

# Advancing Health Equity by Design and Health Information Technology: Proposed Approach, Invitation for Public Input, and Call to Action Comment

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This document was submitted by the Massachusetts Health Data Consortium (MHDC) and its Data Governance Collaborative (DGC) on June 10, 2024 in response to Advancing Health Equity by Design and Health Information Technology: Proposed Approach, Invitation for Public Input, and Call to Action posted on the ONC website in April, 2024 and found here:

[https://www.healthit.gov/sites/default/files/2024-04/ONC-HEBD-Concept-Paper\\_508.pdf](https://www.healthit.gov/sites/default/files/2024-04/ONC-HEBD-Concept-Paper_508.pdf)

## About MHDC

Founded in 1978, MHDC, a not-for-profit corporation, convenes the Massachusetts's health information community in advancing multi-stakeholder health data collaborations. MHDC's members include payers, providers, industry associations, state and federal agencies, technology and services companies, and consumers. The Consortium is the oldest organization of its kind in the country.

MHDC provides a variety of services to its members including educational and networking opportunities, analytics services on both the administrative and clinical side (Spotlight), and data governance and standardization efforts for both clinical and administrative data (the Data Governance Collaborative/DGC and the New England Healthcare Exchange Network, respectively).

## About DGC

The DGC is a collaboration between payer and provider organizations convened to discuss, design, and implement data sharing and interoperability among payers, providers, patients/members, and other interested parties who need health data. It is a one stop interoperability resource. The DGC primarily focuses on three areas:

1. Collaboration: Development of common understanding of and specifications for data standards, exchange mechanisms, and what it means to participate in the modern health IT ecosystem
2. Education: helping members understand their regulatory obligations, the data and exchange standards they're expected to use, and modern technology and related processes
3. Innovation: Identification and development of projects and services needed to make modern health data practices and exchange a reality

## General Comments

This section comments on the general approach taken by ONC provide comments on areas that cross multiple sections of or items in the plan.

## Repetition of Key Content

We understand that outlining the importance of health equity by design is essential and a major point of this document, but we found the repetition of specific content a bit overwhelming. For example, slight variations on the following statement appear over and over again, particularly in the first two sections of the document (the

introduction and section I):

“The use of an HEBD approach with health IT ensures that equity considerations are identified and incorporated as a core principle in the design, build, and implementation of health IT systems”

We agree with the sentiment, but having it appear nearly verbatim in so many places is distracting from other key points that may be nearby, and the level of repetition may be sufficient to cause some readers to zone out or decide they’ve already gotten the point and stop reading the document.

This was by far the most egregious example, but not the only one. Judicious use of repetition to make sure people understand important ideas can be a useful tool, but we urge ONC to carefully assess the amount of repetition and cut back to a level that highlights important ideas without the potential negative consequences from overdoing it.

## Document Organization

We appreciate the idea of splitting the document into three main sections, each with a specific and distinct purpose and expected content (four if you include the introductory section), but we were sometimes confused by how the content was actually distributed across these sections.

For example, there’s a bulleted list toward the end of section I (at the bottom of page 6) that starts with:

“In order to foster shared learning and encourage public feedback, this discussion draft”

This seems like document framing material better suited to the introductory section. In fact, it duplicates much material from that section (but we do see benefit from having it in one place in a cohesive list were it in a more expected location within the document)

Another example is the inclusion of high level “what is ONC doing?” information in Section I which we were told up front would be the subject of section III.

## Applying Population Characteristics to Individuals

Participants in our Data Governance Collaborative note that there can be a tendency to look to population characteristics when individual data isn’t readily available. For example, to apply geographic norms to individuals in a particular location. This concept was not stressed in this document, but it did come up every so often. We caution against relying on this practice without comment that it is not the preferred/ideal practice, and suggest recommending some type of provenance that indicates the data is not directly provided but inferred in some when this method is used.

## Response to Specific Items in the Document

This section will address specific items in the draft.

### Foundationally Equity Enforcing

Participants in our Data Governance Collaborative found the concept of health equity by design being foundationally equity enforcing intriguing, but did not feel ONC unpacked the idea sufficiently to either make it clear exactly what this means or show that it is, in fact, true.

We welcome further expansion of this idea, what ONC means by it, and why ONC feels that it is true.

### Section II - General

We appreciate the power of examples and understand why ONC chose to include several in this document, but the example choices seem very arbitrary and, in general, do not provide enough detail to be actionable. Some of the examples are not presented clearly or result in many questions that may interfere with the purpose of including the examples in the first place.

We will provide specific feedback on individual examples below, but perhaps one addition that could help is providing links to materials such as relevant slides and recordings from the HITAC meeting referenced as the

source of these examples.

## Georgia SDOH Example

We appreciate the potential power of this example, but it was not well explained in the document. In particular, once GaHIN is introduced, the example seems to veer off into providing some not clearly pertinent information about the HIE, the Morehouse School of Medicine, and the power of HIEs generally. None of this is tied directly to the SDOH example. For example, the data flow from the pediatric provider is not directly followed once it enters GaHIN and the specific role of the HIE (or Morehouse) within the context of the example is not specified.

Further, the document appears to go off on a tangent about the power of HIEs, but most of the items it highlights there seem to be either more generally examples of the power of interoperability/data exchange or have no clear connection to HIE functionality (for example, assisting the digital divide by providing broadband access).

We urge ONC to revisit this example and more clearly discuss the pediatric clinic example, following the data flow to GaHIN and/or Morehouse if appropriate, but only with explicit explanations of how they fit in/how the data flows through the system specific to this particular pediatric program.

## ADT Example

This was an interesting example that leads to some complex questions that were not addressed within this draft.

While the point about considering unhoused or inconsistently housed individuals is very valid from an equity perspective, the opposite side of the coin is not addressed at all: address is widely considered one of the most important elements for ensuring correct patient matching. In fact, ONC itself pushed the Project US@ effort as a key step forward in better patient matching. That project was completely focused on standardizing and exchanging better address information.

Any useful examination of the issue must look at the balance of equity issues and the ability to ensure correct patient matching and protecting the privacy of patients that would otherwise be violated should incorrect matches be made. As presented, the example currently implies that addresses should not be part of any patient matching project.

## Artificial Intelligence and Machine Learning Example

This clearly is an example that touches on areas that have health equity implications and are right in the wheelhouse of ONC/rife for the application of health equity by design. However, the list of identified areas is not sufficient information to help readers understand what the potential biases are or how to think about avoiding them if applying health equity by design practices to their own AI efforts. Without this, the example is significantly less useful than it could be as it doesn't really include a specific call to action or direction on how to apply it to other efforts.

## Digital Divide and FHIR

Participants in our Data Governance Collaborative find the mechanism of promoting FHIR usage under the rubric of solving the digital divide a bit odd. We certainly all agree that the lack of broadband access in certain locations is a major issue and barrier to care, as are the less frequently discussed cell service deserts that often occur under different conditions (as part of our discussion we determined that more than 20% of the people participating in our discussion - taking place among individuals working in health data or health IT in the Greater Boston area - had difficulties with obtaining cell service either at home or at work or both). This issue is important, and both components should be discussed and addressed as possible.

However, we feel like FHIR as an aide to promoting health equity is worth promoting in of itself. ONC points out the promise of using FHIR to power apps in multiple languages to serve the many people who are not strong English speakers. This is a major equity issue that affects many people whether or not they have access to broadband internet. There are many other use cases that could improve health equity for everyone.

That said, we do agree that having access to mobile apps (likely powered by FHIR) in areas with no or limited broadband access is important, just as having access to desktop or other apps (likely powered by FHIR) would be helpful in areas with limited cell service.

## Response to Specific Questions

This section will address specific questions asked by ONC in the draft

### **Do you think this draft identifies the core issues and heads in the right direction? Are there changes you recommend based upon your own experiences with health inequities and health equity by design?**

As noted in our comments throughout, we believe there are many ways this document could be improved. However, we applaud the general idea of health equity by design and agree that a document outlining what it is, examples of ways to apply it, actionable tips, and what ONC and/or other agencies within HHS are doing to apply health equity by design is worthwhile.

To reiterate a few key points made above, some of the changes we recommend include:

- Reducing repetitious content
- Providing more directly actionable tips from examples and other content
- Balancing examples of health equity concerns with impacts of changes in other areas when they exist
- Promoting FHIR directly rather than primarily as a solution to the digital divide

We also urge ONC to take a look at equity issues that may not be getting as much attention generally, especially those that are technology related (such as the aforementioned cell service deserts) but also areas that could be helped by better data standards/definition in areas not yet being addressed (such as disability accommodations data, an area we have explored in some detail that has not yet gotten much attention across the wider industry).

### **What are the leading barriers to health equity and health equity by design that you experience in your efforts? How do you think ONC can help?**

We believe that lack of clear data standards is a major issue that falls right in ONC's wheelhouse. While efforts are ongoing to expand relevant demographic and SDOH data, the level of definition of common elements is not specific enough to provide consistent data across a myriad of users.

Further, the data currently under discussion is often not specific enough to be actionable. Our Data Governance Collaborative has explored this in detail both around the various different ways common demographic data can be interpreted depending on the specific use case in question when it's collected and how the data collected is not specific enough to be actionable.

For example, religion can be needed to determine if clerical services should be offered to hospitalized patients, to determine dietary standards and needs, to determine whether screening for certain diseases is warranted, etc – whether the religion is by birth, by choice, or by culture might make a difference for the correct answer for each use case and if someone is just sent a religion they may not know which context it was collected under.

Two good examples of the lack of specificity of the currently collected data include:

- understanding the underlying cause of an SDOH issue like food insecurity; currently much of the time there's a default assumption that the issue is financial which is not always the case. Without knowing the cause it's impossible to try to properly address it/assist the patient with the need
- understanding the accommodations needed for disabled patients. It's not enough to know that someone has a visual impairment (for example); you need to know the modifications to standard processes needed to accommodate that patient so they have a successful encounter, test, evaluation, etc.

## **Are there any activities described above that you think are having unintended, adverse effects on health equity by design?**

We do think it would be appropriate to have some discussion around how health equity by design works in conjunction with other factors to result in useful, equitable health IT solutions for all. For example, while it is essential to consider impact on the unhoused and inconsistently housed in all projects, it is reasonable to consider how changes designed to improve access for this constituency impacts the effectiveness of a key task like patient matching. Any decrease in matching accuracy by removing address requirements should be quantified and decisions around whether the loss in accuracy from not using addresses is acceptable or, if not, how to address the unhoused in other ways.

We urge ONC to take a more holistic view without losing its firm belief of the importance of health equity and addressing the impact of specific choices on a wide variety of potentially disadvantaged populations.

## **How will you heed this call to action? What practical steps will you take, both near term and long term, to use and design technology for health equity improvement purposes?**

MHDC and our Data Governance Collaborative take health equity very seriously. We regularly review documents, guidance, RFIs, NPRMs, and other regulatory actions related to different components of equity and comment upon them as possible. As noted above, we discuss equity-related data in detail, and work to consider equity in all of our activities.

Our Director of Policy, Technology, and Innovation (Janice Karin, who also leads our Data Governance Collaborative) is also the Co-Chair of the WEDI Health Equity Workgroup and regularly participates in industry events related to health equity including WEDI events beyond the workgroup, CMS Health Equity conferences, relevant ONC events, and more. She brings an equity lens to all of her discussions within MHDC and across the industry.