

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.

Project 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.

Project Impact

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

| Project Leads | Email |
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| Devaki Thavarajah (Industry) | devaki.thavarajah@gmail.com |
| Paula Rowley (PHUSE Project Assistant) | paula@phuse.global |

| Project Members | Organisation |
|------------------------|--------------------------------|
| Benjamin C Shim | Eli Lilly |
| Devaki Thavarajah | Industry |
| George Allan | Janssen Research & Development |
| Laila Albanna | Privacy Analytics |
| Mekhala Acharya | Takeda |
| Nathalie Jullian | UCB |
| Nicole Hinton | Ultrageynx |
| Rene Allard | Industry |
| Sarah Balay | Privacy Analytics |
| Sanjay Bagani | Xogene |
| Shannon Lefavre | Roche |
| Sherry Meeh | Janssen Research & Development |
| Sharon Niedecken | Pfizer |
| Sophia Zilber | Pfizer |
| Subhayan Das | BMS |
| Taniya Rade | Industry |
| Viveka Rydell-Anderson | Blockchains, Inc and Stanford |

| Objectives & Deliverables | Timelines |
|---|-----------|
| 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. | Q1 2022 |
| 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 2022 |

CURRENT STATUS Q3/4 2022

- Continue video and animation development work with vendor.
- Draft scripts to be completed and finalised for videos 2 to 6.

