

Establishing The Mental Health Needs of People With Spinal Cord Injury

Quantitative Information and Consent Form

Last Edited: 24.03.2021

Ethical Approval 27.04.2021

Establishing the Mental Health Needs of People With Spinal Cord Injury

Please take some time to read the information sheet below and complete the consent form before participating in the study. If you have any further questions, please do not hesitate to contact the researchers using the details provided.

Thank you!

School of Psychology and Clinical Language Sciences Whiteknights Reading RG6 6AL

Investigator(s): Email: Telephone:

Dr Katherine Finlay katherine.finlay@reading.ac.uk Tel: +44-(0)118-378-8523

Dr Margaret Tilley margaret.tilley@buckingham.ac.uk Tel: +44-(0)128-082-8322

Researcher:

Phoebe Brook-Rowland p.i.brook-rowland@reading.ac.uk

Establishing the Mental Health Needs of People With Spinal Cord Injury: An Action Research Project

PARTICIPANT INFORMATION SHEET We would be grateful if you could assist us by participating in our online study. The Spinal Injuries Association (SIA), in partnership with The University of Reading and The University of Buckingham, is carrying out research investigating how common it is for people to experience mental health problems following spinal cord injury. Therefore, we want to hear from people with both good and bad mental health. We are also investigating how easy it is for people with those difficulties to access mental health support services and looking to identify gaps in the services currently available. We are looking for people with spinal cord injury, both with and without mental health problems, to take part in this research and we hope that you might be interested in doing so.

What will I be asked to do?

In this survey, you will be asked questions about yourself (gender, age, marital status, location, ethnicity, education, employment), your injury (injury details) and your mental health. We will ask for your postcode to understand how location impacts accessing mental health services. Then you will be asked to complete a number of questionnaires regarding mental health, resilience, life satisfaction, pain and coping strategies. Lastly, you'll be asked about any experiences or recommendations you have regarding accessing mental health services as a person with a spinal cord injury. At the end of the survey you will have the option to opt into a prize draw to win a £100, £50 or £25 online shopping voucher. You will also be asked whether you would like to participate in further research, in which a few of the respondents will be invited for an optional online interview to explore your experiences in more detail. The survey should take no longer than 20 minutes. You will not receive your individual results from your participation in this survey and your individual results will not be clinically assessed. However, if your responses raise a significant concern about your mental health we will attempt to contact you, within a week, using the contact details you provide on the Consent Form to discuss with you whether you would consider seeking help and advice from a clinically qualified professional such as your General Practitioner.

Can I take part in the study?

To be eligible to take part in this study you must be at least 18 years old and have a spinal cord injury. You are unable to take part in the study if you have a spinal cord injury due to an active cancer or malignancy. This is because cancer can have a significant impact on mental health and this study wants to understand the impact of spinal cord injury on mental health in isolation.

How will my information be stored?

Your survey data will be kept confidential and securely stored, with only an anonymous number identifying it. Data collected from this study will be preserved and made available in anonymised form, so that data can be re-used by others.

Are there any risks involved in taking part in the study?

We foresee few risks during the survey, but because the questions ask you about your current mental health there is a chance you may find some questions upsetting. You can choose to skip any questions you do not feel comfortable answering. You can stop

taking part in the study by exiting the online survey without any consequences. Your answers will not be stored for analysis but we will still attempt to contact you if your responses raise a significant concern about your mental health.

What can I do if I am concerned about my mental health? 24-03-2021 11:31

projectredcap.org

If you have concerns about your mental health we would recommend first seeking help and advice from a clinically qualified professional such as your General Practitioner. Additionally, support services are available via charities such as MIND or SIA, you may want to visit the links below for more details.

www.mind.org.uk www.spinal.co.uk

Is taking part voluntary?

Taking part in this study is completely voluntary; you may withdraw at any time without having to give any reason. Please feel free to ask any questions that you may have about this study at any point by contacting the investigator at the email address below.

This application has been reviewed by the University Research Ethics Committee and has been given a favourable ethical opinion for conduct ([SREC OR UREC NUMBER]).

If you have any questions or concerns about the research, please feel free to contact Dr Katherine Finlay. Email:

katherine.finlay@reading.ac.uk Thank you for your help.

Please take some time to read the information sheet below and complete the consent form before participating in the study. If you have any further questions, please do not hesitate to contact the researchers using the details provided.

Thank you!

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CONSENT FORM

I agree



I understand that my participation in this study is voluntary and that I may withdraw any time without giving any reason.

I have read and understood the information sheet about this study and its procedure.

Confidential

Page 3

I have been given the opportunity to ask any questions that I may have about the study and, if asked, these have been answered to my satisfaction.

I understand that the data collected from me in this study will be preserved and made available in anonymised form, so that they can be consulted and re-used by others.

I confirm that my spinal cord injury is not the result of an active cancer or malignancy

I authorise the Investigator to
about my mental health.

Contact me if significant concern is raised

I am happy to be contacted about future studies (optional)

First name

Last name

Contact telephone number

Please use the link here to add your signature

24-03-2021 11:31

projectredcap.org

Establishing The Mental Health Needs of People With Spinal Cord Injury

Qualitative Information and Consent Form

Last Edited: 23.03.2021

Ethical Approval 27.04.2021

Establishing the Mental Health Needs of People With Spinal Cord Injury: Interviews

Please read the information below and click 'next page'

Please take some time to read the information sheet below and complete the consent form before participating in the study. If you have any further questions, please do not hesitate to contact the researchers using the details provided.

Thank you!

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PARTICIPANT INFORMATION SHEET We would be grateful if you could assist us by participating in our research. The Spinal Injuries Association (SIA), in partnership with The University of Reading and The University of Buckingham, is carrying out research investigating the occurrence of mental health problems following spinal cord injury, and how easy it is for people with those difficulties to access mental health support services. You have been contacted because when you completed our online survey you expressed an interest in taking part in the second stage of this research. This second stage is looking in more detail at your experience of changes to and management of mental health problems since your spinal cord injury.

What is the study about?

The study is aiming to understand more fully the mental health needs of people with spinal cord injury and to identify the gaps in the services available to support people with mental health problems. To do this we are exploring peoples' experiences of living with spinal cord injuries and mental health problems. We are also interested in whether people have been able to access mental health support services (e.g. through the NHS, privately, or through a charity) and if they have, how satisfied they are with the support they received. If they have not accessed any support services, we are interested in what might have prevented them from doing so.

What will I be asked to do?

In this study, you will be asked to take part in a one-to-one interview via Microsoft Teams. The interviewer will ask you to give yourself a pseudonym. This is to ensure that your responses will be kept anonymous. That way we can be sure that what you tell us remains confidential. The interviewer will then ask you questions about your mental health and whether you have tried to access support services. You will be encouraged to discuss your experiences in this regard. After the interview, you will be debriefed and we will email you a £10 online shopping voucher to thank you for the time you have invested. It is expected that the interview will last between 60 and 90 minutes.

Can I be involved in this study?

To be eligible to take part in this study you must be at least 18 years old and have a spinal cord injury. Unfortunately, you are unable to take part in the study if you have a spinal cord injury due to an active cancer or malignancy. This is because cancer can have a significant impact on mental health and this study wants to understand the impact of spinal cord injury on mental health in isolation.

How will my information be stored?

Your interview responses will be kept confidential and securely stored, with only your pseudonym identifying it. Data collected from this study will be preserved and made available in anonymised form, so that data can be re-used by others.

We foresee few risks during the interview, but because you will be asked about your current mental health there is a chance you may find some questions upsetting. You can choose not to answer any questions you don't like and if you would like to pause the interview for a while, or stop it completely you will be able to do that. If you choose to stop the interview entirely your interview data will be deleted and not used in the study.

What can I do if I am concerned about my mental health?

If you have concerns about your mental health we would recommend first seeking help and advice from a clinically qualified professional such as your General Practitioner. Additionally, support services are available via charities such as MIND or SIA, you may want to visit the links below for more details.

www.mind.org.uk www.spinal.co.uk

Do I have to take part?

Taking part in this study is completely voluntary; you may withdraw at any time without having to give any reason. Please feel free to ask any questions that you may have about this study at any point.

This application has been reviewed by the University Research Ethics Committee and has been given a favourable ethical opinion for conduct ([SREC OR UREC NUMBER]).

If you have any questions or concerns about the research, please feel free to contact Dr Katherine Finlay. Email:

katherine.finlay@reading.ac.uk Thank you for your help.

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CONSENT FORM

I agree

1)

I understand that my participation in this study is voluntary and that I may withdraw any time without giving any reason.

2) I have read and understood the

information sheet about this study and the study procedure.

3)

Confidential

Page 3

I have been given the opportunity to ask any questions that I may have about the study and, if asked, these have been answered to my satisfaction.

4) I understand that the data collected from me in this study will be preserved and made available in anonymised form, so that they can be consulted and re-used by others.

5) I confirm that my spinal cord Injury is not the result of an active cancer or malignancy

6) I am happy to be contacted about future studies (optional)

7) First name _____

8) Last name _____

9) Please use the link here to add your signature _____

Establishing The Mental Health Needs of People With Spinal Cord Injury

Qualitative Information and Consent Form: Friends and
Family

Last Edited: 23.03.2021

Ethical Approval 27.04.2021

Establishing the Mental Health Needs of People With Spinal Cord Injury: Friends and Family Interviews

Please read the information below and click 'next page'

Please take some time to read the information sheet below and complete the consent form before participating in the study. If you have any further questions, please do not hesitate to contact the researchers using the details provided.

Thank you!

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PARTICIPANT INFORMATION SHEET

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What will I be asked to do?

In this study, you will be asked to take part in a one-to-one online interview via Zoom. The interviewer will ask you to give yourself a pseudonym. This is to ensure that your responses will be kept anonymous and so we can be sure that what you tell us remains confidential. You will then be invited to share your thoughts on possible causes of mental health problems following spinal cord injury, and the impact this has had on you. You will also be asked to talk about your experiences of mental health services and how well they meet the needs of your family member/friend/significant other. Lastly, you'll be asked what services are needed to improve the management of mental health problems in people with spinal cord injury. It is expected that the interview will last between 60 and 90 minutes. After the interview, we will post you a £10 online shopping voucher to thank you for the time you have invested.

Can I be involved in this study?

To be eligible to take part in this study you must be at least 18 years old, live in the UK, be the family member/friend/significant other of someone who has a spinal cord injury and have their consent to discuss their mental wellbeing with the research team. Unfortunately, you are unable to take part in the study if your family member/friend/significant other has a spinal cord injury due to an active cancer or malignancy. This is because cancer can have a significant impact on mental health and this study wants to understand the impact of spinal cord injury on mental health in isolation.

How will my information be stored?

Your survey data will be kept confidential and securely stored, with only an anonymous number identifying it. Your interview responses will be kept confidential and securely stored, with only your pseudonym identifying it. Data collected from this study will be preserved and made available in anonymised form, so that data can be re-used by others.

Are there any risks involved in taking part in the study?

We foresee few risks during the interview, but because you will be asked about your family

What can I do if I am concerned about my or my significant other's mental health?

If you have concerns about your, or your significant other's, mental health we recommend individuals first seek help and advice from a clinically qualified professional such as their General Practitioner. Additionally, support services are available via charities such as MIND or SIA, you may want to visit the links below for more details.

www.mind.org.uk www.spinal.co.uk

Do I have to take part?

Taking part in this study is completely voluntary; you may withdraw at any time without having to give any reason. Please feel free to ask any questions that you may have about this study at any point.

This application has been reviewed by the University Research Ethics Committee and has been given a favourable ethical opinion for conduct (2021-033-KF).

If you have any questions or concerns about the research, please feel free to contact Dr Katherine Finlay. Email:

katherine.finlay@reading.ac.uk Thank you for your help.

The next page will ask you to give consent to taking part in the study and to provide contact details so a member of the research team can contact you to arrange an interview. You will then see a PDF of your consent form. Please press submit on the PDF and continue.

Please take some time to read the information sheet below and complete the consent form before participating in the study. If you have any further questions, please do not hesitate to contact the researchers using the details provided.

Thank you!

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I agree

1)

Confidential

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I understand that my participation in this study is voluntary and that I may withdraw any time without giving any reason.

- 2) I have read and understood the information sheet about this study and the study procedure.
- 3) I have been given the opportunity to ask any questions that I may have about the study and, if asked, these have been answered to my satisfaction.

4) I understand that the data collected from me in this study will be preserved and made available in anonymised form, so that they can be consulted and re-used by others.

5) I confirm that my family member's/friend's/significant other's spinal cord injury is not the result of an active cancer or malignancy.

6) I have obtained consent from my significant other to discuss issues regarding their mental wellbeing

7) I am happy to be contacted about future studies (optional)

8) First name

9) Last name

10) Please provide a contact number

11) Please provide an email address

12) Please use the link here to add your signature

The next page will show you a PDF of your consent form, please then press submit to continue