

 **Tool 1.1: ENGAGING STROKE/CAREGIVER PARTNERS ON**

 **YOUR PLANNING TEAM**

**Section in Planner: Phase 1 Step 1 (1.1)**

**Why is this important?**

Factors known to promote meaningful engagement of stroke/caregiver partners on the planning team include: offering convenience for participants, being clear about the type of contribution and interaction, addressing support requirements, ensuring inclusivity and appreciation, and recognizing the perceived benefits of participation.\*

**How to use this tool:**

This tool has three components:

1. A **template invitation for engaging stroke/caregiver partners** on the planning team.
2. **Questions to assess stroke/caregiver partner preferences for involvement**: After you introduce the project to a potential stroke/caregiver partner, consider using these questions to guide a more detailed discussion with them about their interests, availability, preferences, and needs.
3. **TIPS** for engaging and working with stroke/caregiver partners on the planning team.

Use and adapt these resources to suit your own setting and circumstances, as needed.

**User Comments:**

*“Actively involving and engaging key-stakeholders and users of programs* (people with stroke) *to be part of the planning and implementing process is critical. They know best what they need and can identify areas in need that otherwise might not be known to program developers.”* (Person with stroke)

*“It’s not necessarily feasible or appropriate for them (*people with stroke /caregivers*) to be at every planning team meeting, so connect with them 1:1 after planning team meetings to get their input on key items.”* (Physiotherapist)

\* Guidance is adapted from the PEIR (Patient Engagement in Research) Workbook developed by the University of British Columbia and Arthritis Research Canada, 2018; <http://www.arthritisresearch.ca/wp-content/uploads/2018/06/PEIR-Plan-Guide.pdf>

**1. Invitation to a stroke/caregiver partner to participate on the planning team**

*Modify this template as needed to introduce your project to a potential stroke/caregiver planning partner. Provide sufficient time to read and reflect on the information; encourage potential partners to ask questions to help them make informed decisions about joining the planning team.*

Dear [*Name*],

**Would you like to be part of an exciting opportunity to co-design a community-based exercise program for people with stroke?**

Exercise can have many physical and social benefits for people living with the effects of stroke. However, many people living with stroke do not have access to community-based exercise programs that meet their needs. We are forming a team to co-design a new community-based exercise program for people with stroke.

Your lived experience as [*a person living with stroke or a caregiver*] is essential to creating a successful program. To ensure that the exercise program will optimally meet the needs of our community, we need people with stroke and their caregivers to contribute their knowledge and experience to the planning process.

We would like to invite you to be part of the planning team. This letter provides some information about the planning team, our approach, and what we hope to accomplish.

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**What is the “planning process” for the new program?**

Together, our team will work through several steps to plan and implement a community-based exercise program for people with stroke. Not every team member needs to be involved in every step. You may choose which parts of the planning process are most aligned with your interests, skills, and availability. To summarize, we will:

form a planning team to co-develop a strategy for implementing a new exercise program;

explore the needs of the community and how the new program can address these needs;

select an exercise program that matches community needs and interests

identify potential challenges and strengths for delivering the selected program;

develop strategies to address key challenges;

decide how we will monitor and evaluate the success of the program;

promote, launch and deliver the program;

monitor the use and outcomes of the program and make adjustments as needed to support the success of program participants and maintain the program over the long-term.

**Who can join our planning team?**

Individuals who are living with the effects of stroke

Individuals caring for people with stroke (e.g., caregiver, family, friends)

The planning team will also include [*fitness professional, health care professionals, program manager, etc.*].

**What will I do?**

Between [*month, year*] to [*month, year*], attend a [*monthly, bi-monthly*] meeting. These [*one hour*] meetings will be conducted [*specify method – online, in-person*]. At these meetings, we will work through the planning process described above.

We will circulate materials prior to each meeting.

If you are a person living with stroke, you will also be invited to participate in the exercise program so that you can provide feedback on your experience. The opportunity to enroll in the exercise program is optional and not required to participate on the planning team.

Based on your interest and availability, we can determine a time commitment that works for you. We will make every effort to accommodate your needs and preferences.

**Will I be compensated?**

In appreciation of your time commitment to the planning process, you will receive an honorarium of [*specify amount and methods: $X, gift card*].

If taking part in this planning team results in any out-of-pocket expenses, you will be reimbursed. For example: [*specify what will be reimbursed: parking, transportation, caregiving costs; also indicate whether any fees for the exercise program will be waived*].

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Thank you for considering joining the planning team. Your voice as [*a person with stroke or caregiver*] is essential in the planning and implementation of an exercise program that will truly meet the needs of people with stroke in this community.

If you would like more information or have any questions, or would like to participate, please contact me at [*phone number*] and/or [*email address*].

Sincerely,

[*Add name and contact information*]

**2. Questions to assess stroke/caregiver partner preferences for involvement**

*After you introduce the project to a potential stroke/caregiver partner, use the questions below to guide a more detailed discussion with them about their interests, availability, preferences, and needs.*

|  |  |
| --- | --- |
| **Sample questions** | **Responses** |
| * Do you have any questions about the planning process and the steps involved?
	+ - Are there specific step(s) or aspects of the planning process that interest you most?
 |  |
| * What benefit(s) do you hope to get out of taking part in this project?
 |  |
| * Do you have any special needs or limitations that would impact your ability to read project materials, take part in meetings, etc.?
	+ - How can we best accommodate these needs?
 |  |
| * How much time do you have to participate in planning?
 |  |
| * What days and times are most convenient for you?
 |  |
| * How would you like to take part in meetings?
	+ - In-person? By phone? Online?
		- In a group setting? Or 1:1?
 |  |
| * How would you like to be kept up to date on the project?
	+ - Email updates?
		- Brief phone call updates?
 |  |
| * Would it be helpful to receive materials in advance of meetings?
 |  |
| * Will taking part result in any out-of-pocket expenses for you?
	+ - Reimbursement for travel? Parking?
		- [for stroke partners] - Reimbursement to have an attendant/caregiver assist you to participate in meetings?
		- [for caregiver partners] - Reimbursement for alternate care for person with stroke while you attend meetings?
 |  |
| * Is there anything else you would like to share with me?
 |  |
| * Do you have any questions?
 |  |

**3. TIPS for engaging stroke/caregiver partners on the planning team**

*Study stroke advisors offered these additional considerations for partnering with people with stroke and/or their caregivers:*

* Enable people with stroke to participate to the fullest extent they would like. Be aware of visual, auditory, communication, or cognitive challenges and accommodate any needs.
* Ensure planning materials are available in an accessible format (e.g., large font size).
* Minimize the use of jargon in your communications. Ensure communications are brief and written in plain language so they are easily understood. Limit the use of acronyms and medical terminology.
* Introduce stroke and caregiver planning partners to the team and make them feel welcome.
* Ask stroke and caregiver planning partners which part of the planning process is of greatest concern to them and where they feel they could make the most meaningful contribution.
* Consider keeping meeting times brief to accommodate potentially limited physical and cognitive energies.
* Be open to alternate methods of communication e.g. a planning team member might connect 1:1 with a stroke/caregiver planning partner after a team meeting to allow for a brief, focused discussion of relevant items.