

Data Privacy and Data Sharing in Clinical Trials



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The PHUSE Educate the General Population on Data Privacy and Data Sharing in Clinical Trials project, part of the Data Transparency Working Group, is producing short videos to enable the general public to better understand clinical studies, with a focus on data privacy and data sharing when participating in a clinical trial.

Two videos have already been published on YouTube:

Introduction: <https://youtu.be/UKZmYLygP-0>

Video 1: Importance of Clinical Trials: <https://youtu.be/LhSF7DZmwkc>

The videos are the first of their kind for the PHUSE Data Transparency Working Group. Five more videos are planned, where the team will be going into more detail. The goal is to help understand the use of data in clinical trials and create awareness around rights, policies and benefits. It can be challenging to explain such concepts, and any help in promoting or developing these videos would be much appreciated.

This PHUSE Community Forum is an open and flexible space to discuss ideas. It is an opportunity to provide your input on the distribution and dissemination of the videos. The focus of the event will be on a set of survey questions which have been distributed by PHUSE. If you haven't already, please fill out the survey to submit your feedback.

Following the Community Forum, post meeting discussions will take place on Disqus. This is a great opportunity to discuss your ideas further and provide feedback on the videos.

All information collected in the survey and in the Community Forum will be summarised and shared in the form of a PHUSE blog discussing how your feedback has helped shape the journey of creating the video series. Participants' personal details will remain anonymous. Your input will be extremely valuable in steering the direction of this project.

This Community Forum took place over Zoom on 21 February 2023. Please post any questions/comments on the Disqus forum below.

Catch up here!

This Community Forum took place 21 February 2023. Catch up by viewing the [recording](#).
Got a question for the presenters? Submit it to the online Disqus forum posted below!



Presenter

Bio



Devaki Thavarajah
Instem

Devaki Thavarajah, *Instem*

Devaki partners with pharmaceutical clients, members of the research and healthcare community globally to help meet their clinical trial transparency and disclosure requirements.



Deborah Collyar
Patient Advocates in Research (PAIR)

Deborah Collyar, *Founder and President, Patient Advocates in Research (PAIR)*

Deborah Collyar has been a leader in patient engagement and advocacy since her first cancer diagnosis. Her business leadership, IT, and communication skills bridge gaps between scientists, medical providers, and patients. Deborah founded the Patient Advocates in Research (PAIR) international communication network in 1996, "where research meets reality," and consults with health and medical research communities.

Deborah infuses patient representatives into projects and gathers relevant input from patients. Her work encompasses many diseases, programs and policies at grassroots, national and international levels with companies, academia, and governments. Key insights are delivered throughout development, clinical trials, results reporting, data-sharing, standards, transparency, and into practice.

Resources

[Video 0: Introduction](#)

[Video 1: Importance of Clinical Trials](#)

[PHUSE Data Privacy and Data Sharing in Clinical Trials – Video Dissemination Information Gathering Exercise](#)