



Patients Canada



Welcome!

Webinar 5: Creating Patient Partnerships
Thursday, January 19 2017, 12:30 – 1:30 pm

Get started now:

Check if your **speakers** are working: use the Audio Setup Wizard to test your speakers. To access the wizard, select '**Audio**' under the '**Tools**' menu. You don't need a microphone or webcam.

Any issues?

Contact Technical Support at 1-866-435-1396 or 709-864-8700 (Option 3).

How to participate in this webinar

The screenshot shows the Blackboard Collaborate interface. On the left, the 'AUDIO & VIDEO' section has 'Talk' and 'Video' buttons. Below it, the 'PARTICIPANTS' section shows a list of participants in the 'MAIN ROOM'. A red circle highlights the 'Raise Hand' icon (a hand with a checkmark) in the participant list. Below the participants list is the 'CHAT' section, also circled in red, showing a list of chat messages. The main area displays a presentation slide titled 'Participant Interactions' with the JISCnetskills logo. A smaller inset window shows a detailed view of the 'PARTICIPANTS' list for 'Alice Brown (College of Knowledge)'. Red arrows point from text labels to various icons in this inset: 'Step Away' points to the hand icon, 'Your details' points to the name, 'Raise Hand' points to the hand with checkmark icon, 'Emoticons' points to the smiley face icon, 'Voting' points to the 'Yes', 'No', and 'None' buttons, and 'Moderators' points to the 'Moderator' label. A notification box at the bottom right shows a message: 'Andrew Treloar 1 #2 joined session.' with a 'Dismiss All' button.

Participant Interactions

Blackboard Collaborate Orientation for Participants

JISCnetskills

Step Away

Your details

Raise Hand

Emoticons

Voting

Moderators

All Participants (listed alphabetically)

© JISC Netskills 2011

3 notifications Dismiss All Dismiss

Introduction

Moderator:

(Lidewij) Eva Vat, Training and Capacity lead –
NL SUPPORT

Guest speaker:

Alies Maybee, patient advisor and former
business analyst



Support for a change in
the way we do research.

NL SUPPORT offers the opportunity to create an entirely new research culture in Newfoundland and Labrador: focused on achieving real-world results for patients.

Webinar #5

Creating Patient Partnerships





Patients Canada

Partnering with citizens in research

What's helpful from our perspective

Patient Advisor Authors:

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



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

alies.maybee@gmail.com



Who are you?

Have you partnered with patients in research?

- Yes
- No



Who are you?

Are you a patient partner in research?

- Yes
- No



Contents

1. Context, considerations and concepts
2. Planning for involving citizens

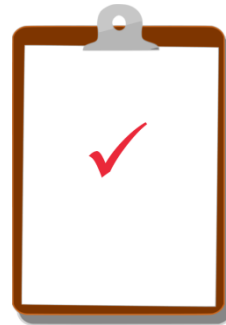
The context for researchers

Citizens are 'in'



Engaging 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



Key concept: patients as partners vs subjects

Working together



Studying the subject



Dealing with our concerns

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



What other concerns do you think patients have about partnering in research?

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



What other concerns do you have about partnering with patients in research?

Considerations – how to treat us

- Acknowledge our expertise
- Factor in our limitations
- Confidentiality goes both ways



Considerations – how to work with us

- Should we partner on all types of research?
- Prepare us – brief us on terms and concepts
- Keep us up-to-date



Considerations – what is needed

- Who wants to partner – why do they – and where are they?
- Resources and funds
- Time to develop productive relationships



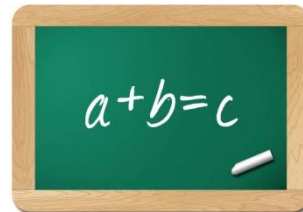
Ingredients for creating productive partnerships

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



Contents



1. Context, considerations and concepts
2. Planning for involving citizens

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



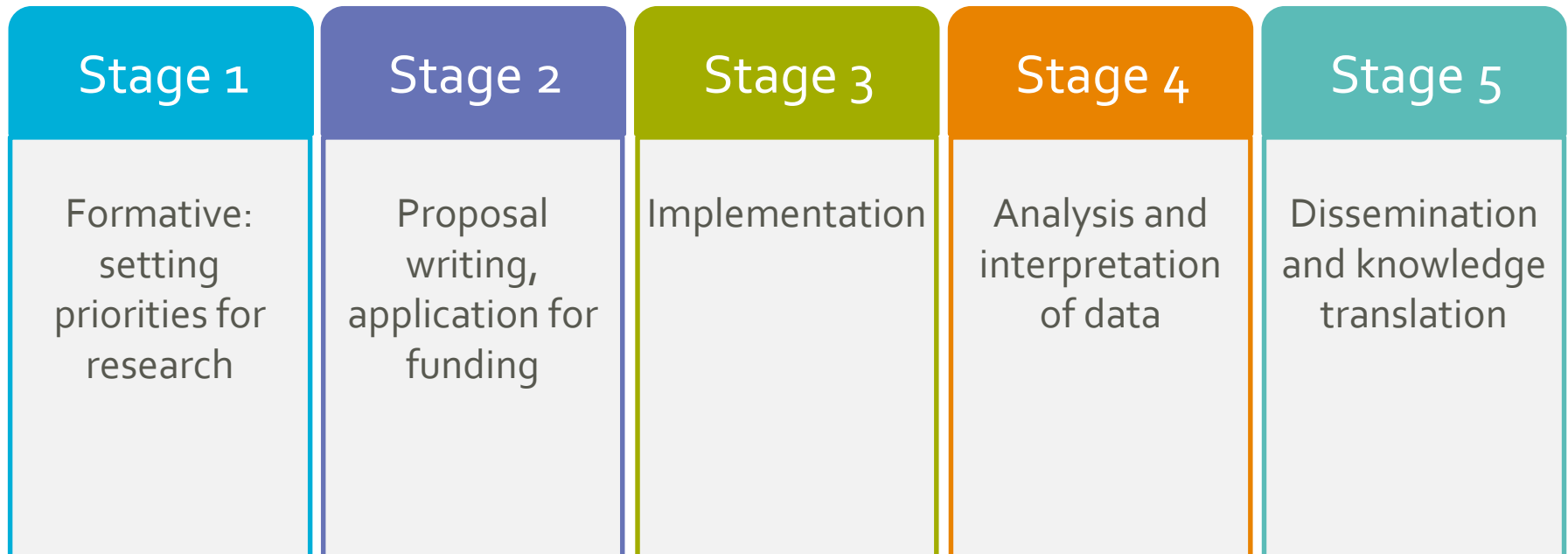
On a citizen group



Patients Canada
Make your experience count

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

Framework for public involvement

INFORM

CONSULT

COLLABORATE

PARTNER

What are ways of involving us?

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

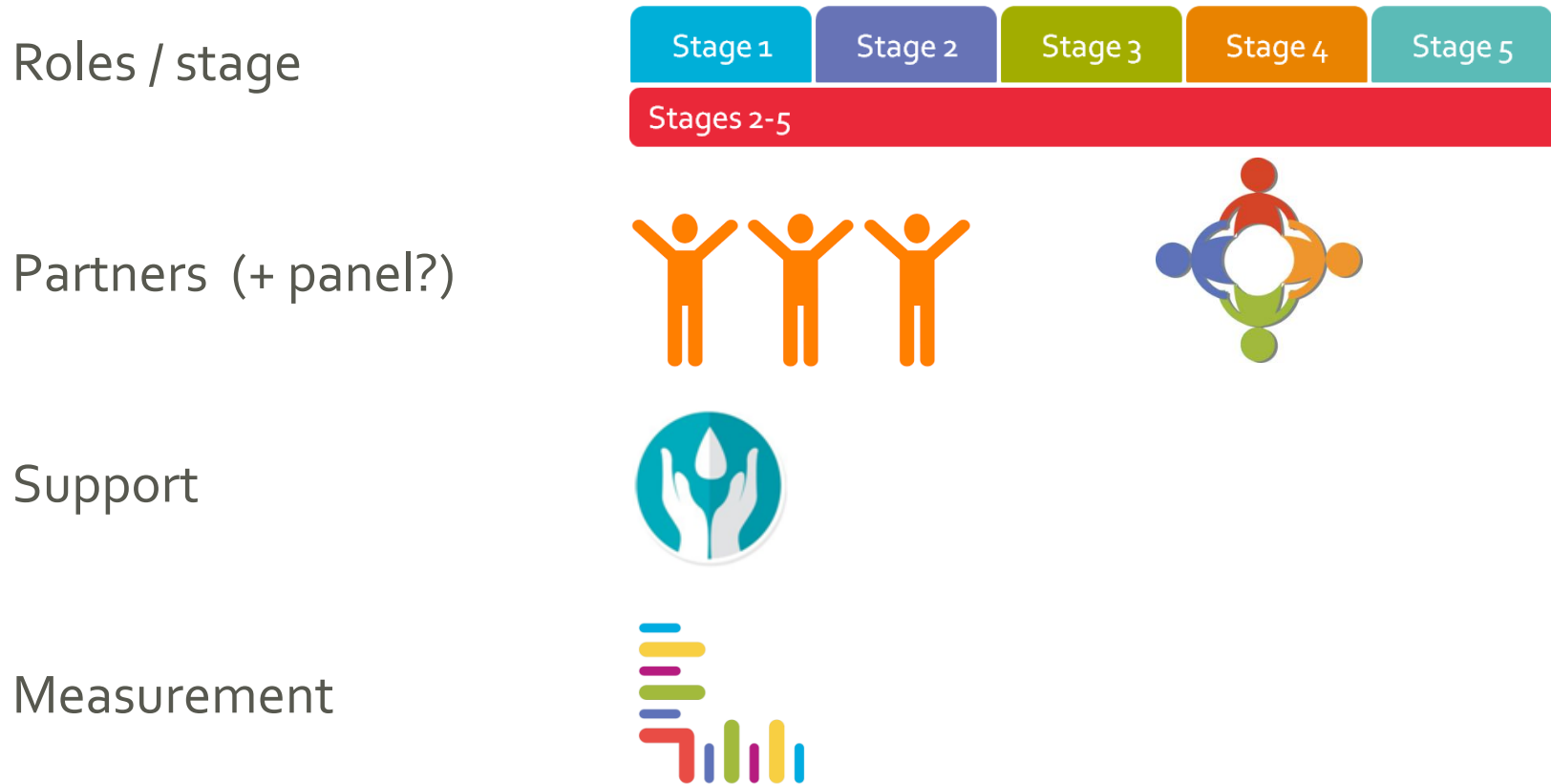
Partnership impact on the application

The partnership plan can impact on the following sections:

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

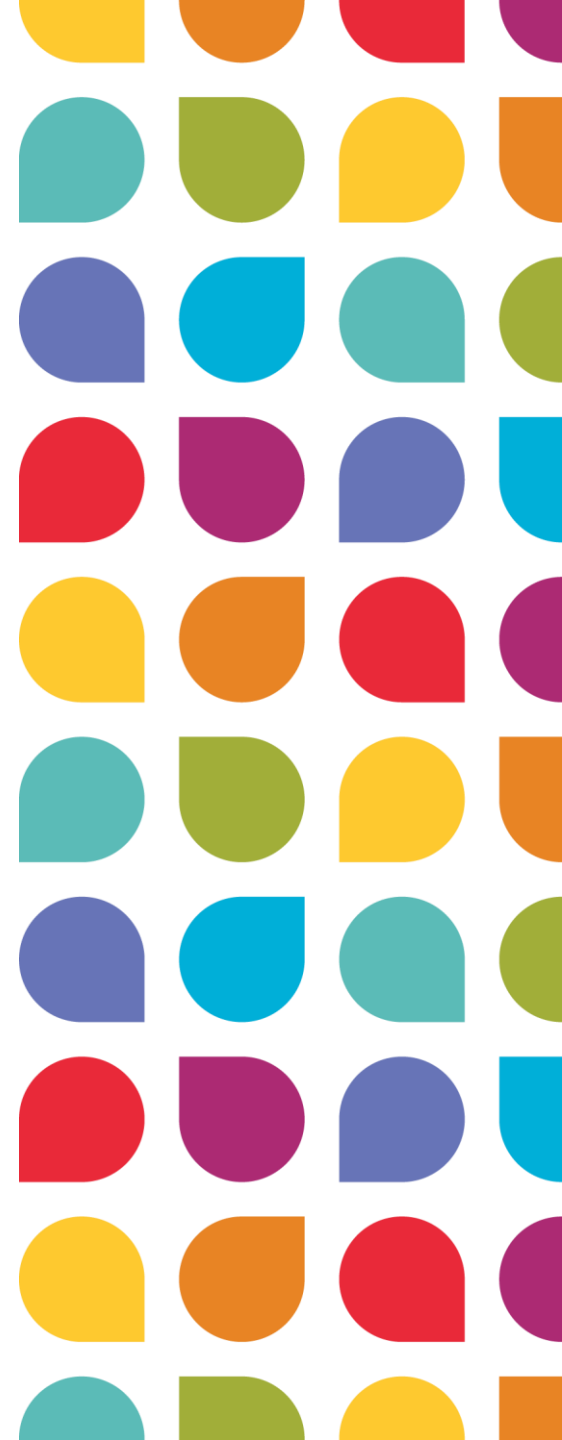


Summary: Developing a Partnership Plan



Questions

Thanks for participating!



Further learning / tools

- [Patient and Public Engagement Planning Template](#)
- [Tools for partnering with patients in health research](#)
- [Patient Advisors Network Canada](#)

Are you interested in becoming involved as a Patient Advisor in Newfoundland and Labrador?

Contact Eva Vat, eva.vat@med.mun.ca or 709 864 6654

Upcoming sessions

Save the date:

Webinar 6: Make an impact

Thu, 16 February 2017 12:30 PM – 1:30 PM
NST

Dr. Sheila Garland, Clinical Psychologist and
Assistant Professor of Psychology and
Oncology at Memorial University

Go to <http://nlsupport.eventbrite.ca> to register

Help us to improve

Please share your comments and experiences

Go to:

<https://www.surveymonkey.com/r/webinarNlsupport>
to complete the evaluation of this session.

End of session

Thank
you



Patients Canada
Make your experience count