[Title]

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Abstract

[Add informative summary text here]

MyData is the human-centric movement to

MyData

Data Silos being created

Access to health data

Harmonization across

Diabetes

Outline

Introduction
- history of medical data creation
- use of digital technologies creating an abundance of health data (IoT)
- creating data silos
- movements to empower patients
- MyData principles
- access to health data
- control
    - can I get access
    - can I do something useful

Problem Statement
- silos of data
    - public health providers (Finland, UK) have silos of data from patient-generated and - allow us to innovate to create better health outcomes
- mechanisms for health data access and health data control are uncertain
- Patient's signing away access rights to clinical trial data
- Clinicians have access to clinical data, patients don't. Patients have access to patient-generated health data, clinicians don't. Merging these is important for both

Health example
- Diabetes

Mechanisms to Solving Problems
- there are two different approaches to try and harmonize health data across healthcare
- getting the raw data moving helps to bring value through stakeholder involvement
    - developers having access to health data
    - evidence of health data helping diabetes patients to show how the MyData 'mindset' is affecting real people
    - using access to health data to influence behaviour change to support chronic disease management
- in clinical trials will access to health data occur right away
    - FDA is innovative and advocates for patient empowerment (EMEA in Europe)

Clinical trial
- Paul to look into Aleglitazar, diabetes drug that Roche has developed. Check CDASH (earliest source data standard for CDISC). Mention of "Real World" data.
- CDASH - https://www.cdisc.org/standards/foundational/cdash
- HL7 FHIR - https://www.hl7.org/fhir/

Notes

Points

300-500 words

Casandra -

Paul - MyData Language, making sure that different actors within a trusted framework can use interoperable data objects, informed consent undercurrent

Christoph - Diabetes case - use of health data for behaviour, self-empowerment may be possible and what we proposed to do (patients perspective)

Joss - Diabetes case - industry view, systematic and decentralized, how MyData ecosystem model and what challenges those crease, clinician as the operator (opposed to Christoph)

Our title needs: MyData, Health, Diabetes, Solutions

Text

Introduction (500 words)

Purpose of my data as related to health

- MyData white paper concept (why it developed and grounding in the digital health revolution)
- discuss the health aspects
- current challenges in the data economy
- ecosystem vs. individual

Case of Diabetes (750 words)

- how do we semantically transfer consent (containers)
- how do we empower the patients
- machine process user

Proposed Solutions (1000 words)

- Semantic Containers

    - portability or mobility?
- ODCA
- Consent recipients (meaningful informed consent)
- Ethics as related to GDPR and RTBF

Conclusion (250 words)

Acknowledgements

This section is optional. If you do acknowledge someone by name, be sure to obtain permission to do so.

Disclaimers

The opinions expressed in this article are the author's own and not necessarily shared by his employer or EMWA.

Conflicts of interest

This section is required.

Example:

The author is employed by XYZ Pharmaceutical Company, which manufactures the medication discussed in this article.

If no conflicts:

The author declares no conflicts of interest.

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Examples:

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Author information

Example:

1

2 Casandra Grundstrom is a Ph.D. candidate at the University of Oulu, Finland. Her research focus is on health data access between the public and private sector to balance the distribution of power for equal benefit in the data economy. MSc Grundstrom has regularly published in international journals and conferences.

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