Population-based strategies to enable advance care planning and improve goals of care conversations
Presenters:

- Dr. Michael McKenzie and Dr. Carole Robinson (Co-chairs), Canada
- Dr. Gillian Fyles, Canada
- Dr. Rebecca Sudore, USA
- Dr. Mike Rabow, USA
- Dr. Peter Kirkbride, UK
Aim of the Session

- Summarize the role effective goals of care conversations have on quality of care and quality of life
- Outline resources
- Describe initiatives to promote and improve goals of care conversations
- Discuss applicability in other settings, including developing countries
What is Advance Care Planning (ACP)?

“A process of reflection and communication in which a capable person makes decisions with respect to future health and/or personal care in the event that they become incapable of giving informed consent.

The process may involve discussions with health care providers and significant others with whom the person has a relationship.

ACP may result in the creation of an advance directive”

Dunbrack Health Canada ACP Glossary Project 2006
Outcomes of ACP

- Improves QOL
- Increases patient and family satisfaction with care
- Decreases caregiver burden and stress
- Increases compliance with patient wishes
- Better utilization of health care resources – i.e., ICU, ER, hospice usage etc.

(Brinkman-Stoppelenburg 2014, Bernacki 2014)
**Advance Care Planning Terminology**

**Advance Care Planning** = Planning in Advance of Serious Illness

**Serious Illness Care Conversation** = Planning in the context of progression of serious illness

**Goals of Care Discussion** = Decision making in context of clinical progression / crisis / poor prognosis
Communication about “Goals of Care in Serious Illness (GCSI)” (instead of ACP)

- Now thinking about these discussions this way - not just for EOL, also for decision-making thru-out course of a serious illness.

- Patients want us to raise these issues → may not know how to broach themselves and waiting for us to do so.

- Canadian and U.S. Cancer Care Guidelines recommend:
  - that ACP be initiated early in disease process
  - should be discussed with competent patients during outpatient visits
  - should be physician - initiated with multidisciplinary involvement

- We have provided resources to make these discussions easier to have and document for appropriate patients.
Implementing Advance Care Planning & Goals of Care Conversations in a Canadian Provincial Cancer Care Organization

- The British Columbia Cancer Agency’s mandate is to:
  - reduce the incidence of cancer, reduce the mortality rate of people with cancer, and improve the quality of life of people living with cancer
  - Population of BC is 4 million people
  - 18,528 new patients seen per year through 6 Regional Cancer Centres
Background

- Legislation 2011 legalizing advance directives; provincial initiatives mandating ACP; improved outcomes with ACP

- ACP Working Group with broad provincial representation

Initially:

- Developed Policy and Processes
- Education sessions across BCCA and an online mandatory ACP module
- Developed manuals with CHPCA:
  - “Cancer and ACP – Tips for Oncology Professionals
  - “Cancer and ACP - You’ve Been Diagnosed with Cancer – Now What?”
• **Train Clinicians** – Rounds, Pilots, Workshops, Manuals

• **ID Pts at Risk** – Surprise Question: would you be surprised if this pt died in the next year?

• “Trigger Conversations” in OPD – eg when initiating 2nd line chemo

• **Educate pts and families** – My Voice, PREPARE, CHPCA booklets

• **Use a checklist or Conversation Guide** – Ariadne Serious Illness Conversation Guide

• **Improve communication of critical info in Med Record** – paper and electronic locations – “Greensleeves”, Goals of Care Order Form and Discussion Records

• **Measure and Report Performance** – audits completed in 2015
Serious Illness Conversation Guide
a framework for best communication practices

Organized as 2 parts: Checklist + Language

**LEFT SIDE**
Clinician Steps
- Prompts essential steps
- Follow this intentional sequence

**RIGHT SIDE**
Conversation Guide
- Critical topics
- Proven language
- Pre-visit patient letter
- Family Comm’n Guide

### Serious Illness Conversation Guide

<table>
<thead>
<tr>
<th>CONVERSATION FLOW</th>
<th>PATIENT-TESTED LANGUAGE</th>
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| 1. Set up the conversation  
Introduce the idea and benefits
Ask permission | “I’m hoping we can talk about where things are with your illness and where they might be going — is this okay?” |
| 2. Assess illness understanding and information preferences | “What is your understanding now of where you are with your illness?” |
| 3. Share prognosis  
Tailor information to patient preference
Allow silence, explore emotion | “How much information about what is likely to be ahead with your illness would you like from me?” |
| 4. Explore key topics  
Goals  
Fears and worries  
Sources of strength  
Critical abilities  
Tradeoffs  
Family | Prognosis: “I’m worried that time may be short.”  
or “This may be as strong as you feel.” |
| 5. Close the conversation  
Summarize what you’ve heard
Make a recommendation
Affirm your commitment to the patient | “What are your most important goals if your health situation worsens?”  
“What are your biggest fears and worries about the future with your health?”  
“What gives you strength as you think about the future with your illness?”  
“What abilities are so critical to your life that you can’t imagine living without them?”  
“If you become sicker, how much are you willing to go through for the possibility of gaining more time?”  
“How much does your family know about your priorities and wishes?” |
| 6. Document your conversation | “It sounds like _______ is very important to you.”  
“Given your goals and priorities and what we know about your illness at this stage, I recommend…”  
“We’re in this together.” |
In Summary - Provided:

- Policy, Procedures and Standard Operating Procedures for each Centre/FAQs
- Launch of forms and resources late April 2015 including Prognostication Tool, GCSI Guide
- Booklets and other resources for HCPs and Pts/Families
- Multiple education opportunities for HCPs
- GOC Order Form and Discussion Record
- Electronic Medical Record Documentation
British Columbia Cancer Agency
Contacts and Resources

Contacts:
- Michael McKenzie mmckenzi@bccancer.bc.ca
- Gillian Fyles gfyles@bccancer.bc.ca
- Carole Robinson carole.robinson@ubc.ca

Resources:
- http://www.bccancer.bc.ca/health-professionals/professional-resources/advance-care-planning
- https://www.ariadnelabs.org/areas-of-work/serious-illness-care/
Implementing Serious Illness Conversations in the UK

Dr Peter Kirkbride
Medical Director
Clatterbridge Cancer Centre
England

One-year pilot funded by NHS England
To improve the lives and personalise the care of all people with serious illness through meaningful conversations with their clinicians about their goals and priorities.

Better Conversations – Better Care
Goals for Serious Illness Care Programme (UK)

**Goal 1**
Sufficient numbers of clinicians use the Serious Illness Conversation Guide with their seriously ill patients

**Goal 2**
Clinics have a system of evaluation and continuous improvement in serious illness conversations and care

**Goal 3**
Patients, families, and care teams are engaged in the conversation and care planning process
The Serious Illness Care Programme UK

Tools

- Serious Illness Conversation Guide
- Clinician Reference Guide
- Patient Preparation Materials
- Family Communication Guide

Education

- Training Master Trainers
  - Course 101
  - Course 201
- Train Clinicians
  - Primary Clinician Training (1 day)
- Coaching

Train-the-Trainer

- Course 101
- Course 201

Systems Change

- Patient Identification
- Reminder System
- Conversation using the Guide
- Document Conversation
- Patient & Family Support

Measurement and Improvement (QI)
Evaluation of Programme

Clinician Training:
- Number of Clinicians trained
- Evaluation of the Training Day

Patient Screening
- Number of patients screened each month
- Number of patients identified as high risk
- Number of conversations taking place
- Number of patients who decline a conversation

Documentation
- Date patient identified as high risk
- Date of initial conversation or conversation declined
- Date conversation recorded in HER
- Date of follow-up conversations
- Date of death

Patient Evaluation
- Patient survey after each conversation
Documenting the Conversation
Clatterbridge Cancer Centre

Answer text here

What’s Important: Live as long as possible no matter what, Not be a burden
Question 5: What are your biggest fears and worries about the future with your health?
Answer 5: Answer text here

Fears/Worries: Pain, Finances, Being a burden
Question 6: What gives you strength as you think about the future with your illness?
Answer 6: Answer text here

Sources of strength: Family (this is a group response comment text)
Question 7: What abilities are so critical to your life that you cannot imagine living without them?
Answer 7: Answer text here

Unacceptable functions: Being unconscious, Ability to eat
Question 8: If you become sicker, how much are you willing to go through for the possibility of gaining more time?
Answer 8: Answer text here

Question 9: How much does your family know about your priorities and wishes?
Answer 9: Answer text here

Family: Family attend and are involved
Additional Information: additional information text here
Clinical Suggestion for Management: clinical management text here
Follow Up: follow up text here

Yours Sincerely

Peter Robson
Value of Research for Service Improvement Interventions

• All interventions may have benefits and harms, some of which are predictable, others less so.

• Designing and carrying out robust research is imperative to identify unintended/expected benefits and harms, whilst supporting ongoing development and implementation.

• Particularly for ‘systems wide’ multi component interventions, research prior to wider roll out is essential, in order to:
  • identify key components of the intervention;
  • explore contextual factors important for implementation.¹

¹ Sleeman K and Higginson IJ, 2016 - http://spcare.bmj.com/content/early/2016/09/16/bmjspcare-2015-001059/reply#bmjspcare_el_679
Serious Illness Care Programme UK
National Research Programme

The National Research Programme is led by Clatterbridge Cancer Centre and the Marie Curie Palliative Care Institute Liverpool, in collaboration with Ariadne Labs, Boston.

Research 1: Pre pilot-implementation (completed):
• ‘Face Validity’ of the Serious Illness Conversation Guide:
  • refined guide; format suitable for use in the UK.

Research 2: Pilot-implementation (underway):
• Feasibility study, at Clatterbridge Cancer Centre:
  • study methodology; recruitment; outcome measures

Research 3: Post pilot-implementation (in development)
• Pilot Cluster RCT:
  • programme efficacy; develop evidence base; support wider implementation.
Our Mission
To improve the lives and personalise the care of all people with serious illness through meaningful conversations about their goals and priorities.

The Serious Illness Care Programme UK aims to transform the patient experience and enhance clinical care and support for people with serious illnesses. It is a partnership led by The Clatterbridge Cancer Centre NHS Foundation Trust, with Marie Care Palliative Care Institute Liverpool and Ariadne Labs, Boston USA.

Meet The Team
The Programme is a partnership led by The Clatterbridge Cancer Centre NHS Foundation Trust, with Marie Care Palliative Care Institute Liverpool and Ariadne Labs.

Training
Only well-trained, competent and confident staff can bring professionalism, compassion and skill to the most difficult and intensely
Contact details:

Dr Peter Kirkbride, Clatterbridge Cancer Centre, Bebington, Wirral, CH63 4JY, England

peter.kirkbride@nhs.net

www.betterconversations.org.uk
Advance Care Planning in California

Michael W. Rabow, MD

Director, Symptom Management Service
Helen Diller Family Comprehensive Cancer Center
Helen Diller Family Chair in Palliative Care
Professor of Clinical Medicine and Urology
University of California, San Francisco
USA
California ACP

- 12% of the serious illness & dying in the US
- Key players in statewide change:
  - Private Foundations
  - University of California
  - MediCal
  - CA Department of Public Health
Funders and Support

- California HealthCare Foundation
  - Support for SB1004
- Stupski Foundation
  - Funding for palliative care across California
- Coalition of Compassionate Care of California
  - ACP training and 27 POLST coalitions
- University of California
  - Tie leader bonuses to rate of completion of ADs
MediCal and PRIME

- Government health insurance for the poor
- Elective project in palliative care
- Primary Care patients w/ Cancer, COPD, HF
- Pay for reporting / performance
  - ACP or surrogate discussion-maker
  - Preferences for life-sustaining treatment (code status), AD, or POLST
- Many institutions making universal changes
SB1004

- California law for Managed MediCal plans
- Requires the provision of palliative care to patients with CA, COPD, HF, Liver Disease
- Details still being developed
- ACP, case management are expected to be central
An Online Advance Care Planning Tool

Rebecca L. Sudore, MD
Associate Professor of Medicine, UCSF
Easy-to-read Advance Directive RCT

- Overwhelming preferred regardless of literacy level
- 6-mo. completion rates doubled

FREE
10 languages

http://www.iha4health.org/our-services/advance-directive/

California Advance Health Care Directive

This form lets you have a say about how you want to be treated if you get very sick.

This form has 3 parts. It lets you:

**Part 1:** Choose a medical decision maker.
A medical decision maker is a person who can make health care decisions for you if you are too sick to make them yourself.

**Part 2:** Make your own health care choices.
This form lets you choose the kind of health care you want.
This way, those who care for you will not have to guess what you want if you are too sick to tell them yourself.

**Part 3:** Sign the form.
It must be signed before it can be used.

You can fill out Part 1, Part 2, or both.
Fill out only the parts you want. Always sign the form in Part 3.
2 witnesses need to sign on page 11 or a notary public on page 12.

Your Name: ____________________________

1
“We got the DNR in writing. But in making the decisions, which there were many, that was just one. Because the first decision was to put him in a nursing home. We were married 30 years and I could no longer take care of him (tearful). Then the second decision was whether to put him on a feeding tube because he had stopped eating and I wasn’t ready to let him go.”

Sudore RL et. al., J Pain and Symptom Management, 2012
Redefining the “Planning” in Advance Care Planning: Preparing for End-of-Life Decision Making

Rebecca L. Sudore, MD, and Terri R. Fried, MD
Welcome to PREPARE!

PREPARE is a program that can help you:

- make medical decisions for yourself and others
- talk with your doctors
- get the medical care that is right for you

You can view this website with your friends and family.

Click the NEXT button to move on.
Welcome

View the PREPARE Pamphlet

1. Choose a Medical Decision Maker

2. Decide What Matters Most In Life

3. Choose Flexibility for Your Decision Maker

4. Tell Others About Your Wishes

5. Ask Doctors the Right Questions

Your Action Plan
Creating PREPARE

- Expert panel
  - Health Literacy
  - Geriatrics & Palliative Care
  - Behavior change

- 13 focus groups*
  - Patients, surrogates

- Cognitive interviews

- Videos that model behavior: HOW

* Sudore RL et. al., J Pain and Symptom Management, 2012
Creating PREPARE

- Easy to understand
  - 5th-grade reading level, large font
  - Voice-overs & closed captioning

- Balanced content of videos:
  - Race/ethnicity, gender
  - Aggressive vs. comfort care
  - Surrogate availability
  - Decision making preferences

* Sudore RL et. al., J Pain and Symptom Management, 2012
Step 1: Choose a Medical Decision Maker

- Why this is important
- What you need to do
- How to do it - how to say it

Step 2
Step 3
Step 4
Step 5
Action Plan

Click the NEXT button to move on.
How to Ask Someone to Be Your Decision Maker

You can watch this video with your friends and family.
How to Ask Someone to be Your Decision Maker

How to say it:

"My doctor thinks it is important to choose someone to help make medical decisions for me in case I get sick in the future and cannot make my own decisions. If this happens, would you be willing to work with my doctors to help make medical decisions for me?"

This is one example. Your situation may be different.
Choosing a decision maker can be hard.

Here are some examples of how other people made it easier.
Click the pictures to see their stories.

For **Jorge**, thinking about it was scary

**Helen** would rather leave her health to prayer

Click the NEXT button to move on.
How To Tell Others About Your Wishes
How to Ask Questions

How To Ask Doctors the Right Questions
Summary of My Wishes

Talk to your doctor about your medical wishes.
You will do this by July 30.

Summary of All Steps

Step 1: Choose a Medical Decision maker
- You have chosen and asked John Doe (your spouse/partner) to be your decision maker.
- You want John Doe to make medical decisions for you only if you cannot make your own decisions.

Step 2: Decide What Matters Most in Life
- What is most important to you are: family and friends, religion, living on your own and caring for yourself, not being a burden on your family.
- You feel that there may be some health situations that would make your life not worth living, such as never being able to wake up from a coma.
- You want to try treatments for a period of time, but stop if you are suffering.

Step 3: Choose Flexibility for Your Decision Maker
- You chose TOTAL flexibility in medical decision making for your decision maker.

Step 4: Tell Others About Your Wishes
- You have close family and friends who may have strong opinions about your medical care.
- You told your decision maker about your wishes. But you have not yet told your doctor and family and friends.

Step 5: Ask Doctors the Right Questions
- When making decisions with your doctor, you want to share decision making with your doctor.
- When making decisions with your family and friends, you want your family and friends to make all medical decisions for you.
- You WOULD want your doctor to tell you how sick you are or how long you have to live.
For Your Medical Provider

Goals of Care Information: This document reflects preferences your patient chose on the advance care planning website called PREPARE (www.prepaforyourcare.org). This is not a legal document.

SURROGATE DECISION MAKER

Who is the surrogate:

John Doe (your spouse/partner)

When surrogate is to make decisions:

- [x] I ONLY want someone to make medical decisions for me if I become too sick to make my own decisions.
- [ ] I want someone else to make medical decisions for me now, EVEN when I can make my own decisions.
- [ ] I am not sure.

Flexibility or leeway for the surrogate: Meaning permission to change prior medical decisions.

- [x] TOTAL FLEXIBILITY: It is OK for your decision maker to change any of your prior medical decisions if the doctors think it is best for you at that time.
- [ ] SOME FLEXIBILITY: It is OK for your decision maker to change some of your medical decisions. But, some decisions you NEVER want changed, even if the doctors recommend it.
- [ ] NO FLEXIBILITY: Your decision maker must follow all of your medical wishes exactly, no matter what. It is NOT OK to change your decisions, even if the doctors recommend it.
- [ ] I am not sure
To help you fill out advance directive forms

Your Name: ________________________________

Medical Decision Maker

Some forms call a medical decision maker by different names:
- a health care proxy
- or, a durable power of attorney for health care
- or, a surrogate decision maker

You chose John Doe to be your decision maker.
You would write his or her name on that part of the form.

Some forms ask about when you want your decision maker to make decisions for you.

You chose that you want your decision maker to make medical decisions for you ONLY if you cannot make your own decisions.

Some forms ask about flexibility for your decision maker. On some forms, flexibility is called leeway.

You chose that your decision maker can have flexibility when making medical decisions for you.

Health Care Wishes

Some forms ask about treatments that are used to try to keep people alive, such as CPR or a breathing machine.

You chose wanting to try treatments for a period of time, but stop if you are suffering.
People who agree with this often mark down that they would be willing to try CPR and/or a breathing machine, but only for a little while.
Talk to your doctor about the options that may be right for you.
PREPARE Improves Patient Engagement in ACP

- Senior centers, 70 years, 92% never used a computer

Confidential & Proprietary © 2015 UCSF All Rights Reserved

Patient-facing ONLY Trial: 410 Veterans
PREPARE Increases ACP Documentation

- 1% at 6 months before baseline
- 25% at Easy-to-Read AD
- 35% at AD + PREPARE

*p = .004
Gordon & Betty Moore Funding

Palliative and End-of-Life Care Exploration

California Advance Health Care Directive

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It must be signed before it can be used.

You can fill out Part 1, Part 2, or both.
Fill out only the parts you want. Always sign the form in Part 3.
2 witnesses need to sign on page 11 or a notary public on page 12.

Your Name: ____________________________
PREPARE as a Movie

**Toolkits** for creating group visits and movie events for libraries, churches, senior centers
Current Technology

- Easy-to-use, patient-centered, English & Spanish
- Responsive platform, o/s clinical environment
- Guide to complete advance directives
- Tangible values summaries + advance directives
  - Ongoing discussions & documentation
Tailored & Flexible

Capacity for:
- White labeling
- Data reporting for consumers

Use in clinical environments
- Prescription of steps
- Email or patient portal
- "Movie" version → group settings