

**DIGITAL INCLUSION, IDENTITY, TRUST AND  
AGENCY (DIITA) INDUSTRY CONNECTIONS  
PROGRAM: DIGNITY AND AGENCY IN IDENTITY  
WORKSTREAM – ACTIVITY REPORT**

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# DIGITAL INCLUSION, IDENTITY, TRUST AND AGENCY (DIITA) INDUSTRY CONNECTIONS PROGRAM: DIGNITY AND AGENCY IN IDENTITY WORKSTREAM

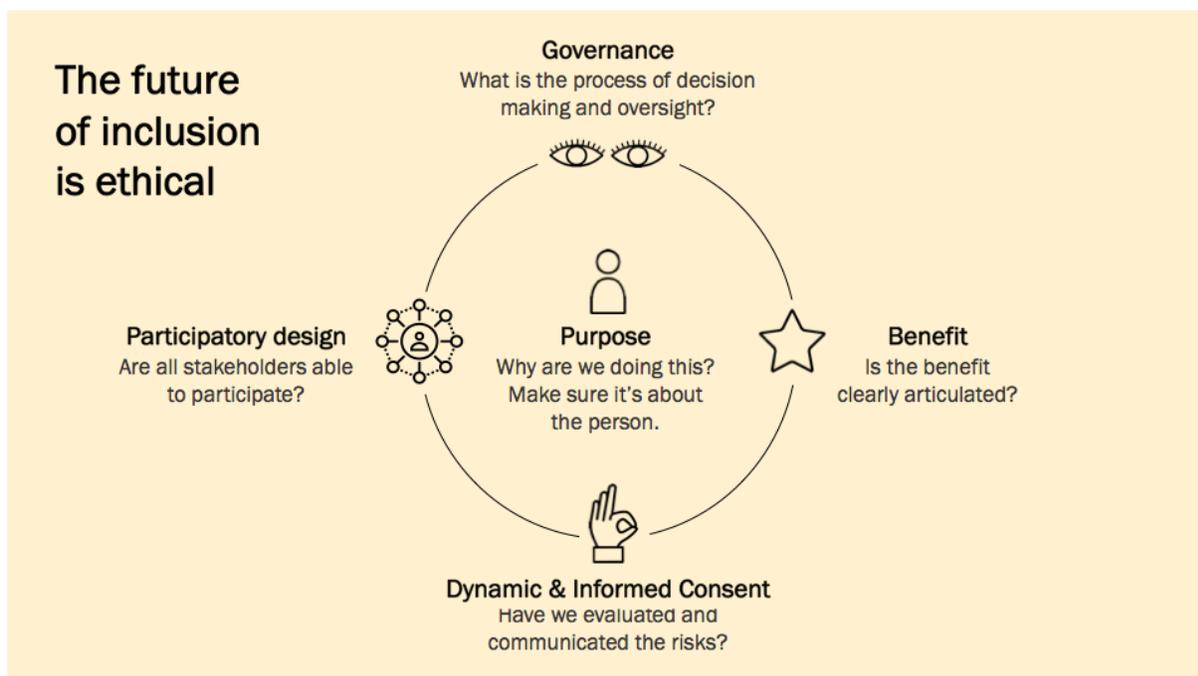
**Workstream Charter:** Protect, develop, and promote dignity through digital agency.

## Project:

- Phase 1: Study use of AI on vulnerable individuals: How AI can be used to enhance capabilities of individuals with decision impairment.
- Phase 2: Develop principles that can drive an ethical framework for the use of the AI technology in this use case.
- Phase 3: Identify mechanisms to protect, develop, and promote dignity when using AI technology in this use case.

As part of the DIITA program, Dignity and Agency work stream phase 1, experts from the Society for Social Implications of Technology (SSIT) attended a roundtable to develop an ethical framework to use AI technology and share data in order to support decision making and augment autonomy for people with a decision impairment.

Together, the experts discussed the first steps of what an ethical approach looks like, and the result of these discussions is illustrated below:



## 1. Identifying purpose and benefits to the individuals is key to the development of an ethical framework

The questions that first arose were:

Should the purpose and benefits be identified at the outset of the project? Or

Can the purpose and benefits of the project be derived from the data insights provided by the AI solution?

Experts identified the following key problems, which if solved, would significantly benefit individuals with decision impairment:

1. It is difficult to identify and recognize if an individual is in pain;
2. Choice is not often provided to the individual, especially in relation to the living arrangement; and
3. The level of care is fluctuating, there is a need in particular to reduce the turnover of carers and to enhance their capabilities.

The position adopted was that it is imperative that both purpose and benefits be defined at the outset. The rationale being that introducing AI in a community where perceptions are different and consent cannot necessarily be expressed constitutes a significant risk, and that risk must be addressed by articulating a clear purpose and benefits to the individuals.

On the other hand, some experts argued that as AI technology provides insight to the data by correlation, AI can reveal key problems and offer solutions and benefits that were not previously visible, and once these are revealed, the purpose of the project could then be specified.

The following concepts were also discussed:

## 2. Is it legal —above the legal benchmark?

The experts noted that the data collected in this project is health data, which is sensitive data, and that individuals with decision impairment are more vulnerable. Accordingly, the experts considered whether in this case a higher legal standard, such as the one set by the GDPR in Europe, should be adopted.

They considered the concept of “dynamic consent,” and whether it is possible to ensure the engagement of the individual by renewing consent throughout the project (either directly or via the appointed tutor).

## 3. What is fair?

The predominant question was: “How to determine what is reasonable?”

To answer this question, the experts adopted a risk/benefit approach and considered:

1. How to determine the benefit to different stakeholders (individuals with a decision impairment, visitors, staff, families)?
2. And are these benefits are compatible?

Experts acknowledged the need for:

1. Feedback throughout the project from the different stakeholders;
2. A clear statement defining what the data should not be used for; and
3. A risk assessment process to identify potential unintended consequences.

Some experts argued that not using AI technology to inform how to improve the wellbeing of the individuals was a considerable opportunity risk.

#### **4. What could go wrong: vulnerability and surveillance**

Using AI to better understand and enhance the capabilities of individuals with decision impairment requires data to be acquired on these individuals, and effectively an increased monitoring of their daily activities and interactions with other individuals (carers, families, etc.).

Increased monitoring is always contentious in society, and more so when vulnerable individuals are involved. The question becomes why the need for monitoring- to obtain insights to enhance the capabilities of these vulnerable individuals.

Experts considered the following key questions:

- Is the promise rather than the guarantee of improvements/benefits sufficient? And why?
- How do you determine and measure improvements/benefits?
- How do you prevent any potential abuse from occurring/misuse of the data and AI insights?
- How do you re-contextualize the AI insights?

#### **5. Aligning the human and technology perspective: A participatory design**

Experts considered how the wellbeing of the individuals can be maintained, supported, and enhanced during and after the project. And the first step to achieve this goal is through a participatory design of the project with all relevant stakeholders.

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