

Participant Information Sheet

The title of the research project

Understanding how people in the UK make sense of a near-death experience (NDE): Insights for fostering the wellbeing of those who are not traditionally religious

Invitation to take part

You are being invited to take part in a research project. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please feel free to ask Alex Fry (contact details at the end of this sheet) if there is anything that is not clear or if you would like more information.

Who is organising/funding the research?

This research is funded by the John Templeton Foundation, administered by Queen's University, Belfast and conducted by Dr Alex Fry, a Lecturer in the Sociology of Health and Illness at Bournemouth University.

What is the purpose of the project?

This project seeks to understand how near-death experiencers (NDErs) in the UK seek to make sense of their NDE and the extent to which this impacts their wellbeing. More specifically, it seeks to listen to the experiences of those who would not consider themselves to be traditionally religious— this could be those who would say they are not formally religious but still believe that there is something 'out there' or beyond the physical world we see around us. It can also be those who do not believe that there is anything beyond the physical world. Such people can be called 'spiritual but not religious', 'agnostic', 'atheist' or a number of other labels, but they are not religious in the traditional sense of the word; they do not subscribe to a traditional understanding of God/gods as found in the major world religions.

By listening to the NDEs of others, how people make sense of them, and the impact this has on them, will allow Alex to discern what steps to making sense of a NDE are frequently helpful to people. He will use this information inform those supporting individuals who have had a NDE to make sense of it more effectively, to enhance their wellbeing. A further aim is to educate academia and the wider public on such experiences and how they influence people's belief systems—the way they think about the world, find meaning in life, and discern truth.

Why have I been invited?

You have been invited because you are associated with a NDE network or support group, such as NDE UK or IANDS and are believed to have had a NDE yourself.

Please note that invitation to participation is based on the assumption that you are at least 18 years old and do not have a mental health diagnosis that predisposes you to harm when recounting your NDE.

Participation requires participants to be able to discuss their NDEs and related topics without it causing further trauma or leading participants to relive trauma. Although it is thought that many would find the opportunity to discuss their NDE therapeutic, because of the risk of relived trauma, all participants need to have support in place. This can be a professional therapist or a group or community such as NDE UK or an IANDS regional group, for example.

Alex is especially interested in talking to those who do not consider themselves to be traditionally religious (e.g., church-going Christians). This can include (but is not limited to) those who consider themselves spiritual, atheists, and agnostics.

Participants need to be UK-based.

If you have any questions about this, please do feel free to be in touch with Alex.

Do I have to take part?

It is up to you to decide whether or not 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 participant agreement form. We want you to understand what participation involves, before you make a decision on whether to participate.

If you or any family member have an on-going relationship with BU or the research team, e.g., as a member of staff, as student or other service user, your decision on whether to take part (or continue to take part) will not affect this relationship in any way.

Can I change my mind about taking part?

Yes, you can stop participating in study activities at any time and without giving a reason. All you need to do is email Alex: afry@bournemouth.ac.uk and he will honour your request.

If I change my mind, what happens to my information?

After you decide to withdraw from the study, Alex will not collect any further information from or about you.

As regards to the information already collected before this point, your rights to access, change or move that information are more limited. This is because, as a researcher, Alex needs to manage your information in specific ways in order for the research to be reliable and accurate.

Further explanation about this is in the Personal Information section below. However, Alex is able to remove all information that you have provided if you notify him of your withdrawal from the research by the 31st December 2023. This is because analysis of the data will not be complete by then and so withdrawal will not skew the research.

What would taking part involve?

You will be asked to take part in a one-to-one informal interview with Alex that will last between 75-90 minutes. It will feel more like a conversation. If you would like an additional person present, who you trust for moral support, you are welcome to. Please let Alex know beforehand if this is the case. Whilst the questions are designed to be sensitive and will focus on the below topics, you are welcome to refuse to answer any question if it makes you uncomfortable. This is absolutely fine. You are also free to ask for the interview to be paused (including the recording) or ended at any time. Again, Alex would be very willing to accommodate this request.

The conversation will take place online using either Microsoft Teams, Zoom, or similar. Alex would like talk about your religious upbringing (if any), the major cultural references you had growing up (e.g., music tastes, political movements etc), the nature of your NDE, how you have sought to make sense of the NDE, your experience of wellbeing in the process, and your thoughts about what happens when we die.

Will I be reimbursed for taking part?

Unfortunately, there is no financial reward for participating in this research. However, all informal interviews will take part online to avoid participants incurring any costs related to the project.

What are the advantages and possible disadvantages or risks of taking part?

Participants often find talking about personal matters to an independent party a useful way to discuss topics that they do not often get the chance to but would like to.

The information gathered will also allow Alex to find patterns in how NDErs make sense of their NDE. He will use this information to recommend ways that others can do likewise, to enhance their wellbeing. Participation will therefore have an advantage for other NDErs too. Alex will also disseminate the research findings to academic audiences as part of his commitment to increasing society's understanding of NDEs.

A potential risk is the reliving of trauma for those who had particularly difficult NDEs, particularly if the person has not yet been supported by the relevant professionals. This is why having some support in place is a pre-requisite for participating in the research. *There are also support lines listed at the bottom of this information sheet, in case that they would benefit participants, should they find recounting their NDE challenging.*

Will I be recorded, and how will the recorded media be used?

This call would also be recorded so that Alex can look over a transcript as he compares the conversations between participants. However, the recording will be deleted at the end of the study in June 2024. You are welcome to ask Alex to delete the recording prior to this time if you wish and he will oblige. No other use will be made of them without your permission, and no one outside the project will be allowed access to the original recordings. However, Alex would like anonymised transcripts (with any identifying information removed) to be made available publically so that others can benefit from hearing about participants' NDEs. However, this is optional and you can let Alex know at any point before the 1st of June 2024 if you would rather the transcript was not used in this way. He will honour your request.

How will my information be managed?

Bournemouth University (BU) is the organisation with overall responsibility for this study and the Data Controller of your personal information, which means that we are responsible for looking after your information and using it appropriately. Research is a task that we perform in the public interest, as part of our core function as a university.

Undertaking this research study involves collecting and/or generating information about you. We manage research data strictly in accordance with:

- Ethical requirements; and
- Current data protection laws. These control use of information about identifiable individuals, but do not apply to anonymous research data: "anonymous" means that we have either removed or not collected any pieces of data or links to other data which identify a specific person as the subject or source of a research result.

BU's [Research Participant Privacy Notice](#) sets out more information about how we fulfil our responsibilities as a data controller and about your rights as an individual under the data protection legislation. We ask you to read this Notice so that you can fully understand the basis on which we will process your personal information.

Research data will be used only for the purposes of the study or related uses identified in the Privacy Notice or this Information Sheet. To safeguard your rights in relation to your personal information, we will use the minimum personally-identifiable information possible and control access to that data as described below.

Publication

You will not be able to be identified in any external reports or publications about the research. Your information will only be included in these materials in an anonymous form, i.e. you will not be identifiable.

Research results will be published in an open-access academic journal article, which will be freely available to anyone who wishes to read it. Those who inform Alex of this interest either in the interview or by email will be emailed the article at the end of the study.

Security and access controls

BU will hold the information we collect about you in hard copy in a secure location and on a BU password protected secure network where held electronically.

Personal information which has not been anonymised will be accessed and used only by appropriate, authorised individuals and when this is necessary for the purposes of the research or another purpose identified in the Privacy Notice. This may include giving access to BU staff or others responsible for monitoring and/or audit of the study, who need to ensure that the research is complying with applicable regulations.

Further use of your information

The information collected about you may be used to support other research projects in the future and access to it will not be restricted. You will not be able to be identified in the data. To enable this use, the data will be added to an appropriate research data repository such as IANDS: this is a central location where data is stored, which is accessible to the public.

Keeping your information if you withdraw from the study

If you withdraw from active participation in the study we will keep information which we have already collected from or about you, if this has on-going relevance or value to the study (unless you request to withdraw by 31st December 2023). As explained above, your legal rights to access, change, delete or move this information after this date are limited as Alex need to manage your information in specific ways in order for the research to be reliable and accurate. However, if you have concerns about how this will affect you personally, you can raise these with Alex when you withdraw from the study.

You can find out more about your rights in relation to your data and how to raise queries or complaints in the Privacy Notice.

Retention of research data

Project governance documentation, including copies of signed **participant agreements**: we keep this documentation for a long period after completion of the research, so that we have records of how we conducted the research and who took part. The only personal information in this

documentation will be your name and signature, and we will not be able to link this to any anonymised research results.

Research results:

As described above, during the course of the study we will anonymise the information we have collected about you as an individual. This means that we will not hold your personal information in identifiable form after we have completed the research activities.

You can find more specific information about retention periods for personal information in our Privacy Notice.

We keep anonymised research data indefinitely, so that it can be used for other research as described above.

Contact for further information

If you have any questions or would like further information, please contact Alex Fry, who would be happy to help however best he can. His email is afry@bournemouth.ac.uk

In case of complaints

Any concerns about the study should be directed to Professor Jane Murphy, Deputy Dean for Research & Professional Practice, Faculty of Health and Social Sciences, Bournemouth University by email to researchgovernance@bournemouth.ac.uk.

Finally

If you decide to take part, you will be given a copy of the information sheet and a signed participant agreement form to keep.

Thank you for considering taking part in this research project.

Support lines

Free listening services:

Samaritans: 116 123 (or email jo@samaritans.org)

Shout Crisis text line: Text 'SHOUT' to 85258

NHS: The NHS has local urgent mental health helplines- please see

<https://www.nhs.uk/service-search/mental-health/find-an-urgent-mental-health-helpline> for more details.

If you cannot speak to your urgent mental health helpline, you can call 111.