

Family Caregiving Advisory Council Meeting

February 11 – 12, 2020

Day 2



The Agenda

February 12, 2020

1:00 – 1:15 Welcome, Roll Call, Re-Cap Day 1

1:15 – 1:45 Overview of the Driver Diagram Process

1:45 – 3:30 Establishing a Framework to Achieve Goals

3:30 – 3:45 Outlining Technical Assistance Needs and Future Planning

3:45 – 4:00 Wrap-up and Charge to Sub-committees

Welcome and Roll Call

Greg Link, Director
Officer of Supportive and Caregiver Services
Administration for Community Living

Wendy Fox-Grage
Project Director
National Academy for State Health Policy (NASHP)

Preliminary Revised Goals

- Expand access to services to optimize the health and wellness of caregivers and care receivers
- Empower family caregivers and care recipients to be at the center of all healthcare and LTSS settings.
- Protect financial and workplace security of family caregivers
- Promote research and the adoption of evidence-based practices
- Strengthen program administration, governance and collaboration

Overview of the Driver Diagram

Bruce Finke, MD

Director (acting)

Nashville Area Indian Health Service

NAPA Driver Diagram

Bruce Finke
Laura Gitlin
Rohini Khillan

Driver Diagrams

▶ A Driver Diagram...

- Is a **logic model** that provides a visual display of a team's **theory of action**.
- Posits the actions necessary to achieve the shared aim.
- Shows the relationship between the overall aim of the project, the primary drivers that contribute directly to achieving the aim, the secondary drivers that are components of the primary drivers, and specific change ideas to test for each secondary driver.*
- Is a useful tool for communicating across a range of stakeholders and a team that is working toward a shared aim.

▶ A Driver Diagram is not...

- A hard and fast, set in concrete, plan

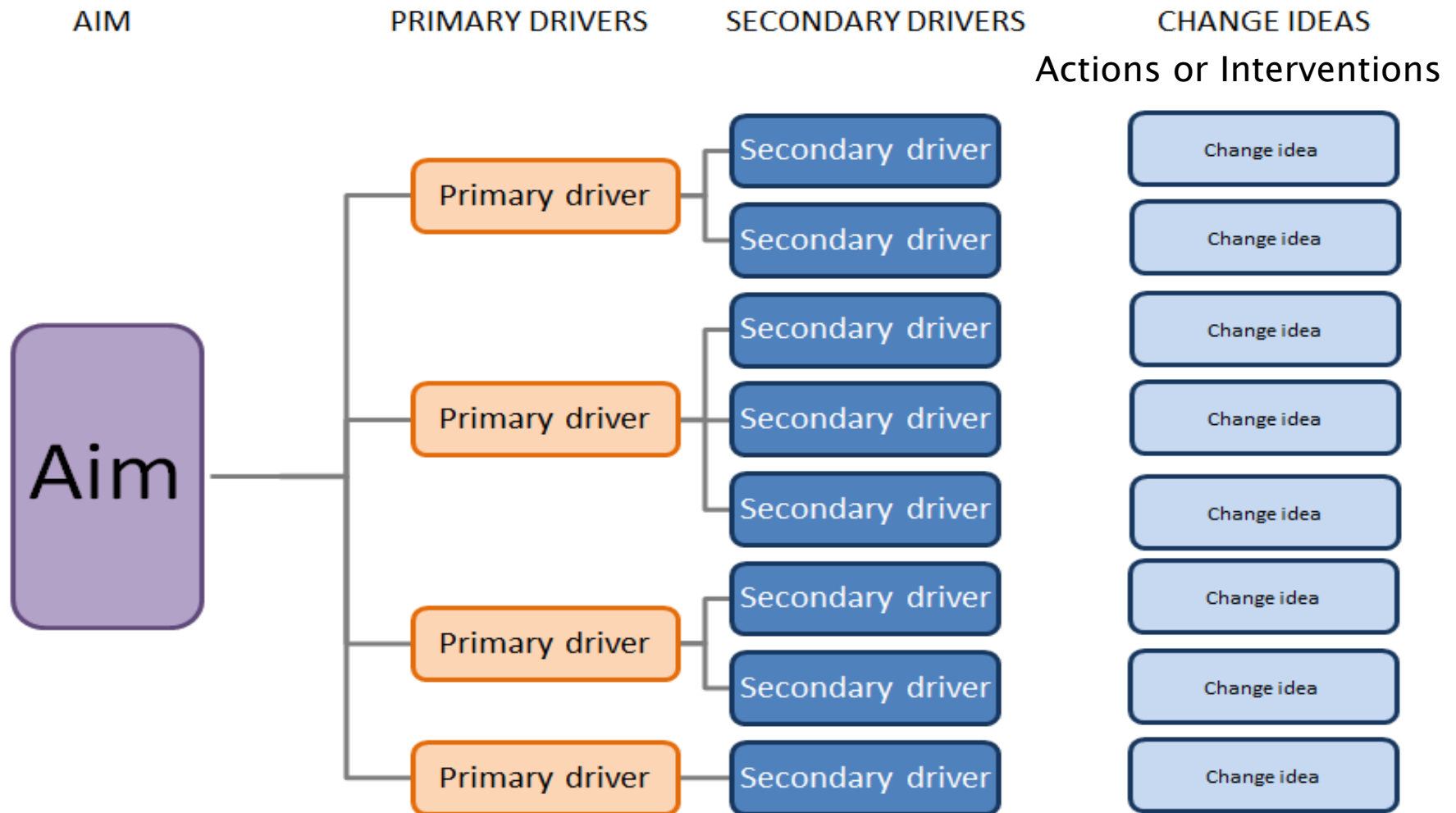
*Institute for Healthcare Improvement's Definition

Driver Diagrams

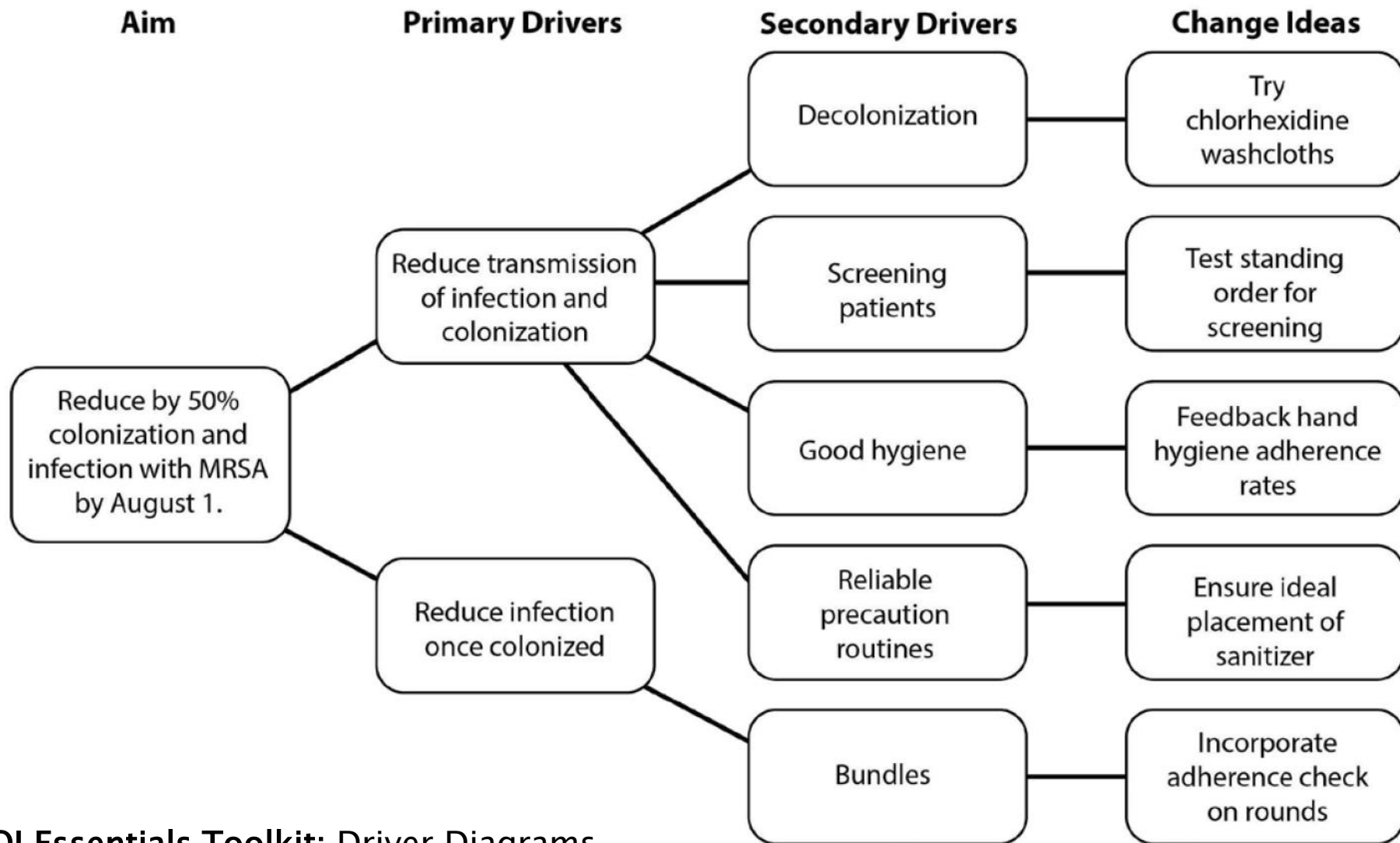
► Basic format:

1. Start with a clearly defined aim
2. Identify “drivers” necessary to achieve that aim.
3. Capture drivers – and set these out in the diagram format.
4. Identify actions or interventions for each driver.
5. Identify measures for drivers and actions – that help you understand progress toward the aim..

Driver Diagram Template



Example: Driver Diagram



What Can a Driver Diagram Do?

- ▶ Communicate the "theory of the case"
 - What we hope to accomplish.
 - How we will accomplish it.
- ▶ Make explicit the actions we believe are necessary to achieve our aims
 - Avoids "magical thinking"
- ▶ Facilitate measurement of progress toward our goals
 - Measure the work in the drivers as interim outcomes well and key processes.

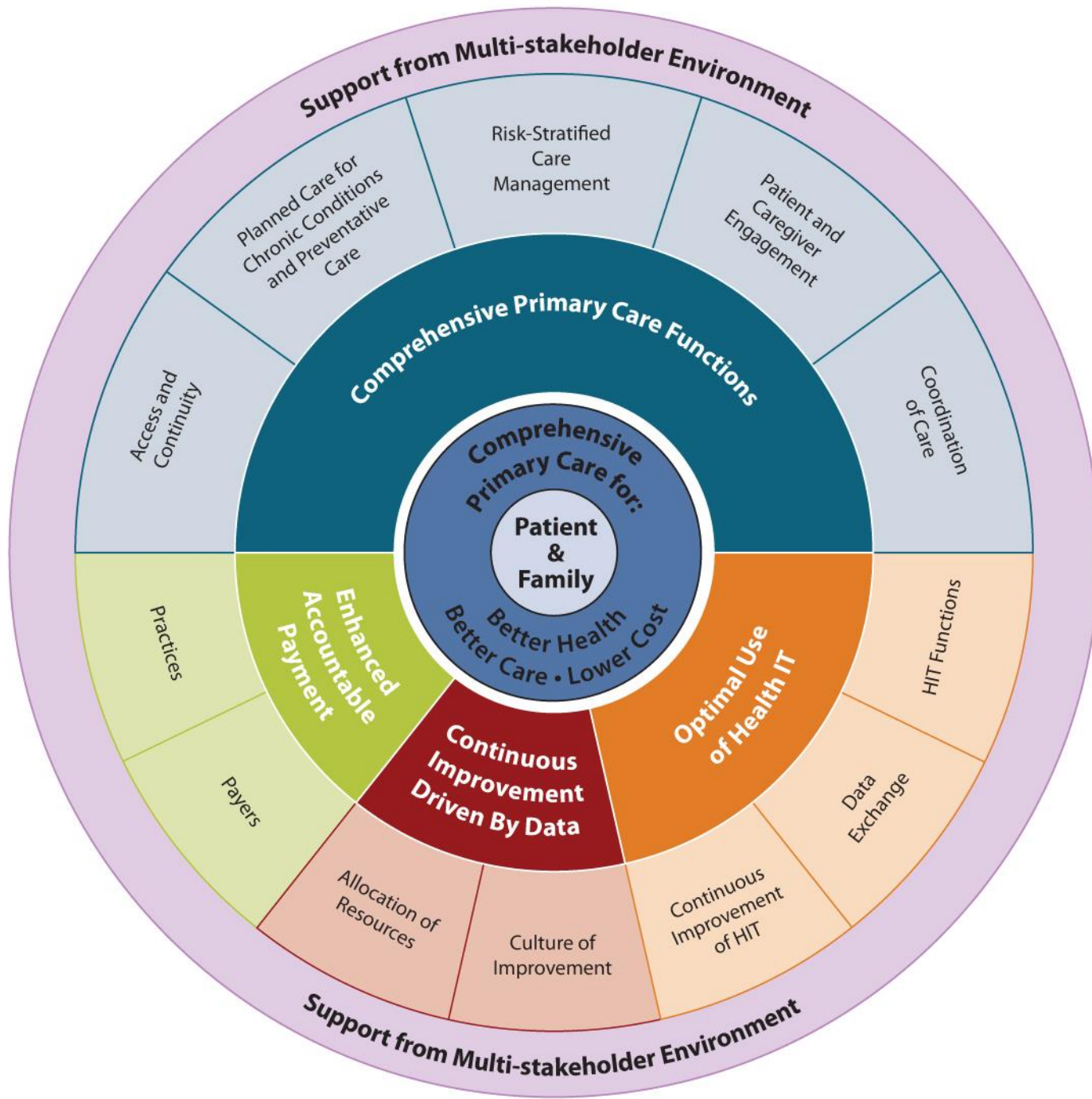
NAPA Driver Diagram

- ▶ The intent was to lay out clearly how the various aspects of NAPA work and tie together
 - National Plan, Council recommendations, Summit work, federal and non-federal activities to address recommendations
- ▶ Provides a broad overview of where things fit together and affect each other
- ▶ Intended to be very flexible, but will hopefully allow us to see the progress made over time

Aim	Primary Driver	Secondary Driver
Eliminate the burden of Alzheimer’s Disease and Related Dementias	Prevent and Effectively Treat Alzheimer’s Disease by 2025	Identify Research Priorities and Milestones
		Expand Research Aimed at Preventing and Treating
		Accelerate Efforts to Identify Early and Pre–symptomatic Stages
		Coordinate research with International Public and Private Entities
		Facilitate Translation of Findings into Medical Practice and Public Health Programs
	Enhance Care Quality and Efficacy	Build Workforce
		Ensure Timely and Accurate Diagnosis
		Educate and Support People with Dementia and their Families
		Identify High–Quality Dementia Care Guidelines and Measures Across Care Settings
		Explore the Effectiveness of New Models of Care
		Ensure Safe and Effective Transitions between Care Settings and Systems
		Advance Coordinated and Integrated Health and Long–Term Services and Supports
		Improve Care for Populations Disproportionately Affected by Alzheimer’ Disease and for Populations Facing Care Challenges
	Expand Supports for People with Alzheimer’s Disease and Related Dementias and their Families	Ensure Receipt of Culturally Sensitive Education, Training, and Support Materials
		Enable Family Caregivers to Continue to Provide Care while Maintaining Their Own Health and Well–Being
		Assist Families in Planning for Future Care Needs
		Maintain the Dignity, Safety and Rights of Persons with ADRD
		Assess and Address the Housing Needs
	Enhance Public Awareness and Engagement	Educate the Public
		Work with State, Tribal, and Local Governments to Improve Coordination and Identify Model Initiatives to Advance Awareness and Readiness across the Government
		Coordinate United States Efforts with Those of the Global Community
	Track Progress and Drive Improvement	Enhance the Federal Government’s Ability to Track Progress
		Monitor Progress on the National Plan

Example

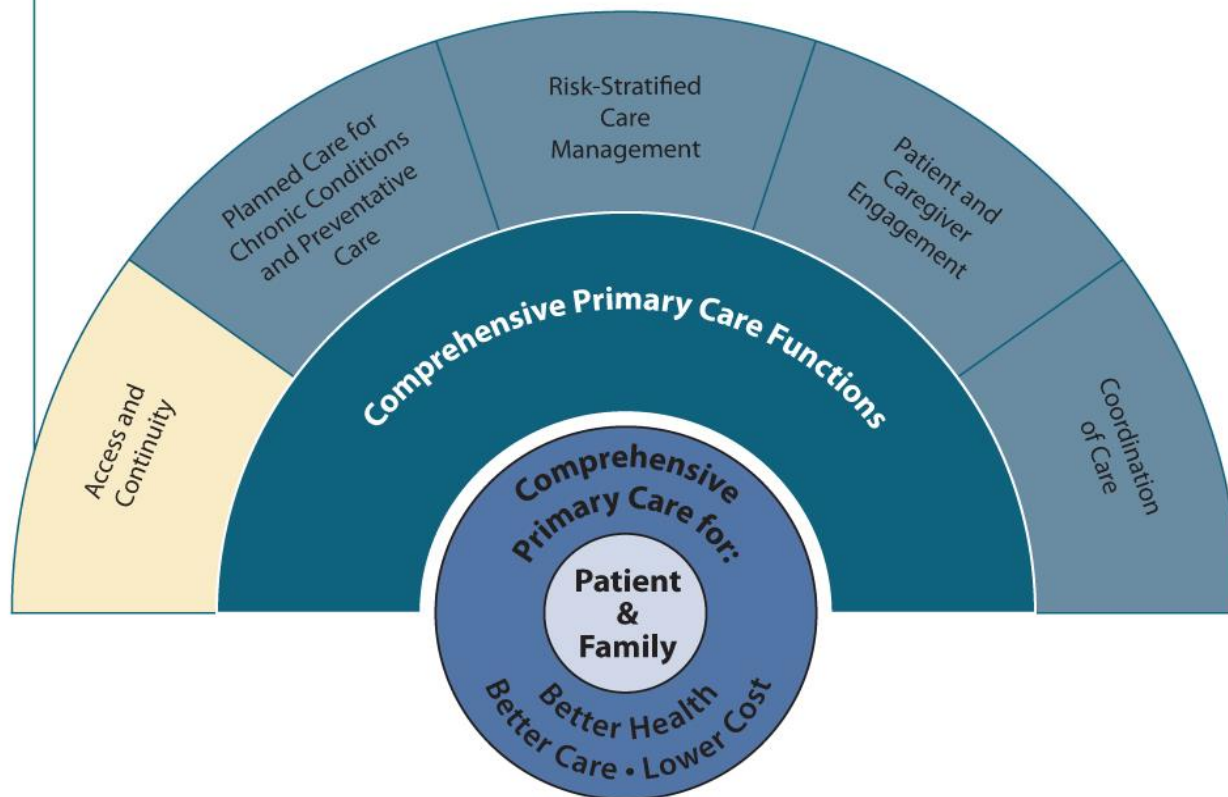
Aim	Primary Driver	Secondary Driver	Theme/ Concept	Theme/ Concept	Rec	Rec (2017 Rec)	Activity (Fed Response)
Eliminate Burden of ADRD	Prevent and Effectively Treat ADRD by 2025	Identify Research Priorities and Milestones	Research Subcom Theme	Robust Research Road Map for achieving Goal	Research Subcom Rec	The 2017 National Plan should continue to provide a robust, comprehensive, and transformative scientific Road Map for achieving the goal of preventing, effectively treating, and providing effective care and services for AD/ADRD by 2025	NIH: AD and ADRD Summits continue to provide guidance on developing a research roadmap. The annual Bypass Budget provides further assistance in developing a roadmap



Change Concept

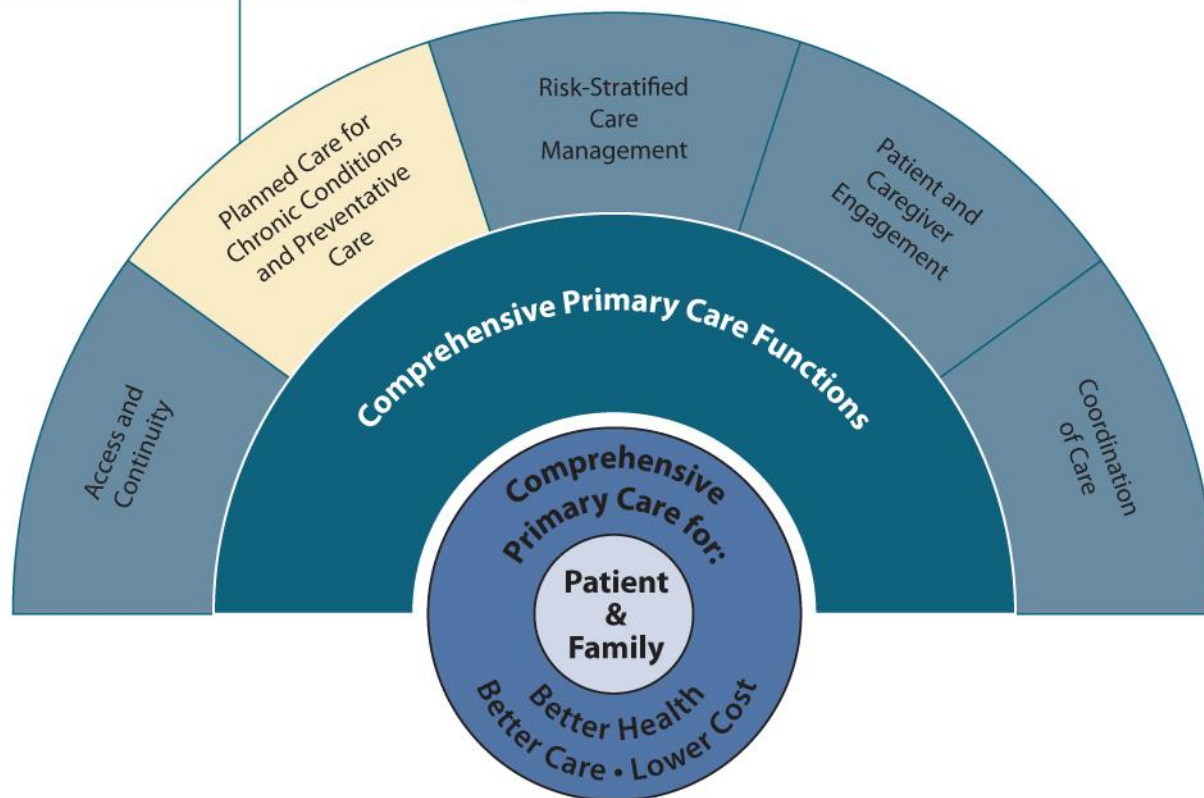
- A. Optimize timely access to care guided by the medical record.
- B. Empanel all patients to a care team or provider.
- C. Optimize continuity with provider and care team.

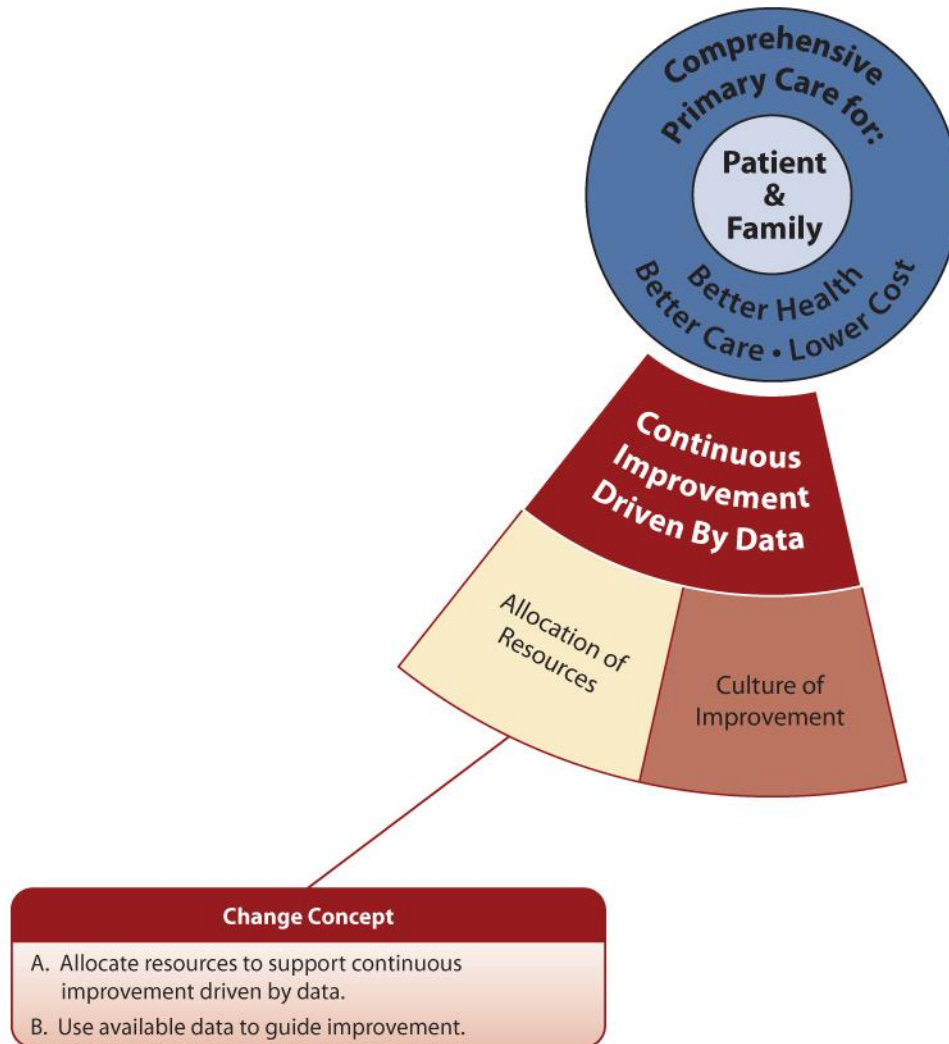
“Empanelling” is the process of associating individual patients with individual primary care providers (PCPs) within a primary care practice. This organizational activity within a primary care practice is key to patient-centered care. The PCP is the leader of an established care team; this team is responsible for the ongoing comprehensive and coordinated care of its empanelled patients. The team works together to provide high-quality care through patient-centered processes with lead responsibility for their identified, empanelled patients. Empanelment does not in any way limit a Medicare beneficiary's freedom to choose their own primary care provider.

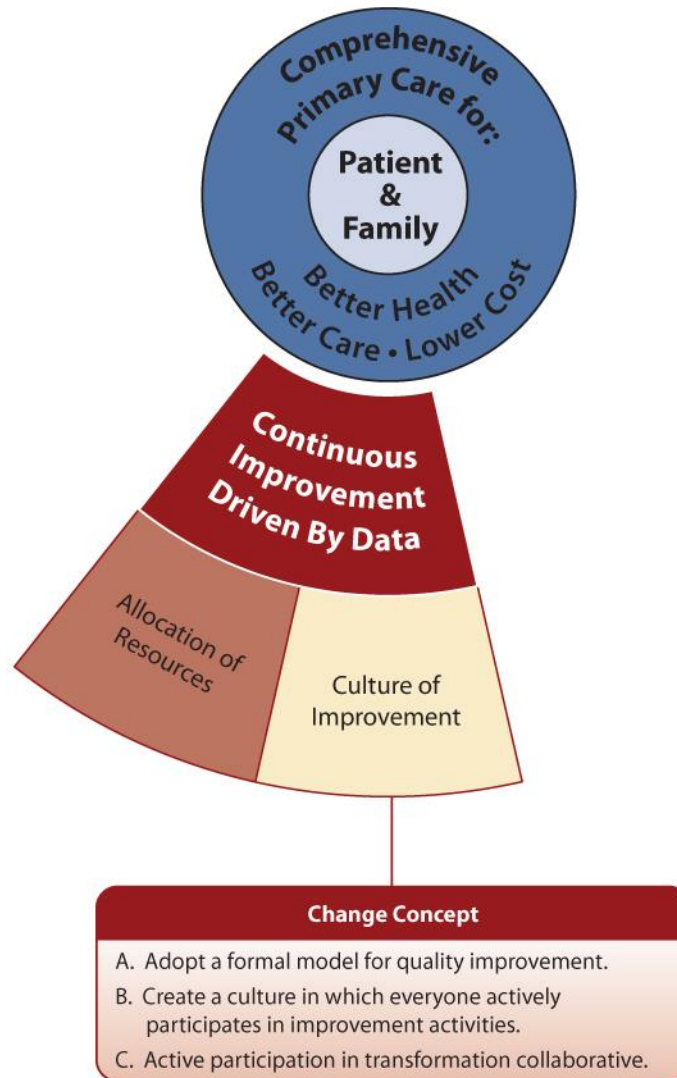


Change Concept

- A. Use a personalized plan of care for each patient.
- B. Manage medications to maximize therapeutic benefit and patient safety at lowest cost.
- C. Proactively manage chronic and preventive care for empanelled patients.
- D. Use team-based care to meet patient needs efficiently.







Discussion

Establishing a Framework to Achieve Goals

Nancy Murray, M.S.

President

The Arc of Greater Pittsburgh at Achieva

Exercise

Outlining Technical Assistance Needs and Future Planning

Pamela Nadash, Ph.D.
Associate Professor
Department of Gerontology
McCormack Graduate School
University of Massachusetts

Learning from Family Caregivers

**Workplan for Conducting Listening Sessions for the
RAISE Family Caregiving Advisory Council
2-12-2020**



Research Objectives

- Reach out to family caregivers and other stakeholders to provide multiple forums for expressing needs and challenges;
- Help identify the specific services, supports, or policy initiatives that might better meet their caregiving needs; and
- Inform the development of federal, state, and community blueprints for programs and services that can enhance the resilience of a diversity of family caregivers.

Three Unique Forums



- Detailed analysis of comments from the Request for Information (RFI)
- Web-based focus groups
- In-person listening sessions

RFI Response Analysis



- Roughly 1800 responses
- Two questions: issues and recommendations
- Analysis will identify key themes across responses
- Council feedback on the results will help areas of exploration in the subsequent stages of the research



Web-based Focus Groups

- Allow us to explore priority issues in more depth
- Advantages of web-based approach:
 - Caregivers whose circumstances might not permit travel to an in-person meeting can participate
 - Can gather input nationally
- Will convene 12 sessions, working with project team to develop and evolve discussion guide

In-Person Listening Sessions

- Convened at community-based settings involving key stakeholders within a given community
- Two in English and one in Spanish
- One in the DC area



Project Team Expertise

- **Community Catalyst** – National non-profit consumer advocacy organization. Works with state and federal policymakers to make systems more responsive to consumer needs through research and policy development;
- **LTSS Center at UMass Boston** – Subject matter experts and research expertise with consumers, family caregivers and LTSS stakeholders, including states and federal government. Skilled at qualitative research;
- **ET Consulting** – Expertise in consumer focus group design on a broad range of LTSS topics, including several projects in collaboration with U Mass Boston.

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Research.....Project Management

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Research bridging policy and practice



Project Timeline

Time Period	Activities
1 st Quarter	Analysis of Federal Register comments
2 nd Quarter	Research design and kick off for web-based focus groups
3 rd Quarter	Continue focus groups and begin In-Person Listening Sessions
4 th Quarter	Complete Listening Sessions, analysis of findings, Project Presentation

Thank you.



COMMUNITY CATALYST

Because we all should have a say
in decisions that affect **our health**



Wrap-up and Charge to Sub-committee

Greg Link, Director

Office of Supportive and Caregiver Services
Administration for Community Living

Wendy Fox-Grage, Project Director

National Academy for State Health Policy (NASHP)