DELIVERABLE

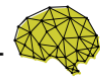Project Acronym: **Precise4Q**

Grant Agreement number: **777107**

Project Title: **Personalised Medicine by Predictive Modelling in Stroke for better Quality of Life**

D1.8 – Release of the deliberative dashboard

Revision: 1.0

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Revision History, Status, Abstract, Keywords, Statement of Originality

Revision History

Revision	Date	Author	Organisation	Description
0.1	20.01.20	J. Amann	ETH Zurich	Preliminary outline
0.2	30.01.20	J. Amann	ETH Zurich	First draft dashboard (wireframes)
0.3	04.02.20	J. Amann	ETH Zurich	Feedback (A. Blasimme, E. Vayena)
0.4	10.03.20	J. Amann	ETH Zurich	Review (A. Blasimme, E. Vayena)
0.5	14.03.20	J. Amann	ETH Zurich	Finalized wireframes, pre-selection of ethics resources
0.6.	23.04.20	J. Amann	ETH Zurich	Revision: V. Madai (CUB), A. Garcia (GUT)
1.0	29.04.20	J. Amann	ETH Zurich	Final version

Date of delivery	Contractual:	30.04.2020	Actual:	30.04.2020
Status	final ☒ /draft ☐			

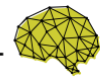| Abstract (for dissemination)	This document presents the outcome related to the activities conducted in relation to T1.6. More specifically, this document presents the prototype of the deliberative dashboard, a web-based platform created to facilitate the discussion of ethical issues and priorities within the Precise4Q consortium.
Keywords	Ethics, stroke, machine learning, patient autonomy, justice, data protection and privacy, disclosure, responsibility, empathy

Statement of originality

This deliverable contains original unpublished work except where clearly indicated otherwise. Acknowledgement of previously published material and of the work of others has been made through appropriate citation, quotation or both.

Table of Content

Executive Summary

PRECISE4Q sets out to minimize the burden of stroke for the individual and for society through multi-dimensional predictive modeling. The PRECISE4Q consortium unites researchers from a variety of different disciplines, thus presenting a rich pool of diverse skill sets and knowledge. This interdisciplinary approach is one of the core strengths of the project and presents an excellent opportunity for mutual learning and the generation of novel insights.

The deliberative dashboard presented here is designed as an interactive platform to channel and capture these conversations and insights. Specifically, it provides the consortium partners with a forum to facilitate exchange and discussion on ethical issues that arise within the project. It is our hope that the deliberative dashboard will encourage project partners to reflect and act on the ethical issues that may arise within the project. Discussions among the partners will also inform the development of an ethical framework for PRECISE4Q (D1.6 and D1.7) that is agile and responsive to different stakeholders' needs and suitable to guide decision making in stroke research and clinical practice.

In addition to the interactive forum, the deliberative dashboard also provides consortium partners with a curated list of relevant ethics resources. The selection of resources was guided by findings of the qualitative study on clinicians', patients', and caregivers' attitudes towards predictive modeling in stroke (D1.5), the categorized and ranked clinical challenges and needs (D1.2) and the use cases and their inputs/outputs specifications (D1.3). Ethics resources will be continuously reviewed and updated throughout the course of the project.

Each consortium partner will receive personalized login information (i.e. user name and password) to access the deliberative dashboard. In addition, a guest login has been created. To ensure that the dashboard meets the evolving needs of the consortium partners through the course of the project, it will be continuously evaluated and revised (e.g. restructuring of the forum sections) based on the consortium partners' feedback.

The deliberative dashboard is available online and can be accessed here:

URL: https://p4q-ethics.ch
User name: P4Q_Guest
Password: Personal1zedMed1c1ne!

1 Overall objective and scope of the deliverable

This document presents the outcome related to the activities conducted in relation to T1.6. More specifically, this document presents the prototype of the deliberative dashboard, a web-based platform created to facilitate the discussion of ethical issues and priorities within the Precise4Q consortium.

The PRECISE4Q consortium unites researchers from a variety of different disciplines and backgrounds. This interdisciplinary approach presents an excellent opportunity for mutual learning and the generation of novel insights when it comes to the ethical questions that arise within the project. Yet for this interdisciplinary collaboration to achieve its full potential, a common language and understanding of relevant ethical concepts are needed. The deliberative dashboard presented here aims to cultivate such a common language and understanding of relevant ethical concepts in the context of predictive modelling in stroke. As such, the deliberative dashboard will support communication among the consortium partners and help to prevent misunderstandings resulting from different use and understanding of terminology.

Insights derived from this interdisciplinary exchange among the consortium partners will complement findings generated from the empirical study on clinicians', patients', and caregivers' attitudes towards predictive modeling in stroke (D1.5). The deliberative dashboard will inform the development of an ethical framework for PRECISE4Q (D1.6 and D1.7) that is agile and responsive to different stakeholders' needs and suitable to guide decision making in stroke research and clinical practice.

2   Deliberative Dashboard

This section presents a schematic overview of the deliberative dashboard. Each of the subsections below, provides a brief description of the respective feature and is illustrated with screenshots taken from the platform. In terms of design, the deliberative dashboard follows the PRECISE4Q design guidelines (see https://www.precise4q.eu). To view the online version of the deliberative dashboard, please use the information provided below.

The deliberative dashboard is available online and can be accessed here:

URL: https://p4q-ethics.ch
User name: P4Q_Guest
Password: Personal1zedMed1c1ne!

2.1   Login Page

Each consortium partner will receive personalized login information (i.e. user name and password) to access the deliberative dashboard. In case a partner forgets their password, a new password can be requested.

2.2   Forum

The forum constitutes the heart of the deliberative dashboard. It aims to encourage consortium partners to ask questions, share ideas, and voice concerns in relation to ongoing and planned PRECISE4Q activities. To facilitate and guide this exchange, an "About this forum" post will be pinned to all subsections of the forum for good visibility. This post will link to an existing glossary of relevant ethical concepts and terms[1], as well as an existing ethical framework for AI developed by Floridi et al (2018)[2]. These contents aim to make ethical concepts and terms accessible to all partners and to promote the adoption of a common terminology.

(Floridi et al., 2018)
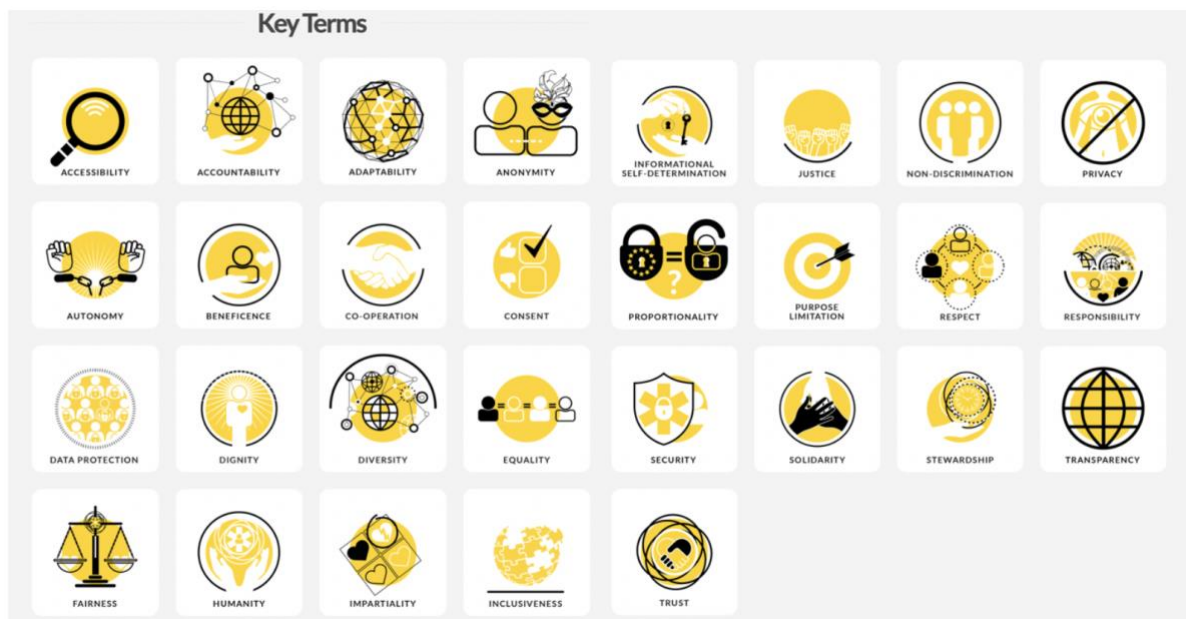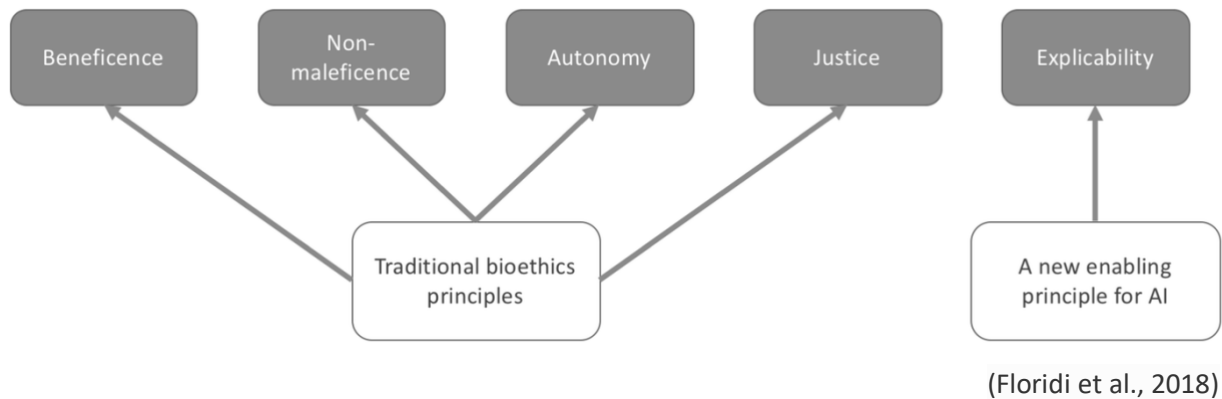
(isITethical, 2020)

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[1] isITethical (2020). Key Terms. Accessed April 23 2020: http://www.isitethical.eu/key-terms/

[2] Floridi, L., Cowls, J., Beltrametti, M. et al. AI4People—An Ethical Framework for a Good AI Society: Opportunities, Risks, Principles, and Recommendations. Minds & Machines 28, 689–707 (2018). https://doi.org/10.1007/s11023-018-9482-5

To further facilitate and channel discussion among the consortium partners, the forum is divided into six subsections, corresponding to the elements of the data lifecycle:

- Data collection
- Data processing
- Data sharing
- Data storage
- Predictive modeling
- Application (CDSS)
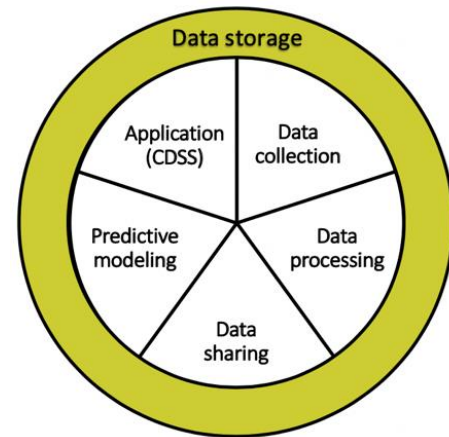
Adapted from Abouelmehd et al. (2018)[3]

The forum also features a search function (top right corner) to allow users to easily identify relevant information within the forum. Forum statistics at the bottom provide an overview of the number of topics, number of posts, number of views, number of users, and number of users currently online.
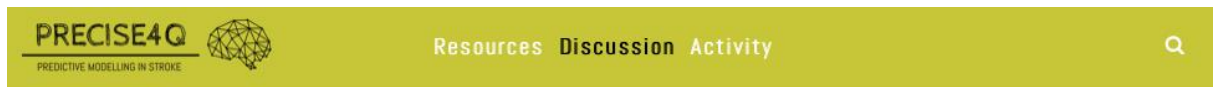

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[3] Abouelmehdi, K., Beni-Hessane, A. & Khaloufi, H. Big healthcare data: preserving security and privacy. J Big Data 5, 1 (2018). https://doi.org/10.1186/s40537-017-0110-7

2.2.1   Profile page

Each partner will have a profile page which will provide an overview of recent member activities (i.e. Post History; Number of Topics Started, Number of Replies Created; Number of Likes Received).

2.2.2   Member overview

The forum also includes an overview of all members, indicating their number of posts and the last time they logged onto the Deliberative Dashboard.

2.2.3   Subscriptions

Project partners will have the opportunity to subscribe to manage (i.e. add or remove) their forum subscriptions, meaning they can indicate when they want to receive notifications. They can manage subscriptions either individually, get notified about all new topics, or get notified about new topics and posts.
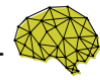
2.2.4 Forum activities

All users will have an overview of ongoing forum activities (i.e. new topics created, replies to topics).

2.3 Ethics resources

In addition to the interactive forum, the deliberative dashboard also provides consortium partners with a curated list of relevant ethics resources, including scientific publications, policy documents, online resources and other relevant materials. The selection of resources is guided by findings of the qualitative study on clinicians', patients', and ca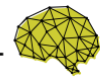regivers' attitudes towards predictive modeling in stroke (D1.5), the categorized and ranked clinical challenges and needs (D1.2) and the use cases and their inputs/outputs specifications (D1.3). While not all materials will be specific to predictive modeling in stroke, these resources aim to inform the discussions around the ethical challenges within PRECEISE4Q.

Ethics resources will be continuously reviewed and updated by ETH throughout the course of the project to ensure that all consortium partners have access to the latest insights and recommendations regarding the ethical use of predictive modelling in stroke research and clinical practice. In addition, consortium partners will be invited to submit relevant resources to be included in the selection.

As for the forum, a search function (top right corner) will allow users to easily identify relevant materials in the resources section. In addition, partners will be able to filter contents according to category:

- Conferences and Events
- Guidances
- News Coverage
- Online Resources (e.g. websites)
- Policies
- Scientific Publications
- Videos

PRECISE4Q
PREDICTIVE MODELLING IN STROKE

Resources Discussion Activity

🔍

Categories

THE COLLECTION, LINKING AND USE OF DATA IN BIOMEDICAL RESEARCH AND HEALTH CARE: ETHICAL ISSUES

29. April 2020 / Guidances

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29. April 2020 / News Coverage, Scientific Publications

Understanding the patient's perspective – their concerns, hopes, fears, and priorities – is instrumental to uncovering and tackling the ethical challenges that arise with the... Read More »

AMA HEALTH POLICY: AUGMENTED INTELLIGENCE IN HEALTHCARE

29. April 2020 / Policies

The American Medical Association (AMA) supports the use and payment of augmented intelligence (AI) systems that enhance the patient experience of care and outcomes, improve population health, reduce overall costs for... Read More »

ETHICS IN AI: KEY TERMS AND CONCEPTS

29. April 2020 / Online Resources

A comprehensive glossary of key terms and concepts was developed by the isITethical? Exchange, an initiative directed by a group

3   Implications and outlook

The deliberative dashboard presented here will help to channel and capture the consortium partners ethical concerns and priorities in relation to the project. It is our hope that the deliberative dashboard will stimulate discussion and encourage project partners to reflect and act on the potential ethical issues that may arise within the project.

To foster active engagement with the deliberative dashboard, consortium partners will be notified via email about updated resources and discussions where their input might be needed. ETH, who is maintaining the deliberative dashboard, will also use the monthly project calls to identify emerging ethical issues and to encourage the consortium partners to use the deliberative dashboard to collaboratively tackle these issues. To ensure that the dashboard meets the evolving needs of the consortium partners through the course of the project, it will be continuously evaluated and revised (e.g. restructuring of the forum sections) based on the consortium partners' feedback.

Insights derived from this interdisciplinary exchange among the consortium partners will complement findings generated from the empirical study on clinicians', patients', and caregivers' attitudes towards predictive modeling in stroke (D1.5). The deliberative dashboard will inform the development of an ethical framework for PRECISE4Q (D1.6 and D1.7) that is agile and responsive to different stakeholders' needs and suitable to guide decision making in stroke research and clinical practice.