

NEWSLETTER

Let's FACILITATE



LET'S FACILITATE WEBINAR

Join us for the [Let's FACILITATE 2024 Webinar](#): an insightful overview and roundtable discussion of the [project](#) and its promising innovations to enable data return to clinical study participants. Do not miss this opportunity and save the date!

April 19, 2024
02:00PM-03:30PM CET

Let's FACILITATE Public Webinar

Maximizing the societal benefit and lasting impact of clinical trials

[Register here](#)



[Go to glossary](#)

GLOSSARY FOR PATIENT

To go-in-depth with FACILITATE, enter our [glossary](#), a new and useful tool to delve into the world of our [patient-centered](#) project. Use this selected list of words to better understand the meaning of some commonly used terms in clinical research and data sharing. Explore them to have an insight into the responsible return of [clinical trial data](#) to participants!




TRANSCCELERATE WEBINAR


Enabling Individual Participant Data Return (iPDR)

Prof Johanna Blom, IHI-FACILITATE Deputy Coordinator, has been invited to present the project and its implications in clinical trial data sharing scenario at the TransCelerate webinar on [Individual Participant Data Return \(iPDR\) Package](#), a comprehensive set of materials that provide general considerations to enable data return to clinical study participants. Join the event!


Featured Panelists:




Paula Boyles
External Clinical Trial Data Sharing Program Lead,
Pfizer




Angela Bilkhu
Global Patient Partnership Leader, Rare Blood Disorders,
Roche




Amy Fesmire-Baus
Associate Director, Patient Engagement and Recruitment Lead and Patient Advocate,
BMS





Sylvia Baedorf Kassis
Program Director,
Multi-Regional Clinical Trials Center of Brigham and Women's Hospital and Harvard



Johanna Blom
Professor of Psychobiology Pediatric & Behavioral Neuroscience, University of Modena, and Coordinator, IHI FACILITATE

 **March 28, 2024**

 **09:00AM to 10:00AM EST**



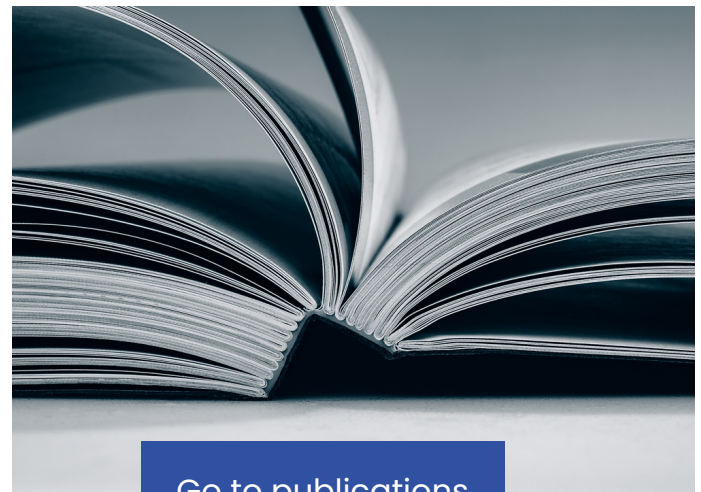
Scan QR code or [click here](#) to sign up.

TransCelerate webinars may be recorded in whole or in part.

[Register here](#)

PUBLICATION CORNER

FACILITATE carries on its dissemination mission with two publications on peer-reviewed journals. The first is a discrete choice experiment survey administered to a sample of residents in 12 European countries, investigating public preferences for digital health data sharing ([Biasotto et al. 2023](#)). The second explores the role of social alliance as fundamental for participatory clinical research, starting with initiative such as FACILITATE ([Blom et al. 2023](#)).



[Go to publications](#)

FOLLOW THE PROGRESS!

FACILITATE's challenging path in the return of clinical trial data involves meeting predetermined targets, established from the beginning of the project. Advancement in the various topics of FACILITATE patient-centered research and achievement of legal, ethical and technological outcomes are now available on our website, a witness to the project's progress. Enjoy your reading!



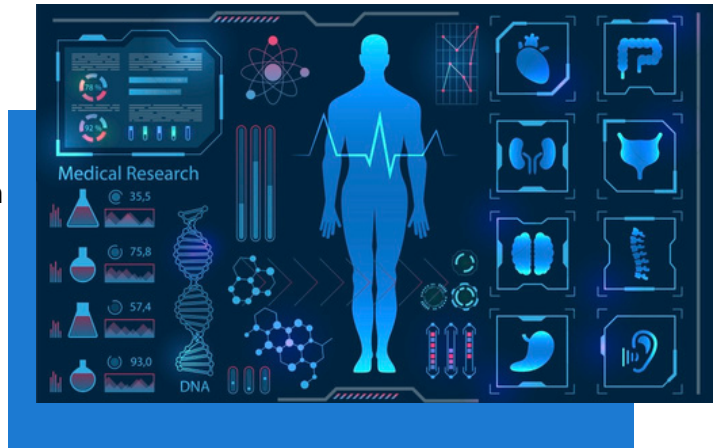
FACILITATE D3.1 - Report on the ethical frameworks

DOWNLOAD PDF

[Go to Deliverables](#)

THE TIME IS RIPE

On November 29, at the [Clinical Trials Europe 2023 meeting](#) held in Barcelona, FACILITATE made a significant contribution to this important annual gathering. Prof Johanna Blom, Deputy Coordinator of the project, delivered a compelling presentation titled "Patient Engagement from a Data and Ethical Perspective."



Her address delved into critical ethical considerations surrounding patient centricity in clinical trials, highlighting issues that hold paramount importance in the context of the IHI project, such as:

- developing a feedback mechanism that actively involves patients and recognizes them as crucial stakeholders within the clinical trial framework.

- gaining insights into the effectiveness of clinical trials from the viewpoint of the patients: what works and what fails.
- evaluating the ethical implications of the clinical trials community making decisions for patients, possibly overstepping their autonomy.

[Read more](#)

FACILITATE CONSORTIUM MEETS IN BORDEAUX

Two impactful days - 14 and 15 December 2023 - at the FACILITATE General Assembly were held in the lovely French city, filled with updates, workshops, discussions, and decisions that will shape our work ahead. Researchers highlighted the crucial role of communication and empowering individuals in the complex world of clinical trials, an essential topic for the FACILITATE consortium.

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