**Utah Health Data Committee (HDC) Meeting Minutes**

**Tuesday, September 19, 2023**

3:00 PM:

The meeting was called to order by HDC Chair, Charles Hawley.

Members attended virtually and via phone. Pursuant to the Utah Open and Public Meetings Act, an anchor location was available at the Cannon Health Building, room 125. Access information was posted on the Utah Public Notice Website.

The meeting was scheduled from 3:00 PM to 4:30 PM.

**IN ATTENDANCE:**

**Members Present**: Charles Hawley, Stephen Foxley, David Crockett, Jeffrey Eason, Laura Summers, Alan Ormsby, David Cook, Susan Longfield, Patrice Hirning, Tanji Northrup, Stephen Neeleman, Curtis Newman

**Members Absent**: Terri Nehorai, Russell Trujillo

**Staff Present**: Lori Savoie, Rick Little, Mike Martin, Bri Murphy, Sydney Groesbeck, Ryan Christenson, Julie Olson, Qing Xiao, Matthew Rose, Matt Cottrell, Ryan Jubber, Kimberly Partain McNamara

**Guests Present**: Jahn Barlow. Joseph Delli Gatto

1. **Welcome**

Charles Hawley, HDC Chair, called the meeting to order.

**2. Approval of May 16 Minutes**

*A motion to approve the May 16 minutes was made by Stephen Foxley; the motion was seconded by Curtis Newman. The motion passed with a vote of 12-0-0.*

**Yeas – 12 Nays - 0 Abstaining-0 Not Present**

Charles Hawley Russell Trujillo

Stephen Foxley Terri Nehori

David Crockett

Jeffrey Eason

Patrice Hirning

Stephen Neeleman

Laura Summers

Tanji Northrup

Susan Longfield

Alan Ormsby

David Cook

Curtis Newman

1. **HDC Officer Nominations – Chair & Vice-Chair**

*Charles Hawley nominated Stephen Foxley to serve as chair. Laura Summers seconded that nomination. No other nominations were proposed. A vote was taken and passed with a vote of 12-0-0 for Stephen Foxley to serve as HDC Chair.*

**Yeas - 12 Nays - 0 Abstaining-0 Not Present**

Charles Hawley Russell Trujillo

Stephen Foxley Terri Nehori

David Crockett

Jeffrey Eason

Patrice Hirning

Stephen Neeleman

Laura Summers

Tanji Northrup

Susan Longfield

Alan Ormsby

David Cook

Curtis Newman

*Charles Hawley nominated David Cook to serve as the next vice-chair. Jeff Eason seconded that nomination. No other nominations were proposed. A vote was taken and passed with a vote of 12-0-0 for David Cook to serve as HDC Vice-Chair.*

**Yeas - 12 Nays - 0 Abstaining-0 Not Present**

Charles Hawley Russell Trujillo

Stephen Foxley Terri Nehori

David Crockett

Jeffrey Eason

Patrice Hirning

Stephen Neeleman

Laura Summers

Tanji Northrup

Susan Longfield

Alan Ormsby

David Cook

Curtis Newman

1. **Utah Payers Advisory Subcommittee Chair**

*Stephen Foxley nominated Joseph Delli Gatti to serve as the next chair for the Utah Payers Advisory Subcommittee Chair. The nomination was seconded by Patrice Hirning. A vote was taken and passed with a vote of 12-0-0 for Joseph Delli Gatti to serve as the Utah Payers Advisory Subcommittee Chair.*

**Yeas - 12 Nays - 0 Abstaining-0 Not Present**

Charles Hawley Russell Trujillo

Stephen Foxley Terri Nehori

David Crockett

Jeffrey Eason

Patrice Hirning

Stephen Neeleman

Laura Summers

Tanji Northrup

Susan Longfield

Alan Ormsby

David Cook

Curtis Newman

**Sub-Committee Reports**

1. **Transparency Advisory Group (TAG)**

Alan Ormsby reported that the group has decided to meet once every two months except for holding meetings in January and February. The Group last met in August and spent time talking about the Clinic Quality Comparison Report, the factors that go into that, and how it can be distributed more widely and in the hands of people who can benefit from it. The group also talked about databytes and possible topics coming up and putting that information in front of the Governor’s Taskforce for feedback.

1. **Data Use Sub-Committee (DUS)**

Jahn Barlow reported that the Data Use Sub-Committee has met three times since the last HDC meeting. They reviewed eight new applications from the University of Utah. Four of those were brand new, one was an application that had lapsed and needed to be renewed, and three amendments. Four of the eight requested Medicaid data. There was a variety of topics: cancer, home births in Utah, palliative care, outcomes for deceased children of surviving parents, Alzheimer’s disease risk related to women’s reproductive health, and outcomes among rural cancer caregivers.

1. **Utah Payers Advisory Subcommittee (UPAS)**

Stephen Foxley reported that the UPAS met on August 2. The DSG changes going from 4.0 to 4.1. The changes for the DSG with clarifying language and guidance will be submitted for formal approval. **Action Item:** Staff will send a redlined version of the DSG 4.1 to HDC members before the next meeting to highlight the clarifying language. Joseph suggested holding off on making changes official until the issues with Prism were resolved. Lori said we’re not changing the standard, just clarifying the language. If anyone would like to know the changes, clarifying language on the DSG before the next meeting, please reach out to Lori or Julie.

1. **Utah Healthcare Facilities Subcommittee (UHFS)**

David Crockett reported that the Utah Healthcare Facilities Subcommittee met on August 3. Office staffing and new goals were reviewed. Different projects and uses of facility data were also discussed – things like adverse events for neonatal and maternal health, severe maternal mortality, Recover annual reports, and finished with the new ambulatory surgery flag.

**New Business**

1. **Updates to HDC Bylaws – Lori Savoie**

*A motion to accept all updates to the HDC Bylaws was made by Stephen Foxley. The motion was seconded by Patrice Hirning. The motion passed with a vote of 12-0-0.*

**Yeas - 12 Nays - 0 Abstaining-0 Not Present**

Charles Hawley Russell Trujillo

Stephen Foxley Terri Nehori

David Crockett

Jeffrey Eason

Patrice Hirning

Stephen Neeleman

Laura Summers

Tanji Northrup

Susan Longfield

Alan Ormsby

David Cook

Curtis Newman

**6. Legislative Updates – Lori Savoie**

* Sunset review of UCA 26B-8-5, Utah Health Data Authority

The Health Data Authority Act is coming up for Sunset review, which is done every ten years. We have submitted a formal response, which was circulated to the Committee approximately a month ago. DHHS is recommending, on behalf of the HDC, that the Act continues at least for the next 10 years. We also have asked that the Sunset requirement be struck from the statue itself. We have been able to work with Representative Lesser and she has been willing to propose a bill asking that the Health Data Authority Act be struck from the Sunset Review schedule. She plans to introduce that in the next session. There was an HHS Interim subcommittee that was held yesterday, and she presented this request to enter this bill. The subcommittee came back and asked for additional information as far as the value that our stakeholders are receiving from the data that we collect, as well as the analysis and dissemination of this data. We did communicate that we have received in the past communication that our stakeholders see the value in this and that it is utilized across state agencies, such as for the health price transparency tool that the State Auditor's Office is mandated to produce, contributions to evaluating air ambulance charges, contributions aiding in reducing traffic-related injuries and mortality rates, the Utah Cancer Registry, and more. We did indicate that we do have some input regarding the Primary Spend Report. We received letters of support from Co-magine, AARP, a Utah chapter of the AAF. We are seeking to receive more letters of support from our stakeholders.

**Action Item:** In the coming weeks, each of the members are asked to reach out to their individual network and ask if they can provide summaries or examples of how the data, letters of support (Facilities data, APCD data, Hedis & CAHPS data) that is produced under this Act benefits the community, what the impact would be if we no longer had the HDC and the Health Data Authority Act in place, what the impact would be as far as to public health into the community overall. (The next HHS committee interim meeting is in November).

We're hopeful that once we provide this additional information, as far as what we produce and the associated value of it, that we’ll be able to proceed with seeking approval to have the act removed from the Sunset Review going forward.

* Repeal of UCA 26B-8-513, Identifying potential overuse of non-evidence-based health care.

The mandated reporting for potential overuse of non-evidence based healthcare was repealed effective December 31st of 2023, which means that this will be the final year that DHHS HDC will be producing this report. However, we see the value of this report and have heard the value that everybody sees in this report. It is our intention to work with Utah One Collaborative. We’ve had some conversations with them as far as how we can partner up and how we can support their organization in producing this report just to ensure that the data and the information that has been provided in the past can continue to be. There was funding associated with producing this report ($100,000), which paid for software licensing ($90,000 going toward the Health Waste Calculator Tool. With the mandate being repealed and losing the funding, we don't have the ability to continue to produce this report solely at our level.

1. **Health encounter data cell suppression guideline < 30 encounter or visits suppressed in a year – Lori Savoie**

**Background:**

* This conversation about suppression of data, prior to distributing it to our approved users, was brought up in the September 2022 meeting as an open agenda item. The HDC did discuss it, the lead analyst at that time, Brantley Scott, had four areas that he was seeking input on. It was suppression of ZIP codes with less than 30 visits in a calendar year, suppression of physician taxonomy for hospitals with less than 30 beds, payer names with less than 30 visits within a calendar year, and then age, sex, and zip code suppression, if the discharge involved substance abuse or HIV infection.

**Historical Timeline:**

* In 2018, it was decided after consulting with the HDC as well as UDOH Legal Counsel that we would not suppress data, but we would put those cell suppression requirements on the approved user that was receiving the data. Thus, we included a cell suppression provision within our data submission guide that the receiver of the data is required to agree to, and that whoever signs that DSG on behalf of the organization or the entity must have binding authority.
* Sometime in 2022, it was discovered that we went back to starting to suppress the data less that 30 cell size prior to distributing it to our approved users. So, we’re back to age old question of do we suppress it prior to providing these data extracts to approved users or do we put the onus on the approved user to suppress the small cell sizes per the guidelines given within the Data User Agreement, as well as the DHHS guidelines which is available on the IBIS website. Those requirements are the 11 or less cell size, and then there's additional guidance as far as if you are using population data. Those are in line with the ResDac guidelines.
* Ryan recently discovered that there are roadblocks that this causes as far as the usefulness and the value of the data depending on the geographic location. For example, we received a request for some tribal data and we discovered that if we started applying these cell suppression of 30 encounters or less that it didn't make the data useful. So, we started having these conversations internally once again, i.e., What's the value of this? Should we go back to what we have been doing prior in 2018, as far as making the data available so that the data requestor could do the research in their analysis and then put those suppression requirements on them if they are to publish or present the data in any other format. The suppression provisions that we currently have in the Data Submission Guide is that they must follow the DHHS Cell Size Suppression Policy, which is available on the DHHS website. It follows, the industry standards of suppressing less than 11 observations for discharges, services, admissions for any person or entity that's not specified. They can't provide that data to anybody that is not included within the data sharing agreement as well as the requirement that they could not display any percentages

or other mathematical formulas that can result in the display of a cell less than 11 observations. They also can't just distribute individual health records and need to take some complementary cell suppression and techniques into account to ensure that cells with fewer than 11 observations can't be identified by manipulating the adjacent rows of the data that would make it so that they could re-identify those encounters or those observations, specifically focusing on geographic location, age that is greater than 8,9 diagnosis and procedure codes, and things like that.

* During the September 2022 HDC meeting, the committee recommended that we seek out what our data management vendors do. We did reach out to Mercer, which handles our health facilities encounter data, and they indicated that they follow the industry standard, that they do the suppression of 11 or less observations. As far as population, if they're less than 20,000, then they do the three-digit zip code. If it's a smaller population, then they fill it with zeros.

Ryan Christenson continued with the history.

* In the data request from Indian Health Services, what we ran into is that per our guideline that we publish as part of our Data User Manual, we let people know we do suppress zip codes if the cell size is less than 30. After some internal conversation, we decided if we're able to give them more detailed information there, even with the low population zip codes, which with the Indian Health Service, many of the zip codes were impacted, we had to suppress essentially all of the zip codes except just a handful. This situation is why we are revisiting this conversation as this data request was impacted severely by this guideline that we try to follow.

Charles Hawley clarified with Lori that when you say industry standard, you're referring to the research entity responsible for managing the release of CMS data out of the University of Minnesota. He also asked Ryan that when you say less than 30, that's specifically related to the presentation of data that's made available for public reporting particularly through Ibis because of more local ruling guidance. Ryan responded that he couldn’t speak for Ibis - they may use the less than 11 standard, which is the DHHS policy. The 30 is more language that appears in our data user manual.

Charles Hawley asked if the difference is related to the nature of the data products that are being released? Is the 30 in our data use agreements or is it specific to the hospital data user manual and the fact that those data are often packaged and released as part of the process of getting those data ready to go.

Ryan Christenson responded that the language that we have in the Facilities Data user manual is more specific and concrete about this cell suppression at less than 30 than in the APCD.

**Recommendation:** The recommendation would be to go back to doing the less than 11 and providing as much data as possible (all of the available data) using a course minimum necessary and putting the onus of the cell suppression requirements prior to publishing or redistributing any type of information on the data requestor through the data use agreement, following the DHHS

suppression guidelines, opposed to us applying the suppression before even giving the data extract to the user.

Jeffrey Eason commented that this is for protecting identifiability, but also the reliability of the data. We would be putting this on the requester because they're able to run a statistical test to measure that. And if we are not transparent with the data, they're not able to gain insights and for example. His team is looking at rare health conditions in small population sizes. They may be able to gain insight at that more granular level, which cannot be shared, but they're able to detect things that they may not otherwise detect. Since this issue has gone through legal review and there's an acceptable risk here, as perceived from that legal review, this is just moving towards greater transparency in the data, and ultimately improved insight into health outcomes.

Charles Hawley voiced concern on the commercial vs. academic data requestors and fast tracking of data and the risk that some requestors might publish data without going through the process of de-identifying data.

**Summary:** Lori reiterated that every time that limited or fully identifiable data is requested, it does go through a thorough process review process, whether it's through the DUS or through an Internal review process. Internally, we look at the application and determine if the data elements that they're requesting are in line with what their proposed use. If we feel like they're requesting something that's above minimum necessary, then we do have that follow-up conversation with them.

Once at the HCS level, if we feel comfortable with it, then it is submitted for review by our Privacy and Security office, it goes through our legal review, it goes through review by our Division Director, Kyle Lunt. Hence, there are several eyes that are put on it. We do require that not only do they provide the IRB determination, but we are now requiring that they provide the IRB full protocol so that we can review it and we can confirm that what they have been approved for use within our IRB is in alignment with the actual data elements that they are requesting from us.

In addition, we require that the entity, whether it's commercial or academic, sign the data sharing agreement, and that whoever is signing that agreement can bind their organization legally. We fall on the fact that they are binding, that they agree to abide by our requirements, our terms and conditions. I would hope that anybody that uses the date is in this arena of investigating, market analysis, research, that they would understand the importance of protecting the data, that they would understand the importance of ensuring that they're not releasing something that is in violation of the legal agreement that they have with the Department of Health and Human Services. If they did, then they're not going to be approved to receive data going forward, and we could seek legal recourse from them. Even though the data use subcommittee isn't seeing everything we do go through a very strict protocol to ensure that what they’re requesting and what we're releasing is not only in alignment with our statute, but then taking in all of those data protections and privacy safeguards.

Finally, anytime a user of our data that's been approved submits a presentation that's going to be displayed externally from the data users that are approved, they're required to submit that to us for our review and approval. We do have the ability to go back and express our concerns that the information that's being presented may put a risk as far as reidentification, or if we feel that it's misrepresenting the data itself, we do have the ability to go back and say they’re not allowed to include this data that they obtained from DHHS until it is corrected. In addition, if we are releasing the de-identified or aggregate data, then that's the level that we release. We don't provide any type of identifiable, limited or fully identifiable if the requestor is just requesting identified or aggregate data itself.

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| **8. Public Comment**No public comment.**9. Adjourn**  |  |  |

*A motion was made by Alan Ormsby to adjourn the meeting. There were no objections.*

The meeting was adjourned at 4:30 PM

*Next Meeting: Tuesday, September 19, 2023 (Virtual)*