Developing a bladder assessment and management toolkit – clinical evaluation

What is the purpose and aim of this study?

We are developing a bladder assessment and management toolkit, which we hope can be used by healthcare professionals who care for people with Parkinsonism. This is intended to make this easier, and also help patients receive appropriate treatment for their bladder symptoms quicker. It has taken the form of an easy to follow flow chart to aid its use in busy consultations, as well as accompanying handbook.

This is intended to help with all types of parkinsonism, including people with atypical parkinsonism, vascular parkinsonism and idiopathic Parkinson's disease.

Why have I been invited to take part?

You have been approached because of your experience and expertise in caring for people with Parkinson's. We would be very grateful for your involvement because of this.

What will taking part involve?

Taking part will involve completing a questionnaire, which will briefly ask you about your views on the assessment and management of bladder symptoms in patients with parkinsonism, as well as detailed about your service. You will then be provided with a link to the toolkit to view at your convenience, once this has been finalised. Questionnaire responses will help develop the first iteration of the toolkit, ensuring this is as applicable as possible to multiple clinical settings.

At a later date, we will ask you to complete the brief questionnaire again. There will also be questions specific to the toolkit which we will also ask you to complete regarding your views on this. A free text box will also be available for comments and feedback.

We will look to incorporate further feedback into the final toolkit, which is envisioned to be made available throughout the UK and beyond.

We will keep you upto date as to progress by email, and let you know the outcome of the evaluation process, as well as details of the final output.

For a small selection of participants, an invitation to participate in an interview on the topic the toolkit will be given, however is an optional part of taking part in the project. These will take place over an online video platform such as Teams and will last roughly 30-45 minutes. Unfortunately we will only be able to interview a small selection of toolkit users, who will be chosen at random.

Who is funding this work?

This work is funded by Parkinson's UK, through an Excellence Network Grant.

Use of the toolkit and how it was created

The toolkit is the product of expert consensus and opinion, as well as evidence from existing scientific literature.

The toolkit is intended to aid and guide clinicians, but is not a replacement for clinical judgement. Responsibility for patient care lies solely with the clinician, and the University of Bristol and Parkinson's UK cannot be held liable for its use and application.

What are the outputs of the process?

The main output will be a finalised bladder assessment and management toolkit for patients with parkinsonism, which can be used practically by clinicians. We will aim to publish this in a peer-reviewed publication, and look to have the toolkit made freely available online.

What data will you be collecting and how will this be used?

We will collect your questionnaire responses as described above. These will be stored pseudo-anonymously with the combined responses assigned an identifying code number. Your speciality/role will be collected and stored within this data set, but not your name or location/place of work.

We will also collect your name and contact details to facilitate participation in the study. This will be stored in a separate database, along with the identifying code number assigned to you.

Can I withdraw from the study?

You are free to discontinue from participation at any time. Upto the point of data analysis, your responses can be deleted (withdrawn) by identifying your responses through the code number.

Once at the data analysis stage, data cannot be deleted or removed, however you are free to discontinue participation in study procedures.

How will data be stored?

Questionnaires for the evaluation will be stored on Survey Monkey. Their data processing and storage policies can be read here: https://www.surveymonkey.com/mp/legal/privacy/

Personal data (name and contact details) will be stored on a database held on secure University of Bristol servers. This will not be held on the Survey Monkey website.

Pseudo-anonymised questionnaire data will be transferred onto a database in secure University of Bristol servers at the point of data analysis.

Interviews as part of the evaluation process will not be recorded and specific quotes provided will not used in subsequent publications. Interview data will not be shared at the end of the study.

The trial is being undertaken in full compliance with data protection legislation, specifically Article 6.1(e) of the General Data Protection Regulation, as it is covered by a public task, and Article 9.2(j) as it relates to scientific research.

The University of Bristol will be the data controller for this trial. You can find out more about how the University ensures information is handled appropriately here: http://www.bristol.ac.uk/secretary/data-protection/policy/research-participant-fair-processing-notice/

What can I do if I have concerns about how my data is being used or stored?

If you have any concerns about how your personal data is being handled in the trial, you can contact the Data Protection Officer at the University of Bristol:

Email: data-protection@bristol.ac.uk or telephone: 0117 3941824

If you have concerns, you have the right to complain to the Information Commissioner's Office (ICO). Further details can be found at www.ico.org.uk

Who can I contact if I have questions about the study?

This study is being lead by Dr Matthew Smith, who can be contacted at matthew.smith@bristol.ac.uk

What about if I have a concern of complaint regarding this study?

Please get in contact with the research governance team and the University of Bristol who can be contacted at researchgovernance@bristol.ac.uk