NHS
Nottingham
University Hospitals

Co-production of a falls management tool for adults with intellectual disabilities in community settings- views of healthcare professionals and carers

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Participant Information Sheet; Version 1.0, Dated 01Apr2021

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Research & Innovation

1. What is the purpose of the study?

The number of falls is higher in adults with intellectual disabilities than that of the general population and there is a need to develop falls prevention strategies specifically for adults with intellectual disabilities. The Guide to Action (GtA) Tool is a falls management tool that identifies falls risk factors and supports action to reduce these risks. The GtA tool was co-produced by clinicians, care staff and researchers and is clinically used across community settings in the general older adult population. The current GtA for older adults needs adapting for adults with intellectual disabilities who have specific reasons why they might fall and are supported by difference services in the community. We will co-produce, with people who have intellectual disabilities, carers and health professionals a revised of the GtA tool to meet their needs, accounting for the different risk factors and the different settings where people are supported.

As part of the development of the tool we want to explore the views of healthcare professionals, carers and support workers who work with adults with intellectual disabilities. We want to explore views on your experiences of managing falls as well as the content and layout of the revised version of the GtA. We will interview up to 15 healthcare professionals and 15 carers and support workers.

2. Who has reviewed this study?

Research in the NHS is usually looked at by an independent group called a Research Ethics Committee, to protect your safety, rights, well-being and dignity. This study has been reviewed and given a favourable opinion by the NHS, Wales 5, Bangor, Research Ethics Committee.

The study has also been reviewed and approved by the Health Research Authority and the Research & Innovation department of Nottingham University Hospitals NHS Trust. The Nottingham University Hospitals NHS Trust will act as the 'Sponsor' (i.e., the lead NHS hospital) for this research. The National Institute for Health Research -Research for Patient Benefit funding stream will fund this research.

3. Why have I been asked to take part?

You have been asked to take part as you are a healthcare professional, carer or support worker who has experience in supporting adults with intellectual disabilities.

It is up to you to decide whether or not to take part. If you decide to take part you will be given this information sheet to keep and be asked to sign a consent form (or verbally consent if the interview is conducted over the phone/video call) to confirm that you understand what is involved when taking part in this study. If you decide to take part you are free to leave the study at any time and without giving a reason.

If you withdraw, we will still keep records relating to the treatment given to you, as this is valuable to the study. A decision to withdraw at any time, or a decision not to take part, will not affect the quality of care you receive.

4. What do I have to do?

If you decide to take part you will be invited to take part in a one-off interview. The interview can be undertaken face-to-face at a location convenient to you or undertaken over the telephone or video call. With your permission the interview will be recorded and then transcribed. The interview will last up to 60 minutes. Travel expenses up to a 50 mile round trip will be reimbursed if the interview is undertaken face-to-face.

The interview will explore your views on managing falls as well as your views on the guide to action tool content, format and layout. You will be sent a copy of the draft guide to action tool before the interview to allow you to develop your views before the interview.

5. What are the possible benefits?

There will be no direct benefit to you from taking part in this research but your contribution may help to support the development of the guide to action tool for adults with intellectual disabilities.

6. What are the disadvantages?

There are no identified risks in taking part other than giving your time for the interview.

7. What will happen to my data?

All the information about your participation in this study will be kept confidential. We will keep all information about you safe and secure. If you consent to take part in this study, the records obtained while you are in this study will remain strictly confidential at all times. The information will be held securely on paper, and electronically at Nottingham University Hospitals NHS Trust under the provisions of the General Data Protection Regulation and the Data Protection Act. Your name will not be passed to anyone else outside the research team or the sponsor, who is not involved in the trial. You will be allocated a trial number which will be used as a code to identify you on all trial forms. If you withdraw consent from further involvement in the study your data will remain on file and be include d in in the final study analysis.

In line with Good Clinical Practice guidelines, at the end of the study, your data will be securely archived for a minimum of 5 years. Arrangements for confidential destruction will then be made.

The information collected about you may also be shown to authorised people from the UK Regulatory Authority (Health Research Authority) and the independent Ethics Committee to ensure that the study is carried out to the highest possible scientific standards. All will have a duty of confidentiality to you as a research participant.

We will need to use information from you for this research project. This information will include your name and contact details to allow us to contact you to conduct the interview. No personal information will be used in any publications.

We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

You can find out more about how we use your information:

- at www.hra.nhs.uk/information-about-patients/
- our GDPR leaflet available on request from researchsponsor@nuh.nhs.uk; or by the following link www.nuh.nhs.uk/gdpr
- by asking one of the research team
- by emailing the Data Protection Officer for NUH at dpo@nuh.nhs.uk,

- by ringing the Data Protection Officer for NUH on 0115 924 9924 (extension 63975)
- by visiting www.nuh.nhs.uk/gdpr

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

If you don't want to carry on with the study you are free to withdraw without giving a reason. If we have already conducted the interview the anonymised data will still be used in any analysis and publications.

9. What happens when the study is finished?

The findings from the interviews will be used to develop the second draft of the guide to action tool. The final tool will be agreed through an expert consensus process.

We aim to publish the findings of the interviews in academic journals and present at clinical conference. We will produce a lay summary of the findings which will be sent to participants. Direct quotes from the interviews may be used in this report, however no personal information will be included.

10. What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak with the researchers who will do their best to answer your question.

If you remain unhappy and wish to complain formally, you can do this through the sponsor team. Email researchsponsor@nuh.nhs.uk, or by phoning 0115 970 9049.

In the event that something does go wrong and you are harmed during the research study there are no special compensation arrangements. If you are harmed and this is due to someone's negligence then you may have grounds for a legal action for compensation but you may have to pay your legal costs. The normal NHS complaints mechanisms will still be available to you.

11. Further Information

You are encouraged to ask any questions you wish before, during or after your treatment. If you have any questions about the study please speak the researcher who will be able to provide you with up to date information about the study procedures involved. If you require any further information or have

any concerns while taking part in the study please contact your researcher (listed at the top of this document).

If you decide you would like to take part then please read and sign the consent form. You will be given a copy of this information sheet and the consent form to keep. A copy of the consent form will be filed with the study records.

You can have more time to think this over if you are at all unsure.

Thank you for taking the time to read this information sheet and to consider this study.