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UNIVERSITY OF
CALGARY



Advance Care Planning: Transforming quality of care with Albertans

J Simon, K Fassbender, N Hagen,
P Biondo and M Douglas on behalf of ACP CRIO

On behalf of the ACP CRIO Team

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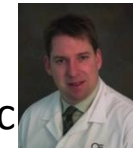
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Dr. Jonathan Howlett



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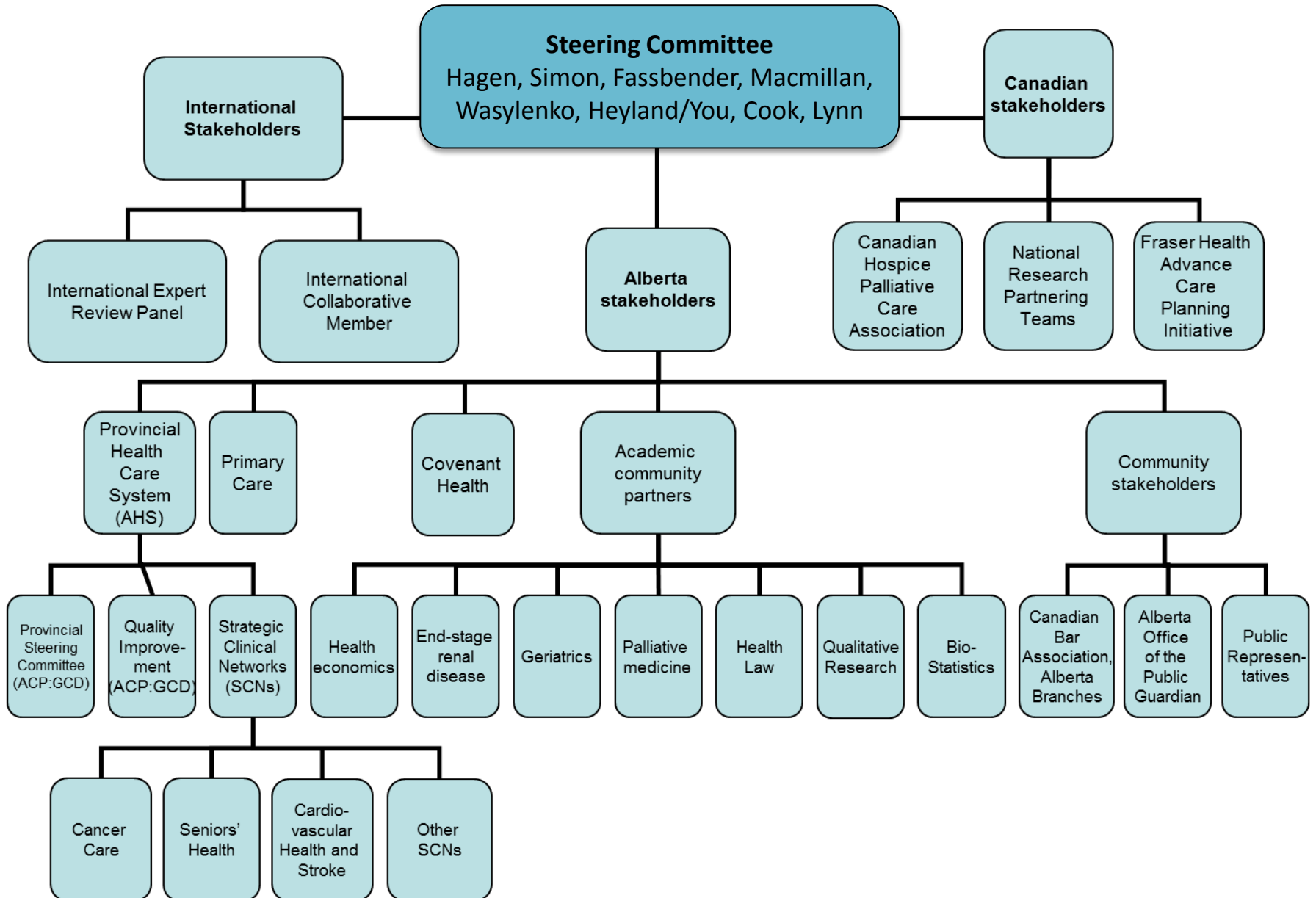
Dr. Ann Syme



Tracy Lynn
Wityk Martin

Et al.

Acknowledgements



International Advisors



Bernard Hammes



Rebecca Sudore

Seminar Format

- Welcome to those joining online!
 - Use Chat box to send questions/comments
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Who's here today? Are you a:



Clinician **A**

Researcher **B**

Administrator **C**

Legal professional **D**

Student **E**

Public **F**

Other **G**

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What's your generation?

Millennials: Born 1977 to 2000

Generation X: Born 1965 to 1976

Baby Boomers: Born 1946 to 1964

Traditionalists or Silent
Generation: Born 1945 and before

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Session Objectives

1. Increase awareness of ACP and GCD
 2. Apply knowledge of barriers and facilitators in Alberta
 3. Act on strategies, including evaluation
- ...To improve ACP GCD uptake in your context**

Outline

1. Background in Alberta: The why and what
2. ACP CRIO research questions and theories
3. What are the barriers and facilitators?
4. How can we improve engagement in ACP & GCD processes?
5. What indicators best monitor uptake?
6. What are the economic consequences?
7. Summary – What will success look like?

BACKGROUND – THE WHY AND WHAT OF ACP

Which aim do you think ACP will most readily achieve?

Improved provider
experience

Improved patient
experience

Improved health of
the population

Decreased per capita
costs

At risk to not achieve
any of these

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Why ACP?



TITLE**ADVANCE CARE PLANNING AND GOALS OF CARE DESIGNATION****DOCUMENT #****HCS-38****INITIAL APPROVAL DATE****January 21, 2014****APPROVAL LEVEL****Chief Executive Officer****INITIAL EFFECTIVE DATE****April 1, 2014****SPONSOR****Seniors Health****REVISION EFFECTIVE DATE****NA****CATEGORY****Health Care and Services****NEXT REVIEW****January 21, 2015**

If you have any questions or comments regarding the information in this policy, please contact the Clinical Policy Department at clinicalpolicy@albertahealthservices.ca. The Clinical Policy website is the official source of current approved clinical policies, procedures and directives.

PURPOSE

- To guide **health care professionals, patients and alternate decision-makers** regarding the general intentions of clinically indicated health care, specific interventions, and the service locations where such care will be provided.
- To serve as a communication tool for health care professionals to assist in rapid decision-making in the clinical environment.

Advance Care Planning Conversations

*“**All adults** should be given the opportunity to participate in Advance Care Planning as a part of **routine care, started early** in a longitudinal relationship with a healthcare provider **and revisited** when the health or wishes of an adult changes”*

Goals of Care Conversations

*“Goals of care conversations shall take place, **where clinically indicated with the patient, as early as possible** in a patient’s course of care and/or treatment. These discussions explore the patient’s wishes and goals for clinically indicated treatment framed within the therapeutic options that are appropriate for the patient’s clinical condition”*

Care
Consistent
with Patient Values
& Clinical Context

Advance Care Planning

Selection of agent (alternate decision maker)
Sharing values
Illness expectations

Goals of Care Designations

Focus of Care
Location/Transfers
Interventions

Documentation



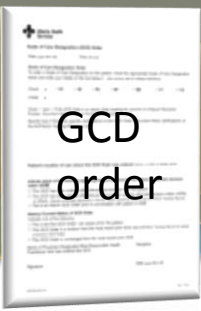
Personal
Directive



Green
Sleeve



Tracking
Record



GCD
order

Goals of Care Designation Order

Medical order
Communicating focus of care
Specific interventions
Transfer decisions
Locations of care



M

Medical care



R

Resuscitative Care



C

Comfort Care

Alberta had great scaffolding

Infrastructure

- Province-wide Policy & Procedure
- Green Sleeves, documents
- Aligned Personal Directive and Consent Policy

Engagement

- Resources: web, videos
- Guidebook: 7 languages
- Public booths/seminars

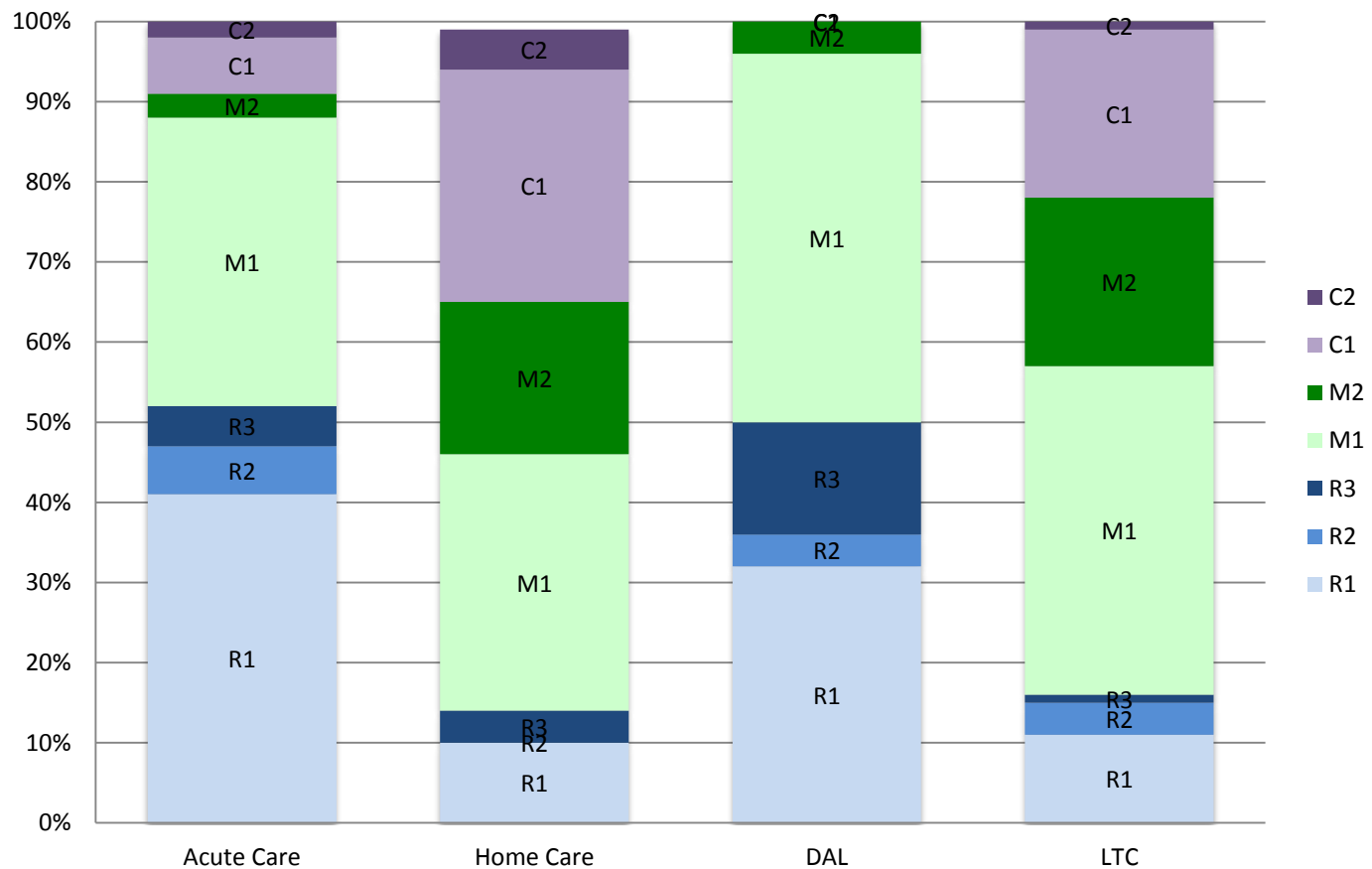
Continuous QI

- Recurrent Audits

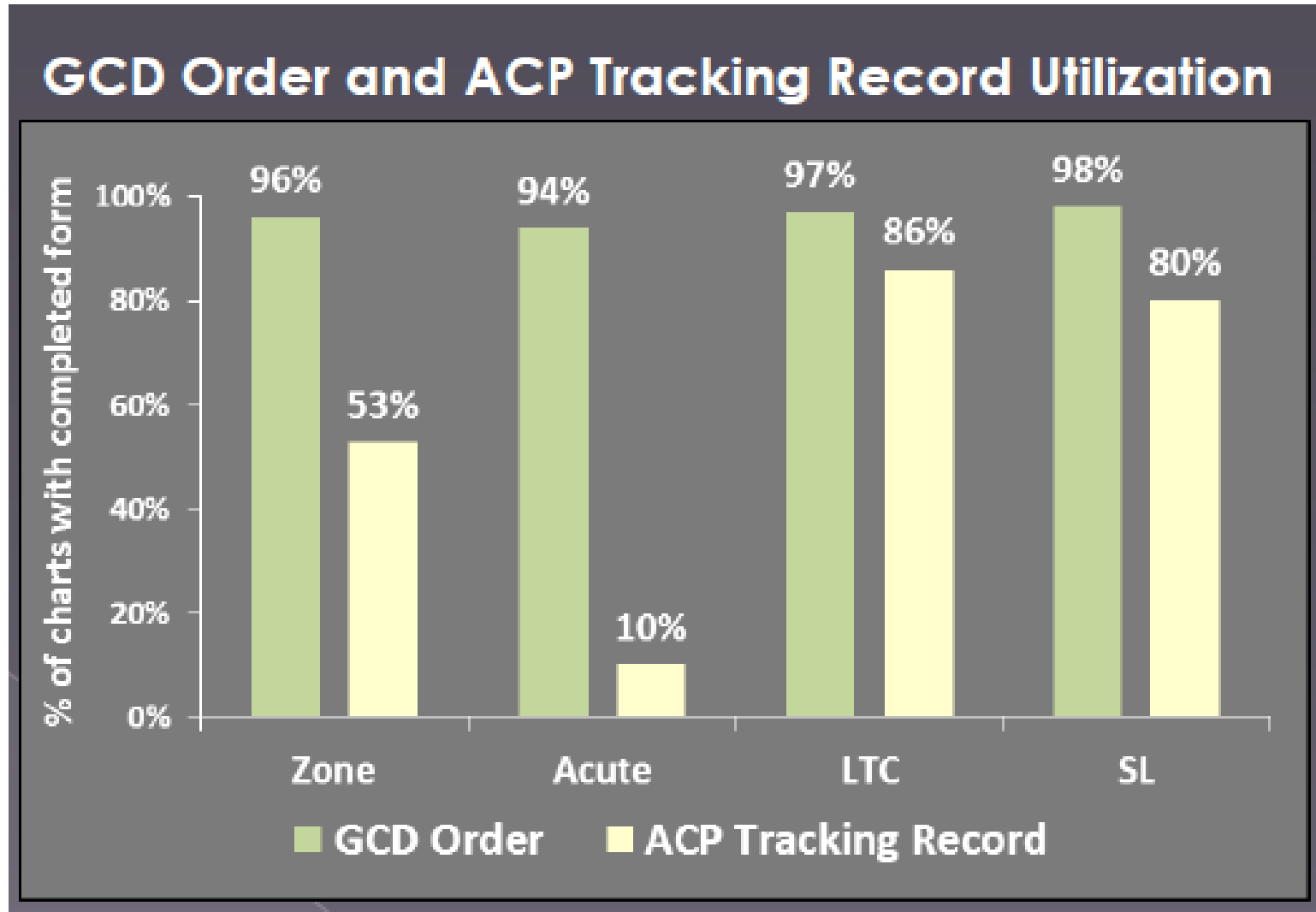
Education

- E-module
- Seminars

GCD differ appropriately across sectors



Tracking Record inconsistently used



ACCEPT Study: Poor concordance



3 Prior Cycles 2011-2015

Canadian, multi-center, prospective study of sick, older hospitalized patients' and family members' engagement and perceptions of Advance Care Planning and Goals of Care conversations.



Key Alberta Findings

No meaningful improvement was seen over time in the frequency or quality of ACP in Alberta or nationally.



27%

Concordance between patients' preferences for use of life sustaining therapies and their documented medical orders

Nationally: 30%



87-100%

Patients discussed wishes regarding life sustaining therapies with family members

Nationally: 88-92%



53%

Patients discussed wishes regarding life sustaining therapies with any health care provider but low levels of key discussion elements were reported

Nationally: 50%



Biggest mismatch was frequency of patients preferring comfort care who did not have medical orders reflecting that preference



The more conversation elements that were discussed in-hospital, the more likely a patient's preferences and medical orders were concordant



Low levels of satisfaction found with discussions about future location of care, use of life sustaining technologies, and what to expect at end stages of illness

7 what % of Albertans had spoken with Health
care providers (HCP) about their wishes for life-sustaining care

1%

10%

20%

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HQCA poll data

Answer B = 9%

Advance Care Planning and Goals of Care Alberta: A Population Based Knowledge Translation Intervention Study “ACP CRIO”



Research Activities

How to optimally implement widespread uptake of a formalized ACP framework across a large population and throughout a complex, multi-sector health care system?

Activity 1:

Assess **barriers, facilitators and readiness** to participate in ACP from public and HCP perspectives

Activity 2:

Assess **tools** for education and engagement & evaluate how best to adapt to local environment

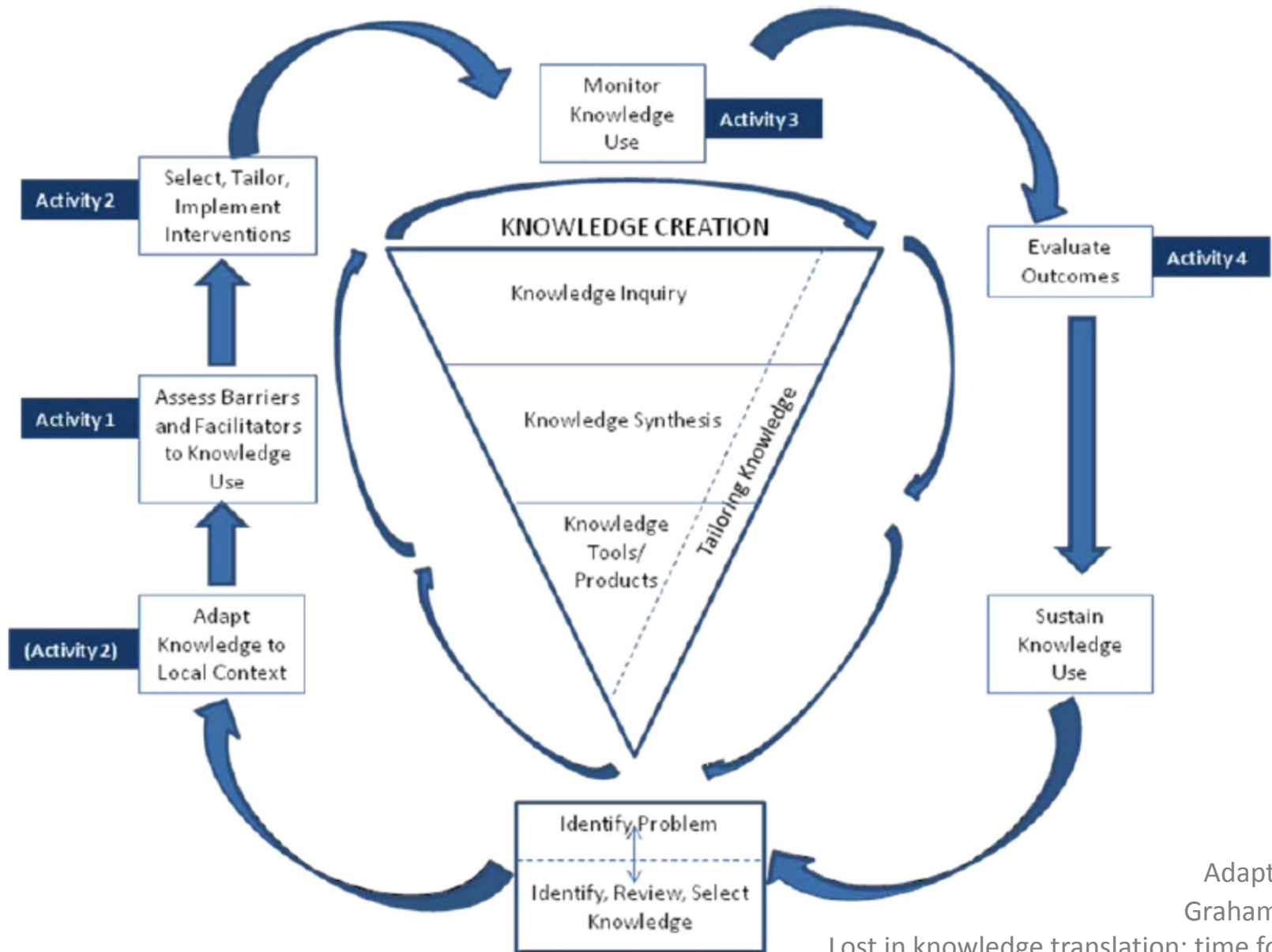
Activity 3:

Assess **indicators** to monitor ACP uptake & guide continuous quality improvement

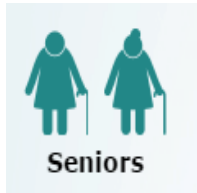
Activity 4:

Determine the **economic consequences** of ACP implementation

The Knowledge to Action Cycle



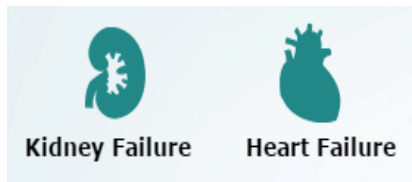
Adapted from:
Graham ID, et al.
Lost in knowledge translation: time for a map?
J Contin Educ Health Prof. 2006;26:13-24.



Seniors (supportive living facilities)



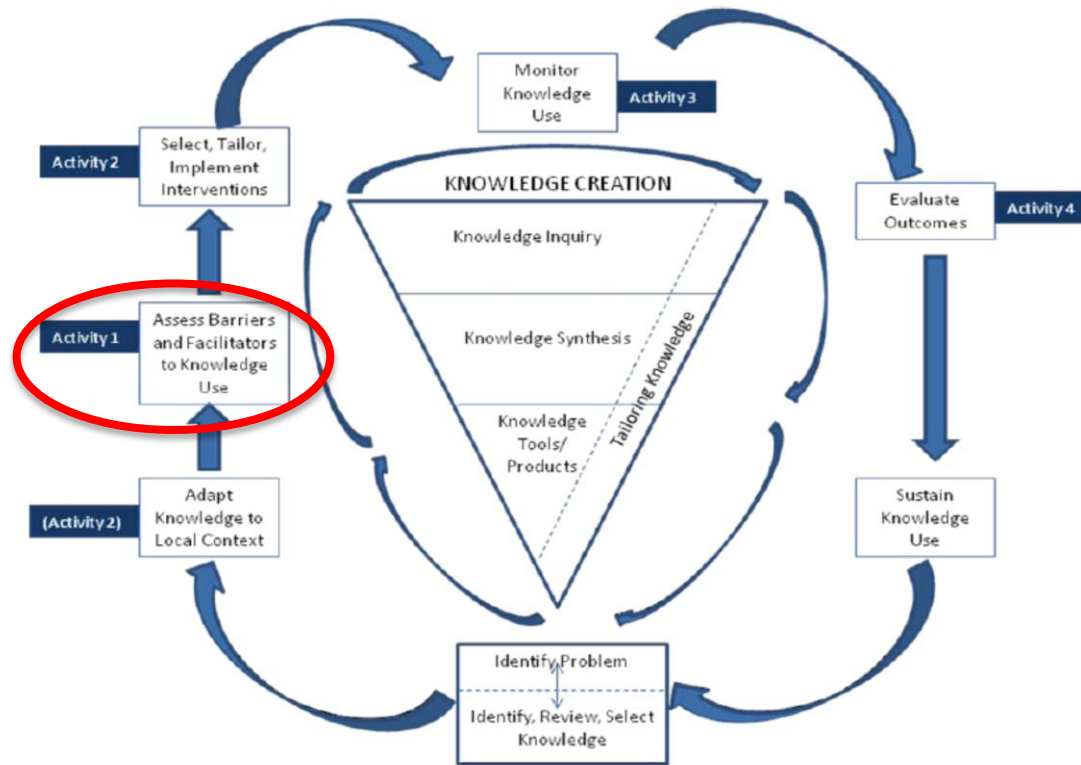
Cancer (out-patient clinics)



Chronic disease (renal and heart failure)

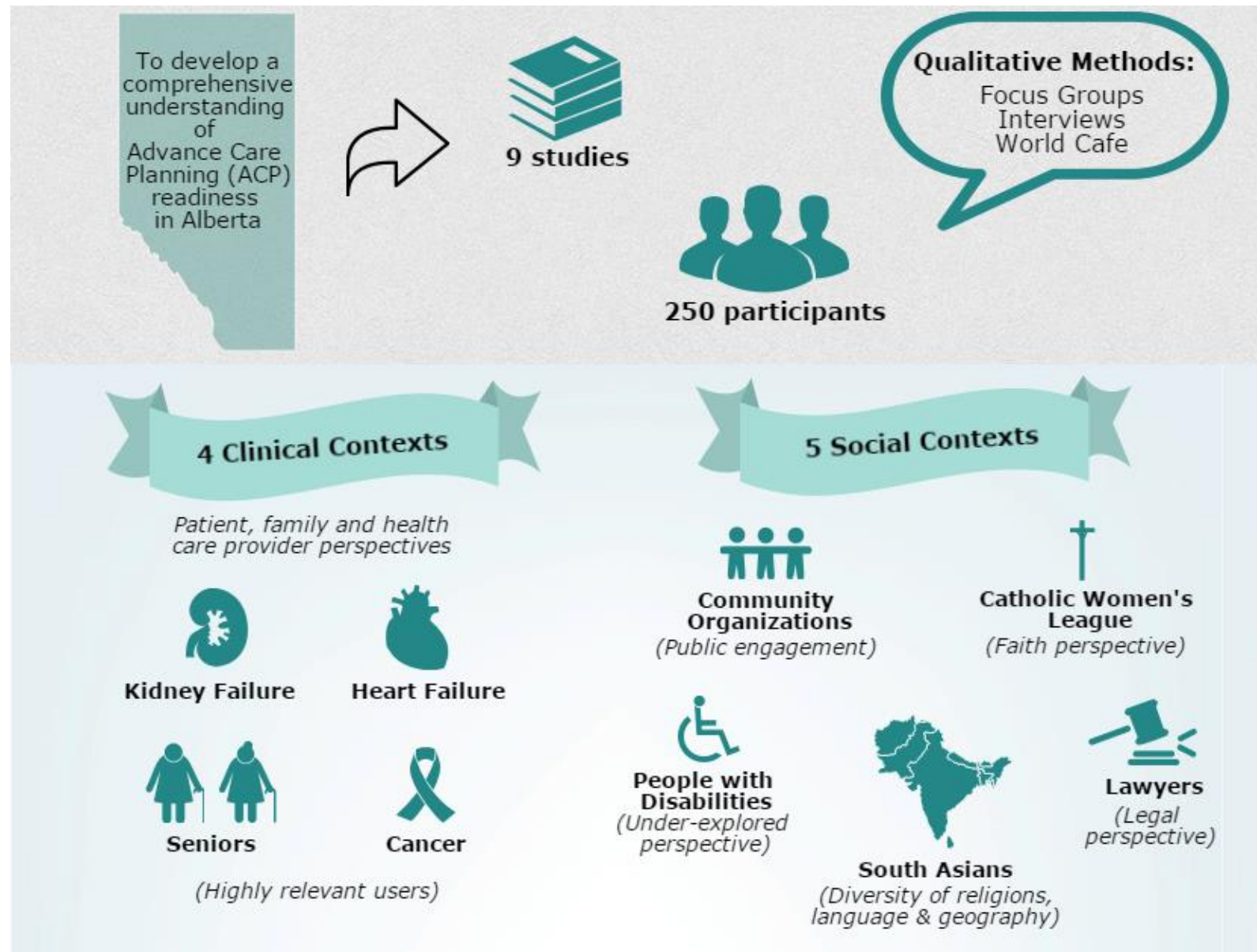
- Patients, families, public
- Healthcare providers (HCP)
- Legal professionals
- Health system





Activity 1

WHAT ARE THE BARRIERS AND FACILITATORS TO UPTAKE?





2 studies



593 participants

Strategic Clinical Networks



Healthcare Providers



Kidney Failure



Heart Failure



Seniors



Cancer

Michie's Theoretical Domains Framework & COM-B model

14 Domains

Knowledge

Skills

Social/Professional Role/Identity

Beliefs about Capabilities

Beliefs about Consequences

Goals

Memory, Attention & Decision Process

Environmental Context & Resources

Social Influences

Emotion

Behavioral Regulation

Intentions

Optimism

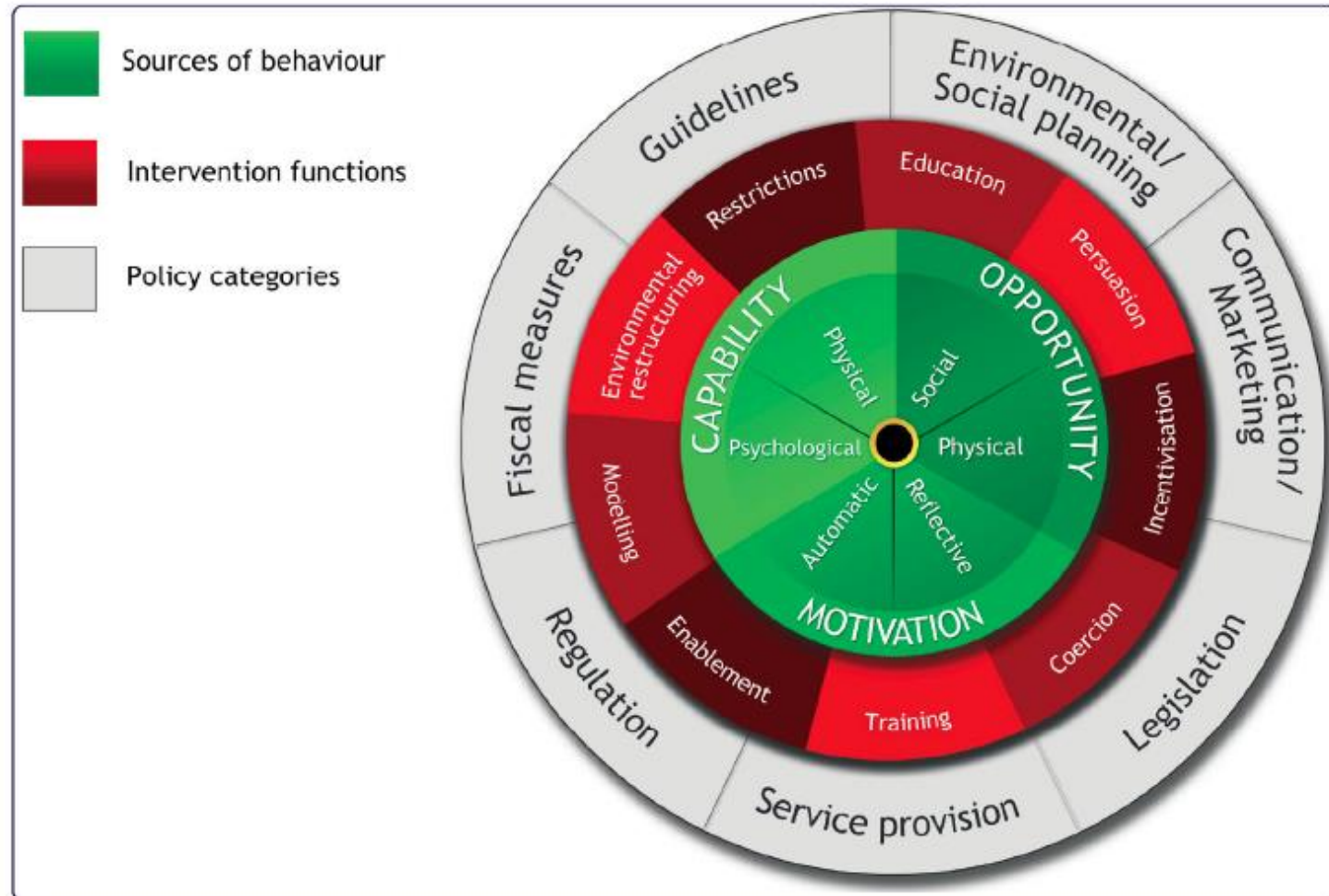
Reinforcement



www.implementationscience.com/content/6/1/42

Behaviour Change Wheel

- Synthesis of 19 frameworks to classify interventions
- **Centre ring:** COM-B model
- **Inner ring:** 9 intervention elements
- **Outer ring:** 7 policy categories



(Michie et al., 2011)



think the biggest barrier to ACP policy uptake the health system lens?



Insufficient public
engagement

Too many conflicting
initiatives

Insufficient infrastructure
(expert staff)

Lack of time for
conversations

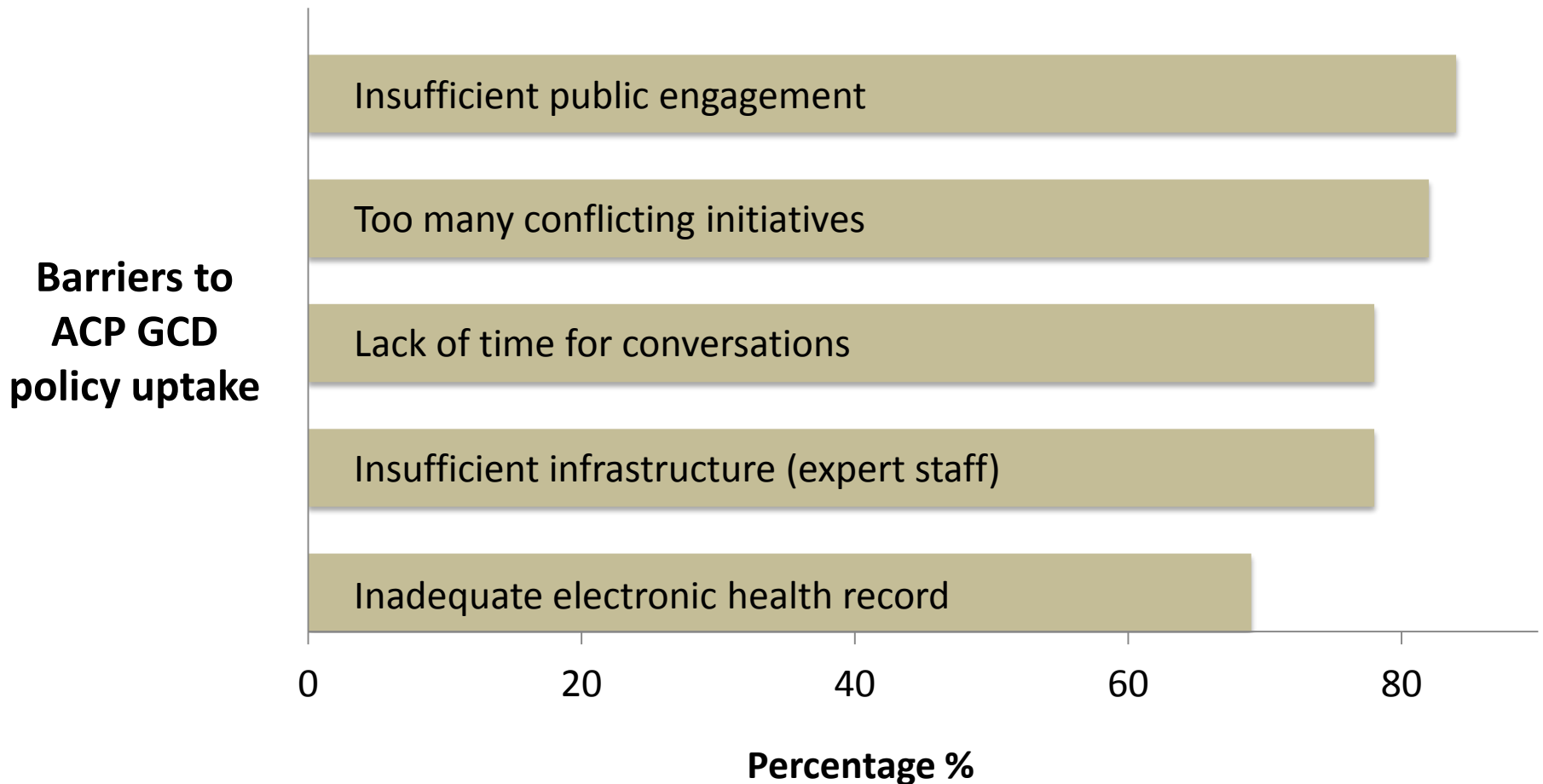
Inadequate electronic
health record (EHR)

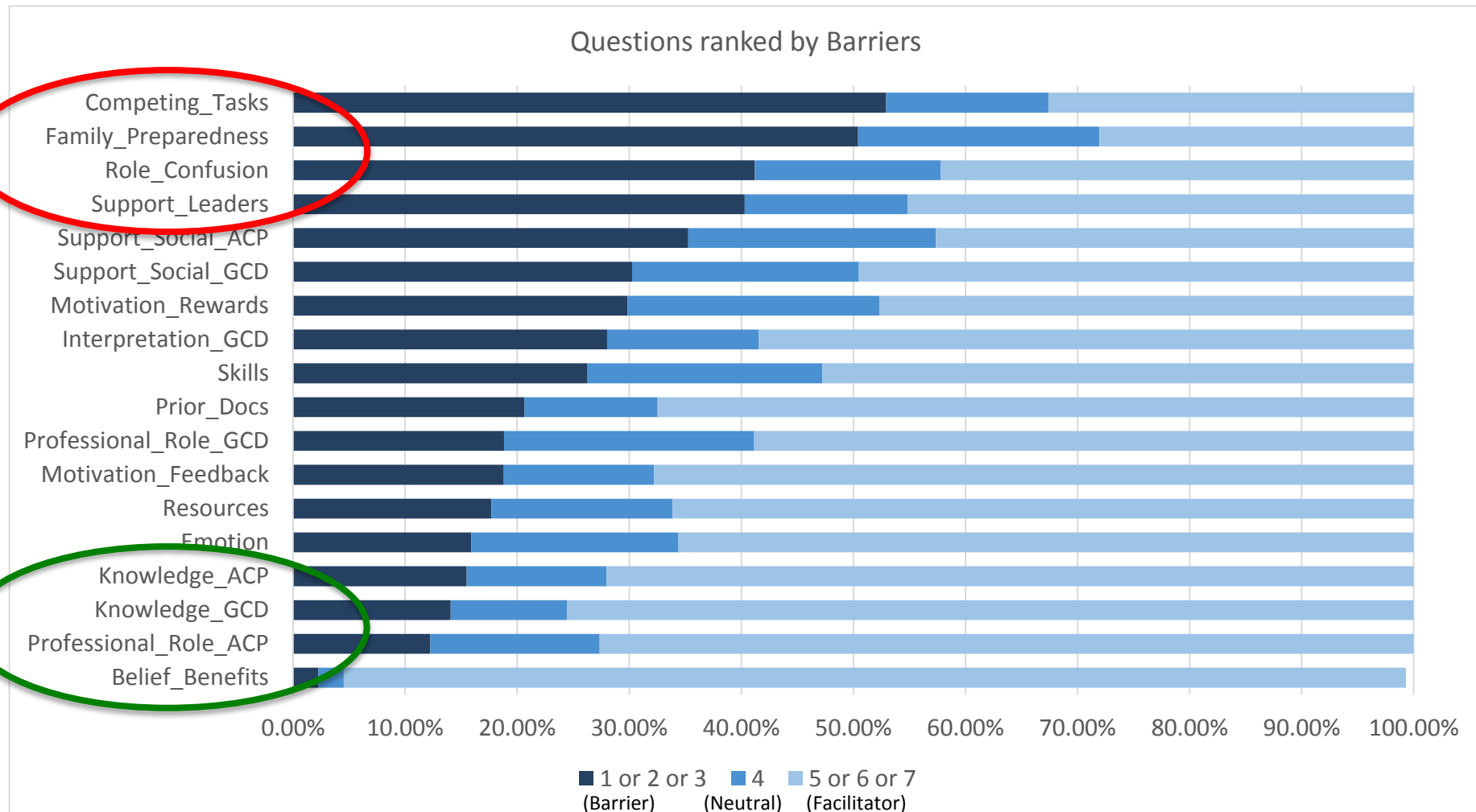
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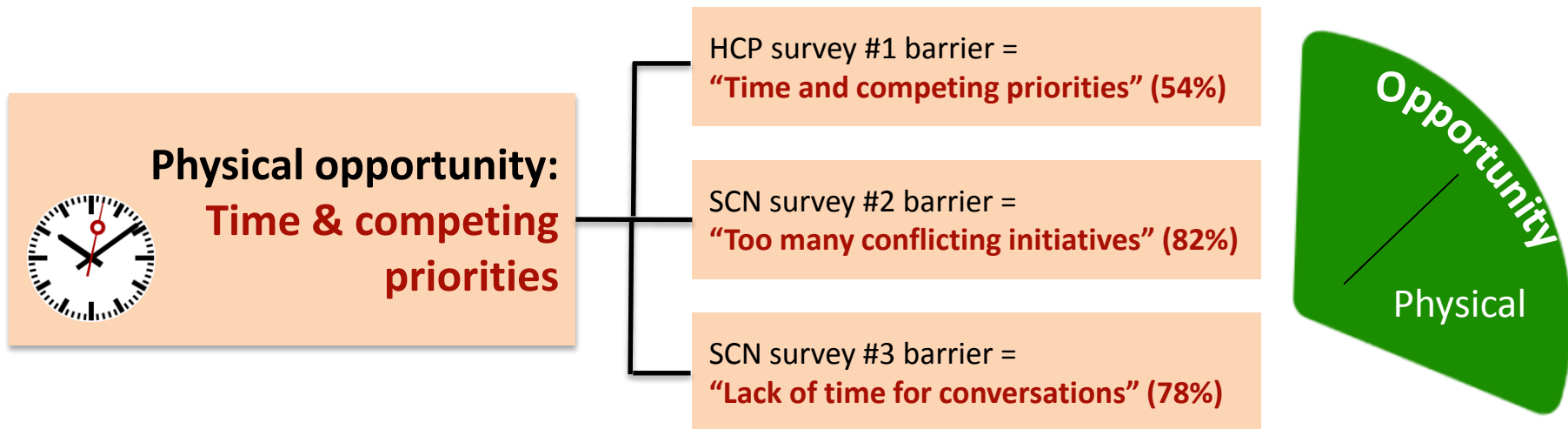


Strategic Clinical Network results





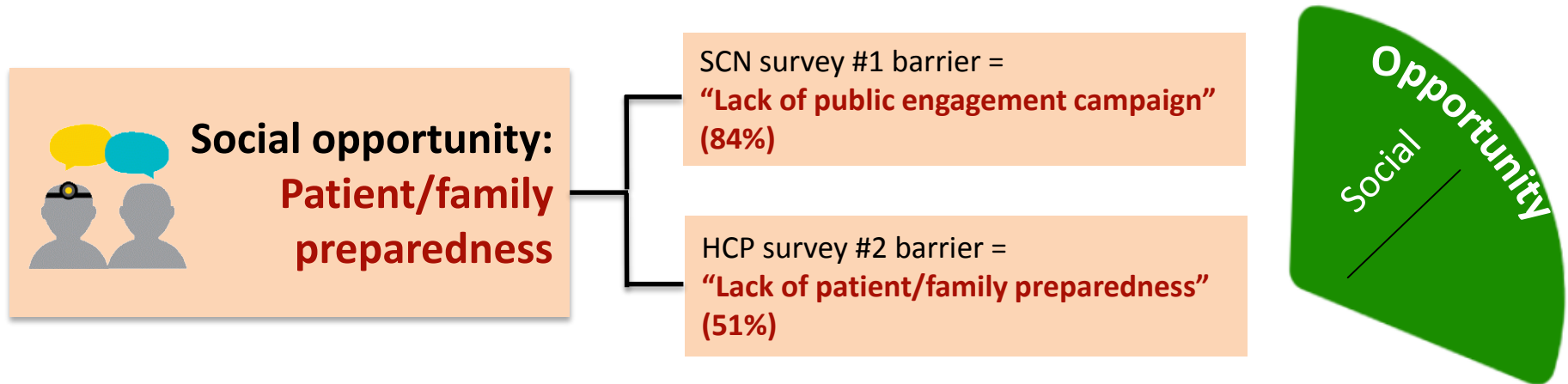
Opportunity – the greatest barrier



"Time hinders those conversations, because we're focusing on different aspects of nursing care." (Renal nurse)

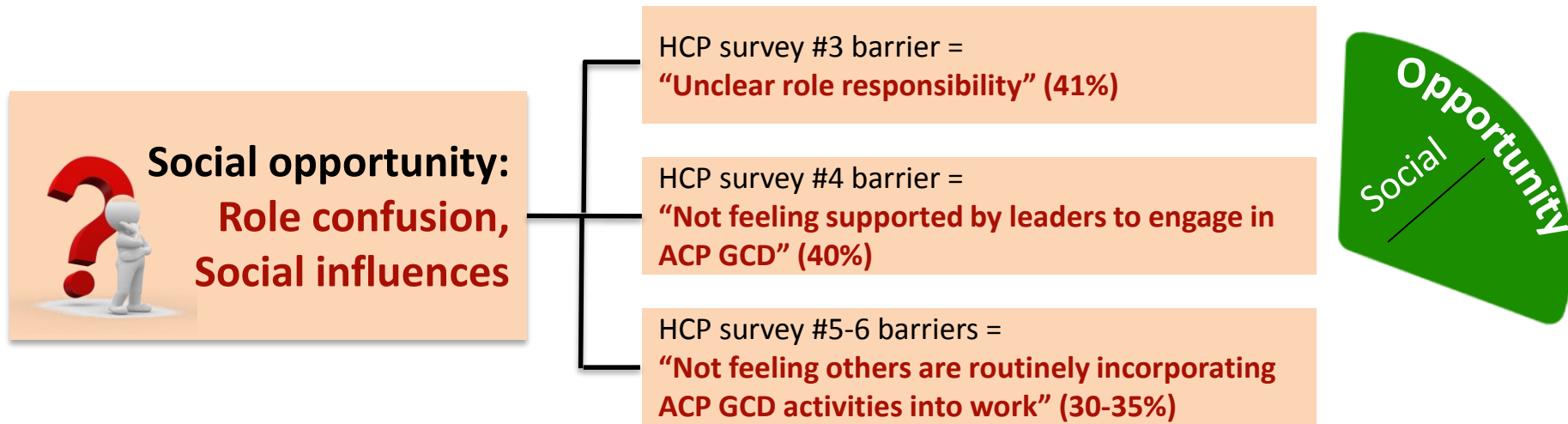
"I think it takes some more time and I think that's what ties most people down is time is short" (Cancer doctor)

"Doctors [have] no time to discuss with people. How does this happen within a 1/2 hour allotment during a doctor visit?" (Community group participant)



*"Well, this subject is sorely lacking out there in the – in my opinion, in the big field. A public service campaign to get people talking. Public campaign may have impact."
(CWL participant)*

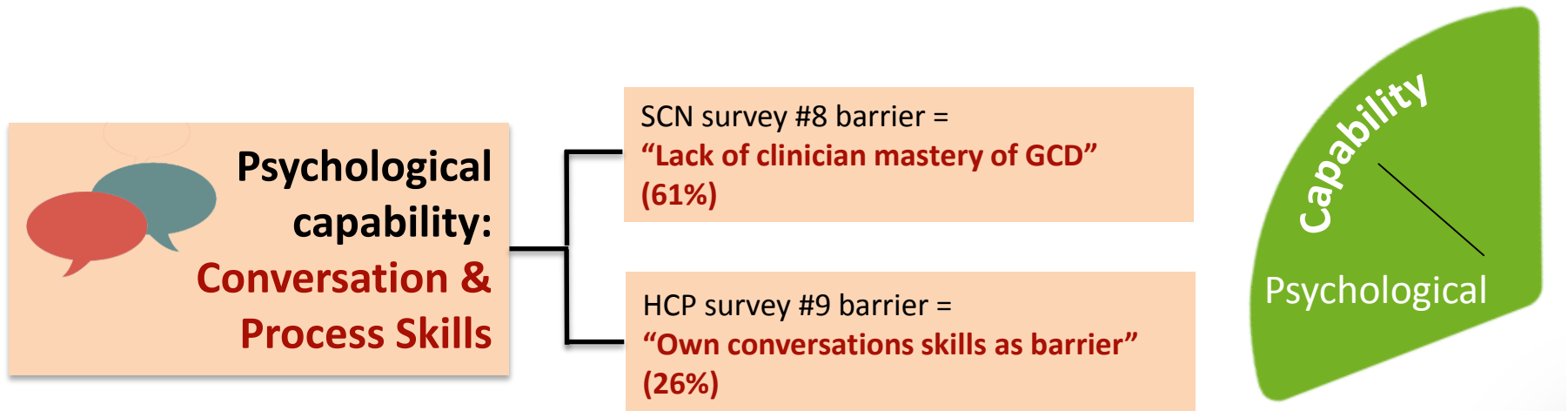
*"Need to advertise, let people know to normalize the activity"
(Community group member)*



"They (nurses) don't know whether - how far they should go, what they should do." (Supportive Living nurse)

"When anyone in the family is faced with a difficult situation, everyone intuitively knows what their role is and what to do, and then right decisions are just made without us planning ahead"
(South Asian participant)

Capability – less of a barrier

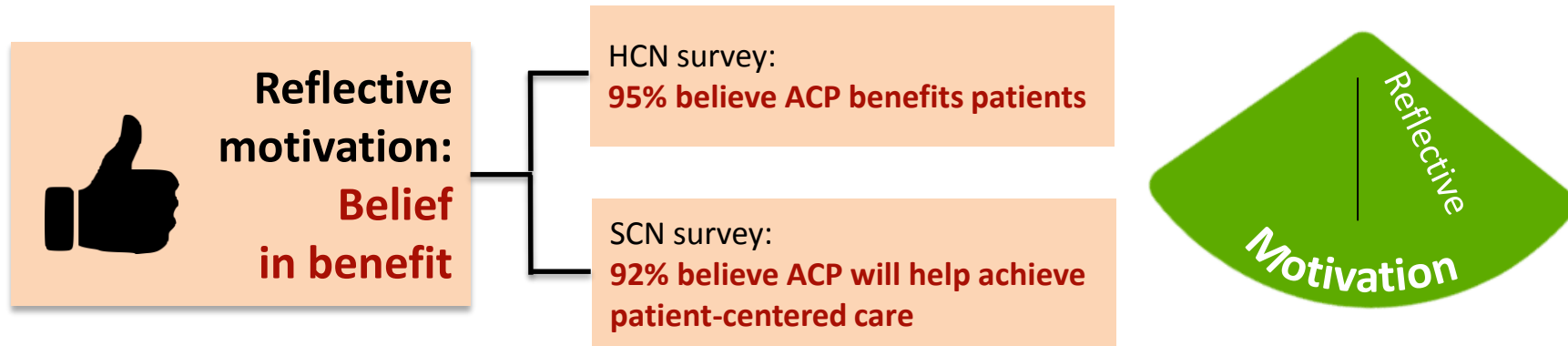


‘It should be almost an automatic thing... They sit people down and they start a process and they help people get through it.’ (Renal family member)

"It's just like anything else. Uh, do you have an allergy? Are you on any medications? What are your goals...what do you want us to achieve here?" (Physician, Cancer)

“I would say...do you know about this program, and it could maybe ease your family and yourself...reduce the stressors...if you can plan ahead as to how you would want things done.” (Nurse, HF)

Motivation – mostly a facilitator



“A lot of people are never really prepared for stuff like that and I guess most people don’t like to think about it but you know that’s part of life, and we feel really good about it” (Family member, Supportive living)

- Motivation is high
- Capability is mixed
 - Knowledge gaps: Tracking Record use, how to use Green Sleeve
 - Skills gaps: patient-centered conversations
- Opportunity needs most work
 - Leadership, prioritization, social processes



§ Collaboration of

Legal professional and educational organizations	Lawyers from private practice, legal guidance, health authorities, nursing home/retirement residence provider
Patient advisors	Palliative Care physicians
Social worker	Medical ethicists
Provincial lead for AHS, Physician consultants for ACP/GCD	Office of Public Guardian/Public Trustee, private trustees

§ Activities

- Focus groups
- Education event for lawyers
- Survey of Alberta lawyers
- Publications



Lawyers' (and Clients') Greatest Needs

■ Best practices

- Resources/worksheets for lawyers/client, client/key others
 - Biggest barrier: patients' lack of preparedness
- Guide, Q&A/script for lawyers
- Equip agents
- Communication tools/conflict resolution

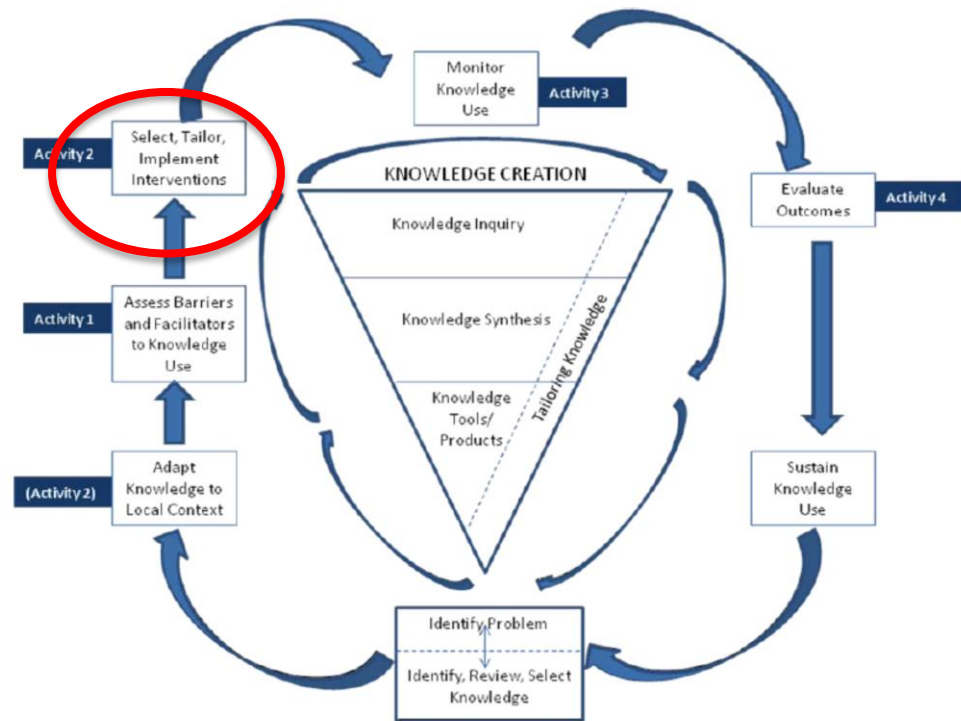
■ Education for lawyers

- Health policies - GCDs (**75%** assist with wishes for future health care interventions yet **49%** don't know/unsure what GCD is)

■ Proposed framework



■ Health and Legal Sector Collaboration to Support ACP: Friday 13:15



HOW CAN WE IMPROVE ENGAGEMENT IN ACP?



Would you help healthcare providers to address known barriers in Alberta?



Education

Enablement

Incentivisation

Training

Environmental
Restriction

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Common Misconception



ACP GCD is a Team Process



Collaborative Team Process Improvement Project



AIW
Process
Improvement



eSIM
Team
Function



- ✓ Up-stream and down-stream clinical collaboration
- ✓ Structured & collaborative approach
- ✓ Education embedded in project
- ✓ Evaluation of change
- ✓ Readiness to sustain
- ✓ Knowledge & success sharing



ACP GCD
Calgary Zone
Education

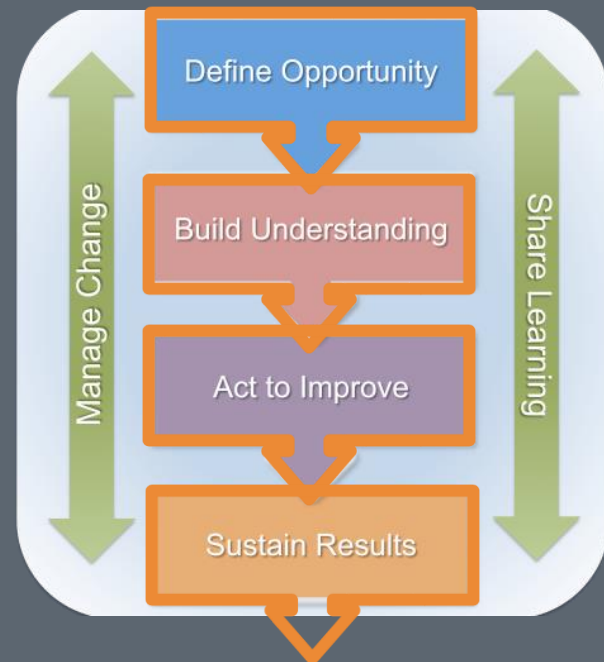


ACP CRIO
Advance Care Planning Collaborative Research
& Innovation Opportunities Program

ACP CRIO
Research
Evaluation

Project Structure – AHS Improvement Way

2016	June	Sign-off charter / Ethics submission Pre - Measures Problem & Goal Statement
	Sept	Process Map Gaps identification
	Oct	Actions brainstorming
	Feb	Quick wins Education E-sim Collaborative table top exercise
2017	Mar	Post Measures Prepping Sustain Plan
	Apr	Sharing & Celebrating



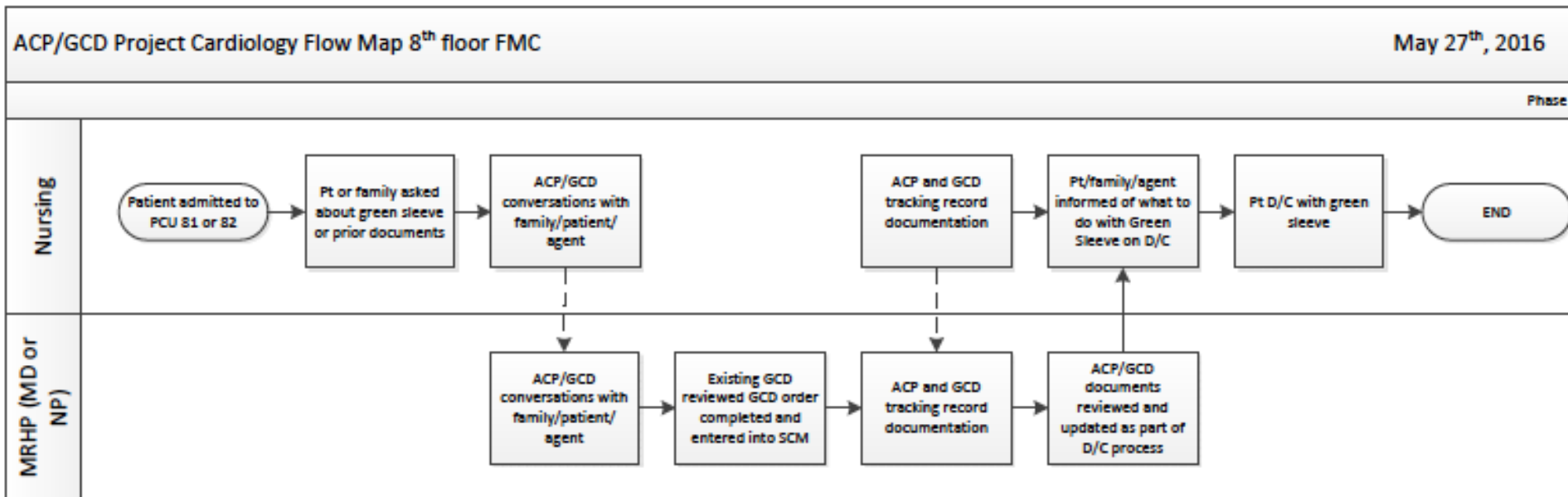


Unit 81

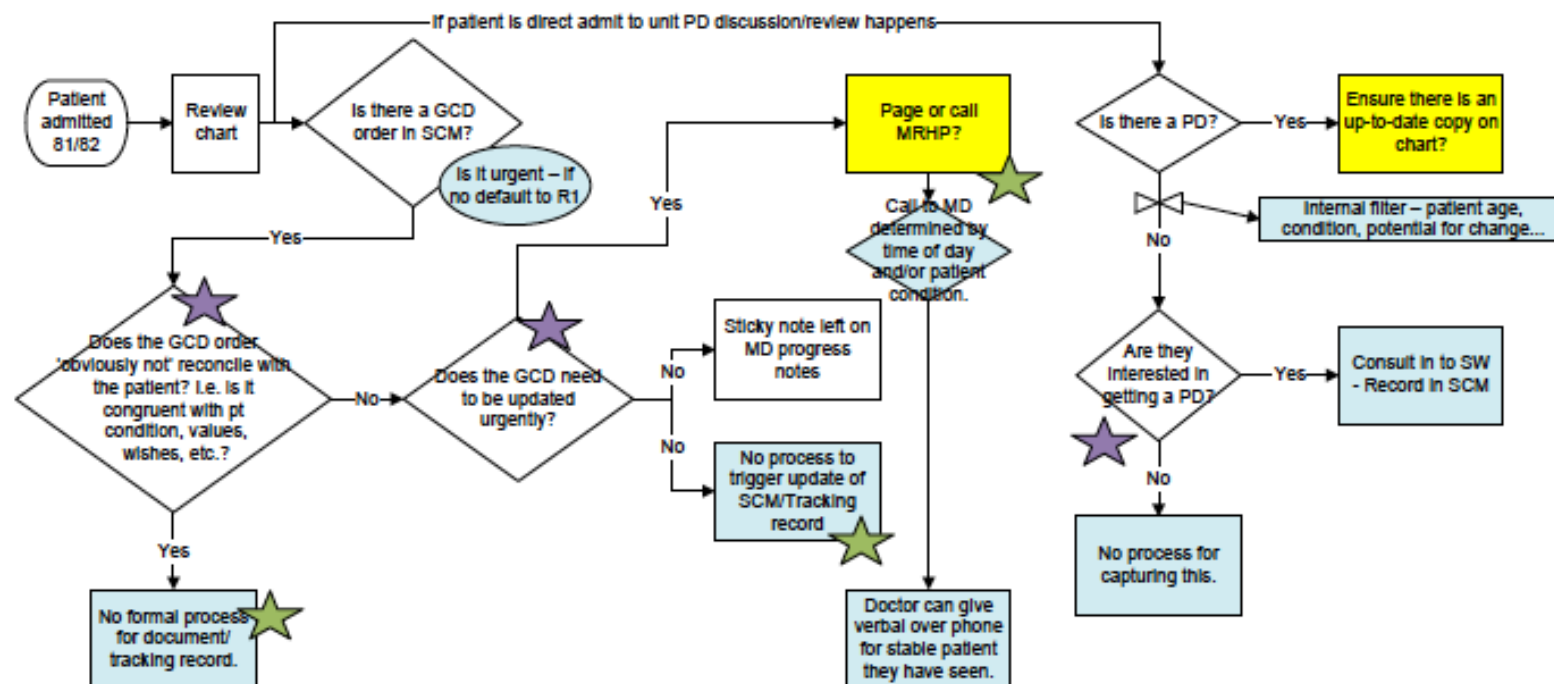
FMC, Calgary



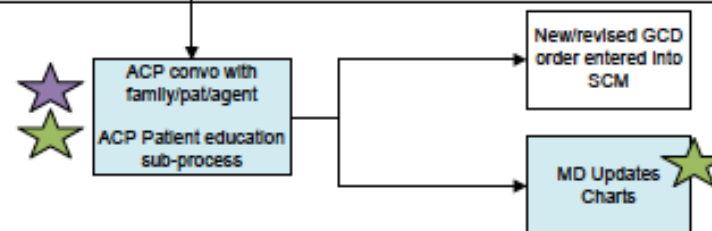
Initial Process Map



Nursing



MRHP (MD or NP)



Sure of process



Opportunity for improvement



Opportunity for e-Sim

Change in pt condition-where does this go in the process?

Patient has to leave unit - no process around GCD/ACP for In-patient movement.

Some areas have SCM access-allied health, usually endo, others?

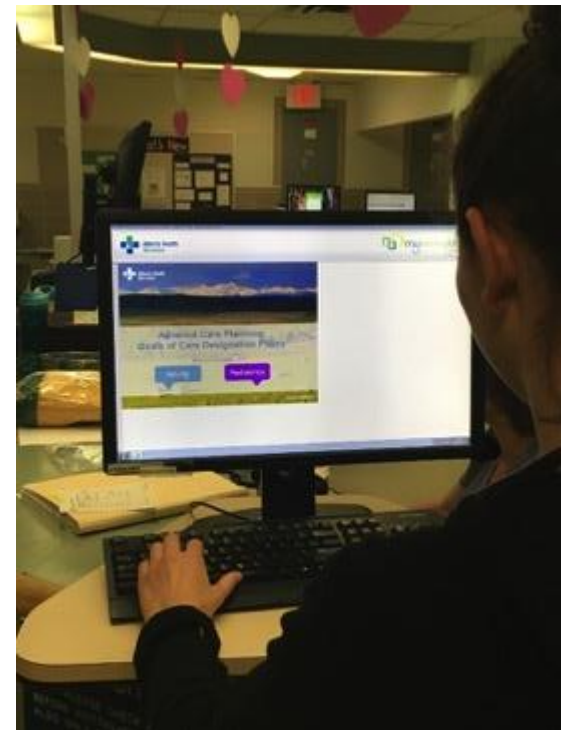
Other areas do not have SCM access-TBCC-what is this process?



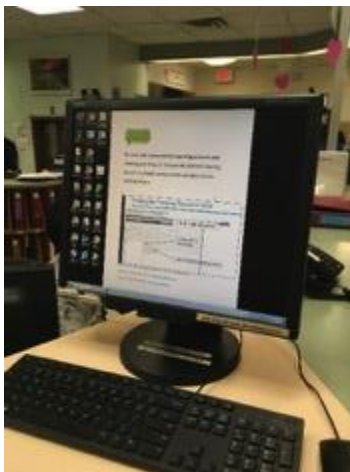
document 15052123

UNIT 81 Actions Taken - STRATEGIES

Environmental Restructuring



Enable Tracking record use





UNIT 81

Staff Quotes

“It (GCD Conversation) was a grey area before with a lack of role clarity. Now, I am aware that I could open up the dialogue and Is not required to complete the process.” RN

“Staff are now aware of expectation about green sleeves and what to do with them on admission, hospital stay and discharge.” RN

“A patient kept refusing care which contradicted their GCD. Team met with patient and identified patient wishes and worked to engage patient, family and physician in discussion to meet patient’s wishes.” RN

“It was really interesting to see how others do this and understand what I can and can’t expect from them.” MD

50% of goal metrics achieved with 3 month implementation period

Measure	Acute Care		Primary Care		Out-pt Clinic		Home Care	
	Pre %	Post %	Pre %	Post %	Pre %	Post %	Pre %	Post %
Tracking Record Use	0	6	0	2	34	64	13	42
Patients aware of GCD	17	34	75	60	69	79	50	42
Competing priorities as barrier	54	69	45	67	83	75	83	50
Role confusion as barrier	54	31	27	17	17	0	17	50

What does your process look like now?

How could it look?

Use the Tracking Record! 😊

- Don't bury the conversation in progress notes
- Tracking record available in paper and SCM

1. Click "enter document"

2. Type "A" in the search box

3. Select ACPGCD Tracking Record

The screenshot shows the 'Document Entry Worksheet' window. At the top, there's a toolbar with various icons. Below it, a 'Patient name' field is visible. The main area contains fields for 'Authorid', 'Date', 'Time', 'Authorid by', 'Co-Sign', 'Mark Note As', and 'Priority'. A 'Manual Entry' section is at the bottom, showing a search box with 'A' entered and a list of document types: 'ACPGCD Tracking Record', 'Acute Pain Service Summary Note', and 'Advance Care Planning'. Red arrows point from the numbered instructions to the corresponding UI elements.

The screenshot shows the 'Structured Notes Entry - Document: Struct - ACP / GCD Tracking Record' form. It has a 'CREATE' tab and a 'Preview' tab. The 'CREATE' tab is active, showing a form with sections for 'Record of ACP / GCD Discussion' and 'Record of Goals of Care Discussion'. The 'Record of ACP / GCD Discussion' section includes a 'Purpose' field and a 'Date of Discussion' field. The 'Record of Goals of Care Discussion' section includes a 'Core Elements' section with checkboxes for 'Discussed', '1. Prognosis and Anticipated Outcomes of current treatment', '2. Values and understanding/expectation of treatment options', '3. Life Sustaining Measures/Degree of Benefit', '4. Comfort Measures', and '5. Resources available'. There is also a 'Key Decisions / Next Steps / Outcomes' section with a 'Segue UI' field and a 'enter narrative notes in this section' field. At the bottom, there is a 'Who was involved in discussion' section with checkboxes for 'Patient', 'Wife', 'Husband', 'Son', 'Daughter', and 'Other'. The form also has a 'Save' button and a 'Cancel' button.

Tracking record is in "Documents" section on SCM

Improvement package in development

- Web based
- Foundations with starting point measures and stakeholder readiness
- Suggestions for Enablement (education and simulation) and Environmental restructuring
- Reassessment measures and sustaining changes
- Direction to AIW resources

Other projects in Activity 2

- Conversation Analysis
- Guidebook acceptability
- RCT of AHS ACP and GCD videos
- Behaviour change survey “BACPACS”



Community Identified Strategies

8

Recommendations to increase Albertans' awareness of and participation in Advance Care Planning.



Make Advance Care Planning resources easily accessible to community groups



Provide education and facilitation opportunities for community groups, healthcare providers, and business professionals



Simplify healthcare system processes and increase support for conversations



Use stories/make use of personal experiences



Increase marketing of Advance Care Planning to the public



Capitalize on opportunities to integrate Advance Care Planning into major life events



Include business partners in Advance Care Planning (e.g. legal, financial, insurance)



Standardize Advance Care Planning terminology across the country

“ All groups could normalize Advance Care planning

- World Café participant ”

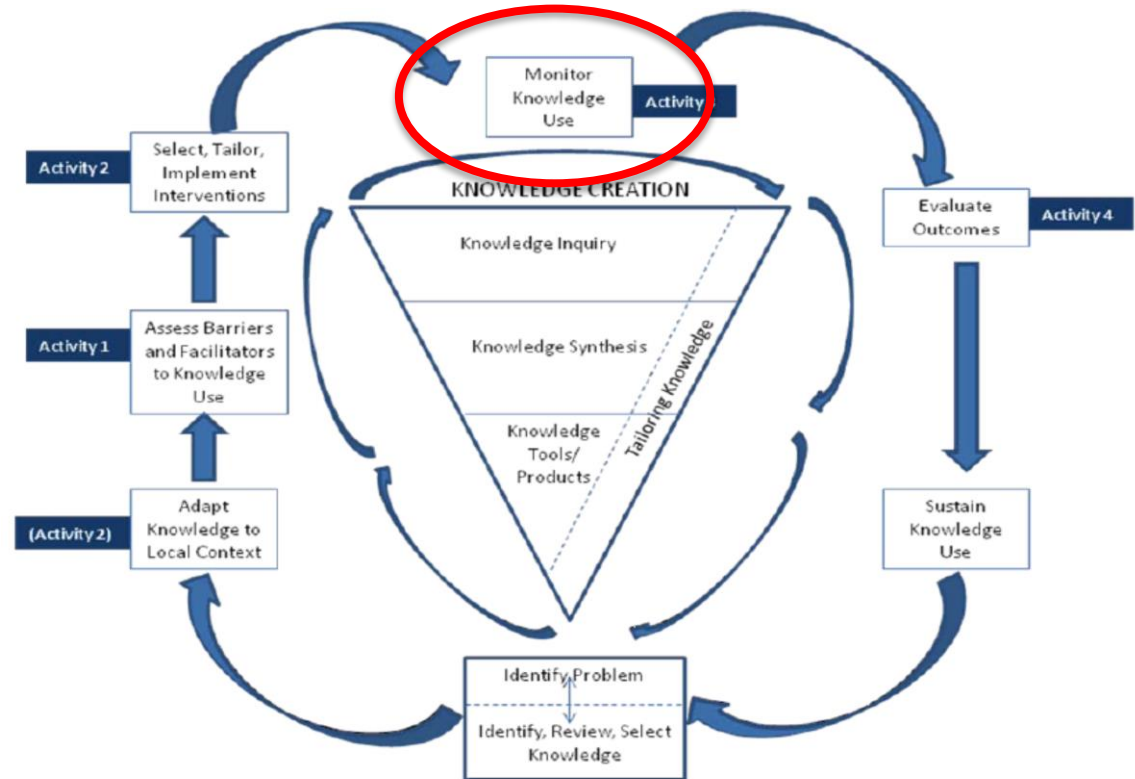


In sharing these recommendations we hope to stimulate collaborative action amongst Advance Care Planning stakeholders, including levels of government, health services, related businesses and community groups themselves, to ensure Albertans receive healthcare that is concordant with their wishes and values.

Lessons learned

Resources and education alone don't change behaviours as much as

Improving team processes to increase opportunities for ACP and GCD



WHAT INDICATORS BEST MONITOR UPTAKE?

Which measure is most indicative of policy uptake

% patients with a GCD

% patients with a tracking
record

% patients where care at death
matched GCD

% patients/alternate
decision-makers satisfied with
goals of care discussion

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We have indicators for uptake

Performance Indicators (percentages)		Data source
1	Healthcare providers who have completed the AHS Advance Care Planning/Goals of Care Designations- Adult eLearning module	Administrative data
2	Charts with GCD order(s) in the Green Sleeve	Chart audit
3	Patients with a GCD order anywhere in the chart	Chart audit
4	Patients with a completed ACP/GCD tracking record	Chart audit
5	Patients with a Personal Directive in the health record	Chart audit
6	Patients and/or alternate decision-makers who have had an Advance Care Plan conversation with a healthcare provider	Telephone survey
7	Deceased patients who die having had an M1,M2,C1, or C2 GCD in the week prior to their death, who received resuscitative or life-support interventions in advance of death	Administrative data, chart audit
8	Deceased long term care and home care patients with a C2 GCD who were transferred to acute care and/or ICU	Administrative data, chart audit
9	Patients or family members/friends satisfied with ACP conversation	Telephone survey

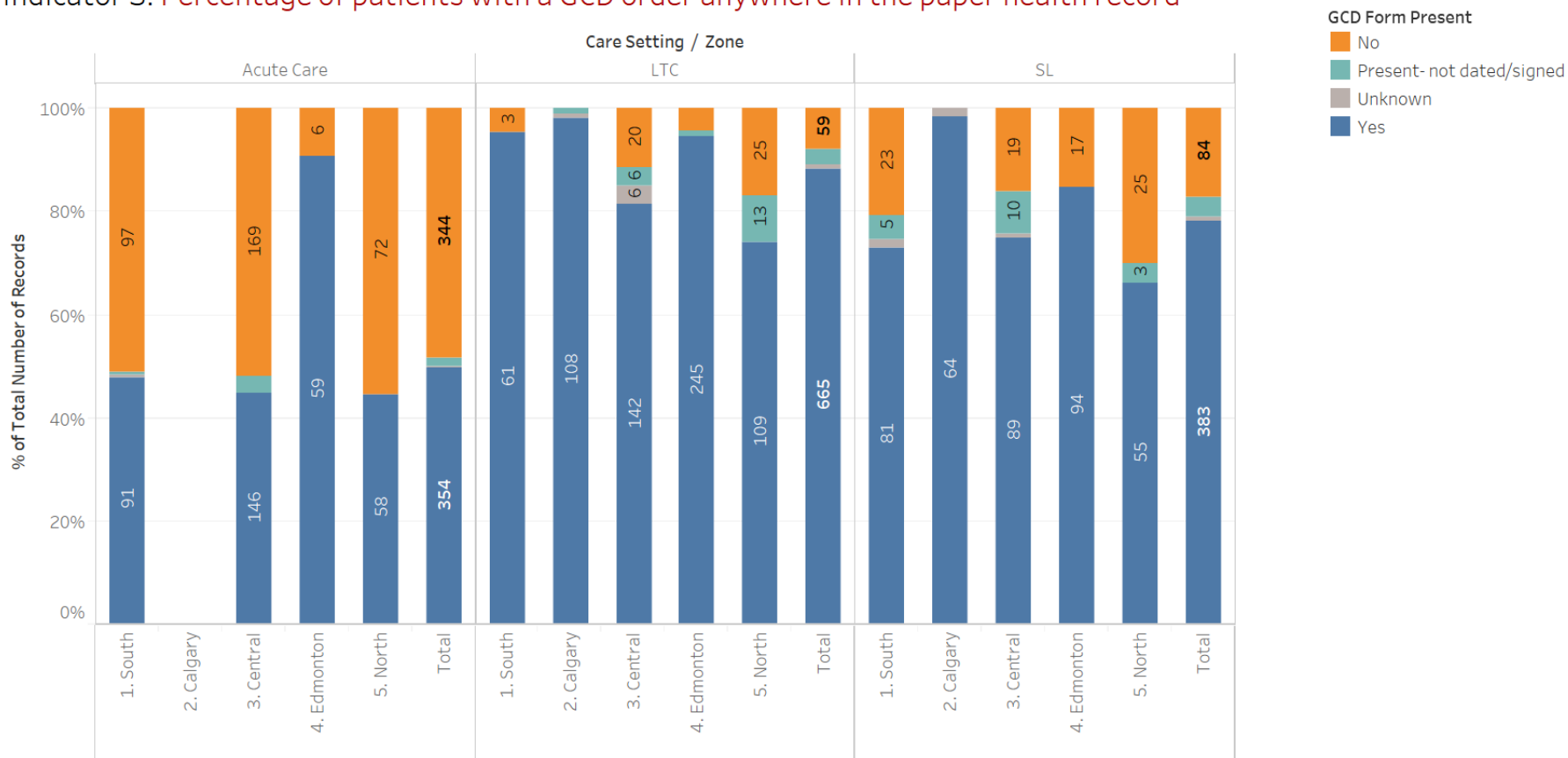
What will the indicators tell us about health care quality? ²

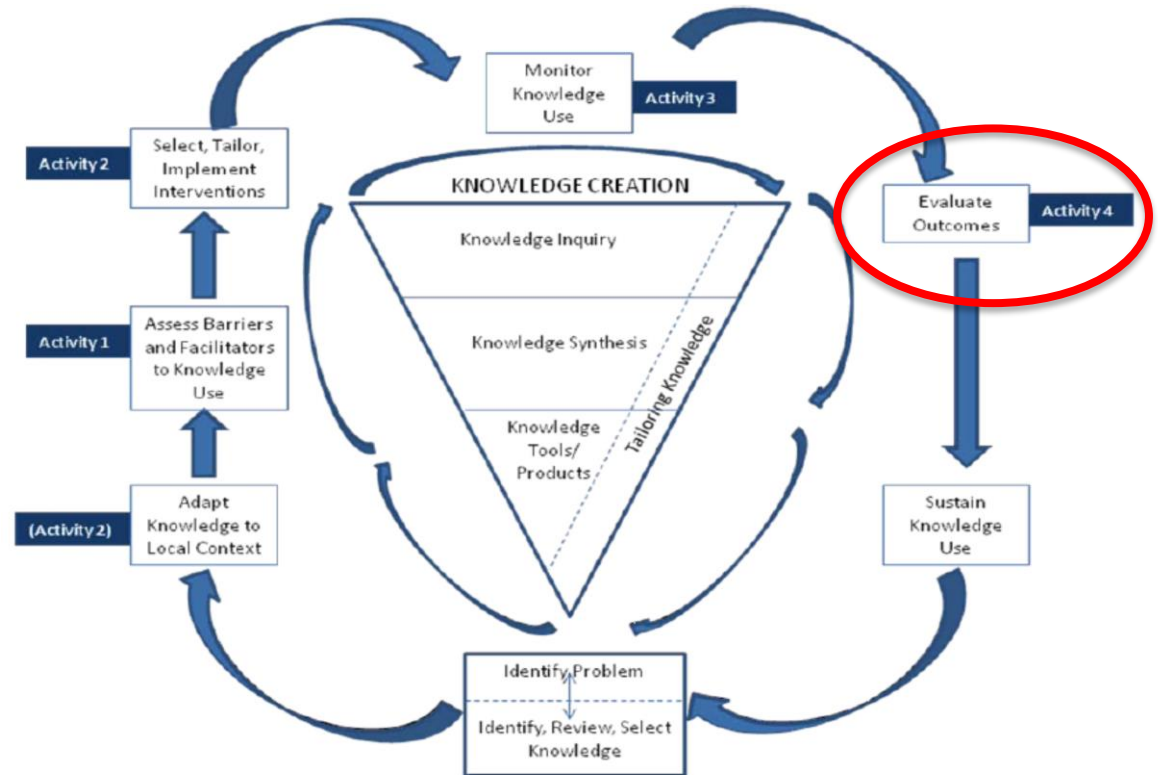
Key

	Structure	Process	Outcome	
Timely	★2			attributes of settings in which care occurs
Safe		★4	★7	Process
Patient-centered		★6	★9	what is done in giving and receiving care
Effective	★1	★3 ★5 ★6	★7	Outcome
Efficient	★2	★4	★8	the effects of care on the health status of patients and populations
Equity				

Screenshot of current dashboard indicator

Indicator 3. Percentage of patients with a GCD order anywhere in the paper health record





WHAT HAVE WE BEEN FINDING?

1. Data Overview

Data from AHS, Calgary Zone

- **Data Set 1:** All electronic GCD orders from 1 Dec. 2008 to 31 Dec. 2014.
- **Data Set 2:** Monthly admissions by site and patient age (denominator data for % calculation)
- Validation for monthly admissions: Quarterly AHS Performance Reports.

GCD data: variables

Variable Name	Description
Care Level	Where the order was made (6 categories)
RHRN	Zone 2 Patient ID ($n=251038$)
Encounter	Encounter ID ($n=416087$)
DOB	Month/Day/Year (1900-2014)
Gender	M/F
Admit Date	Date, Time
Discharge Date	Date, Time
Location	Site, Unit

GCD data: variables

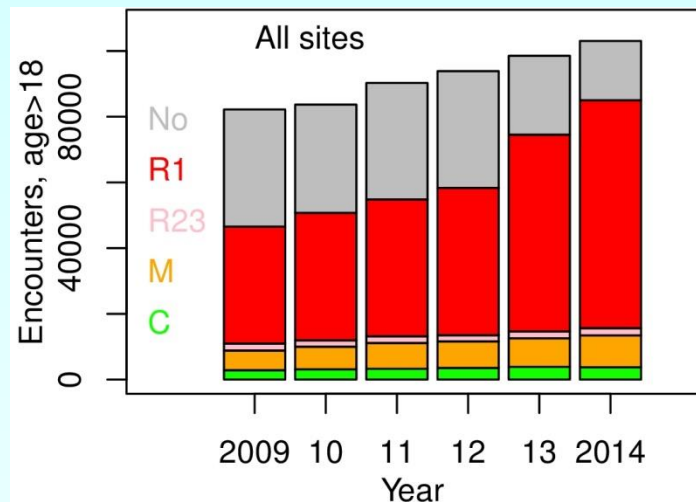
Variable Name	Description
Attending Physician	Full name
Attending group	258 Att. Phys. Groups, combined into 5 categories
Order	7 Adult and 13 Pediatric order types
Start Date	Date, Time
Stop Date	Date, Time
Order Requested By	Full name
Order Requested Occupation	66 occupations

2. Totals and trends

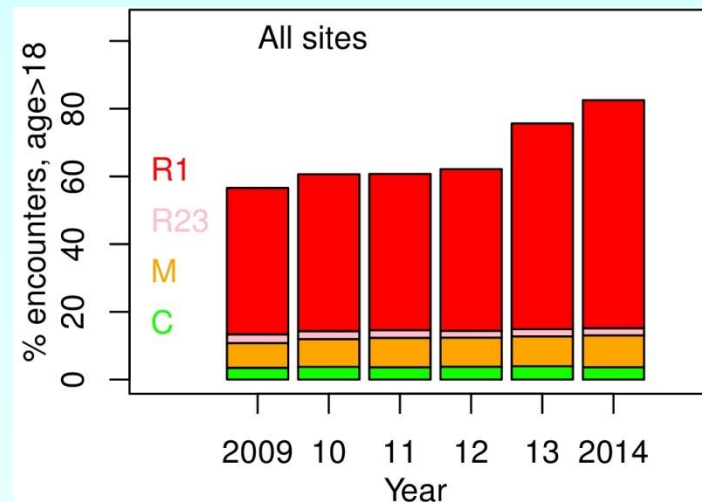
Total numbers by year and by site.

Adult encounters with completed GCD: All sites, by year

Absolute numbers



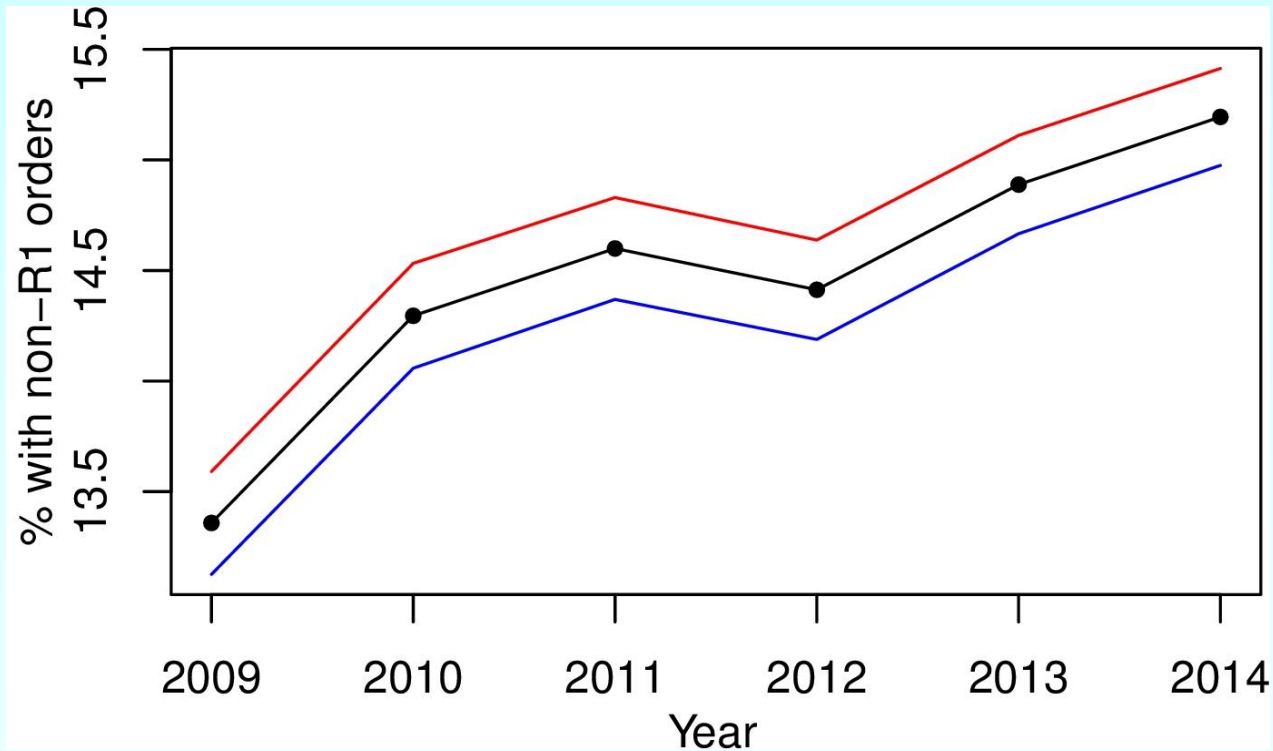
Percentage



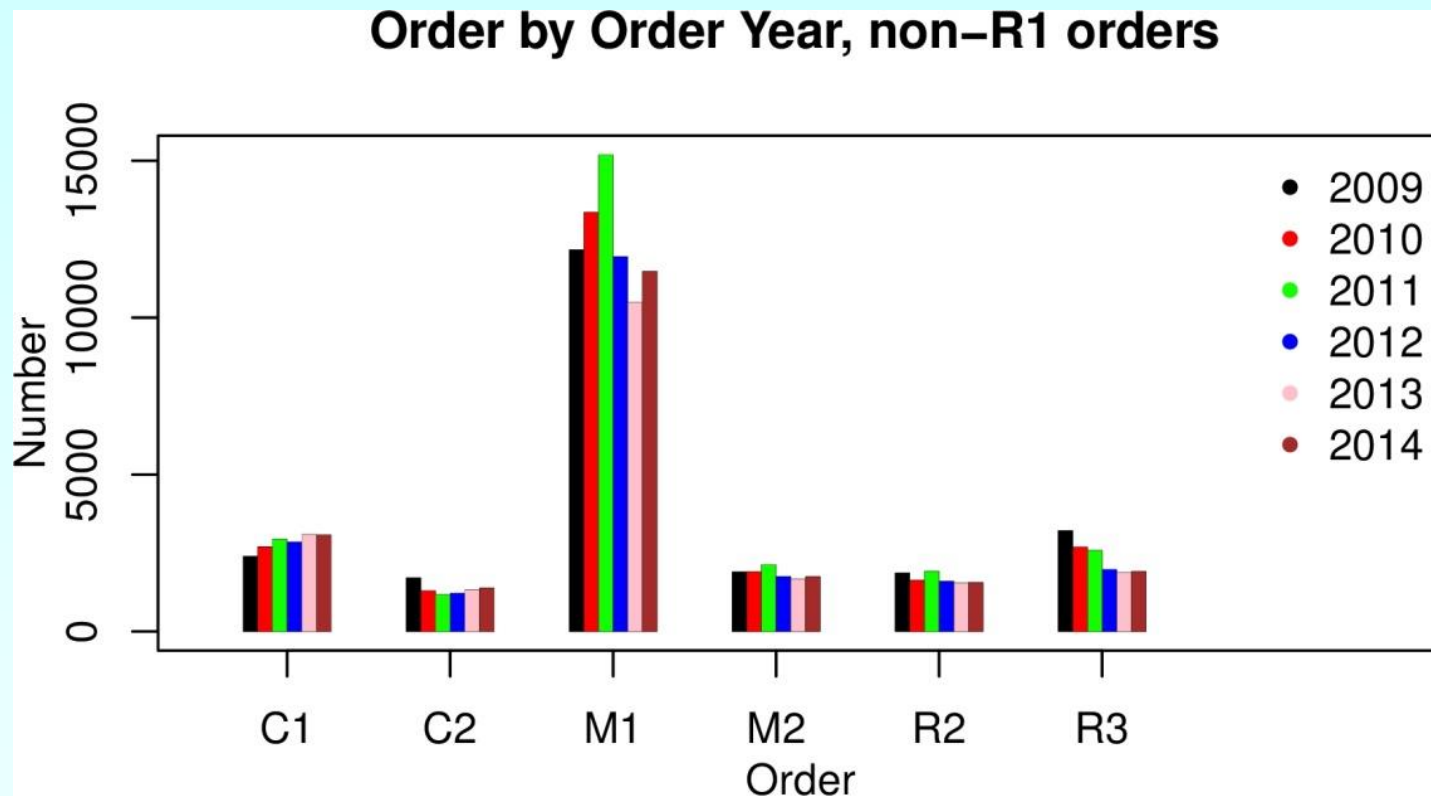
C – Encounters with at least one C-order; M - at least one M and no C;
R23 - at least one R2/R3 and no M or C; R1 – only R1 orders

% Encounters with at least one non-R1 order

95% Confidence Interval



The number of **non-R1** orders, by year

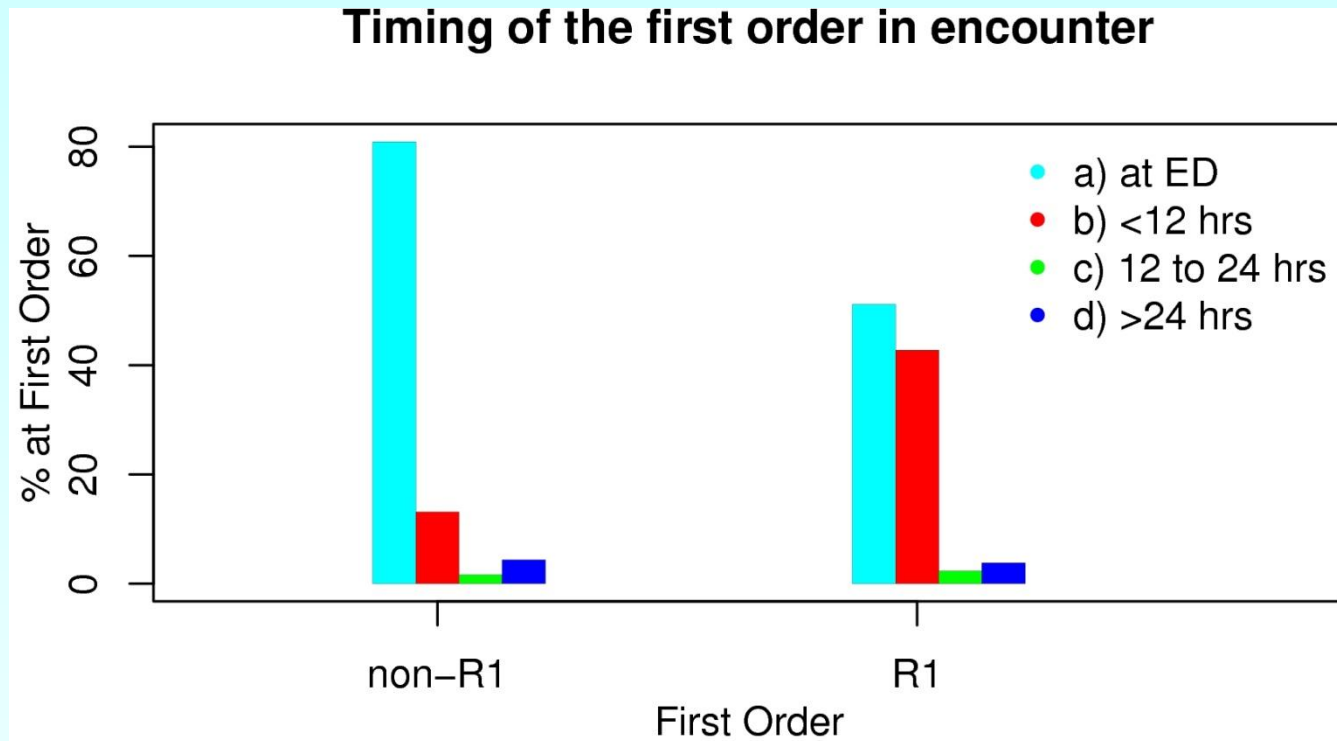


3. Timing

When the first GCD order has been made relative to the admission?

- In ED;
- Within 24 hours from admission;
- Later than 24 hours from admission.

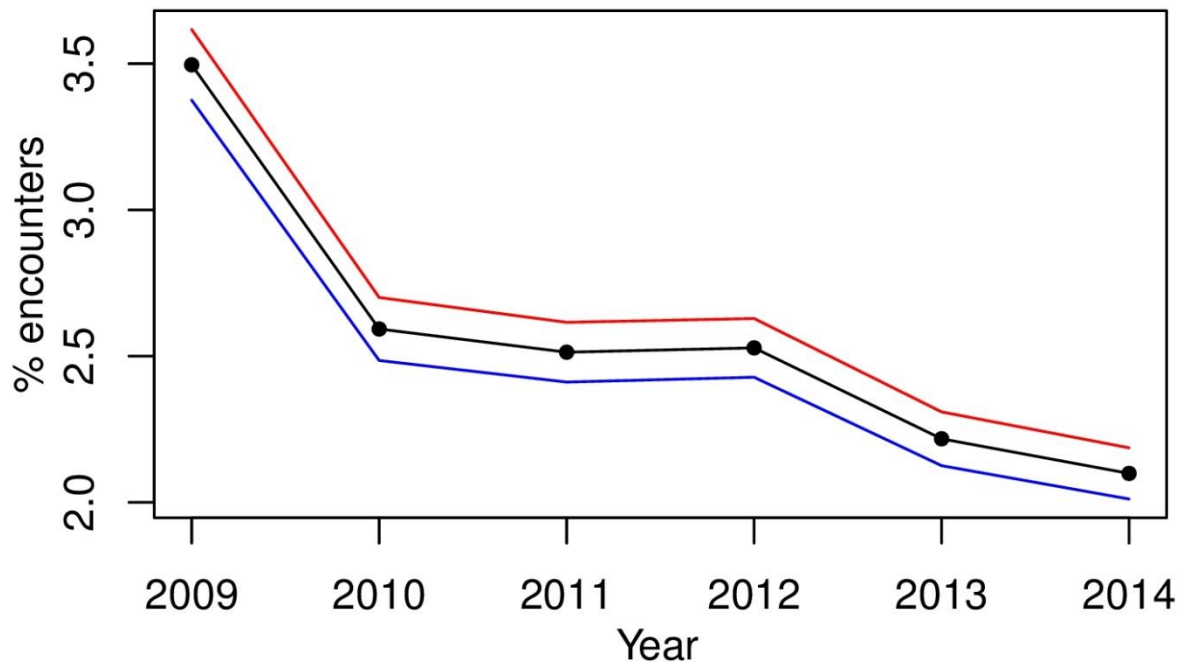
Interval between admission and the first order



- The majority of first orders is made in ED.
- Only 3.9% of all first orders are made later than 24 hours from admission.

Interval between admission and the first order

% of encounters with order after 24hrs from admission, 95% CI

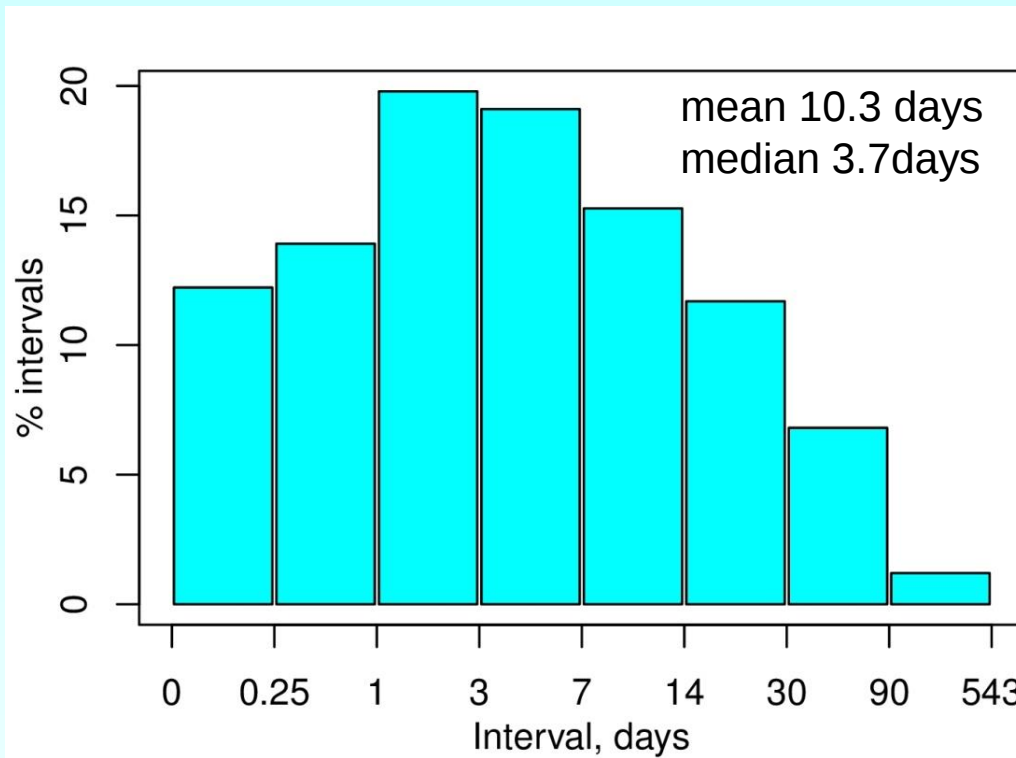


Shown % of all admitted patients (all encounters, including those without an order)

4. Order Frequency

- 48% patients with GCD have 1 order
- 25% patients have 3 or more orders
- 67% encounters with GCD have 1 order
- 5.5% encounters have 3 or more orders
- Multiple orders are often renewals

Intervals between order changes within encounters (renewals excluded)



- 7.4% of encounters have order changes
- 88% of order changes imply focus of care change (R2/3, M, C)

Top 10 Changes (out of 42)	% cases
M1→C1	18.2
R1→M1	17.9
R1→R2	8.9
M2→C1	6.1
M1→C2	5.5
M1→M2	5
R1→R3	4.6
R3→M1	3.9
C1→C2	3.5
R2→M1	3.1

Order sequences within and across encounters (including renewals)

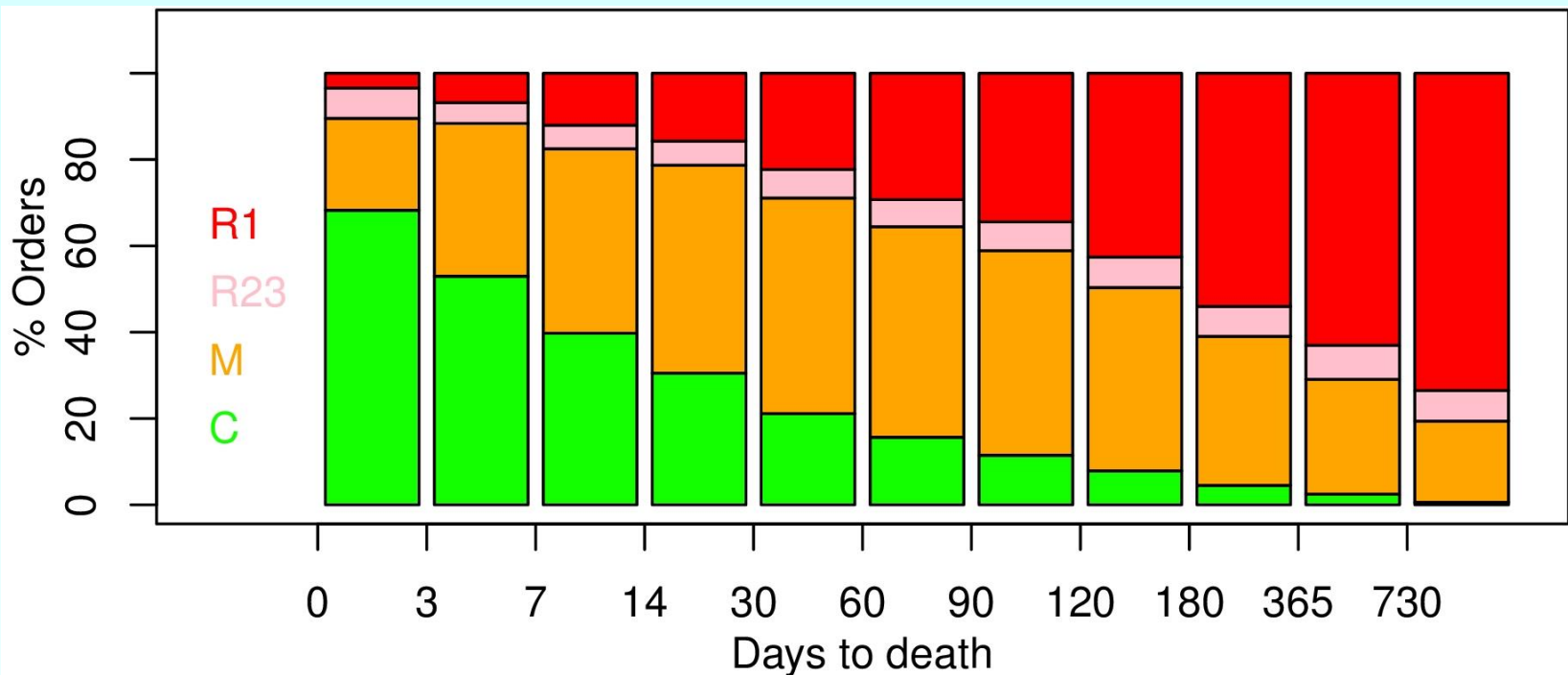
Order keep/change	% in encounters	% for patients
Keep R1	78.4	81.0
Keep R2/3, M or C	14.8	5.9
Natural progression R→M→C	6.5	12.3

Natural R→M→C : any of R1→R2,R3, R→M, M→C

More than 50% of R→M→C changes are made at the beginning of encounters

GCD Orders for Deceased Adult Cancer Patients, 2008-2014, Calgary zone

---C--- ← ---M--- ← ---R1---



5. Determinants

- Administrative changes
- Patient Care Unit type
- Patient age
- Multivariate modeling with model selection

GCD orders assigning

- As a result of ACP/GCD conversation.
- As a part of an order set.

From Dec 2008 to Dec 2014

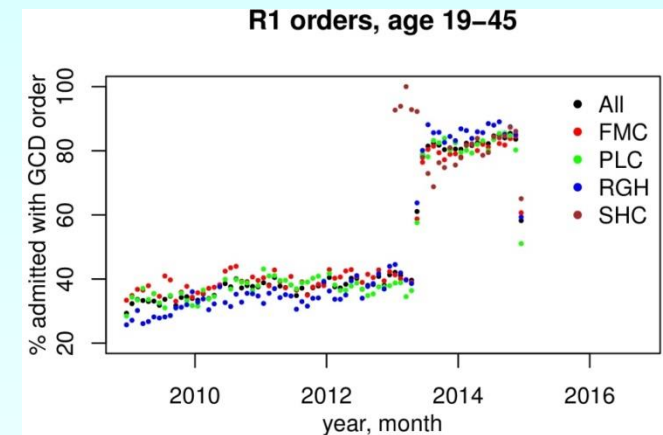
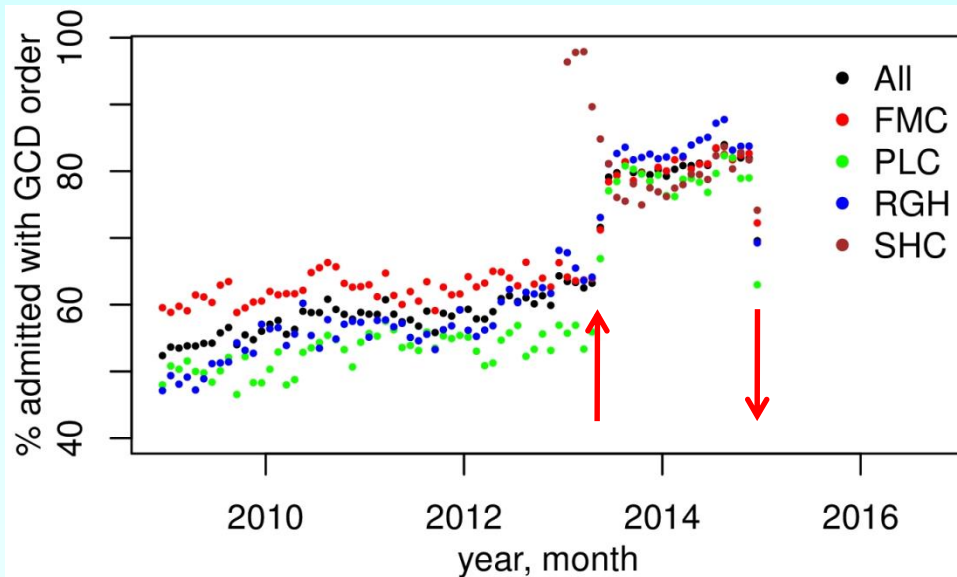
- **106 order sets that contained the GCD item,**
- **49 preselected as R1,**
- **2 preselected as C2.**

(Information from AHS, 21.5.2015)

- Both types of orders are pooled together
- After discharge, the electronic GCD order (SCM) stops, but the printed copy remains valid if exists.

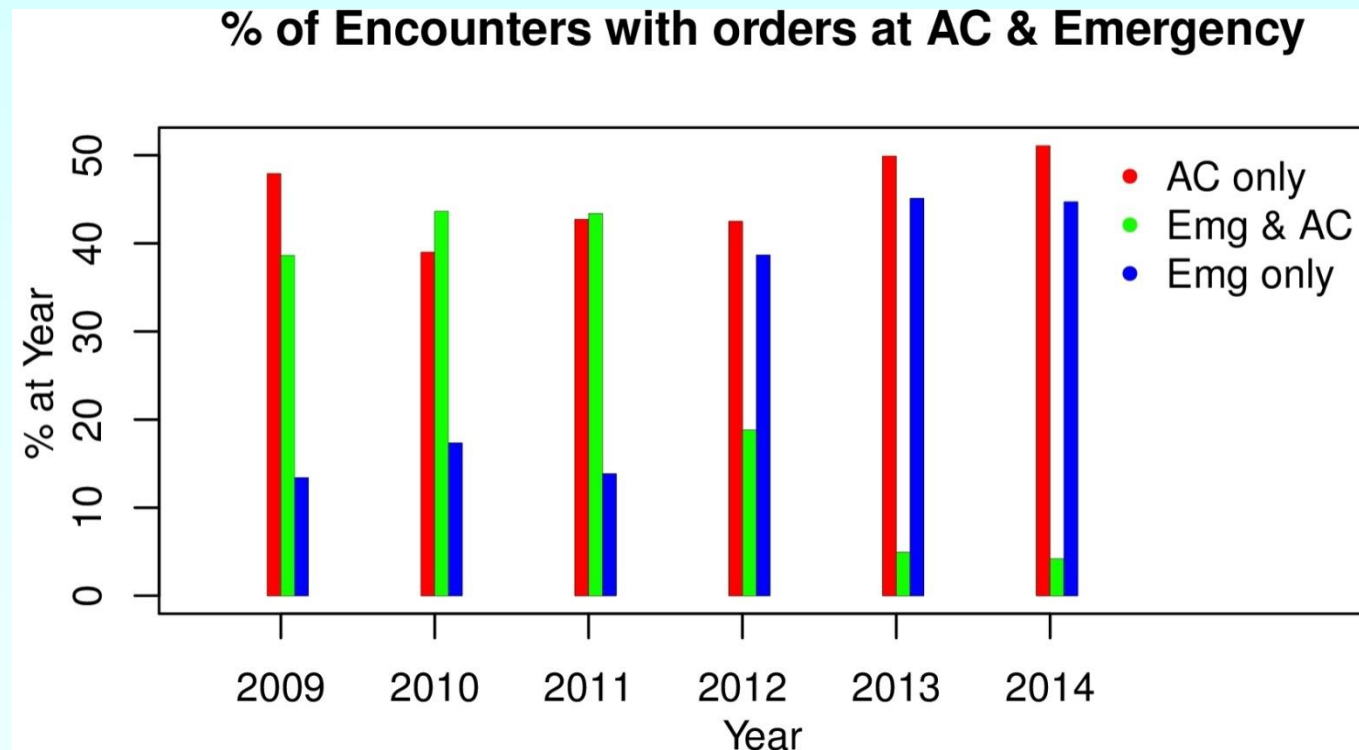
Jumps in % of completed GCD due to changes in one order set

- Order set in obstetrics (May 2013 - December 2014, Affects females of age 19-45)



April 2012 – Continuous Encounters

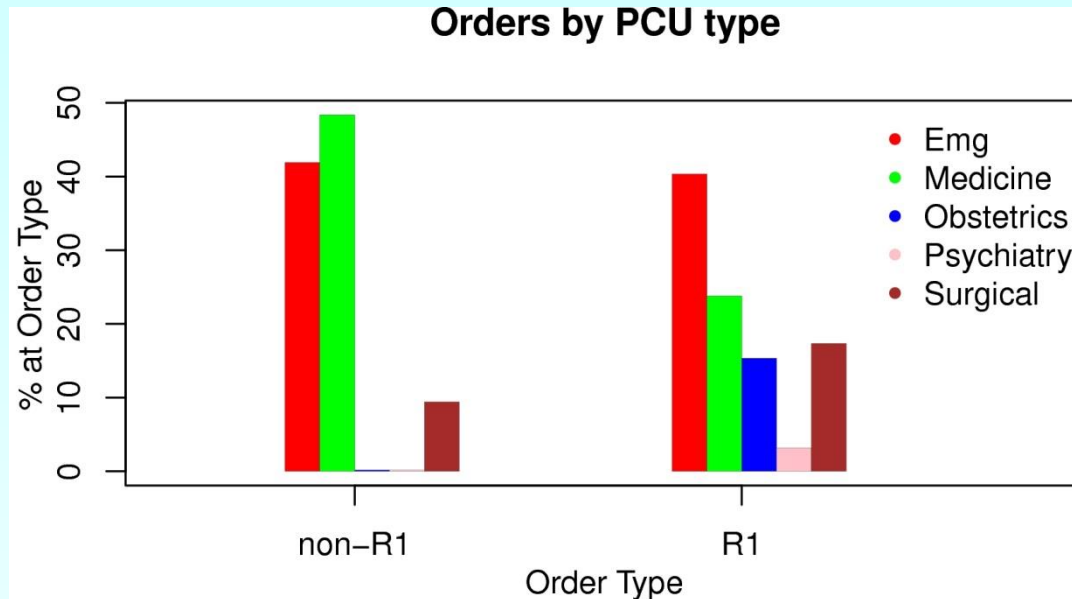
% of Encounters with GCD orders made only in Emergency increases from ~15% to ~50%
(and fewer orders with short duration)



Patient Care Unit (PCU) Types

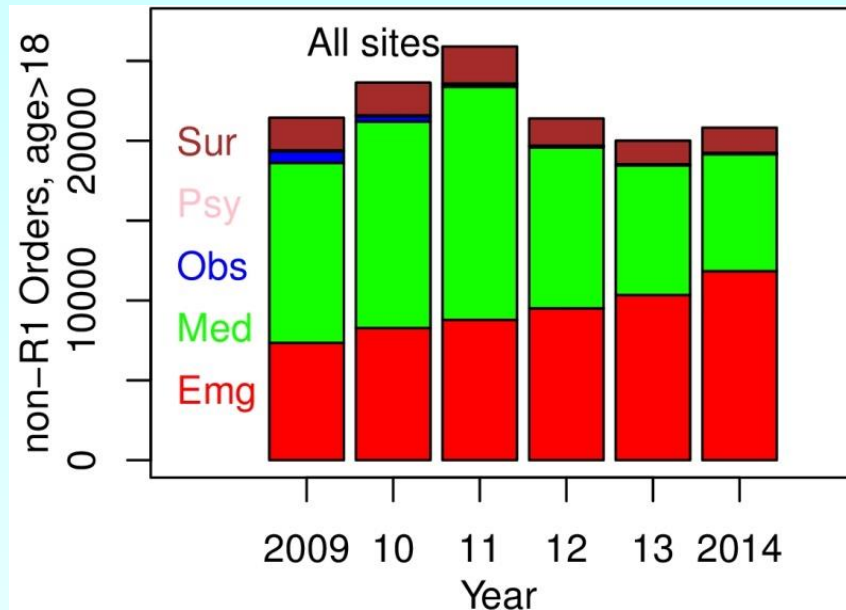
- Most of Patient Care Units can be classified as **Medicine, Surgical, Obstetrics, Psychiatry** and **Emergency**.
- For the patients' location data, PCU types were verified by Site Directors and by Clinibase information.

Orders by PCU Type

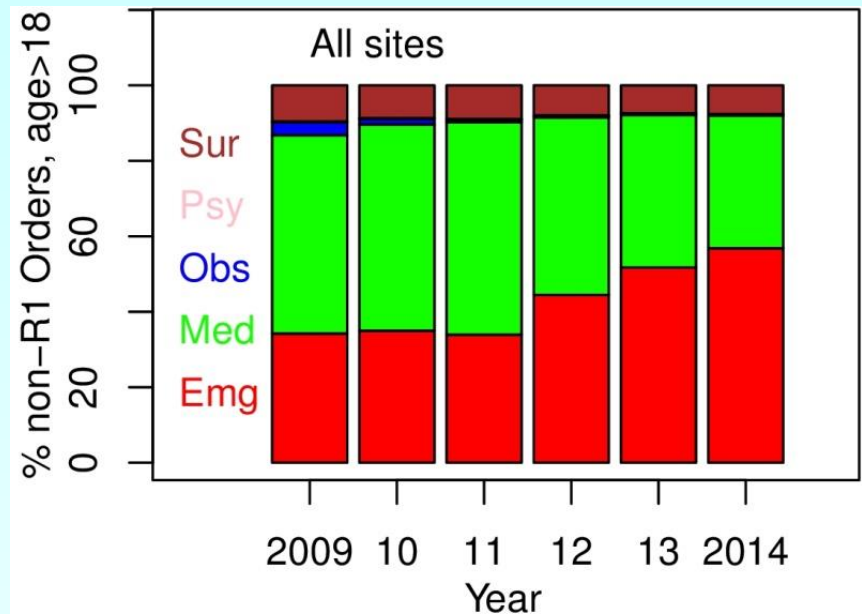


About 90% of non-R1 orders are made in Medicine and Emergency units.

Non-R1 Orders Location (PCU Type) by Year



Numbers



Percentage

In 2012-2014 steady growth of % non-R1 orders made in Emergency units.

6. Multivariate Model:

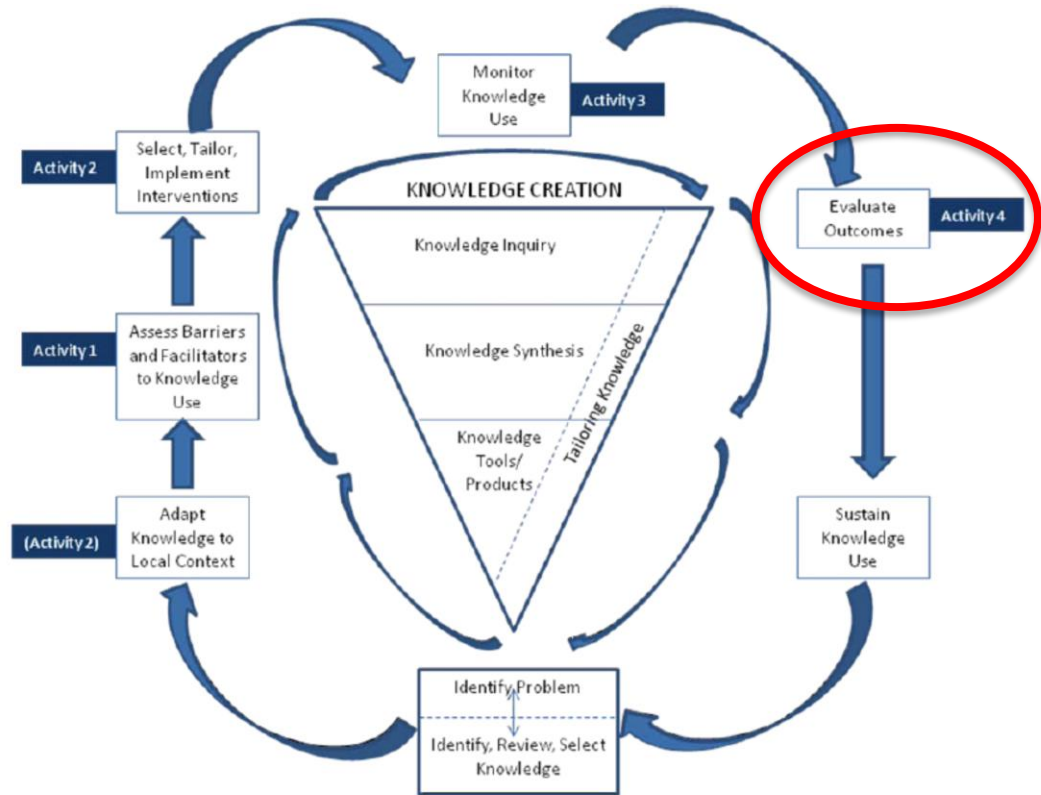
Probability(non-R1 GCD) in Encounter

Explains 41% of deviance, all $p < 0.0001$

Factor	d.f.	Contribution to explained deviance, %	Odds Ratio
Age	10	80.7	29.1 to 0.11
PCU type	4	8.2	4.71 to 0.42
Admission >6 days	1	4.8	2.53
GCD in Emergency	1	4.1	3.39
After April 2012	1	1.8	1.88
Gender (male)	1	0.5	0.73

Acknowledgements

- **Bev Berg**, AHS Palliative and End of Life Care;
- **Barb Wheler**, AHS Palliative/End of Life Care – CZ;
- **Denis Langlois**, AHS SCM Clinical Documentation and Patient Care Orders;
- **Erika Kenny**, AHS CZCS Clinical Data;
- **Ayn Sinnarajah**, AHS Palliative/End of Life Care - Calgary Zone;
- **Many other people from AHS** who spent their valuable time answering our questions.
- This work was supported by **Alberta Innovates Health Solutions** (AIHS) Collaborative Research and Innovation Opportunities Program Grant #201201157.



**WHAT ARE THE ECONOMIC
CONSEQUENCES OF POLICY
IMPLEMENTATION?**

Cost Analysis Basics

$$\text{Cost} = \sum_{\text{Classes}} \sum_{\substack{\text{Events} \\ \text{in class}}} [\text{Cost of Standard Event in Class}] \times [\text{Rel. event cost}]$$

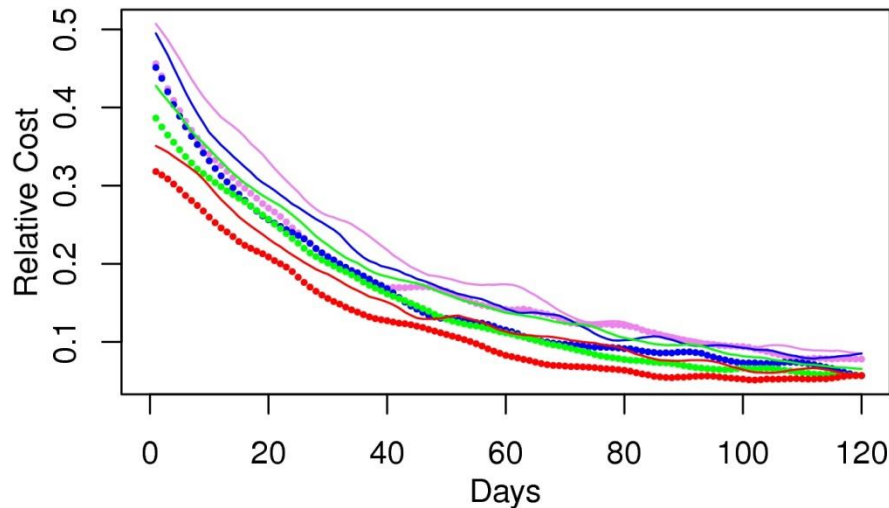
CLASSES:

- IP (DAD): CPWC (\$6-7K), RIW (typical 0.2 - 2) [GCD-Z2]
- ED (Ambulatory, NACRS): CPWC(\$5-6K), RIW (typical ~0.08)
- Continuing Care – No standard measures...,
Home Care – cost of nursing hour (~\$80).

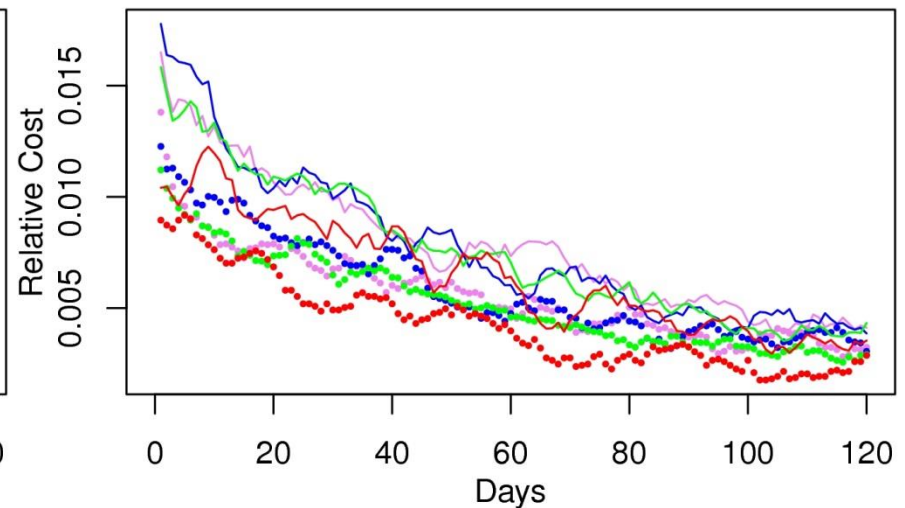
Relative IP&ED costs/day in Z2 before and after GCD program

Acute Care Admissions Days Before Death **ED Visits**

Zone-2, x-IP-window-7



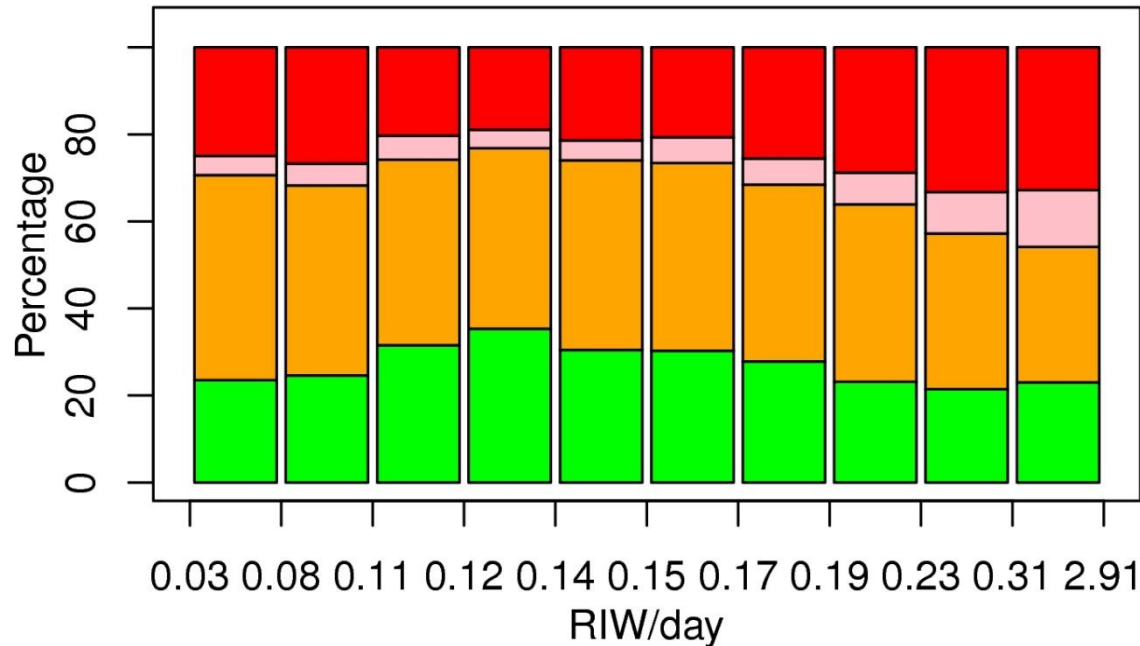
Zone-2, x-ED-window-7



Relative cost per day before (●●) 2008/9 and after (--) for age groups 18-60, 61-70, 71-82, 83+ at days before death.

Costs Increased after 2008. Is it GCD-related? Perhaps not.

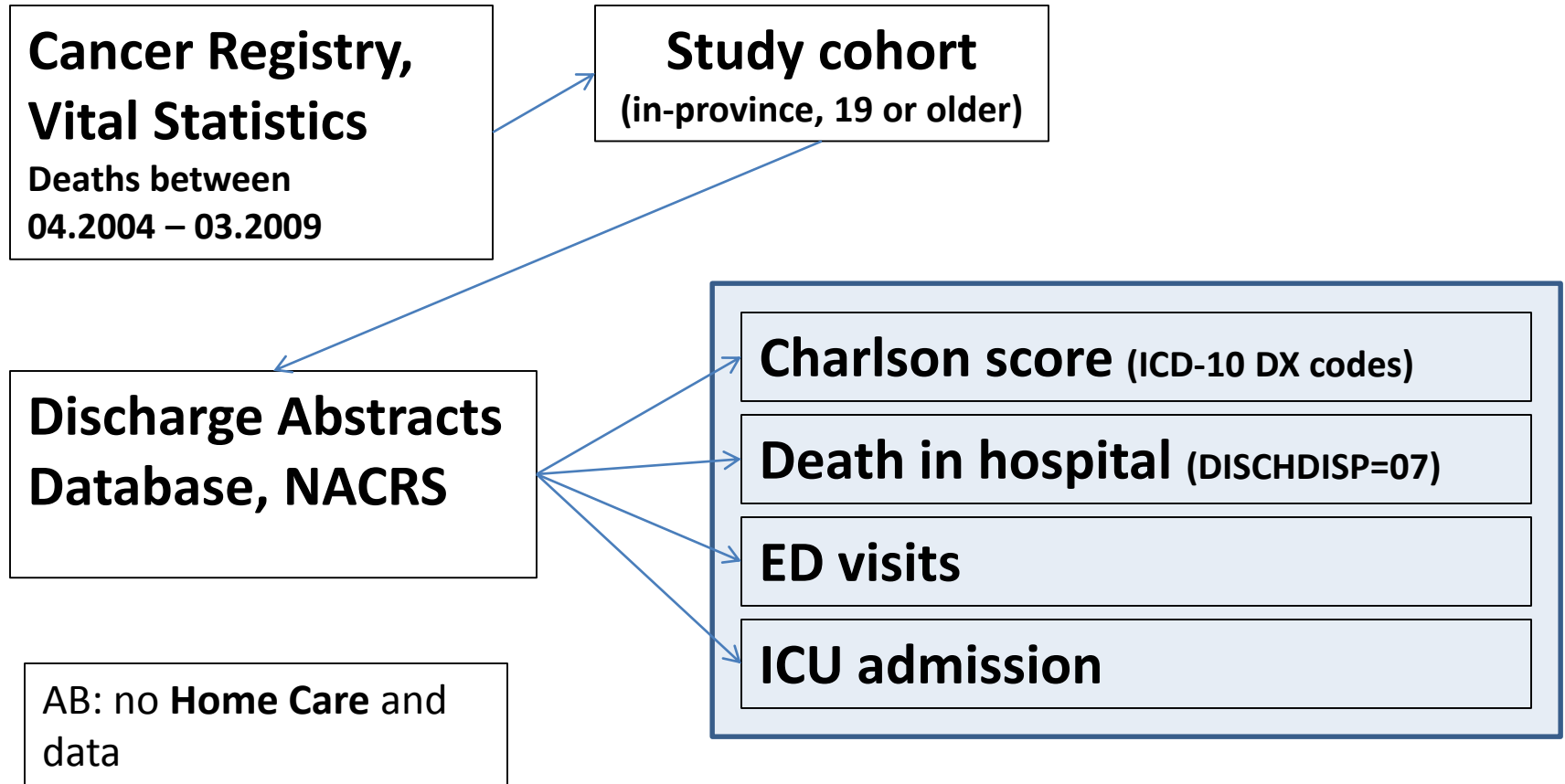
Relative IP Costs for GCD groups



GCD orders: **R1**, **R2/R3**, **M1/M2**, **C1/C2**

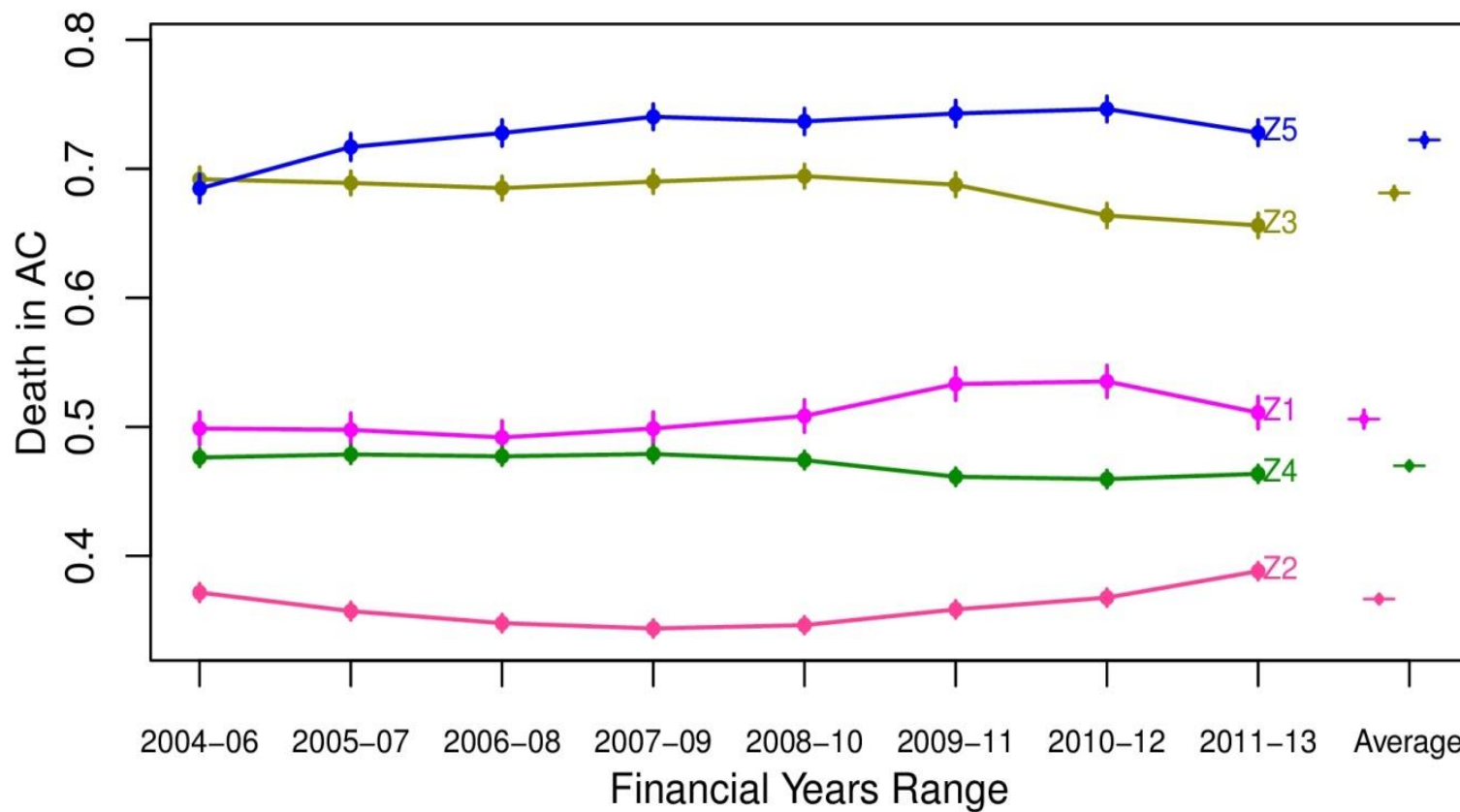
R1,2,3 orders have more costly cases, however the effects should be small compared to overall costs volatility.

4-province study: Data sources



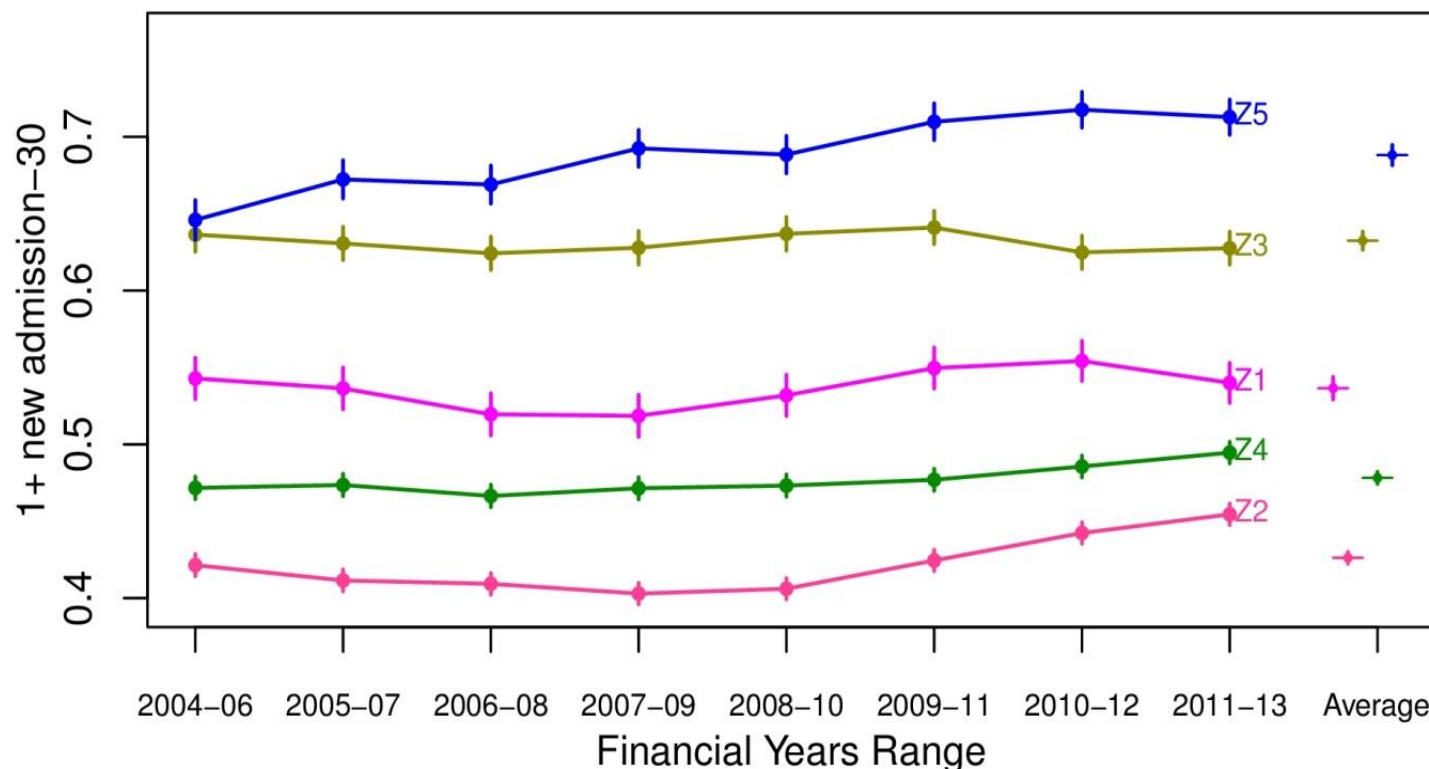
Trends: 3-year averages 2004-2013

1. Death in Acute Care



Trends: 3-year averages 2004-2013

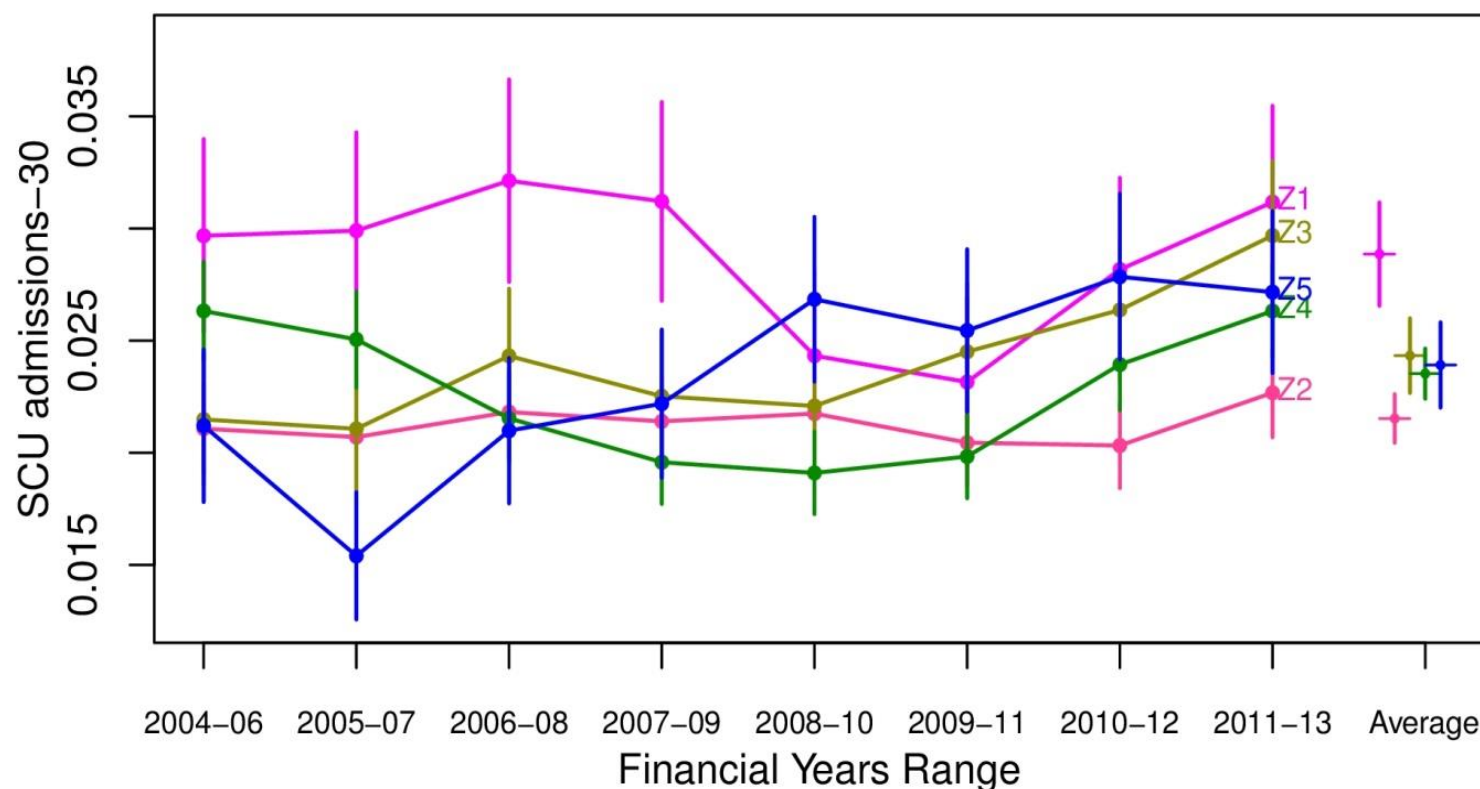
2. One or more acute care admission in the last 30 days (Exclusions: patients who spent all 30 days in AC)



Trends: 3-year averages 2004-2013

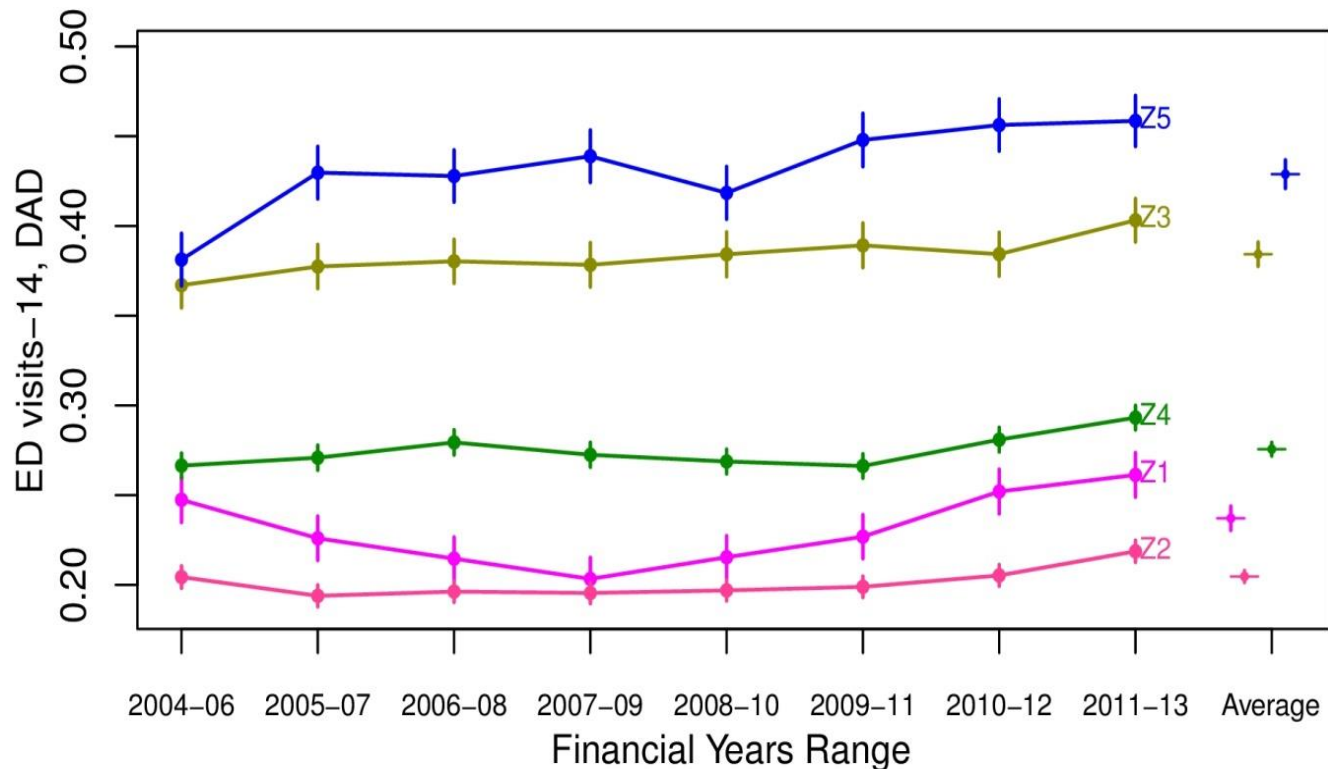
3. One or more ICU admissions in the last 30 days

(Exclusions: patients who spent all 30 days in AC)



Trends: 3-year averages 2004-2013

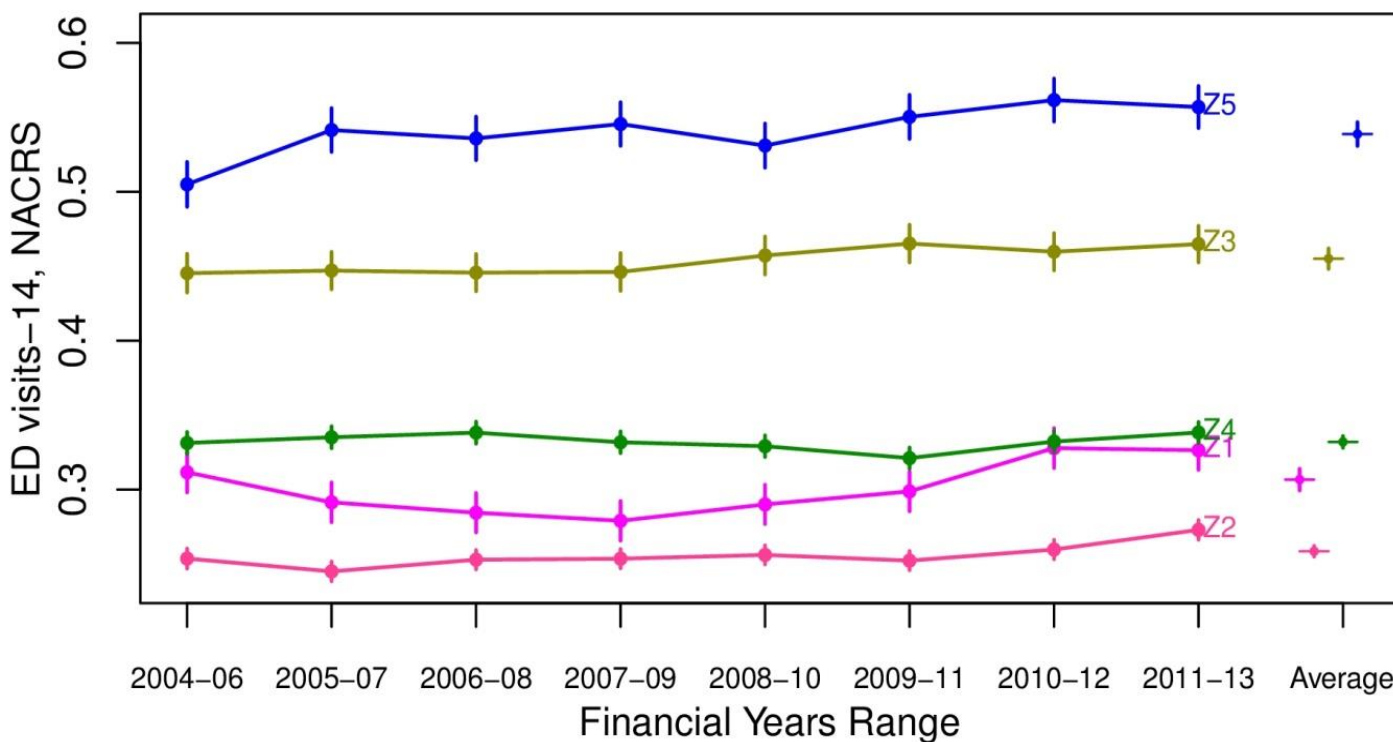
4. One or more ED visit in the last 14 days, source DAD (accounts for AC admissions through Emergency) (Exclusions: patients who spent all 14 last days in AC)



Trends: 3-year averages 2004-2013

5. One or more ED visit in the last 14 days, source **NACRS** (accounts for all Emergency visits)

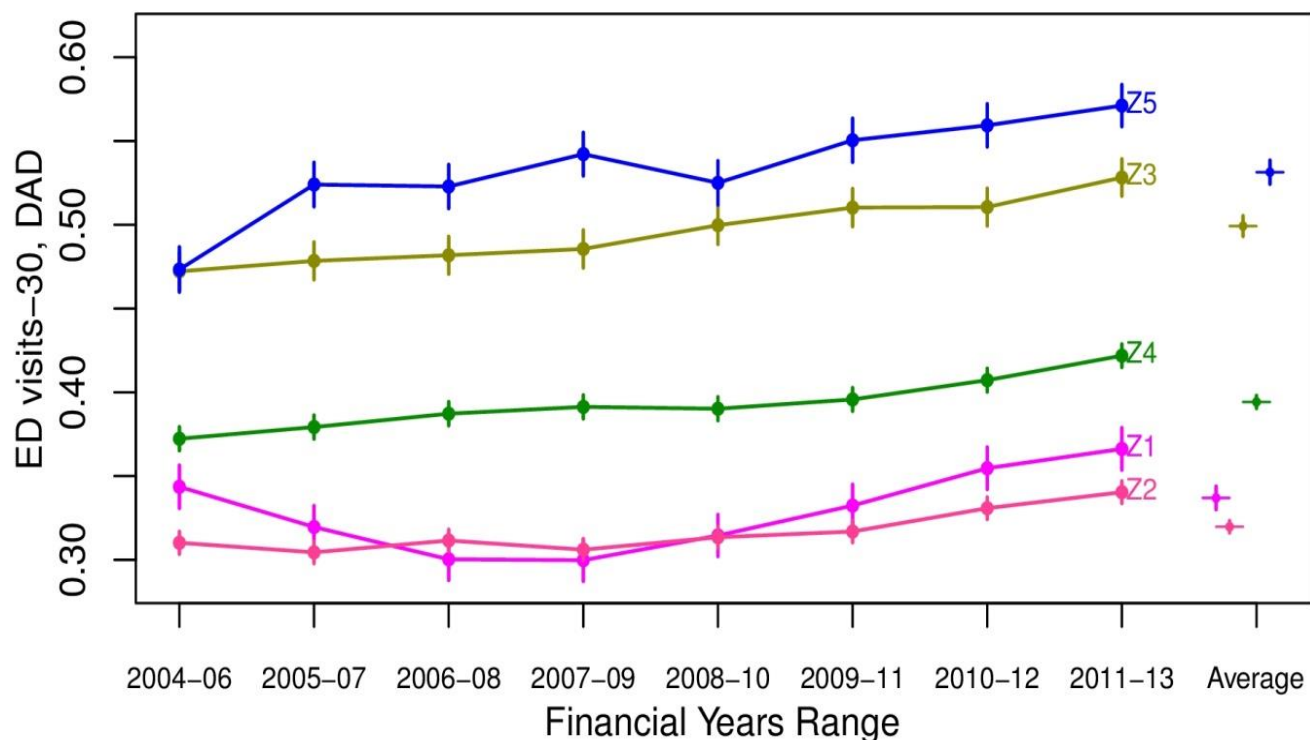
(Exclusions: patients who spent all 14 last days in AC)



Trends: 3-year averages 2004-2013

6. One or more ED visit in the last 30 days, source DAD (accounts for AC admissions through Emergency)

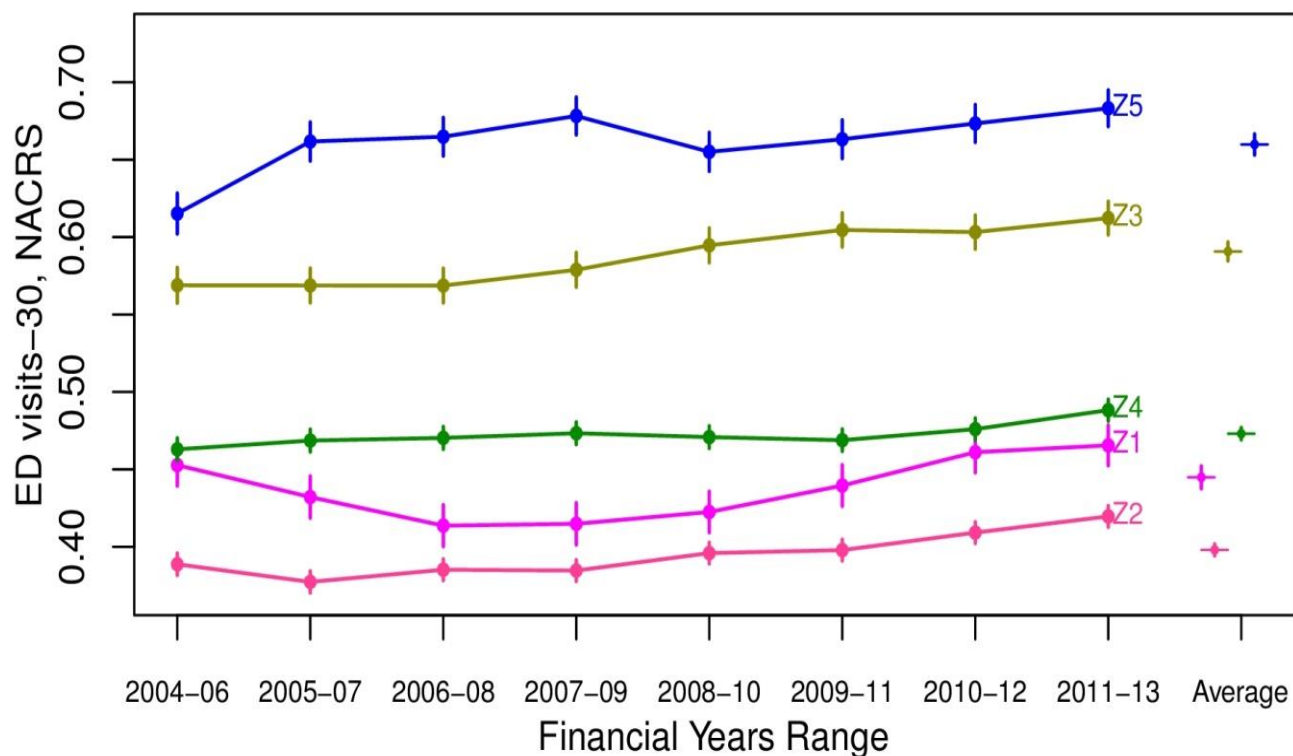
(Exclusions: patients who spent all 30 last days in AC)



Trends: 3-year averages 2004-2013

7. One or more ED visit in the last 30 days, source **NACRS** (accounts for all Emergency visits)

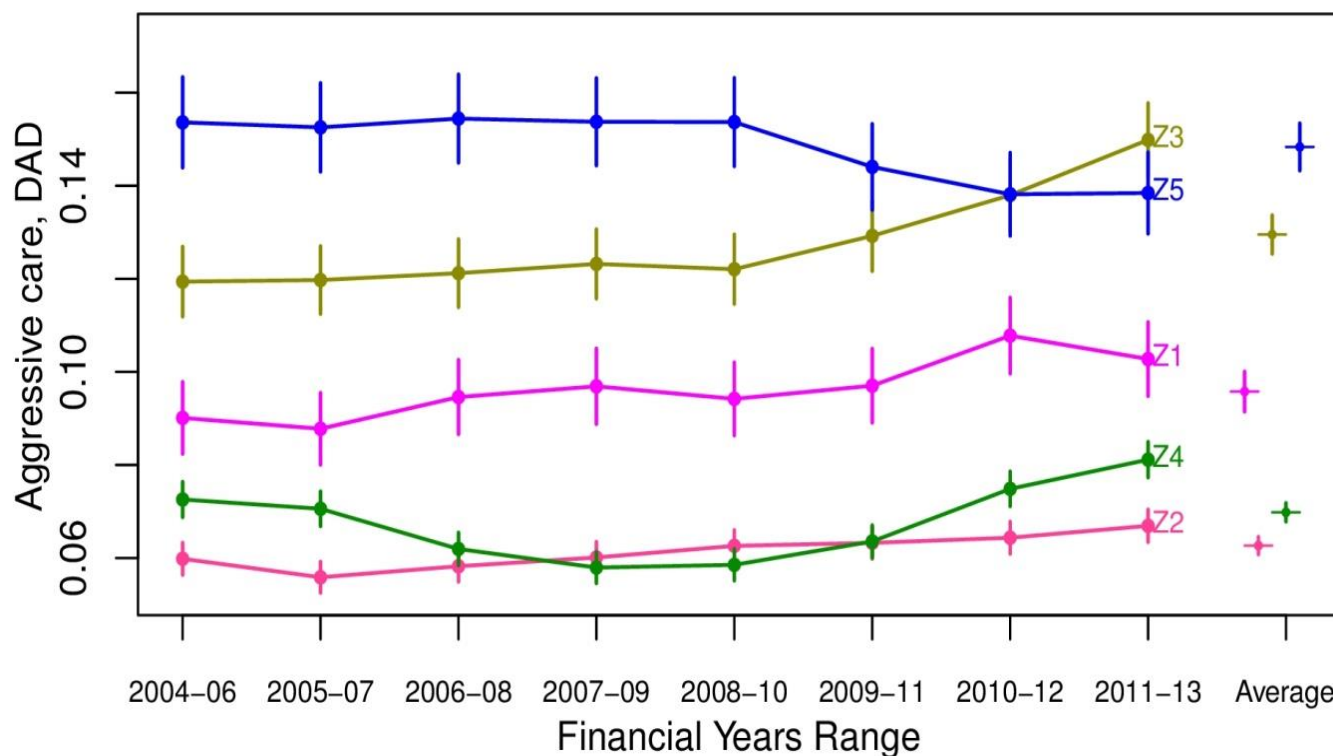
(Exclusions: patients who spent all 30 last days in AC)



Trends: 3-year averages 2004-2013

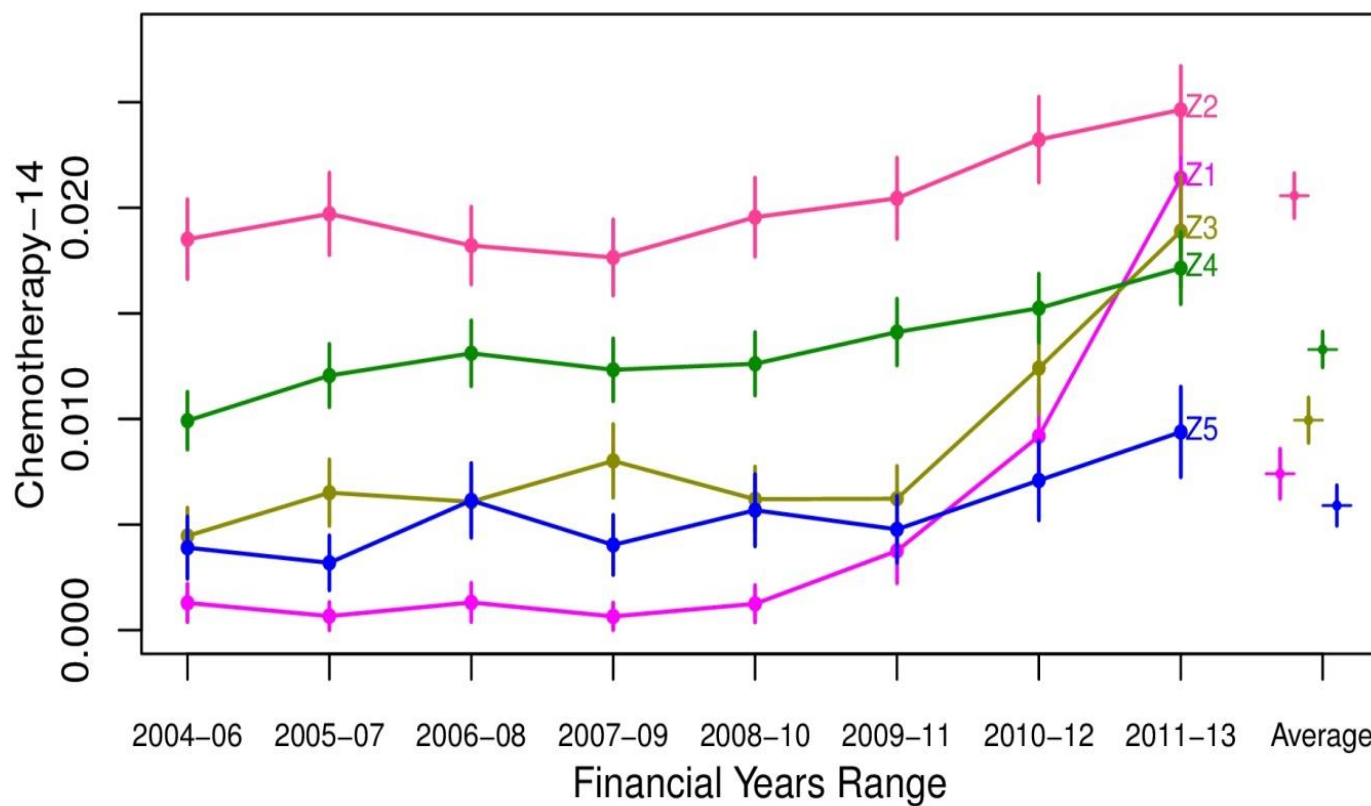
8. Aggressive care: 2 or more ED visits OR new admission OR ICU/SCU admission in the last 30 days

(Exclusions: patients who spent all 30 days in AC)



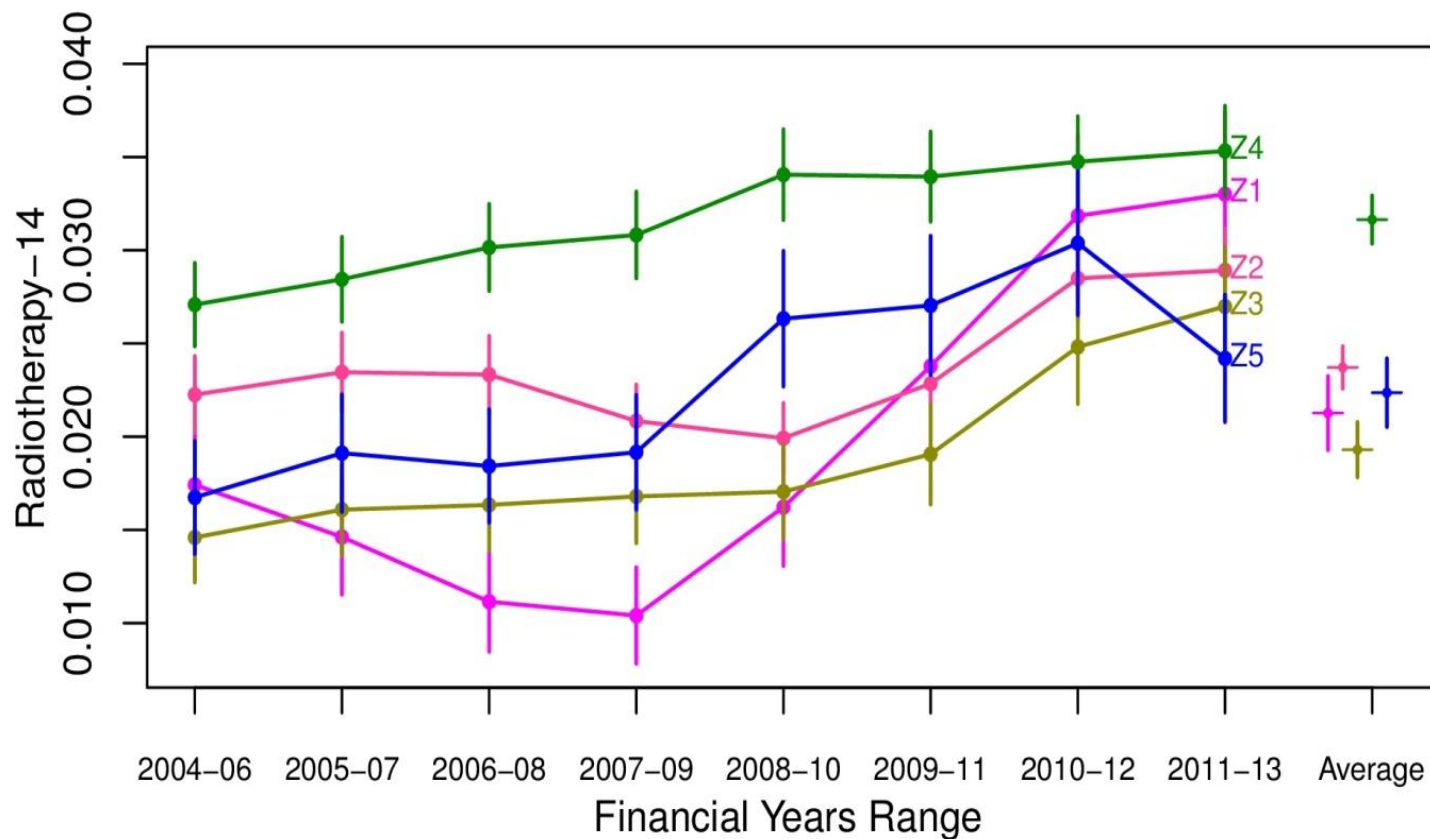
Trends: 3-year averages 2004-2013

9. Chemotherapy within last 14 days



Trends: 3-year averages 2004-2013

10. Radiotherapy within last 14 days



What is the impact of ACP on healthcare resource use?

- Studies differ in perspectives adopted: are healthcare costs borne by individual payers, public or private insurers, or society as a whole?
- Resources utilized for health care include inpatient care, clinic visits, emergency visits, physician and other professional care, home care, long-term care, medication, medical devices and supplies, hospice care, or insurance or program implementation costs.
- Resources identified may be measured by natural units such as days hospitalized or number of clinic visits.
- Resource use may be measured through primary or secondary data gathering with administrative data or retrospective chart reviews (Baladi 2006).
- Dollar value is assigned by calculating costs for patients, or charges to patients and insurers.
- Five literature or systematic reviews evaluated the impact of ACP discussion and/or documentation, or participation in a multi-activity ACP intervention, on healthcare resource use or costs

How does ACP impact resource use?

Systematic Review by Brinkman-Stoppelenburg et al. (2014)

- 113 studies examined
- PICOS
 - All populations and settings
 - Documentation (DNR, DNH, AD, DPOA, LW), Discussion, and “Complex” ACP interventions; Comparator: Usual or Standard Care (without ACP)
 - Outcomes examined:
 - **Effects on medical treatment in the last phase of life**
 - Effects on quality of life and patients’ and families’ satisfaction with care
 - Effects on patients’ and families’ prevalence and/or severity of symptoms
 - Study design: all study designs included
- Medical treatment in the last phase of life is measured as quantitative health utilization outcomes in ‘natural units’ including number of admissions and length of stay

How does ACP impact resource use?

Systematic Review by Brinkman-Stoppelenburg et al. (2014) (continued)

	Utilization Outcomes [Number of studies and impacts: (+/-/mixed results/no difference)]			
	Hospitalization	ICU use	Hospice and/or palliative care	Life-sustaining treatment
<i>DOCUMENTATION</i>				
Do-not-resuscitate orders	8: (-) 4: (+) 2: (No difference)	2: (-) 3: (+) 3: (No difference)	6(+)	
Do-not-hospitalize orders	8: (-) 1: (No difference)		5: (+)	3: (-)
Advance directives/living will/DPOA	2: (-) 1: (+) 5: (No difference)		5: (+) 2: (No difference)	10: (-) 1: (Mixed results) 11: (No difference)
<i>COMPLEX INTERVENTIONS OR DISCUSSION</i>				
Complex ACP interventions or ACP discussions	3: (-) 1: (Mixed results)		2: (+) 3: (Mixed results)	3: (-) 2: (Mixed results)

Adapted from Brinkman-Stoppelenburg (2014)

- **Aggregated impacts of ACP:**
 - **Decreased use of hospitals:** [21(-), 5(+), 2 (no diff. or mixed results)]
 - **Increased ICU use:** (as measured by studies that account for existence of DNR orders)
 - **Increased use of hospice or palliative care** [18(+), 5 (no diff. or mixed results)]
 - **Decreased use of life-sustaining treatment** such as cardiopulmonary support, resuscitation, mechanical ventilation. [18(+), 5 (no diff. or mixed results)]

How does ACP impact costs?

Literature Review by Emanuel (2006)

- 6 studies examined
- PICOS
 - All populations and settings
 - Intervention: Advance Directive document or participation in comprehensive ACP program (SUPPORT); Comparator: Usual or Standard Care (without ACP)
 - Outcomes examined: Average costs or charges (\$)
 - Study design: all study designs included. Included studies had randomized control trial, retrospective observational study, and prospective observational study designs.
- Results:
 - 3 studies: Cost savings between \$6000 and \$64827 (in 1995 dollars)
 - 2 studies: Cost increases between \$9234 and \$16500 per patient (in 1995 dollars).
 - 1 study: Showed cost savings of \$198 with assessment of data from last month of life, and cost increases of \$16500 from enrollment in program to death.
- In summary, 3/5 studies showed cost savings and one showed mixed results
- Shortcomings of review: No comprehensive search strategy was carried out

How does ACP impact costs?

Systematic Review by Taylor, Heyland, and Taylor (1999)

- 6 studies examined
- PICOS
 - Hospitalized patients only
 - Intervention: Documentation and Discussion (“Any expression of patient wishes (written, verbal or otherwise)”); ; Comparator: Usual or Standard Care (without ACP)
 - Outcomes examined: Average costs or charges (\$)
 - Study design: All study designs included. Included studies had randomized control trial, retrospective chart review, and prospective cohort study designs.
- Search strategy: 5 databases systematically searched, covering period 1966 to 1997
- Results:
 - 4 studies: Cost or charge savings between \$6000 and \$64827 per patient
 - 2 studies: Cost or charge increases between \$9235 and \$16900 per patient
- Shortcomings of review: Only included hospitalized patients

How does ACP impact costs?

Systematic Review by AHFMR (2005)

- 1 studies examined (Molloy et al. 2000)
- PICOS
 - Seniors 55 years of age and older, residents in a long term care facility. Non-acute health care settings (such as nursing homes and senior centres).
 - Intervention: Documentation (AD, LW, DPAHC, DNR, Let Me Decide order); Comparator: Usual or Standard Care (without ACP)
 - Outcomes examined: Mean costs (\$) per patient; mean costs for specific categories reported
 - Study design: All study designs included. Included study had randomized control trial design.
- Search strategy: 8 core databases searched, covering years up to 2005.
- Results:
 - Mean hospitalization costs: Cost **savings** \$2097 per patient
 - Mean nursing home drug costs: Cost **increase** \$236 per patient
 - Mean program implementation costs: \$113 per patient
 - Mean total cost per resident: Cost **savings** \$1749 per patient
- Shortcomings of review: Limited study population

How does ACP impact costs?

Systematic Review by Marckmann, Klinger, in der Schmitten (2013, 2015)

- 7 studies examined
- PICOS
 - All populations and settings
 - Intervention: Documentation (resuscitation order, AD, LW), Discussion, or “Comprehensive” ACP programs; Comparator: Usual or Standard Care (without ACP)
 - Outcomes examined: Average costs or charges (\$)
 - Study design: All study designs included. Included studies had randomized control trial, retrospective observational, and prospective observational (longitudinal) designs.
- Search strategy: 5 databases systematically searched
- Results:
 - 6 studies: Cost or charge savings between \$1041 and \$64830 per patient
 - 1 study: Resource use ratio of 1.05 (no evidence of cost savings)
- Shortcomings of review: No meta-analysis conducted or reported to show comparisons among heterogeneous results with different units and periods of assessment

Summary of reviews

- Systematic Review on **Resource Use in Natural Units** from ***all perspectives*** (Brinkman-Stoppelenburg et al. 2014)
 - Decreased hospitalizations, decreased use of life-sustaining treatment, increased palliative care and hospice use, and increased ICU use
- Literature Review on **Costs and Charges** from ***all perspectives*** (Emanuel 1996)
 - Trend: Majority of studies showed **decreased costs or charges** (3 studies – decreases; 2 studies – increases; 1 study – increase and decrease)
- Systematic Reviews on **Costs and Charges** with ***limited perspectives***:
 - Hospitalized patients only (Taylor, Heyland and Taylor 1999):
 - Trend: Majority of studies showed **decreased costs or charges** (4 studies - decreases; 2 studies - increases)
 - Long term care residents only (AHFMR 2005)
 - Trend: **Decreased mean total costs** per resident, **decreased mean hospitalization costs** per resident, **increased nursing home drug costs** per resident (One study cited - Molloy 2000)

Conclusion

- All reviews show general decreased levels of median or mean charges or costs per individual. Charges may have been covered by individuals or insurance providers. Costs to the public healthcare system were also used in some cited studies.
- Out-of-pocket costs were not examined in any cited studies.
- Cost-shifting may take place with the presence of ACP programs
 - Increases in use of some resources by either cost or natural units: Palliative or hospice care, use of ICU
 - Decreases in hospitalization and overall individual costs
 - Some studies assessed program evaluation costs, although these costs have not been systematically assessed
- Shortcomings of present reviews
 - No quality appraisal or meta-analysis was conducted
 - Whether costs or charges are measured and how they are compared has implications for cost to individuals, government, and society.
 - Charge data may be inflated measures of true costs.

Economic impacts of ACP: Families and informal caregivers

- ACP may have a significant impact on non-professional caregivers including family and friends, who utilize significant resources in caring for friends and family members
- 19% of Canadians Atlantic provinces and said they had cared for a family member or close friend with a “serious health problem” in the last 12 months
 - Lowest percentage (14%) across Manitoba & Saskatchewan, followed by Atlantic provinces (15%), Quebec (17%), Alberta (20%), Ontario (21%) and British Columbia (22%)
 - 41% used personal savings to manage, 30% took one or more months off from work, 18% accessed other employer benefits, 12% quit work to care for this person, 12% claimed the Caregiver Tax Credit, and 12% took advantage of other government tax benefits

(Health Care in Canada Survey 2014)

- Caregivers face reduced current income and foregone future income, including foregone job-related benefits and reduced employment-related pension benefits
 - More than 1/3 of caregivers incur out-of-pocket expenses
 - About 80% spent \$6000 or less per year on average (2007 data) (Fast and Keating 2013)
- In 2012, 6.1 million employed Canadians providing care—35% of workforce (Employment and Social Development Canada 2015)
- Estimated cost to employers in lost productivity: \$1.28 billion per year, **as calculated by value of missed days /hours of work and job losses (2007data)** (Conference Board of Canada 2012); another 2009 estimate used replacement costs **of hiring paid caregiving**, and valued unpaid caregiving between \$25 and \$26 billion (2002 data, (Hollander, Liu, and **Chappell** 2009)
- 2014 Economic Action Plan announced Canadian Employers for Caregivers Plan to help maximized caregivers’ labour market participation through tax measures, income replacement, and targeted programs
- Relationship between having Advance Directive and strain perceived by caregiver inconclusive. However, caregiver strain associated with symptom distress in patients and increased hospice enrollment (Tilden et al. 2004).
- ACP and patient decisions may influence caregiver strain and burden

Economic impacts of ACP: Legal and Financial Sectors

- Lawyers involved in the process of ACP to inform patients about consequences of expressing healthcare wishes, how wishes factor into consent, how wishes will be used and interpreted, to give legal authority to substitute decision makers (CBA 2010)
 - Assist with drafting of documents including instructional and proxy directives. The availability of standard forms and type of directive provided for in legislation varies by jurisdiction. For example, in New Brunswick, a healthcare power of attorney must be executed under seal.
 - Fixed hourly fees and hourly fees may be charged in drafting of wills
 - National fees range from \$191 for a power of attorney to \$370 for a “simple will” up to \$1093 for an individual complex will (Canadian Lawyer 2013)
- Lawyers’ involvement in wills and estates
 - 6% of lawyers in wills and estates; 10% practice family law (British Columbia) (Law Society of British Columbia 2013)
 - Presently, high level of use of lawyers in wills and estates planning: In Alberta, 78% of Albertans who reported using lawyers accessed services in wills and estates (the second highest in access, compared with 84% using real estate services) (Law Society of Alberta 2010)

Economic impacts of ACP: Legal and Financial Sectors

- Financial planners and accountants may advise on planning to meet financial needs at the end of life, including advising on use of:
 - Future living costs or cost in the event of illness, funeral costs
 - Current and future sources of income and use of programs including: Disability insurance, Canada Pension Plan Disability, Registered Disability Savings Plans, Long-Term Care Insurance, Retirement Accounts and Pensions, Old Age Security, Medical Expense Tax Credit
 - Medical Expense Tax Credit may be claimed by individuals and their caregivers for above-average, itemizable medical and disability-related expenses
- Legal and Financial sectors:
 - Legal and financial services combined accounted for 22% of total employment in professional services sector (Statistics Canada 2012)
 - High proportions of self-employed people (35% - accounting services; 28% - legal services) (Statistics Canada 2012)
 - Professional, Scientific, and Technical Services: 13.5% increased sales over 2007-2011, reaching \$122.3 billion in 2011. In 2011, legal services and accounting, tax preparation, bookkeeping, and payroll services saw declines in sales (Industry Canada 2013)
- ACP and associated end-of-life planning and discussions may serve as value-added services for clients in these industries

What are the economic impacts of ACP: other sectors

- Spiritual care providers provide support within healthcare facilities, pastoral counseling centres, parishes and congregations, and private practices (CASC 2015)
 - Significant levels may be provided by volunteers
 - Chaplains usually found in healthcare facilities: nationally, 1.5 chaplains for every 228 patients (Woodland and Tayler 2009)
- Organizations such as Partners in Care Alliance (PICA) involves healthcare workers along with funeral and cemetery works in end-of-life planning issues
 - ACP may lead to increased family and individual planning
 - Cost of a funeral in Canada \$8000-\$10000 (2013 estimates) (**National Post 2013**)
 - Number of funeral directors and embalmers has increased significantly due to rise in mortality and diversification of services provided by funeral homes. Customization of services and directors serving as advisors to families to ensure that preferences—including location and customs performed, match their needs (Service Canada 2014).

h of a risk do you see in linking ACP with cost

High risk

Moderate
risk

Low risk

Start the presentation to activate live content

If you see this message in presentation mode, install the add-in or get help at PollEv.com/app

What Will Success Across Alberta Look Like?

1. Open and documented ACP GCD communication between patients, families, HCP, lawyers
2. HCP understand their roles and teams work collaboratively
3. A fluid and consistent process of ACP GCD communication occurs across sectors
4. Patients and families are prepared & have ongoing ACP GCD conversations.
5. Community culture expects ACP (woven into life events with legal, business, government all supporting ACP).

Summary...

How to optimally implement widespread uptake of a formalized ACP framework across a large population and throughout a complex, multi-sector health care system?

Build together on the scaffolding

Infrastructure

- EHR
- TRACKING RECORD REVIEW
- LEADERSHIP

Engagement

- PUBLIC CAMPAIGN
- INTERSECTORAL WORKING GP
- MEDICO-LEGAL COLLAB

Continuous QI

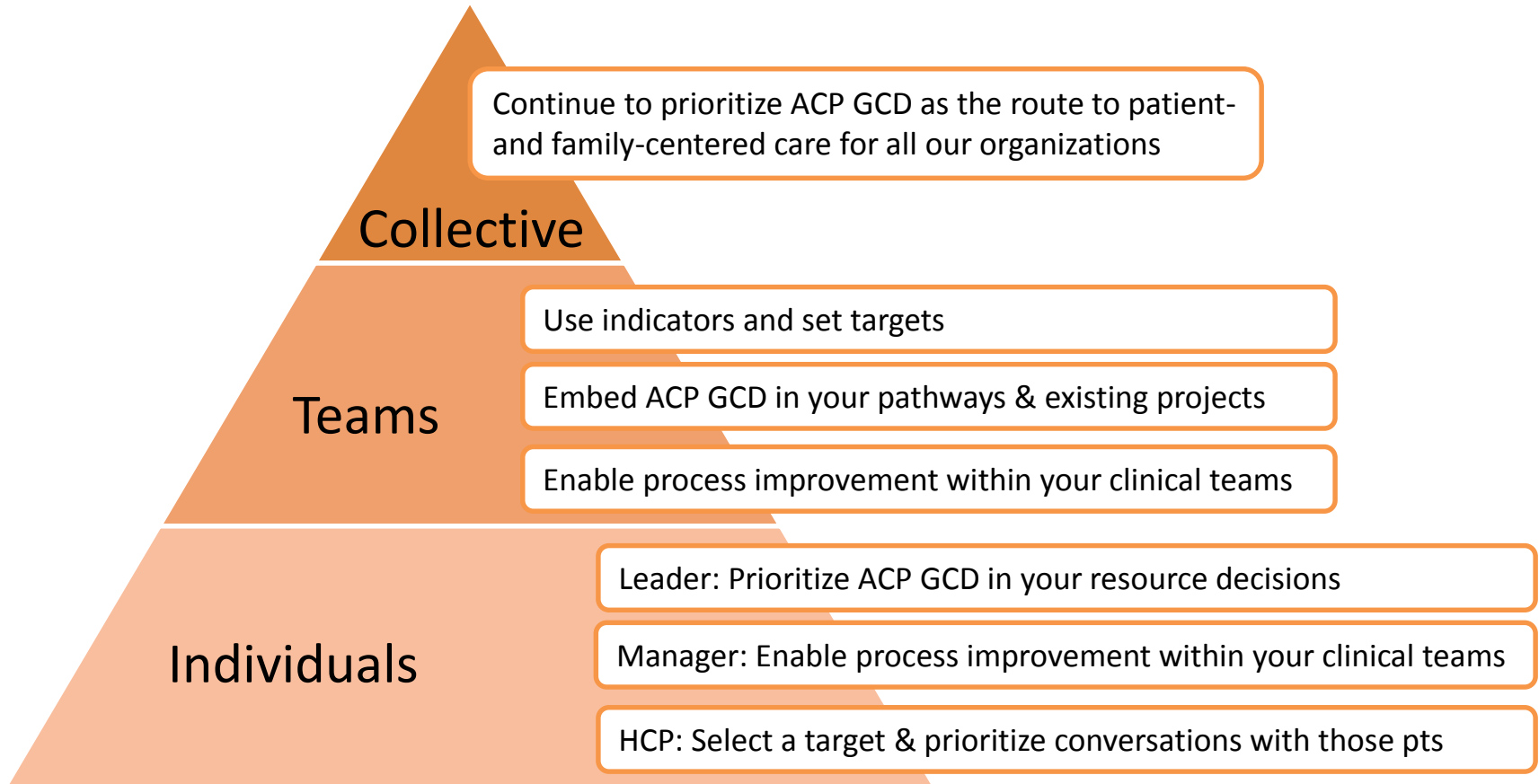
- DASHBOARD
- TEAM PROCESS IMPROVEMENT

Education

- SIC PROGRAM
- PEER to PEER EDUCATION

And focus on enabling and environmental restructuring
to increase OPPORTUNITIES for ACP and GCD

What's one thing I can do to achieve success in ACP GCD?



Our sincere appreciation of all ACP CRIO participants

- Patients
- Communities
- Healthcare providers
- Legal Professionals
- Administrators
- Access to data from AHS, HQCA and others

And Thank you!

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CHALLENGING QUESTIONS...

- What are your ideas for embedding deeper within/across sectors and beyond healthcare?
- How do we achieve sustained leadership for prioritizing ACP and GCD?
- How to achieve ACP as a public health issue and funded campaign

Certificate of Attendance

Please e-mail

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if you require a certificate of attendance
for the ACP CRIO Pre-Conference
Workshop

Health Research to Impact Framework

AIHS Mission & Vision

