Global Initiative to Standardize Fairness in the Trade of Data
Industry Connections Activity Initiation Document (ICAID)
Version: 2.0, June 5, 2019
IC19-001-02 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.
- 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: Richie Etwaru
Email Address: Richie@hu-manity.co
Employer: Hu-manity.co
Affiliation: Hu-manity.co

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. <u>Purpose</u>

3.1. <u>Motivation and Goal</u>
Briefly explain the context and motivation for starting this IC activity, and the overall purpose or goal to be accomplished.

The global debate on gathering of unprecedented amounts of data and its use in algorithmic systems, and issues around data privacy, data ownership, data ethics, and the trade of inherent human data are breaking new ground and even social order. The impact affects consumers, communities, corporations and countries. The motivation of this industry collaboration is to draft and propose a standards framework that could assist consumers, communities, corporations and countries to operate in a new agreement around inherent human data. The goal is - starting with the health care sector - to engage a global multi-stakeholder group of practitioners, academics, and from the public sector into a two-year work plan where the work product is to propose an adequate standards framework around a consensus-based definition of fairness with respect to data trade.

3.2. <u>Related Work</u>
Provide a brief comparison of this activity to existing, related efforts or standards of which you are aware (industry associations, consortia, standardization activities, etc.).

The scope of this project is relatively new from a standardization perspective. Existing published work will be identified by the founding team during the first stage of the program.

3.3. <u>Previously Published Material</u>
Provide a list of any known previously published material intended for inclusion in the proposed deliverables of this activity.

The scope of this project is relatively new from a standardization perspective. Existing published work will be identified by the founding team during the first stage of the program.

3.4. <u>Potential Markets Served</u>
Indicate the main beneficiaries of this work, and what the potential impact might be.

The proposed standards are anticipated to serve consumers, communities, corporations and country organizations that transact inherent human data, starting with the health care sector. Those leveraging and/or complying to the proposed standards will transact with a consensus-based definition of fairness in the trade as it relates to inherent human data enabling them to meet a new and consisting standard in the areas of data privacy, data ownership, and data ethics.

3.5 <u>How will the activity benefit the IEEE?</u>

The commoditization of data and ownership/usage rights is a rapidly evolving field, with little to no formality in place on consensus based processes and metrics to assure consistency and fairness for all stakeholders. IEEE will benefit from this project by establishing its leadership in this new area, and being first to market with a standards framework that can become the global de facto standards governing human data transactions.

4. <u>Estimated Timeframe</u>
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: March 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. <u>Proposed Deliverables</u>
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.

The work product of the initiative will be a recommendation for standards. Ancillary to the recommendation for standards will be schematics to visualize and represent key concepts, content to be used by participants at conferences and workshops to share ideas and receive feedback, and a series of recommendations to right-fit the proposed standards for individual groups, industries and geographies. During the two-year period, participants of the initiative will write excerpts of the work in progress for publication for feedback such as blogs, videos, and/or white papers.

6. <u>Funding Requirements</u>
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.

This Industry Connections Initiative will be self-funded, with IEEE-SA administrative support. It will also seek support by outside contributions from other partners in the Initiative where additional funds may be needed for identified work products.

7. <u>Management and Procedures</u>

7.1. <u>IEEE Sponsoring Committee</u>

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?: NO

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

Sponsoring Committee Name: Committee Name
Chair's Name: Full Name
Chair's Email Address: who@where

Additional sponsoring committee information, if any.

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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 by an executive committee of approximately 5-8 members (to be agreed upon by members at the initial activity meetings).

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.

Modified baseline *Industry Connections Activity 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.

Large and small corporations, nonprofits and think tanks, experts in specific areas from academia, policy influencers and public sector, and community leaders from different demographics, cultures and geographies.

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.

Three to five founding members, including an appropriate number of invited individual experts.

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 individual-based activity:

Individual		Employer	Affiliation
Krishna Cheriath	https://www.linkedin.com/in/krishnacheriath/	Bristol Meyer Squibb	Chief Data Officer
Jennifer Miller	https://www.linkedin.com/in/jennifermillerbioethics/	Yale School of Medicine; Bioethics International	Assistant Professor; Founder
Richie Etwaru	https://www.linkedin.com/in/richieetwaru/	Hu-manity.co	Chief Executive Officer
Keerthika Subramanian	https://www.linkedin.com/in/kesubramanian/	Mintz, Levin, Cohn, Ferris, Glovsky and Popeo, P.C.	Securities & Policy Attorney
Christopher Boone	https://www.linkedin.com/in/datahippie/	Pfizer	Vice President, Head of Real World Data and Analytics
Saul Kaplan	https://www.linkedin.com/in/saulkaplan/	Business Innovation Factory	Founder and Chief Catalyst