eCare Plan for People with Multiple Chronic Conditions (MCC)

PC-WG work plan for MCC eCare Plan

Joe Bormel, Lorraine Constable, Tom Hicke
Cognitive Medical Systems

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See Implementation Guide for comprehensive references to contributors.
Agenda

- Three Ps

  - **Progress**
    - review last meeting
    - provided additional outcomes/goal model input
    - reviewed Diabetes elements
    - value set tooling considerations
  
  - **Plans**
    - value set naming practices applied to MCC eCare Plan
    - review CardioVascularDisease elements
  
  - **Problems** - no new issues
  
  - **Open Discussion** with specific questions for the WG
Progress

- **2020**: Chronic Kidney Disease
- **2021**: Heart Disease
- **2022+**: Diabetes, Pain
Progress

Last Meeting: Slides: 2021-03-17 Recent Project Overview here: link
- Shared novel issues identified for modeling goals in the MCC eCare Plan
- Briefly touched on expectations of better documentation of care plan from V-Safe (CDC)
- Reviewed known goals in MCC eCare Plan IG
- Reviewed data element and value set creation pipeline work to date
- Presented content scope for Type 2 Diabetes (chronic condition)
- Discussed Author and Contributor Elements, and Maintainer and Custodian roles
Plans
Plans:

- Update on Value Set Naming practices for MCC
- Review data elements associated with Cardiovascular Disease
Value Sets Quality Criteria

Standardization of value sets is imperative, as it enables value set comparison across data sets. Adherence to these quality criteria facilitates reuse of well-defined value sets to advance clinical research studies and interoperability of health informatics analysis systems. Value set authors should clearly understand major principles that define high quality value sets:

- **Clinical Validity**: Value set authors should assure that all included codes correspond to the intent and purpose from a clinical perspective. For example, a code defining breast malignancies might be considered clinically irrelevant in a value set that defines eye disease. However, there might be more subtle nuances in clinical meaning one may need to consider.

- **Metadata Completeness**: Authors must provide complete and complete metadata and add any missing metadata as defined by the data model they use or program under which the authors work. Value sets defined by different clinical data models will have specific sets of metadata. The VSAC Authoring Tool indicates which metadata elements are mandatory. Authors should not populate free-text fields with meaningless information, as this will hinder the collaborative process of eliminating value set redundancy and harmonization efforts of the value set user community.

- **Non-redundancy**: Ideally, a given data element should be presented by one and only one value set for a given code system. Multiple value sets with the same codes should be eliminated to facilitate maintenance and prevent inconsistency over time. For example, duplicate value sets should be avoided, and values that share a majority of codes should be considered for merging or revision to assure the value sets are as complete as possible.

- **All Value Set Codes Are Valid in the Code System**: The authors should consider only currently valid codes for inclusion into a value set. This assures proper maintenance of the value sets. In some specific cases the author will need to specify a specific version of the code system and would thus create a static snapshot of the code system. Such cases should generally be an exception of the rule, limited whenever possible, and properly described in the purpose statements.

- **Descriptors Match Code System Descriptors**: Authors should make sure any descriptors they add manually to the value sets match the descriptors in the code system to which the codes belong. The VSAC Authoring Tool provides a descriptor check as a built in function. The VSAC Authoring Tool performs this validation during batch import of codes into a value set, and during manual insertions of codes and descriptors.

- **Code List Completeness**: A value set should contain all the relevant codes for a particular data element. The coverage of codes should be correct. **Authors should make sure the lists are lean and they should scrutinize large value sets.** You should devise working rules and quality assessment tests to determine whether or not a concept or code is a proper member of a value set. Authors should describe such rules and tests in the required value set purpose statement.

- **Logical Correctness**: A value set should contain only the relevant codes for a particular data element and the codes contained in the value set should **strictly align with the described Purpose**.

- **Proper Terminological Hierarchies (terminological correctness)**: Only root codes and their descendants should be present in the value set. Presence of codes rooted at a different concept normally indicates incorrect choice of codes. In complex cases, value set authors should consult terminology experts.

- **Concept Property Similarity**: Value set member concepts should not vary in respect to their properties and attributes, such as semantic type, term type, etc. For example, a value set intended for prescribable drugs should only contain drugs with the property, "Prescribable." This is applicable for concepts that have such properties. The properties should be more similar than dissimilar. For complex cases, value set authors should seek guidance on the matter from terminology experts.

- **Code System Alignment to Standards**: Value set authors should base their value set on the code system recommended by the standards depending on the purpose of their value set and the data model (such as the National Quality Forum Quality Data Model) to which the value set authors may be adhering. Please refer to the Quality Data Model Categories with Office of the National Coordinator (ONC) Health Information Technology (HIT) Standards Committee Recommended Vocabularies, in the most recent version of the CMS Measures Management System Blueprint.

Value Set Purpose

The Purpose Statement is a multi-part free-text mandatory entry. It is designed to provide a clear and comprehensive description of the membership of the value set. This important metadata element must take into account how the members will be used in a clinical measure or in any other intended application. The Purpose Statement cannot be validated automatically, so authors should spend time to make this text as informative as possible for human readers to understand the intent of the value set, and how the value set is put together. To avoid redundancy, there should be only one value set for a given purpose. Authors should add Purpose Statements to value sets (whether created or inherited) if they are not present.

The Purpose Statement includes four separate fields that the value set author needs to complete:

1. Clinical Focus - a free text statement describing the general focus of the value set as it relates to the intended semantic space. This can be the information about clinical relevancy, or the statement about the general focus of the value set, such as a description of types of messages, payment options, geographic locations, etc.
   Example: This set of values contains medications that are prescribed for anticoagulant therapy at hospital discharge for patients following acute ischemic stroke.

   **Purpose:**
   Clinical Focus:
   This set of values contains medications that are prescribed for anticoagulant therapy at hospital discharge for patients following acute ischemic stroke.

   **Inclusion Criteria:**
   Include oral and injectable drug forms. Include Warfarin, heparins and direct thrombin inhibitors.

   **Data Element Scope:**
   The intent of this data element is to identify patients who are prescribed anticoagulant therapy at discharge following acute ischemic stroke. Using the Quality Data Model, this particular element would map to the Medication category.

   **Exclusion Criteria:**
   None.

2. Data Element Scope - a free text statement describing how the Data Element in the intended information model defines the concepts to be selected for inclusion in the value set.
   Example: The intent of this data element is to identify patients who are prescribed anticoagulant therapy at discharge following acute ischemic stroke. Using the Quality Data Model, this particular element would map to the "Medication" category.

   **Purpose:**
   Clinical Focus:
   This set of values contains medications that are prescribed for anticoagulant therapy at hospital discharge for patients following acute ischemic stroke.

   **Inclusion Criteria:**
   Include oral and injectable drug forms. Include Warfarin, heparins and direct thrombin inhibitors.

   **Data Element Scope:**
   The intent of this data element is to identify patients who are prescribed anticoagulant therapy at discharge following acute ischemic stroke. Using the Quality Data Model, this particular element would map to the Medication category.

   **Exclusion Criteria:**
   None.

Value Set Naming - Do’s and Don’ts

The name of a value set is a crucially important and descriptive metadata element. Value set authors should adhere to specific naming guidelines to assure value sets can be found manually and through automated processing, to encourage reuse of the value sets and to discourage their redundancy. The following guidelines will help you create concise, descriptive value set names that capture the purpose of each value set.

Do’s:

- Name the value set exactly for what it is, not what you wanted it to be. Avoid including descriptions of the content that was intended but not achieved. Correct the name accordingly if during the course of the work you discovered you were not able to align the value set content with the initial name given to the value set. For example, if you initially named the value set “Oral Anticoagulants” when the intent was to capture only oral anticoagulants for chronic atrial fibrillation, change the name to “Oral Anticoagulants for Chronic Atrial Fibrillation” to align it with the intended purpose.

- Write the value set name to convey the specific distinguishing characteristics of the member concepts. See the name in the previous bullet for a good example.

- Use sufficiently descriptive names. Using the example from the first bullet, the value set name “Oral Anticoagulants” is not sufficiently descriptive because it does not describe the scope of the value set. The value set name “Oral Anticoagulants for Chronic Atrial Fibrillation” is a better name because it effectively describes the scope of the value set.

- Separate multi-word terms by spaces and not by any other characters.

- Capitalize first letters of all words, except prepositions, as in a title.

- Make unique value set names. Due to the uniqueness of the value set purpose and content, name redundancy ought to be a very rare occurrence.

- Limit the value set name to as few words as possible, and no more than 128 characters.

Don’ts:

- The following characters are technically prohibited and you will get a system warning if they are used: +=?,: !’%.

- Avoid abbreviations, unless they are widely accepted in the medical literature.

- Do not include the name of the steward responsible for the value set. The steward name is separate metadata bound to the value set and captured in the VSAC database.

- Avoid including the name of the Quality Data Model data element to which the value set will be linked if the value set is to be referenced as part of a Clinical Quality Measure.

- Do not include the name of the Program that sponsors the system in which the value set is used, unless it describes a primary distinguishing characteristic of the value set.

- Do not include the name of the code system used to obtain the concepts, unless it describes a primary distinguishing characteristic of the value set. For example, extensional value sets that belong to a grouping value set might be an appropriate case in which you would include the code system name.

- Do not include the concept category that characterizes the context of use, unless it describes a primary distinguishing characteristic of the value set requirements. For example, only include the word “Procedure” when the context of the main focus is ambiguous.

- Avoid using the word “Other” as an alternative to another value set. Each value set name must be understandable independent of any other value set.

- Do not include “CamelCase” or other composite and delimited words or phrases.

- Avoid using code descriptors within the value set name.

- Do not use names of measures types for which the value set is intended. For example, do not include “hospital measure,” “patient measure,” etc. Include this information in the value set Purpose statements.

Content Review for Cardiovascular Conditions:
Applying the Process for Chronic CardioVascular conditions:

High prevalence conditions, identified and named by the Expert Panels

1. Hypertension
2. Congestive Failure
3. Ischemic disease

<table>
<thead>
<tr>
<th>Condition</th>
<th>Description</th>
<th>Diagnosis/Procedure</th>
<th>Reference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hypertension</td>
<td>Documented diagnosis of hypertension</td>
<td><a href="https://docs.google.com/spreadsheets/d/1Wiigfw8mfwPQylMqWFCTCrp0U00EjPVGSKuzkWify/edit#gid=925661123">https://docs.google.com/spreadsheets/d/1Wiigfw8mfwPQylMqWFCTCrp0U00EjPVGSKuzkWify/edit#gid=925661123</a></td>
<td></td>
</tr>
<tr>
<td>Secondary Hypertension</td>
<td>Documented diagnosis of secondary hypertension</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ischemic disease</td>
<td>Documented diagnosis of ischemic disease</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Congestive Failure</td>
<td>Documented diagnosis of congestive failure</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

https://docs.google.com/spreadsheets/d/1Wiigfw8mfwPQylMqWFCTCrp0U00EjPVGSKuzkWify/edit#gid=925661123
Cardiovascular data elements: Vasculature, Muscle, Valves/Flow

<table>
<thead>
<tr>
<th>Hypertension</th>
<th>Document diagnosis of hypertension</th>
</tr>
</thead>
<tbody>
<tr>
<td>&gt; Essential/primary hypertension</td>
<td>Document diagnosis of primary hypertension</td>
</tr>
<tr>
<td>&gt; Secondary hypertension</td>
<td>Document diagnosis of secondary hypertension</td>
</tr>
<tr>
<td>Hypertension stage</td>
<td>Indication of patient's stage of hypertension (hypertension stage 1 is 130-189 or 85-89 mm Hg, and hypertension stage 2 is &gt;140 or &gt;90 mm Hg)</td>
</tr>
<tr>
<td>Presence of blood pressure cuff in home</td>
<td>Indication of whether the person has a blood pressure cuff at home</td>
</tr>
<tr>
<td>Coronary artery disease</td>
<td>Documented diagnosis of CAD</td>
</tr>
<tr>
<td>Coronary revascularization history</td>
<td>History of a coronary revascularization procedure (e.g., PCI, CABG)</td>
</tr>
<tr>
<td>Congestive heart failure</td>
<td>Documented diagnosis of CHF</td>
</tr>
<tr>
<td>Chronic Heart Failure with Reduced Ejection Fraction (systolic heart failure)</td>
<td>Diagnosis of chronic heart failure with reduced EF (LVEF where left ventricular EF [LVEF] is &lt;40%)</td>
</tr>
<tr>
<td>Chronic Heart Failure with Preserved Ejection Fraction (diastolic heart failure)</td>
<td>Diagnosis of chronic heart failure with preserved or normal EF (LVEF where LVEF is ≥50%).</td>
</tr>
<tr>
<td>&gt; Cardiomyopathy</td>
<td>Diagnosis of</td>
</tr>
</tbody>
</table>
| NYHA Heart Failure Functional Classifications | Indication of the class of heart failure/disease the person is experiencing: 
  | Class I: No limiting symptoms; Class II: Mild symptoms; Class III: Severe symptoms; Class IV: Very severe symptoms |
| American Heart Association Heart Failure Stage | Indication of the stage of heart failure/disease the person is experiencing: 
  | Stage A: New; Stage B: High risk; Stage C: Established disease; Stage D: End stage; Stage E: Heart failure due to other causes |

Valvular disease | Documented diagnosis of valvular disease |
| Peripheral vascular disease | Documented diagnosis of PVD |
| Framingham Risk Score - Coronary heart disease (FRS-CHD) | Person's score on the FRS-CHD 10-year risk measure (or code indicating category of risk) |
| Framingham Risk Score - Cardiovascular disease (FRS-CVD) | Person's score on the FRS-CVD 10-year risk measure (or code indicating category of risk) |
| American College of Cardiology/American Heart Association ASCVD risk score (ACC/AHA ASCVD risk) | Person's score on the ACC/AHA ASCVD 10-year risk score (or code indicating category of risk) |
| Atherosclerotic Cardiovascular Disease | Documented diagnosis of Atherosclerotic Cardiovascular Disease |
| Acute coronary syndrome | Diagnosis is history of ACS events |
| Acute Myocardial infarction | Diagnosis is history of MI events |
| ST-segment elevation myocardial infarction (STEMI) | Diagnosis is history of STEMI events |
| non-ST segment elevation myocardial infarction (NSTEMI) | Diagnosis is history of NSTEMI events |

Angina | Indication that the person is experiencing angina |
<p>| Unstable Angina | Indication that the person is experiencing unstable angina |
| Ischemic Heart Disease | Diagnosis of IHM |
| Left ventricular hypertrophy | Diagnosis of left ventricular hypertrophy |
| Cerebral vascular disease | Diagnosis of cerebrovascular disease |
| Stroke history | Diagnosis history of stroke |
| Ischemic stroke | Diagnosis history of ischemic stroke |
| Hemorrhagic stroke | Diagnosis history of hemorrhagic stroke |
| Transient ischemic attack | Diagnosis history of TIA |
| Aneurysm | Diagnosis history of an aneurysm |
| Cerebral aneurysm | Diagnosis history of cerebral aneurysms |
| Abdominal aortic aneurysm | Diagnosis history of abdominal aortic aneurysms |
| Thoracic aortic aneurysm | Diagnosis history of thoracic aneurysms |
| Thoracic abdominal aortic aneurysm | Diagnosis history of thoracic-abdominal aortic aneurysms |
| Aortic disease | Diagnosis of aortic disease |
| Carotid stenosis | Diagnosis of carotid stenosis |
| Intracranial stenosis | Diagnosis of intracranial stenosis |
| Pulmonary edema | Diagnosis of pulmonary edema |
| Arrhythmia | Indication that person is experiencing arrhythmia (diagnosis code of PRO) |</p>
<table>
<thead>
<tr>
<th>id</th>
<th>Data Element</th>
<th>Conformant Value Set Name</th>
<th>Data Element Definition</th>
<th>Clinical Focus</th>
<th>Data Element Scope</th>
<th>Inclusion Criteria</th>
<th>Exclusion Criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>43</td>
<td>&gt; Essential/primary hypertension</td>
<td>Essential or Primary Hypertension</td>
<td>Document diagnosis of primary hypertension</td>
<td>This set of values addresses terms representing Essential or Primary Hypertension.</td>
<td>The intent of this set of values is to identify patients who have a/an document diagnosis of primary hypertension.</td>
<td>Includes SNOMEDCT codes for Essential or Primary Hypertension.</td>
<td>Terms not representative of observable encoded terms that may have values indicating Essential or Primary Hypertension.</td>
</tr>
<tr>
<td>44</td>
<td>&gt; Secondary hypertension</td>
<td>Secondary Hypertension</td>
<td>Document diagnosis of secondary hypertension</td>
<td>This set of values addresses terms representing Secondary Hypertension.</td>
<td>The intent of this set of values is to identify patients who have a/an document diagnosis of secondary hypertension.</td>
<td>Includes SNOMEDCT codes for Secondary Hypertension.</td>
<td>Terms not representative of observable encoded terms that may have values indicating Secondary Hypertension.</td>
</tr>
<tr>
<td>45</td>
<td>Hypertension stage</td>
<td>Hypertension Stage</td>
<td>Indication of person's stage of hypertension (hypertension stage 1 is 130-139 or 80-89 mm Hg, and hypertension stage 2 is 140-149 or 90-99 mm Hg)</td>
<td>This set of values addresses terms representing Hypertension Stage.</td>
<td>The intent of this set of values is to identify patients who have a/an indication of person's stage of hypertension</td>
<td>Includes SNOMEDCT codes for Hypertension Stage.</td>
<td>Terms not representative of observable encoded terms that may have values indicating Hypertension Stage.</td>
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<tr>
<td>ID</td>
<td>Data Element</td>
<td>Conformant Value Set Name</td>
<td>Data Element Definition</td>
<td>Clinical Focus</td>
<td>Data Element Scope</td>
<td>Inclusion Criteria</td>
<td>Exclusion Criteria</td>
</tr>
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<td>-----------------------------------------------------------------------------------------------------------</td>
<td>----------------------------------------------------------------------------------------------------------</td>
<td>----------------------------------------------------------------------------------------------------------</td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>Prediabetes (borderline diabetes)</td>
<td>Prediabetes (Borderline Diabetes)</td>
<td>Documented diagnosis of prediabetes</td>
<td>This set of values represents the diagnosis of prediabetes.</td>
<td>The intent of this set of values is to identify patients who have a documented diagnosis of prediabetes.</td>
<td>Terms not representative of observable encoded terms that may have values indicating Prediabetes.</td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>Maturity-onset diabetes of the young (MODY)</td>
<td>Maturity Onset Diabetes of the Young (MODY)</td>
<td>Documented diagnosis of maturity-onset diabetes of the young (MODY)</td>
<td>This set of values represents the diagnosis of maturity-onset diabetes of the young.</td>
<td>The intent of this set of values is to identify patients who have a documented diagnosis of maturity-onset diabetes of the young (MODY).</td>
<td>Terms not representative of observable encoded terms that may have values indicating Maturity Onset Diabetes of the Young.</td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>Autonomic neuropathy</td>
<td>Autonomic Neuropathy</td>
<td>Documented diagnosis of autonomic neuropathy</td>
<td>This set of values represents the diagnosis of autonomic neuropathy.</td>
<td>The intent of this set of values is to identify patients who have a documented diagnosis of autonomic neuropathy.</td>
<td>Terms not representative of observable encoded terms that may have values indicating Autonomic Neuropathy.</td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>Polyneuropathy</td>
<td>Polyneuropathy</td>
<td>Documented diagnosis of polyneuropathy.</td>
<td>This set of values represents Polyneuropathy.</td>
<td>The intent of this set of values is to identify patients who have a documented diagnosis of polyneuropathy.</td>
<td>Terms not representative of observable encoded terms that may have values indicating Polyneuropathy.</td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>Diabetic proximal neuropathy / diabetic amyotrophy</td>
<td>Diabetic Proximal Neuropathy / Diabetic Amyotrophy</td>
<td>Documented diagnosis of diabetic proximal neuropathy/diabetic amyotrophy.</td>
<td>This set of values represents Diabetic Proximal Neuropathy or Diabetic Amyotrophy.</td>
<td>The intent of this set of values is to identify patients who have a documented diagnosis of diabetic proximal neuropathy/diabetic amyotrophy.</td>
<td>Terms not representative of observable encoded terms that may have values indicating Diabetic Proximal Neuropathy or Diabetic Amyotrophy.</td>
<td></td>
</tr>
</tbody>
</table>
Metadata:
Example:

Value set built as part of CKD (Chronic Kidney Disease)
Not every steward populates metadata:
Summary of Value Set Naming and Creation:

- Using systematic approach from input definitions, current state research and other Expert Panel input.
- Conforming to Best Practices from VSAC - Do’s and Don’ts
- Automation and software recognized special cases
- Careful attention to purpose and scope, through the code expansion review process
- Formal Title Case
- Consideration of available tools recommended by this community if any
- Feedback from pilot site regarding which existing information is exposed as expected through FHIR end point
Semantic Tool Example
Open Discussion
Open discussion and questions

1. Consideration of available tools recommended by this community for value set creation, beyond NLM VSAC?

2. Ideas on how to get the value sets created better, faster, and with less work?

3. Any work in pipeline that should inform the MCC eCare Plan work (R5, advances in terminology services, ...)

4. Other FHIR initiatives related to cardiovascular disease as a chronic condition ?