léon Bérard (Lyon), École Polytechnique, the Seintinelles association and the Qualité de Vie et Cancer national program.

Funding: The WeShare infrastructure has been awarded a grant from the French government, managed by the Agence Nationale de la Recherche as part of the France 2030 investment program for the future. reference ESRE-0017.

Hosting: HDS AZ Network (France).

Results

The Exploration and Preparation phase assembled 100 stakeholders, organized around several working groups for 6 pilot studies (2 longitudinal cohort study, 1 cross-sectional survey, 3 randomized controlled studies). Qualitative evaluation and beta-testing allowed to identify and fix technical and ergonomic points. 2 studies were launched using the ePRO module. Diversity, inclusion, equity and co-design working groups were created to build associated digitally-enabled toolkits. Technology engagement features are being implemented to improve patient experience in research.

Conclusion

An ePRO module for clinical studies was co-created and is currently being implemented in pilot studies. Our ambition is to conduct the first 100% decentralized study via WeShare in 2024. This could facilitate and accelerate research in oncology, particularly in SHS and QOL, and will also bring benefits to patients, users and citizens.

Future modules in WeShare: digital tools for qualitative research (video functionality and automated transcription), application program interfaces for automatic collection of clinical data and remote data capture).

Information on the platform and its modules is available on the **WeShare website** <https://weshare.unicancer.com>

Contact us: weshare@unicancer.fr



Provide researchers with the technical tools (for quantitative and qualitative data collection, facilitate interventional research, study management) needed to properly conduct investigative research focused on quality of life, including research in social sciences and humanities applied to oncology.



Build a public, standardized data repository of patient-reported outcomes (PROs), clinical, behavioral and socioeconomic data that will allow the conduct of large-scale ancillary or secondary studies applied to oncology (using FAIR standards).



Advance and facilitate research in quality of life, social sciences and humanities applied to oncology, linking researchers to a community of patients and healthy individuals.

The development of the first WeShare modules, e-consent, randomization, ePRO, wearables, is being performed, following the Exploration, Preparation, Implementation, Sustainment (EPIS) framework :

- Exploration and preparation with: multidisciplinary working groups that co-created the ePRO module through iterative focus groups (FG) and interviews
- Implementation using pilot studies to formally evaluate Reach, Adoption and Satisfaction of the ePRO module using surveys and FG

