

**MyData Health / IEEE Whitepaper Consortium**  
**Industry Connections Activity Initiation Document (ICAID)**  
**Version: 1.1, 28 May 2019**

IC19-003-01 Approved by the IEEE-SASB 11 June 2019

### **Instructions**

- Instructions on how to fill out this form are shown in red. It is recommended to leave the instructions in the final document and simply add the requested information where indicated.
- **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](mailto: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:** Moira Schieke

**Email Address:** [health@mydata.org](mailto:health@mydata.org), moira@cubisme-inc.com

**Employer:** MyData Health

**Affiliation:** MyData Health

IEEE collects personal data on this form, which is made publicly available, to allow communication by materially interested parties and with Sponsors 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.

MyData Health seeks to create a consortium with the IEEE for the purpose of creating a participatory design process for creation of whitepapers on the topic of creating a fair health data economy.

The potential economic power of health data is massive, with a \$7.2 trillion dollar worldwide market, and a \$3.5 trillion US market. In many areas of the world, there is felt to be overrepresentation of industry on topics of ethical use of patient data. The impact of this imbalance is a misalignment of stakeholder interests with patient data being used in ways not in the interests of patients and healthcare providers.

MyData Health seeks to “level the playing field” for all stakeholders in this important conversation on how to create a “fair” health data economy to serve the potential benefits for each individual patient, global public health, and society at large.

Given the demonstrated excellence of MyData Global and IEEE in successful participatory design systems and process, MyData Health feels a consortium between these groups creates the perfect conduit for creation of respected and credible global intellectual content on the topic of health data and global economics to foster better alignment between the various stakeholders’ interests and goals.

The goal of this consortium is to use a participatory design process to assist in the development of whitepapers on the general topic of creation of the fair patient data economy. We define a “fair patient data economy” as one where each and every individual retains the ability to freely and knowingly participate and substantially contribute to the data economy. A key component for a fair economy thus includes protection of core individual digital rights. Given the excellence of both the IEEE and MyData in participatory design processes, a consortium between these organizations provides excellent core processes and governance infrastructure to assure the integrity of a participatory design process.

#### **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.).

Recent and related work and achievements by MyData Global includes:

- started collaboration with European Commission’s Next-Generation Internet program
- was awarded as one of the most impactful European initiatives shaping a new culture around Next-Generation Internet, for “Data as human right”
- called for international collaboration in the French National Assembly

- took part in an event on data portability held in the French National Assembly and hosted by the French Member of Parliament Paula Forteza. The aim is to support the progress and concrete examples of applications for portability and data protection
- MyData 2019 is an official associated event of the Finland's EU Presidency. Data economy is one of the key priorities of the Presidency
- MyData presentation at the STI Forum event held in UN Headquarters New York and to the World Bank
- Input will be collected from:
  - Roundtable where industry can express what they want within the principles of MyData on patient rights. The forum would address how to create a social climate that incentivizes innovators.
  - Roundtable for patient groups and doctors to better understand IP issues and address misalignments with corporate concerns.

### **3.3. Previously Published Material**

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

MyData Global has produced a number of well-respected whitepapers that can be found at this link: <https://mydata.org/papers/>

### **3.4. Potential Markets Served**

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

The global healthcare economy is \$7.2 trillion dollars, the US healthcare economy is \$3.5 trillion dollars, and the European healthcare market is approximately \$200 billion. The economic value of health data globally is massive.

### **3.5. How will the activity benefit the IEEE?**

This activity supports IEEE's goal of advancing technology for humanity by addressing the digital rights of patients through an inclusive and participatory process that takes into consideration the voices of patients, practitioners, and technologists, as well as industry. MyData's work with the EU, UN, World Bank and the Finnish EU-presidency will assist IEEE in achieving its goals, and enhance IEEE's reputation for addressing key challenges in technology adoption. Additionally, this work will help inform standards processes for smaller standards committees.

## **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:** 06/2021

IC activities are chartered for two years at a time. Activities are eligible for extension upon request and review by ICCOM and the IEEE-SA Standards Board. 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.

Proposed whitepaper titles:

- Processes for establishing a patient data economy in compliance with applicable policies
- Digital rights for patient data

Plus, many more potential whitepaper titles decided by group process.

## **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.

MyData Health expects costs for scribes and proven professional writers to attend working group meetings and help build text from group edits and commentary, projected to cost \$5,000.00 per month.

The Activity will offset costs by seeking support from outside contributors via targeted sponsorships and events (<https://www.mydatahealth.org/events-meetings>).

In addition, we request support from the IEEE marketing arm to publicize and distribute the group-generated whitepapers.

## **7. Management and Procedures**

### **7.1. IEEE Sponsoring Committee**

Indicate whether an IEEE sponsoring committee of some form (e.g., an IEEE Standards Sponsor) has agreed to oversee this activity and its procedures.

**Has an IEEE sponsoring committee agreed to oversee this activity?:** Yes

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

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

**Chair's Name:** Carole Carey

**Chair's Email Address:** c.carey@ieee.org

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### **7.2. Activity Management**

If no IEEE sponsoring 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).

The Activity will be managed as defined in the Activity's Policies and Procedures

### **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*, (b) Sponsor policies and procedures accepted by the IEEE-SA Standards Board, or (c) Working Group policies and procedures accepted by the Working Group's Sponsor. If option (a) is chosen, then ICCom review and approval of the P&P is required. If option (b) or (c) is chosen, then ICCom approval of the use of the P&P is required.

This activity will follow a modified Industry Connections Activity Baseline Policies and Procedures.

## **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.

Healthcare industry including machine vendors, pharmaceutical companies, and electronic health record companies

### **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.

My Data Health will seek > 100 participants/year representing a fair distribution of stakeholders via whitepaper working groups, roundtable and meeting discussions, and social media participation.

### **8.3. Initial Participants**

Provide a number 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 entity-based activity:

<b>Entity</b>	<b>Primary Contact</b>	<b>Additional Representatives</b>
Entity Name	Contact Name	Name

Use the following table for an individual-based activity:

<b>Individual</b>		<b>Employer</b>	<b>Affiliation</b>
Moira Schieke	Chair	Cubismi, Inc	MyData Health
Adrian Gropper			Patient Privacy Rights
Casandra Grundstrom			MyData Health
Victoria Hailey		Vicky Hailey Group	Cubismi, Inc
Paul Knowles		Dativa	MyData Health
Viivi Lähteenoja			MyData Global
Deborah Peel			Patient Privacy Rights
Sille Sepp			MyData Global
Anna Tuomainen			MyData Global