University of UH Hertfordshire

UNIVERSITY OF HERTFORDSHIRE PARTICIPANT INFORMATION SHEET (MedCAM project)

Study title: An evaluation of the use of a patient and carer medication consultation aide-memoire: a feasibility study

Introduction

You are being invited to take part in this study, which aims to explore service user's views on the development of a patient and carer led medication consultation aide-memoire also known as a medication consultation aid. Before you decide whether to do so, it is important that you understand the study that is being undertaken and what your involvement will include. Please take the time to read the following information carefully and discuss it with others if you wish. Do not hesitate to ask me anything that is not clear or for any further information you would like to help you make your decision. Contact details are provided towards the end of this information sheet. Please do take your time to decide whether or not you wish to take part.

What is the purpose of this study?

Age-related vulnerability, multiple long-term conditions and the resulting need to take multiple medicines expose older people to a higher risk of medication errors. A more engaged partnership in decision-making about medicines use between patients, carers and the healthcare team is essential to facilitate the reduction of medicines-related harm. Good communication between older patients, their carers and the healthcare team can contribute to this goal. A patient-centred medication communication aid may help facilitate a medication related consultation. A Medication Consultation Aide Memoire (MedCAM) has been designed to support older patients and their carers to ask questions about their medicines when in consultation with a member of the healthcare team, usually but not exclusively a doctor, pharmacist or nurse. Evidence based knowledge on the use of communication aids around medicines related consultation for older patients are extremely limited. Since there are no validated examples of communication aids similar to the MedCAM, an evaluation and review of the MedCAM by older patients and carers would be valuable. Older people and carer's perspectives on the usefulness and feasibility of use of the MedCAM will be a useful stating point in contributing to the eventual design of the communication aid. This study is also being undertaken for educational purposes, as part of a Masters Degree programme.

Why am I being asked to take part?

You are being asked to take part in this study because you are an older patient (65 years and over) on at least one prescribed medicine or a carer who has responsibility for managing an older patient's medicines. Carers in this context include relatives or friends who have informal carer responsibilities for the medicines management of an older patient.

Do I have to take part?

It is completely up to you whether or not you decide to take part in this study. Agreeing to join the study does not mean that you have to complete it. You are free to withdraw at any stage without giving a reason. A decision to withdraw at any time, or a decision not to take part at all, will not affect your healthcare in any way.

How long will my part in the study take?

If you decide to take part in this study, you will be involved in it for a maximum of 1 hour. Details of your involvement are provided further on in this document.

What will happen to me if I take part?

We have liaised with your group representative to permit us to have a focused group discussion, which will also involve a review of the MedCAM. You will be asked to attend one focus group discussion, which should last no more than 1 hour. We would ask all group members who wish to take part to remain within the room where the discussion would take place and hence implied consent would be presumed. Following a review of the MedCAM, we would ask questions of the group, in relation to the perceived usefulness and feasibility of use of the MedCAM. Participants in the focus group discussion will include the principal investigator, a Masters research student and members of your group. The principal investigator will ask questions relating to your view of the MedCAM. The focus group discussion will be undertaken where the group usually meets or a mutually agreed venue familiar to the group and at a scheduled time convenient to the group. Refreshments will be provided during the session.

What are the possible disadvantages of taking part?

There are no disadvantages; however, this will be a group discussion with your peers, the principal investigator and research student. You may feel that you are uncomfortable expressing your views on certain topics during the discussion. If this happens, you do not have to contribute during the relevant specific segment of the discussions. However, it is hoped that you are able to express your views in the capacity within which you feel comfortable.

What are the possible benefits of taking part?

There may not be any direct benefit to you. It is hoped that by sharing your views, the development of this communication aid will truly reflect the perspectives of potential users.

How will my taking part in this study be kept confidential?

All the information that you provide will be kept confidential and secure. The focus group interview will be audio recorded. Audio recordings will be stored in a locked cupboard on University premises. Audio recordings will be transcribed into text by the principal investigator and the research student. No other person will have access to the recordings. The data collected and transcribed into text form will be stored electronically, in a password-protected environment, for 12 months, after which time it will be destroyed under secure conditions. The data will be anonymised prior to storage. Transcripts of audio recordings will not contain your personal identifiable information. This means that you will not be identified in any report that is produced about the study.

What will happen to the results of the research study?

The results of the study will be reported in a Masters Dissertation as well as publication in healthcare and education related journals and conference proceedings. You will not be identified in any publications.

Will the data be required for use in further studies?

The data will not be used in any further studies

Who has reviewed this study?

The following method used in this research, namely focus group interviews was employed in accordance with the University of Hertfordshire's Health, Science, Engineering and Technology Ethics Committee with Delegated Authority protocol number cLMS/CL/UH/05039 dated 2 August 2018.

Factors that might put others at risk

Please note that if, during the study, any non-medical circumstances such as unlawful activity become apparent that might or had put others at risk, the research team may refer the matter to the appropriate authorities.

Who can I contact if I have any questions?

If you would like further information or would like to discuss any details personally, please get in touch with me, in writing, by phone or by email:

Dr Nikkie Umaru

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Although we hope it is not the case, if you have any complaints or concerns about any aspect of the way you have been approached or treated during the course of this study, please write to the University's Secretary and Registrar at the following address:

Secretary and Registrar University of Hertfordshire College Lane Hatfield Herts AL10 9AB

Thank you very much for reading this information and giving consideration to taking part in this study.