



# Partnering with citizens in research

## What's helpful from our perspective

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## 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

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# Agenda

1. Understanding the basics
2. Developing a partnership plan
3. Recruiting and on boarding partners



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## Understanding the basics

1. Context
2. Partnering with us as citizens
3. Key considerations
4. Guiding principles
5. Levels of engagement
6. Productive partnerships

# 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



# The shift to engaging citizens in healthcare

There is a general move to have us as patient and family advisors:

- In hospitals
- For health authorities, ministries, arms-length gov't bodies
- For other healthcare service organizations like LTCs

And we are already involved in research:

- Cochrane
- UK – INVOLVE
- US – PCORI
- On research teams driven by CIHR and other funders

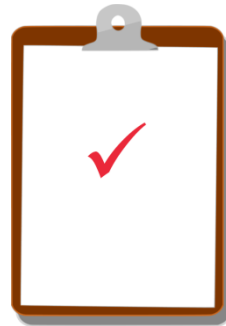
# The challenge for researchers

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



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# 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



# Us as partners vs us as subjects

Working together

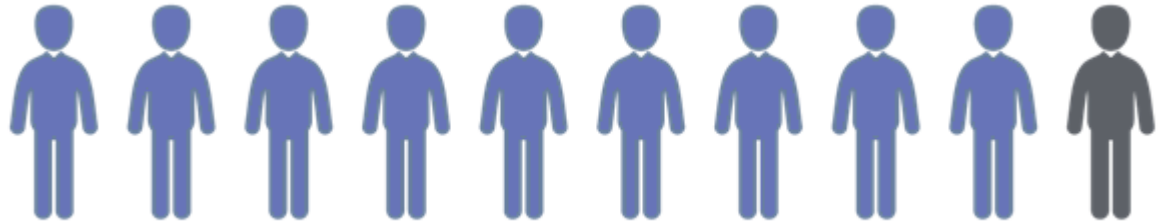


Studying the subject



# Canadian attitudes to health research

Health and medical research improves healthcare



Health research benefits the economy



Not aware of opportunities to participate



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<http://www.rc-rc.ca/polling/2015-poll>

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# Key considerations in working with us

Ethical

Literacy

Practical

- Acknowledging our expertise
- Confidentiality goes both ways
- Should we be on all types of projects?



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# Key considerations in working with us

Ethical

Literacy

Practical

- Level the playing field – brief us on terms and concepts
- Keep us up-to-date
- Can we help popularize the research?



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## Key considerations in working with us

Ethical

Literacy

Practical

- Who wants to partner, why and where are we?
- Resources and funds needed to support us
- Extra time to develop productive relationships with us



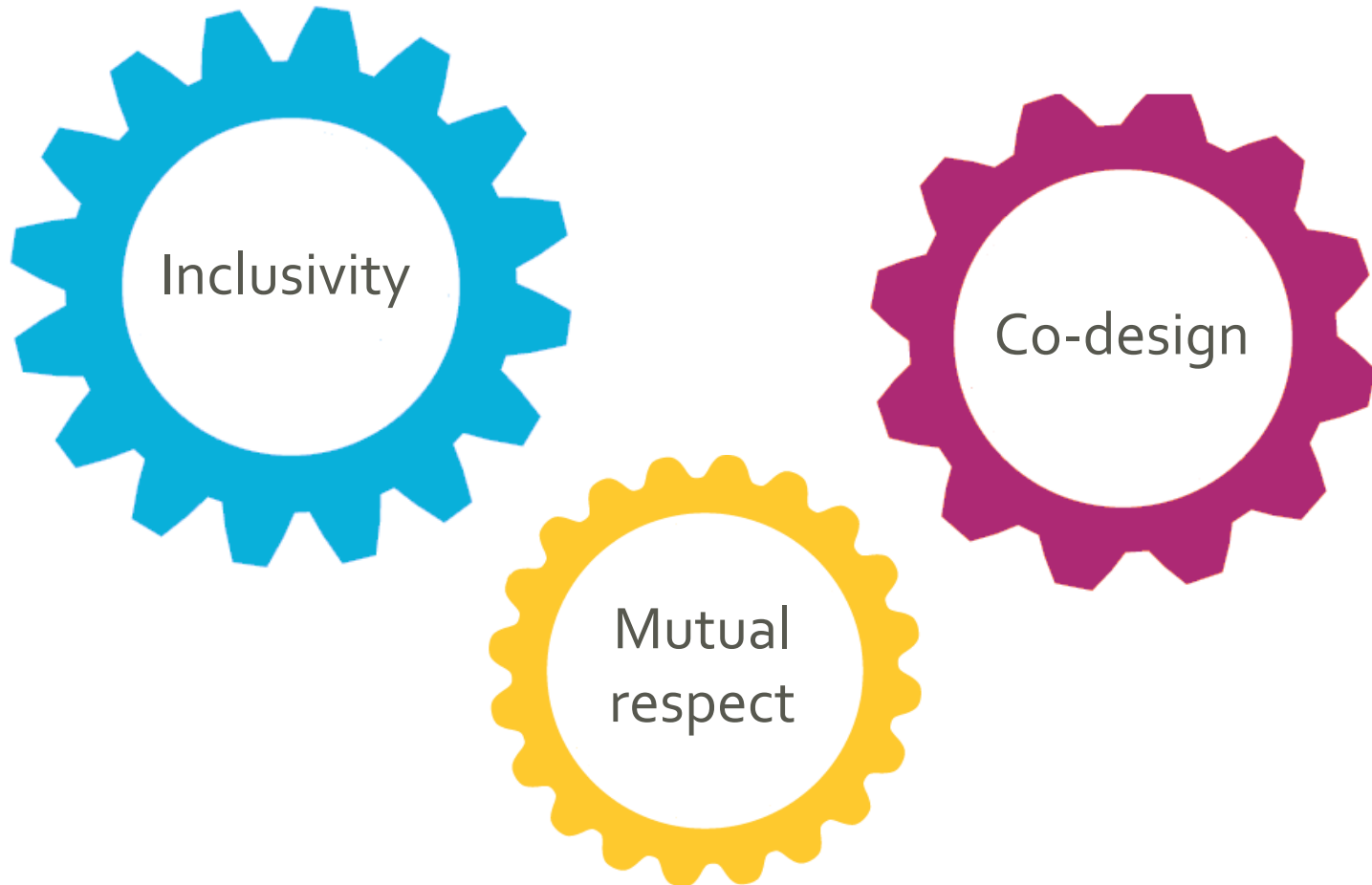
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# Guiding principles for partnership



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INFORMATION  
SHARING

CONSULTATION

COLLABORATION

PARTNERSHIP

# What are ways of involving us?



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# Involvement guide

## Understanding levels of involvement

INFORMATION  
SHARING

CONSULTATION

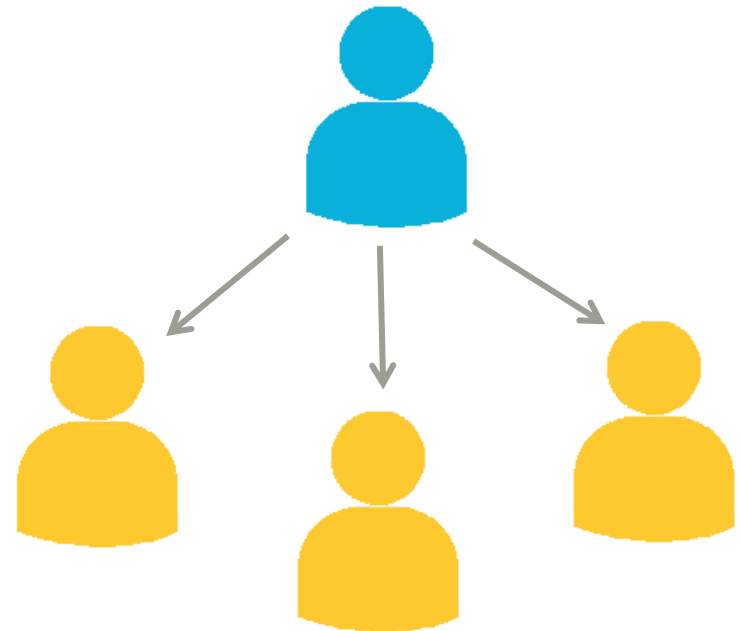
COLLABORATION

PARTNERSHIP

Provide information to us for understanding

- problems
- opportunities
- solutions

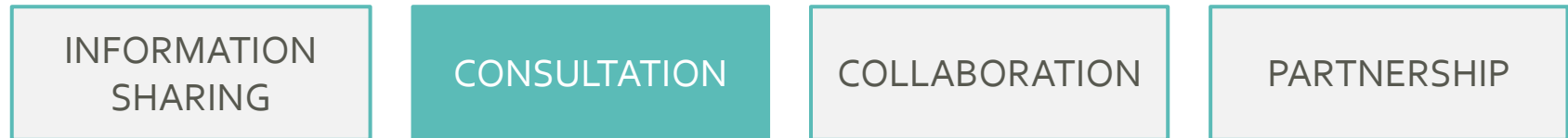
Ex: fact sheets, website, mass media, open house





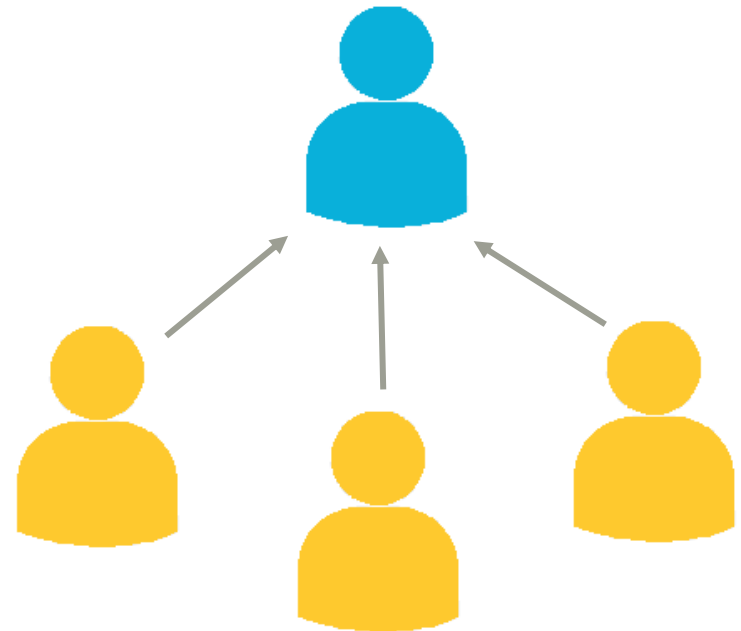
# Involvement guide

## Understanding levels of involvement



Getting feedback from us

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



# Involvement guide

## Understanding levels of involvement

INFORMATION  
SHARING

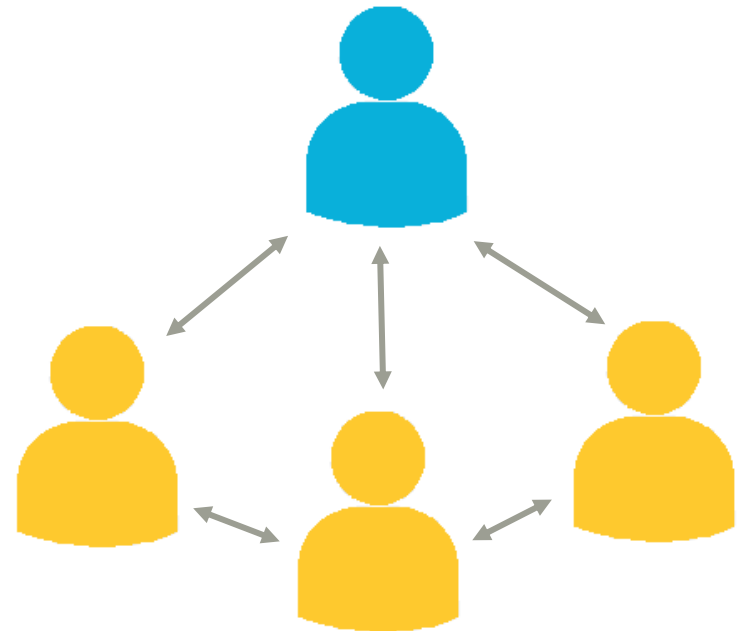
CONSULTATION

COLLABORATION

PARTNERSHIP

Involving us continuously throughout  
the research process

Ex: mentorship programs, webinars  
and workshops, conferences



# Involvement guide

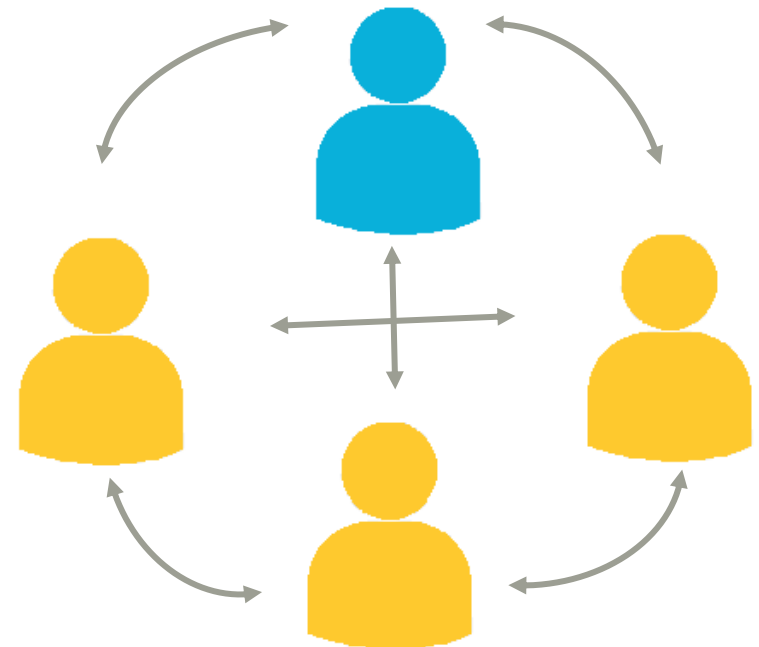
## Understanding levels of involvement



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



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# Dealing with our concerns

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

# Recognizing your concerns

- Time to involve and partner with us
- We, as citizens, 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

## 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



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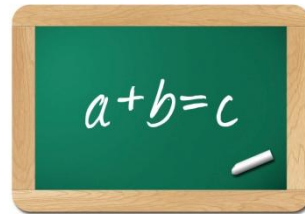
# Ingredients for creating productive partnerships

## 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



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# Agenda

1. Understanding the basics
2. **Developing a partnership plan**
3. Recruiting and on boarding partners

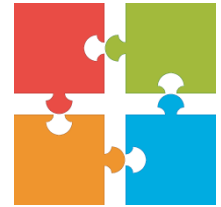


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## Developing a partnership plan



1. Defining the project for the public
2. Approaches to partnership
3. Mapping the research process for partnership roles
4. Defining support
5. Measuring success
6. Impact on the funding application

# Defining the project for the public

What is the relevance of the project to us, the public?

Who benefits and how?

Is it sustainable?

What are the research success measures?

“Citizen engagement is meant to ensure that funded research reflects the needs and values of Canadians...”

CIHR’s Framework for  
Citizen Engagement

# Approaches to partnership

We can be....



Individual citizens  
on the team



On a citizen panel



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# Considering a panel of citizens

Why have a panel? What will it do?

How will the panel relate to the team?  
Advisory vs decision-making

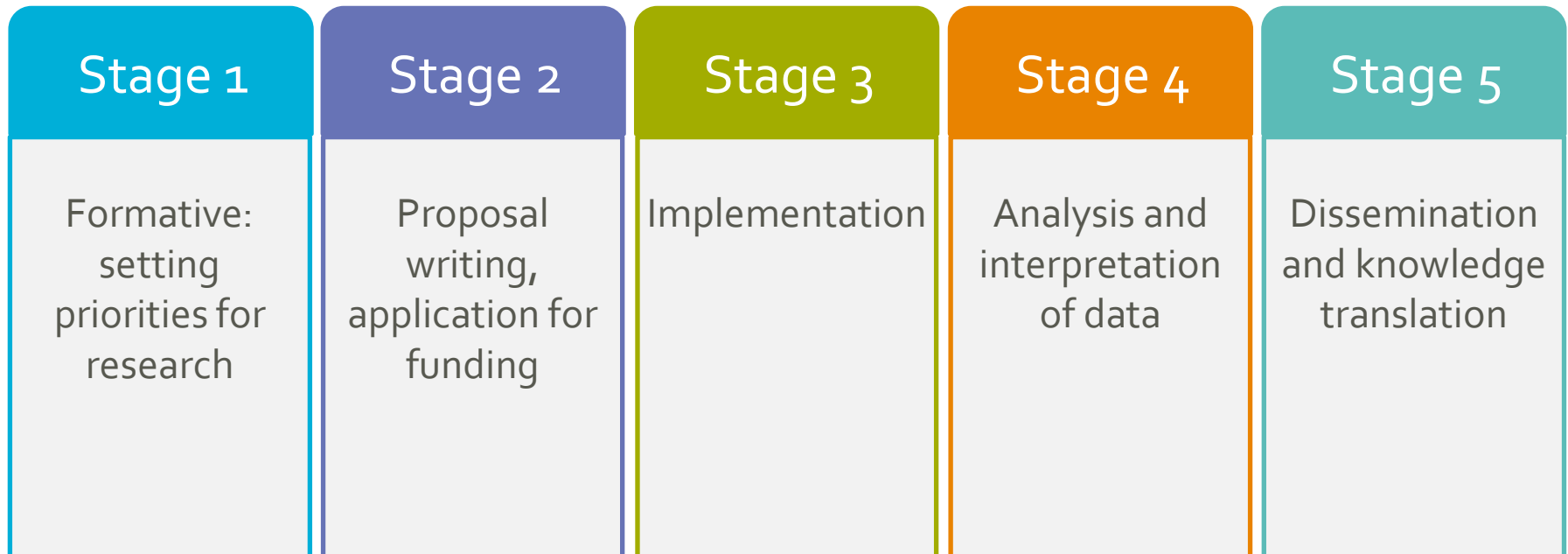
Practical considerations:

- Support for meeting attendance
- Terms of Reference
- More coordination required



# Mapping out the research process

Exploring possibilities for partnership



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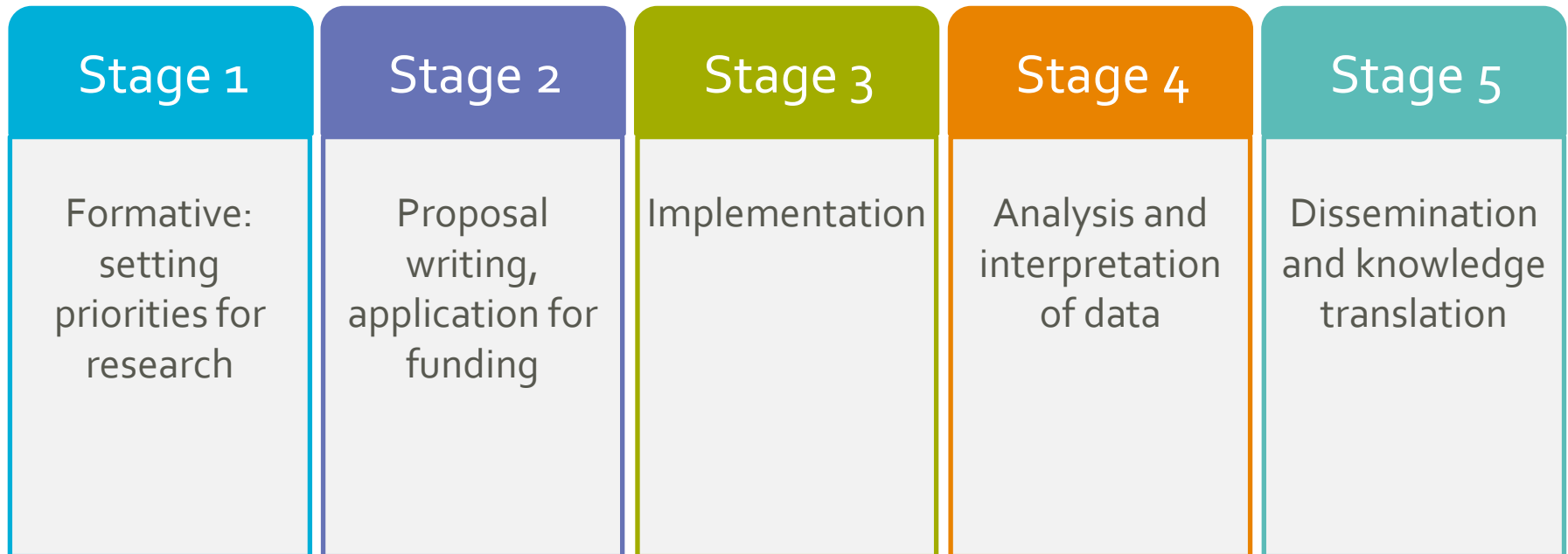
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Developing a partnership plan

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# Mapping out the research process

Exploring possibilities for partnership



Stages 2-5

Developing and implementing a marketing/communications plan



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# 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...



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## 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



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# 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...



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# Stage 3: Implementation

## Stage 3

### Implementation

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

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



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# 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...



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# Our partner roles

Develop a role or “job” description from the review of the stages



Review the partnership approach and assign roles

- Individual partners
- Panel
- Both



# Building a partnership timeline and budget

## Time factors

- Building the partner plan
- Recruiting, on boarding and orientation
- Coordinating and supporting



## Budget factors

- Expenses
- Honoraria
- Extra time and resources to coordinate partners



# Planning support for us as partners

## Who

- Which team member?
- Peer support?



## How

- Admin help
- Expenses
- Access and attendance considerations
- Proactive check ins
- Quick resolution of any issues
- Consistent updates and follow ups

# What does partnership success look like?



With the partners,

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



# Evaluating the partnership

- How do you 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?

# Partnership impact on the application

The partnership plan can impact on the following sections:

- Summary
- Detailed description
- Knowledge transfer
- Team roles
- Patient engagement
- Timelines
- Budget



# Summary: Developing a Partnership Plan

Roles / stage

Stage 1

Stage 2

Stage 3

Stage 4

Stage 5

Stages 2-5

Partners (+ panel?)



Support



Measurement



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# Agenda

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3. Recruiting and on boarding partners



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# Recruiting and on boarding partners

1. Recruitment process
2. Profiling candidates and our role
3. Attracting and sourcing candidates
4. Selecting partners and panelists
5. On boarding



# Recruitment process

This is **not** like recruiting subjects for research. It's more like a hiring process:

1. Develop a candidate profile and job description
2. Making the need known – the flyer and the method
3. Screening and interviewing candidates
4. Signing up us up as partners and panelists
5. Bringing us on board

# Who do you need and what will we do

Assemble the 'job' description:

- From the **Partnership Plan** identify our partner or panelist roles per stage
- Include characteristics of the research project impacting who you are looking for
- Include the team's commitment to us as partner or panelist

Profile the type of person who makes the best candidate:

- Who can do the 'job'
- Who 'fits' the team



# Project elements impacting recruitment

Method



- Quantitative
- Qualitative
- Mixed methods

Location



- Geographic scope
- Sites of care
- Rural - urban

Commitment



- Project length
- Time commitment



# Role description

What are the roles outlined in the Partnership Plan?

- Patient partners on the research team > “job” description
- Panel members > Terms of Reference

Include locations and time commitments



# Commitment is a 2-way street

The 'job' description for the team partner and Terms of Reference for panelists include:

- What we will do for the project
- What you will provide us as support
- How do you keep us in the loop



# Profiling a prospective partner

What type of person will add value to your project?

Experiences:

- Patient and/or caregiver
- Time and ability to move beyond our own personal issues
- Real world
- Patient advisor

Soft skills:

- Communication
- Collaborative
- Confidence



# Profiling a prospective panelist

What type of panelists? How many?

Experiences:

- Patient and/or caregiver
- Time and ability to move beyond our own personal issues
- Real world
- Diversity

Soft skills:

- Communication
- Collaborative
- Confidence



# Attracting and sourcing candidates

Two things are needed to attract and find those of us willing to be candidates:

- An excellent recruitment flyer
- A game plan for where and how to distribute the flyer

# Recruitment flyer

This is not the same as the subject recruitment flyer.

This is the “sales” flyer – it includes:

- The research story (the hook or sales pitch)
- Target candidate = those of us with interest in the research area
- Commitment required
- Contact info
- Catchy design/look



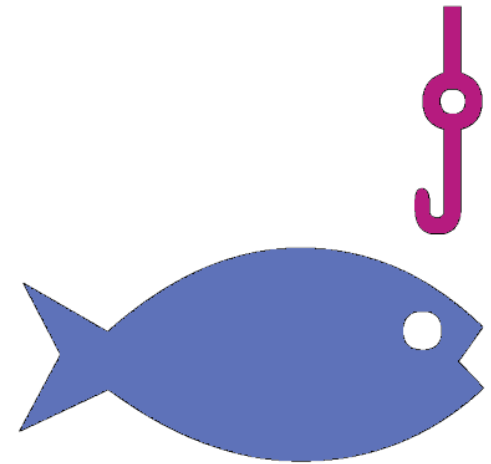
# The research story – what's the hook?

Why is the research important to us?

What is the potential societal good of the research?

Why is it important that we be involved?

What is the benefit to us in partnering on this research?



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# Where and how to distribute the flyer

Physical locations that permit posting flyers

Social media - with attachment or link to online site

Informal networks – emails to those you know



# Sources

Where to find those of us who might be interested in research:

- Your network
- PFAs
- Community organizations
- Community centres
- Health centres
- Disease based organizations
- Patient, caregiver groups
- Social media



## Selecting partners and panelists

Select at least 2 of us as team partners and at least 2 as extra panelists to handle potential attrition over the duration of the project

- Screen those of us who are candidates by phone
- Interview us with more than one team member to ensure fit – for the team and for us

Schedule on boarding activities

# On boarding

Pre-participation materials

Orientation to partnership

- For patient partners
- For panelists
- For researchers and other team members

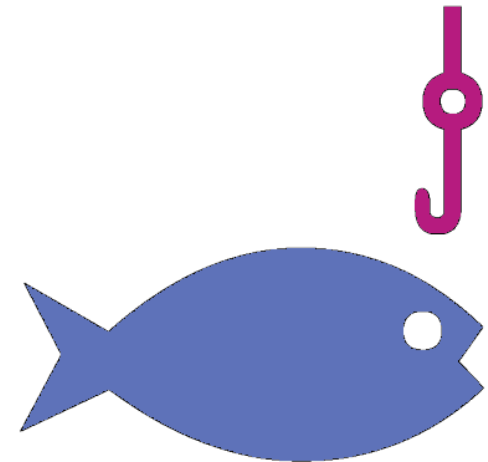
Introductions and initial team meeting



# Summary: Building a Recruitment Plan

Define:

- What we will do
- Who we are
- Where to find us
- How to reach us
- How to bring us on board





## 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

# Questions

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



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