NIH Collaboratory Steering Committee Meeting

Generalizable Lessons Learned and Sustainability from the Demonstration Projects

May 9, 2016 from 4:30 p.m. – 5:15 p.m.

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## Barriers Scorecard

<table>
<thead>
<tr>
<th>Barrier</th>
<th>Level of Difficulty</th>
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</thead>
<tbody>
<tr>
<td>Enrollment and engagement of patients/subjects</td>
<td>NA</td>
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<tr>
<td>Engagement of clinicians and Health Systems</td>
<td>XX</td>
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<tr>
<td>Data collection and merging datasets</td>
<td>XX</td>
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<tr>
<td>Regulatory issues (IRBs and consent)</td>
<td>XX</td>
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<tr>
<td>Stability of control intervention</td>
<td>NA</td>
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</tbody>
</table>
| Implementing/Delivering Intervention Across Healthcare Organizations | 1 = little difficulty  
5 = extreme difficulty | XX |
Figure 1. Stratification and randomization of nursing home facilities

Total eligible facilities
N=360

Genesis Healthcare eligible facilities
n=297
- Intervention
  n=98
- Control
  n=199

PruittHealth eligible facilities
n=63
- Intervention
  n=21
- Control
  n=42
Target Patient Sub-groups

**Target population 1:**
Patients $\geq 65$ years old who are long stay ($\geq 90$ days) with ADVANCED DEMENTIA:
- Alzheimer's disease or other dementia
- Advanced cognitive impairment (score of 3 or 4 on the Cognitive Function Scale based on variables from MDS 3.0)
- Extensive or total assistance needed for eating and transferring

**Target population 2:**
Patients $\geq 65$ years old who are long stay ($\geq 90$ days) with ADVANCED COPD/CHF:
- CHF/COPD
- Shortness of breath sitting or lying flat
- Extensive or total assistance walking in room, transferring, walking in corridor, locomotion on/off unit, or dressing

**All other patients $\geq 65$ years old**

**Active tracking:**
- Hospitalizations
- Advance directives (DNH, DNR, no tube-feeding)
- Burdensome treatments (feeding tubes, parenteral therapy)
- Hospice use

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Q1 - Are there any special considerations that should be considered when designing a Multiple Chronic Condition PCT?

- Really depends upon the intervention

- PROVEN focuses on Advanced Care Planning where the focus is on all patients with multi-morbid conditions that makes them at risk of dying and for which only limited life prolonging treatment might be available

- PROVEN focuses on two diagnostic phenotypes with significant functional impairment: Advanced Dementia and CHF/COPD; specific diagnoses are less relevant than is functional impairment
Q2 - Was the UH2 planning period useful—what did it allow you to do?

- Essential
  - Finalized and tested the staff training materials
  - Finalized and tested the content of the videos
  - Tested the practical mechanics of showing the videos and how to make available to visiting family, etc.
  - Demonstrated acceptability of videos to staff & patients
  - Identified need for using generic Advanced Care Planning video for "healthy" post-acute patients returning home
  - Tested the data exchange and viability of a video report documentation record in the EMR
  - Provide a framework for addressing the regulatory issues
Q3 - What worked/didn’t work about the UH2 phase?

- Specific to PROVEN...
  - Decided to ask staff to document each time video was OFFERED not just viewed
  - Decided to shift to a “pre-random assignment” paradigm
  - Decided to have larger NH corporation partner train via webinar, while other smaller NH partner did in-person

- General Issues:
  - Shortened UH2 timeline was challenging
  - Investigators more involved in implemention of pilot than in UH3, so an interim phase might be useful
Q4 - Were the milestones for the UH2 phase appropriate and clear enough?

- Yes; all accomplished
Q5 - What changes would you recommend about the UH2 phase and transition?

- May have divided UH2 into two stages:
  - Preliminary test of training, procedures, data exchange, etc.
  - Secondary test of several more facilities with revised materials and procedures to learn how best to deal with facility implementation challenges

- Testing the mechanics is not the same as testing full blown implementation
Q6 - How has the Coordinating Center assisted your project?

- Provided feedback and assistance with regulatory considerations
- Useful to hear other projects’ progress during regular Steering Committee calls
- In-person meeting highly valuable with statistical group
- Provided help in suggesting the members of our Stakeholders’ Group
Q7 - What could the Coordinating Center have done to provide more assistance?

- We attempted to use the NIH Collaboratory SharePoint site for our project collaboration space and website, but it had limited functionality and did not meet our needs.
Q8 - Feedback on the UH3 transition process: information letter to PIs, review criteria, submission process, and approval process

- Useful information helped guide the UH3 submission
- Review criteria were useful, although some were ambiguous regarding the relative weight of the proposed methodology vs. accomplishing milestones
- Out-of-compliance technical submission process required repeated submission
- Communication about grant approval was good