

## Comments from Health IT Advisory Council Members on the Draft Five-Year Statewide Health IT Plan and Office of Health Strategy Responses

HITAC Members Comments	OHS Responses
<p><b>Comment submitted by Dina Berlin, HITAC member, designated by Senator Martin Looney, President Pro Tempore of Connecticut State Senate</b></p> <p><i>Yikes. I intended to submit comments but did not. I guess I would just say we need to be sure the patients' health, best interest, autonomy, and control are front and center.</i></p>	<p><i>Thank you for your comment and for working to ensure the Statewide Health IT Plan is accountable to the patient-focused principles in Connecticut's enabling legislation for health information exchange. OHS agrees wholeheartedly and extends those principles to apply to the broader scope of the Health IT Plan which is to support a person-centered system for health and healthcare, inclusive of the social services and supports that are critical contributors to individual and population health outcomes and health equity.</i></p>
<p><b>Comment submitted* by Vanessa Hinton, HITAC member, designated by Manisha Juthani, MD, Commissioner of Connecticut Department of Public Health</b></p> <p><b>*Comment was submitted on behalf of Stephen McConaughy, CT Department of Public Health Information Technology Manager</b></p> <p><i>This is lacking a couple of key components to make any of this from an interesting discussion to an actionable project:</i></p> <ul style="list-style-type: none"><li>● <i>There is no architecture plan here as to what a Health Information Exchange system would look like or how it would function.</i><ul style="list-style-type: none"><li>○ <i>Where is the data housed (think of the Maven kind of model based on a MS-SQL database, or the RNR hub from the CDC?</i></li><li>○ <i>Who defines the data elements and structure?</i></li><li>○ <i>What does a Web services interface look like to deposit client data - or get data out look like ... and who manages that?</i></li><li>○ <i>How do anticipated interfaces to the providers get established?</i><ul style="list-style-type: none"><li>■ <i>Extracts from Epic?</i></li><li>■ <i>Direct entry web-based User Interfaces?</i></li></ul></li></ul></li></ul>	<p><i>Thank you for your comment and questions. The Statewide Health IT Plan is designed to coalesce the vision and strategic focus areas over the next 5 years. Specific initiatives such as one listed below (under action steps) will provide opportunities for these questions, and others that may arise, to be thoroughly vetted, and for the DPH Information Technology team to be highly involved in designing the optimal technical architecture and the optimal service delivery of bidirectional information exchange functionality between providers, local public health agencies, and the essential public health data systems for clinical care, public health protection and planning, and policymaking.</i></p> <p><b>Action Step:</b></p> <p>→ The Department of Public Health (DPH) and OHS can collaborate to evaluate local public health IT infrastructure needs and will provide</p>

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*Our presenting need at DPH is to provide a common repository where all providers can upload mandated reporting instances for all mandated reportable diseases and conditions. Instead of sending files (or faxes --- yes we are still getting faxes --- to DPH) This does not appear to meet that need so DPH would not be able to participate fully in this effort as a replacement technology at this point.*

recommendations on the feasibility of a central Public Health Gateway for reporting to and querying high-priority public health registries. The recommendations will consider the pros/cons of DPH or Connie providing the technical Gateway functionality.

### **Success Metric:**

→ A **Public Health Gateway Evaluation Report** will be developed and shared with HITAC for guidance.

### **Comment from Mark Gilda, HITAC member representing Hartford Healthcare**

*Sorry that I am getting to this so late, as the end of the year has been extremely busy for me with Hartford Healthcare. I looked over the documents, and they look good to me. I do not feel that I am in a place with this Council yet, where I can provide any feedback that would change the work that has been done. I am very new to this Council and look forward to becoming more involved in the planning, and decision making in the future.*

*Thank you for your comment. OHS looks forward to your contributions as a HITAC member as the action steps in the 2022 Statewide Health IT Plan are implemented, refined, and measured, and as additional focus areas and action steps are added over time.*

### **Comments from Dr. Susan Israel, HITAC member designated by Senator Kevin Kelly, Connecticut State Senate Minority Leader**

*Thank you very much for this opportunity to comment. Please submit the following comments on the 5-Year Plan and the MRPC Final Report which discussed patient consent but were not definitive as to the degree of patient consent to be allowed by Connecticut. The breadth of my comments seems necessary at this time because BPMH and Connie now are proceeding to determine how much medical information may be transmitted and shared without patient consent. To understand why this is of concern, please review the comments made by Connie's legal counsel at the 12/1 meeting of the BPMH group. One example of how these legal comments are germane to the resolution of consent and privacy issues is that instead of giving patients the right of consent over the creation of their extensive drug database in the first place, patients may only be allowed to consent to whom it is shared. All of the valid and needed uses of sharing medical data ought not to obfuscate the inherent privacy problems in doing so nor keep patients from receiving complete consent options. The legal counsel spoke of providers getting psychiatric, HIV and medication data without consent under certain circumstances but did not mention all others who would see the data along with the providers, perhaps due to*

*Thank you for your comments and questions. Thank you also for working to ensure the Statewide Health IT Plan is accountable to all, with strong protections of individuals' rights for privacy and control over how, and with whom, information about their health and care will be shared and used in the increasingly digital world we live in.*

*OHS believes part of your specific questions are related to privacy practices of healthcare provider organizations, pharmacies, health plans, medical labs, imaging centers, and also contracted technology vendors and contracted consultants working for the types of organizations listed above. While it is important for adequate state and federal regulations and oversights to be in place for*

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*lack of time at the meeting. Unfortunately, HIPAA is not a golden rule because HHS took away the need to get patient consent in 2003, not to be moral or out of concern for patient privacy but to make it easier for insurers and hospitals to move identified data around among themselves and their business associates, while following the HIPAA rules for non-disclosure which is not privacy.*

*It is compelling to say that providers need to see data for treatment, but it is also crucial to spell out to patients the exact details of who, besides providers, would see records when handled by Connie and the BPMH. My understanding of what the counsel said was that HIPAA and Connecticut laws may allow the providers to share psychiatric, HIV and medication data without patient consent, including for medical reconciliation, by making a distinction between the sharing of the data between providers versus the sharing of data for health care operations and possibly for payment. But is it even technically possible, given the ways medical record systems are configured, to separate out our data to be shared only with providers and not with all others who have access to the records?*

*Thus, if these psychiatric, HIV and medication data are included with the rest of the electronic medical record, patients may have some confidentiality but no privacy because of all those allowed by HIPAA to have access to a record, such as oversight, quality control, technology staff, business associates, etc. And if a provider system makes no discrimination between the types of providers, then your dietician, dentist, optometrist, etc. might have the same access to your psychiatric, HIV, urology and Ob-Gyn records as your primary care provider. Additionally, it seems that Connie plans to give your health insurer access to your record while you are their client. But again, how will those data be separated out of the record by time frames of treatment and from the cumulative medical history?*

*The legal counsel said that medical reconciliation can occur by providers without patient consent. But who all is included in processing medical reconciliation? I do not think it was meant that would just be the providers doing it. BPMH is planning a very inclusive system with access to the BPMH by many people besides the MDS, PAs, and NPs themselves. And if the diagnoses are added, the pharmacy personnel, beside the pharmacists themselves, are one example of all the auxiliary personnel across the treatment spectrum who will have access to much of a patient's lifetime medical history, including psychiatric data. Another example of auxiliary personnel having access to records is that providers may designate anyone of their choice to enter the PDMP program for them in order to save time. It was noted in the MRPC Report that the mandated PDMP also includes behavioral health medication that also are controlled substances.*

*ensuring privacy practices are set and adhered to, we believe some of the issues you raised are not within the current scope of the OHS legislative purview, or within the scope of the Statewide Health IT Plan.*

*OHS also believes that some of the questions posed within your comments cannot be answered at this time because there is a great deal of additional planning ahead of the specific data-sharing examples you have included in your comments. That **does not** mean the questions are not deserving of answers, however OHS believes the specific action steps and success metrics outlined in Focus Area # 5 of the Statewide Health IT Plan (below) will offer many conduits for thoughtful discussions around the questions you have raised. OHS believe the action step of establishing a Patient Health Information Protection Office in Connecticut will provide the critical ongoing attention to the issues of individual privacy, and the right organizational construct for policies, procedures, technical and business requirements, training programs, communication campaigns, and other actions and remedies to be considered, recommended, and/or implemented, depending on whether future actions are regulatory, supportive, or educational in nature. OHS looks forward to your ongoing participation in these and other activities.*

### Action Steps:

→ Plan and conduct consumer town halls / listening sessions on health information exchange with state officials, Connie leadership, and interested individuals across the state.

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As presented at our meetings, it will not only be providers who see data but all of the business associate companies arranged by OHS and Connie to process identified patient records, medication and claims. Mentioned were CRISP and Velatura - Connie, Surescripts type - BMPH, Appriss - PDMP, OnPoint - APCD, possibly PBMs - BPMH, etc. In addition, research groups may be able to buy patient data from Connie.

Is OHS considering legislative action to override patient consent and mandate that pharmacists send all prescription data, not just the controlled substances of the PDMP, to the Connie BPMH data base, including those drugs paid out of pocket? The Obama HHS said that if a patient pays out of pocket for a treatment and maybe a drug, that information may not go to their insurer for privacy reasons. If this is correct, how will the providers, Connie and the BPMH separate that information from the medical record which the insurers will see?

To be more complete about the breadth of patient privacy, is the issue of genetic information in the medical record and particularly of it being shared with one's insurer through Connie. My understanding is that genetic reports by the providers' labs are put into the regular electronic record without additional access controls. If it is spelled out that one's children have inherited/genetic diseases, should that information go to the insurers? Should they know that your children are carrying the risk to get sick? Are there databases where the insurers will store that data? Connie says that insurers cannot use those data to evaluate eligibility and set premium amounts, but how can that possibly be monitored and prevented over time?

And is there, in fact, legislation which supports Connie's plans to give the insurers access to one's record versus the practice of providers just sending the relevant medical information to pay a particular claim? Even though Connie may not be used by providers to send insurers data for payment, it seems that Connie would be providing additional urology records, for example, to the insurers when they only might have received cardiology data to pay a claim for a particular cardiac treatment.

Another privacy issue mentioned, is the "break the glass" system whereby in an emergency, patient consent is overridden, and information is given to an emergency department or an EMT. Again, the patient ought to have given prior consent for their data to be shared in an emergency such as when they are unconscious. Hopefully, technology would be implemented to incorporate only the needed medical data to treat the patient into the emergency provider's system, but not the whole remainder of the patient's medical record.

Additionally, there is the issue of adding the commercial health insurer claims, APCD, to the rest of the medical record. Medicare and Medicaid already turn over identified claims data to Connecticut. But the APCD claims were mandated to be sent by the health insurers to the private company, OnPoint, in identified form but only to be released for study or use in de-identified form. Thus, is OHS now planning to ask for legislative changes to

- Provide recommendations on standardized consent management protocols as part of the work in Focus Area #6.
- Consider establishing a new Patient Health Information Protection Office within Connecticut state government.
- Conduct Request for Information (RFI) process to assess electronic consent management software solutions for state agency needs.
- Request for proposals (RFP) process (if agency leadership wishes to move forward with this option).
- Develop and disseminate educational materials and media on privacy directed at consumers.

### Success Measures:

- A facilitation vendor will be procured to support privacy town halls.
- An RFI process for consent management vendor solutions will be completed.
- Support and funding for creation of **Patient Health Information Protection Office** will be established
- Agency leaders will decide whether to conduct an RFP to select a consent management solution.

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*allow them to use the identified APCD commercial claims data to mix it with its identified medical record? It must be noted that this eventual lifetime of identified APCD claims contain much of one's medical history which was taken without patient consent.*