

Updates and Follow-Up from January Meeting

Laura N. Gitlin
Rohini Khillan

1

Updates

- ▶ Three subcommittees have ongoing meetings to discuss:
 - 2018 recommendations
 - Driver diagram
 - Recommendations will be discussed by entire committee in July
- ▶ Responses to various requests/letters
- ▶ Final report with recommendations from National Research Summit on Care and Services available on line
- ▶ Date is set for next Summits

2

Driver Diagram Update

- ▶ Added new columns to help subcommittees better formulate recommendations and to address questions raised at the last meeting
 - Who will do this and who are the partners (feds and non-feds)?
 - What constitutes success?
 - What is the timeframe?
 - What progress has been made?
 - Opportunities / next steps?
- ▶ Still need a way to address prioritization

3

Bypass Budget FY19 Response

SEC. 230. Hereafter, for each fiscal year through fiscal year 2025, the Director of the National Institutes of Health shall prepare and submit directly to the President for review and transmittal to Congress, after reasonable opportunity for comment, but without change, by the Secretary of Health and Human Services and the Advisory Council on Alzheimer's Research, Care, and Services, an annual budget estimate (including an estimate of the number and type of personnel needs for the Institutes) for the initiatives of the National Institutes of Health pursuant to the National Alzheimer's Plan, as required under section 2(d)(2) of Public Law 111-375

4

Response to Letter from Senator Markey

- ▶ Senator Markey sent a letter to the NAPA Council regarding our work on dementia-capable acute care, and cost-effective solutions for persons living with dementia
- ▶ Response:
 - The Council has an active interest in care across all settings including acute care
 - Results from the Care Summit
 - April 27 NAPA meeting theme and presentations
 - Creating a NAPA working group focused on quality care across settings
 - Invitation to attend and participate in July meeting

5

“Hey Siri – how do you change dementia care and bring evidence to practice?”

6

Thinking Differently Preparing today to implement future dementia treatments

March 2018, Alzheimer's Research UK

- ▶ “By 2025, there will be over 1 million people living with dementia in the UK. Currently, there are no treatments that can delay the onset or slow the progression of the diseases that cause dementia. But with promising treatments in late stages of clinical trials, we need to prepare now so people living with dementia will be able to benefit from future treatments once they are developed.”

7

“Many Ways to Many”

McCannon, Massoud, & Zier, *Stanford innovations*

- ▶ “Organizations seeking the best way to “many” shouldn’t ask which is the “best” method; it’s much better to consider which path will **work best** for a given circumstance. The appropriate networked learning methods for spreading a complex care protocol to clinics in rural South Africa will differ significantly from the method to spread a simple practice to urban hospitals in the United States. (The table below enumerates key factors in determining which methods to apply, and when.)”

8

Characteristics of effective ways of getting evidence out:

- ▶ An emphasis on shared, quantifiable aims that ties together the work of participants
- ▶ A rejection of the idea that passive dissemination (through books, meetings, web sites, etc.) can lead to meaningful behavior change
- ▶ A commitment to high-tempo application of knowledge (i.e., daily or weekly testing of new practices, reviewing what's being learned, and revising approaches accordingly)
- ▶ A commitment to connecting frontline actors to one another to accelerate learning
- ▶ An emphasis on providing just-in-time access to the practical "how to" details of applying an innovation or solution (also known as **tacit knowledge**)
- ▶ Provision of actionable data, arrayed over time (in formats like run charts and control charts) that give participants regular feedback on progress to inform learning
- ▶ Opportunism in taking advantage of existing networks and infrastructures (such as professional societies, associations, and interest groups) to mobilize participation (versus building networks from scratch)
- ▶ Willingness to use many technology platforms to facilitate interaction and learning

9

RE-AIM Model

- ▶ **Reach** – # and characteristics (representativeness) of individuals who participate in a given program/intervention
- ▶ **Effectiveness** – impact or effect observed from the program/ intervention
- ▶ **Adoption** – # and characteristics (representativeness) of settings or staff members who initiate the program/intervention
- ▶ **Implementation** – how program protocol is followed and how the program is established at the organization or setting level.
- ▶ **Maintenance** – extent to which the program becomes part of the routine practices of the organization or practitioners

Glasgow, R. E., Vogt, T. M., & Boles, S. M. (1999). Evaluating the public health impact of health promotion interventions: The RE-AIM framework. *American Journal of Public Health*, 89, 1322-1327.

10

- ▶ “The high unmet need for people living with dementia and [their family members] means [we] should be set up for early adoption.” (p. 27)

April 27, 2018 -- Advisory Council Meeting #28

The meeting was held on Friday, April 27, 2018, in Washington, DC. During the meeting, the Clinical Care Subcommittee took charge of the theme, focusing on advancing consensus on dementia care elements to guide new outcomes measurement. The Council heard speakers in two sessions, one focused on developing consensus about dementia care elements, and the second on models that are informing outcomes measurement. The meeting also included updates on work from the previous meetings, a presentation on the final report from the October 2017 Care Summit, and federal workgroup updates. Material available from this meeting is listed below and at <https://aspe.hhs.gov/advisory-council-alzheimers-research-care-and-services-meetings#Apr2018>.

Comments and questions, or alerts to broken links, should be sent to napa@hhs.gov.

General Information

| | |
|-----------------------------|--|
| Agenda | [HTML Version] [PDF Version] |
| Meeting Announcement | [HTML Version] [PDF Version] |
| Meeting Summary | [HTML Version] [PDF Version] |
| Public Comments | [HTML Version] |

Handouts

| | |
|---|--|
| Main Summit Recommendations | [HTML Version] [PDF Version] |
| National Research Summit on Care, Services, and Supports for Persons with Dementia and Their Caregivers: Report to the National Advisory Council on Alzheimer's Research, Care, and Services | [HTML Version] [PDF Version] |

Presentation Slides

| | |
|--|--|
| Age-Friendly Health Systems | [HTML Version] [PDF Version] |
| Alzheimer's Disease and Related Dementias Research Update | [HTML Version] [PDF Version] |
| Care Planning and Health Information Technology: How to Aid Dementia Quality Care | [HTML Version] [PDF Version] |

| | |
|---|--|
| Clinical Care Subcommittee Agenda: Advancing Consensus on Dementia Care Elements to Guide New Outcomes Measurement | [HTML Version] [PDF Version] |
| Clinical Subcommittee Update | [HTML Version] [PDF Version] |
| Defining Quality Dementia Care | [HTML Version] [PDF Version] |
| Final Report to the NAPA Advisory Council | [HTML Version] [PDF Version] |
| Long-Term Services and Supports Committee Update | [HTML Version] [PDF Version] |
| Quality Care from the Perspectives of People Living with Dementia | [HTML Version] [PDF Version] |
| Research Summit on Dementia Care: Building Evidence for Services and Supports Process Report | [HTML Version] [PDF Version] |
| Testing the Promise of Primary Care: Comprehensive Primary Care Plus (CPC+) | [HTML Version] [PDF Version] |
| Updates and Follow-Up from January Meeting | [HTML Version] [PDF Version] |

Videos

| | |
|---|-------------------------|
| Introductions and Updates | [Video] |
| Clinical Care Agenda Session 1 | [Video] |
| Public Comments | [Video] |
| Clinical Care Agenda Session 2 | [Video] |
| Care Summit Final Report | [Video] |
| MEETING WRAP-UP: Final Report to the NAPA Advisory Council | [Video] |

Last Updated: 06/09/2018