

GDPR compliant reuse of medical data: encouraging patients to contribute to research (video)

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Introduction

Data acquired for clinical purposes are often unreachable for scientific research. The General Data Protection Regulation (GDPR) in the EU introduced new safeguards to ensure patient privacy, including the transparency principle that states that information about data protection should be easily accessible in a concise and clear way, using plain language.^{1,2,3} Patients are often unaware that they can become active participants in the scientific process by allowing the reuse of their medical data and that privacy protection rules guarantee safe data-sharing.

Having these challenges in mind, the European Cooperation in Science and Technology (COST) Action ‘Glioma MR Imaging 2.0’ (GliMR; glimr.eu) has developed an animation video that can be used to inform patients. GliMR is a network of clinicians, researchers and other stakeholders, that attempts to streamline and improve the diagnosis, prognosis, follow-up, and evaluation of treatment of brain tumours using advanced MRI techniques.⁴ Previously, a joint-initiative from GliMR and the Open Brain Consent resulted in the development of a GDPR-compliant template consent form and associated data user agreement.⁵ These templates are valuable tools to inform patients and healthy volunteers about data usage and sharing related privacy regulations, and facilitate the collection of consent. Unfortunately, patients are only exposed to this information when recruited specifically for scientific studies.

Therefore, GliMR released an animation video as a tool for communication towards patients, which can be used as part of the data protection strategy within hospitals and healthcare institutions across Europe.

Methods

The video was developed by the private video company, WellPlayed Video (Ghent, Belgium), supported by the expertise and feedback from researchers and clinicians from GliMR, a GDPR-specialist and hospital data protection officer, and patients assembled by the International Brain Tumour Alliance (theibta.org) and Patiëntenadviesraad voor Wetenschappelijk Onderzoek (PAWO) UZ Gent. The video had to be short, clear, visual, and have on-screen text crucial for situations in which no sound is available, e.g. in waiting rooms, as illustrated in Figure 1 and 2. Additionally, a patient testimonial format was chosen, with glioma as a case sample. The video was developed in 17 languages: Bulgarian, Croatian, Czech, Danish, Dutch, English, Estonian, French, German, Greek, Italian, Norwegian, Polish, Portuguese, Romanian, Slovak, and Spanish. Videos were released during the International Brain Tumour Awareness Week 2021, and distributed via the GliMR-members to over 21 countries and 72 hospitals and research centers. Additionally, a press release has been released on AlphaGalileo.⁶



Figure 1 - Still from the video, illustrating the style of the animations.

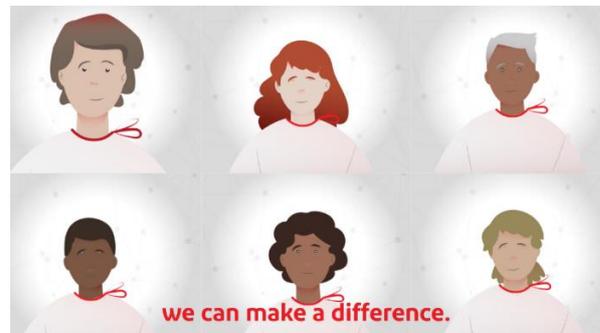


Figure 2 - Screenshot from the animation video. Key words and sentences appear as on-screen text to increase clarity in situations during which no sound can be played, for example in a general practitioner's or hospital waiting room.

Results

A short and clear animation video is available in 17 languages, with and without subtitles. The video focuses on three main messages:

1. Reusing and sharing medical data for scientific purposes is possible.
2. When data is reused for scientific research, multiple safeguards are in place to keep the patients' privacy protected.
3. Medical data is needed: by sharing their medical data, each patient can make a difference to help discover more about pathologies and their cures.

The videos are publicly available under a CC-BY-ND Creative Commons license. For each language, a web page is available, which can be found via glimr.eu/gdpr-video. These web pages provide context about the video and information on its use.

This information is mainly for data protection officers, healthcare professionals, clinicians and researchers who want to use the video to inform their patients.

Discussion and conclusion

Within this project, an animation video was developed to inform patients about the reuse of their medical data and the protection of their privacy. More importantly, the video tries to involve patients in medical research, by stressing the importance of their data for future scientific breakthroughs.

The video is a useful tool to comply with the transparency principle of GDPR, by providing data privacy related information in a concise, transparent and intelligible manner. In the video, clear and plain language is used, verified by laypeople and patients. It can be used for free by all types of healthcare professionals, hospitals, institutions, patient organizations and other relevant stakeholders. The video can be broadcasted in the waiting room, embedded on a website, or shared via social media. Therefore, this video can be part of the data protection strategy as the first layer of information. However, it cannot be used as the sole resource of information for patients, as it only provides an overview of the major safeguards to protect patient privacy. Each institution, hospital, and healthcare professional is responsible to provide additional layers of information and correctly implement other European, national and local privacy-related measures.

In conclusion, this video can be part of the data protection strategy of hospitals and healthcare institutions throughout Europe. The implementation of this video in daily clinical and research practice is expected to engage patients and facilitate the reuse of medical data.

References

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