

# Ethical Assurance of Data-Driven Technologies for Mental Healthcare Industry Connections Activity Initiation Document (ICAID)

Version: 2.0, 11 May 2023

IC21-007-02 Approved by the CAG 10 July 2023

## **Instructions**

- Instructions on how to fill out this form are shown in red. Please leave the instructions in the final document and simply add the requested information where indicated.
- Spell out each acronym the first time it is used. For example, "United Nations (UN)."
- Shaded Text indicates a placeholder that should be replaced with information specific to this ICAID, and the shading removed.
- Completed forms, in Word format, or any questions should be sent to the IEEE Standards Association (IEEE SA) Industry Connections Committee (ICCom) Administrator at the following address: industryconnections@ieee.org.
- The version number above, along with the date, may be used by the submitter to distinguish successive updates of this document. A separate, unique Industry Connections (IC) Activity Number will be assigned when the document is submitted to the ICCom Administrator.

#### 1. Contact

Provide the name and contact information of the primary contact person for this IC activity. Affiliation is any entity that provides the person financial or other substantive support, for which the person may feel an obligation. If necessary, a second/alternate contact person's information may also be provided.

Name: Matthew Denis

Email Address: m.j.dennis@tue.nl

**Employer:** Eindhoven University of Technology

Affiliation:

VICE CHAIRS

Becky Inkster

email: becky@beckyinkster.com

Affiliation: Digital Mental Health Neuroscientist (Independent Consultancy)

**Lily Frank** 

email: l.e.frank@tue.nl

Employer: Eindhoven University of Technology

IEEE collects personal data on this form, which is made publicly available, to allow communication by materially interested parties and with Activity Oversight Committee and Activity officers who are responsible for IEEE work items.





## 2. Participation and Voting Model

Specify whether this activity will be entity-based (participants are entities, which may have multiple representatives, one-entity-one-vote), or individual-based (participants represent themselves, one-person-one-vote).

Individual-Based

## 3. Purpose

#### 3.1 Motivation and Goal

Briefly explain the context and motivation for starting this IC activity, and the overall purpose or goal to be accomplished.

The purpose of this IC activity is to extend this project by exploring whether/how ethically-oriented technical and data standards could be developed to support the assurance of properties such as patient autonomy, respect for mental integrity, and explainability. Although the focus of the activity is on the methodology and framework of ethical assurance, there will be significant overlap with existing programmes that focus on the development of existing bodies of work (e.g. IEEE Global Initiative on Ethics of Autonomous and Intelligent Systems). As such, there is also the possibility of mutual support and development between existing industry connection programmes, as the focus on assurance (and also governance) may expose gaps for further research and development.

#### 3.2 Related Work

Provide a brief comparison of this activity to existing, related efforts or standards of which you are aware (industry associations, consortia, standardization activities, etc.).

As mentioned, there is significant overlap with the IEEE Global Initiative on Ethics of Autonomous and Intelligent Systems, and its mission to "ensure every stakeholder involved in the design and development of autonomous and intelligent systems is educated, trained, and empowered to prioritize ethical considerations". By focusing on *participatory assurance*, the project I am proposing will engage in deliberative exercises with affected stakeholders, industry representatives, and policy-makers to ensure that the assurance of digital mental healthcare technologies promote individual and social welfare.

However, there is also an abundance of external projects that are related. For example, there is overlap with existing efforts to bolster <u>cybersecurity in digital mental health</u> (a project led by Becky Inkster and Alissa Knight), to <u>develop governance toolkits</u> (a project by the World Econonmic Forum), and to identify current and developing trends in how intelligent and autonomous systems will <u>shape the future of mental healthcare</u> (a project run by the UK's National Healthcare Service).

#### 3.3 Previously Published Material





Provide a list of any known previously published material intended for inclusion in the proposed deliverables of this activity.

- Burr, C., Morley, J., Taddeo, M., & Floridi, L. (2020). Digital Psychiatry: Risks and Opportunities for Public Health and Wellbeing. IEEE Transactions on Technology and Society, 1(1), pp. 21–33.
- Burr, C., & Floridi, L. (2020). Ethics of Digital Well-Being. Springer.
- Burr, C., & Morley, J. (2020). 'Empowerment or Engagement? Digital Health Technologies for Mental Healthcare'. In C. Burr and S. Milano (Eds.) The 2019 Yearbook of the Digital Ethics Lab, pp. 67–88.
- Morley J, Machado CCV, Burr C, Cowls J, Joshi I, Taddeo M, Floridi L. (2020). The ethics of AI in health care: A mapping review. Social Science & Medicine. 260, 113172.
- [Lily to add works here]

#### 3.4 Potential Markets Served

Indicate the main beneficiaries of this work, and what the potential impact might be.

The focus of this project will be to explore how ethical assurance—supported by ethically sound and rigorous standards—can a) promote trust in the use of digital technologies for mental healthcare and b) support transparent communication between stakeholders. While the starting point for this project will be the public sector and the governance needs that arise in this context (e.g. formal healthcare systems, public health), it is recognized that the needs of industry and developers must be considered due to the close interaction between public and private interests (e.g. procurement of technology in private-public partnerships). The markets served include:

- Patients/Users of technology
- 2. Clinicians/clinical support staff (prescribers of technologies)
- 3. Regulators and public health organizations
- 4. Technology developers

#### 3.5 How will the activity benefit the IEEE, society, or humanity?

Describe how this activity will benefit the IEEE, society, or humanity.

Even prior to the global pandemic caused by the spread of SARS-CoV-2, the incidence of common mental health disorders had been rising globally. For example, the World Health Organisation stated that between 2005 and 2015 the total estimated number of people living with depression increased by 18.4% and 14.9% for anxiety disorders<sup>1</sup>. Emerging evidence has suggested that these figures have continued to rise as a result of myriad social factors caused by the pandemic (e.g. social isolation, economic and health anxieties), and have further exacerbated existing socioeconomic inequities in health outcomes<sup>2</sup>. Unfortunately, a lack of trust in healthcare institutions within some communities and the absence of sufficient social license in digital alternatives for healthcare means that there are potentially many missed opportunities for digital mental healthcare. By

 $<sup>^2\,\</sup>underline{\text{https://www.health.org.uk/news-and-comment/blogs/emerging-evidence-on-covid-19s-impact-on-mental-health-and-health}\\$ 



<sup>&</sup>lt;sup>1</sup> World Health Organisation, 'Depression and Other Common Mental Disorders: Global Health Estimates', World Health Organisation, Geneva, 2017.

https://www.who.int/mental health/management/depression/prevalence global health estimates/en/



focusing on the *participatory assurance* needed to establish trust and social license, this project will seek to develop the social preconditions for improving the mental health outcomes of affected individuals and groups. In doing so, the project will also build upon and extend existing efforts of the IEEE (see above).

## 4. Estimated Timeframe

Indicate approximately how long you expect this activity to operate to achieve its proposed results (e.g., time to completion of all deliverables).

**Expected Completion Date:** 06/2025

IC activities are chartered for two years at a time. Activities are eligible for extension upon request and review by ICCom and the responsible committee of the IEEE SA Board of Governors. Should an extension be required, please notify the ICCom Administrator prior to the two-year mark.

## 5. Proposed Deliverables

Outline the anticipated deliverables and output from this IC activity, such as documents (e.g., white papers, reports), proposals for standards, conferences and workshops, databases, computer code, etc., and indicate the expected timeframe for each.

At present, there are three proposed deliverables for this project:

1. An industry-targeted white paper that focuses on how developers and organizations can work with affected stakeholders to identify needs and opportunities for promoting mental health and well-being, while also being receptive to ethical, legal, and social considerations that are likely to limit opportunities for obtaining contracts with public sector health providers.

Whitepaper 1 – target publish Q1 2024 Publication 2 – target publish Q4 2024

- 2. Mini-fire side chat interview virtual series with experts highlighting the challenges and needs for practical and open-source solutions in utilizing digital technologies in mental healthcare therapeutics.
- 3. Optionally, a proposal for standards that could underpin and support the assurance of digital technologies in mental healthcare, helping developers operationalize ethical principles, such as patient autonomy and respect for mental integrity.

Opportunities for additional deliverables will be pursued as the project evolves.

#### **5.1 Open Source Software Development**

Indicate whether this IC Activity will develop or incorporate open source software in the deliverables. All contributions of open source software for use in Industry Connections activities shall be accompanied by an approved IEEE Contributor License Agreement (CLA) appropriate for the open source license under which the Work Product will be made available. CLAs, once accepted, are irrevocable. Industry Connections Activities shall





comply with the IEEE SA open source policies and procedures and use the IEEE SA open source platform for development of open source software. Information on IEEE SA Open can be found at <a href="https://saopen.ieee.org/">https://saopen.ieee.org/</a>.

Will the activity develop or incorporate open source software (either normatively or informatively) in the deliverables? No

## 6. Funding Requirements

Outline any contracted services or other expenses that are currently anticipated, beyond the basic support services provided to all IC activities. Indicate how those funds are expected to be obtained (e.g., through participant fees, sponsorships, government, or other grants, etc.). Activities needing substantial funding may require additional reviews and approvals beyond ICCom.

There are no funding requirements.

## 7. Management and Procedures

#### 7.1 Activity Oversight Committee

Indicate whether an IEEE Standards Committee or Standards Development Working Group has agreed to oversee this activity and its procedures.

Has an IEEE Standards Committee or Standards Development Working Group agreed to oversee this activity? No

If yes, indicate the IEEE committee's name and its chair's contact information.

IEEE Committee Name: Committee Name

Chair's Name: Full Name

Chair's Email Address: who@where

Additional IEEE committee information, if any. Please indicate if you are including a letter of support from the IEEE Committee that will oversee this activity.

IEEE collects personal data on this form, which is made publicly available, to allow communication by materially interested parties and with Activity Oversight Committee and Activity officers who are responsible for IEEE work items.

#### 7.2 Activity Management

If no Activity Oversight Committee has been identified in 7.1 above, indicate how this activity will manage itself on a day-to-day basis (e.g., executive committee, officers, etc.).

**IC Program Chair** 





IC Program Secretary – Reporting to IC Program Chair Sub-Program Chairs, Project Workstream Leaders [Reporting into Program Chair] Project Workstream Participants [Reporting into Sub-Program Chairs]

#### 7.3 Procedures

Indicate what documented procedures will be used to guide the operations of this activity; either (a) modified baseline *Industry Connections Activity Policies and Procedures* (entity, individual), (b) *Abridged Industry Connections Activity Policies and Procedures* (entity, individual), (c) Standards Committee policies and procedures accepted by the IEEE SA Standards Board, or (d) Working Group policies and procedures accepted by the Working Group's Standards Committee. If option (a) is chosen, then ICCom review and approval of the P&P is required. If option (c) or (d) is chosen, then ICCom approval of the use of the P&P is required.

## (b) Industry Connections P&Ps Abridged Version

## 8. Participants

#### **8.1 Stakeholder Communities**

Indicate the stakeholder communities (the types of companies or other entities, or the different groups of individuals) that are expected to be interested in this IC activity and will be invited to participate.

There are four broad groups of stakeholder communities that will be involved in this project:

- Academic researchers (e.g. individuals who are involved in clinical psychiatry, human-computer interaction and other relevant disciplines)
- Technology Designers, "Big Tech," Developers and System Engineers (e.g. individuals and industry organisations responsible for developing and deploying products and services)
- Digital mental health providers (physicians)
- Policy-makers and Decision-makers (e.g. those working in the public sector who are responsible for implementing technology into formal health care or social care systems).
- Patient representatives and advocacy groups (e.g. charities, NGOs, and third sector organisations who represent the interests of patients and affected stakeholders).

## **8.2 Expected Number of Participants**

Indicate the approximate number of entities (if entity-based) or individuals (if individual-based) expected to be actively involved in this activity.

100

#### 8.3 Initial Participants





Provide a few of the entities or individuals that will be participating from the outset. It is recommended there be at least three initial participants for an entity-based activity, or five initial participants (each with a different affiliation) for an individual-based activity.

Use the following table for an individual-based activity:

Individual Name	Employer	Affiliation
Becky Inkster		Alan Turing Institute
Shaneel Pathak		Zemplo
Mehdi Snene		I-DAIR
Adrian Weller		Univ of Cambridge
Kate Devlin		Kings College London
Kirstie Whittaker		Alan Turing Institute
David Leslie		Alan Turing Institute
Geoff Keeling		Stanford Univ

## **8.4 Activity Supporter/Partner**

Indicate whether an IEEE committee (including IEEE Societies and Technical Councils), other than the Oversight Committee, has agreed to participate or support this activity. Support may include, but is not limited to, financial support, marketing support and other ways to help the Activity complete its deliverables.

Has an IEEE Committee, other than the Oversight Committee, agreed to support this activity? Yes

If yes, indicate the IEEE committee's name and its chair's contact information.

**IEEE Committee Name:** IEEE Engineering in Medicine and Biology Society (EMBS)

Chair's Name: Esteban Pino

Chair's Email Address: epino@ieee.org

Please indicate if you are including a letter of support from the IEEE Committee.

