



UNIVERSITY OF
CALGARY



EAPC 2016

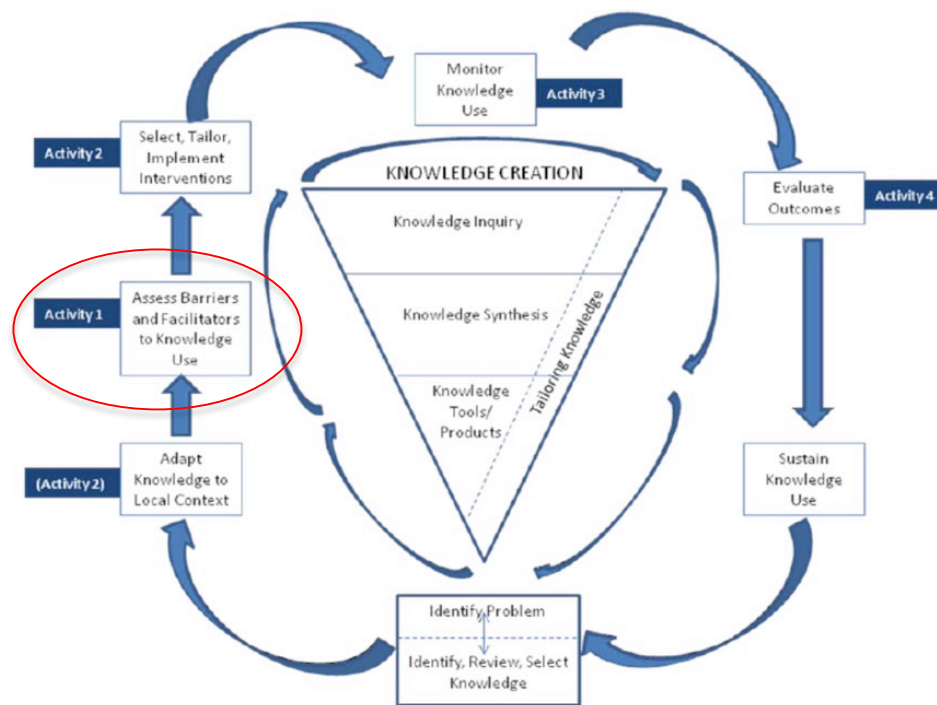
Understanding Advance Care Planning within the South Asian Community

Patricia Biondo, Rashika Kalia, Rooh-afza Khan, Nancy
Marlett, Svetlana Shklarov, Jessica Simon
for the ACP CRIO program

- Physician Consultant, Advance care planning and goals of care, Calgary Zone, Alberta Health Services

- Context: Part of larger ACP CRIO research program
- Distinct method: Community members as researchers
- Findings and their application

- Advance Care Planning and Goals of Care Alberta: A Population Based Knowledge Translation Intervention Study
- 2014 province-wide policy & framework



Knowledge to Action Cycle, Adapted Graham et al. www.Ktclearinghouse.ca

Elicit perspectives on Advance Care Planning (ACP) within the South Asian Community:

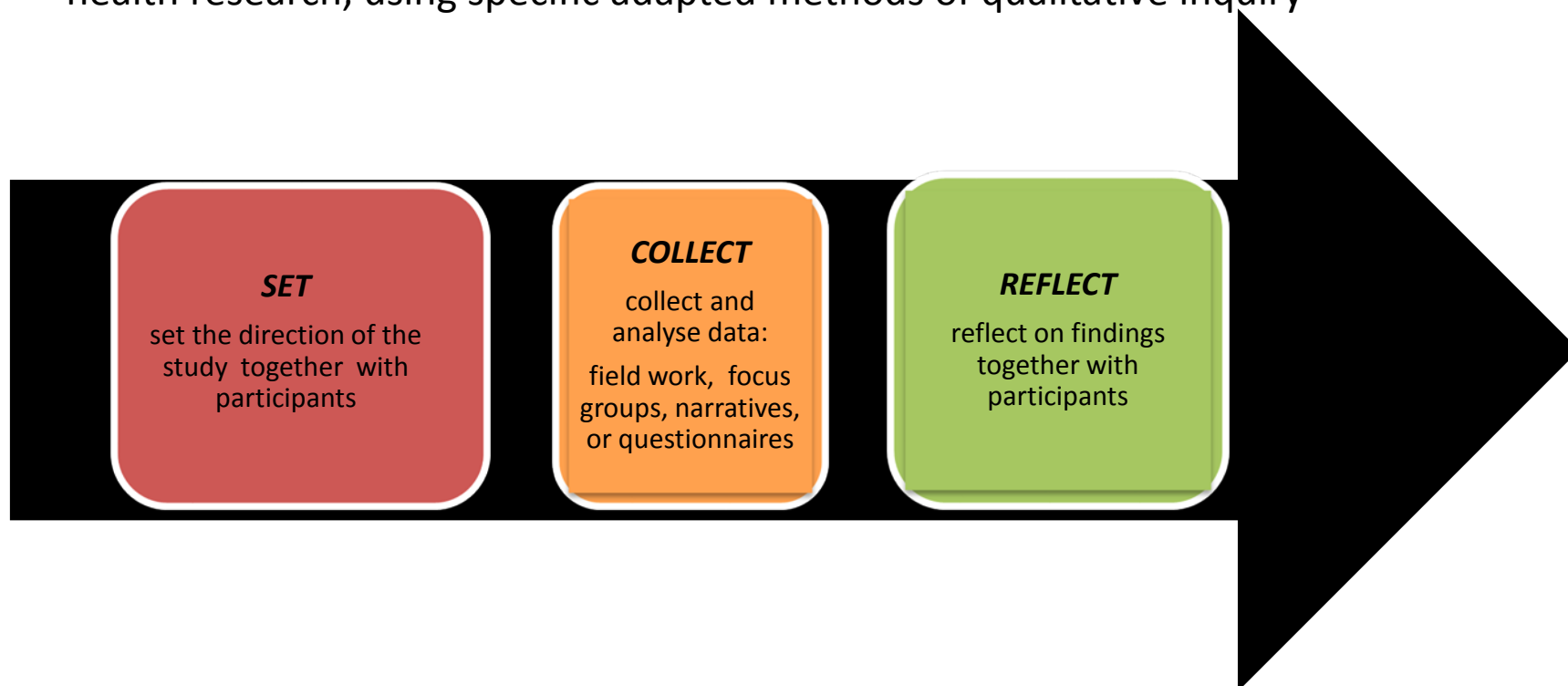
- Gain understanding of barriers and facilitators around ACP
- Determine ways in which members of the community would like to engage in ACP



- Languages
 - Hindi, Urdu, Punjabi
- Religions
 - Hindu, Islam, Sikh



Patient and Community Engagement Researchers (PaCERs) are people with various health conditions/experiences, trained to design and conduct health research, using specific adapted methods of qualitative inquiry



Marlett et al. (2015). Building New Relationships in Research: A Model of Patient Engagement Research. *Quality of Life Research*, 24(5), 1057-67 (Patient Engagement Special Section). DOI 10.1007/s11136-014-0845-y.

SET

15 women
Focus group



COLLECT

8 family interviews
23 participants
Age range 22-72
Narrative analysis

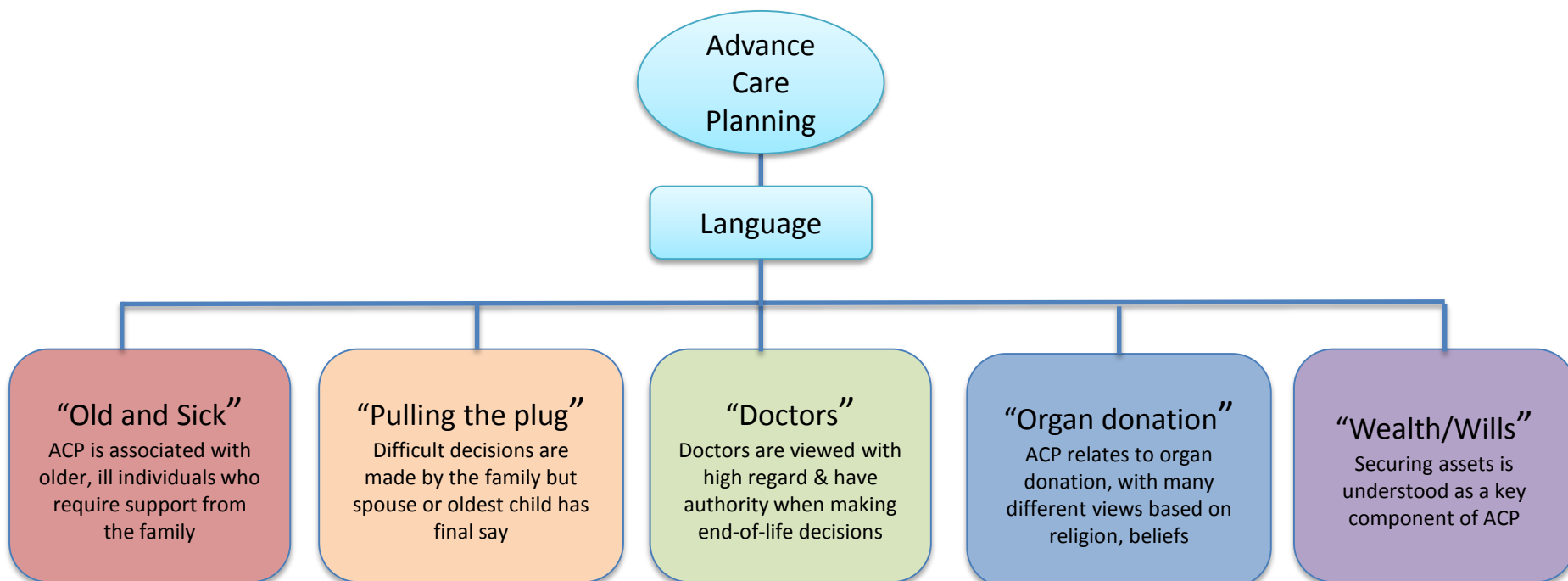


REFLECT

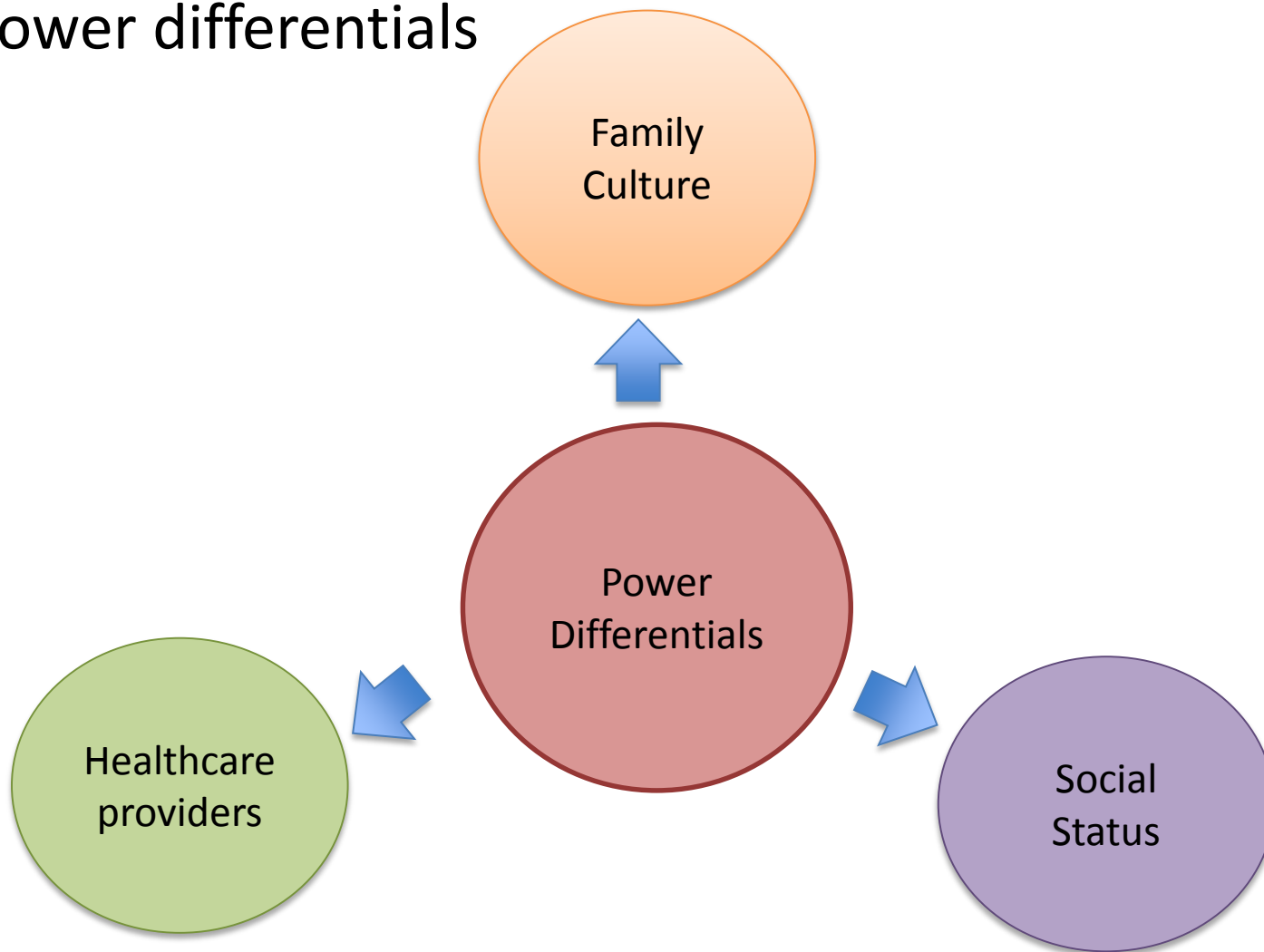
19 men & women



1. Importance of Language & expressions of ACP



2. Power differentials



Collect “narrative scripts”

✓ **Foreign Ideas**

✓ **Cultural Norms**

✓ **Don't talk about it**

✓ **Leave it to God**

✓ **Too busy with life**

✓ **Wealth vs. Health**

“We don’t plan about death and severe health conditions as we believe it is not in our control. Discussing and preparing for it puts us in control rather than God and the higher power.”

“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.”

“When I fall ill, I make sure that my finances are in order, so that my family doesn’t fight over it.”

“When I don't know much about a new foreign idea, I simply cannot make any decisions, and then I ask for more information so I can deal with it.”

“When I anticipate any unfortunate scenario, I am immediately told to shut up and not to dwell upon it, so we don’t prepare for problems, we just face them.”

“I am so busy with making a living in Canada that I have no time to think of anything else that might be important in my life.”

- Respect cultural norms
- Include family members in discussions
- Forums & Seminars at religious/community centres
- Involve community leaders
- Encourage family doctor initiate
- Multipronged approach to accessing information

“Alberta Health Care should write a letter asking and telling them their legal rights about their health decisions because we take them seriously like Revenue Canada.”

- Recognize & build on community & cultural capacity (family networks, community ties, shared norms)
- Tell stories to aid understanding

- Themes consistent with literature

(Con 2007, Health Canada; Ebrahim 2011, J Pall Care; Sharma 2011, J Gen Intern Med; Hofstede 1991 Cultures and organizations : software of the mind ; Millender 2011, J Contin Educ Nurs)

- Lack of shared conceptual models

- Recommendations echoed in World Café of community groups



Creating report for stakeholders

Questions/Comments?

Jessica.simon@ahs.ca

www.acpcrio.org