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**Participant Information Sheet** IRAS Project ID: **279591**

**Research Project:  *GPs’ difficult decisions about acute illness in people with dementia***

**What is this study about?**

We are interested in understanding more about GPs’ experience of difficult decisions in dementia patients with an acute illness.

The purpose of this is to better understand how GPs make decisions for dementia patients in primary care. The study does not aim to assess knowledge in terms of what professionals know about dementia management. Rather it aims to explore how professionals handle difficult situations when managing dementia patients with acute illnesses such as Covid-19 and other similar acute illnesses.

This research is being conducted as part of a Dementia theme Academic Clinical Fellowship by Dr Samuel Lassa, who is a GPST3 ACF in the Academic Unit of Primary Medical Care, University of Sheffield.

Why have I been invited?

We are looking for GPs who would be happy to be interviewed regarding the experiences of GPs while involved in difficult decision making for dementia patients with an acute illness in primary care. We are focusing on GPs who work in the South Yorkshire region.

Do I have to take part?

You do not have to take part in the study if you do not want to. If you decide not to take part, you don’t have to give a reason. If you do decide to take part but change your mind later, you just have to let us know and you won’t be contacted again.

What does this study involve?

If you agree to take part, we will arrange a telephone interview with the main researcher. First, we will have a phone discussion about the appropriate time for a telephone interview. Before the telephone interview the main researcher will ask you to take a few minutes to reflect on a few difficult situations you have experienced when managing dementia patients with acute illnesses before the time of the interview. During the interview you will be asked to describe in your own words why they were difficult situations and how you drew on different sources of knowledge or experience and available resources in dealing with them. This interview will last 30 minutes and will stop after that time. We aim to make the interview into a conversation – in which you say what matters to you – not a set of questions that need answers.

The main researcher will audio record the interview so that there is an accurate record of what you have said. After the interview you will be reimbursed a flat rate of £60 for your time.

How will the information from this study be used?

We aim to interview about 15 GPs. We will carry out an analysis of the interviews in which we will look for common patterns in what participants say about difficult decisions when managing dementia patients with acute illnesses. The findings from the interviews will be triangulated with findings and theories from related research.

The results of this analysis will be used by the main researcher in a paper, conference presentations and as preliminary results for a larger study. He will be supervised by Prof Chris Burton, who is a professor of primary medical care at the University of Sheffield and Dr Jon Dickson who is also an experienced primary care researcher. When the analysis is complete, we will present results of the study at conferences and in scientific journals. If you wish, we will send you a summary of the results.

Will there be any harm from taking part in the study?

It is very unlikely that the discussions in the interview will cause you any distressed, but the choice of patients to discuss is fully up to you. It is important that participating you do not discuss patients in a way that may reveal the patient’s identity. This is in accordance with the GMC’s principles on reflection – avoiding identifiable names / situations.

In the unlikely event that interviewees describe practices or attitudes which run counter to good medical practice, the research team will discuss whether that information needs to be shared with colleagues experienced in medical appraisal.

Who will have access to my personal information?

* Your name and details will be removed - anonymous
* Information will be stored under lock and key or secure passwords if on a computer
* Only authorised people will be able to see your information
* We will only use this information for this study – if we wanted to look at the interviews again we would have to go to a special meeting.

What will happen to information you collect about me during the study?

We plan to share the study results with other people who work in the area, this might be through writing in journals or at conferences. Your name and details will not be put in these but we might use some quotes from you. You will not be able to be identified from these. We will post a copy of the overall results to yourself and invite you to come to a public event as part of the audience for a presentation.

The University of Sheffield is the sponsor for this study. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. The University of Sheffield will keep identifiable information about you for 5 years after the study has finished.

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. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

You can find out more about how we use your information at <https://www.sheffield.ac.uk/govern/data-protection>

As a university we use personally-identifiable information to conduct research to improve health, care and services. As a publicly-funded organisation, we 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, we will use your data in the ways needed to conduct and analyse the research study. 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. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

Health and care research should serve the public interest, which means that we have to demonstrate that our research serves the interests of society as a whole. We do this by following the UK Policy Framework for Health and Social Care Research.

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. 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).

Our Data Protection Officer is Anne Cutler and you can contact her at dataprotection@sheffield.ac.uk

We will use your name and the contact details you provide us to contact you about the research study and to oversee the quality of the study. Individuals from the University of Sheffield and regulatory organisations may look at your medical and research records to check the accuracy of the research study. The only people in the University of Sheffield who will have access to information that identifies you will be people who need to contact you to audit the data collection process. The people who analyse the information will not be able to identify you and will not be able to find out your name or contact details.

Who has reviewed the study?

All research in the University of Sheffield is looked at by an independent group of people, called a Research Ethics Committee to protect your safety, rights, well-being and dignity. This study has been reviewed and given favourable opinion by University Ethics Committee. In addition, this study has been reviewed by the NHS Research Ethics Committee and giving a favourable outcome to proceed.

Who is doing the research?

This study is being carried out by Dr Samuel Lassa, an Academic Clinical Fellow supervised by Professor Chris Burton and Dr Jon Dickson from the Academic Unit of Primary Medical Care. The study sponsor is the University of Sheffield.

Who can I contact for further information?

If you have any questions or would like more information about this study before deciding whether to take part, please contact one of the following research team members or using the contact details below:

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