

Negotiation for patient-centric health data sharing in clinical research

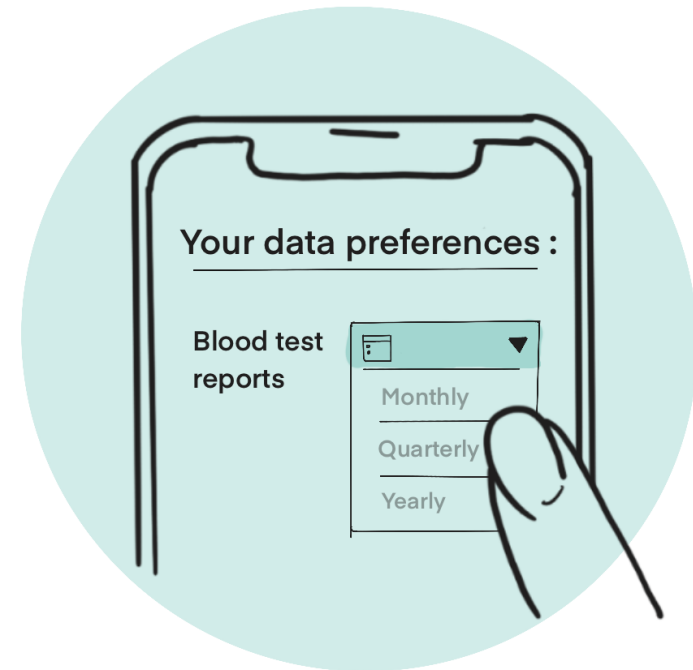
Lack of transparency is found to hinder health data sharing practices through data sharing platforms. Individuals lack adequate information regarding data use and control over their participation.

Negotiated Consent examines the role of mutual responsibility between individuals, data sharing platforms, and research industry in offering transparency to individuals for health data sharing in clinical research.

Individual choice to enroll is supported by information regarding data use and a negotiated control over data shared is offered.

"I feel like being offered a choice already informs me more.."

90% Individuals were found to prefer Negotiated Consent over current consent practice



Research industry takes on new responsibilities for a transparent practice of data processing by the platform.

Data sharing platforms can support clinical research practices through the use of Machine Learning, such that health data is shared in a secure and encrypted way.

NEGOTIATED CONSENT FORM

INFORM

LONG TERM EFFECTS OF ROUTINE MORPHINE INFUSION: EXAMINATION OF USE OF MORPHINE FOR THOSE IN CHRONIC PAIN (#IPY5436)*

- STUDY DETAILS** To evaluate detection thresholds, functioning of the HPA-axis and risk of chronic pain in adults between 25-40 years of age who experienced pain and received morphine in neonatal period.
- AFFILIATIONS** Dr. Leon Young, University of Health, Rotterdam
- DATA TO BE COLLECTED**
 - Blood test results (birth to present)
 - Follow up for 1 year (monthly/quarterly/yearly)
- DATA PROCESSING**
 - We process encrypted data and submit anonymised results to researchers.
 - Data processing is carried out through the use of privacy-preserving technology.
 - We adhere to GDPR compliance, click [here](#) for more information on our practice.
- RISKS**
 - Subjects aren't in any risk by participating in this study.
 - Data processing risks are evaluated in data management plan.

What do you think?

NEGOTIATE

PARTICIPATION PREFERENCES

RESEARCH BENEFITS

Monetary benefits :
I consent to -

E-TRANSFER VOUCHER DONATE

Research results :
I consent to -

FULL DISCLOSURE NOT INTERESTED

DATA PREFERENCES

Blood test results :
I consent to -

BIRTH TODAY

10 YEARS

Follow up visits for 1 year :
I consent to visits -

MONTHLY QUARTERLY YEARLY

REVIEW

CONSENT

STUDY DETAILS

DATA PROCESSING

YOUR PREFERENCES

I acknowledge that I have read the provided information about the research and understand the nature of my participation.

I CONSENT TO MY PARTICIPATION

* STUDY IS MADE FOR DEMONSTRATION PURPOSES AND DOES NOT REFLECT ANY CURRENT INDIVIDUAL OR INSTITUTE