

Educate the General Population on Data Privacy and Data Sharing



Project Scope

To create engaging content on data privacy and data sharing that can be understood and used by the general population (any member of the public regardless of their sector or profession) covering topics such as what is being done to share clinical trial data and information, where data goes and how it is used, what data privacy is, why it is needed, why it is important and the differences between mandatory vs. voluntary data sharing. The project is to follow a similar approach to the Data Transparency (DT) Terminology Harmonisation project, this time aiming towards a more general audience to address commonly asked questions surrounding data privacy and data sharing. The Terminology Harmonisation project creates an excellent set of deliverables better suited for those who work with data sharing on a more technical level.

Problem Statement

There is increasing interest among the general public in data privacy and sharing, and most publicly available information is targeted towards individuals with training/experience/expertise in these areas.

Problem Impact

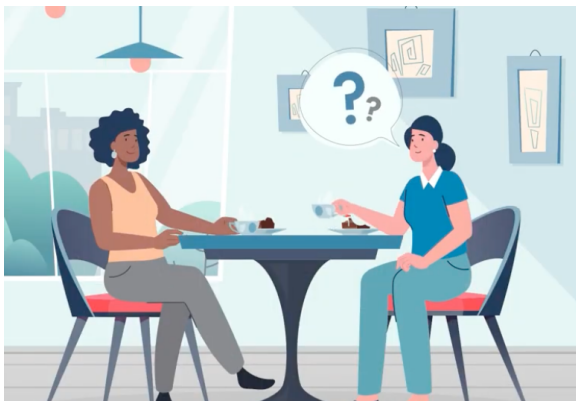
Accessible and understandable content will increase general public knowledge (and accuracy).

Project Leads		Email	Objectives & Deliverables	Timelines
Devaki Thavarajah, <i>Independent</i>		devaki.thavarajah@phuse.global	Write a script for 5 or 6 short videos, around 3 minutes each, to cover different aspects of data sharing, incorporating real-life examples (case studies) to help the audience see how it relates to daily situations. Develop infographics and/or narrative, depending on the content, in parallel with the video to provide context. The first video will be an introduction/high-level overview of clinical transparency and include an interactive element whereby the audience are asked to suggest what topics they would like us to address next	Q2 2024
Vicky Andrews, <i>PHUSE Senior Project coordinator</i>		vicky@phuse.global		
<div>CURRENT STATUS</div> Q2 2024				
<ul style="list-style-type: none">Project Team and Leadership approved publishing of Video 2: 'What Will I Receive and When Will I Receive It?'.Finalised Video 3: 'What is Clinical Data?' .Joint collaboration between PHUSE and The Multi-Regional Clinical Trials (MRCT) Center of Brigham Women's Hospital and Harvard for the creation of additional deliverables in the form of infographics to go alongside with our video series.Collaborative infographics finalised.			Potentially also create a 'lay summary' of some of the PHUSE DT Working Groups deliverables, to educate the general public on what we have done so far. At this current time, the summaries are an optional element of our project and we will see first how the main deliverables are progressing	Q2 2023
Video Resources			Collaborative Educational Resources by PHUSE and the MRCT C	

Data Privacy and Data Sharing in Clinical Trials – Introduction (Video 0)



Data Privacy and Data Sharing in Clinical Trials – Importance of Clinical Trials (Video 1)



Data Privacy and Data Sharing in Clinical Trials – What Will I Receive and When Will I Receive It? (Video 2)



A joint-collaboration between PHUSE and MRCT Center commenced in November 2023 for the creation of additional deliverables in the form of infographics to accompany the PHUSE video series. Collaborative infographics are almost finalised for the following topics:

- **Infographic #1:** 'Your Data, Your Information'
- **Infographic #2:** 'What Happens to Data During a Research Study?'
- **Infographic #3:** 'What Happens to Data After a Research Study?'
- **Infographic #4:** 'What is a Data Repository?'

