ACP CRIO
Advance Care Planning Collaborative Research & Innovation Opportunities Program

Alberta Innovates Health Solutions

Alberta Health Services

UNIVERSITY OF CALGARY

UNIVERSITY OF ALBERTA

Covenant Health

Mary O'Connor Conference 2016

Are we there yet?
A snapshot of research findings about advance care planning in Alberta

Dr Jessica Simon
for the ACP CRIO program

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Disclosure: Confluence of interest

- ACP GCD, Physician Consultant, CZ, AHS

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Outline

1. Introduction to ACP CRIO research program
2. Learning from Supportive living residents, families and HCP (qualitative)
3. Learning from acute care GCD orders (quantitative)

- *Take home message*

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Alberta Health Services

Care Consistent with Patient Values & Goals

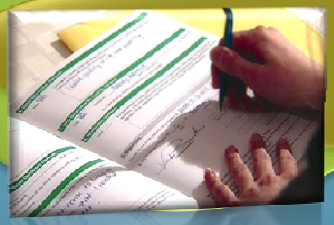
ACP Conversations

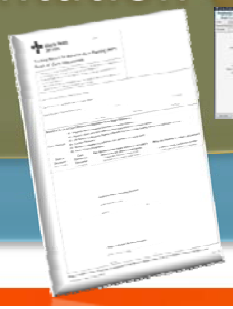
- Values
- Wishes
- Fears
- Choosing an agent

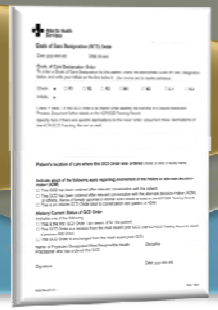
GCD Conversations

Review personal goals, preferences
Illness understanding
Prognosis
Anticipated outcomes
Appropriate treatment options

Documentation







ACP CRIO Team

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Research Questions

1. **What are the barriers & facilitators** to ACP uptake and readiness in Alberta for different stakeholders?

2. **Are ACP tools are effective** to engage users, increase knowledge and change behavior? What tailored improvements or methods of implementing tools will change their effectiveness?

3. **What are the most informative measures** to monitor practice change and communicate results to end-users?

4. **What is the impact of ACP/GCD** on the trajectory of *care and costs* for dying patients?

Study contexts

- Seniors (supportive living facilities)
- Cancer (out-patient clinics)
- Chronic Disease (renal and heart failure)

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Three lenses

- Patients, Families, Public
- Healthcare providers (HCP)
- Health systems

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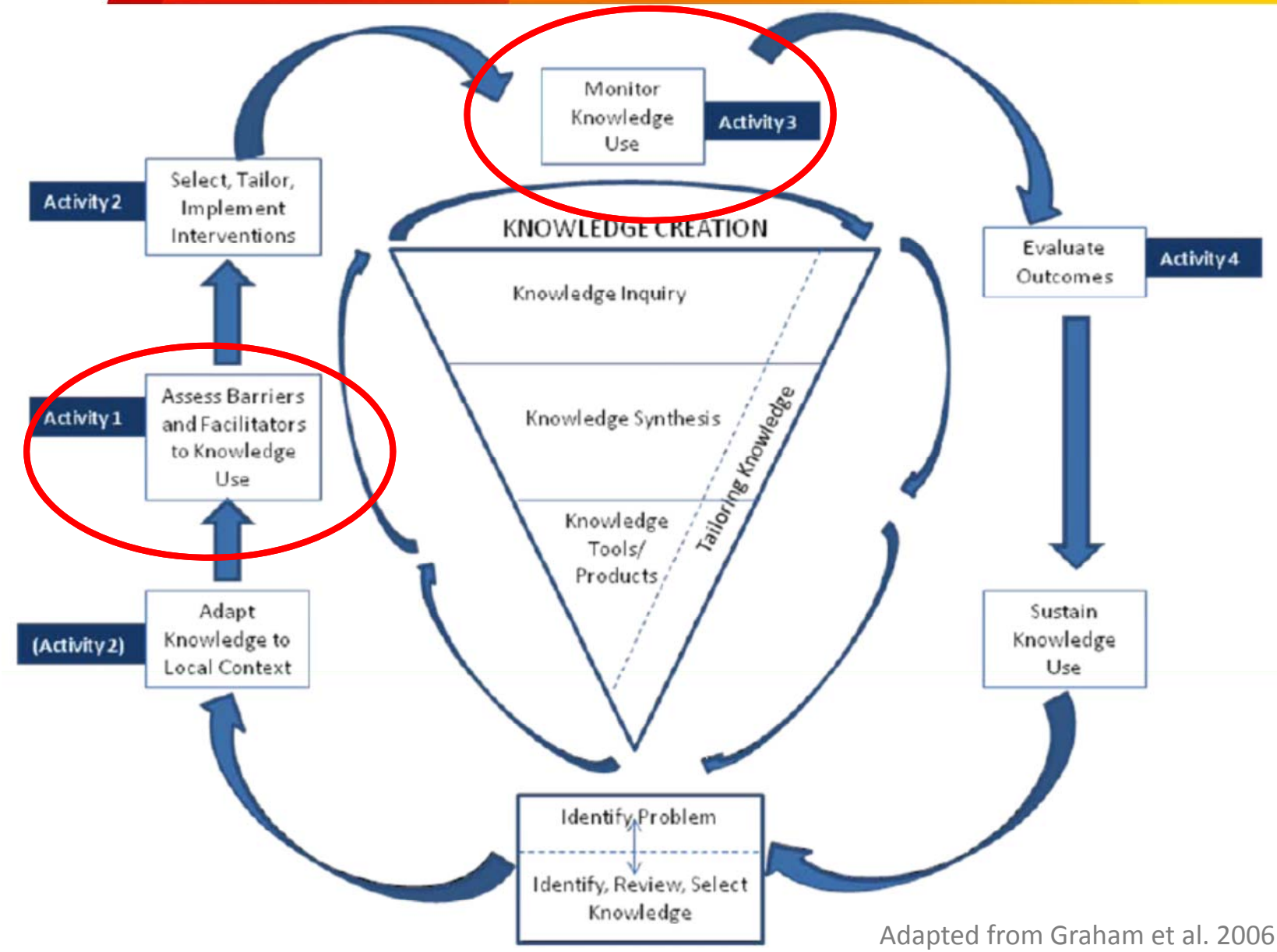
Knowledge to Action Cycle



Adapted from Graham et al. 2006

Variable conception: Health care Providers

ACP as a way to communicate values:

"…I do my best to elaborate the conversation to...get a better understanding of the patient's values, attitudes and beliefs"

Determining GCD as a task:

"...typically, those Goals of Care were being reviewed at annual conferences"

"I have to make some choices about ACP and about where were gonna send this person, whether we're gonna keep them, medical choices"

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HCP concerns

"But ah, I really think that the multi-disciplinary team does not do a good job at all, of it, in the sense that they don't know there's this huge role"

"I'm a little bit unsure…sometimes I feel we push...and I've been challanged a little bit on the team here because...I've actually been told that anyone coming in here must have it"

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Nature of ACP Readiness and Engagement in SL

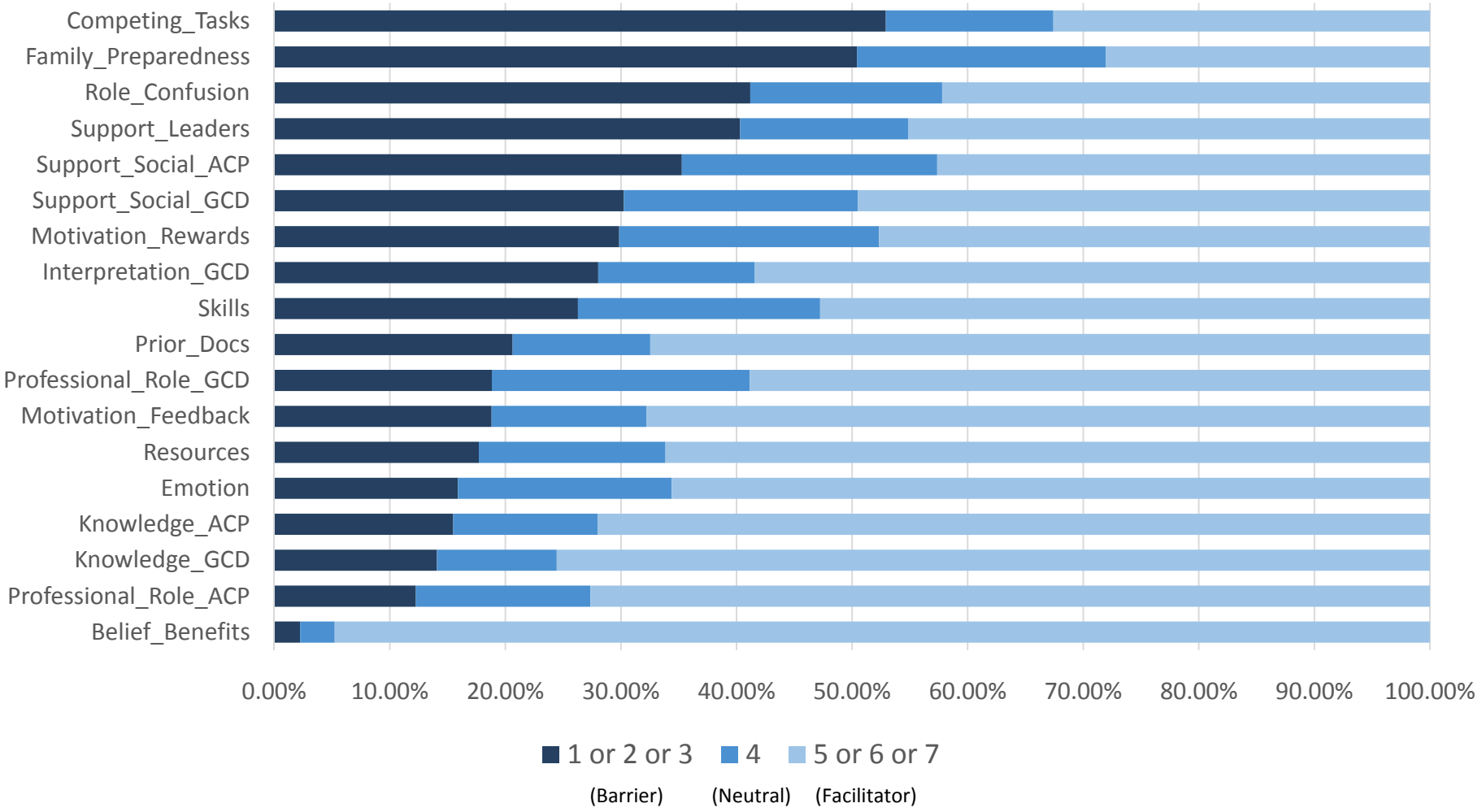
	Variable Conceptualization of ACP	Factors Reflective of Readiness vary with Participant Group		
	Differing Definitions	Prior Experience	Motivation and Attitude	Roles in ACP
Resident	- Confusion around ACP/GCD terminology and process, despite high engagement. - Little recollection of interaction with clinicians around completion of medical order GCD forms.	- Prior experience in EOL care for others, personal decision-making and ACP shapes perspectives on preparing for health change and outlook on life course.	- Highly practical regarding discussions and documentation related to ACP and EOL. - Accepting of life and health circumstances, especially after transition to SL.	- Clarity in their own roles, role of family members and role of clinicians. - Confident that decisions would be made well on their behalf.
	Differing Definitions	Prior Experience	Motivation and Attitude	Roles in ACP
Family Member	- Understanding of general purpose of ACP - Difficulty understanding technical medical GCD order terminology.	- Prior experience with EOL decisions and care common among FM. - Prior experience makes current situation easier and strengthens appreciation of medical limitations.	- Appreciation for how ACP enables FM to experience loved one's EOL. - Despite ACP engagement, struggle with making difficult decisions at EOL.	- Acceptance of their decision-making role. - Aware of role challenges. - Some frustration with clinicians, in hospital but grateful for clinician ACP role.
	Differing Definitions	Prior Experience	Motivation and Attitude	Roles in ACP
Clinician	- High literacy on ACP terminology and process - Differing focus (Medical GCD order forms or broader ACP discussions of values and preferences).	N/A	- Variability in comfort with ACP engagement. - Variable ethical concern around ACP process and GCD expectations in SL setting.	- Uncertainty about role accountability in ACP, especially in interdisciplinary teams. - Social workers and nurses ideal to engage patients in ACP.

Shaw et al Submitted for publication

Healthcare provider survey of barriers and facilitators

n=542

Questions Ranked by Barriers



Lauren Anderson, Sunita Ghosh, Jessica Simon manuscript in development

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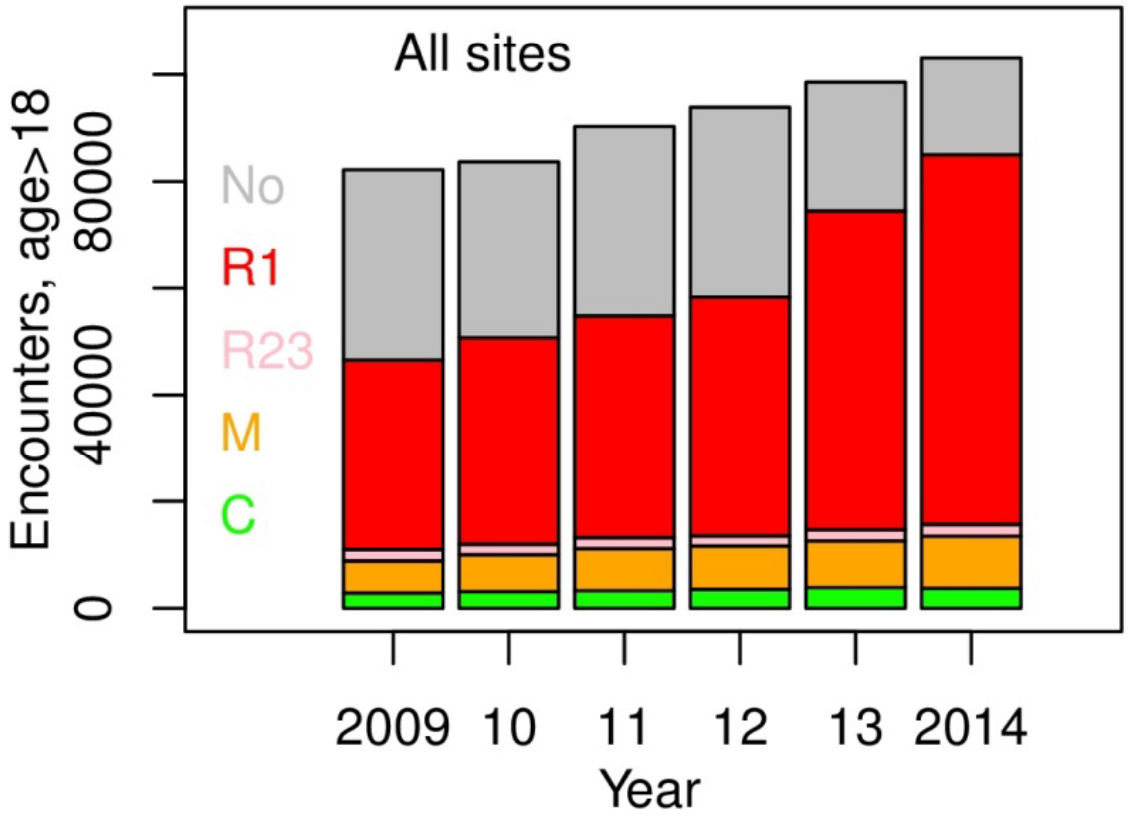
What's happening in acute care?

Adult encounters with completed GCD by year

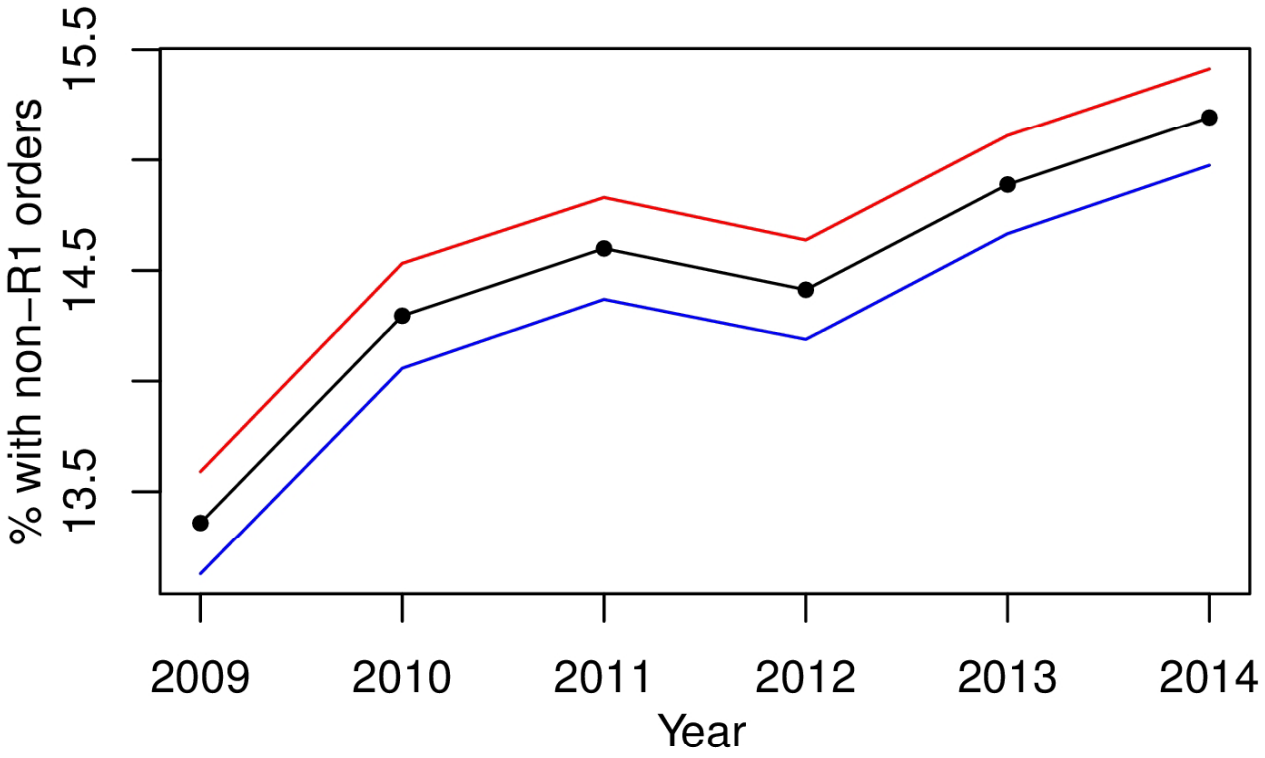
n=525284 GCD orders



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

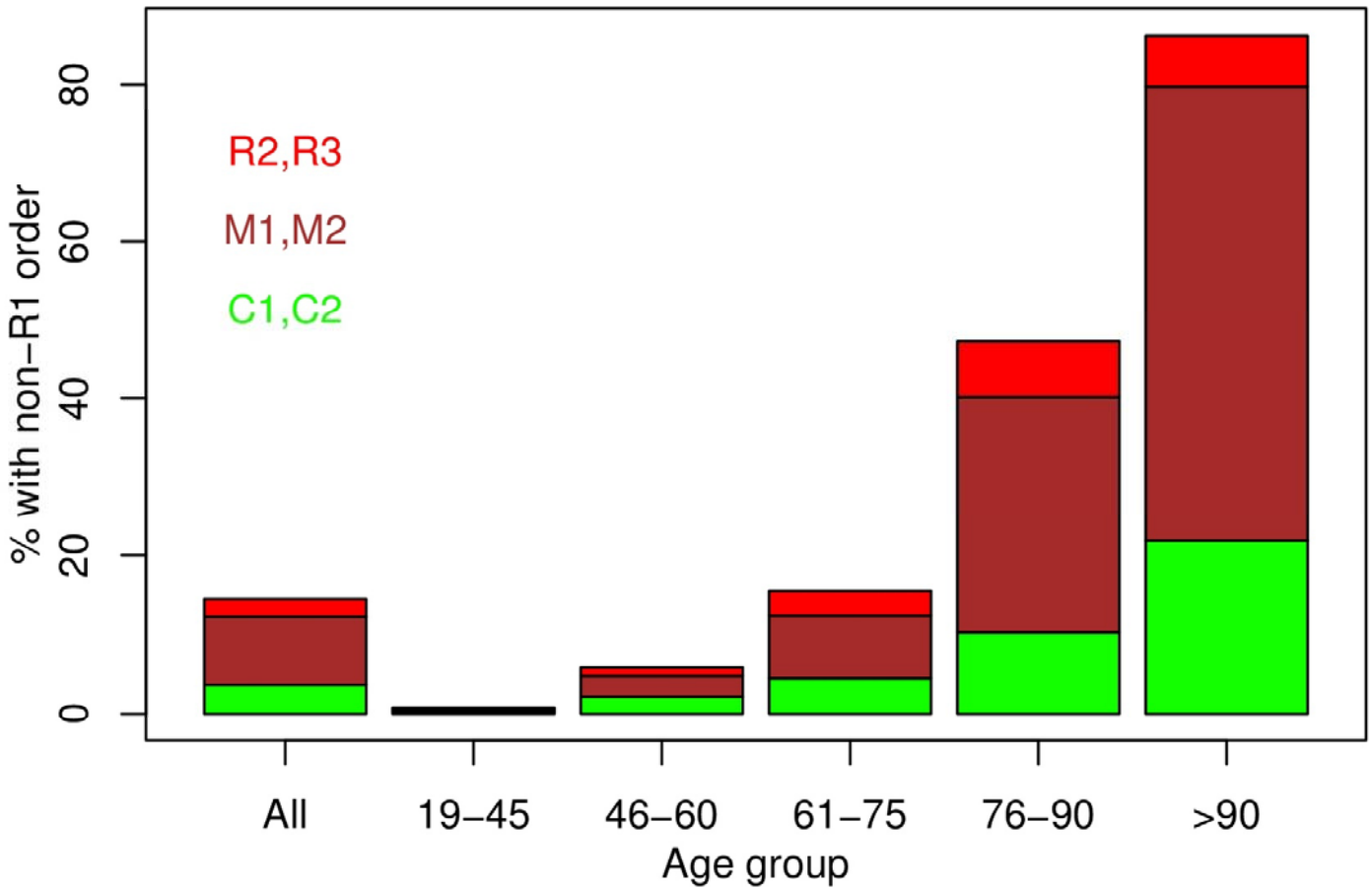
% Encounters with at least one non-R1 order

(trend with 95% confidence interval)

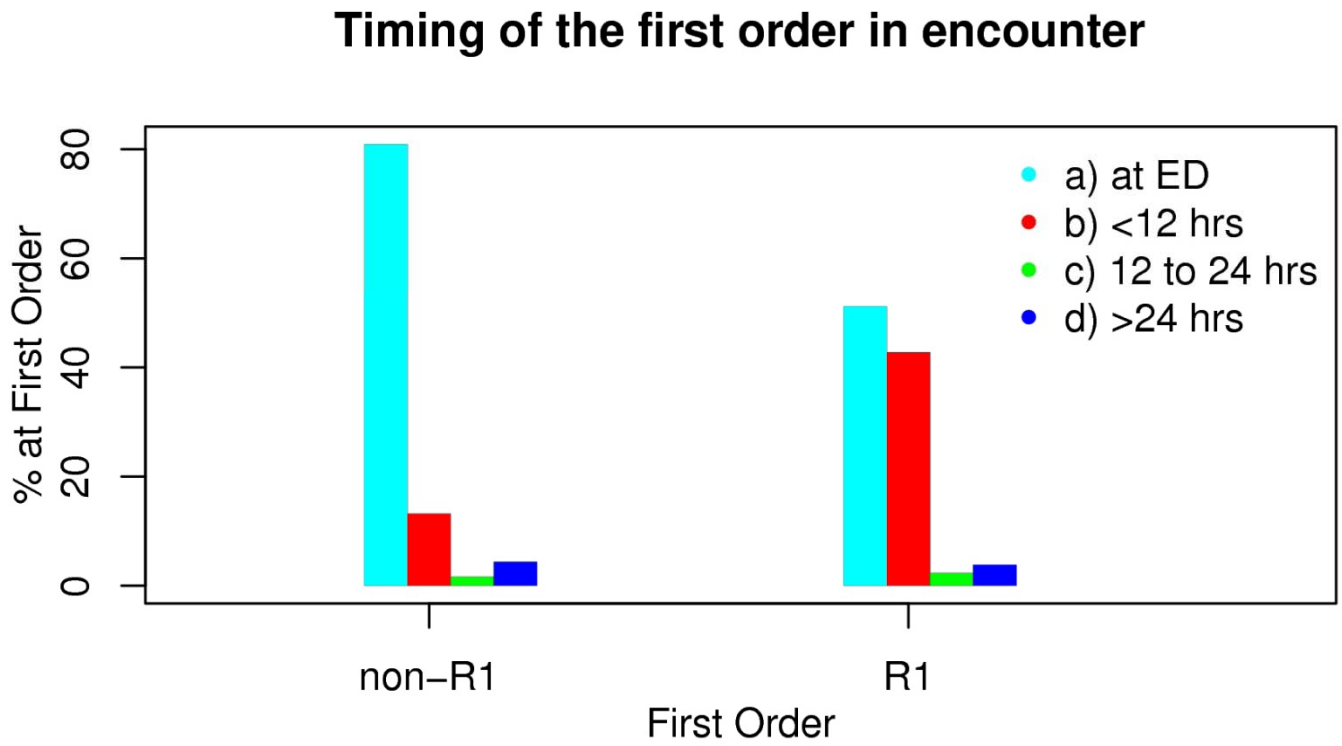


Slight increase in non R1 orders over the years

Age: % encounters with **non-R1** GCD



Timing of first order



- The majority of first orders are made in ED.
- Only 3.9% are made later than 24 hrs from admission.
- About 90% of non-R1 orders are made in Emerg & Medicine units.

Once ordered few GCD change

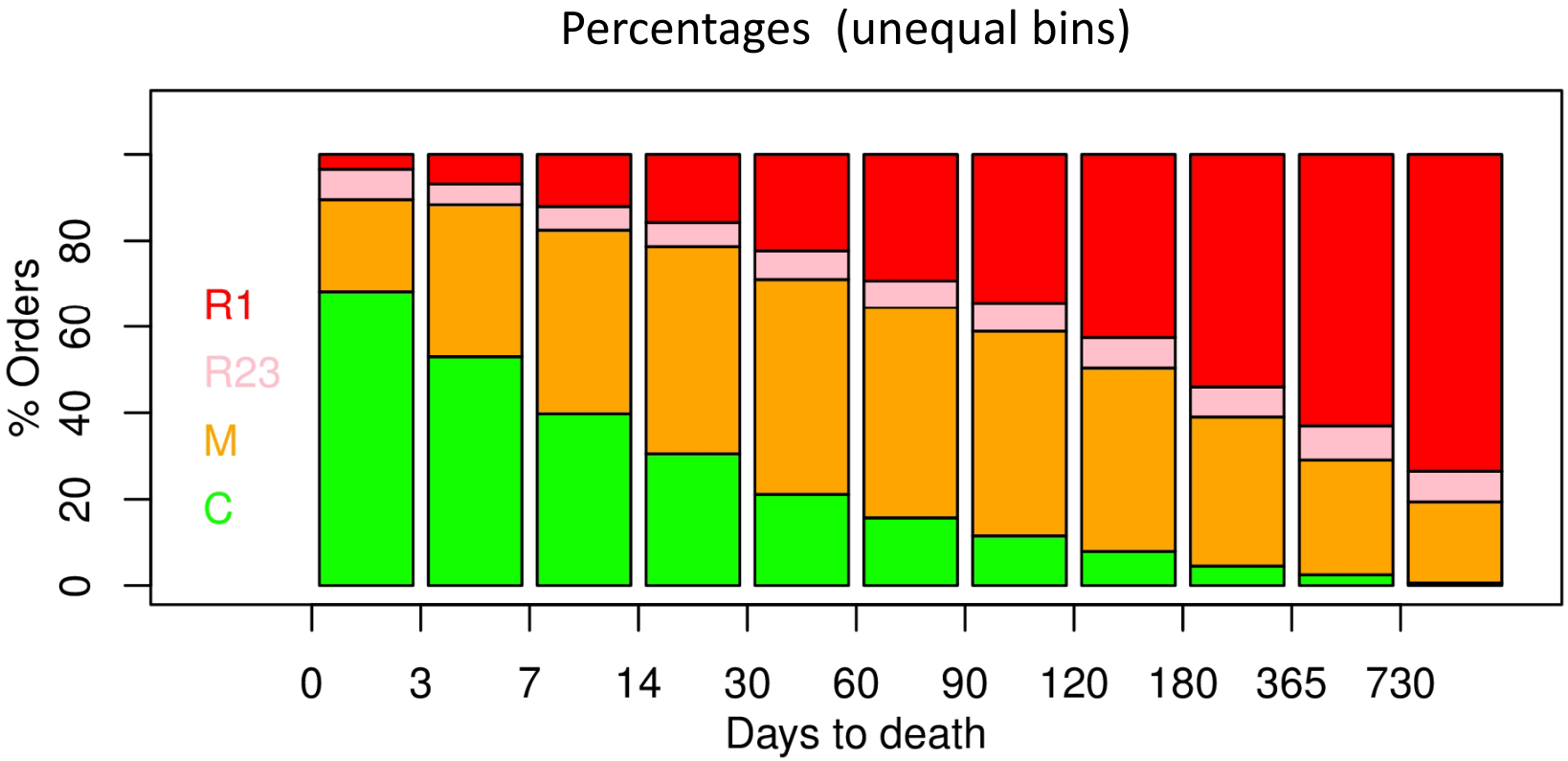
Order sequence	% in encounters	% for patients
Keep R1	78.4	81.0
Keep R2/3, M or C	14.8	5.9
Natural progression R→M→C	**6. 5**	**12.3**

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

GCD appear to change appropriately as death nears



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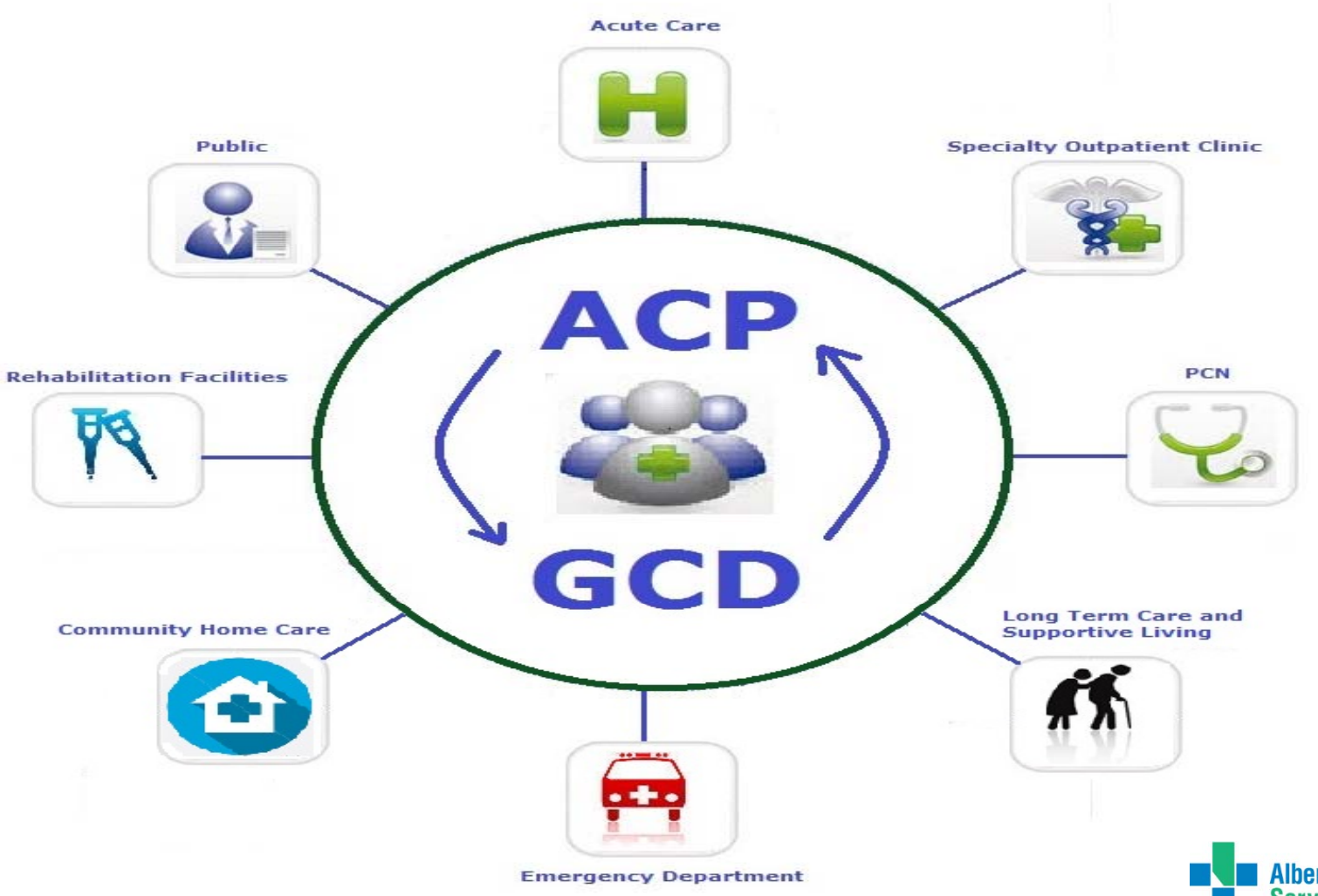
Implications: for acute care and at home

- Conversations before Emerg are so important
- Focus education in Emerg and medicine
- Develop process for reviewing GCD before discharge/ LOS > 6 days and back at home.

Feed forward – navigating the journey

We each have a role in encouraging ACP, eliciting patients' personal goals and supporting patients' understanding of their GCD.



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