

Healthy Volunteer's Information Sheet

Final version 1.0:

Title of Study: Effects of Written and Verbal Narrative Interview on the Traumatic and Stressful Experiences and Posttraumatic Growth

Ethics reference No: 113-1809 Study ID – 2016/20

Name of Researcher(s): Andrea Kocurkova PhD in Clinical Psychology Nigel Hunt Associate Professor/Supervisor/Lead Investigator

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. Your participation is voluntary, and you may change your mind about being involved, or decline to answer a particular question. You are free to withdraw at any point before or during the study. Withdrawal does not require a reason.

What is the purpose of the study?

Presented research focuses on people's experiences of writing about life-changing events that had caused an intense emotional response. It looks at online writing and further development of existing expressive writing paradigm within trauma population, aiming to determine whether change in specific language patterns can reliably predict stress or trauma symptom change from time of writing onset to the last writing session. The aims of this study will be to examine individual's experience of trauma and stress on their well-being.

Why have I been invited?

You have been chosen, because you responded to the advert, and you meet the criteria for inclusion in this study:

- healthy adult;
- fluent in English language
- **above age 18** at the time of participation.
- currently not undergoing psychotherapy;
- if you are currently taking anti-depressants, you have been taking them for at least 3 months (Note: If you are currently taking anti-depressants, and have been doing so for less than three months, you will not be able to participate).

We aim to recruit as many adults as possible within the limited timeframe of the project duration. We are inviting all those people who experienced traumatic or stressful event and are willing to share their experience, feelings, opinions and emotions with us. The final decision to take part or not is **your choice**. So, if you decide to take part you will need to have read this information as well as sign the consent form

Do I have to take part?

It is up to you to decide whether to take part. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part, you are still free to withdraw at any time and without giving a reason. The consent form will be sent to you through a link to a survey web page.



What will happen to me if I take part?

- If you decide to take part in this research, firstly you will be asked to fill in **demographics** and a **questionnaire**. For this you will be sent a link to a survey web page to fill the demographics information in (*Paper form is available upon request*).
- Then you will be asked to spend 20-30 minutes over the course of either <u>3 days</u> (each day one writing session) or <u>3 weeks</u> (one writing session per week) writing about an event or experience in your life that you consider having been life-changing and had caused an intense emotional response. This will take place over the internet (email), on a date and time that is suitable for you.
- Alternatively you might be asked to participate in **two writing sessions** (first and third week) and **one interview session** during the second week (this would take place over email or in person/skype, depending on your availability).
- After your third writing you will be sent the same **questionnaire** together with a **questionnaire** about approximately two weeks after finishing your last writing session.
- In the end you will receive a full transcript of the work. Finally, I will contact you again after two months to fill in some post-test questionnaires and a feedback survey. This is to ensure your wellbeing and to gather enough data from the whole writing process.

All the data collected during this study will be confidential. Information gained will be retained in the study archives, but **personally identifiable information will be removed**. This means that although some of the data collected might be used in my thesis (anonymous direct quotes may be used in the study reports) and/or shared with my supervisor, all the data will remain anonymous. If you want to give it a try but change your mind at any point during the study, you are free to leave without any questions asked and any material collected will be destroyed immediately.

Expenses and inconvenience allowance

Participation in the study does not imply any financial benefits.

What are the possible disadvantages and risks of taking part?

There are not serious risks in taking part to this study; the main issue could be the emotional reaction that you might have after the interview. Sensitive topics will be discussed and there might be a chance to feel more sad or anxious. Support will be given if needed and a break will be provided if required.

What are the possible benefits of taking part?

Benefits from this study include free examinations and treatments that may reduce intensity and frequency of symptoms that arose from extremely stressful experiences. Furthermore, the information we get from your participation in this study may help understanding the real impact of written and verbal storytelling on experience of traumatic event.

Will my taking part in the study be kept confidential?*see full privacy notice below

All information which is collected about you during the course of the research will be kept on a password protected database and will be kept strictly confidential. Any information about you which leaves the research unit will have your name and address removed so that you cannot be recognised from it.

Your personal data (address, telephone number) will be kept for up to two years after the end of the study so that we are able to contact you about the findings of the study *and possible follow-up studies* (unless you advise us that you do not wish to be contacted). All other data (research data) will be kept

securely for 7 years. After this time, your data will be disposed of securely. During this time, all precautions will be taken by all those involved to maintain your confidentiality, only members of the research team will have access to your personal data.

We would also like to seek your consent so that the data may be stored and used in possible future research during and after 7 years – this is optional (please, indicate you agree to this on the consent form).

What you will share during the interview will be kept confidential unless you reveal something of concern that may put yourself and/or someone else at risk. The researcher may feel it necessary to report this to the appropriate persons.

What will happen if I don't want to carry on with the study?

Your participation is voluntary, and you are free to withdraw at any time without giving any reason. However, if you decided to withdraw more than 7 days after the interview has taken place then the information collected so far cannot be erased and the information may still be used in the study analysis.

What will happen to the results of the research study?

The result will be kept safe at The University of Nottingham and will be part of a final dissertation project that will probably be completed in 2020 at the end of a PhD programme in Clinical Psychology. In the event in which the dissertation will be published, you will be informed of it and a copy of the article will be provided, if you want one. All the data will remain confidential and you will not be identified in any report/publication.

Who is organising and funding the research?

This research is being organised and funded by the University of Nottingham.

Who has reviewed the study?

All research in the University of Nottingham is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the Faculty of Medicine & Health Sciences (FMHS) Research Ethics Committee.

What if there is a problem?

If you have a concern about any aspect of this study, you should contact the Chief investigator e-mail: nigel.hunt@nottingham.ac.uk. The full contact details of the research team are given at the end of this information sheet. If you remain unhappy and wish to complain formally, you should then contact the FMHS Research Ethics Committee Administrator, c/o The University of Nottingham, Faculty PVC Office, B Floor, Medical School, Queen's Medical Centre Campus, Nottingham University Hospitals, Nottingham, NG7 2UH or via E-mail: <u>FMHS-ResearchEthics@nottingham.ac.uk</u>

Further information and contact details

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THANK YOU FOR YOUR TIME AND PARTICIPATION!



*Full Privacy Notice for Research Participants

How the University of Nottingham processes your personal data

The University of Nottingham, University Park, Nottingham, NG7 2RD (0115 951 5151), is committed to protecting your personal data and informing you of your rights in relation to that data.

The University of Nottingham is registered as a Data Controller under the Data Protection act 1998 (registration No. **Z5654762 –** <u>https://ico.org.uk/ESDWebPages/Entry/Z5654762</u>).

One of our responsibilities as a data controller is to be transparent in our processing of your personal data and to tell you about the different ways in which we collect and use your personal data. The University will process your personal data in accordance with the General Data Protection Regulation (GDPR) and the Data Protection Act 2018 and this privacy notice is issued in accordance with the GDPR Articles 13 and 14.

We may update our Privacy Notices at any time. The current version of all of our Privacy Notices can be found at <u>https://www.nottingham.ac.uk/utilities/privacy.aspx</u> and we encourage you to check back regularly to review any changes.

The Data Protection Officer

The University has appointed a Data Protection Officer. Their postal address is: Data Protection Officer, Legal services A5, Trent Building, University of Nottingham, University Park, Nottingham Ng7 2RD They can be emailed at <u>dpo@nottingham.ac.uk</u>.

Your personal data and its processing

We define personal data as information relating to a living, identifiable individual. It can also include "special categories of data", which is information about your racial or ethnic origin, religious or other beliefs, and physical or mental health, the processing of which is subject to strict requirements. Similarly information about criminal convictions and offences is also subject to strict requirements. "Processing" means any operation which we carry out using your personal data e.g. obtaining, storing, transferring and deleting.

We only process data for specified purposes and if it is justified in accordance with data protection law. Detail of each processing purpose and its legal basis is given in each privacy notice listed below, please select the one most relevant to your relationship to the University.

Why we collect your personal data

We collect personal data under the terms of the University's Royal Charter in our capacity as a teaching and research body to advance education and learning. Specific purposes for data collection on this occasion are for the purpose of broadening existing research on expressive writing and for the purpose of Doctoral Thesis.

Legal basis for processing your personal data under GDPR

The legal basis for processing your personal data on this occasion is Article 6(1a) consent of the data subject.



Special category personal data.

In addition to the legal basis for processing your personal data, the University must meet a further basis when processing any special category data, including: personal data revealing racial or ethnic origin, political opinions, religious or philosophical beliefs, or trade union membership, and the processing of genetic data, biometric data for the purpose of uniquely identifying a natural person, data concerning health or data concerning a natural person's sex life or sexual orientation.

The basis for processing your sensitive personal data on this occasion is Article 9(2j) processing is necessary for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes.

How long we keep your data

The University may store your data for up to 25 years and for a period of no less than 7 years after the research project finishes. The researchers who gathered or processed the data may also store the data indefinitely and reuse it in future research. Measures to safeguard your stored data include email and file encryption protocol, pseudonymisation procedure, anonymisation of data, and regular testing of IT systems ensuring the confidentiality of sensitive data (i.e. protecting it from unauthorised access).

Who we share your data with

Extracts of your data may be disclosed in published works that are posted online for use by the scientific community. Your data may also be stored indefinitely on external data repositories (e.g., the UK Data Archive) and be further processed for archiving purposes in the public interest, or for historical, scientific or statistical purposes. It may also move with the researcher who collected your data to another institution in the future.

Your rights as a data subject

You have the following rights in relation to your personal data processed by us:

Right to be informed

The University will ensure you have sufficient information to ensure that you're happy about how and why we're handling your personal data, and that you know how to enforce your rights.

The University provides information in the form of privacy notices. Our Privacy Notices pages can be found at <u>https://www.nottingham.ac.uk/utilities/privacy/privacy.aspx</u>.

Right of access / right to data portability

You have a right to see all the information the University holds about you. Where data is held electronically in a structured form, such as in a database, you have a right to receive that data in a common electronic format that allows you to supply that data to a third party - this is called "data portability".

To make a request for your own information please see the link here: <u>https://www.nottingham.ac.uk/governance/records-and-information-management/data-protection/data-protection.aspx</u>

To receive your information in a portable form, send an email your request to <u>data-protection@nottingham.ac.uk</u>



Right of rectification

If we're holding data about you that is incorrect, you have the right to have it corrected. Please email any related request to <u>data-protection@nottingham.ac.uk</u>.

Right to erasure

You can ask that we delete your data and where this is appropriate we will take reasonable steps to do so.

Please email any related request to data-protection@nottingham.ac.uk.

Right to restrict processing

If you think there's a problem with the accuracy of the data we hold about you, or we're using data about you unlawfully, you can request that any current processing is suspended until a resolution is agreed.

Please email any related request to data-protection@nottingham.ac.uk.

Right to object

You have a right to opt out of direct marketing.

You have a right to object to how we use your data if we do so on the basis of "legitimate interests" or "in the performance of a task in the public interest" or "exercise of official authority" (a privacy notice will clearly state to you if this is the case). Unless we can show a compelling case why our use of data is justified, we have to stop using your data in the way that you've objected to.

For direct marketing, there will be an opt-out provided at the point of receipt. To object to how we use your data, email your request to <u>data-protection@nottingham.ac.uk</u>.

Rights related to automated decision making including profiling

We may use a computer program, system or neural network to make decisions about you (for example, everyone that is on a particular course gets sent a particular letter) or to profile you. You have the right to ask for a human being to intervene on your behalf or to check a decision.

Please email any related request to data-protection@nottingham.ac.uk.

Withdrawing consent

If we are relying on your consent to process your data, you may withdraw your consent at any time.

Exercising your rights, queries and complaints

For more information on your rights, if you wish to exercise any right, for any queries you may have or if you wish to make a complaint, please contact our Data Protection Officer.

Complaint to the Information Commissioner

You have a right to complain to the Information Commissioner's Office (ICO) about the way in which we process your personal data. You can make a complaint on the ICO's website.

Privacy notices

Please consult the privacy notice that best fits your relationship with the University.