



UNDERSTANDING CAUDA EQUINA SYNDROME (UCES)

Quick Start Guide

All files mentioned below are available for download from www.bntrc.co.uk or <https://www.dropbox.com/sh/94skrnk5mtc1d7x/AADpewsDc80sALxg8Fj7NVQ9a?dl=0>

1. Identify potential participants

- Admitted between 1st June 2018 and 31st May 2019
- Over 18 years (no upper age limit) and able to provide informed consent
- Have a diagnosis of clinical CES and structural compression of the cauda equina on imaging. *Clinical CES includes any disturbance of saddle sensation, bladder function, bowel function, sexual dysfunction and bilateral sciatica associated with radiological compression of the cauda equina. The cauda equina compression can be due to any cause, including, but not limited to, disc, tumour, infection, fracture, etc.*

2. Discuss study with potential participant and give them the participant information sheet, the GDPR information sheet, and the consent form to read and then sign

- Ensure the correct centre details and contact details are on the forms
- Ensure the patient's contact details are filled in on the consent form
- If the patient does not wish to participate or give contact details, still proceed with steps 3 & 4, but tick that they did not want to participate in the database
- If the potential participant has already been discharged, you can phone them to discuss the study and send the information sheets and consent form in the post. *Be sure to include a return address / envelope so you receive the consent form.*

3. Enter clinical details into the study database at: www.castoredc.com

- Write the new participant ID assigned by Castor (e.g. GB-EDI-00001) on the consent form
- Follow the guide to Castor data entry
- If you don't have a login for Castor, contact julie.woodfield@ed.ac.uk
- Once you have entered the participant's email address into Castor, they will receive questionnaires to complete. If the participant doesn't have an email address, or wants to complete the questionnaires on paper, give them the admission and discharge questionnaires, label these with the Castor participant ID and return them to the address on the questionnaires. *Paper questionnaires are only available in the dropbox folder as the permissions prevent them being published on the BNTRC website.*

4. Enter patient details onto the local Excel spreadsheet

- This links the participant ID assigned by Castor and the patient's contact details
- Save this version on your local NHS computer and **DO NOT DELETE** for 5 years after the end of the study. *If you leave the NHS Trust, forward it to someone who still has an account at that trust, e.g. the consultant you have been working with.*

5. Send GP letter

- Stick a patient label on your local version of the GP letter and send this to the GP

6. File the consent form in a folder in a locked NHS office

- If you leave the NHS Trust, let the consultant you have been working with know where the consent forms are stored.