28/09/2022

Guidance for UPD public guide and media pack on large datasets

Summary/overview of project

Understanding Patient Data (UPD), a programme based at the Wellcome Trust, has identified a lack of public awareness about the way large datasets are used in healthcare. This guide aims to address this topic.

Entitled **'What happens to health data: A guide to large datasets',** the guide is the result of collaboration between UPD, health data experts, and members of the public who contributed through workshops. It aims to explain key terms related to large datasets, contextualise the subject, and address core questions that are commonly posed by the public.

The guide is available under a creative commons license and we hope that it is useful to your organisation's outreach and communication work. It is hosted in its original format on the UPD site, but we encourage organisations to host it themselves, and also adapt and use it within the license however best suits their purposes.

We've created this media pack to aid your use of the guide.

Contents of pack:

1. The guide

2. Social media stills

3. Animations

4. Poster

1. The guide

The core resource is the guide itself. Although it is intended for public use, UPD is not a public-facing organisation and as such, we hope that other organisations will host it on their websites.

Location: https://understandingpatientdata.org.uk/sites/default/files/2022-09/What%20happens%20to%20health%20data%20-%20a%20guide%20to%20large%20datasets.pdf

Format: Interactive pdf

Audience: Professional and public

Contents:

- What health data is and why is it collected

- The potential benefits of large health datasets

- The potential harms of large health datasets

- How patients' privacy is protected

- Who can and cannot access health data

- How health data is stored in a secure way

- The future of large health datasets

- Where more information about health data can be found

How to use:

The main use of the guide is to communicate information on large health datasets to the public.

If you are a professional-facing body, this communication may be indirect. For example, healthcare professionals can use the guide to inform conversations with patients about health data, they may attach the guide to an email to a patient or direct patients to a website or digital platform where the guide is hosted.

If you are a public-facing organisation, this communication may be more direct, for example by hosting the guide in the relevant place on your website and sharing the guide directly with the public through your social media channels, newsletters or blog.

These are just a few examples of the way that the guide can be used. Both professional- and public-facing organisations are free to make use of the guide in any way that is most appropriate within the licence and to share it to network contacts for others to use.

2. Social media stills with suggested post text

To accompany the guide, and increase awareness of its publication, a suite of social media stills has been created. Each social media still is accompanied by suggested text for the social media post.

Location: Sent to you via email as part of the UPD pack

Format: PNG and PDF

Audience: Professional and public

Contents: 12 Twitter Cards

4 'explainers':

1. Why health data is collected

2. What is a large dataset

3. Large dataset factoid

4. Pseudonymisation

8 'teasers':

1. What is health data and why is it collected?

2. What are the potential benefits and harms of large datasets?

3. How is privacy protected in a large health dataset?

4. Who can and cannot access health data?

5. How can health data be stored in a secure way?

6. Where can I find out more about the use of health data?

7. What is a large health dataset?

8. Why can't health data always be completely anonymised?

How to use:

Social media stills 1- 4 are 'explainers', meaning they draw on information from the guide in a social media card and therefore can be used to address specific questions about large datasets.

Social media stills 5 – 12 are 'teasers' meaning they present the viewer with key questions that are answered in the guide.

It is very important to include a URL link to the guide in the post text (whether that is the link generated by your organisation should you host the guide, or the link to the guide on the UPD website). As it comes, the suggested post text has a 'Bitly' link to the guide on the UPD website, but this can be easily changed to your organisation's link on social media platforms.

3. Animations

A set of five animations have been created to help explain key topics from the guide in an engaging and direct way. The animations also encourage viewers to read more in the guide.

Location: Sent to you via email as part of the UPD pack

Format: MP4

Audience: Professional and public

Contents: 5 animations:

1. A health data journey
2. What are large datasets
3. What are the benefits and risks of large health datasets
4. Who can and cannot access health data
5. Why are large datasets created

How to use:

You may choose to upload the animations on your organisation's social media channels (such as Twitter or YouTube), include them in blog posts or newsletters, or use them on your website to explain key topics about large datasets.

As with the social media stills, it is very important that you include a URL link to the guide in the description of your post or the caption of the video.

4. Poster

The final supplementary material that we have created is a poster. This will be in a PDF format and can be printed to encourage viewers to visit the guide.

Location: Sent to you via email as part of the UPD pack

Format: PDF

Audience: Public

Content: 1 poster

- What do you need to know about large datasets?

How to use:

If your organisation is a stakeholder in public-facing spaces, such as a GP practice or a hospital, you may want to print and display this poster. The poster features questions about health data that are commonly posed by the public. It offers a QR code and URL link, which leads to the guide on the UPD website.

To ensure consistency in your communications, you may want to replace the URL link and QR code in the poster with your organisation's URL link to the guide (should you decide to host it). As the poster will be sent as a PDF, the URL link and QR code can be changed in Foxit or Adobe Acrobat.