**Canadian Heart Failure Alliance**

**Patient/Person with Lived Experience Intake Form**

# The Canadian Heart Failure Alliance (CHFA) is a patient-driven research network that brings the top Canadian researchers and clinical experts in heart failure (HF), together with patients, caregivers, Indigenous Elders and Knowledge Holders, government, policymakers, knowledge users, not-for-profit organizations, health care providers, academic institutions, and industry partners. The Alliance aims to improve the prediction, prevention, diagnosis, and management of HF across the lifecycle.

The CHFA is patient-driven and the partnerships with patients, caregivers, and the public are a vital and expected part of Alliance activities and research. This intake form is designed to provide an overview of the different key elements for developing partnerships with patients in health research, including exploring specific needs, preferences, and priorities. For the purposes of this document and accordance with our main funder (CIHR), the term ‘patient’ is used as an inclusive term to include those with lived experience, caregivers, family members, friends, and community members.

This intake form includes guiding questions for patient engagement in Alliance governance or themes, as well as questions that can guide engagement planning for individual research projects. Once completed, the Patient Engagement and Empowerment Platform will use the information to support the recruitment and matching of patient partners, along with identifying specific support needs to optimize the partnership processes and outcomes. All parties are asked to complete the relevant sections.

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| **Section 1** | **Perspectives on Patient Partnership & Empowerment** |
| 1.1 | In lay terms, provide a high-level description of the planned engagement activities. |
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| 1.2 | How will patient engagement support and advance the project/initiatives? Please be as specific as possible. |
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| 1.3 | When you think about your patients or patient partners in research, what key characteristics come to mind? |
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| 1.4 | When you think about your patients or patient partners in research, who is the most involved with their own HF healthcare and services? |
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| 1.5 | What kinds of patients do you think may be best positioned to participate in the planned research activities? |
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| 1.6 | Are there specific experiences (e,g., type of HF), characteristics (e.g., sex or gender), or knowledge (e.g., experience of particular health system services) that you feel is important to the planned engagement activities? |
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| 1.7 | Total number of patient partners you wish to be involved in this project (Note: depending on the project, it is advisable to have two or more patient representatives involved in a single project). |
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| 1.8 | Please consider the level of engagement you expect. You may identify the level of engagement planned (e.g., Inform, Consult, Involve, Collaborate, & Empower) by using the [International Association of Public Participation (IAP2) spectrum](https://iap2canada.ca/Resources/Documents/0702-Foundations-Spectrum-MW-rev2%20%281%29.pdf) as a guide |
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| 1.9 | Are there patients that may experience challenges in engaging in their healthcare? Are these perspectives important to your planned research? |
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| 1.10 | Do you perceive any barriers to patient engagement in the planned activities (e.g., Physical Space, Washroom accessibility for mobility aids, Cognitive processing needs, Differentiated instruction options, Sensory needs, Fine/gross motor requirements)? |
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| 1.10 B | What kinds of supports might be valuable to support participation? |
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| 1.11 | Will participants be able to engage in both National languages? Will other languages be supported? |
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| 1.12 | Is the planned scope regional, provincial, national or international? Please describe if any travel is required and what activities will be offered remotely |
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| 1.13 | Does the patient partner need to be in a relatively stable state of health at the time of engagement? |
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| 1.14 | How do you plan to evaluate the success of this engagement opportunity? You may consider using tools, such as the [Public and Patient Engagement Evaluation Tool](https://ppe.mcmaster.ca/our-products/public-patient-engagement-evaluation-tool) (PPEET)). |
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| 1.15 | How will patient partner contributions be recognized?Please indicate initial thoughts on authorship, recognizing contributions, and compensation. |
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| **Are you looking for patient partners for:** |
| **☐** | **Alliance Governance & Themes (Continue to section 2, skip section 3)**- These activities include leadership and oversight roles that are beyond individual projects. |
| **☐** | **Research Projects (Continue to section 3, skip section 2)**- These activities include partnerships on individual research projects within the Alliance. |

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| **Section 2** | **Patient Engagement in Alliance Governance & Themes** |
| **Committee/ Theme Name** |  |
| **Primary Contact**  | **Name** |  |
| **Email** |  | **Phone** |  |
| 2.1 | In lay terms, provide a high-level description of the committee/theme and key functions within the Alliance. |
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| 2.2 | Are other stakeholders/knowledge users engaged in the committee/theme? If so, please provide an overview (e.g., healthcare providers, decision-makers, policy-makers, researchers). |
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| 2.3 | Please indicate your plans regarding patient partner compensation. |
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| 2.4 | What types of activities will patient partners be responsible for within the planned activities? |
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| 2.5 | Are there specific timelines or commitments that are expected of patient partners? Consider hours per month/days per year. |
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| **Section 3** | **Patient Engagement in Research Projects** |
| **Project/ Initiative Name** |  |
| **Project Lead** | **Name** |  |
| **Email** |  | **Phone** |  |
| **Primary Contact** (if different from project lead) | **Name** |  |
| **Email** |  | **Phone** |  |
| 3.1 | In lay terms, provide a high-level description of the project, data collection methods, and the desired outputs/outcomes. 4-6 PowerPoint slides may also be used if available. |
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| 3.2 | Who is the primary audience for the project outputs? |
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| 3.3 | Has your project received ethics approval? If so, by which institution? |
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| 3.4 | Please indicate your project funding sourceif there are funds from outside the base Alliance funding. Please indicate your plans regarding patient partner compensation. |
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| 3.5 | What types of activities will patient partners be responsible for within the research project? |
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| 3.6 | Are there specific project timelines that require increased input from patient partners? Please be as specific as possible. Consider hours per month/days per year. |
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