



POPLAR NETWORK LUNCH 'N' LEARN WEBINARS EDIIA IN RESEARCH

Part 2:

Building Research Projects with an EDIIA Lens



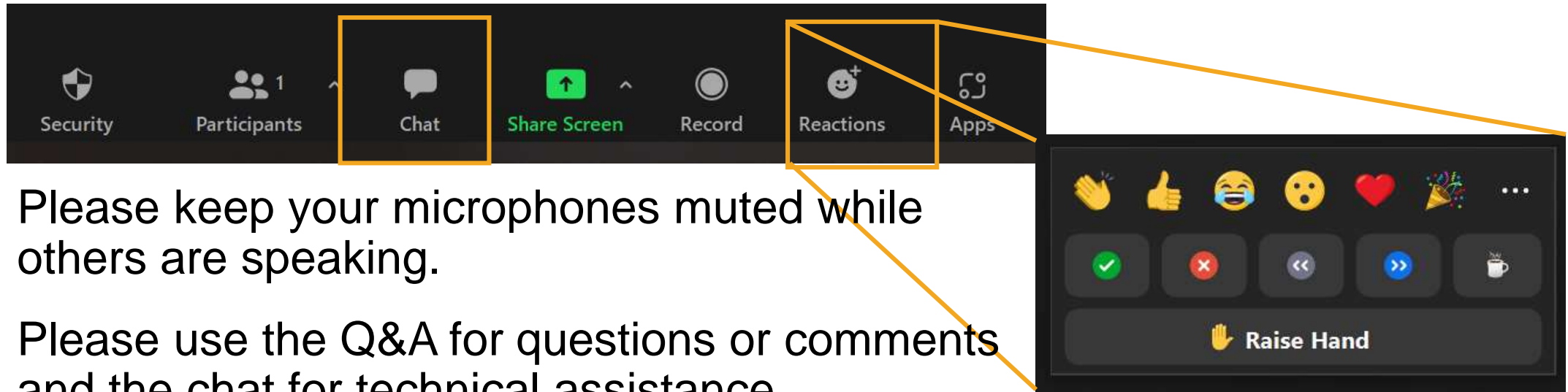
Alliance for Healthier Communities
Advancing Health Equity in Ontario



Welcome & Introduction

- Housekeeping
- Land Acknowledgement
- Speaker Introduction
- Building Research Projects with an EDIIA Lens | Vivian Ramsden
- Q&A / Discussion

Housekeeping



- Please keep your microphones muted while others are speaking.
- Please use the Q&A for questions or comments and the chat for technical assistance.
- Open the “reaction” button to access “raise hand” and other tools.

Acknowledgement of Traditional Indigenous Territories

We recognize that the work of the Alliance for Healthier Communities, our members, and the POPLAR Network takes place across what is now called Ontario, on traditional territories of Indigenous people. They have lived here since time immemorial and have deep connections to these lands. We further acknowledge that Ontario is covered by 46 treaties, agreements and land purchases, as well as unceded territories. We are grateful for the opportunity to live, meet and work on this territory.

Ontario continues to be home to vibrant, diverse Indigenous communities who have distinct and specific histories, needs, and assets as well as constitutionally protected and treaty rights. We honour this diversity and respect the knowledge, leadership and governance frameworks within Indigenous communities. In recognition of this, we commit to building allyship relationships with First Nation, Inuit and Métis peoples in order to enhance our knowledge and appreciation of the many histories and voices within Ontario. We also commit to sharing and upholding our responsibilities to all who now live on these lands, the land itself, and the resources that make our lives possible.

Introduction

Dr. Vivian Ramsden (she/her)

Professor and Research Director, Department of
Academic Family Medicine, University of Saskatchewan



Building Research Projects with Communities: Applying an EDIIA Lens

Vivian R Ramsden, RN, PhD, MCFP (Hon.)
Professor, Department of Academic Family Medicine
University of Saskatchewan

Learning Objectives

At the conclusion of this activity, the:

- Participants will be able to describe the elements of equity, diversity, inclusion, allyship and accessibility.
- Participants will have an opportunity to reflect on how this could be used in their clinical practice and/or current research project.

EDIIA Definitions

- Equity – the fair and respectful treatment of all peoples and the creation of opportunities and outcomes with diverse communities.
- Diversity – recognizes and respects each individual’s unique attributes regardless of the setting.
- Inclusion – creating opportunities in which peoples are authentically engaged; and everyone’s expertise is valued and celebrated.
- As indicated by the Office of the Treaty Commissioner in Saskatchewan, “We are all Treaty people.”
- Accessibility – “the ease with which a person can obtain needed care (including advice and support) from the practitioner of choice within a time frame appropriate to the urgency of the problem” – Haggerty et al, 2011.

Context

Primary health care as defined by the World Health Organization (WHO) in 1978 was:

- essential health care;
- based on practical, scientifically sound, and socially acceptable methods and technology;
- universally accessible to all in the community through their full participation;
- at an affordable cost; and,
- geared toward self-reliance and self-determination.

World Health Organization, UNICEF (1978). Alma-Ata 1978: primary health care. Geneva, Switzerland: World Health Organization.

Context

The World Health Organization (WHO) in 2018 committed to: building sustainable primary health care through but not limited to:

- prioritizing disease prevention and health promotion.
- meeting all people's health needs across the life course.
- people-centred and gender-sensitive services.

World Health Organization, UNICEF (2018). Declaration of Astana. Accessed on March 18, 2019 from <https://www.who.int/primary-health/conference-phc/declaration>. Geneva, Switzerland: World Health Organization.

Context

The World Health Organization (WHO) in 2018 committed to: empowering individuals and communities through their participation in the development and implementation of policies and plans that impact on health. They went on to indicate that:

- they will support people in acquiring the knowledge, skills and resources needed to maintain their health or the health of their loved ones guided by health professionals.
- protect and promote solidarity, ethics and human rights.
- increase community ownership.

World Health Organization, UNICEF (2018). Declaration of Astana. Accessed on March 18, 2019 from <https://www.who.int/primary-health/conference-phc/declaration>. Geneva, Switzerland: World Health Organization.

Context

Thus, as a strategy, primary health care focuses on:

- individual and community strengths (assets) and opportunities for change (needs);
- maximizes the involvement of the community;
- includes all relevant sectors but avoids duplication; and,
- uses only health technologies that are accessible, acceptable, affordable and appropriate.

Ramsden VR, McKay S, Crowe J (2010). The pursuit of excellence: engaging the community in participatory health research. *Global Health Promotion*, 17(4), 32-42.

Jones L, Wells K (2007). Strategies for academic and clinician engagement in community-participatory partnered research. *JAMA*, 297(4), 407-10.

Context

Often in the past, programs and strategies have been developed in response to “what feels good” rather than “working with” people to develop strategies that would fit within their context.

Mezirow J & Associates (2000). *Learning as transformation: Critical perspectives on a theory in progress*. San Francisco, CA: Jossey-Bass Publishers.

Context

Trusting people to solve problems generates higher levels of motivation and better solutions.

Bolman LG & Deal TE (2001). *Leading with soul: An uncommon journey of spirit*.
San Francisco, CA: Jossey-Bass.

Definition

- The peoples/community as an expert is a true or authentic partnership between the patient/community, health care professional(s) and researcher(s). Often the members of the research team have more than one role e.g. nurse, researcher.

Donaldson L (2003). Expert patients usher in a new era of opportunity for the NHS. *BMJ*, 326(7402), 1279. doi: <https://doi.org/10.1136/bmj.326.7402.1279>.

Ramsden VR, Transition to an Integrated Primary Health Services Model Research Team (2003). Learning with the community – Evolution to transformative action research. *Canadian Family Physician*, 49(2), 195-197.

Definition

- Co-creation of research is seen as “a collaborative approach to research that equitably involves all partners in the research process and recognizes the unique strengths that each brings to the project.”
- The research begins with a research topic of importance to the community or in fact may be community-led with the aim of combining knowledge and action to bring about change/transformation.

Wallerstein N, Duran B, Oetzel J, Minkler M (2018). Community-based participatory research for health: Advancing social and health equity. San Francisco, CA: John Wiley and Sons.

Ramsden VR, Crowe J, Rabbitskin N, Rolfe D, Macaulay AC (2019). Authentic engagement, co-creation and action research. In, How to do primary care research, F Goodyear-Smith and B Mash (Eds.). Boca Raton, FL: CRC Taylor & Francis Group. pp. 47-56.

Construct – What is Community?

- Community engagement is a process that establishes a collaborative interaction between a clinician, researcher or research team and the community engaged in asking and answering the research question(s).
- Each community is unique so may not be scalable in the usual ways.

Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada (2014). *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans*. Accessed on March 12, 2017 from <http://www.pre.ethics.gc.ca/eng/policy-politique/initiatives/tcps2-eptc2/Default/>.

Construct – Interaction between Community and Engagement

- The need to respect a community's cultural traditions, customs and codes of practice is critical in working with the community to answer their question.
- Building authentic, reciprocal, and trusting relationships takes time.

Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada (2014). *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans*. Accessed on March 12, 2017 from <http://www.pre.ethics.gc.ca/eng/policy-politique/initiatives/tcps2-eptc2/Default/>.

Historical Perspective - Reflections

- It is clear that history has shaped current research relationships in one way or another.

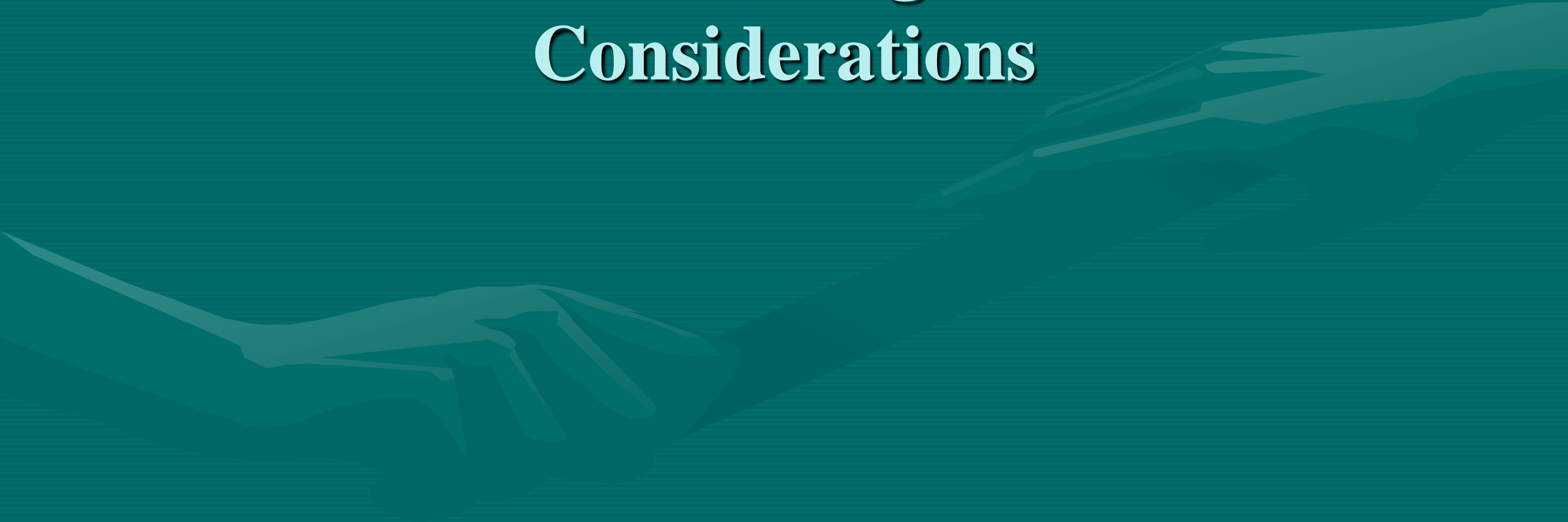
Graham, H. (2011) Narrative Descriptions of Miyo-Mahcihoyan (Well-Being) from a Contemporary Nehiyawak (Plains Cree) Perspective. Saskatoon, SK: Dissertation.

Historical Perspective - Reflections

- It is through building trust and mutually beneficial research relationships that the past historical relationships may be ameliorated.
- It is time for both worlds, Western and Indigenous, to establish mutual and respectful spaces to negotiate and advance research for all participants.

Ermine, W., Sinclair, R., & Jeffery, B. (2004). The ethics of research involving Indigenous peoples: Report of the Indigenous Peoples' Research Centre to the Interagency Advisory Panel on Research Ethics (PRE). Regina, SK: Indigenous Peoples' Health Research Centre.

Methodological Considerations



Methods

- The overall approach used in the process of integrating the principles/values into practice is the application of participatory research (PR) which includes authentic engagement, respect and action research.
- Research done “with” – viewed as a partnership.

Minkler M & Wallerstien N (Eds.) (2003). *Community-based Participatory Research for Health*. San Francisco, CA: Jossey-Bass.

Constructs

- The fundamental principles of co-creation /participatory research became equitable co-ownership and co-decision-making with full partner engagement with academic researchers, locating power and ownership at every stage of the research process or however the individual teams decide what is equitable.

Macaulay AC (2017). Participatory research: What is the history? Has the purpose changed? *Family Practice*, Jun 1;34(3):256-258.

Constructs

- The engagement of individuals/patients and/or communities has become important in all aspects of the research process.
- Research that is co-created with individuals /patients and/or communities is designed to improve health and well-being and to minimize health disparities.

Ramsden VR, Crowe J, Rabbitskin N, Rolfe D, Macaulay AC (2019). Authentic engagement, co-creation and action research. In, How to do primary care research, F Goodyear-Smith and B Mash (Eds.). Boca Raton, FL: CRC Taylor & Francis Group. pp. 47-56.

Constructs

- This partnership approach to research equitably involves individuals/patients and/or communities and researchers in all aspects of the process and in which all partners contribute expertise and share decision-making and ownership.

Ramsden VR, Crowe J, Rabbitskin N, Rolfe D, Macaulay AC (2019). Authentic engagement, co-creation and action research. In, How to do primary care research, F Goodyear-Smith and B Mash (Eds.). Boca Raton, FL: CRC Taylor & Francis Group. pp. 47-56.

Constructs

- Research that is co-created is utilized to explore and address community-identified issues through a collaborative and empowering action-oriented process that builds on strengths and assets of individuals/patients and the community.

Ramsden VR, Crowe J, Rabbitskin N, Rolfe D, Macaulay AC (2019). Authentic engagement, co-creation and action research. In, How to do primary care research, F Goodyear-Smith and B Mash (Eds.). Boca Raton, FL: CRC Taylor & Francis Group. pp. 47-56.

Elements of Co-creation

- Co-create a set of values that will describe how the team will work together.
- Co-create a conceptual framework using participatory principles.
- Identify and engage individuals/patients and/or communities as early as possible in order to build sustainable relationships, which will maximise the input and impact.
- Provide support, encouragement and recognition for individuals/patients, organisations and communities by recognising them as experts and members of the research team.

Ramsden VR, Crowe J, Rabbitskin N, Rolfe D, Macaulay AC (2019). Authentic engagement, co-creation and action research. In, How to do primary care research, F Goodyear-Smith and B Mash (Eds.). Boca Raton, FL: CRC Taylor & Francis Group. pp. 47-56.

Elements of Co-creation

- Co-create, using the principles of consensus, the purpose, objectives and questions to be asked and data collection methods to be used in the grant/proposal.

Ramsden VR, Crowe J, Rabbitskin N, Rolfe D, Macaulay AC (2019). Authentic engagement, co-creation and action research. In, How to do primary care research, F Goodyear-Smith and B Mash (Eds.). Boca Raton, FL: CRC Taylor & Francis Group. pp. 47-56.

Co-creation: a Look at What to Do

- Be clear on the roles and responsibilities for each member of the research team - determine these together so that each member of the team contributes what they do best.
- Ensure a trusting and positive work environment by providing structural supports, e.g. honorariums, food, childcare, bus tickets/taxis.
- Provide relevant training for all members of the research team, e.g. TCPS2 Core Tutorial.

Ramsden VR, Crowe J, Rabbitskin N, Rolfe D, Macaulay AC (2019). Authentic engagement, co-creation and action research. In, How to do primary care research, F Goodyear-Smith and B Mash (Eds.). Boca Raton, FL: CRC Taylor & Francis Group. pp. 47-56.

Co-creation: a Look at What to Do

- Co-create/co-develop a document that describes what is going to be undertaken in this grant/proposal and by whom and have every member of the team critique it so that the research process is transparent.
- Develop a Data Sharing Agreement (written or oral) so that everyone is aware of the principles of Ownership, Control, Access and Possession (OCAP) which enables self-determination over all research.

Ramsden VR, Crowe J, Rabbitskin N, Rolfe D, Macaulay AC (2019). Authentic engagement, co-creation and action research. In, How to do primary care research, F Goodyear-Smith and B Mash (Eds.). Boca Raton, FL: CRC Taylor & Francis Group. pp. 47-56.

Co-creation: a Look at What to Do

- Reflect on the results/findings and the processes.
- Return data to individuals/patients and/or communities for interpretation, decision-making and identification of new questions before external dissemination.
- Identify insights, prioritize actions to be taken, and subsequently disseminate the results first at the level of the individuals/patients and/or communities and then in ways that are meaningful to all members of the research team.

Ramsden VR, Crowe J, Rabbitskin N, Rolfe D, Macaulay AC (2019). Authentic engagement, co-creation and action research. In, How to do primary care research, F Goodyear-Smith and B Mash (Eds.). Boca Raton, FL: CRC Taylor & Francis Group. pp. 47-56.

Elements of Sharing Information

- Debrief and provide feedback on the quality of data gathered on a regular basis e.g. q1-2weeks.
- Co-analyze data collected.
- Return the data to the community for celebration, reflection and interpretation.
- Co-present/co-publish the results/findings.
- Team begins working on the next priority.

Ramsden VR, Transition to an Integrated Primary Health Services Model Research Team (2003). Learning with the community – Evolution to transformative action research. *Canadian Family Physician*, 49(2), 195-197.

Salsberg J, Parry D, Pluye P, Herbert CP, Macaulay AC (2015). *Successful strategies to engage research partners for translating evidence into action in community health: a critical review*. *J Environ Public Health*, 2015, 191856. doi: 10.1155/2015/191856.

Elements of Sharing Information

- Funding needs to be built into the grant/proposal to ensure that co-creation/co-development of how best to share the results is clearly identified in the grant/proposal.
- The individuals/patients or community members need to be able to travel to present at some if not all of the conferences with researchers, as well as, being able to determine where the data should be presented and to whom.

Ramsden VR, Crowe J, Rabbitskin N, Rolfe D, Macaulay AC (2019). Authentic engagement, co-creation and action research. In, How to do primary care research, F Goodyear-Smith and B Mash (Eds.). Boca Raton, FL: CRC Taylor & Francis Group. pp. 47-56.

Elements of Sharing Information

- Particular attention needs to be paid to including individuals/patients in dissemination activities including publications, provides an obvious description of authentic engagement on the research continuum.
- It also minimizes the risk of potential stigmatization of individuals/patients and/or communities.

Ramsden VR, Crowe J, Rabbitskin N, Rolfe D, Macaulay AC (2019). Authentic engagement, co-creation and action research. In, How to do primary care research, F Goodyear-Smith and B Mash (Eds.). Boca Raton, FL: CRC Taylor & Francis Group. pp. 47-56.



Findings/Discussion & Examples

Co-creating Research - Practical Aspects

- Engagement in research has been shown to enhance the ability of individuals/patients and communities while ensuring that researchers/graduate students understand the individual's and community's priorities.
- Contemporary approaches to engagement involve co-design, co-production, co-leadership and mutual learning frequently within a systems model.
- The principles espoused are found within the constructs of participatory research.

Co-creating Research - Practical Aspects

- As part of community engagement, experiences and knowledge are important, providing learning opportunities for researchers/graduate students to make decisions.
- Relationships are key, in co-design, co-production, co-leadership and mutual learning.

Woolf SH, Zimmerman E, Haley A, Krist AH (2016). Authentic engagement of patients and communities can transform research, practice, and policy. *Health Affairs (Millwood)*, 35(4), 590-594. doi: 10.1377/hlthaff.2015.151.

Co-creating Research - Practical Aspects

- Education and training need to be facilitated with faculty, clinicians, students, and community members so that each is better able to contribute to the project.

Ramsden VR, Rabbitskin N, Westfall JM, Felzien M, Braden J, Sand J (2017). Is knowledge translation without patient or community engagement flawed? *Family Practice*, Jun 1;34(3):259-61.

Co-creating Research - Practical Example

- The Green Light Program was co-created by community members from the Core Communities in Saskatoon to identify and celebrate homes that were free from the misuse/non-traditional use of tobacco.
- In SK, there are currently 2247 homes & 3 communities in which 50% of the homes are smoke-free.
- Publications/presentations have been with individuals from each of the four original communities:
 - Participatory health research: celebrating smoke free homes. Canadian Family Physician. 2013 Sep;59(9):1014-1015.
 - Engaging with the Community to Enhance Primary Health Care (Book Chapter in Promoting Change through Action Research).



**BUILDING ON SUCCESS:
CELEBRATING
SMOKE FREE HOMES**



UNIVERSITY OF
SASKATCHEWAN

WEST WINDS
PRIMARY HEALTH CENTRE



Co-creating Research

- Practical Example

- que miskahsoh (finding yourself): Breaking the Cycle is a research endeavour that evolved from the community.
- As a result of colonization, the number of Indigenous peoples (men, women and two spirited) in custody (incarcerated) are over-represented.
- An Indigenous Elder, a Métis mother and grandmother, an Educator with a PhD in participatory social justice and my colleagues from the Centre for Forensic Behavioural Science and Justice Studies came together about a month before the grant was due to co-create a grant application.

Co-creating Research - Practical Example

- The goal of this grant application is to build a Community-Led: Breaking the Cycle Program with the peer-researchers/collaborators in the community that will be sustainable long after the grant has been completed.
- This will be unique but with similar to one that I had the opportunity to collaborate on in British Columbia with women with incarceration experience.
- It is hoped that access to both primary care and research will be less problematic in the future for individuals with incarceration experience, health care providers providing care and researchers engaged in enhancing wellness.

Advantages....

For the Community

- Power to determine research priorities, allocation of resources, outcomes.
- Control of community-related data.
- Increased capacity and skills.
- Job creation and/or economic development.
- Sustainability of research outcomes.

Advantages....

For Researchers

- Better quality of community-related data.
- Transformative learning experience.
- Incorporation of local knowledge.
- More accurate interpretation of findings.
- Responsibility for outcomes shared by all.

Conclusions/Summary

A faint, semi-transparent image of two hands shaking is visible in the background, centered behind the text. The hands are rendered in a light teal color, matching the background, and are positioned as if in a firm handshake. The background is a solid, dark teal color.

Conclusions/Summary

- The integration of principles/values of co-creation/participatory research builds capacity and changes practice.
- Sustained engagement demonstrates respect for people and the traditions and norms that they share.
- Engaging with an individual/patient and/or community results in outcomes that are both clinically relevant and meaningful.

What we leave behind?

- It is not what we did or did not do. It is what we said or did not say; respect the power of words.
- Choose them with care because in the end it is what we leave behind with the people and the communities with whom we engage/work.
- In the words you choose are the values which you espouse and translate into action.

Questions??



Questions/Discussion

Please type questions into the Q&A panel and we will moderate them.

If you prefer, you may raise your hand and we'll call on you to ask your question aloud.



Thank you!

For follow-up questions:

viv.ramsden@usask.ca

LHS@AllianceON.org

info@poplarnetwork.ca