Citizen Engagement:
The Frail Elder Voice

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Perspectives for TVN: Improving Care for Frail Elderly Canadians
Altarum Institute integrates independent research and client-centered consulting to deliver comprehensive, systems-based solutions that improve health and health care. A nonprofit, Altarum serves clients in both the public and private sectors. For more information, visit www.altarum.org

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What We Want in Old Age....
While old age may always be challenging, we have made it unnecessarily terrifying and miserable.
Single Classic “Terminal” Disease: “Dying”

- **Function**: Mostly cancer
- **Onset incurable disease**: Function
- **Time**: Often a few years, but decline usually over a few months
- **Death**: Hospice starts
Onset could be deficits in ADLs, speech, ambulation.

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<th>Function</th>
<th>Time</th>
<th>Death</th>
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<td>Mostly frailty and dementia</td>
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<td>Now, most Americans have this course.</td>
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<td>The numbers will triple in 30 years.</td>
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Quite variable, often 6-8 years
Self-care disability = 2.8 yrs ave.
Identification of Frail Elders in Need of Medicaring

Age \( \geq 65 \)

AND one of the following:
> 1 ADL deficit or
Requires constant supervision **OR**
Expected to meet criteria in 1-2Y

Unless Opt Out

Frail Elderly

Age \( \geq 85 \)

Want a sensible care system

With Opt In
Why Engage Citizens, and Who?

▲ Clinical
  ▪ To match services with needs
  ▪ To match services to individual preferences

▲ Research
  ▪ To prioritize concerns
  ▪ To participate as research subjects
  ▪ To increase use of findings

▲ Political
  ▪ To demand reforms, change power relationships

▲ Who? Family Caregivers! (and frail elders and paid caregivers)
Activation Is Developmental

**Level 1**
*Starting to take a role*
Patients do not yet grasp that they must play an active role in their own health. They are disposed to being passive recipients of care.

**Level 2**
*Building knowledge and confidence*
Patients lack the basic health-related facts or have not connected these facts into larger understanding of their health or recommended health regimen.

**Level 3**
*Taking action*
Patients have the key facts and are beginning to take action but may lack confidence and the skill to support their behaviors.

**Level 4**
*Maintaining behaviors*
Patients have adopted new behaviors but may not be able to maintain them in the face of stress or health crises.

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Judith Hibbard, PhD University of Oregon
ACE: Altarum Consumer Engagement - Domains

http://altarum.org/our-work/ace-measure
Improving Patient Activation…

▲ Coleman patient activation model - http://carentransitions.org/
▲ Motivational Interviewing
▲ Broad change of cues and supports in medical care settings
▲ Public health messages
Steps in optimal care planning

1. Targeting

2. Care Planning
   A. Current patient/family situation
   B. Likely future situation(s) with various strategies
   C. Patient/family priorities – hopes, fears, values – goals
   D. Negotiated, patient-driven care plan
   E. Available to those who need it, promptly

3. Evaluation and Feedback – system learning

4. Care plan use in system management – supply and quality issues for community
Measuring Quality for Elders

Currently, mostly professional standards for younger persons – so, we need:

▲ To exclude frail elders from the denominator in most current quality measures – often harmful or irrelevant.

▲ To reflect scope of elders’ concerns generally – fatigue, finances, fears, hopes

▲ To reflect specifics of this elder’s concerns

▲ To provide feedback and guide quality improvement, as well as ensuring accountability

▲ To report geographically – for communities
Patient-Reported: “Are we helping you do what is most important to you?”

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Ideal Score = 4
What to Monitor? Try geographic populations

Jönköping hospitals and municipalities

Olämpliga läkemedel¹ hos personer 65 år eller äldre i Jönköpings län, 06-2012

Anteckningsdatum: ¹ ¹Anteckningsdatum

Antipsykotiska läkemedel hos personer 65 år eller äldre i Jönköpings län, 06-2012

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4. Antipsykotiska läkemedel hos personer 65 år eller äldre i Jönköpings län, 06-2012
Fighting to Honor a Father’s Last Wish: To Die at Home

By NINA BERNSTEIN  SEPTEMBER 25, 2014
The “bottom line” for Mr. Andrey

▲ Last year of life included 4 nursing homes and a dozen ERs and hospitalizations
▲ Cost >$1 million to Medicare and Medicaid
▲ And he did not get his only wish…

To be at home.
NorthStar – What to aim for
NorthStar – What to Aim For

▲ Fully integrated eldercare system, with monitoring and management
▲ Honest and effective care plans
▲ Client/family perspective guides system and care
▲ Adequate supply of critical supportive services
▲ Medical services routinely attentive to function, comfort, meaningfulness – available at home, 24/7
▲ Sustainable – to family, community, and country
The Road to System Reforms

Get Angry!

ENCOURAGE EFFECTIVE COMPLAINING & ADVOCACY

Complain Effectively
The road to reforms

▲ Encourage allowing innovation – including some local management and control
▲ Require population-based metrics
▲ Demand appropriate measures of quality
▲ Develop language that can enable us to deal honestly and sensitively with frailty and death – (see http://caregivercorps.org)
▲ Talk with every political leader and wannabe about services and finances for elders
The MediCaring Community Model: *Core Elements*

1. Frail elders enrolled in a geographic community
2. Longitudinal, person-driven care plans
3. Medical care tailored to frail elders (including at home)
4. Incorporating health, social, and supportive services
5. Monitoring and improvement guided by a Community Board
6. Core funding derived from shared savings from current medical overuse
How to Engage Citizens on Frailty Issues?

▲ Clinical
  - Activate patients and caregivers; teach and support activation
  - Measure quality in relation to person-driven care plans
  - Involve frail persons and caregivers in prioritizing reforms

▲ Research
  - Involve frail elders and caregivers in research design
  - Enable participation in research as subjects
  - Engage frail elders and caregivers in using research findings

▲ Political
  - Support key organizations
  - Converge on agendas
  - Teach political activism; demonstrate and enable it
We can have what we want and need
When we are old and frail

But only if we deliberately build that future!