



# Patients Canada

## For citizens partnering in research

### Preparing to partner from our perspective

*Funding is provided by Ontario SPOR SUPPORT Unit, which is supported by the Canadian Institutes of Health Research and the Province of Ontario.*



### Patient Advisor Authors:

- Alies Maybee, SPOR Team Lead
- Brian Clark
- Annette McKinnon
- Emily Nicholas Angl

*Some materials created by Joyce Resin and Associates, licensed to, and modified by, Patients Canada*



This work is licensed under a [Creative Commons Attribution-NonCommercial-ShareAlike 4.0 International License](https://creativecommons.org/licenses/by-nc-sa/4.0/). ©2016

© Joyce Resin & Associates

©2016



## Who we are

We are a group of patient advisors each of whom are partnering with a number of different research teams.

We are learning “on the job” with our researchers how to partner effectively. We share our understandings here with you.

We are still in the early stages of experiencing and learning about these partnerships. We welcome insights from you as you go along this road.

Alies Maybee  
amaybee@sideren.com

# Agenda

1. Why should we be involved?
2. On being partners in research
3. Understanding the project and our role

# Why should we, as patients and citizens, be involved in research?

## Some reasons – add your own

- It's **our health** – shouldn't we have a say in what and how researchers focus their time and expertise?
- It's **our money** – we are paying for most of the health research as tax payers, shouldn't we have a say on what our money is spent on?
- It's **our system** – we “own” the health system in Canada as citizens, shouldn't we be sure it works for us now and our loved ones in the future?
- We can **make a difference** for us and for others

# How and why is healthcare different today than even 50 years ago?



**Patients Canada**  
Make your experience count



# The patient challenge defined

## With acute disease

- Body to be treated – a single individual
- Focus on disease or repair
- Try prescribed treatment
- Health card name



## With chronic condition

- Person with history – and family/friends
- Resource on their own health team
- Try different approaches/options
- Person with healthcare experience





# Changes in the landscape of healthcare

Across the Western world there is a growing recognition that

- We as patients should be at the centre of the healthcare system
- We as citizens cannot continue to pay the growing costs for healthcare

Therefore

- New ways to deliver care are required
- And we need to be involved



# What do these changes mean for us?

# Our growing involvement

- We are becoming more engaged with our own care
- We are becoming involved in all aspects of healthcare
  - As PFAs in hospitals
  - On advisory councils to not-for-profits and health agencies
  - On family and residents councils in long term care
  - And now as **partners in research**



# Our growing involvement in research is global

- In 1996, the UK created **INVOLVE** to support public involvement in health research
- In 2010, the US created **PCORI** to involve the public in the process of identifying questions most relevant to patients
- In 2011, Canada created a strategy - **SPOR** - through CIHR
  - Grant applicants must have a patient engagement plan and a patient on their team
  - SPOR is administered through provincial/territorial SPOR support units

# Citizen engagement defined

“Citizen engagement is the timely, meaningful and appropriate involvement of citizens in research policy or program development, from agenda setting and planning to decision-making, implementation and review.”

Adapted from the Canadian Institutes of Health Research

# Agenda

1. Why should we be involved?
2. On being partners in research
3. Understanding the project and our role

# Why is it challenging for us to be involved in research ?

## Some of our concerns

- Tokenism
- Not being taken seriously
- Time and financial commitments
- Not understanding what is being discussed
- Apathy and discouragement ... nothing changes ...
- Others???





# Some considerations

## Our Value



- We have expertise
- We can help -- plan, co-design, review research
  - popularize research
  - plan communications with subject patients

## Level Playing Field



- Confidentiality goes both ways
- Explanation of terms and concepts
- Kept up-to-date
- Develop relationships

## Practical Needs



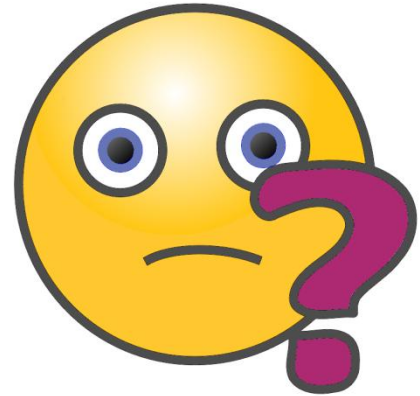
- Contact person
- Expenses covered
- Consideration for meeting access – elevators, easy seating



# Why is it challenging for researchers to be involved in research ?

## Recognizing researchers' concerns

- Time and resources to involve and partner with us
- As citizens, we may not know enough to contribute
- Dealing with our emotions arising from bad experiences as patients
- Lack of clarity of our role
- Lack of clarity for how to involve us



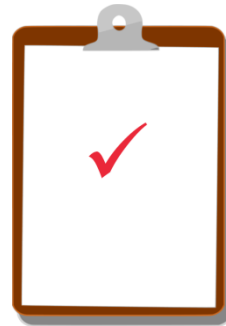
# The challenge for researchers

Citizens are 'in'



Involving us in healthcare is more and more the norm

Criteria for \$



Many funders require we be on the research team

New venture



Researchers are not yet experienced with us as partners



**Patients Canada**  
Make your experience count

# Us as partners v.s. us as subjects

Working together



Studying the subject



INFORMATION  
SHARING

CONSULTATION

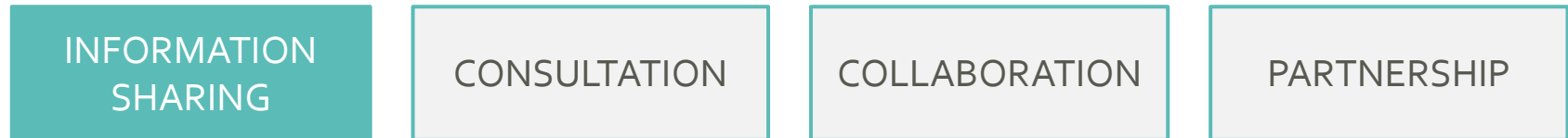
COLLABORATION

PARTNERSHIP

# What are ways of involving us?

# Involvement guide

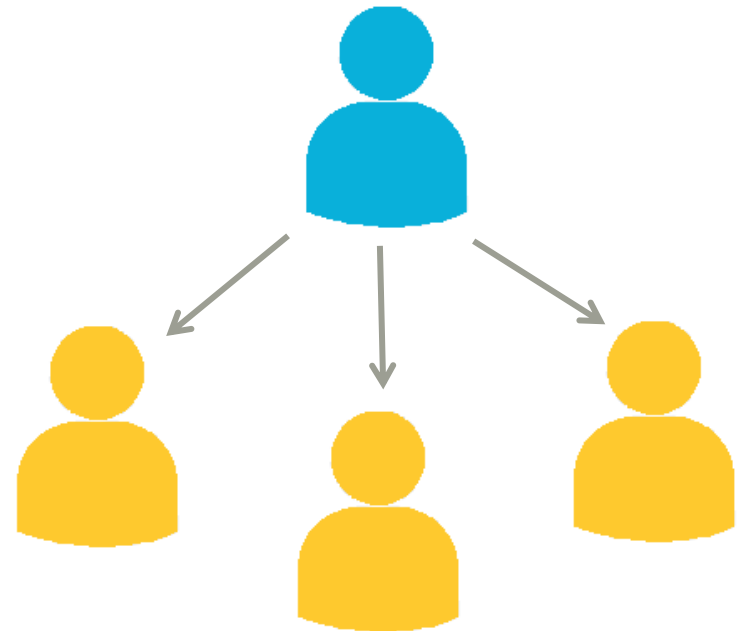
## Understanding levels of involvement



Provide information to us for understanding

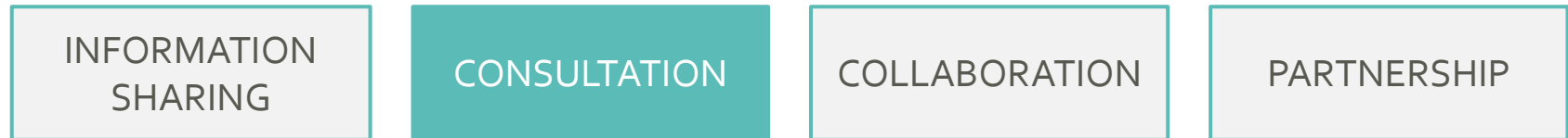
- problems
- opportunities
- solutions

Ex: fact sheets, website, mass media, open house



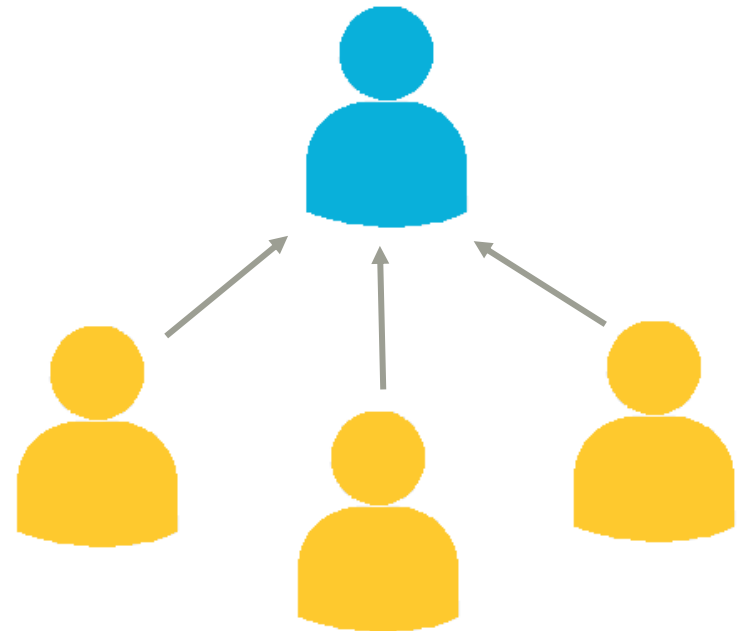
# Involvement guide

## Understanding levels of involvement



Getting feedback from us

Ex: fact sheets, website, mass media, open house





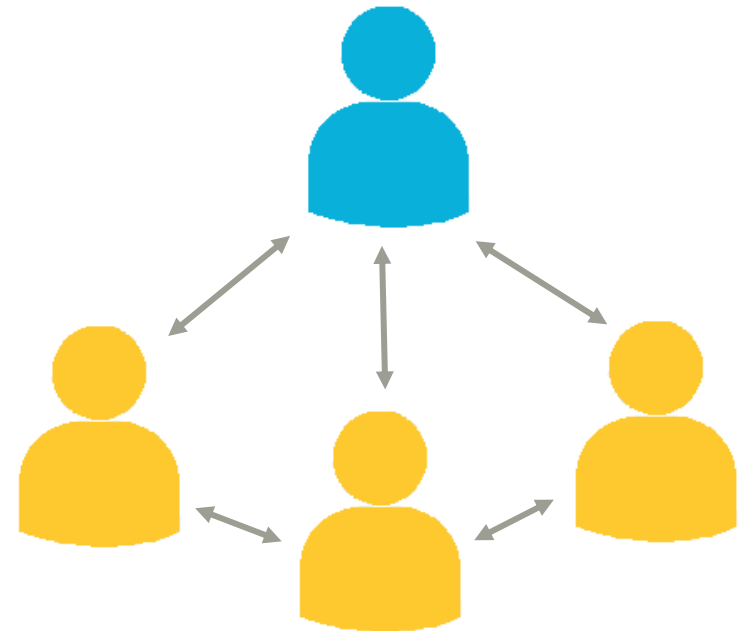
# Involvement guide

## Understanding levels of involvement



Involving us continuously throughout the research process

Ex: mentorship programs, webinars and workshops, conferences



# Involvement guide

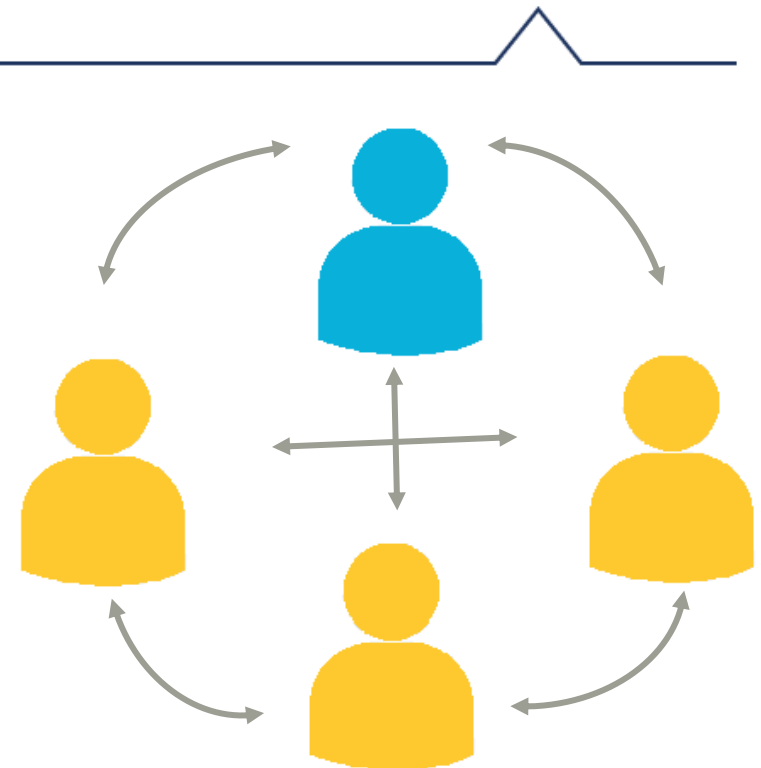
## Understanding levels of involvement



We are partners in decision-making...

- developing the research concept
- contributing to the design
- supporting knowledge translation

Ex: As partner on the research team itself, as a panelist



© Joyce Resin & Associates

On being partners in research 26

©2016

# Approaches to partnership

We can be....



Individual citizens  
on the team



On a citizen panel



# Agenda

1. Why should we be involved?
2. On being partners in research
3. **Understanding the project and our role**

# What do we need to know to be effective partners?

# Preparation before coming on board the project

To be effective partners we need:

- Background materials
- Orientation to partnership for us as:
  - Patient partners
  - Panelists
- Introduction to the whole team including roles, bios and even pictures
- And a good understanding of the project, our role and expectations



# Understanding the project

The Principal Investigator (PI) describes the project and we discuss:

- Why the topic was chosen
- What the research question might be
- Current stage of the project process
- How it might be implemented – including methods
- How it might be analyzed – use of patients and their data
- How the results might be used and spread



# Understanding the practicals

Timelines – or when things are due

- Meetings
- Tasks
- Duration of the project



Expenses and compensation

- Travel, parking, meals, accommodation - admin
- Any honoraria, gift cards and so on



Access

- Challenges to participation – physical access, language, vision

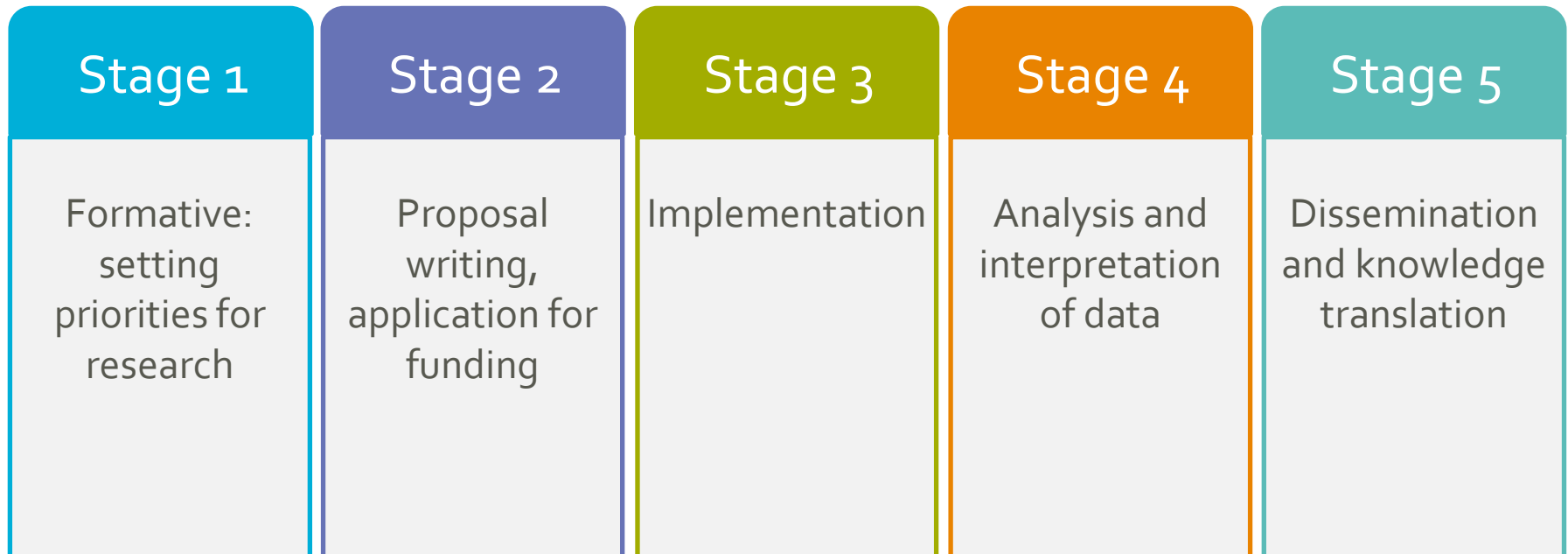




# What is our role as a partner or panelist at each stage?

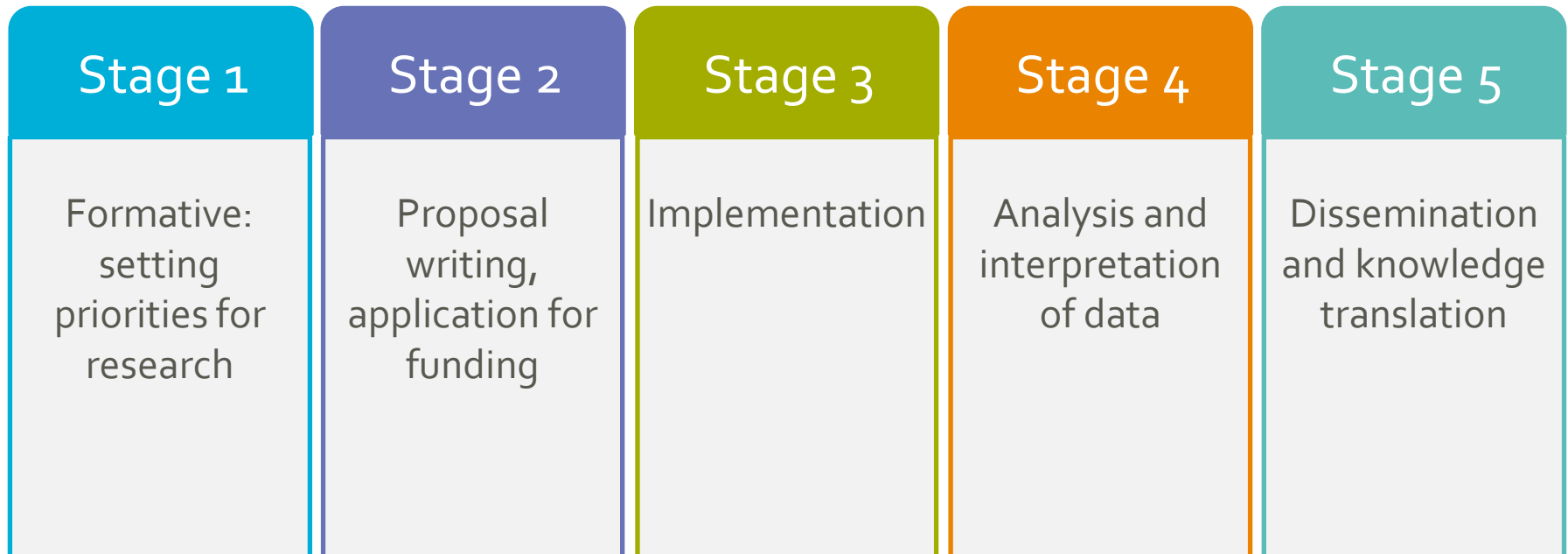
# Mapping out the research process

Exploring possibilities for partnership



# Mapping out the research process

Exploring possibilities for partnership



Stages 2-5

Developing and implementing a marketing/communications plan



**Patients Canada**  
Make your experience count

# Stage 1: Formative

## Stage 1

Formative:  
setting  
priorities for  
research

How can we help contribute to the development of the research plan?

- Determining public relevance
- Setting priorities from our perspective
- Defining outcomes from our perspective
- Defining approach
- Planning for communications and KT
- Identifying partnership approach
- Developing partnership strategy
  
- And more...

## Stages 2-5: Marketing/communications

**GOAL:** To connect research more directly with the people it serves.

How can we help contribute to the development and implementation of a marketing/communications plan?

- How to enlist the public as an influencer from the start?
- Can social media be used to inform public and other stakeholders?
- What organizations should be aware and track progress?
- Can results be designed for the public audience?
- Can this drive interest by opinion leaders – on TV, print, radio?

Stage All

Developing and implementing a marketing plan

# Stage 2: Proposal

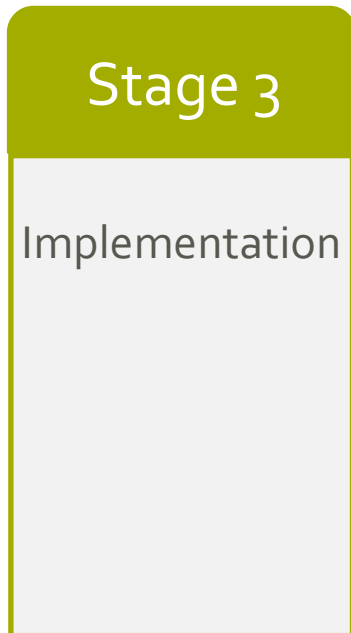
## Stage 2

Proposal writing, application for funding

How can we help contribute to the writing of the application?

- Help develop the partnership approach and strategy
- Review drafts of the application especially the Summary and Patient Engagement sections
- Contribute to the Patient Engagement sections
- Contribute to the timeline and budget decisions
- Contribute to the KT (and marketing) sections
  
- And more...

# Stage 3: Implementation



How can we help contribute to the implementation of the research?

- Help develop patient/caregiver subject communications materials
- And more...

# Stage 4: Analysis

## Stage 4

Analysis and  
interpretation  
of data

How can we help contribute to the analysis and interpretation of data?

- Review the preliminary results of the analysis
- And more...



# Stage 5: KT and spreading the word

## Stage 5

Dissemination  
and knowledge  
translation

How can we help contribute to the spread of the research results?

- Coordinate with the marketing/communications plan
- Help develop a public-friendly version of results
- Help develop a social media approach
- Co-publish in non-academic materials
- Co-present findings
  
- And more...

## Our partner roles

Co-develop a role or “job” description from the review of the stages



Review the partnership approach together and assign roles



- Individual partners
- Panel
- Both

# Commitment is a 2-way street

The 'job' description for us as partners and Terms of Reference for us as panelists include:

- What we will do for the project and our partners
- What our research partners will provide us:
  - Information
  - Support – admin help, expenses
  - Feedback
- What we will provide each other – respect, listening, commitment



# What does partnership success look like?



Discuss what successful partnership means to us

- Develop key indicators of success
- How to measure
- When to measure

What does success look like

- for the project?
- for the partnership?

# Evaluating the project

- What outcomes do our research partners want?
- What outcomes do we want?
- What do we want to happen with the research?
  - Should there be policy changes, practice changes?
  - If there is uptake for the results of the research, what does success look like?



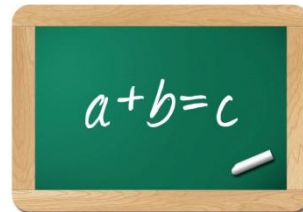
# Ingredients for creating productive partnerships

## Time



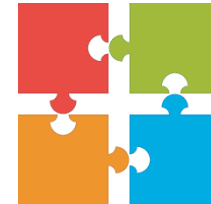
Investing time in our partnership is necessary

## Preparation



Good preparation leads to a fruitful partnership

## Plan



Planning yields clarity and direction for all partners

# Evaluating the partnership

- How do our research partners know when things are going well?
- How do we know when things are going well?
- Once you have evaluated....
  - How do we all spread the good news?
  - What do we and you do when things go wrong?







## Conclusion: Successful partnerships ...

1. Include planning, preparation and commitment
2. Can differ from team to team
3. Must be supported with staff time and financial resources
4. Must be measured for improvement

## Benefits of partnering with us



Improve the relevance and translation of research into practice and policy



Contribute to more effective health services and products



Contribute to quality of life and a strengthened Canadian health care system

# Questions

Thanks for participating!  
[amaybee@sideren.com](mailto:amaybee@sideren.com)