



All Payer Claims Database Data Submission Guide Responses to Public Comment Period July 2023

SUMMARY

In accordance with the policies and procedures of the All Payer Claims Database (APCD), OHS, provided a 30-day public comment period on proposed updates to the APCD Data Submission Guide (DSG) also known as the Data Submission Companion Guide, to enable the collection of new data elements: 1) dental claims, 2) fully denied claims, and 3) Race, Ethnicity and Language ([REL](#)) data in accordance with [Conn. Gen. Stat. §19a-754d](#). The comment period began Friday, May 19, 2023, and ended Saturday, June 17, 2023, 11:59 p.m. EST.

RESPONDENTS

Comments were submitted by the following individuals and entities.

- Melinda Kennedy on behalf of Aetna/CVS Health
- Kiran Chigurupati on behalf of Express Scripts
- Mary Poulin on behalf of Point32Health
- Supriyo B. Chatterjee and Dr. Velandy Manohar
- Lisa Stump on behalf of Yale New Haven Health and Yale Medicine
- Megan Drost

Responses to all questions and comments are provided below in the order in which they were received and by submitter.

Comments submitted by Melinda Kennedy on behalf of Aetna/CVS Health

Q1. *Can you confirm that you want the new ME033 Language Code values in lowercase as they show on the listing?*

Thank you for your comment. The ME033 language code is case sensitive. Values should be in uppercase.

Q2. *What will be the timeline for implementation of the DSG changes after the DSG updates are finalized? We normally need 6 months to change over for DSG updates.*

Thank you for your comment. In accordance with [APCD Policies and Procedures](#), “any such revisions [to the DSG] shall not be effective until ninety (90) days following publication of the final revisions on the APCD website or such later date” as shall be determined by OHS.

In consideration of the scope of this change and the timeframe requested by some stakeholders as part of this public comment period, OHS is setting the deadline for payers to submit data in the new format to January 1, 2024. After January 1, 2024, all data should be submitted according to the DSG changes made in 2023. Upon finalization of the DSG, OHS/Onpoint will notify submitters.

On and after January 1, 2024, each payer shall submit denied, dental, REL data monthly (January data will be submitted in February, February data submitted in March, and so forth).

Q3. *Is it your intention to receive RX Rejects? These are the only “Denied” RX claims.*

Thank you for your comment. OHS intends to collect both Rejected claims for pre-authorization and Denied claims. Include truly denied claims using the NCPDP list to identify the claims and exclude all claims that cannot be paid unless additional/corrected information is submitted.

Q4. *We want to let you know that the CARC codes are not always available from our claim systems so some denied claim lines will have blanks.*

Thank you for your comment. OHS recognizes CARC codes will only exist in applicable claims.

Q5. *We only receive Race and Ethnicity codes if the member chooses to answer the questions, limited population.*

Thank you for your comment. In accordance with Conn. Gen. Stat. §19a-754d, clients/patients are not required to provide Race, Ethnicity or Language (REL) data to receive care or services; the statutes also require REL data to be self-reported by the client/patient.

Comments Submitted by Kiran Chigurupati on behalf of Express Scripts:

Q1. *Once the new changes are decided, when is the data due in the new format? Will it be February submissions for January 2024 data?*

Thank you for your comment. Yes, February submissions for January 2024 data.

Q2. PC110 – Claim Line Type – *We are planning to leave this field blank for denied claims as there is not a corresponding value. For example, other states have a value of “D” to represent the claim is denied. Please let us know if another value should be selected.*

Thank you for your comment. For denied claims, report the following:

- Claim Status Code (PC025) = 4
- Denied Claim Indicator (PC116) = 1
- Denial Reason (PC117): report the code that defines the reason for the denial of the claim using the National Council for Prescription Drug Programs (NCPDP) code set

Q3. PC117 – Denial Reason – *We do not have the NCPDP code set available in our information warehouse. Consequently, we will utilize guidance from this field to continue to report our existing values. Please see the values in the attached reference table as requested (ESI IW Service Message Reject Codes), which will be populated.*

Thank you for your comment. In this case any submitter that is unable to use the NCPDP code set will be required to provide us with a reference table with all non-standard values. The *ESI IW Service Message Reject Codes will be satisfactory.*

Q4. ME033 – Language Preference Code – *We do not have the ISO codes in our information warehouse. Consequently, we will continue to report using the historical three-character language identifier as the field guidance allows.*

[Conn. Gen. Stat. §19a-754d](#) requires the collection of REL data, already being collected in the APCD, to align with the new standards. Based on the statute requirements, OHS has developed REL data collection standards that align with recommendations from the OHS Community and Clinical Integration Program (CCIP), the U.S. Office of Management and Budget (OMB), and the International Organization for Standardization (ISO). In support of this requirement, DSG specifications has been updated to cite a list of codes released in 2022 by OHS to serve as a reference table (available here: <https://portal.ct.gov/-/media/OHS/Health-IT-Advisory-Council/REL/PA-21-35-REL-Data-Collection-Standards.pdf>).

Thank you for your comment. Health insurers are asked to use this code set when reporting their data to the APCD. Insurers that are unable to satisfy this requirement can continue to report REL-related data using legacy code values until their capabilities are brought into alignment.

In accordance with APCD Policies and Procedures, organizations may request a waiver of data submission requirements as noted below:

“Waivers of Data Submission Requirements: The Administrator may waive particular data submission requirements for a Reporting Entity that demonstrates to the Administrator’s satisfaction that those required data elements are not currently available in the Reporting Entity’s systems. As a condition for granting a waiver, the Administrator may require a Reporting Entity to submit a plan for improving conformance to data submission requirements.”

Q5. *Please let us know which period the new requirements will be effective. Thank you for the opportunity to provide feedback.*

Thank you for your comment. The deadline for payers to submit data in the new format is January 1, 2024. Beginning January 1, 2024, all data should be submitted according to the DSG changes made in 2023. Each monthly submission shall now include denied, dental, and REL data (January data will be submitted in February, February data submitted in March, and so on).

In consideration of the scope of this change and the time required for systems to be updated to comply with the DSG, OHS is extending the deadline for payers to submit data in the new format to January 1, 2024. OHS/Onpoint will notify submitters, post information on data submission, and offer support services including:

- 1) Onboarding meeting to discuss the submission updates;
- 2) Webinars for stand-alone dental submitters:
 - a) Training on registration
 - b) Training on SFTP & PGP encryption requirements
 - c) Training on CDM & the variance request process

Comments Submitted by Mary Poulin on behalf of Point32Health

Q1. *To make the changes and updates stand out clearly, could the final requirements be published in a red-line version? Alternatively, could both old and new requirements be published as Word documents so that they can be compared, and changes noted explicitly? We are concerned that subtle differences in such detailed specs might otherwise escape our notice.*

Thank you for your comment. OHS will publish a cover letter and DSG change log that will provide comprehensive overviews of the updates.

Q2. *When will the deadline be for implementation? We are requesting that we have six months from the date of the publication of the final regulations. If the final specs are sent out in July, then we'd like to have until data for January 2024 are required in February 2024.*

Thank you for your comment. In accordance with APCD Policies and Procedures, after a public comment period of 30 days, “any such revisions [to the DSG] shall not be effective until ninety (90) days following publication of the final revisions on the APCD website or such later date as shall be determined by the Administrator [OHS].”

In consideration of the scope of this change and the time required for systems to be updated to comply with the DSG, OHS is extending the deadline for payers to submit data in the new format to January 1, 2024. OHS/Onpoint will notify submitters, post information on data submission, and offer support services including:

- 1) Onboarding meeting to discuss the submission updates
- 2) Webinars for stand-alone dental submitters:

- a) Training on registration
- b) Training on SFTP & PGP encryption requirements
- c) Training on CDM & the variance request process

Q3. *Only a small portion of our membership is eligible for dental benefits and we do not receive reliably reportable dental data from our vendors. How can we waive the requirement to submit dental claims?*

Thank you for your comment. Please reference the APCD Policies and Procedures regarding exclusions and waivers of data submission requirements. The Policies and Procedures may be found on the OHS website [here](#). Submitters with 3,000 or more members must submit data according to the APCD Policies and Procedures.

Exclusions (P&Ps)

Data related to the following types of policies shall be excluded from the files submitted by Reporting Entities: hospital confinement indemnity coverage; disability income protection coverage; accident only coverage; long term care coverage; TriCare Supplemental Coverage; travel health coverage; and single service ancillary coverage, with the exception of dental and prescription drug coverage.

Reporting Entities that have fewer than a total of 3,000 Members enrolled in plans not otherwise excluded from the files that are offered or administered by the Reporting Entity on October 1 of any year and are exempt from the data submission requirements set forth in this Policy and Procedure for the following calendar year, except that all Reporting Entities shall comply with Annual Registration Requirements.

Waivers can be submitted to the APCD administrator, OHS. The process is outlined below.

Waivers of Data Submission Requirements (P&Ps)

The Administrator may waive particular data submission requirements for a Reporting Entity that demonstrates to the Administrator's satisfaction that those required data elements are not currently available in the Reporting Entity's systems. As a condition for granting a waiver, the Administrator may require a Reporting Entity to submit a plan for improving conformance to data submission requirements.

Comments submitted by Supriyo B. Chatterjee and Dr. Velandy Manohar:

Testimony by Supriyo B. Chatterjee and Dr. Velandy Manohar may be viewed starting on page 8 of this document.

Thank you for your comment. Thank you also for your past participation in the two OHS committees mentioned in your submittal and for your detailed and thoughtful comments that pertain to the Health Information Exchange (HIE) and the APCD program. Potential bias introduced by artificial intelligence (AI) into analysis is a concern for all stakeholders. OHS is monitoring developments as pertains to AI. The State of CT's Office of Policy and Management will be developing and establishing policies and procedures on development, procurement, implementation, utilization and ongoing assessment of systems that employ artificial intelligence and may be use by state agencies. Currently, OHS has no plans to utilize AI.

Comments Submitted by Lisa Stump on behalf of Yale New Haven Health and Yale Medicine

Q1. In response to the request for comments, we would ask that medical and Rx claims for Medicaid patients be available to organizations/entities who are approved to receive data extracts from APCD. I don't recall why Medicaid is not included.

OHS in collaboration with the Department of Social Services will evaluate the suggestion to make Medicaid data available to external requestors consistent with the APCD's mission.

Comments Submitted by Megan Drost

I am writing in regards to the merger of ECHN and Yale. I would like to share some positive thoughts on this pending transaction.

I do believe that bringing in the structure and expertise Yale can provide into the Eastern CT community via a merger with ECHN will be beneficial to the community and those who live in it. This merger will allow the residents of Eastern CT world class care. I thank you for your time and consideration of my thoughts.

Thank you for taking the time to submit feedback. However, this comment opportunity only applies to the APCD Data Submission Guide and does not address the certificate of need (CON) process which is reviewing the Yale/Prospect acquisition. We will forward your comments to the CON unit for its consideration.

SUPPLEMENTAL INFORMATION

Modifications

The following modifications approved by the APCD Advisory Group address four primary areas updated in the APCD's data collection specifications:

- 1. Race, ethnicity, and language (REL) data collection.** [Conn. Gen. Stat. §19a-754d](https://portal.ct.gov/-/media/OHS/Health-IT-Advisory-Council/REL/PA-21-35-REL-Data-Collection-Standards.pdf) requires OHS to develop REL data collection standards that align with recommendations from the OHS Community and Clinical Integration Program (CCIP) and with standards from the U.S. Office of Management and Budget (OMB) and the International Organization for Standardization (ISO). In support of this requirement, DSG specifications has been updated to cite a list of codes released in 2022 by OHS (available here: <https://portal.ct.gov/-/media/OHS/Health-IT-Advisory-Council/REL/PA-21-35-REL-Data-Collection-Standards.pdf>). Health insurers are asked to use this code set when reporting their data to the APCD. Insurers that are unable to satisfy this requirement can continue to report REL-related data using legacy code values until their capabilities are brought into alignment. This change affects coding for five eligibility fields in the DSG related to race (ME021, ME022), ethnicity (ME025, ME026), and language (ME033).
- 2. Denied claims data collection.** Requirements have been updated to standardize the reporting of both partially and fully denied claims using a common set of codes instead of the current array of insurer-specific codes. Denied claims should now be reported to the CT APCD using Claim Adjustment Reason Codes maintained by the Accredited Standards Committee (ASC) X12 (available here: <https://x12.org/codes/claim-adjustment-reason-codes>).

As with REL data, insurers that are not prepared to update their approach can continue to report carrier-defined codes if those codes and their descriptions are provided to the CT APCD prior to submission. This change impacts the Denial Reason codes reported in the medical claims, pharmacy claims, and dental claims (see below) using fields MC124, PC117, and DC095, respectively.
- 3. Dental claims data collection.** Following a 2022 determination by the APCD Advisory Group that dental claims are a high-value data set missing from the CT APCD, the DSG has been expanded to include a new file layout to support dental data collection in alignment with industry and national standards.
- 4. Updating DSG Fields:** The date modified column that did not add value to submitters was removed, the Risk Adjustment Covered Plan field was also modified. In addition, the denial reason was updated in the DSG to highlight details for submitters.

The full final Data Submission Guide can be viewed in PDF format on the OHS website here: <https://portal.ct.gov/-/media/OHS/Health-IT-Advisory-Council/Publications/APCD-Related-Publications/CT-APCD-Data-Submission-Guide-Final.pdf>

The full final Data Submission Guide can be viewed in Excel format on the OHS website here: <https://portal.ct.gov/OHS/Services/HIT-Health-Innovation-Consumer-Engagement/Health-Information-Technology/All-Payer-Claims-Database>

A Public Comment submitted to the Connecticut Office of Health Strategy (OHS)

By

Dr. Velandy Manohar MD., DLFAPA*

Supriyo B. Chatterjee MSc MBA MA (Econ)¹

June 16, 2023

Re: 2023 CT OHS All-Payer Claims Database (APCD) Data Submission Guide (DSG)

Thank you for this opportunity to present a public comment on the Office of Health Strategy (CT OHS)'s All Payer Claims Database (APCD) Data Submission Guide (DSG)². The views expressed in this testimonial are our own.

We served in two important OHS committees - The Community Advisory Board (CAB), Practice Transformation Task Force (PTTF), and the Population Health groups within the State Innovation Model (CT SIM) program. Later, in the OHS Community Advisory Council (CAC). We attended numerous meetings of the Health Information Technology Advisory Council (HITAC) committee and the State Health Care Cabinet. As part of the CAB and CAC committees, we obtained perspectives from the community in their programs and events. Our reports and testimonials are available on the OHS website. In addition, we have submitted public testimonials in support of state legislation for improvements in health equity, health information technology (HIT), and school-based health centers. Several such pieces of legislation were passed into state statutes. Our experience includes working with medical records, and healthcare information systems and utilizing AI analytics in various health outcomes, and chronic disease management algorithms for cost-effective interventions.

Health data concerns – new regulations and newer technologies

While the security and privacy of health data remain a major concern³ – its secondary and tertiary use has garnered an additional concern through the use of newer AI algorithms. On

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² APCD Data Submission Guide (DSG) for Public Comment | CT OHS 5/18/2023

<https://portal.ct.gov/OHS/Press-Room/Announcements/CT-APCD-Public-Comment-Period-Announcement-2023>

³ In the US, patient data privacy is an illusion | The BMJ 6/1/2023

<https://www.bmj.com/content/381/bmj.p1225>

June 7, 2023, the Legislative Bill 2023 SB 1103 was passed (now PA 23-16)⁴. This statute addresses the data algorithms in use with various state agencies and related organizations including CT OHS. Earlier, the Federal agency ONC proposed in the HTI-1 Rule - Algorithm Transparency and Information Sharing updates⁵. In addition, the recent display of Artificial Intelligence (AI) and its power over the consumer – has garnered increasing public concern about the use of AI and the need for consent⁶. We believe both the aforementioned statutes will be increasingly influential over CT OHS operations with other entities. As such, due consideration must be factored in with HIT and APCD development. This includes revisiting the current ‘Consent Policy’ that is exercised by CT OHS.

CT OHS oversees ‘Connie’ (Health Information Exchange - HIE)⁷, APCD Development⁸, Race, Ethnicity, & Language (REL) Data collection (within multiple entities and State agencies)⁹, Health Information Technology Advisory Council (HITAC), and other future development.

The collection of REL Data and its inclusion into EHR medical records is now codified under CT OHS Statutes¹⁰. The section below elaborates on the implication of REL Data on Health Equity and the importance of consent management. The updated (August 11, 2022) APCD Group Charter¹¹ describes the roles and functions of CT OHS and HITAC in APCD development.

The APCD database contains over 950 million records of medical claims, pharmacy claims, eligibility, and provider files from commercial, Medicare, and Medicaid payers¹². This database is expected to grow more with the advent of new data entities from Dental and other provider sources. (Dental records were not stated in the Wave 1 & Wave 2 Use Cases recommendations¹³).

⁴ MFIA Research Fuels New Connecticut Law Regulating State Use of Algorithms | Yale Law School 6/7/2023
<https://law.yale.edu/yls-today/news/mfia-research-fuels-new-connecticut-law-regulating-state-use-algorithms>

⁵ ONC offers an overview of HTI-1 proposed rule expectations | Healthcare IT News 4/26/2023
<https://www.healthcareitnews.com/news/onc-offers-overview-hti-1-proposed-rule-expectations>

⁶ We need to bring consent to AI | MIT Technology Review 5/2/2023
<https://www.technologyreview.com/2023/05/02/1072556/we-need-to-bring-consent-to-ai/>

⁷ ‘Connie’ – Connecticut Health Information Exchange (HIE) | OHS HIA <https://connect.org/>

⁸ CT OHS - All-Payer Claims Database (APCD) | <https://portal.ct.gov/OHS/Services/HIT-Health-Innovation-Consumer-Engagement/Health-Information-Technology/All-Payer-Claims-Database>

⁹ CT OHS - Race, Ethnicity and Language Data Collection - Public Act 21-35 Section 11 Mandate
<https://portal.ct.gov/OHS/HIT-Work-Groups/Race-Ethnicity-and-Language>

¹⁰ CT OHS - Sec. 19a-754d. Collection of demographic data re ancestry or ethnic origin, ethnicity, race or primary language. Inclusion in electronic health record systems.

https://www.cga.ct.gov/current/pub/chap_368dd.htm#sec_19a-754d

¹¹ Group Charter - All-Payer Claims Database Advisory Group Aug 11, 2022
<https://portal.ct.gov/OHS/HIT-Work-Groups/APCD-Advisory-Group/Members>

¹² CT OHS - CT All-Payer Claims Database APCD Data Release Process
<https://portal.ct.gov/OHS/HIT-Work-Groups/APCD-Data-Release-Committee/Data-Request>

¹³ HIE Use Case Design Group Report and Recommendations | October 2017

For unexplainable reasons, Dental records were prioritized over REL development in the HIE CONNIE development during the pandemic). **However, it should be noted that currently, the APCD database only reflects ~3% of the said REL population¹⁴.** Add to it the numerous new systems of providers and claims that will need to conform to REL Submission requirements. Updating this database with REL information will be a considerable task, not only in terms of volume but to maintain data integrity so as not to introduce any “bias” in the data and the algorithms used. “Bias” in medical AI models cannot be underestimated and it particularly impacts the minority population.¹⁵

Meaningful Consent – a framework for CT Office of Health Strategy (CT OHS)

The current implementation of a ‘Consent Policy’ still falls short of a framework to address complexities that may be encountered by CT OHS in ‘Connie’ HIE, APCD, and future development. Whether it is an ‘opt-out’ or ‘opt-in’ of the submission of their data, the patient would still like to know the choices before making a decision. ***‘Meaningful consent occurs when the patient makes an informed decision and the choice is properly recorded and maintained.’¹⁶***

The patient’s meaningful choice in a decision is defined as¹⁷:

1. *Made with advanced knowledge/time,*
2. *Not used for discriminatory purposes or as a condition for receiving medical treatment,*
3. *Made with full transparency and education,*
4. *Commensurate with circumstances for why health information is exchanged,*
5. *Consistent with patient expectations, and*
6. *Revocable at any time.*

The patient’s decision-making and interests incorporate four key factors:¹⁸

- *Who could access their health information?*
- *What type of information could be accessed or shared?*

<https://portal.ct.gov/OHS/HIT-Work-Groups/HIE-Use-Case-Design-Group/Publications>

¹⁴ Connecticut APCD Advisory Group Meeting, February 11, 2016

http://www.ct.gov/hix/lib/hix/Presentation_02112016.pdf

¹⁵ Bias in AI-based models for medical applications: challenges and mitigation strategies | Nature Digital Medicine 6/14/2023

<https://www.nature.com/articles/s41746-023-00858-z>

¹⁶ Meaningful Consent In Electronic Health Information Exchange: A Technology-Centric Approach | Health Affairs 9/17/2013

<https://www.healthaffairs.org/doi/10.1377/hblog20130917.034263/full/>

¹⁷ Meaningful Choice: Patient-Centered Decision Making in Electronic Health Information Exchange - HealthIT Gov 10/3/2012

<https://www.healthit.gov/buzz-blog/privacy-and-security-of-ehrs/meaningful-choice-electronic-health-information-exchange>

¹⁸ Supra note 13.

- *How is information protected and secured?*
- *Why may the information be accessed or shared (i.e., the purpose of use)?*

This ‘Meaningful Consent’ framework can aid the patient in their decision-making and contribute towards patient education and health literacy (especially in health equity matters – explained below). This framework helps CT OHS to function in a ‘patient-centric’ manner. This complements the efforts of the healthcare providers in their ‘patient-centered’ approach.

The current state of CT OHS Consent policy – ‘opt-out’ and ‘trust but verify’.

On May 3, 2021, ‘Connie’ HIE was rolled out and commenced operations¹⁹. Earlier, in March 2020, public comments were welcomed by OHS HITAC on the Consent Guiding Principles²⁰ of the Design Group’s Final Report and Recommendations²¹. The questions raised and the answers received, assuaged some of the concerns regarding the State HIE. However, since the roll-out, Connie HIE has shown less than an ideal ‘Consent Policy’ management²². It is not known how consent validation and consent trail by logging are performed. This should audit all consent transactions made and attempted. This is different than the usual annual/biannual system audits. Transaction audit logs perform a ‘trust but verify’ action that can mitigate liability should an infringement occur (or in the case of a cyber breach).

Most Consent Management Solution (CMS) systems incorporate validation and audits²³. ***This is regardless of the consent policy choice of ‘opt-in’ or ‘opt-out’ or a combination of both (giving granular control of choice elements).*** A CMS system should be considered to perform validation and audit logs of transactions within the Connie HIE system and APCD development.

The future of ‘Connie’ HIE and APCD – Patient-centric health data availability.

Currently, ‘Connie’ is based on the premise – “As the HIE builds its technical capabilities, a robust *consent management solution* will be identified that expands patient options for

¹⁹Connie is ready to connect! Connie, commences operations on May 3, 2021.

<https://portal.ct.gov/OHS/HIT-Work-Groups/Health-Information-Alliance>

²⁰ OHS Seeks Feedback on DRAFT Consent Guiding Principles

https://portal.ct.gov/-/media/OHS/Health-IT-Advisory-Council/Reports/OHS-Seeks-Feedback-on-Consent-Guiding-Principles_021420.pdf

²¹ Consent Design Group Final Report and Recommendations - CT Office of Health Strategy

https://portal.ct.gov/-/media/OHS/Health-IT-Advisory-Council/Reports/OHS_Consent-Design-Group_Final-Report_2020.pdf

²² HITAC Advisory Council meeting – May 20, 2021

<https://portal.ct.gov/OHS/HIT-Work-Groups/Health-IT-Advisory-Council/Meeting-Materials/May-20-2021>

²³ Consent management | Wikipedia. Accessed 6/16/2023 https://en.wikipedia.org/wiki/Consent_management

managing access to their personal health information (PHI)”²⁴. This does not show a priority to address the concerns and currently puts limitations on ‘meaningful consent’ by the lack of a Consent Management Solution (CMS). Furthermore, it is not known whether validation and audit logs of access transactions are performed in any form. A CMS system can also help facilitate the important requirement of having patient-centric data provisions - the 21st Century Cures Act and the Interoperability and Patient Access final rule (CMS-9115-F)²⁵. A CMS is utilized in conjunction with the ‘Master Patient Index (MPI)’ for consent validation for the individual patient.

The 2021 ‘Information Blocking’ regulations are limited to structured healthcare data. **However, the majority of health data (estimated at 80% and growing 47% per year)²⁶ remains unstructured and must be accommodated within the ‘Connie’ HIE and other related OHS systems.** As the Office of the National Coordinator for Health IT, Micky Tripathi pointed out – ***“making healthcare organizations responsible for sharing that structured data as well as some unstructured data, presenting a bigger challenge”***²⁷. The implication of this directive which is now current will vastly affect data management, data analytics, and data quality: ***“The only way that we’ll be able to get our arms around that is by using algorithms, machine learning, and other kinds of approaches, such as natural language processing, to be able to take advantage of on behalf of the patient, on behalf of better quality, to be able to take advantage of that broader, comprehensive information that’s available.”***²⁸ This is not feasible without a CMS and revising data collection and management procedures.

REL Data and Health Equity – ‘opt-in’ and ‘selection biases’.

²⁴ Consent Design Workgroup Guiding Principles - Response to Public Comments - page 8
https://portal.ct.gov/-/media/OHS/Health-IT-Advisory-Council/Design-Groups/Consent-Design-Public-Comment/OHS_Consent_GPs_Response_to_Comments_Draft-07022020.pdf

²⁵ The key to interoperability: safe, secure access to patient health data - Medical Economics 4/5/2021
<https://www.medicaleconomics.com/view/the-key-to-interoperability-safe-secure-access-to-patient-health-data>

²⁶ How to Navigate Structured and Unstructured Data as a Healthcare Organization | HealthTech Magazine 5/8/2023
<https://healthtechmagazine.net/article/2023/05/structured-vs-unstructured-data-in-healthcare-perfcon>

²⁷ ONC Leader Tripathi Offers Tips for Interoperability Rule Success - EHR Intelligence 4/22/2021
<https://ehrintelligence.com/news/onc-leader-tripathi-offers-tips-for-interoperability-rule-success>

²⁸ *ibid*

While Race, Ethnicity, & Language (REL) data acquisition and management could lead to systemic improvements²⁹ – it is no easy task³⁰. It is presumed that CT OHS REL data conforms to industry standards, such as CDC Race and Ethnicity Code Set³¹. Varying cultural groups call for a concerted effort in patient education and health literacy to ‘opt-in’ their REL data elements and ‘opt-out’ of ‘Connie’ HIE and APCD. Regardless of state statutory requirements – REL data elements cannot be mandated upon patients without their explicit consent. However, the consent response needs to be recorded even if data de-identification is conducted. This is because it may be used in stratification analysis and to gauge allocation, population health³², and health inequities. In applying algorithmic functions - missing data elements can introduce ‘biases’. The recent discovery of bias in a decision-making algorithm³³ has garnered interest in the medical press³⁴ and the State of New York regulatory body³⁵. A recent study found the need for corrections of algorithmic bias across several clinical fields – from cardiology to urology³⁶. Algorithms need complete data elements with transparency, accountability, and ‘explainability’ to mitigate clinical, ethical, and legal issues.

It behooves CT OHS to seriously consider a more robust Consent Management Solution (CMS) system and procedures which will also help mitigate data “bias” and assuage public concerns. We welcome a discussion as an agenda item in a CT OHS HITAC meeting.

Thank you,

Dr. Velandy Manohar, MD DLFAPA
Supriyo B. Chatterjee, MSc MBA MA (Econ)

²⁹ There is no equity without standardized race, ethnicity and language data | CT Mirror 4/9/2021

<https://ctmirror.org/category/ct-viewpoints/there-is-no-equity-without-standardized-race-ethnicity-and-language-data/>

³⁰ Racial differences in patient consent policy preferences for electronic health information exchange - JAMIA May 2020

<https://pubmed.ncbi.nlm.nih.gov/32150259/>

³¹ ONC offers an overview of HTI-1 proposed rule expectations | Healthcare IT News 4/26/2023

<https://www.healthcareitnews.com/news/onc-offers-overview-hti-1-proposed-rule-expectations>

³² Facilitating the ethical use of health data for the benefit of society: electronic health records, consent and the duty of easy rescue - Royal Society Pub Dec 2016

<https://royalsocietypublishing.org/doi/10.1098/rsta.2016.0130>

³³ Dissecting racial bias in an algorithm used to manage the health of populations – SCIENCE - Oct 25, 2019

<https://science.sciencemag.org/content/366/6464/447>

³⁴ Discovery of racial bias in health care AI wins STAT Madness ‘Editors’ Pick’ - STAT News 4/6/2020

<https://www.statnews.com/2020/04/06/stat-madness-editors-pick-racial-bias-in-health-care-ai/>

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