Health and Legal Sector Collaboration to Support Advance Care Planning

Workshop Goals

- Understand health-legal barriers and enablers to ACP at individual, organizational and system levels
- Explain the benefits of health-legal collaboration and community action approaches to promote ACP
- Choose strategies to improve the quality and effectiveness of ACP that align with client preferences, professional roles and community aspirations

Chairs: Nola Ries and Elizabeth Tobin-Tyler

Along with: Amy Waller and Bernadette Richards

What we've heard about the law so far

- Legal frameworks that enable ACP
- Confusion and worry about the law
- Some documents are not clinically useful

Many people who have a written directive are most likely to have had help from:

a) Doctor
b) Other healthcare provider
c) Lawyer
d) Family member or friend

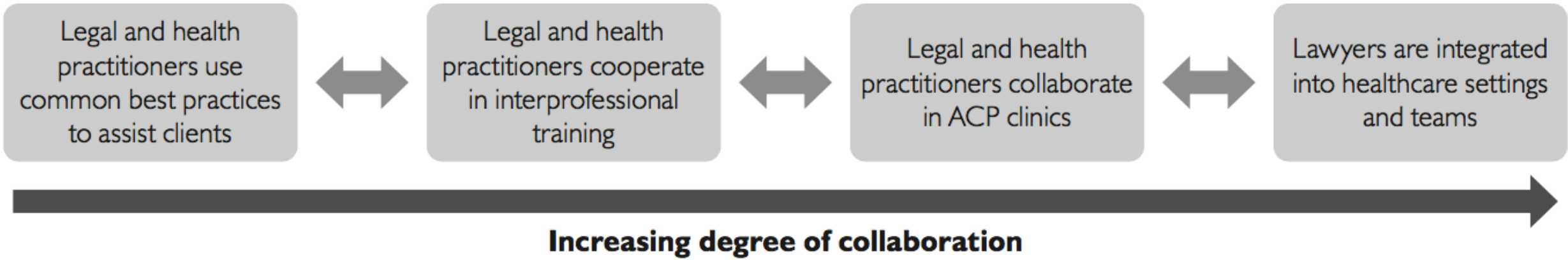
See: NM Ries. Lawyers and Advance Care and End-of-Life Planning: Enhancing Collaboration between Legal and Health Professions. *Journal of Law and Medicine* 2016;23: 887-906

Key Findings - Alberta Survey

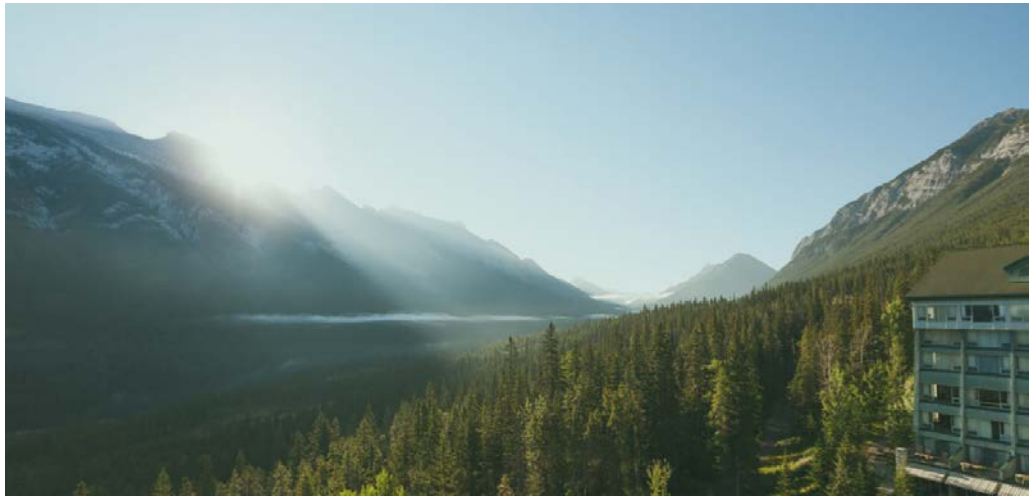
- Significant part of professional role
- Main barrier is client lack of readiness
- But siloes

See: NM Ries, M Douglas, J Simon & K Fassbender. How Do Lawyers Assist Their Clients with Advance Care Planning? Findings from a Cross-Sectional Survey of Lawyers in Alberta, Canada. *Alberta Law Review* 2018;55(3).

FIGURE 1. Framework for health–legal collaboration



See: NM Ries, M Douglas, J Simon & K Fassbender. Doctors, Lawyers and Advance Care Planning: Time for Innovation to Work Together to Meet Client Needs. *Healthcare Policy* 2016;12(2):12-18.



The Medical-Legal Partnership Approach for Integrating Lawyers into Health Care Teams

Liz Tobin-Tyler, JD, MA
Assistant Professor of Family Medicine &
Health Services, Policy and Practice
Senior Advisor, National Center for Medical-Legal Partnership

International Society of Advance Care Planning and End of Life Care
September 8, 2017

What is Medical-Legal Partnership?

Medical-legal partnership embeds lawyers alongside health care teams to improve both individual and population health.

Making the connection:

Legal problems are health problems

Common Civil Legal Problem	Social Determinant of Health
Families wrongfully denied food supports or housing subsidies	Lack of basic resources
Children living in housing with mold or rodents, in violation of housing laws	Physical environment
Seniors wrongfully denied long-term care coverage	Lack of access to insurance

Civil Legal Issues and Health

Civil legal aid helps people solve legal problems of every day life

Legal Needs That Impact Health (I-HELP Model)

Income & Insurance

- Insurance access & benefits
- Food stamps
- Disability benefits
- Social Security benefits
- Debt relief

Housing & energy

- Shelter access
- Access to housing
- Sanitary housing conditions
- Utilities access

Education & Employment

- Americans with Disabilities Act compliance
- Discrimination
- Individuals with Disabilities in Education Act compliance
- Unlawful termination

Legal Status

- Immigration asylum, Violence Against Women Act)
- Criminal record issues

Personal & family stability

- Guardianship, custody, divorce
- Domestic violence
- Child abuse & neglect
- Advance directives, estate planning

PARTNERSHIPS ACROSS THE U.S.

Hundreds of the nation's leading health care organizations have adopted legal services as part of their approach to improving the health of children, elderly individuals, Native Americans, veterans, and people with chronic illnesses. See below for organizations currently engaged in medical-legal partnership activities.

155	139	34	126	52	64
Hospitals	Health Centers	Health Schools	Legal Aid Agencies	Law Schools	Pro Bono Partners

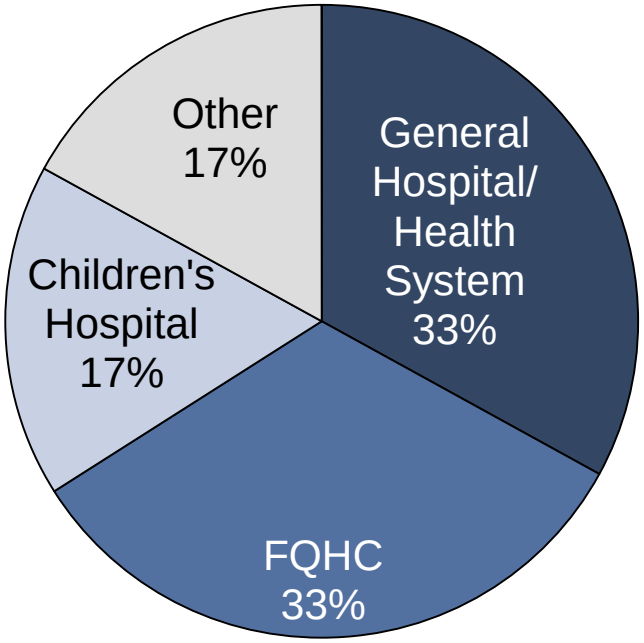
Find MLP Partnerships in your state

See which health care and legal organizations in your community participate in medical-legal partnerships.

STATE SELECT

Reset

MLP Health Care Partners by Organization Type



Notes: n=129.
Source: 2016 NCMLP Survey.

The medical-legal partnership approach

Individual patient interventions are pathways to finding policy interventions for improving population health.

Medical-Legal Partnership continuum

Referral Network	→	Joint Training & On-Site Legal Care	→	Full Persons-to-Populations MLP
Referral to legal aid can address health need, but capacity limited		Ability to detect problems upstream = more capacity & better health outcomes		Detect patterns, treat at population level with policy solutions

How MLPs differ from referrals

- Work onsite and participate in clinical meetings
- Establish formal screening processes of patients' health-harming social needs
- Share data and communicate about patient-clients
- Detect and address patterns of systemic need

MLP: Measuring Impact

Studies show that when legal problems are addressed:

People with chronic illnesses are admitted to the hospital less frequently.
Studies showed that legal assistance targeted at improving housing conditions improved the health of asthma patients (*Journal of Asthma* and *Journal of Health Care for the Poor and Underserved*), and another study showed medical-legal partnership's positive impact on the health of sickle cell patients (*Pediatrics*).

People more commonly take their medications as prescribed.
(*Journal of Health Care for the Poor and Underserved* and *Journal of Clinical Oncology*)

People report less stress.
(*Journal of Health Care for the Poor and Underserved*).

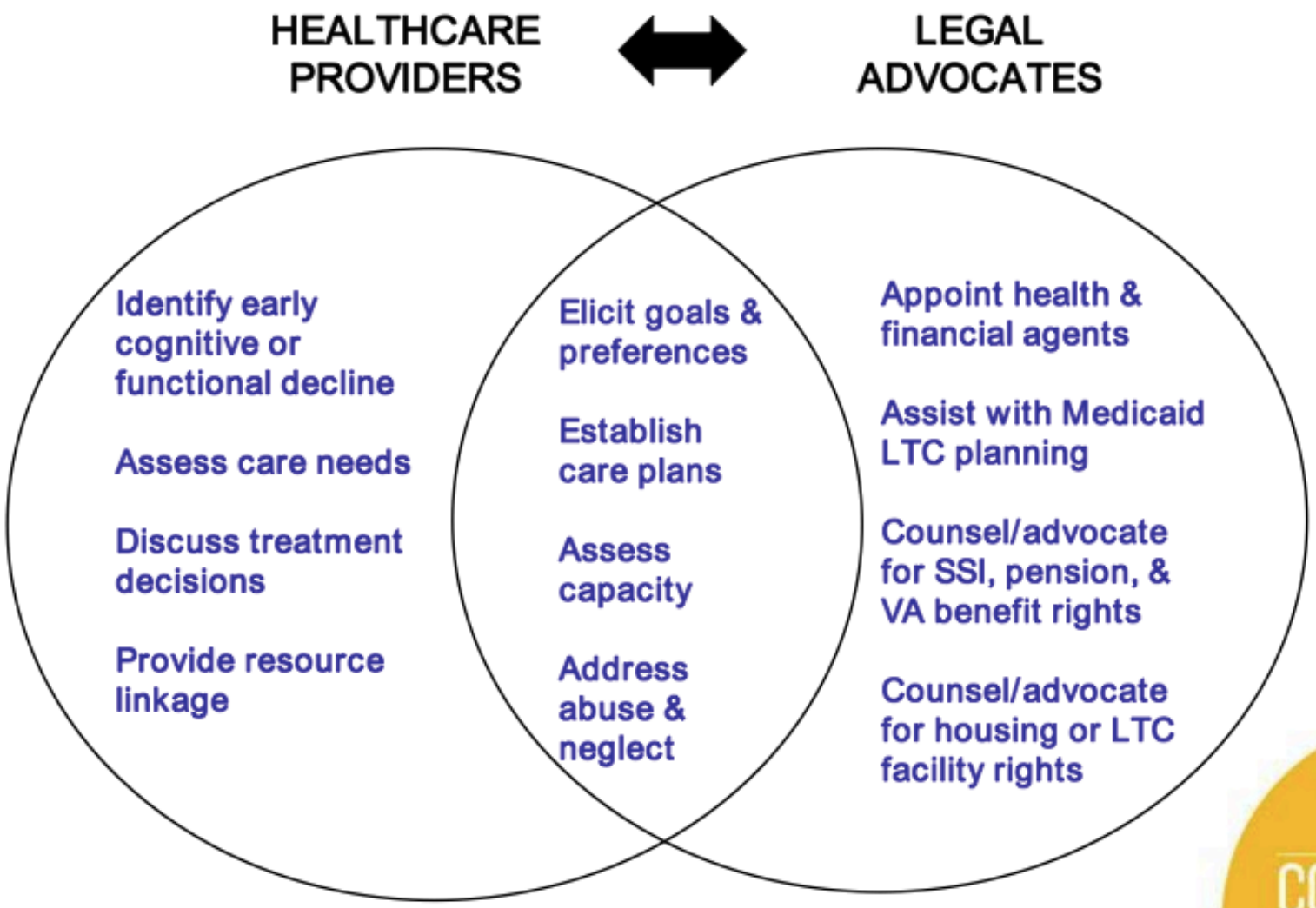
Less money is spent on health care services for the people who would otherwise frequently go to the hospital.
One study showed that medical-legal partnership services reduces health care spending on high-need, high-use patients (*Health Affairs*).

Clinical services are more frequently reimbursed by public and private payers.
Medical-legal partnerships have been shown to save patients health care costs and recover cash benefits (*Journal of Health Care for the Poor and Underserved* and *Journal of Palliative Medicine*).

MLP and Advance Care Planning

Models from Geriatric Care & Palliative Care

MLPs Can Provide Safe, Comprehensive Upstream Planning



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UCSF UC HASTINGS
CONSORTIUM
ON LAW, SCIENCE & HEALTH POLICY

Features of Comprehensive ACP in MLPS

- ➔ Incapacity/disability planning, not just death planning
- ➔ Clarifying goals and needs, then optimizing resources that support care plan
- ➔ Not a document mill: time-intensive approach
- ➔ Prevention-oriented: reduce risk of eviction, abuse, conservatorship

About the SF Medical-Legal Partnership for Seniors

- Established 2012
- Legal partners:

  UC Hastings law faculty and students

  Pro bono partners at Manatt, Phelps, & Phillips
- Medical partners:

  UCSF Center for Geriatric Care

  San Francisco VA Medical Center (new)
- Target population: low-income older adults (up to 400% poverty)
- Patient/clients seen in clinics or at home

SLC

SeniorLAW Center

Protecting the Rights of Older Pennsylvanians

HELP SUPPORT ELDER JUSTICE!

SeniorLAW Center's MLP for LIFE, a Medical-Legal Partnership with Mercy LIFE

SeniorLAW Center is pleased to announce its first Medical-Legal Partnership (MLP), our newest method of bringing legal services to seniors in the communities where they live. SeniorLAW Center is partnering with Mercy LIFE, a "Living Independently for Elders" program of all-inclusive care for the elderly which provides medical and social services – and now legal services — to nursing home-eligible seniors, enabling them to age in their own homes and communities. Since March 2016, SeniorLAW Center's Skadden Aarps Public Interest Fellow Kristen Valosky, Esq. has been onsite to perform intake and provide free legal assistance to Mercy LIFE participants at their adult day center in South Philadelphia. By collaborating with Mercy LIFE, we will address civil legal needs which may adversely affect the health of vulnerable seniors with a goal of enhancing their quality of life. Medical-legal partnerships embed legal professionals alongside health care teams to detect, address and prevent health-harming social conditions for people and communities. According to The National Center on Medical-Legal Partnerships at George Washington University

Medical-Legal Partnership & Palliative Care

Nebraska Medical-Legal Partnership:
Nebraska Medical Center Oncology & Nebraska Legal Aid

Predominant legal issues:

- ACP: health care proxies, powers of attorney, wills
- Permanency or custody planning and guardianships
- Benefits advocacy (disability, insurance or food assistance)
- Housing

New hospital program offers cancer patients legal help

by Andrea McMaster, The Nebraska Medical Center | September 02, 2009

The last thing that a hospitalized patient who is battling serious cancer needs is a thorny legal problem.
Thanks to a unique medical-legal partnership between Legal Aid of Nebraska and The Nebraska Medical Center, a legal problem, in fact, is the last thing many cancer patients will have to stew about.

Kerry Rodabaugh, M.D.

The partnership was the brainchild of Kerry Rodabaugh, M.D., associate professor in obstetrics-gynecology for UNMC and a gynecological oncologist at The Nebraska Medical Center who moved to Omaha after practicing in Buffalo, N.Y.

"I found myself taking care of women with recurrrent cervical cancer, and when it's recurrent, it's usually terminal," Dr. Rodabaugh said. "Many of these women were single parents with young children and had no legal arrangements in place for the children."

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MLP & Palliative Care: Measuring Impact

A Medical–Legal Partnership as a Component of a Palliative Care Model

Kerry J. Rodabaugh, M.D.,[1] Maureen Hammond, M.S.W.,[2]
Dawn Myszka, Esq.,[3] and Megan Sandel, M.D., M.P.H.[4]

Abstract

Introduction: A medical–legal partnership (MLP) incorporated as part of a comprehensive palliative care model addresses unmet social and material needs for patients. This study retrospectively reviews the experience of one MLP and quantifies the benefits of the program for both patients and the host health care institution.
Methods: The Legal Services Program, an MLP, reviewed their program referral and outcomes from April 1, 2004 to December 31, 2007 to document legal needs resolved. The patient accounts manager in the host health care institution reported on the revenue reimbursed to date on a subset of benefits advocacy cases.
Results: The Legal Services Program received 297 referrals from April 1, 2004 to December 31, 2007 and resolved multiple legal issues. Seventeen benefits advocacy cases successfully overturned benefit denials, with the institution receiving $923,188 for current and past health services rendered. Two patient–client case studies are described in-depth.

MLP & ACP: Research Opportunities

Patients and Families:

- Treatment conforms with patient preferences
- Patient & family satisfaction with ACP process (quality patient-centered care)

Systems:

- Reduced legal barriers or challenges
- Reduce health care costs

- Other ideas?

More information & contact

www.medical-legalpartnership.org

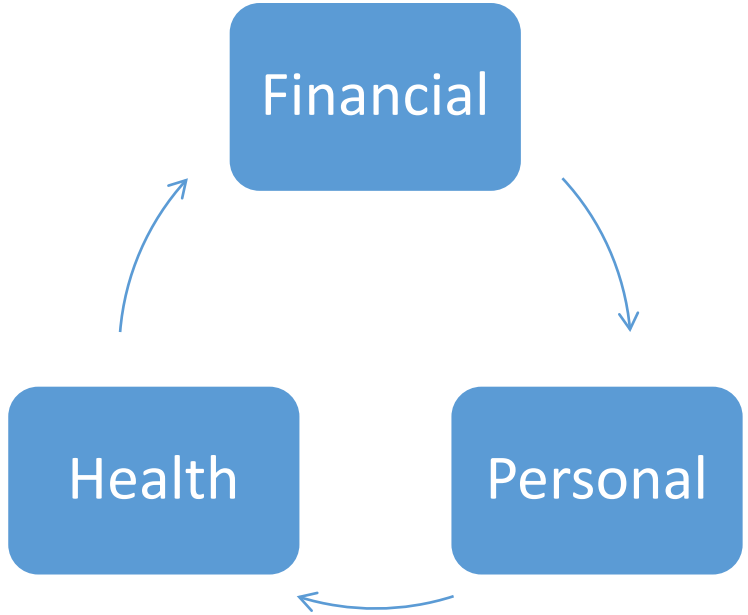
NCMLP

National_MLP

- Elizabeth Tobin-Tyler: elizabeth_tobin-tyler@brown.edu

Increasing advance personal planning: The need for action at the community level

- Few engage in the full range of APP activities
- More likely to prepare financial instruments
- ACD ownership is low and variable
- Appointment SDMs occurs infrequently



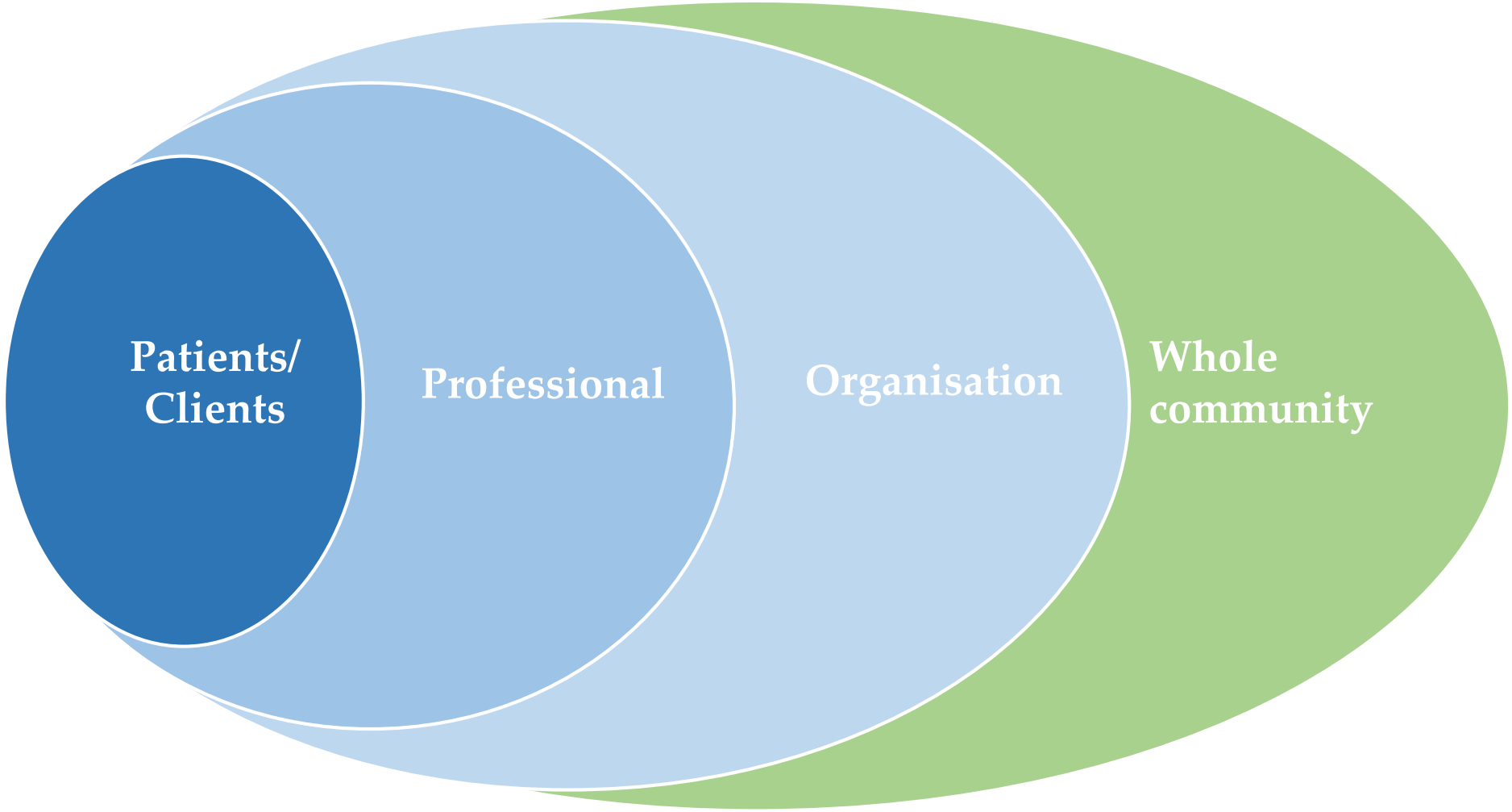
- First conversation typically delayed until imminently dying or admission

Mack et al JCO 2012, White et al MJA 2014; Aw QJM 2012; Silveira NEJM 2010; Rao et al Prev Med 2014; Texeira et al BMJ PSC 2015; Wilson JPC 2013; Jeong et al, JCN 2015.

Challenges of delayed APP

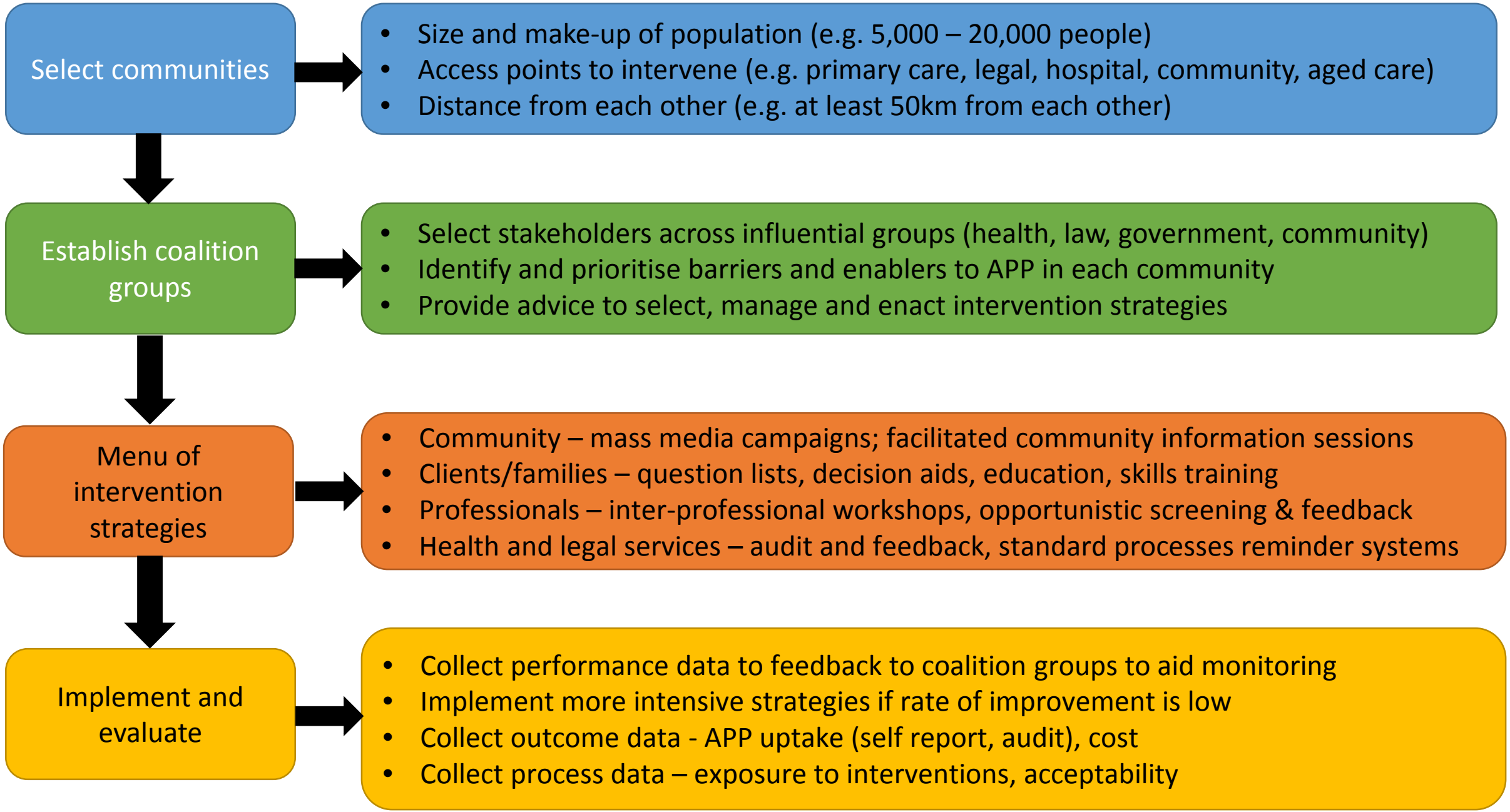
- Patient decision-making capacity may be lacking
- SDMs - not appointed, unaware of patient wishes or unavailable
- Limited time, skills or knowledge of health professionals
- Limited opportunity for inter-professional collaboration
- Underserved, vulnerable groups may miss out
- Sustainability is challenging

Reaching a broader audience in a more timely manner: a ‘whole community’ approach



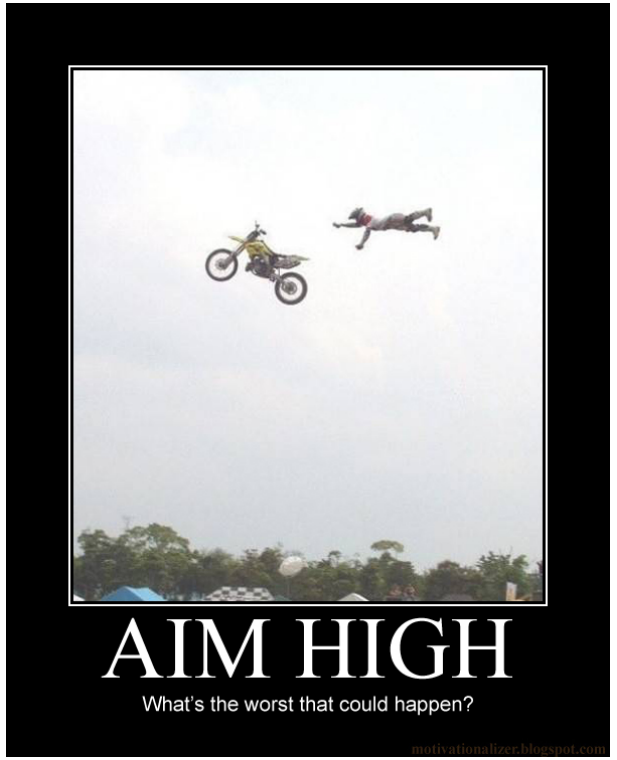
What is ‘community action’?

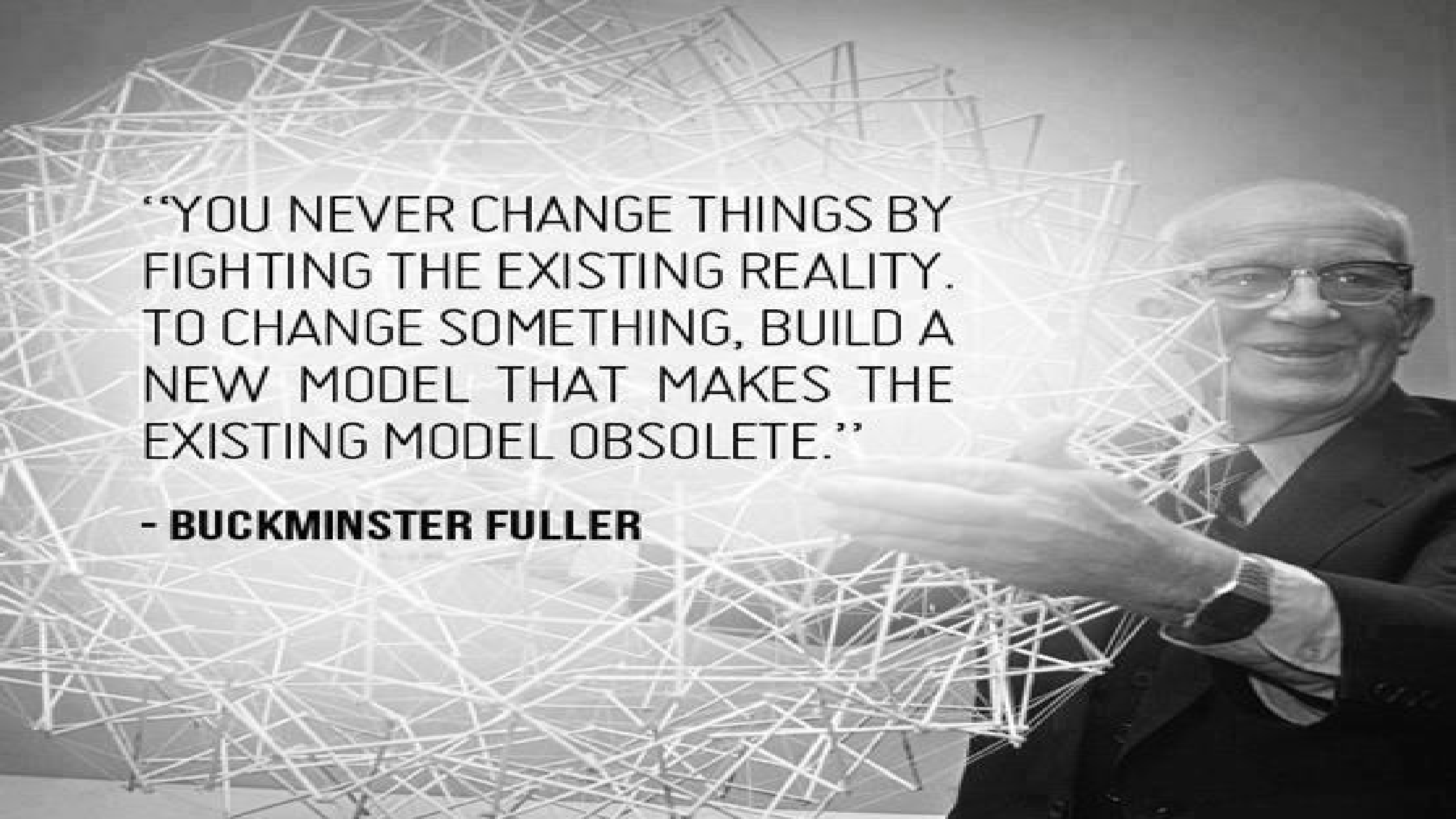
- Multiple evidence-based strategies implemented across settings
- Members collaborate via a coalition to create and implement strategies
- Communities choose which strategies to implement
- Community participation is integral to success
- Designed to build capacity within communities


Select communities
• Size and make-up of population (e.g. 5,000 – 20,000 people)
• Access points to intervene (e.g. primary care, legal, hospital, community, aged care)
• Distance from each other (e.g. at least 50km from each other)
Establish coalition groups
• Select stakeholders across influential groups (health, law, government, community)
• Identify and prioritise barriers and enablers to APP in each community
• Provide advice to select, manage and enact intervention strategies
Menu of intervention strategies
• Community – mass media campaigns; facilitated community information sessions
• Clients/families – question lists, decision aids, education, skills training
• Professionals – inter-professional workshops, opportunistic screening & feedback
• Health and legal services – audit and feedback, standard processes reminder systems
Implement and evaluate
• Collect performance data to feedback to coalition groups to aid monitoring
• Implement more intensive strategies if rate of improvement is low
• Collect outcome data - APP uptake (self report, audit), cost
• Collect process data – exposure to interventions, acceptability

Why community action for APP….

- Recognises barriers to APP are multi-factorial
- Choice can enhance generalisability, adherence and buy-in
- Bridge service provision to meet social, economic and health needs
- Demonstrates principles of equity and access
- Establish ‘demonstration models’ which can be observed and replicated




"YOU NEVER CHANGE THINGS BY FIGHTING THE EXISTING REALITY. TO CHANGE SOMETHING, BUILD A NEW MODEL THAT MAKES THE EXISTING MODEL OBSOLETE."
- BUCKMINSTER FULLER

CRICOS PROVIDER 00123M

ADVANCE CARE PLANNING
TOGETHER

ADVANCE CARE PLANNING: Can on size fit all?

Investigating the inclusion of vulnerable populations in Advance Care Planning: Developing complex and sensitive public policy, APP1133407 Partnership Project

adelaide.edu.au

seekLIGHT

- National Framework
- South Australian Legislation (*Advance Care Directives Act 2013* (SA)
- Vulnerable Voices Pilot Study

Background to the project

Improving Care at the End of Life: Our Roles and Responsibilities

- Only 17% of physicians believed that most of the time, doctors know the patients' preference for end-of-life care, and

- Approximately 1/3 indicated that they had observed, at least once a week, treatment being provided to patients that was inconsistent with the patients' wishes.

Let’s talk about death and dying….

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The National Framework

Guiding Principles

ADVANCE CARE PLANNING
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- Greater use of advance care planning will assist the community to **recognise the limits of modern medicine** and the role of health-promoting palliative care

- **Mutual recognition** of Advance Care Directives across all states and territories will be facilitated through harmonisation of formats and terminology

- **Growing numbers of Australians will contemplate their future potential loss of decision-making capacity,** and will appreciate the benefits of planning where and how they will live and be cared for, and of communicating their future life and care choices in advance.

- Advance Care Directives **will be well established across Australia** as a means of ensuring that a person's preferences can be known and respected after the loss of decision-making capacity

Guiding Principles

- Decisions by **substitute decision-makers** chosen and appointed under Advance Care Directives will be respected and will reflect the preferences of the person

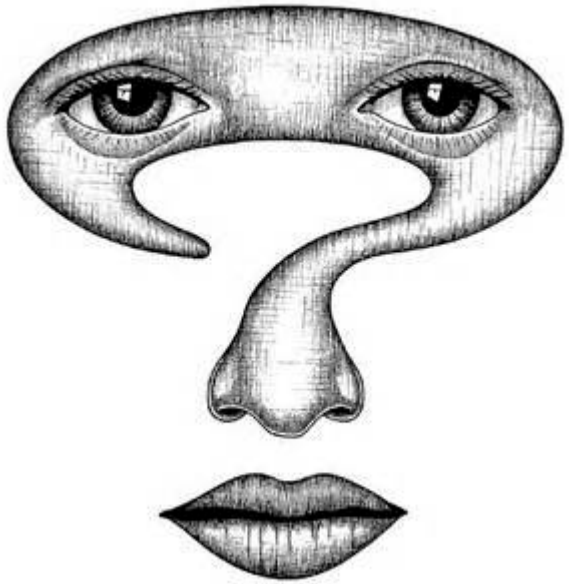
- Advance Care Directives will be **readily recognised and acted upon with confidence** by health and aged care professionals, and will be part of routine practice in health, institutional and aged care settings

- **Clinical care and treatment plans** written by health care professionals will be **consistent with the person's expressed values and preferred outcomes** of care as recorded in the Advance Care Directive

In short:

- realistic end of life objectives,
- engagement with the process of advance care planning,
- consistency,
- authority and,
- the recognition of preferences and values

What is autonomy?



What is an advance care directive (ACD)?

ACDs can record a person's values, life goals and preferred outcomes, or directions about care and treatment refusals and can formally appoint a SDM – or a combination of these

Autonomy & the Framework

Autonomy can be exercised in different ways according to the person's culture, background, history or spiritual and religious beliefs and this specifically includes an exercise of autonomy by self-determined decisions, delegating decisions to others, making collaborative decision.

Autonomy is valued differently by different people depending upon their cultural, spiritual and religious beliefs or background. It should be recognised that as well as inter-cultural diversity there will also be intra-cultural diversity. Laws and policies should allow for autonomy to be exercised in a range of ways, including using an ACD to exercise self-determination, to formally delegate decisions to others, to ensure decisions are made collaboratively with or by the family, and a combination of these approaches.

Autonomy & the Framework

Given Australia's Indigenous heritage and increasingly multicultural population, it cannot be assumed that individual autonomy is the prevalent ethic in all communities or that normative western values and decision-making norms will apply to all families

However it must be recognised that ACDs are not appropriate for every person or every community, and that a person may choose not to complete an ACD. Nevertheless, legislation should not introduce barriers to Indigenous and multicultural families seeking to use ACDs; such families may need specific advice and support to complete ACDs if they choose to use them.

ADVANCE CARE PLANNING TOGETHER

Substitute Decision-Making Pathway

Step 1
Assess capacity to make the decision required
- if substitute decision required, then appointed or assigned substitute decision-maker proceeds to step 2

Step 2
Establish whether preferences relevant to the situation have been previously expressed in an Advance Care Directive or in previous discussions

Step 3
For health-related decisions, consider the advice of health care professionals about treatment options and likely outcomes in light of the person's wishes:
- interventions considered overly burdensome or intrusive
- outcomes of care to avoid

Step 4
Respect specific refusals of medical treatments and interventions if intended by the person to apply to the current circumstances

Step 5
Give particular weight to other preferences and directions in the ACD relevant to the current decision

Step 6
If no specific relevant preferences and directions, consult with others close to the person to determine any relevant previously expressed views and social or relationship factors he or she would consider in decision-making

Step 7
Consider the person's known values, life goals and cultural, linguistic, spiritual and religious preferences and make the decision that the person would make if he or she had access to current information and advice

Step 8
Where several treatment options satisfy these decision-making criteria, choose the least restrictive option that best ensures the person's proper care and protection

Step 9
For residential decisions, consider the adequacy of existing informal arrangements for the person's care and the desirability of not disturbing those arrangements

Step 10
If there is no evidence of what the person would have decided, make the decision that best protects the person's personal best interests

The Framework in brief:

- It is aspirational
- Aimed at simplicity, consistency and clarity
- Empowering individuals
- Emphasising autonomy – recognises that it is a culturally sensitive concept, and
- Is values based in its language

Advance Care Directives Act 2013 (SA)

An Act to:

- To protect health practitioners and others giving effect to the directions wishes and values of a person who has given an ACT
- Enable competent adults to give directions about their future health care, residential and accommodation arrangements and personal affairs
- Express wishes and values in respect to above
- Allow future decisions to be made by another person on their behalf
- Ensure as far as practicable and appropriate that health care accords with the expressed directions, wishes and values
- To ensure that the wishes and values are considered in dealing with the person's residential and accommodation arrangements and personal affairs
- To protect health practitioners and others giving effect to the directions wishes and values of a person who has given an ACD
- Provide mechanisms for disputes

s7 defines **impaired decision making**:

Not capable of understanding or retaining or using information or communicating decision

Importantly:

- Not incapable of understanding merely because not able to understand technical or trivial information
- Not able to retain merely because can only retain for a short time
- May fluctuate between being impaired and not
- <u>Not impaired merely because a decision made results, or may result, in an adverse outcome</u>

Binding and Non-Binding Provisions

s19 **Binding and non-binding provisions**

Refusal of particular health care will be a *binding provision*

This means that directions about living arrangements etc are non-binding, and of course there is no ability to demand treatment

The Reality:

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- A procedural Act
- Specific guidelines for witnesses
- “Simple English Guides” are far from simple at 74 pages

Best described as:

- A well intentioned but unworkable document

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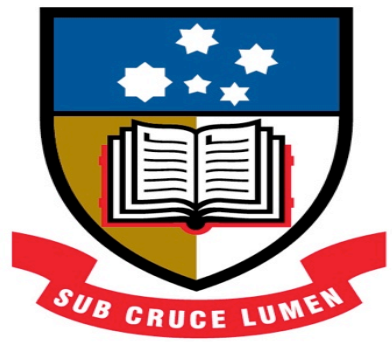
The current system:

Investigating the inclusion of vulnerable populations in Advance Care Planning: Developing complex and sensitive public policy, APP1133407 Partnership Project

- **University of Adelaide**
  - Professor Gregory Crawford, School of Medicine
  - Dr Teresa Burgess, School of Public Health
  - Dr Jaklin Eliott, School of Public Health
  - Associate Professor Bernadette Richards, Adelaide Law School
  - Dr Tanya Zivkovic, School of Social Sciences
  - Dr Debbie Faulkner, Centre for Housing and Urban Planning
  - Associate Professor Terry Dunbar, Yaitya Purruna Indigenous Health Unit
- **University of South Australia**
  - Professor Ian Olver, Sansom Institute for Health Research
- **Project Officer**
  - Dr Katherine Hodgetts, School of Public Health, University of Adelaide

Partners:

- Aged & Community Services SA&NT
- Alzheimer's SA
- Law Society SA
- Modbury Hospital Foundation
- Multicultural Communities Council SA
- Northern Adelaide Local Health Network
- Northern Community Health Foundation
- Northern Health Network
- Palliative Care SA
- SA Health



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