



GDPR may reduce your own health (as well as the health of others)

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Messages



- GDPR may be a way forward from a societal standpoint, but it could hamper advances in digital health.
- If you exercise your right to privacy, you may reduce your own health (as well as the health of others).



GDPR introduces improvements

- Clear language
- Consent from the user
- More transparency
- Stronger rights
- Stronger enforcement



Visit the European Commission's online guidance on data protection reform — available in all EU languages: europa.eu/dataprotection

GDPR (excerpts from factsheet)

MORE TRANSPARENCY	
TODAY	TOMORROW
The user might not be informed when his/her data is transferred outside the EU	Businesses will need to clearly inform the user about such transfers
Sometimes businesses collect and process personal data for different purposes than for the reason initially announced without informing the user about it.	Businesses will be able to collect and process data only for a well-defined purpose . They will have to inform the user about new purposes for processing
Businesses use algorithms to make decisions about the user based on his/her personal data (e.g. when applying for a loan); the user is often unaware about this	Businesses will have to inform the user whether the decision is automated and give him/her a possibility to contest it



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GDPR (excerpts from factsheet) (2)

CONSENT FROM USER	
TODAY	TOMORROW
<p>Businesses sometimes assume that the user's silence means consent to data processing, or they hide a request for consent in long, legalistic, terms and conditions — that nobody reads</p>	<p>The user will need to give an affirmative consent before his/her data can be used by a business. Silence is no consent</p>



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GDPR (excerpts from factsheet) (3)

STRONGER RIGHTS	
TODAY	TOMORROW
<p>Often businesses do not inform users when there is a data breach, for instance when the data is stolen</p>	<p>Businesses will have to inform users without delay in case of harmful data breach</p>
<p>Often the user cannot take his/her data from a business and move it to another competing service</p>	<p>The user will be able to move his/her data, for instance to another social media platform</p>
<p>It can be difficult for the user to get a copy of the data businesses keep about him/her</p>	<p>The user will have the right to access and get a copy of his/her data, a business has on him/her</p>
<p>It may be difficult for a user to have his/her data deleted</p>	<p>Users will have a clearly defined "right to be forgotten" (right to erasure), with clear safeguards</p>



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Beware the downside of GDPR

- A couple of potential issues:
 1. The GDPR may frighten organizations into being very careful about what data they collect and share. Will they be too conservative? Will it lead to less innovation?
 2. GDPR gives individuals with the 'right to be forgotten'.
 - If many individuals exercise this right, this can reduce our ability to obtain valid and precise estimates of the effectiveness and cost-effectiveness of many different types of healthcare interventions.



Can delays in new knowledge arise because of the “accountability principle”?

1. Because of the “accountability principle”, some organizations may be very conservative and not quick to share data with other parties.
 - At the very least, researchers may need more time to acquire data and this will lead to delays in important discoveries.



The “right to be forgotten” may mean smaller datasets and reduced power

- The right to **request erasure of personal data** (“the right to be forgotten”) (Article 17) could lead to databases with fewer individuals.
- This may not lead to problems when researching the causes and treatment of common diseases, but it could lead to problems with researching uncommon subtypes or diseases.
- A database with fewer individuals will mean a reduced ability to:
 - Identify causes of disease
 - Estimate the effectiveness of a treatment
 - Estimate the prognostic/predictive value of biomarkers
 - Etc.



The “right to be forgotten” may also lead to biased results

- If the persons who **request erasure of personal data** are different from others in “important” ways, this will result in biased results and conclusions.
- That is, these people may differ in:
 - their disease risk
 - the safety or effectiveness of a treatment
 - the prognostic/predictive value of a biomarker
 - etc
- Therefore, results based on these people will not generalizable to all people!
- Statistical adjustment may not correct this problem sufficiently.



What's the willingness to share (U.S.)?

Consumers with a chronic condition are more willing to share their tracked data

Survey question: How willing would you be to share the information tracked in your apps or devices for the following reasons?*

	Chronic disease	No chronic disease	Total
Blinded/anonymous contribution to an organization that does health care research	43%	34%	39%
Blinded/anonymous contribution to a device developer to improve device/program	44%	34%	40%
Share with emergency services if experiencing a sudden emergency situation	58%	46%	53%
Alert myself and share with family if in danger due to a fall or other health emergency situation	57%	48%	53%
Share with my doctors to help them provide better care to me	66%	52%	60%

*Chart shows the percentage of respondents who answered 4 or 5 on a 5-point scale, where 1 is "not at all willing" and 5 is "extremely willing."

Note: For the purposes of this research, a "chronic condition" is defined as any disease or health problem that has lasted for three or more months. Examples include arthritis, diabetes, cancer, heart disease, high blood pressure, high cholesterol, asthma, allergies, back pain, depression, alcohol or drug dependence, and others.

Source: Deloitte 2018 Survey of US Health Care Consumers.

Source: <https://www.healthpopuli.com/2018/09/27/sicker-consumers-are-more-willing-to-share-tracked-health-data/>

IMTA



Factors that can reduce the value of digital health (aka some doom & gloom)

1. LACK OF TRUST in the organisations that can improve our health (directly or indirectly)
 - Trust decreases if organisations make poor decisions
→ Example: DeepMind and Royal Free
2. TOO LITTLE FOCUS ON THE FUTURE
 - Many of us live in the present.
→ Example: Many young and healthy people don't register to donate their organs.

Factors that can reduce the value of digital health (aka some doom & gloom)

3. LACK OF INSIGHT ABOUT TECHNOLOGIES

- Many people do not understand digital health technologies and their repercussions!
- Even the well-educated have this problem
 - Proof: Who can explain block chain technology in layman's terms?

World, we have a problem!

If many people exercise their right to be forgotten, this can drastically limit the value of digital health!

Can we find similar situations in healthcare?

- If we conclude that policies like GDPR may severely affect healthcare research and healthcare, how can we convince people that it is better for them (and others) not to be forgotten?
- Can we learn from the experiences in other areas of healthcare?

Example 1: Organ donation

- Some people choose not to register to donate their organs after they die; plus family members refuse it
- This reduces the number of available organs, which increases waiting time for an organ
- Result: poorer health and/or an earlier death
- Question: what can be done?
- Policy options include:
 - 1) Require everyone to donate their organs
 - 2) Give donor refusers a lower priority for organs
 - 3) Do not give donor refusers any organ
 - 4) Provide incentives
 - 5) Provide better health education
- CAN THESE OPTIONS BE USED IN DIGITAL HEALTH?

Example 2: Vaccinations (e.g. MMR/MR)

- Some people refuse to have their child vaccinated.
- Consequence: Their children's MR risk will increase
 - This will also reduce overall coverage, thereby reducing herd immunity and increasing the risk of disease in other children.
- Question: what can be done?
- Policy options:
 - 1) Mandatory vaccination
 - 2) Incentives/disincentives for vaccinations (e.g., ineligibility for other benefits)
 - 3) Better health education
- Options for digital health?



Messages

- Digital health will be the new norm.
- HOWEVER, GDPR may be a way forward from a societal standpoint but it could hamper advances in (digital) health.
- If you exercise your right to privacy, you may reduce your own future health (as well as the health of others).

- We will need ways to encourage people not to be forgotten.
 1. Organisations need to gain the trust of others.
 2. We need to apply incentives/disincentives to discourage people from opting out (ethically)
 3. People need to learn more about the opportunities and dangers of digital health.

