



National Committee on Vital and Health Statistics  
Advising the HHS Secretary on National Health Information Policy

# ICD-11 Environmental Scan: Overview of Findings

Workgroup on Timely and Strategic Action to Inform ICD-11 Policy

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July 27, 2023

# Outline



Purpose

Methods

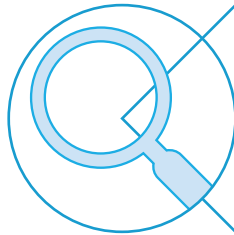
Summary of Findings

Recommendations

# Purpose



Gather ICD-11 research & evaluation studies



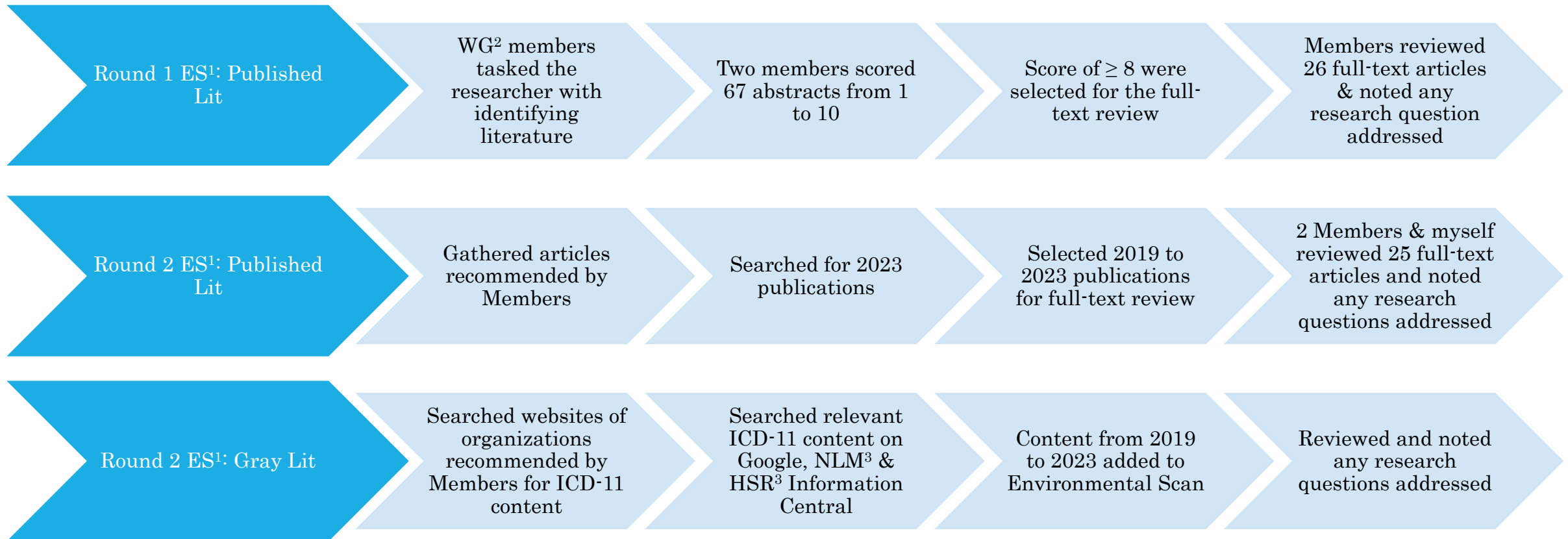
Categorize ICD-11 policy research questions<sup>1</sup>  
addressed by current literature



Identify the gaps in research and evaluation  
needed for ICD-11 Morbidity coding  
policymaking

1: Based on NCVHS Research Questions listed in the Appendix of NCVHS ICD-11 Recommendation Letters from 2019 and 2021

# Environmental Scan Review Process



1. ES: Environmental Scan
2. WG: NCVHS ICD-11 Workgroup
3. NLM: National Library of Medicine
4. HSR: Human Services Research

# 4-Way Mapping to a Consolidated List



## Sources

- Research Questions from NCVHS 2019 Letter
- Research Questions from NCVHS 2021 Letter
- Use Case list generated by ICD-11 Workgroup
- RFI Questions

## Creating the Consolidated List

- Workgroup Created 9 Categories & ~50 subcategories
- 2 WG Members used expert judgement to map each use case or research question into a category/subcategory
- If the meaning of the use case is similar to the research question, the mapper combined the use case and question into one item with modified text for less redundancy

## Mapping Articles

- Matched each full-text article to appropriate category(ies)/subcategories (ies) based on the reviewer's notes
- Reviewers referenced 2019 & 2021 Research Questions Addressed

# Summary: All Content



|   | Round 1 | Round 2: 2023 | Round 2: From Dr. Romano | Round 2: Gray Lit | Total |
|---|---------|---------------|--------------------------|-------------------|-------|
| # Articles/Content Collected (Initial)  | 67      | 137           | 43                       | 8                 | 255   |
| # Articles/Content for Full-Text Review | 27      | 11            | 19                       | 8                 | 65    |
| # Articles/Content for Mapped           | 26      | 11            | 19                       | 0                 | 56    |

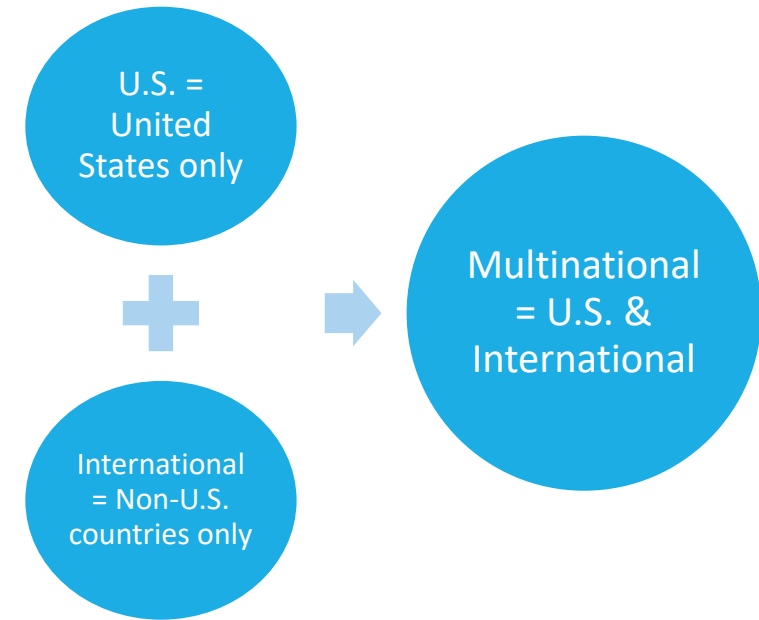
# Summary of Time, Country, and Methods of Published Articles



| Publication Years  | International | U.S. <sup>1</sup> | Multinational | Subtotal  |
|--------------------|---------------|-------------------|---------------|-----------|
| <b>2013-2018</b>   | <b>4</b>      | <b>0</b>          | <b>6</b>      | <b>10</b> |
| With Data Analysis |               |                   |               |           |
| Yes                | 4             | 0                 | 4             | 8         |
| No                 | 0             | 0                 | 2             | 2         |

|                    |           |          |           |           |
|--------------------|-----------|----------|-----------|-----------|
| <b>2019-2023</b>   | <b>18</b> | <b>6</b> | <b>17</b> | <b>41</b> |
| With Data Analysis |           |          |           |           |
| Yes                | 6         | 5        | 11        | 22        |
| No                 | 12        | 1        | 6         | 19        |

|              | International | U.S.     | Multinational |           |
|--------------|---------------|----------|---------------|-----------|
| <b>Total</b> | <b>22</b>     | <b>6</b> | <b>23</b>     | <b>51</b> |



Note: Excluded one study without full article

# Summary by Research Question/Use Case Category



| Care Delivery   | # Publications |
|---|----------------|
| Care planning   | 1              |
| Clinical Decision Support   | 2              |
| Clinical Documentation/<br>Interoperability   | 2              |
| Clinical Documentation  | 3              |
| Sharing of Information <ul style="list-style-type: none"> <li>• DSM-5 Coding for new mental health disorders</li> <li>• Recording and sharing clinical information</li> </ul> | 18             |

| Evaluation of Healthcare Services | # Publications |
|-----------------------------------|----------------|
| Clinical quality Measurement      | 2              |
| Drug and medical device           | 3              |
| Patient safety evaluation         | 5              |

| Healthcare Financing and Planning   | # Publications |
|---|----------------|
| Coverage Determination  | 0              |
| IT cost   | 0              |
| Performance-based payment   | 0              |
| Regulatory oversight  | 0              |
| ROI analysis  | 1              |
| Clinical risk groups  | 2              |
| Benefit and Cost  | 3              |
| Reimbursement   | 4              |
| Budgeting & Service Planning <ul style="list-style-type: none"> <li>• Burden, efficiency, workflow, training and implications for documentation quality (10)</li> <li>• None: Administrative planning, resource consumption, quantitative derived measures; activity-based financing</li> </ul> | 12             |



# Summary by Research Question/Use Case Category



| Population and Public Health               | # Publications |
|--|----------------|
| Registry                                   | 2              |
| Disease Surveillance                       | 2              |
| Public safety, accident, injury prevention | 2              |
| Social Determinants of Health              | 3              |

| Research  | # Publications |
|---|----------------|
| Data  | 2              |
| Electronic phenotyping  | 3              |
| Clinical trial recruitment <ul style="list-style-type: none"> <li>Identify patient subgroups</li> </ul> | 5              |

| Technology  | # Publications |
|---|----------------|
| Functionality   | 3              |
| EHR & Apps <ul style="list-style-type: none"> <li>None: Feasibility of computer assignment of ICD codes; software for post-coordination</li> </ul>              | 10             |
| Compatibility <ul style="list-style-type: none"> <li>Alternative methods/platforms for semantic comparability studies; domain-specific terminologies</li> </ul> | 13             |

# Summary by Research Question/Use Case Category



| Standards/Terminology/Coding   | # Publications |
|--|----------------|
| Maintenance  | 1              |
| SNOMED   | 1              |
| HIPAA  | 3              |
| Stem/Extention codes   | 4              |
| Coordination   |                |
| <ul style="list-style-type: none"> <li>None: Overlaps with other code sets</li> </ul>              | 5              |
| Mapping  | 6              |
| Validation   |                |
| <ul style="list-style-type: none"> <li>Quality of mapping with administrative code sets</li> </ul> | 7              |
| DSM-5  | 13             |

| Implementation                 | # Publications |
|--------------------------------|----------------|
| Adoption                       | 0              |
| Responsibility                 | 0              |
| Stakeholders                   | 1              |
| Test beds                      | 1              |
| Benefits                       | 2              |
| Pilots                         | 3              |
| Timeline                       | 4              |
| Maintenance                    | 5              |
| Clinical Modification-decision | 6              |

| Training  | # Publications |
|---|----------------|
| Workforce   | 2              |
| EHR & Apps  | 3              |
| Approach  |                |
| <ul style="list-style-type: none"> <li>Innovative training</li> </ul>                         | 4              |
| FAQ   |                |
| <ul style="list-style-type: none"> <li>Level of details for clinical documentation</li> </ul> | 7              |

# Summary



1. Environmental scan with a focus on ICD-11 for morbidity was conducted.
2. Published research from 2013 to present was collected and abstracts/articles reviewed to determine if they met the research questions from NCVHS recommendations on ICD-11 in 2019 and 2021.
3. The number of articles per research question/category were summarized and presented
4. The total number of articles by year, those with data analysis, and whether international or US focus was summarized.
5. **Gaps in the research** were found and were mainly focused around adoption/implementation, cost of implementation, tools needed and how it will be used with the EHR and other software
6. Further research in these areas will be needed to engage full adoption of ICD-11 in the US.

# Considerations



- Cost of conversion for EHR vendors, health systems, payers etc. needs more research:
  - Should include:
    - Cost of software tools and revisions to database systems
    - Cost of the revision of automated coding systems (CAC etc.) and coding instructions
    - Cost of the development of new training materials and retraining of coding staff
    - Cost of maintenance of these systems
- Comparability Studies
  - Compare coding quality of ICD-10-CM to ICD-11 and code with both systems for one year to assess before implementation

# Considerations



- ICD-11 Information Repository
  - Create a shared ICD-11 literature database based on the ES related documents (articles, ES worksheets, presentations, recommended changes, etc.) among the Roundtable participants
  - Pass the database to the designated ICD-11 coordination center and the Community of Interests when they are ready
- Communication Plan
  - Evaluate the communication plan in NCVHS recommendations
  - Follow a similar plan to ICD-11 for mortality



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**Thank you!**

# Appendix: Search Strategy



# Appendix: Methods Scoring Criteria



- Score: 1 to 10
  - 10: Outstanding
  - 1: Unacceptable
- Adapted from AAPM review of abstracts<sup>1</sup>
- 3 categories
  - Scientific
  - Professional
  - Educational

## Scientific:

- Scientific Rigor
- Innovation
- Potential Significance
- Interest (to Researchers)

## Professional:

- Clarity
- Quality of Supporting Data
- Accuracy
- Timeliness
- Professional Significance
- Interest to the
- Professional practice of
- Classification Systems

## Educational:

- Educational Innovation
- Innovation already implemented
- Completed Assessment of changes
- Assessment Results Described
- Potential for Broad Dissemination and Implementation





# Appendix: 2019 I. Research Questions—Use Cases

## Use cases for ICD-11

- Healthcare delivery
- Payment
- Pop health
- Safety
- Research and Evaluation
- Clinical Care to Support Decision Making
- Primary Care vs Specialty Care
- Harmonize with terminologies
- Coordinate with detailed clinical documentation
  - SNOMED-CT
  - Clinical Registries
- Benefit
- Cost

- Note: All articles from 2013-2018, except safety from 2019 – 2023



## Appendix: 2019 II. Research Questions—Content Validation

### Evaluate content, consistency and stability of ICD-11

- U.S. verification and validation of ICD-11 content and methodologies for post-coordination and curation
- Maps from ICD-10 to 11 and from ICD-11 back to ICD-10
- Content and methodologies
  - Redundancy
    - Transformed so that a formal software classifier could be used to handle redundancy
  - Ambiguity
  - Meanings change
    - semantic drift of “NEC”
  - Delete codes
  - Post-coordination support complete and safe retrieval of encoded data
  - Adding pre-coordinated codes that were previously represented with post-coordinated codes

- Evaluate content, consistency and stability of ICD-11
  - Multiple synonymous post-coordinated expressions be recognized
  - Cost of missing classifications
  - Evaluate mechanisms of covering content gaps
    - Mandated post-coordinated extensions
    - Base concepts (stem codes or extensions)
    - Domain-specific concepts
    - Accommodating regional and urgent codes (stem or extension) without compromising consistency
  - Evaluate alternative approaches (methods & infrastructure platforms) to support semantic comparability studies
    - ICD-11 vs ICD-10



## Appendix: 2019 III. Research Questions—Adoption/Implementation (1/2)

- Evaluate the feasibility of using ICD-11 for morbidity without a U.S. Clinical Modification (CM). Examples:
  - Criteria to determine if ICD-11 is sufficient for morbidity
  - U.S.-specific criteria for use of extensions & post-coordination
  - Use criteria to evaluate feasibility of ICD-11 in US
  - If not feasible determine the cost of developing a CM
- Evaluate fitness for convergence of clinical, social, and administrative health information standards
  - EHRs and other software support ad-hoc post-coordination or sharing of post-coordination by partners
  - Potential for implementation as a computable service
  - Interoperability of research and clinical terms/classifications/nosologies simplify distribution and deployment of health terminology and vocabulary standards
  - Costs of supporting above by use case
  - Benefits of supporting above by use case
- Evaluate the burden, efficiency, workflow, and consider the implications for documentation quality by use case and stakeholder
  - Changes to clinical burden vs. changes in quality and value of data
  - Tools and methods needed
  - Costs and benefits of implementing tools in EHRs
  - Human factors of implementing tools



## Appendix: 2019 III. Research Questions—Adoption/Implementation (2/2)

- Evaluate alternative approaches to training/ongoing support for using ICD-11 for morbidity
  - Innovative training approaches
  - Computer assisted coding and coding quality assurance
  - Workforce role changes
- Evaluate the interrelationships between ICD-11 and other HIPAA & Promoting Interoperability (PI) standards
  - Technical changes to HIPAA-specified transactions and operating rules
  - Role of PI standards
  - Overlaps with other code sets
- Evaluate feasibility of different timeframes for transitioning to ICD-11 for morbidity
  - Costs and benefits of transition to ICD-11 for morbidity in 2025, 2027, 2030
  - Alternative guard rails to hold stakeholders to an implementation timeline to avoid costly delays
  - Alternative approaches to scaling lessons learned in pilots for broad deployment across the health system
  - Feasibility of re-purposing and re-using for ICD-11 the same test beds, tools, databases and techniques as were used for the conversion to ICD-10

# Appendix: 2021 Research Questions



## Evaluate/Assess...

1. **Burden, efficiency, workflow, training** and implications for **documentation quality** by use case and stakeholder (10)
2. Adherence of ICD-11 to **accepted terminology practices**, especially regarding maintenance (2)
3. Alternative **methods & infrastructure platforms** to support **semantic comparability studies** (4)
4. **Technical and legal** considerations (validation of received ICD-11 value sets & 10-digit vs 11-digit codes) (1)
5. Coordination with **detailed clinical documentation** using **nationally-mandated** interoperability content standards (6)
6. Coordination with **non-clinical national and state mandated** information interoperability content standards (**public health, social services**) (4)
7. Impact of **adding pre-coordinated codes** to ICD-11 that were **previously represented with post-coordinated** codes (2)
8. ICD-11 **Morbidity coding fitness** to contribute to **convergence of clinical, social, and administrative** standards (1)
9. **Potential for implementation as a computable service**, in addition to EHR-captured standardized clinical statements, **using PI1 standards** (2)
10. If interoperable representations of research and clinical terms, classification and nosology simplify the distribution and deployment of health terminology standards (1)
11. Fit of the crosswalk agreement between **ICD-11 and the DSM-5's** ability to capture **behavioral, substance abuse and psychiatric disorder** coding (2)
12. Evaluate the **ICD licensing agreement** to ensure availability and usability for U.S. users without cost burden (0)

# Appendix: RFI Questions



1. What would be the benefits of implementing ICD–11 for morbidity in your setting or organization?
2. What information or research will your organization need in order to inform assessments of cost, benefits, implementation approaches, communications, and outreach regarding the transition to ICD–11?
3. What considerations affect the impact of ICD–11 on clinical documentation, payment processes including risk adjustment, public health, population health, or research?
4. What unique U.S. coding or terminology considerations are essential? For example, coding or terminology related to community health, social determinants of health, essential human needs, sexual orientation, gender identity and expression, obesity, external cause of injury, and information about mental, behavioral, or neurodevelopmental disorders including alignment with the Diagnostic And Statistical Manual of Mental Disorders, Fifth Edition (DSM– 5)?
5. How should HHS implement ICD– 11 in the U.S. for morbidity coding?
6. The World Health Organization (WHO) recommends establishing a national center for ICD–11 implementation. What entity should be responsible for coordinating overall national implementation of ICD–11 for morbidity coding, and how should the implementation be managed?
7. ICD–11 uses an open process in which WHO encourages requests for updates and changes, thus eliminating the main drivers of national clinical modifications. What entity should be responsible for coordinating U.S. requests for updates or changes to ICD– 11? How should this process be managed?
8. What resources, tools, or support will your organization need for implementation?
9. What kinds of technical resources, guidance, or tools should the U.S. Federal Government make available?
10. What workforce, workforce planning, or training will your organization need to support implementation?
11. What are your organization’s requirements for ICD–11 mapping to other coding systems and terminologies, including value sets?
12. What other operational impacts of ICD–11 adoption and implementation should HHS consider?

# Appendix: Research Question/Use Case Category & Subcategories



| Care Delivery (to individual patients)   | Evaluation of Healthcare Services  | Healthcare Financing and Planning   | Population and Public Health   | Research   | Technology   | Standards/Terminology/Coding   | Implementation  | Training   |
|--|--|---|--|--|--|--|---|--|
| <ul style="list-style-type: none"> <li>Clinical Documentation</li> <li>Clinical Documentation/ Interoperability</li> <li>Clinical Decision Support</li> <li>Sharing of Information</li> <li>Care Planning</li> </ul> | <ul style="list-style-type: none"> <li>Clinical Quality Measurement</li> <li>Drug &amp; Medical Device</li> <li>Patient Safety Evaluation</li> </ul> | <ul style="list-style-type: none"> <li>Budgeting &amp; Service Planning</li> <li>Coverage Determination</li> <li>Performance-based Payment</li> <li>Reimbursement</li> <li>Regulatory</li> <li>ROI Analysis</li> <li>IT cost</li> <li>Benefit &amp; Cost</li> </ul> | <ul style="list-style-type: none"> <li>Registry</li> <li>Disease Surveillance</li> <li>Service Planning</li> <li>Clinical Doc</li> <li>Social Determinants of Health</li> <li>Public Safety &amp; Injury Prevention</li> </ul> | <ul style="list-style-type: none"> <li>Clinical Trial</li> <li>Electronic Phenotyping</li> <li>Data</li> </ul> | <ul style="list-style-type: none"> <li>Compatibility</li> <li>Functionality</li> <li>EHR &amp; Apps</li> </ul> | <ul style="list-style-type: none"> <li>Mapping</li> <li>Validation</li> <li>DSM-5</li> <li>Coordination</li> <li>HIPAA</li> <li>SNOMED</li> <li>Stem/Extension Codes</li> <li>Maintenance</li> </ul> | <ul style="list-style-type: none"> <li>CM-decision</li> <li>Maintenance</li> <li>Timeline</li> <li>Stakeholders</li> <li>Pilots</li> <li>Test beds</li> <li>Responsibility</li> <li>Adoption</li> </ul> | <ul style="list-style-type: none"> <li>Approach</li> <li>EHR &amp; Apps</li> <li>Workforce</li> <li>FAQ</li> </ul> |