**Meeting Agenda/Notes**

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| **MEETING TITLE:**  MedMorph Project: Hepatitis C Use Workgroup Meeting | | | | | **DATE SCHEDULED:**  January 17, 2019 | | | | |
| **MEETING PURPOSE:** Making EHR Data More Available for Research and Public Health – Hepatitis C Use Case | | | | | **LOCATION:**  Skype | | | | |
| **PROGRAM/AREA:** Hepatitis C Use Case Workgroup | | | | | **NOTE TAKER:** Tia Taylor | | | | |
| **FACILITATOR**: Abigail Viall & Aaron Harris | | | | | **ONLINE FACILITATOR:** Tia Taylor | | | | |
| **SCHEDULED TIME** | | | | | **NEXT MEETING** | | | | |
|  | **Start**  12:00 PM | **Stop**  1:00 PM | **Total Hours**  1 hour |  |  | **Date**  TBA | **Time**  TBA | **Location**  TBA |  |

**Meeting Agenda**

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| A | **Introductions and Opening Remarks** |
| B | **Review Proposed HCV Use Case Goal and Scope** |
| **C** | **Primary Use Case – Key Data Elements** |
| **D** | **Hepatitis C Use Case – Relevant Authorities for Reporting** |
| **E** | **Announcements/Next Steps** |

**Meeting Summary**

The MedMorph Project: Hepatitis C Use Case Workgroup met on January 17, 2020 for their second meeting. Participants discussed CDC’s Division of Viral Hepatitis’ vision to eliminate viral hepatitis in the United States and worldwide. The goal is to decrease the incidence and prevalence of viral hepatitis to improve health outcomes and reduce viral hepatitis-related health disparities. Their mission is to leverage this project and build on work that already exists.

Below are additional notes taken during the meeting, slides will be provided for reference as well.

**Key Meeting Notes**

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| **Introductions and Opening Remarks** | All new participants introduced themselves and explained their areas of expertise.   * Introduction of presenter: Abigail Viall |
| **Hepatitis C Use Case: Vision, Goals, Scope** | **HCV Use Case: Proposed Primary Use Case**  **Primary Use Case Focus: Reporting priority\* elements of HCV surveillance and care cascade to public health**   * Build on and extend eICR efforts and infrastructure where possible * Primary Use Case is the starting point for communication   **Priority elements include:**   * Key steps along the care cascade * Patient level “risk” data needed to identify key populations   **HCV Use Case: Proposed Use Case Supplements**  **Use Case supplements are introduced because it is a lot of opportunities to improve how we use data and awareness.**  **Use Case Supplement 1:**   * Convey core elements of HCV care cascade to clinical registries and HIEs to support population health management activities by healthcare providers and payers   **Use Case Supplement 2:**   * Leverage reporting paths created under primary use case and Supplemental Case 1 to transfer additional data elements for research, augmented surveillance, and population health management |

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| **Hepatitis C Use Case Primary Goal: Core Elements of Care Cascade** | **Primary Goal: Core Elements of Care Cascade**  **HCV testing**   * Anti-HCV * HCV RNA * HCV genotype   **Hepatitis C diagnosis**  **Treated**   * + Prescribed direct acting antiviral   **Cured (SVR)?**   * + Negative HCV RNA > 3 months after completing treatment * Prioritized Patient Level Risk Data   **Pregnancy status and (select) outcomes**   * + Pregnancy status   + Last menstrual period   + Pregnancy outcome   + Gestational age at outcome   + Infant born with neonatal abstinence syndrome (NAS)\*   **Substance use and abuse, particularly injection drugs**   * + Injected drugs (ever)   + Current drug use (esp. opioids)   + SUD/OUD diagnosis   + MAT prescribed or administered |
| **Questions/ Additional Workgroup Comments** | **Question #1**  **Viet Nguyen:** Does this work relate to the Public Health FHIR Accelerator work? Is this project coordinating with the CodeX FHIR Accelerator, particularly around FHIR resources, profiles, and data elements?  **Maria Michaels:** This project intends on coordinating with any relevant FHIR accelerators. We have included representatives from some of the FHIR accelerators to help with the coordination effort.  ***Additional Feedback*:**  **Anne Fine**: I think at the local level and the state level it may be helpful to make it more explicit to move patients along the care cascade.  **Abigail Viall**: I agree, that would be more helpful to make the data more explicit. We want to take advantage of how much data can help.  **Question #2**  **Brian Gugerty:** Are Use Case Supplements #2 necessary? Does it seem to be an over stretch of information for this project?  **Abigail Viall:** Unclear, I am open to group for additional feedback. Our focus is on the primary Use Case, but Supplement #2 is a stretch of information, but it is only used for supplements.    **Jenna Norton**: Thinking about how data moves in clinical setting and research settings. Potentially, we identify what data elements need to be moved and then determine which will be most helpful.  **Maria Michaels:** Jenna that was great information to open the discussion.  **Question #3**  **Davera Gabriel**: One to the preliminary mechanisms to consider is developing a blanket data use agreement (DUA) to coordinate data exchange by registries and other data “owners” related to the scope comment - a relevant contribution from this group would be what the elements of such a DUA would need to be accomplished for the secondary use case.  **Davera Gabriel**: Clarify data use agreements. Help supplement cases and primary focus.  **Abigail Viall:** That’s very helpful, and part of our strategy that fits within public health reporting.  **Question #4**  **Abigail Vial:** What authorities already exist? What are the issues surrounding this?  **Participant**: CTSA’s have worked on a data blanket use agreement. CTSA is the top academic research organizations in the country. I believe we can collaborate with groups and expand from work that has already been done.  **Abigail Viall**: Can you clarify the CTSA’s?  **Participant:** CTSA- Clinical Translation Science Awardees. A top research organization in the country.  ***Additional Feedback:***  **Participant**: Rather than entering data use agreements, the focus should be managing multiple data releases. Every state has different laws that regulate disclosure.  **Question #5**  **Abigail Viall:** Is anyone opposed to the suggestions for supplements and have any other suggestions or concerns to our projected structure?  **Bill Lober:** Not opposed at all. I think if we concentrate on the core, we should look at all marginal costs of working on the supplements as we go forward.  **Barry Blumenfeld:** Concerns about attainability, forced to refine the case because it is not easily attainable.  **Bill Lober**: I agree with Barry, the focus on the core will help us in determining feasibility rather than a primary consideration on supplements.  **Samantha Olson**: I’m here from SET-NET. I think pregnancy status information looks good. I’m happy to provide more information on what we are looking for, for each of those variables.  **Abigail Viall:** I am open to any changes and would like to ensure nothing is set in stone.  **Question # 6**  **Viet Nguyen**: Is there a clinical practice guideline chosen that can serve as a base for clinical data concepts to be captured?  **Bill Lober:** We gather all data elements for a large HIV project, and they are hard to get. Mainly we get them by patient-reported outcomes (which are clinically validated) -clearly an approach that would not make sense in a large-scale context.  **Question #7**  **Abigail Viall:** What extent do we want to do now? What extent for the future support?  **Barry Blumenfeld:** Things may not be ideal. Conversations addressing the likelihood is getting out of the record.  **Steve Eichner:** Zika investigations could be leveraged  **Samantha Olson:** Create Survey lens of catching an infection during  ***Additional Feedback:***  **Jenna Norton:** Our MCC eCare plan use case is also looking at pain with or without opioid use and will include data elements around SUD/OUD.  **Annie Fine**: Some of this work is probably in the pipeline-standardization of pregnancy  Info was already addressed by ONC (I was on the task force) and elements are now encoded in HL7 I believe. I am not sure where these stands. Ideally, EHR systems will be improving the standardization of how these elements are captured.  **Jenna Norton**: SAMHSA developed an omnibus care plan for behavioral and social issues that addressed sharing of substance use data.  **Maria Michaels:** Thanks for all the feedback, we’re capturing your input**.**  **Question # 8**  **Aaron Harris:** Lab testing/results for HCV pregnancy?  **Michael Wittie:** As far as I know, there’s no standard code that reflects “cured HCV” as opposed to history of HCV (i.e., current infection)  On the Care Cascade slide, the focus in on getting the raw EHR data, to then try to figure out where the patient is on the Care Cascade, which makes sense. A future looking approach (and possible today) is to have standard data elements for the Care Pat itself (e.g., “the patient has been screened for HCV YN”; “the patient has been diagnosed with chronic HCV YN,” “the patient has been treated for HCV YN,” “the patient has virologic cure YN”).  ***Additional Feedback:***  **Anne Fine:** Another huge challenge is the use of local codes as opposed to standard codes, even for lab data.  Is there also a need for an element that indicates whether the patient is eligible for screening? This is a complex element as I understand it.  **Discussion Questions**  **Abigail Viall**: Are previous mapping complete? What are some advantages of the USCDI data?  **Barry Blumenfeld:** There is value. I believe it is a great starting point although it may be difficult understanding the mapping.  Abigail Viall Thank you for the feedback. We will continue our discussion questions in our next meeting |

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| **Announcements/**  **Next Steps** | The next meeting will be the first week of February. |