# Participant Information Leaflet for People Impacted by Life-limiting Conditions Taking Part in an Interview.

**Study Title:** The impact and implications of Covid-19 on the relational, social, and healthcare experiences of hospice care in the West Midlands.

**Investigator(s):** Dr John MacArtney, Dr Abi Eccles and Dr Jo Fleming

**Contact:** Email: icoh@warwick.ac.uk, Phone: 02476 523164

## Introduction

You are invited to take part in a research study. Before you decide, you need to understand why the research is being done and what it would involve for you. Please take the time to read the following information carefully. Talk to others about the study if you wish.

Please ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

## Who is organising and funding the study?

The study is led by the University of Warwick. It is funded by the Economic and Social Research Council. The study has been reviewed by a Research Ethics Committee.

## What is the study about?

The study is being carried out to help us understand how Covid-19 affected hospice services. We are carrying out interviews to learn about people's experiences of Hospice Care during the pandemic, which will feed into recommendations for fair access to hospice care for all service users and those that care for them.

## What would taking part involve?

If you are willing to take part, we would arrange an interview either via phone or video call. A translator can be made available should you wish. During the interview we would discuss your experiences of hospice care and how this has been affected during Covid-19. The interview would be arranged for a time that is convenient to you and last between 45 – 90

minutes. The interview will be recorded and the audio transcribed to help us keep an accurate record of what is discussed.

Before the interview starts, our researcher would explain the study and you would be able to ask any questions you may have. The researcher will then take some background information and your verbal consent to participate, before starting the interview. Once the interview has finished, we will take a few minutes to debrief, and you can ask any further questions you may have.

**Do I have to take part?**

No. Participation in this study is completely voluntary and choosing not to take part will not affect the care you receive or access to services in any way. You can also choose to withdraw your participation at any time up to the end of the study, without giving a reason by contacting one of the research team or via the study email address (icoh@warwick.ac.uk). Further details about withdrawing from the study are provided later on in this leaflet.

**What are the possible benefits of taking part in this study?**

There are no individual benefits associated with taking part in this study. The findings of the study will provide information that we hope be used to improve services for people accessing hospice care.

**What are the possible disadvantages, side effects or risks, of taking part in this study?**

In taking part you will have to give up approximately one hour of your time to talk to a researcher. It is possible we may discuss experiences that were distressing for you during the interview. If at any point you feel uncomfortable or prefer not to discuss certain experience during the interview you can let the researcher know and that topic would not be discussed further. There are also support groups detailed at the bottom of this leaflet that you may wish to access if you decide you would like further support.

**Expenses and payments**

There is no reimbursement or payment for taking part in this study.

**Special Category Data**

You will be asked if you will provide Special Category Data at the start of the interview. Specifically, you will be asked if you would like to identify your ethnic group, your sexuality, what gender you identify as, and whether you have a disability. Each question is voluntary, you can choose which of these questions you want to answer or not.

These Personal and Special Category Data are being asked for because initial reports on the Covid-19 pandemic indicate that factors such as age, ethnicity, sexuality, gender or disability may have an impact on people's experiences of the pandemic. Any findings from the interview will be reported pseudonymously.

**Will my taking part be kept confidential?**

Yes. All the information you provide will be kept confidential. Your hospice provided you with this information leaflet so will be aware that you have been asked to participate, but your interview will not be shared with them.

Your interview will be recorded and automatically transcribed using voice recognition technology. Any identifiable personal information in your interview (such as names or locations) will be removed from the transcripts and the recording from the interview will be destroyed once transcribed. All data will be securely stored on the university's encrypted server and will only be accessible by the research team. Direct quotes from your interview may be used in publications, but any identifiable information will be removed.

Please follow the link below to find out how the University of Warwick handle your personal data processed in connection with the study:
https://warwick.ac.uk/services/sim/privacynotices/research/

If you were to disclose information that you or others are at risk of harm, there would be a duty of care for the researcher to report this to the relevant authorities.

**What will happen to the data collected about me?**

As a publicly-funded organisation, the University of Warwick have to ensure that it is in the public interest when we use personally-identifiable information from people who have agreed to take part in research. This means that when you agree to take part in a research study, such as this, we will use your data in the ways needed to conduct and analyse the research study.

We will be using information from you in order to undertake this study and will act as the data controller for this study. We are committed to protecting the rights of individuals in line with data protection legislation. The University of Warwick will keep information about you for 10 years after the study has finished.

Research data will be pseudonymised as quickly as possible after data collection. This means all direct and indirect identifiers will be removed from the research data and will be replaced with a participant number. The key to identification will be stored separately and securely to the research data to safeguard your identity. You can also choose to withdraw your participation at any time up to the end of the study, without giving a reason by contacting one of the research team members (see below).

**Data Sharing**

At the end of the study we would like to share your pseudonymised interview with the UK Data Service so it can be stored at the UK Data Archive (www.data-archive.ac.uk). Here the interview will be accessible for reanalysis by UK Data Archive approved researchers following their guidelines which are designed to protect the participants' identities. Any content that may identify you will be removed.

If you do not wish for your pseudonymised interview to be stored with the UK Data Archive you can still take part in the study by telling the researcher your decision.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. The University of Warwick has in place policies and procedures to keep your data safe.

This data may also be used for future research, including impact activities following review and approval by an independent Research Ethics Committee and subject to your consent at the outset of this research project.

For further information, please refer to the University of Warwick Research Privacy Notice which is available here: or by contacting the Legal and Compliance Team at GDPR@warwick.ac.uk.

**What will happen if I don't want to carry on being part of the study?**

Participation in this study is entirely voluntary. If you decide to withdraw, this will not affect you in any way. Even If you have agreed to participate and given consent, you may withdraw from the study at any time after the interview and decline any further contact by study staff. You may also choose to stop the interview, but allow us to use the information collected to that point.

If you choose to withdraw from the study after the interview has been completed then it will also be possible to delete your data, other than that which has been included in any outputs to that point, up to the end of the study on 23 March 2022.

If you wish to withdraw from the study, you should inform a study team member via the study email address (icoh@warwick.ac.uk). We will send you a confirmation via email that your data will be removed. Your data will be securely deleted and there will be no further contact.

**What will happen to the results of the study?**

Data collected from interviews and other components of the study will be analysed and the findings published in publicly available reports, as well as in academic papers and conference presentations. The findings will also be summarised for the people who design and deliver hospice care.

**Who has reviewed the study?**

This study has been reviewed and given favourable opinion by the University of Warwick's Biomedical & Scientific Research Ethics Committee (BSREC) reference: BSREC 98/20-21.

**Who should I contact if I want further information?**

If you would like to volunteer to take part in an interview, or if you have any questions, please contact us via email icoh@warwick.ac.uk or phone 02476 523164.

If you have a problem or any questions about any aspect of the study, or your participation in it that is not answered by this participant information leaflet, please contact:

**Dr John MacArtney (Chief Investigator)**
University of Warwick, Coventry, CV4 7AL.
Email: john.macartney@warwick.ac.uk

**Support Groups**

If the interview brings up issues you feel you need further support with, there are resources available to you that you may wish to access.

- Marie Curie Helpline: 0800 090 2309
- Samaritans Helpline: 116123 email: Jo@Samaritans.org
- You may also wish to contact your GP for support.

**Who should I contact if I wish to make a complaint?**

Any complaint about the way you have been dealt with during the study or any possible harm you might have suffered will be addressed. Please address your complaint to the person below, who is a senior University of Warwick official entirely independent of this study:

**Head of Research Governance**
Research & Impact Services
University House
University of Warwick
Coventry
CV4 8UW
Email: researchgovernance@warwick.ac.uk
Tel: 02476 575733

If you wish to raise a complaint on how we have handled your personal data, you can contact our Data Protection Officer who will investigate the matter: DPO@warwick.ac.uk.

If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful you can complain to the Information Commissioner's Office (ICO).

## Thank you for taking the time to read this Participant Information Leaflet