I-GAP
Improving Advance Care Planning in General Practice

Michelle Howard
2015 TVN Advance Care Planning Research Session
September 29, 2015
TVN 2013 Core Grant
This research is funded by TVN, which is supported by the Government of Canada through the Networks of Centres of Excellence (NCE) program

- **Principal investigators**
  - Michelle Howard (McMaster)
  - Daren Heyland (Queen’s)
  - Doris Barwich (UBC)
  - Doug Klein (U of A)
- **HQP**
  - Gabriel Asselin (U of A)
- **Co-investigators and collaborators**
  - Amy Tan (U of A)
  - Carrie Bernard (McMaster)
  - Marissa Slaven (McMaster)
  - Louise Hanvey (Speak Up – CHPCA)
  - Konrad Fassbender (U of A)
  - Jessica Simon (U of Calgary)
  - John You (McMaster)
  - Rebecca Sudore (U California at San Francisco)
Working Definition of ACP

• ACP is a communication process wherein people plan for a time when they cannot make decisions for themselves. It includes reflection, deliberation and determination of a person’s values and preferences for treatments at the end-of-life, communication amongst an individual, his or her loved ones, future substitute decision maker(s), and health care provider(s) about these values and preferences, identification of a substitute decision-maker, and may result in a written expression of preferences (advance care plans), although verbal or other expressions are also useful.¹

• Should inform in-the-moment treatment decisions
• Not a medical decision or consent for treatment

Evidence for ACP

- When patients have engaged in ACP activities, end-of-life experiences are improved for the patient and family members
- Lower rates of depression and other psychological consequences among families
- Lower rates of unwanted escalation of treatments
Why Primary Care?

• Family physician can help in shared decision-making
• Longitudinal relationship (10+ years)
• Effective strategies for ACP:
  – Multi-modal
  – Over multiple visits
  – Time for discussion
  – Incorporated into routines
Knowledge Translation Gap

ACP tools, goals of care documentation tools, decision aids, communication tools
Research Questions

1) To what extent are patients in primary care currently completing key components of ACP?
2) What are the barriers and facilitators to implementing ACP in primary care?
3) What knowledge products/tools can be developed to narrow the evidence-practice gap and do these tools improve ACP engagement?
4) Does this ACP engagement strategy improve ACP rates at the individual primary care site level?
I-GAP Participating Practices (n=20)

- Alberta
- BC
- Ontario

- Comprehensive family practices
- Multiple provinces
- Multiple models of practice
Audit of ACP and barriers in primary care
Oct 2014 – Mar 2015

- ACCEPT audit of patient ACP from acute care adapted and piloted
  - Engagement in ACP, reasons for not
  - Comfort having discussions

- DECIDE survey for physicians, nurses, allied health adapted for primary care and piloted
  - Barriers related to: self, patient, system
  - Engagement, willingness, who should do it
ACCEPT study Methods

- Multi-center family practice audit
- Inclusion
  - ≥50 years of age
  - English speaking
  - Cognitively intact
- Opportunistic sampling, patients attending for routine office visits
- Target 30-50 patients at each participating family practice
- Self-administered questionnaire to answer study questions
- Audited chart for any documentation
ACCEPT Results

- N=810 (response rate > 70%)
- Average age 66.6, range 50-95
- 69% married or living as married
- 88% Caucasian
- 12% vulnerable for frail
- Comorbidity index mean 1.1
ACCEP Results - Engagement

- 69% patients thought about what kinds of medical treatments they would want, or not want, if they were to get very sick and be in a hospital.
- 53% patients have discussed their wishes with someone.
- 32% of patients said they have written down their wishes.
- 50% of patients said they have named someone, in writing, to be their SDM.
- 23% had engaged in all 4 key ACP behaviours
Who have they discussed their wishes with?

53% patients have discussed their wishes with someone

- Family Members (91%)
- Lawyer (23%)
- Family Doctor (18%)
- Other (6%)
- Surrogate Decision Maker (5%)
- Other Doctor (3%)
- Nurse (2%)
- Spiritual Care Worker (1%)
- Social Worker (1%)

N = 404

CARENET
Canadian Association of Research at the End of Life Network

i-GAP
IMPROVING ADVANCE CARE PLANNING IN GENERAL PRACTICE
How comfortable are you talking to your family members?

- Very comfortable: 48%
- Quite comfortable: 16%
- Neutral: 9%
- Quite uncomfortable: 5%
- Very uncomfortable: 2%
- Missing or decline: 2%

N = 760
How comfortable are you talking to your doctor?

- Very comfortable: 56%
- Quite comfortable: 22%
- Neutral: 8%
- Quite uncomfortable: 3%
- Very uncomfortable: 1%
- Missing or decline: 1%

N = 760
ACCEPT Results

• Virtually negligible accurate documentation in chart.
  – 38 charts had documentation of treatment preferences
DECIDE Study Methods

• Multi-centre family practice survey
• Physicians, nurses and other allied health professionals
• Self-administered e-questionnaire to answer study questions (modified Dillman method)
DECIDE study
Sampling Criteria

• Sent surveys to all physicians, nurses and allied health professionals at each participating family practice (20 incubator units).

• Reached out to non-participating family physicians, nurses and allied health professionals through various methods.
## DECIDE study Participant Characteristics (response rate 76%)

<table>
<thead>
<tr>
<th></th>
<th>All (n=186)</th>
<th>Physicians (n=125)</th>
<th>Nurses and other allied health professionals (n=61)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td>45.6 ± 12.7</td>
<td>47.6 ± 11.9</td>
<td>41.7 ± 13.5</td>
</tr>
<tr>
<td><strong>Sex</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>107 (64.5%)</td>
<td>54 (49.0%)</td>
<td>53 (96.3%)</td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>124 (78.0)</td>
<td>85 (68.0)</td>
<td>39 (75.0)</td>
</tr>
<tr>
<td>Asian</td>
<td>34 (21.4)</td>
<td>22 (20.6)</td>
<td>12 (23.1)</td>
</tr>
<tr>
<td>Other</td>
<td>0.1 (1)</td>
<td>0</td>
<td>1 (1.9)</td>
</tr>
<tr>
<td></td>
<td>All (n=186)</td>
<td>Physicians (n=125)</td>
<td>Nurses and other allied health professionals (n=61)</td>
</tr>
<tr>
<td>--------------------------------</td>
<td>-------------</td>
<td>--------------------</td>
<td>---------------------------------------------------</td>
</tr>
<tr>
<td>Years in practice</td>
<td>16.7 ± 13.8</td>
<td>17.9 ± 13.0</td>
<td>14.7 ± 14.8</td>
</tr>
<tr>
<td>ACP skill high priority for learning (4/5 on 5 point scale)</td>
<td>53%</td>
<td>54%</td>
<td>52%</td>
</tr>
<tr>
<td>Extra palliative care certification or training</td>
<td>19%</td>
<td>19%</td>
<td>20%</td>
</tr>
</tbody>
</table>
Your Participation in Doing ACP with Patients

ARE YOU DOING THIS FOR PATIENTS >=50:

- a. Initiate discussions about ACP with patients
- b. Exchange information with patients
- c. Be a decision coach for patients
- d. Participate in finalization of the ACP plan
- e. Help patients communicate their ACP with their families
- f. Help patients communicate their ACP with other health care professionals

Average Scores

0 1 2 3 4 5 6

D

O

Physician

Other professionals

Overall

Not at all

All the time

Average Scores

CARENET
Canadian Association of Research at the End of Life Network

iGAP
Improving Advance Care Planning in General Practice
Your Willingness in Doing ACP with Patients

RATE YOUR WILLINGNESS TO:

a. Initiate discussions about ACP with patients

b. Exchange information with patients

c. Be a decision coach for patients

d. Participate in finalization of the ACP plan

e. Help patients communicate their ACP with their families

f. Help patients communicate their ACP with other health care professionals

CARENET
Canadian Association of Research
at the End of Life Network
Top Ten Barriers

**TOP 10 BARRIERS**

3a Insufficient time

3h Inability to electronically transfer patient's ACP

3c Decreased interaction with my patients due to transfer of care

2b Difficulty understanding the limitations and complications

2e Lack of understanding about how treatment decisions are made

2c ACP is not relevant to them

2h Incapacity of patient

2f Fear of upsetting their families

3b Limited capacity to honor patients’ expectations

3d Getting different messages from the GP and other specialists

Average Scores

- Not at all
- An extreme amount

<table>
<thead>
<tr>
<th>Questionnaire Items</th>
</tr>
</thead>
<tbody>
<tr>
<td>3a Insufficient time</td>
</tr>
<tr>
<td>3h Inability to electronically transfer patient's ACP</td>
</tr>
<tr>
<td>3c Decreased interaction with my patients due to transfer of care</td>
</tr>
<tr>
<td>2b Difficulty understanding the limitations and complications</td>
</tr>
<tr>
<td>2e Lack of understanding about how treatment decisions are made</td>
</tr>
<tr>
<td>2c ACP is not relevant to them</td>
</tr>
<tr>
<td>2h Incapacity of patient</td>
</tr>
<tr>
<td>2f Fear of upsetting their families</td>
</tr>
<tr>
<td>3b Limited capacity to honor patients’ expectations</td>
</tr>
<tr>
<td>3d Getting different messages from the GP and other specialists</td>
</tr>
</tbody>
</table>

**CARENET**

Canadian Association of Research at the End of Life Network
How Acceptable Is It For These Individuals To Initiate Discussions About ACP

INITIATING DISCUSSIONS ABOUT ACP

- 7a. Family physician
- 7b. Family Medicine Resident
- 7c. Medical Student
- 7d. Nurse
- 7e. Advance Practice Nurse
- 7f. Social worker
- 7g. Home care personnel

Questionnaire Items

Average Scores

Extremely unacceptable

Extremely acceptable

Physician
Other professionals
Overall

CARENET
Canadian Association of Research at the End of Life Network

i-GAP
IMPROVING ADVANCE CARE PLANNING IN GENERAL PRACTICE
How Acceptable Is It For These Individuals To Participate in The Finalization of The ACP Plans

- 10a. Family physician
- 10e. Advance Practice Nurse
- 10f. Social worker
- 10b. Family Medicine Resident
- 10g. Home care personnel
- 10d. Nurse
- 10c. Medical Student

PARTICIPATING IN THE FINALIZATION OF THE ACP PLANS

Average Scores

Extremely unacceptable
Extremely acceptable

CARENET
Canadian Association of Research at the End of Life Network

i-GAP
IMPROVING ADVANCE CARE PLANNING IN GENERAL PRACTICE
DECIDE Results– Physicians

- Physicians are confident (avg 4-5 of 6)
- ½ rate as high priority for learning
- Moderately willing to do it; but not doing it
- Willing to have other providers in primary care initiate it (e.g. nurses)
- Slightly less willing to have non-MD or nurse finalize the ACP
DECIDE Results – Other HCP

- Self rated assessment – Limited skill (non-expert)
- Priority for learning – similar to MDs
- Same willing to do it; but not doing it
- Less confident that MD
- Similar barriers but lack of time not so highly ranked; lack of knowledge of ACP higher
Stakeholder Meeting Recommendations

• Screening questions / tailored ACP engagement: Individual and group pathways; Cultural adaptation
• ACP prescribing: Patient engagement with take home ACP tools
• Capacitate MD and non-MD health care providers to do ACP
• ACP tool adaptation/combination to meet decision support needs
• Documentation solutions—electronic format (POLST-like form)
• Patient owns their ACP – Personal health record (PHR)
Speak Up! We’d love to hear from you

- @mhoward101 mhoward@mcmaster.ca
- @eolresearchers (Carenet) www.thecarenet.ca
- @advancercareplan (Speak Up)