**Consumer/Community representative role**

***Project summary***

Constraint Induced Movement Therapy (CIMT) is an effective treatment for arm recovery following stroke. CIMT involves completing high intensity arm exercises with the affected arm whilst constraining the persons unaffected arm (using a mitt) to stop them using it.

While CIMT is a strongly recommended intervention in the Australian National Stroke Guidelines, routine delivery remains poor. Even when therapists are skilled and motivated to do CIMT, a recent study by the chief investigator (L Christie) found that almost half of eligible stroke survivors decline to participate in a CIMT program.

There has been limited research exploring the acceptability of CIMT from a stroke survivor’s perspective. It is well established that when patient preferences for treatment are taken into account uptake and compliance improves, leading to better health outcomes and improved cost effectiveness.

We are planning to investigate patient preferences for arm rehabilitation using a discrete choice experiment. Discrete choice experiments (DCEs) are a type of survey based on theories from economics and psychology. They originated in marketing but are increasingly used in healthcare because they provide a unique way to quantitatively measure patient preferences for health and health care. For example, they allow us to measure how long people would be willing to constrain their unaffected arm for, if it means their recovery is faster.

**Research questions:**

1. What components (attributes) of upper limb therapy are most important to stroke survivors?
2. How can CIMT be delivered to maximise patient uptake?

***Scope of the role***

* The purpose of the role within this study is to provide a consumer perspective and lived experience expertise to the research project, in particular language and design of a survey for stroke survivors
* The aim of the consumer representative role is to facilitate partnership with consumers, community members and researchers to work together.

***Key duties***

* Attend research team steering committee meetings on a monthly basis via telephone/video conference
* Participate in activities of the committee
* Provide advice and expertise relating to stroke survivor experiences and priorities for the research topic area i.e. upper limb rehabilitation after stroke
* Review study documents to ensure they meet the needs of a stroke survivor audience and are written in plain language
* Provide input and feedback in relation to proposed consumer and community participation, interpretation and dissemination activities as part of the study

***Support***

* This study is currently unfunded and there the role would be conducted on a voluntary basis. However, the research team intend to pursue funding options (where available) and if funding were to be secured, an honorarium to cover out of pocket expenses will be paid for each meeting attended.
* Training and support relevant to the consumer representative role will be made available to the consumer representative

For further details, please contact Lauren Christie, Coordinating Principal Investigator, Senior Research Fellow- Allied Health, St Vincent’s Health Network Sydney on Ph: 0436 853 797 or via email: [lauren.christie@svha.org.au](mailto:lauren.christie@svha.org.au)