

Citizen Engagement: The Frail Elder Voice

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Perspectives for TVN: Improving Care for Frail Elderly Canadians



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What We Want in Old Age....

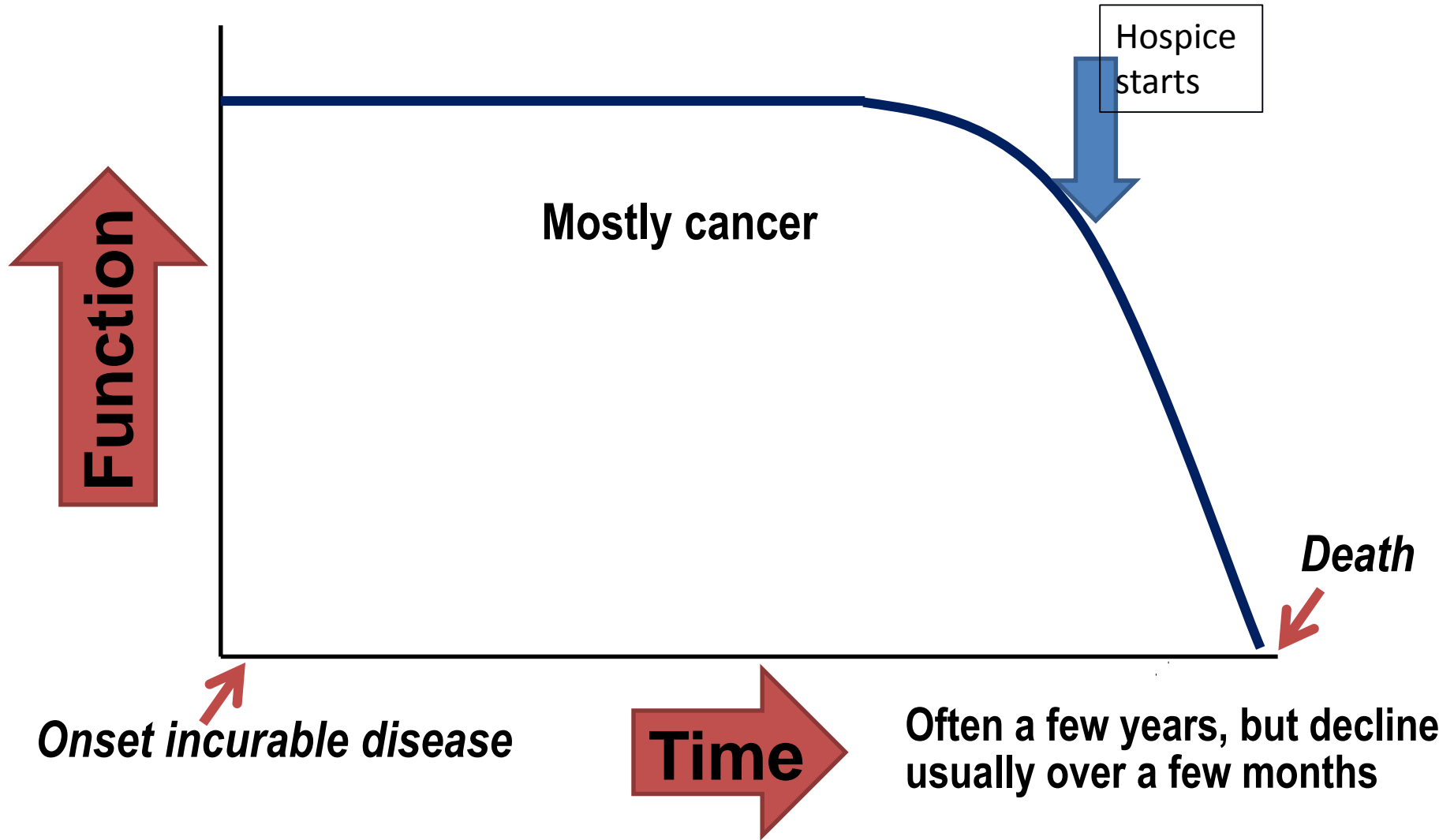


....What We Get

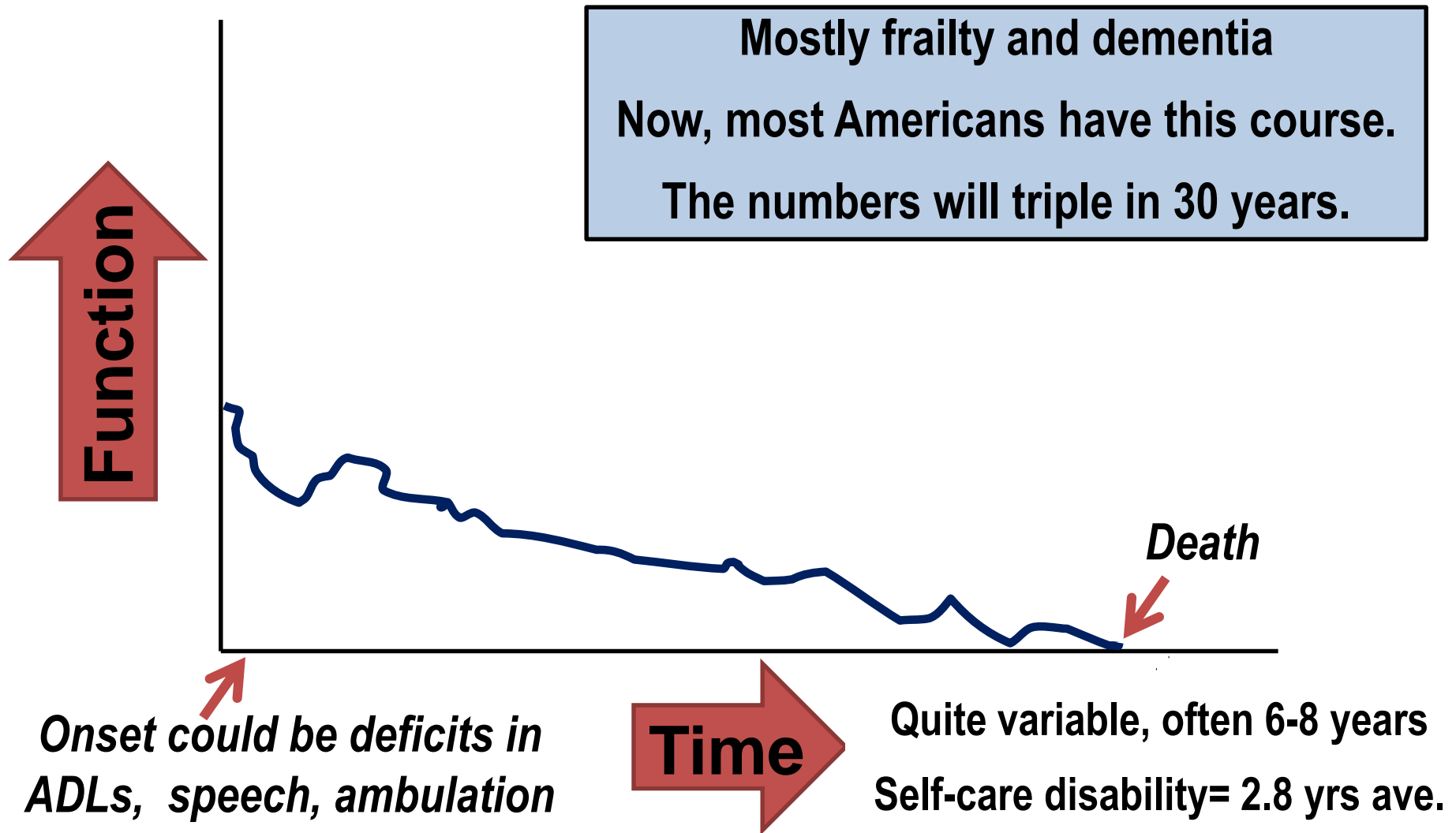


***While old age may always be challenging,
we have made it unnecessarily terrifying and miserable.***

Single Classic “Terminal” Disease: “Dying”



Prolonged dwindling



Identification of Frail Elders in Need of Medicaring

Age ≥ 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 ≥ 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

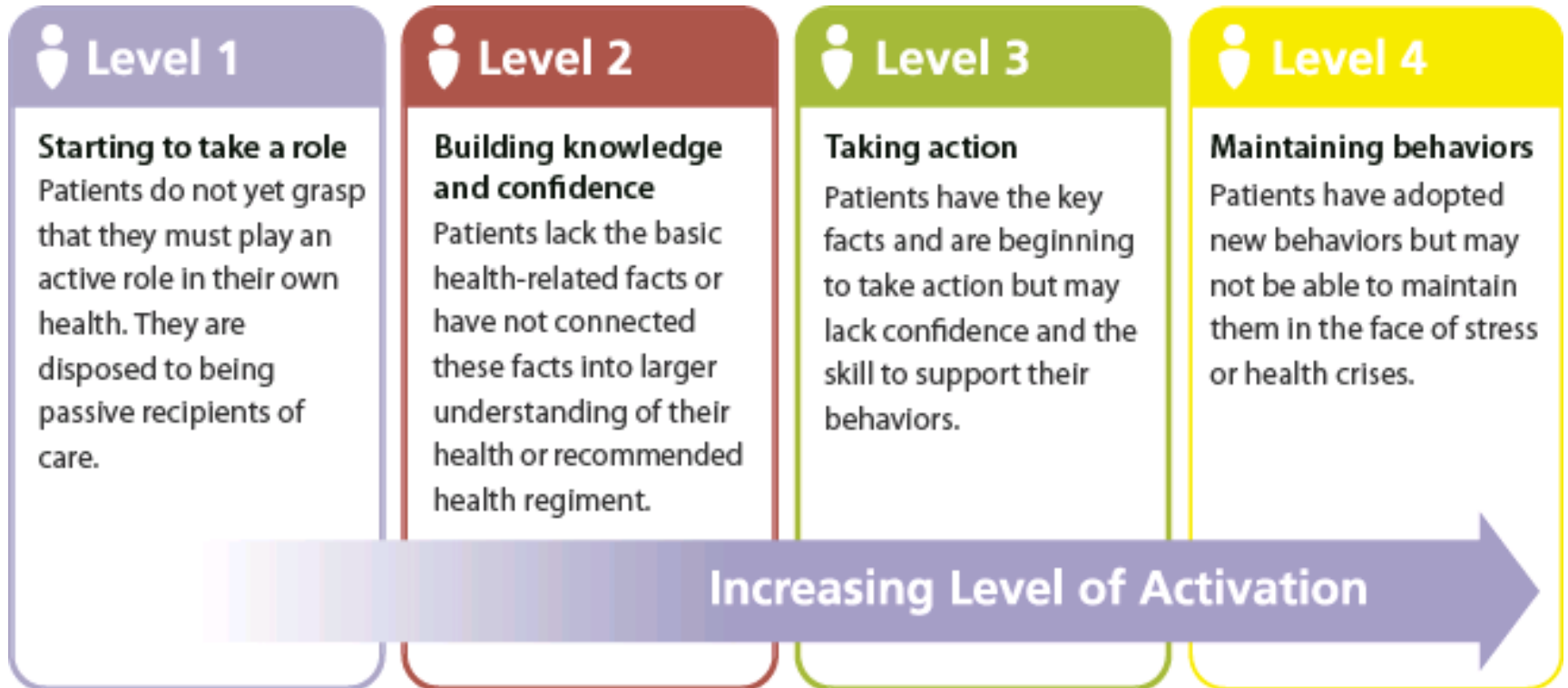
- To prioritize concerns
- To participate as research subjects
- To increase use of findings

▲ Political

- To demand reforms, change power relationships

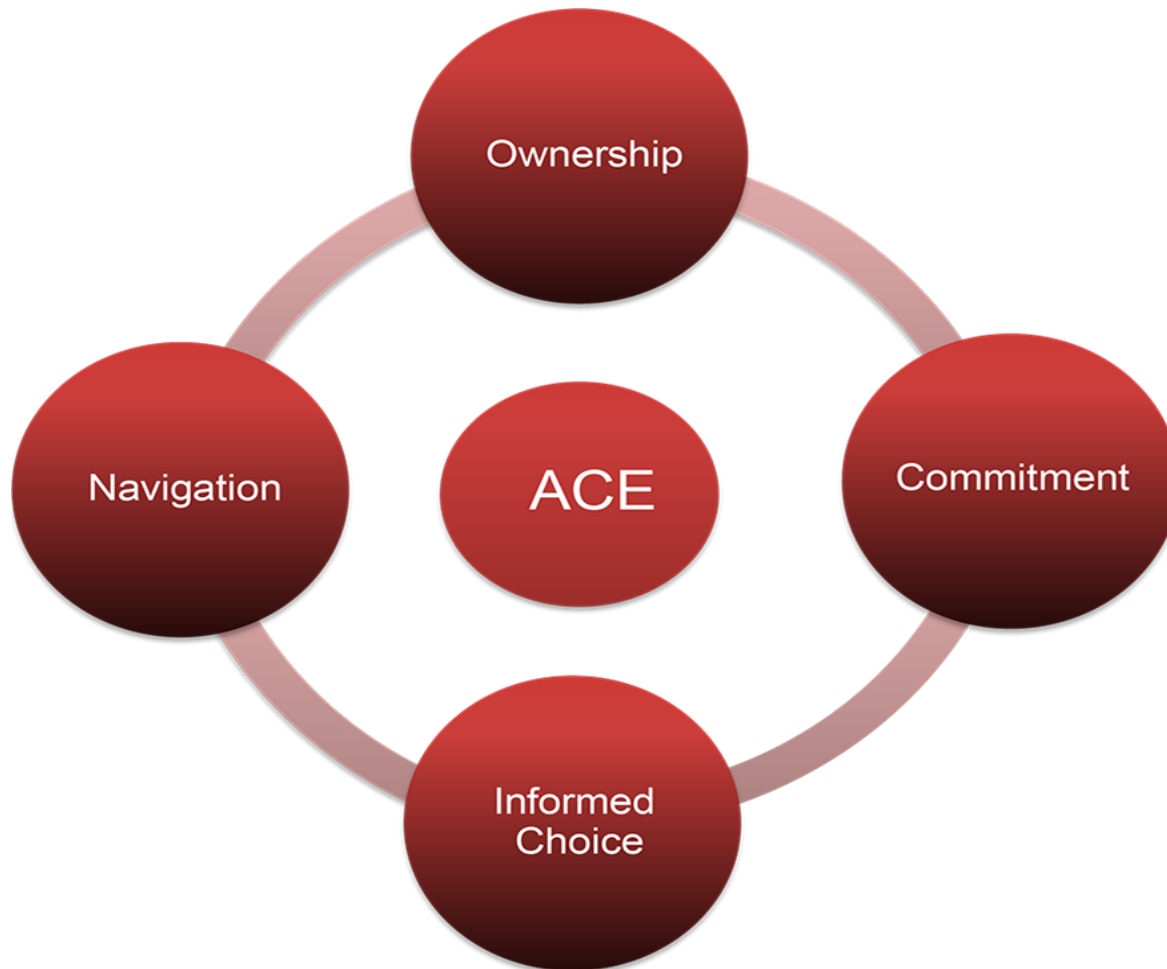
▲ Who? Family Caregivers! (and frail elders and paid caregivers)

Activation Is Developmental



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://caretransitions.org/>
- ▲ Chronic Disease Self-Management model - <http://patienteducation.stanford.edu/programs/cdsm/p.html>
- ▲ 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

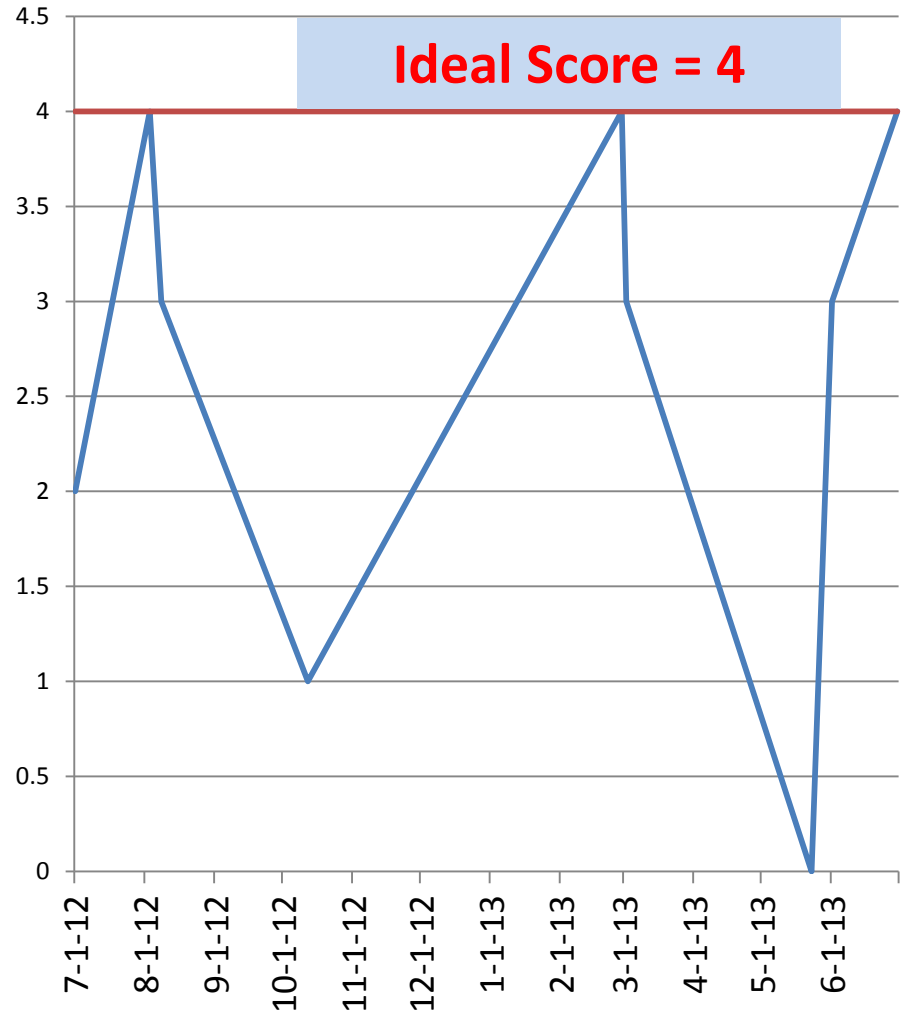
Measuring Quality for Elders

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?”

Date	Score
7/1/2012	2
8/3/2012	4
8/8/2012	3
10/12/2012	1
2/28/2013	4
3/2/2013	3
5/23/2013	0
6/1/2013	3
6/30/2013	4

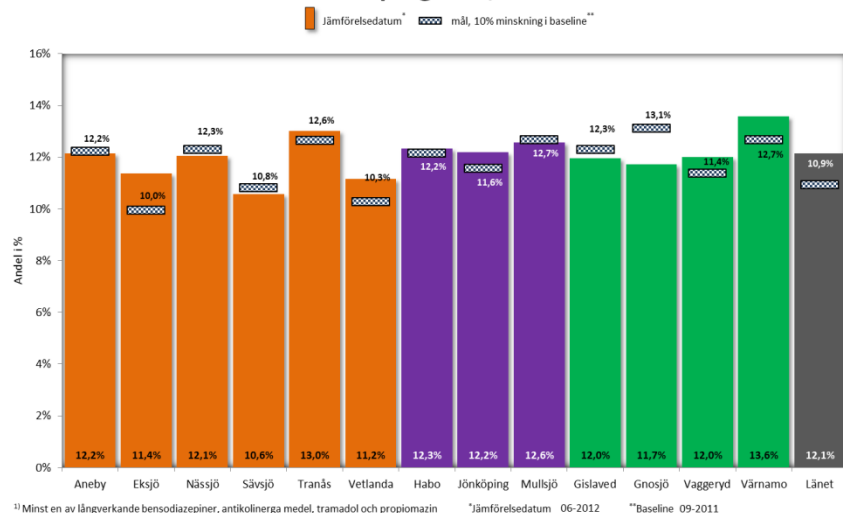


What to Monitor? Try geographic populations



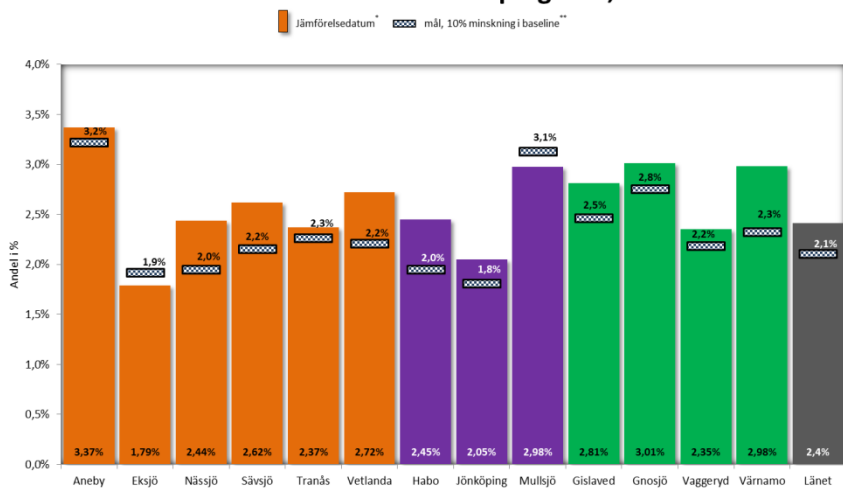
Jonkoping hospitals and municipalities

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



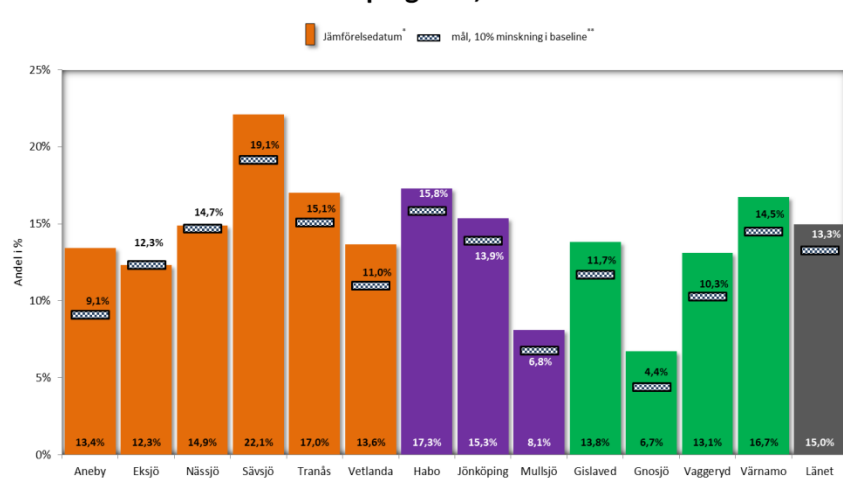
¹Minst en av långverkande bensodiazepiner, antikonvulsiva medel, tramadol och propiomazin *jämförelsedatum 06-2012 **Baseline 09-2011

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



*jämförelsedatum 06-2012 **Baseline 09-2011

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



*jämförelsedatum 06-2012 **Baseline 09-2011

Sad Tale – NY Times Sept 28, 2014

The screenshot shows a web browser window displaying a New York Times article. The address bar shows the URL: <http://www.nytimes.com/2014/09/26/nyregion/>. The article title is "Fighting to Honor a Father's Last Wish: To Die at Home" by Nina Bernstein, dated September 25, 2014. The article has 1019 comments. The main image shows a woman with long blonde hair, wearing a black leather jacket, sitting at the side of a hospital bed. She is looking at an elderly man lying in the bed, who is wearing a hospital gown and has his hand to his chin in a thoughtful or distressed pose. The background is a hospital room with wood-paneled walls.

The “bottom line” for Mr. Andrey

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

To be at home.



NorthStar – What to aim for



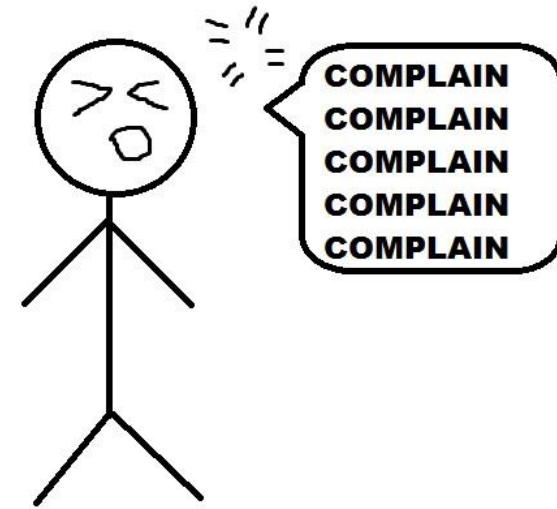
NorthStar – What to Aim For

- ▲ 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

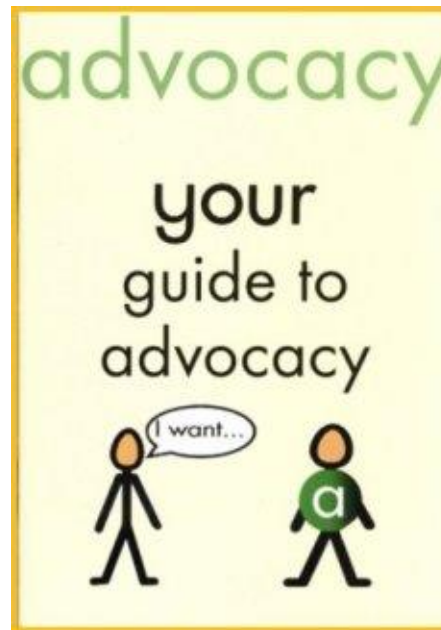
The Road to System Reforms



Get Angry!



Complain Effectively



ENCOURAGE EFFECTIVE COMPLAINING & ADVOCACY

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!**