**Participant Information Sheet**

**Exploring the unmet needs of people who provide support to survivors of stroke using a national survey**

**Protocol Number:**  1.0 Ethics approval number: 35149

|  |  |
| --- | --- |
| **Coordinating Principal Investigator:** Professor Dominique Cadilhac, Head of Translational Public Health Research Division at the Stroke and Ageing Research Group, Monash University **Phone:** (03) 8572 2657**Email:** dominique.cadilhac@monash.edu **Co-Investigators:** Prof Dominique Cadilhac, Dr Jan Cameron, Dr Tharshanah Thayabaranathan A/Prof Nadine Andrews, A/Prof Eleanor Horton, A/Prof Rene Slowly, Dr Elizabeth Lynch, **Project coordinator:** Mr Shaun Hancock, email: shaun.hancock@monash.edu |   |

**Background:** Support people (or informal caregivers such as a spouse, or other family members, or friends) are often central to providing informal care to people living with stroke. Support people can experience unmet needs when they perceive the services required to manage both the health condition of the stroke survivor, or themselves, are inadequate. Experiencing unmet needs can result in adverse health outcomes for the support person and the survivor of stroke. This study is being conducted by Monash University and is intended to help us learn more about the experiences of providing informal care to people living with stroke and to understand if the support person’s needs are being met, or not. This study will provide important information for the planning and developing improved community services and additional support strategies for the support person and survivor of stroke.

Invitation letters were sent out through the Australian Stroke Clinical Registry to survivors of stroke asking if they had a support person that would be interested in participating in this study. We ask that you, as a support person, read this information sheet to be able to make an informed decision about volunteering to complete this survey. **The survey is for completion by the primary support person of a survivor of stroke**.

**What is the purpose of this research?**

We are seeking to understand the unmet needs of people providing support to survivors of stroke within Australia. The researchers will also be able to explore whether the type and extent of unmet needs have changed since the Australian Stroke Survivor and Carer Needs Assessment project conducted in 2011. This information will be used to understand how health and community services sectors can be modified to better meet the needs of people providing informal support to an individual after stroke.

**What do I have to do?**

The study will involve responding to a survey that we anticipate will take only 15-20 minutes to complete. There are multiple ways that the survey can be completed.

1. You are welcome to complete the survey online by typing the link into your search browser from your computer, smart phone, or tablet or scanning the provided QR code.
2. A member of our research team can email you a link to the online survey. If you would like this option, please complete the email form and return it using the reply-paid envelope.
3. A member of our research team can call you to complete the survey over the phone. If you would like this option please complete the telephone form and return it using the reply-paid envelope.
4. You are welcome to complete the survey contained within this package and return it using the reply-paid envelope.

We kindly request a response within 14 days of receiving this invitation.

**Do I have to take part in this research project?**

Participation in any research project is voluntary. If you do not wish to take part, you do not have to. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage. Please note that we will retain any partially completed survey data should you decide to not proceed with fully completing the survey.

**What are the benefits?**

We cannot guarantee that you will receive any direct benefits from completing the survey, but the results may be used to help others, by helping us to understand how health and community services sectors can be modified to better meet the needs of support people after stroke

**What are the risks?**

Apart from giving up 15-20 minutes of your time, we do not expect that there will be any risks or costs associated with taking part in this survey. If you do have any concerns about your participation when completing the survey, then please contact us so we can discuss the best way to manage your concerns.

**What will happen to the questionnaire information?**

All information obtained relating to this survey will be kept confidential. All data will be stored according to Monash University policies that comply with National Health and Medical Research Council (NHMRC) guidelines for the conduct of research. All data collected will be stored on a secure server only accessible by researchers with permission to access this drive on the Monash University network. The results will also be reported in peer-reviewed publications and presented at scientific conferences. Only aggregated data will be reported.

**Consenting to participate in the study and withdrawing from the research**

Being in this study is completely voluntary and you do not have to take part. Submitting your completed survey is an indication of your consent to participate in the study. You can withdraw your responses any time before you have submitted the questionnaire.

**Will I hear about the results of the survey?**

An online summary of the results of the questionnaire can be made available to you at the end of the study. If you would like a copy, please indicate this at the end of the survey by registering your email address. The email address will be kept in a separate section of the database and will not be linked to your survey answers.

**Who can I contact for questions or want more information?**

|  |  |  |
| --- | --- | --- |
| **Name/Organisation** | **Position** | **Email** |
| Shaun Hancock Monash University | PhD student | Shaun.hancock@monash.edu |
| Prof Dominique CadilhacMonash University | Coordinating Principal Investigator | dominique.cadilhac@monash.edu  |

**What if I have a complaint?**

If you have a complaint about any part of this study, please contact:

Executive Officer

Monash University Human Research Committee (MUHREC)

Room 111, Chancellery Building D, 26 Sports Walk, Clayton Campus Research Office

Monash University VIC 3800

Tel: 03 9905 2052

Fax: 03 9905 3831

Email: muhrec@monash.edu