

A Communication Toolbox

for Optimizing Family Engagement in Research

By Mindy Silva & Jennifer Appelton

This pdf download links to free tools to improve early communication for researchers and families engaged in research.

Avoid the pitfalls and roadbumps to relationship building which forms the foundation of any succesful parent-researcher partnership.

The links are current as of December 2019.

Feel free to email us with your thoughts, comments or suggestions.

Hope your project is full of rainbows and unicorns...

Mindy & Jennifer

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IMPORTANT DISCUSSIONS

--> Student Projects / Canchild

--> East Midlands Academic Health Science Network

A QUICK REFERENCE GUIDE:
AUTHENTIC PARTNERSHIP IN RESEARCH

I INCLUSIVITY	M MUTUAL RESPECT	P PARTICIPATION	A ACCOUNTABILITY	C COLLABORATION	T TRANSPARENCY
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PRINCIPLES & VALUES

Inclusivity Integrate diverse patient perspectives and their contributions. Be inclusive of all people and their views.	Mutual Respect Acknowledge and value each other's expertise and understanding. Respect for all views and perspectives. Engage in a respectful and collaborative conversation.	Participation Value the contributions of all stakeholders. Encourage participation from all stakeholders. Share the benefits of research and work together to produce and implement solutions.	Accountability Maintain a safe environment that promotes honest communication. Share information and be accountable to one another for all decisions and actions.	Collaboration Support and flexibility should be encouraged. That they can contribute to the project. Provide a supportive environment to make decisions and actions together with each other's experience.	Transparency Information should be shared readily with all stakeholders and should be available to all stakeholders. Be transparent in all decisions and actions. Share information with each other's experience.
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BEST PRACTICES

PLAN

- Plan together different perspectives. Consider the needs of all stakeholders. Plan together to ensure the project is inclusive and collaborative.
- Identify the goals, objectives, and outcomes of the project. Consider the needs of all stakeholders.
- Identify the roles and responsibilities of all stakeholders. Consider the needs of all stakeholders.
- Identify the resources and support needed for the project. Consider the needs of all stakeholders.

DO

- Monitor and clearly report progress together.
- Monitor and clearly report progress together.
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- Monitor and clearly report progress together.

Effective communication
10 top tips

1. Assume you are the expert in your area.
2. Make your confidence.
3. Be confident your own views matter.
4. Show them.
5. Sum up.
6. Listen.

EMAHSN top tips for patient and public involvement

Written by Drs Sue Deery, Sarah Jones, and Sarah Jones. If you need help understanding or if you have any questions, please contact us at 0115 821 1300 or email us at ema@ema.ac.uk or www.ema.ac.uk

Family Engagement Checklist

- Financial Compensation
- Time Commitments
- Temporary leave & re-engagement options
- Participant/Researchers motivations
- Project Goals
- Project outcome measures related to family engagement
- Timeline Planning
 - a. Start - Stop - Continue Activity
 - b. Dedicated feedback times of projects progress

Start, Stop, Continue Activity source -->

Patient Engagement in Action: A Case Study in Patient Oriented Research

<p>Start "What should we start doing?"</p> <p>List ideas/items that:</p> <ul style="list-style-type: none"> • The group is not doing, but think they should be • New ideas that have come up or not been considered before • Ideas to address new situations or factors that may not have existed at the beginning of a project or task 	<p>Stop "What should we stop doing?"</p> <p>List ideas/items that:</p> <ul style="list-style-type: none"> • Are not working for the team • Are not having the desired outcome • May have proved to be impractical • The team just plain dislikes 	<p>Continue "What should we continue doing?"</p> <p>List ideas/items that:</p> <ul style="list-style-type: none"> • Are working well and the team wants to keep • The team likes and thinks are successful • May be pieces of processes that the team wants to "stop" – keeps team from "throwing the baby out with the bath water"
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Roles & Stages

De Hoogstraat Revalidator UMC Utrecht
Center of Excellence for Rehabilitation Medicine Utrecht

BOSK
Vereniging van mensen met een lichamelijke handicap

INVOLVEMENT MATRIX

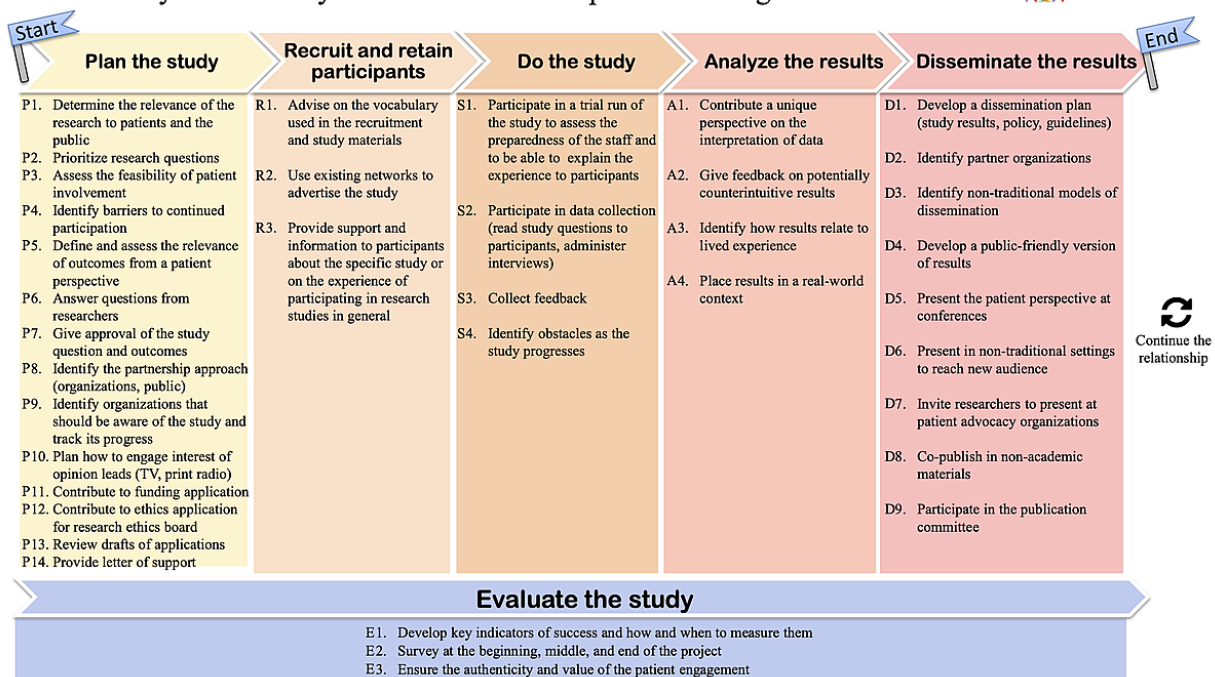
An explanation of the five roles can be found on the next page
Please read the practical guide before using the Involvement Matrix

		ROLE IN PROJECT/RESEARCH				
		Listener <i>Is given information</i>	Co-thinker <i>Is asked to give opinion</i>	Advisor <i>Gives (un)solicited advice</i>	Partner <i>Works as an equal partner</i>	Decision-maker <i>Takes initiative, (final) decision</i>
STAGE OF PROJECT/RESEARCH	Preparation					
	Execution					
	Implementation					

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--> Involvement Matrix Instructions

Ways Community Members Can Participate in the Stages of Research



FINANCES + BUDGETS

--> Get the Decision tool



NHS
National Institute for
Health Research

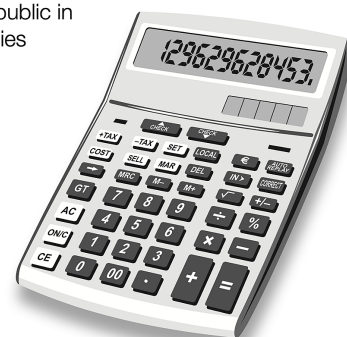
Select your resource:

1. --> [Online Budgeting for Involvement Tool](#)
2. --> [PDF Booklet](#)

Budgeting for
involvement:

Practical advice on
budgeting for actively
involving the public in
research studies

June 2013



TEMPLATES

The templates on the following pages have been kindly shared with us by:

McMasters University

through their

Family Engagement in Research
Course (Canchild)

--> [get more info](#)

Click on the name to jump directly to the template

1. Research Partners Resumé
2. Family Partner Resumé
3. Team Member Intro
4. Family Engagment Plan
5. Brainstorming

Research Partnership Resume
Research Trainee Template

NAME AND CONTACT (phone, email, twitter, LinkedIn, etc.)

EDUCATION:

RESEARCH INTERESTS

PUBLICATIONS/PRESENTATIONS (Highlight five key publications/presentations):

RELEVANT WORK/VOLUNTEER EXPERIENCE

RELEVANT WORK/VOLUNTEER EXPERIENCE

RELEVANT ASSOCIATION MEMBERSHIPS:

(e.g., Autism Canada, Cerebral Palsy Association, etc.)

HOBBIES/INTERESTS

STRENGTHS/SKILLS THAT YOU CAN BRING TO A RESEARCH PROJECT

(i.e., what do you want family stakeholders to know about you)

Research Partnership Resume
Parent Partner Template

NAME AND CONTACT (phone, email, twitter, LinkedIn, etc.)

CHILD'S AGE AND DIAGNOSIS:

TELL US WHAT WE SHOULD KNOW ABOUT YOUR LIVED EXPERIENCE
(e.g. managing complex care, sleep disturbances, augmentative communication, sign language, tracheotomy, gastrostomy, behavior challenges, indigenous communities etc.)

PREVIOUS EXPERIENCE AS RESEARCH PARTNER:

OTHER RESEARCH EXPERIENCE:

RELEVANT ASSOCIATION MEMBERSHIPS:
(e.g., Autism Canada, Cerebral Palsy Association, etc.)

RELEVANT ONLINE GROUPS (e.g., Facebook groups)

HOBBIES/INTERESTS

STRENGTHS/SKILLS THAT YOU CAN BRING TO A RESEARCH PROJECT
(i.e., what do you want researchers to know about you and your strengths/capacities that you bring to a research project?)

Team Member Introduction



Add image here
(.jpeg, .png)

Name:

Town:

Your Role:

Languages:

My background...

My strengths are...

Something I would like to try, learn or continue to work on is...

I would like to be involved in...

Anything else you would like your team to know?



FAMILY ENGAGEMENT PLAN

Who is involved on your research team as a family stakeholder and what are their roles?

Who is your target audience?

How did/will you conduct a family stakeholder needs assessment?

How did/will you involve family stakeholders in the research planning and design?

How will families be involved in data collection and analysis?

What are the barriers in your project to involving families, and how do you intend to overcome them?

What are the intended outcomes of the project for families?





Name:

Team Brainstorming

Describe the project in your own words...

What are your hopes/goals of the project?

Who do you see participating and/or benefiting from the project?

What factors/key questions do we need to consider when developing the project?

In the short term what do you think needs to be done to make the project successful?



COMMUNICATE your way to SUCCESS

PLAY VIDEO ►



Thanks for checking out our resource

Mindy & Jennifer